

Join the **big**



debate

Shaping the
Future of Care Together

Report on the Consultation

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FOREWORD BY PHIL HOPE, MINISTER OF STATE FOR CARE SERVICES



The Green Paper, *Shaping the Future of Care Together*, set out a vision to build a National Care Service. With more people living longer, and expectations rising, we need to consider how to build a system for the future – one that is fair, simple, and affordable.

The Green Paper outlined our vision, but it also highlighted that some big, and difficult, decisions would need to be made. We set out plans to bring about a step-change to our system; and we needed to know what you thought of these proposals.

The Big Care Debate was your opportunity to have your say; and over 68,000 of you took part. I would like to thank everyone who took the time to take part in the debate, because now we have a clear direction.

I have very much enjoyed listening to all your views. I have met people at the public road shows, debated the issues with stakeholders at events and meetings, read comments on the

website and participated in web chats. All these views have been valuable in shaping our thinking as we move towards the creation of the National Care Service.

Through the course of the debate, you have told us you support our vision for a National Care Service and that you agree with the need for reform. You have told us what you think of our funding proposals. And you have given us your views on the areas which concern you, such as reform of benefits and support for carers.

I hope you will enjoy reading this independent summary report and the supporting evidence which summarise all the main themes emerging from the consultation. We have carefully considered everything you have told us in developing the White Paper which is the first step in making our shared vision for a National Care Service a reality.

A handwritten signature in black ink that reads "Phil Hope".

Phil Hope, Minister of State for Care Services

INTRODUCTION

This report summarises responses to the Government's Big Care Debate consultation on the proposal put forward in the Green Paper: *Shaping the Future of Care Together*.

A summary report analysing all the responses to the consultation has been produced by MORI. This report also includes supporting evidence on research conducted by Opinion Leader with harder to reach and less engaged audiences, and a report by COI on events held with stakeholders.

The Big Care Debate, which took place between July and November 2009, set out to be the largest consultation on care and support. Over 28,000 people responded to the consultation formally, but this was only part of the debate. People also responded to the issues raised through No. 10 petitions, commenting on Facebook and Twitter and there was significant debate within Parliament on the proposals outlined in the Green Paper.



The consultation has confirmed that there is support for reform to our current care and support system. Examples of good practice were

highlighted, but there were also many examples cited where people have been disappointed by the care and support they have received. Thus the National Care Service must capitalise on all the good parts of our current system, but also bring about real improvements where the system is not working as it should.

People generally supported the Government's vision, and the six principles underpinning it outlined in the Green Paper, even if there was debate about how to best deliver these services effectively. Many outlined the need for the National Care Service to deliver high quality care and support, and welcomed a push for a wider range, of more joined-up, services. Areas which the Green Paper was perceived to have missed, or not given sufficient emphasis too, were highlighted. This included, among others, the need for further support for carers.

The funding of the new system generated high levels of debate. All the proposed funding models were supported, but the Comprehensive model was the most favoured. Many questioned why a general taxation model was ruled out. Concerns were raised over the reform of benefits, the protection of housing assets, and exclusion of accommodation costs.

This document brings together all the different views on the care and support system and the Government's proposals for its reform. The consultation has been invaluable in shaping the thinking and developing the vision for the National

Care Service. The evidence from the consultation, coupled with independent research, has informed all the policy development for the White Paper.

Following on from the consultation a Care and Support conference was held in February 2009, which brought together key stakeholders. This was a further opportunity for stakeholders to give their views to politicians and help build a consensus on the reform of the system. All the delegates agreed a statement at the end of the conference, which endorsed the vision for the National Care Service and set out further areas for reform.¹

¹ The full text of the statement agreed at the conference can be found on the Care and Support website:
<http://careandsupport.direct.gov.uk/news/2010/02/care-and-support-conference-19th-february-2010/>



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EXECUTIVE SUMMARY

Alongside the publication of the Green Paper: *Shaping the Future of Care Together*, in July 2009, the Government launched the **Big Care Debate**, a consultation on the proposals put forward. Participants contributed through various means, including questionnaires (both on and offline), postcards, stakeholder events, public road shows, comments on the website, competitions in magazines and through letters and emails to the Department of Health. Over 28,000 responses were received and many thousands more contributed via national and local organisations.

Consultation question 1: The vision for the National Care Service

There was general support for the six elements proposed in the Green Paper which make up the vision for the National Care Service:

- Many agreed with the need for **prevention services** and proactivity was identified as a key principle in terms of identifying need at an early stage.
- **National assessment** was viewed positively in terms of maintaining consistency nationwide, but there was a concern that there are regional and local differences that would need to be accounted for.
- A **joined-up service** was seen to be important. People interpreted this as meaning a variety of services should all work together. It was suggested that health care and housing should both be included within the joined-up services. There was, however, concern

surrounding the different funding mechanisms for health and social care.

- Some participants noted that **information and advice** is lacking in the current system. Often seen to be essential, a number noted that information and advice must be clear, timely and accessible to all.
- Many welcomed the idea of **personalised care and support** and the emphasis on choice, although there was concern that there may not be sufficient funding to make this a reality.
- While there was support for funding that is fair, a number of participants were unsure what '**fair funding**' actually meant, and in particular what was classified as 'fair'.

Participants wanted to see greater clarification on exactly how each of the six principles would be implemented, and also suggested a number of further elements that they feel required greater consideration in the proposals:

- The first of these suggestions was a clear definition of care and support. It was often felt that it is unclear what would be included under the new system and what would not be. Some suggested implementing incentives to encourage people to plan ahead for their own care.
- Many suggested that there should be greater attention given to carers and the care workforce and a commitment to achieving high quality care was a strong theme which emerged from the consultation.

- An emphasis on human rights in the proposals was seen as a priority for some participants. They wanted a commitment to inclusion and respect for diversity, as well as prioritising the safeguarding of vulnerable adults. Many participants thought it was a priority for users and carers to be actively involved in the design of services.
- Maintaining independence was seen to be important, and many noted that housing services should be included within the proposals.
- Others wanted to see recognition of changing demographics, and a guarantee that a new service would be sustainable in the future.

Consultation question 2: Delivering the vision

A majority of participants agreed with the three areas set out in the Green Paper – joined-up working, better quality and innovation, and a wider range of services – as important in delivering the vision. A number of other areas were also highlighted, as important, including:

- services for everyone
- well-trained staff
- a cultural change within the sector
- strong, national leadership
- an evolving process with feedback opportunities
- regulation.

There were, however, a number of barriers identified to the implementation of a National Care Service.

Attitudinal barriers

Three key attitudinal barriers were identified: a lack of confidence in the current system; the negative perception of care and support; and choice – which although often a positive, was also seen as a potential problem. There was a perception that too much choice could compromise quality and that without sufficient information, or mental capacity to make informed decisions, handing such choice to the individual could have some negative impacts.

Structural barriers

A number of participants highlighted that failures in the current system should be addressed before a new system is implemented. Different cultures across different service providers was seen to be a barrier to joined-up working, and data protection issues, bureaucracy and concerns about existing management leading a new system were also mentioned.

Some raised the quality of the care workforce and the services provided as a barrier, noting that lack of training and regulation could be detrimental to the implementation of a new system.

Funding was an issue raised by many participants in answering this question. There were concerns about how a National Care Service would be funded overall, with many questioning whether there would be sufficient funding from Government overall. Some saw local authorities as a barrier to effective implementation because they were perceived as likely to look after their own financial interests before the care needs of the local community.

Some participants were concerned that there would be a lack of political will, and that priorities may change after the general election.

Consultation question 3: Funding and managing the National Care Service

All three of the funding options received some support, with Partnership and Comprehensive more favoured than Insurance. In addition, some participants felt that general taxation should not have been ruled out as a funding option.

Other comments focused on broader issues such as the sustainability of the funding options, whether they would deliver reform quickly enough and the extent to which adequate funding would be realised to achieve the vision outlined in the Green Paper.

There were a number of issues raised regarding the future funding of care and support, and in particular a concern that funding should be 'fair':

- participants were generally opposed to benefit reform;
- they were also concerned that the reforms should not penalise those who save; and
- there were differing views about whether accommodation costs should be included in the National Care Service or not.

There was some support for both a fully national care and support system and a part-local, part-national model. On balance, participants tended to opt for national consistency. However, many also argued that some local flexibility would be important to ensure the system delivers high quality, tailored services.

Conclusion

The evidence from the consultation, coupled with independent research, has informed the development of the Government's White Paper.

OVERVIEW OF THE CONSULTATION PROCESS

Background

The reforms discussed during the consultation are ambitious, and they affect everyone in England. It was therefore important for the Government to understand the public and stakeholder views on the current system and the proposed changes.

In May 2008, the Government published *The Case for Change: Why England needs a new care and support system*, a document that laid out why we need a major reform of care and support. This was followed by six months of public engagement to ask for people's views on the principles of reform. The responses to the engagement formed the basis of the Green Paper *Care Support and Independence: Shaping the Future of Care Together*, which was published in July 2009.

Alongside the publication of the Green Paper, the Government launched the Big Care Debate – the consultation on the proposals put forward. The consultation set out to be the largest ever on care and support – reaching out to people across the whole of England. Across England, 37 stakeholder events and 80 public road shows in town centres, shopping centres and county shows were held to promote debate and generate responses to the consultation. The formal public consultation ended on 13 November 2009.

One of the intentions of the Big Care Debate was to raise awareness more widely of the issues facing the care system, and provoke discussion.



People have debated the issues and given their views in many ways, including outside the formal consultation channels. For example, a petition on the No. 10 Downing Street website highlighted people's concerns over the reform of benefits, people commented on the Government's proposals on Facebook and Twitter, and there were a number of parliamentary debates on the proposed reforms. While these have been taken into account by the Department of Health as it develops its proposals, they have not been incorporated into this report's findings, which instead focus on the formal consultation responses.

The findings from the consultation have been important in helping the Government shape its thinking and develop its proposals from the Green Paper through to the White Paper.

Structure of this document

This document sets out the main findings from the consultation. This first chapter gives details on the background to the consultation, how it was run, and who responded, as well as some points on how to interpret the data.

The following chapters detail the analysis of responses. The consultation itself was broken down into three key question areas covering the vision for the National Care Service, how this vision should be delivered, and how it should be funded. While the exact wording of the questions to participants varied across the consultation, all were based around the three core consultation questions, around which this report is structured.

For further technical details on the consultation, please see *Shaping the Future of Care Together: Technical details for consultation report*.

Structure of the consultation

As outlined previously, the Big Care Debate set out to be the largest ever consultation on care and support. A priority was to ensure that as many people as possible could take part and it therefore offered many different ways to engage and debate the issues outlined in the Green Paper, from completing a postcard at a public road show or spending an afternoon in a workshop discussing all the issues in detail. People could respond online or by postal questionnaire, or comment on the website.

There were five main channels for response to the consultation:

- The written consultation process, where participants responded to specific questions via long and short questionnaires (both online, offline and through touch screens and handheld PDA devices at public road shows), postcards, through competitions in magazines, sent comments via letter or email or returned comments responding to Q&A pages of the 'easy-read' version of the Green Paper.
- Website comments – the Big Care Debate website featured an online version of the Green Paper, which allowed comments to be made on specific chapters. Also the website featured a blog by David Behan (Director General of Social Care at the Department of Health) which detailed the progress of the care and support debate. Participants could make comments on this blog.
- Stakeholder events – workshop-style events were held in every region of England, where up to 100 stakeholders per session were presented with information about the proposals and then given the opportunity to discuss and comment upon the various aspects in detail. Toolkits were also produced to allow stakeholders to run their own events following the same structure as the regional events.
- Eighty public road shows were held in locations around England, from city and town centres to county fairs, providing information on the Green Paper and giving people the opportunity to complete questionnaires and write comments on interactive whiteboards.
- Supplementary qualitative research was undertaken with the general public, specific ethnic minority communities and faith leaders, which was designed to ensure that the opinions of under-represented groups would be taken into account. Run independently, this research included 2 deliberative workshops, 14 group discussions and 9 depth interviews.

Responses

There was a total of 28,188 direct responses to the consultation – from the open consultation and stakeholders. There were also over 40,000 indirect responses – from those who were consulted by stakeholder organisations who responded on their behalf. The table below sets out the ways people contributed.

The consultation sought to reach a wide-ranging audience and responses came from both the general public and various stakeholders. Every response is very valuable and ensures that as many opinions as possible are included in the analysis. Throughout this report, key themes are broken down by audience where appropriate.



Open consultation

The largest group, 27,474 participants, responded to the open consultation, via various means. This group comprises both the general public and individuals who may be engaged with the care and support system in some way – they may care for a friend or family member, work in the sector, receive care and support or have an interest in the sector for any other reason. Unfortunately it is not always clear what category the participant falls into, therefore we are unable to break this audience down any further. There may also be participants who responded more than once.

Output	Description	Number received
Paper questionnaire	Long version	991
	Short version	7470
Online questionnaire	Long version	1371
	Short version	5116
Touch screen questionnaire at road shows	Long version	231
	Short version	656
PDA questionnaire	Short version	4811
Postcard		665
Completed Q&A pages from 'easy-read' version of Green Paper		45
Interactive whiteboard comments		7 printouts
Online comments	On the Green Paper	3257
	On David Behan's blog	465
Additional questionnaires, printed in magazines as competitions	<i>Saga</i> magazine	218
	<i>Take a Break</i> magazine	761
Open written responses (including detailed reports from stakeholders)	By letter	722
	By email	1409
Stakeholder events	Regional events run by COI	37 events
	Run by stakeholders using Department of Health 'toolkits'	70 events

While we know that people who responded via the different strands of the Big Care Debate received differing levels of information about the consultation, what we do not know, is how much knowledge each individual had about the care and support system to start with. It is therefore important to bear in mind that responses may be based on differing levels of knowledge.

Research with the general public

Supplementary qualitative research was held with the general public, targeting groups unlikely to be engaged with care and support and therefore likely to be under-represented in the consultation. These participants had little knowledge of the system and were provided with information and opportunities to discuss the reforms through workshops, group discussions and interviews. The research comprised the following: 2 five-hour deliberative workshops with 24 members of the public per event; 14 extended group discussions each lasting two and a half hours with ethnic minority communities (EMC) (Bangladeshi, Pakistani, Somali, Ghanaian, Nigerian and Caribbean) and gay and lesbian audiences; 7 depth interviews with faith leaders representing Muslim, Hindu, Sikh, Roman Catholic, Jehovah's Witness and Jewish faiths; and 2 depth interviews with transgender participants.

Stakeholders

A wide range of stakeholders contributed to the consultation, many of which had extensive knowledge and expertise in care and support.

There were 234 submissions from **national organisations**. This group of stakeholders is likely to be particularly engaged and have much expertise in the subject area, and as a result, many of the submissions comprised detailed, well-researched reports. Many organisations had

conducted further research within their own networks or memberships via surveys, focus groups or meetings, where the views put forward were then represented by the organisation.



There were a further 420 responses from **local organisations** – often regional branches of national organisations. Again, many of these submissions included the points of view of members, following research or meetings. These stakeholder groups were often concerned with local issues, and in reporting back the views of local members were often more similar in theme to the responses from the open consultation than those of national stakeholders.

Some stakeholders responded as **individuals** (60) in a professional capacity where their responses were often an individual opinion and not those of their organisation. Those in this group appeared to be more informed about the care and support system than the general public.

Many stakeholders contributed through regional **stakeholder events** (37 were held across England). During these events, stakeholders were talked through the proposals in detail, by representatives from the Department of Health and discussed various aspects of the consultation as part of round-table discussions.

In their consultation responses, some stakeholders (70) also informed us that they held their own events. 'Stakeholder toolkits' were produced by the Department of Health to facilitate further discussion about the Green Paper by enabling them to hold their own events. These included advice on how to hold an event, further background information and suggested areas for discussion. These events were predominantly held by local groups, meaning that similar themes emerged as those from local organisations and the open consultation.

Many thousands more people may have contributed to the Big Care Debate. We know from analysing the formal responses to the consultation that over 40,000 more people contributed through further research or events organised by stakeholders.

Interpreting the data

Qualitative research

While a consultation exercise is a very valuable way to gather opinions about a wide-ranging topic, there are a number of issues to bear in mind when interpreting the data. First, a consultation such as this is predominantly qualitative in nature. This means that it is exploratory, listening to what people have to say and the way in which they say it, rather than simply asking them to tick a box. Qualitative methods are much-used and well-respected in research. Despite the fact that findings emerge as a number of 'themes' and 'ideas' rather than leading to statistical analysis, this can be just as, if not more, useful in analysing results. Therefore, while some figures are given in this document, these are to illustrate the relative importance of particular issues compared with others.

A number of verbatim comments are included to illustrate and highlight key issues that were raised. These are attributed by audience, and where more specific information is available which adds greater insight into the verbatim, this is included.

The vast majority of responses were spontaneous in nature and as a result a wide range of themes emerged from the consultation. The spontaneous nature of the comments also meant that the absolute numbers mentioning a particular topic were often small compared with the total number of responses to the consultation overall. Not all participants chose to answer all questions, as they often had views on certain aspects of the consultation, and made their views on these clear, but left other questions blank. Therefore, there were many blank responses to certain questions. Many people also responded to the consultation with personal stories outlining their experiences of care and support. Some of these were positive, but many were negative. These have all been read and the comments considered.

Responses from the open consultation were coded to categorise and group together similar responses and identify the key themes. Some of these figures are reported in this document, although they must be treated with caution. While some figures may seem small given the scale of the overall consultation, all those reported on have been highlighted due to their importance relative to other themes, and despite small figures can reflect important themes.

Understanding the audience

While attempts are made to draw out the variations between the different audiences, it is important to note that responses are not directly

comparable. Across the different elements of the consultation, participants received differing levels of information about the proposals, ranging from several sentences of description on a postcard, to several hours at a regional event, where various aspects of the Green Paper were scrutinised and discussed. Some responses therefore are based on more information than others, and may also reflect differing degrees of interest across participants.

Similarly, while every attempt has been made to classify each participant into the correct category for reporting purposes, it is not always clear from the response the specific category to which they belong.

While the consultation was open to everyone, the respondents were self-selecting, and certain types of people may have been more likely to contribute than others. In this instance, it is possible that those participating were more likely to be engaged with the care and support system in some way. This means that the research is not representative of the population as a whole.

A great deal of time and effort has been put into the responses by contributors to the consultation. For example, many individuals described their personal experiences and national and local organisations discussed in detail the specific issues relevant to their organisation and members. All of these responses have been read and analysed.

This report includes responses from stakeholders. It is, however, not possible to encapsulate all the important and detailed issues from stakeholder responses and do justice to the amount of work that has been put into many of the responses

in this summary document. Throughout this report, we have sought to include recurring themes emerging from stakeholder responses, rather than detailing specific, individual issues or outlining every point of view.

Furthermore, through various forms of engagement with stakeholders and members of the public, the Department of Health has been able to hear first hand many different perspectives on care and support. There are a large number of specific, detailed points which the Department has noted and taken forward in developing the White Paper, but which due to the nature of this document could not be included. This document is one of a number which informed the Government's White Paper.

Partners

The Department of Health appointed the Central Office of Information (COI) to work closely with the Department throughout the consultation process, from the initial design work through to the procurement of specialist suppliers in order to ensure that the project was effectively managed.

Ipsos MORI were contracted to analyse the results of the consultation and report back to the Department of Health as an independent body. All responses were returned to the Department of Health and forwarded to Ipsos MORI, where each was logged and included in the analysis. Ipsos MORI worked closely with the Department of Health and COI to produce this document detailing the key findings from the consultation.

THE VISION FOR THE NATIONAL CARE SERVICE

Summary

There was general support across all audiences for the six proposed elements of the National Care Service.

Many agreed with the need for **prevention services**, with proactivity identified as a key principle in terms of identifying need at an early stage.

National assessment was viewed positively in terms of maintaining consistency nationwide, but there was a concern that local and regional differences would need to be accounted for and one size did not necessarily fit all.

A joined-up service was seen to be important. It was suggested that, in particular, health care and housing should be included within the joined-up services. There was, however, concern about whether this was possible, given the different funding mechanisms for health and social care.

Some participants noted that **information and advice** is lacking in the current system. Often seen to be essential, a number noted that information and advice must be clear, timely and accessible to all.

Many welcomed the idea of **personalised care and support** and the emphasis on choice, although there was concern that there may not be sufficient overall funding to make this a reality.

While there was support for funding that is fair, a number of participants were unsure what **'fair funding'** actually meant, and in particular what was classified as 'fair'.

Participants wanted to see greater clarification on exactly how each of the six principles would be implemented.

There were also a number of elements many believed should have had greater consideration in the proposals:

- The first of these suggestions was a clear definition of care and support. It was often felt that it is unclear what would be included under the new system and what would not be. Some suggested implementing incentives to encourage people to plan ahead for their own care.

- Many thought there should be greater attention given to carers and the care workforce, and a commitment to achieving high quality care.
- Many participants wanted to see listening to and involving service users and carers as a priority.
- An emphasis on human rights in the proposals was seen as a priority for some participants. They wanted a commitment to inclusion and respect for diversity, as well as prioritising safeguarding vulnerable adults.
- Maintaining independence was seen to be important, and many noted again that housing services should be included within the proposals.
- Others wanted to see recognition of changing demographics, and a guarantee that a reformed service would be sustainable in the future.

Introduction

There was general acceptance across all audiences – particularly stakeholders – of the need for reform of the care and support system. Some suggested that the care and support system is not currently working as it should and that it would be unsustainable in the future. The earlier engagement work, which informed the Green Paper, showed that there was agreement about the need to reform the system.

The consultation demonstrated that there was broad support for the approach outlined in the Green Paper, and agreement that, at the very least, basic care services should be provided by the Government under a new system. Many of the issues described by participants focused on queries about how the National Care Service would be implemented in practice, rather than on the need for reform.



Questions were raised by a number of participants across all audiences about the language used. The term ‘National Care Service’ was seen to be somewhat confusing because it implied free care at the point of need, along the lines of the National Health Service. Furthermore, there were many comments about the relationship with the NHS; some participants pointed out that they wanted further information on how the National Care Service would work together with the NHS.

One of the major barriers to understanding a new system of care and support was a lack of understanding of how the current system works. Many participants did not fully understand how the system is currently funded and therefore who was eligible for what.

Consultation question 1

The first consultation question proposed a National Care Service that is fair, simple and affordable, and presented six principles that people should be able to expect from the future system. Participants were asked for their views of the six principles, how they envisaged that the service would work and what, if anything, was missing from the approach.

While the exact wording of the questions presented to the participants varied, the first consultation question as set out in the Green Paper, and on which questions to the participants was based, is set out below.

Consultation question

1. We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- prevention services
- national assessment
- a joined-up service
- information and advice
- personalised care and support
- fair funding.

a) Is there anything missing from this approach?

b) How should this work?

There was clear support for a care system that is fair, simple and affordable, and for each of the six elements proposed. Some participants in the open consultation felt such a radical overhaul to be unnecessary, although this was a minority view. There was much agreement that, while

none of the elements were new in themselves, presenting all these elements together in the introduction of the proposed National Care Service represented an improvement on previous proposals. Some participants pointed out that there were many good practices, services and facilities currently in place, with others going on to say that it was important to maintain these in any reforms. For example, the third sector was seen as providing valuable care and support in some settings; a number of participants felt this good practice should be identified and built on alongside state-run care and support services.

When asked what was missing from the list, 7,323 participants in the open consultation said that nothing was missing, while 6,892 made a range of comments on the six key principles. These are described in the sections below.

Prevention services

Prevention was perceived as key in terms of reducing need for care at a later point, and in the long term would be a cost effective strategy. Many national organisations also perceived that prevention was not given sufficient consideration in current Government policy and that local authorities often move away from prevention because they have to prioritise critical care. A number of participants across all audiences supported greater opportunities for people to take more responsibility for looking after themselves, with some welcoming the proposal to focus on prevention. For example, the open consultation pointed to a greater emphasis on health checks at certain ages and the promotion of healthy lifestyles.

“ ‘Prevention services’ needs to be broadly defined to include ‘low-level’ support in the community, sometimes provided by volunteers, and universal services; not just traditional home care.”

(Response to open consultation)

It was suggested by a number of participants that proactivity should be a key principle alongside prevention; that early identification of those likely to need care in the future should be possible by looking at current needs and illnesses or disabilities.

There was seen to be a need for clarification on exactly what ‘prevention’ includes, and who would provide prevention services. A number of participants in the open consultation suggested that a greater awareness of care and support services is needed, and education could be key to prevention.

Some national organisations raised the issue that prevention must consider users’ needs and, like other elements of the proposed service, should not be a ‘one size fits all’ approach. For example, keeping people active was often seen to be a core aspect of prevention, yet for some illnesses, rest rather than activity at an early stage could be vital.

There was recognition that the third sector plays an important role in prevention, and many national and local organisations wanted to see this acknowledged in the White Paper. There was a suggestion that there should be a partnership approach with the third sector, rather than leaving them to fill in the gaps.

There was concern surrounding funding for prevention; in particular that prevention may be marginalised in favour of those in critical need if funding was limited. As such, some organisations suggested that prevention budgets need to be ring-fenced. Some local organisations also asserted that prevention should be partly funded by the NHS, since prevention would also reduce pressure on the NHS in the long term.

A number of participants across all audiences were particularly interested in the inclusion of wider services such as housing, education and leisure facilities in the prevention strategy, as these types of services were seen as playing an important role in helping people to remain independent. There was a concern that there must be a joined-up element to prevention, since many different agencies could play a role. Participants felt that the Government should work with and make the most of these other agencies, as well as financial and other resources that are available, for example, volunteers.



Many participants supported the notion of maintaining independence and keeping people in their own homes for as long as possible. There was support among a number of participants across all audiences for re-ablement, and the provision of support for people being discharged

from hospital. There was, however, a concern for some that this should not be for a set period of time, but should depend on the needs of the individual. Some organisations also thought that keeping people in their own homes was not necessarily the best option for everybody, and in some cases could have a negative impact. They argued that care homes could be more cost effective if a person required a high degree of care and could also provide companionship which is often lacking for people in their own homes.

National assessment

There was general support for national assessment in terms of maintaining consistency across the country, and the need to remove the 'postcode lottery' (where different areas have different eligibility criteria and different levels of access to services) was often cited – particularly by local and national organisations. Some, however, were disappointed that there was no mention of Scotland or Wales in the proposals.

Some national organisations also noted that there must be a guarantee of an end service to meet that need, rather than just an assessment. A number of participants noted that there is currently a disparity between services in urban and rural areas, which they felt disadvantages those living in a rural area. There was a strong assertion by some members of all audiences that a national assessment must be transparent, simple, and easily understood by non-specialists, as well as being open to appeal should the care user disagree with the outcome.

There were, however, concerns among some local organisations that national assessment conflicts with the personalisation agenda. Some noted

that people should not be pigeonholed into a standardised national assessment, as their needs may not fit with such an assessment. Questions were also raised as to what happens when someone has fluctuating needs. For example, if an assessment takes place on a 'good' day, there was a concern that individuals would be overlooked for care and support. Similarly, the general public at the workshops tended to support national assessment, with the caveat that it could be tailored to individual needs – for example cultural or religious needs, or the provision of a culturally appropriate assessor if necessary.

“You need to consider the constantly changing needs of the clients. People with an illness or condition that fluctuates on a daily basis are at risk from your proposal, as they may be assessed on a good day, and not receive the level of care they require on a bad day. Also the reverse is true, in that a lot of time and money could be spent on someone who was assessed on a bad day, but they don't want to be reassessed for fear of having the higher level of care removed when they could need it the next week.”

(Response to open consultation)

A number of participants wanted to see assessments on a 'can do' basis, rather than assessing what people are unable to do for themselves. Some expressed concerns that assessing people on what they could not do may encourage people to overplay their needs. An emphasis on a social approach rather than a medical one was recommended by some participants from all audiences, which takes a 'whole life' approach to assessments and looks at needs beyond basic care.

There were concerns that regional differences, for example in costs, would need to be accounted for. Some stakeholders felt that local authorities were best placed to assess their residents' needs since there is much variation between local authorities – they know the make-up of the local area well and understand any prevailing cultural or other issues. Similarly, there was a concern that needs may change in a different environment, so not all assessments can be portable.

A number of national organisations also noted the possibility of local interpretations of a national assessment. A set of national care standards and regulation by the Care Quality Commission was suggested as a possible way to manage this, and some organisations suggested using a National Resource Allocation System, which should be managed at a national level and delivered locally.

“National Assessment; this would work well if people could move up/down the country and have an assessment from Social Services just like they can do with the Health services. However every local authority has different criteria and long waiting lists partly due to the high level of demand on their resources and partly due to the fact that social workers are at a premium.”

(Response to open consultation)

Participants felt there was a need for further clarity in the White Paper on who would undertake national assessments. There was disagreement about who should do this, though many national organisations noted that this should be undertaken by an independent body. While one stakeholder noted that local authorities were well placed to conduct assessments given their knowledge of the local community, the stronger view from others was that giving local authorities such a role was seen to be a conflict of interest with their other roles to keep costs to a minimum and in commissioning services.

A joined-up service

At workshop events, the general public tended to note that a joined-up service is one of the keys to the success of the entire system. Participants understood 'a joined-up service' to refer to the

whole care and support system, rather than just assessment as outlined in the Green Paper.

A number of local organisations highlighted that this may reduce duplication across the system and some participants in the open consultation wanted a joined-up service to create a quicker transition between referral and services. In order for this to work, some local organisations wanted to see an effective management framework in place, to remove divided responsibility, and ensure all those caring for an individual know who else is involved.

“Too many initiatives are undermined by the separate funding streams of PCTs and local authorities, and the need or desire of both parties to be involved.”

(National organisation)

As the boundary between health and social care was seen to be unclear, a number of participants observed that health care should also be included within this joined-up service. In addition, national and local organisations tended to note many other services and agencies that should be included within this joined-up service, in particular, housing – a service which a number of participants across all of the audiences felt should not be overlooked. Others noted that joined-up services should also include support for young people moving from children’s to adults’ services. There was a concern among some national stakeholder organisations that end-of-life services were not considered explicitly in the proposals,

something which a number feel should be included within a joined-up service.



Some participants in the open consultation envisaged that for such a system to work, health and social care services should work together and there should be good communication between departments. Care recipients tended not to be interested in the politics of who provides what aspect of care; for them, the priority is actually getting this care. From their perspective a National Care Service needs to be seamless.

“Services like Health and Social Care need to joint work and work side by side for the best interest of the people who need their services. There is too much ‘oh that’s health side, we don’t deal with that’ or ‘that needs to come out of their funding’. People who need care don’t want to know the politics, they want services to happen.”

(Response to open consultation)

However, for others there was concern around funding, particularly surrounding the joining-up of health and social care, which are currently funded in different ways. Some organisations suggested pooled budgets between the two systems, particularly for preventative measures, which were seen to benefit both health and social care services.

“Until joined-up services mean joint funding, services will never be joined-up.”

(National organisation)

National organisations observed that the current level of joined-up working varied regionally, and could be hampered by a lack of understanding of what each part of the system does, conflicting requirements, a lack of willingness to share information and poor communication. They noted that it is important for staff at all levels to understand the needs of individuals.

National direction was seen to be crucial by some, and it was suggested that the Government should provide leadership at the national level, while local authorities plan and implement the joined-up approach. There was however, a concern among some local organisations that the Green Paper saw local authorities in a managerial role, which, in some instances, would be seen to be an unnecessary burden when many local authorities are already overstretched. These organisations emphasised that local authorities should have purely a delivery and regulatory role in terms of local services.

There was support for a single assessment, although there was a concern among some of

the older participants that this should not be too intrusive, and that it may not take account of fluctuating needs. Some organisations noted that emphasis on joined-up assessments should be more of a priority than joined-up delivery, to minimise duplication for the individual. However, some stakeholders at the regional events were concerned that just one professional may not possess all the skills needed for an all-round assessment.



Respondents felt that more detail was needed on this component in terms of how the joined-up service would work, how partnership working was to be strengthened, and how the Government would identify better use of existing resources, particularly between the NHS and care and support services. The extent to which budgets would be joined-up was seen as key by some stakeholders. Furthermore, some national organisations felt the detail of how joined-up working would be achieved was the area that would require the most work to make the National Care Service a success.

Information and advice

Participants were very supportive of the proposal to provide high quality information and advice. This was seen as very important in delivering the vision for the National Care Service.

Lack of awareness of what is currently available was seen as one of the key barriers to high quality care and support. Information and advice were described by some as essential, and something that should also be considered a preventative measure. However, some participants noted that many people do not currently know where to access this information and advice.

There was a perception among a number of participants that there is currently much reliance on the third sector for distributing information and advice. As such, there was some concern about the consistency and availability of information given the nature of the funding and spread of third sector organisations. There was therefore support for a national entitlement to information which can be fully relied upon and would be accessible to all.

A number of participants noted that it is imperative that information and advice is timely and accessible to all, regardless of whether people are eligible for care and support or not. National organisations stressed the importance of not excluding people who are unable to leave their homes, or who are in a care home, and would not necessarily actively look for information. Again, proactivity on the part of service providers tended to be seen as important. GPs and nurses were thought to have an important role in terms of signposting, and a number of stakeholders noted that they should be trained to ensure that they are aware of locally available services, and give accurate information and advice.

Participants across all audiences noted that information and advice should be available in different formats. It should be simple and clear, to ensure that people can understand it,

including people whose illness or disability may impact on this – for example, those with learning disabilities. Participants across all audiences stressed the importance of having information that is locally based and joined-up and includes information about all services available in one place. It was thought that this should include information about resources, application and assessment processes, review and feedback, including complaints procedures. A number of organisations cited a physical hub – for example, a ‘one-stop shop’ – where people could access this information. Some older participants particularly, often cited the desire for face-to-face contact to get this information. However, a number of participants across all audiences emphasised that this information must be up-to-date and accurate to be useful. It was perceived that any incorrect information could cause more harm than not having any in the first place.

There was the perception that not everyone would find it easy to navigate the care and support system, and a number across all audiences noted that there should be a service in place where people have access to others who are able to help them. It was suggested that this could take the form of a dedicated information service, but some argued that this should go further, with a greater emphasis on advocacy services to ensure those using care and support get the most out of it.

Personalised care and support

Personalisation of care was raised by many participants in the open consultation as an essential feature of how a new care and support system should work. The emphasis was on involving the service user or their family in decision making (1,059 spontaneous comments in the open consultation) and better assessment,

or assessment by someone with knowledge of the person receiving care (288).

“I think that person centred planning must be at the centre of the provision for the future. People’s support and life needs can be properly discussed with them and they can then enjoy a full life – the family’s needs can also be assessed and discussed.”

(Response to open consultation)

A number of national organisations welcomed the emphasis placed on choice. Some suggested that personalisation should be the core principle of the proposed National Care Service, and it was suggested that it be placed first on the list of key principles, rather than lower down the list. Putting service users and carers to the forefront of a National Care Service and treating them as ‘experts’ was viewed as the optimal way forward by some. This was seen to be different from how the current system works, meaning that a change of culture would be required to enable such choice and the participation of the care recipient. Some believed that service users should be allowed to determine their own needs – some suggested with the support of social workers – and the use of personal budgets enables this. There was a strong sense among some participants in the open consultation that some funds must be in control of individuals themselves through allowances, to allow for costs which may not be considered as ‘care’, such as paying for maintenance of a house, or

taxi fares. A number also felt strongly that the personalisation of residential care should not be ignored in a new National Care Service.

Personalisation was seen to be particularly important for those with fluctuating care needs, and was a point raised by a number of participants. Mental health problems were cited as an example of where care needs can vary greatly over time, and there was a concern that a National Care Service take account of those whose needs are episodic.

Personal budgets were seen to be positive in this respect, in terms of offering choice and flexibility. However, some organisations and participants at stakeholder events noted that these do not suit everyone, and pointed out that some individuals do not feel comfortable managing their own budgets. Some stakeholders also said that there should be safeguards in place to ensure that people are not coerced into using their budgets in certain ways by family members or other care providers.

“We need an independent funded advice and brokerage service for individuals who feel unable or unwilling to deal with budgets and decisions around selecting appropriate services and support.”

(Comment at stakeholder event)

There was a concern among some older people that personal budgets should be large enough to provide for an individual’s care needs. Similarly, some of the stakeholders at regional events noted that personal budgets would only be as

successful as the quality of care services available, and needed to be large enough to provide sufficient payment to carers to ensure that care becomes a respected profession.

Personalising care and support was seen to require a different care workforce, given that professionals might be asked to offer new services or adopt different ways of working to deliver care and support people really want. Some participants noted that there should be an emphasis on social workers and volunteers as well as more traditional carers, and sufficient support must be provided for these groups.

There was, however, concern among some of those responding that there must be sufficient financial support to make this a reality. Lack of time, money and skills were seen to be some of the barriers to personalised care and support. One national organisation also raised the concern that greater personalisation does not necessarily fit with the principle of joined-up services, and suggested that it could lead to greater fragmentation of the system.

Fair funding

Funding tended to be an important issue for some participants in the open consultation. The most commonly mentioned concerns by this group were: that a system should be fully funded by taxation; homeowners or savers should not be penalised; there should be more funding; and that those who have not contributed to the system through their working lives should not be funded. This is discussed in further detail in the section on funding and managing the National Care Service.



“It should not discriminate against those who have worked hard all their lives, spent and saved their money wisely, by forcing them to pay for their care where others, who have been less wise, get it provided free.”

(Response to open consultation)

Several national organisations observed that there is currently no measure of unmet need for care and support, and that accurate research needs to be done on how existing money is being spent, before new structures are put in place.

A number of participants wanted to see further clarity on the principle of fair funding, particularly in terms of what ‘fair’ actually means. Some participants of the open consultation wanted to see funding that was ‘fair’:

- across the country – ensuring everyone has the same level of service;
- across different modes of care – for example payment for family carers;
- over time – increasing with inflation; and
- across socio-economic groups.

A number of stakeholders also cited the need for clarity on eligibility criteria and how those of working age would be funded. A recommendation from a local organisation was to add the word 'transparent' to the point about fair funding, since service users can never know that funding is 'fair' unless the mechanisms and detail are available to them.

There was a concern that some people in need might be excluded from state-funded care and support. Many local organisations opposed means testing, and felt that there would still be people who fall outside of the system, and are not eligible for state funding but are unable to pay for care themselves. Means testing was seen by some to penalise those who have saved throughout their lives, and even to act as a disincentive for people to save. It was also perceived to add an extra level of bureaucracy, and some local organisations noted that the process could be considered to be intrusive and degrading.

"Means testing... means that they lose dignity, something that people have held onto, and goes hand in hand with respect and independence. The government are and have been for some considerable time running a campaign on dignity and respect and we believe that the suggestions from this Green Paper would contradict this campaign."

(Local organisation)

A number of participants also went on to say that there was a need to support everyone, not just those in critical need. Some local organisations also noted that there is inequality in what different people are charged for the same service, and the National Care Service must seek to remove this inequality and ensure that all costs are charged equitably, irrespective of the source of funding, which could be the state, private insurance or the individual.

Personal budgets and handing control to service users themselves was seen positively by some in terms of ensuring that funding is fair, although it was noted that such budgets must be increased each year to keep in line with rising costs. Some of the stakeholders noted that the Government must be clear in terms of what it would and would not provide, including how much funding would be provided and who would be eligible, to allow people to plan accordingly for their own care and support.

Several organisations discussed the current economic climate, and the impact that it is likely to have on fair funding. Not only was it suggested by some that setting up a National Care Service in general would be difficult given the current conditions, but also that thresholds for receiving care and support may be set higher and higher, as service providers try to keep costs to a minimum. Some local organisations expressed a lack of trust that the Government would use allocated funds for social care purposes, if there is currently pressure for funding elsewhere.

What is missing from the six key elements?

While there was support for all six elements, participants identified further elements which they felt should be given more explicit

consideration in the proposals. The following were the issues identified, each of which is discussed further in this section:

- a definition of care and support
- incentives to encourage people to plan ahead
- an emphasis on human rights
- a commitment to listening to and involving service users and carers
- the importance of maintaining independence
- inclusion of housing services
- achieving high quality care
- a commitment to inclusion and respect for diversity
- a commitment to safeguarding vulnerable adults
- a recognition of changing demographics.

The role of carers and the quality of the workforce were also major issues emerging from the consultation. These themes are discussed further at the end of this chapter.



On top of these, there was a need for greater clarification on exactly how each of the six proposed principles would be implemented. There was a concern among some of the participants that the needs of working age adults

had not been sufficiently considered in the proposals, compared to those of older people. Some local organisations asserted that the National Care Service should work in the same way for everyone, irrespective of age, while others noted that those needing care at a younger age have very different needs from older people and should be considered separately. Some organisations also felt that children should have been within the scope of the Green Paper.

A clear message to emerge from the consultation was a need for a definition and explanation of care and support. A number of participants across all audiences indicated that they wanted further information on exactly what would be included, and what classifies as 'basic' care and support, given that people have different ideas and standards. There was an element of confusion among some in what is classified as health care and what is social care, and clarification is needed in this regard. A number of the participants in the open consultation noted that 'care' must also be about improving the quality of life more broadly.

“When you talk about ‘care’ are you solely talking about social care or about health care as well?”

(Response to open consultation)

Linked to this point, it was also pointed out by some organisations and also in the open consultation, that 'support' should be a vital part of the name of the new service, as it suggests less dependence than 'care'. As such, explicitly including the word 'support' in the name of the new service was suggested by some national stakeholder organisations.

“The word ‘care’ in National Care Service ignores the fact that many people, want/need support and not necessarily personal care. The support in ‘care and support’ has been undervalued for too long.”

(Response to open consultation)

Some local organisations highlighted the need to ensure public expectations remain at a realistic level. While the proposals and the emphasis on choice were viewed positively by some, a number felt it was important not to increase expectations too much. There also tended to be a concern that once people can have something for free, they will often want more and more, which can create greater dependency on the state. Some of the local and national organisations stressed that it was important to ensure that people are aware of exactly what would and would not be covered by the state and to provide incentives and a public awareness campaign to encourage people to plan ahead for their own care and support. One national organisation suggested tax relief, or the use of similar incentives to those used for pensions or savings.

An emphasis on human rights was seen to be very important in the proposed National Care Service by some of the participants. While some stakeholders acknowledged that the personalisation principle incorporated human rights, others would like to see this mentioned explicitly in the White Paper. There was also the assertion that the language of human rights should be used, and that people should not be labelled as dependent.

In a similar vein, while personalisation was seen to hint at involving and listening to the service user, some organisations felt that an additional expectation of listening to and involving service users and carers should be added. People who use services and carers were referred to throughout the Green Paper as an essential element of the proposed new service; it was seen to be essential that the involvement, expertise and experience of both these groups should not be overlooked.

Maintaining independence was also prioritised by many organisations who noted that it should be one of the guiding principles for the proposed National Care Service. In terms of achieving this independence, housing and housing related support were also seen to be a key element missing from the list. This was seen by many to be essential in terms of enabling people to remain independent, and some felt it was intrinsically linked with care and support. Similarly, other related services such as education, training and leisure facilities tended to be seen as important.

Some participants felt that the Green Paper did not have a sufficient focus on quality of care, and there were concerns that achieving high quality services cannot be assumed. Some wanted to see a commitment to quality of care stated explicitly in the proposals. There was a suggestion by others that there should be a basic quality threshold below which no service delivery should fall, and that users should be involved in defining what quality means when delivering care and support services.

Inclusion was also seen to be a key issue omitted from the six principles, and a number of both stakeholders and the general public wanted to see a commitment to respecting diversity and providing culturally sensitive services. It was thought by some that a National Care Service should be inclusive of all, regardless of their classification by ethnicity, age or disability, and should take account of differing levels of need.

There were concerns among a number of stakeholders at the regional events that there were not sufficient proposals in place to safeguard vulnerable adults, to ensure that they are included in the new system and not sidelined in any way. Some stakeholders felt that there would be some people who do not qualify for state-funded care and support, but still have care needs for which they are unable to pay themselves. They suggested that there should be some mechanism in place to direct them towards other areas of support. Similarly, 696 participants in the open consultation felt that the proposals failed to meet the needs of the weak and vulnerable.

A number of stakeholders and participants in the open consultation welcomed the acknowledgement of changing demographics in the proposals. However, they would like to see further details on how the new system would respond to this change and reassurance that it would be able to cope with both a continuously changing population and rising expectations.

Carers and the social care workforce

One of the key criticisms to emerge from the consultation was the lack of attention given to both carers and the social care workforce in the Green Paper. Seen by a number of participants to

be the backbone of the care and support system, many believed that there needs to be additional support to help those providing care and support to others.

Carers

A number of participants across all audiences noted that carers are under-supported and not sufficiently recognised. Of the responses to the open consultation, 1,004 participants talked about carers when asked what was missing from the list of six principles.

“It is recognised that informal carers save the economy millions by providing unpaid care and that in order to do so they require support – I don’t see their needs reflected in the list.”

(Response to open consultation)

“What seems to be missing is acknowledgement of the role of parents and families in providing care for people of all ages. The new system should seek to celebrate this contribution and support family and parent carers financially and with personalised training for their circumstances.”

(Response to open consultation)

Carers in particular were seen to lack support, and some of the stakeholders at regional events observed that these carers were often left to deal with low level needs on their own, while services focused on acute needs. Some believed that there needs to be recognition that carers often have differing needs, for example, they may be children, or older people caring for a partner, or son or daughter, and may not always see themselves as carers.

There was much debate surrounding whether or not carers should be paid. Some national organisations and some participants in the open consultation felt strongly that they should receive a salary and the same rights as carers employed in the sector. Other national organisations however, tended to assert that the care given by carers must be recognised and supported, but must also remain voluntary, and not taken advantage of. Some national organisations suggested that there should be some recognition of the skills gained by carers during their time as a carer.

A number of participants across all audiences noted that greater information about services should be available to carers, to ensure that they are able to offer sufficient, accurate advice to the people for whom they care.

Some of the national organisations noted that it was unclear what impact the proposals would have on carer benefits and allowances, but some took the view that Carer's Allowance is of particular importance to allow carers to continue their role. A number of stakeholders at regional events noted that this should continue and take account of any lost earnings due to being a carer.

Social care workforce

Some stakeholders (both organisations and those at regional events) noted that the social care workforce tended to be viewed negatively by the general public. Similarly, some of the participants in the open consultation also noted that the person caring for them often changed between visits, and sometimes they had minimal levels of English.



In order for a National Care Service to work effectively, there was a tendency to think that the perception of carers needs to improve. Training was often cited as a way in which to improve the sector, by providing a proper career path and appropriate remuneration. One national organisation referred to the motives of carers. Given the low pay and often poor conditions in which they work, carers tend to work in the sector for fulfilment, which means that it is important to keep the workforce 'on side' when communicating and managing the changes.

Looking from the other side, some local organisations also asserted that there should be formal qualifications introduced for care staff, as a means of safeguarding those for whom they care.

DELIVERING THE VISION

Summary

The Green Paper outlined that in order to make our vision for the future of care and support a reality, three changes needed to be made. These were better quality and innovation, a wider range of services, and more joined-up working. The majority of participants agreed with these three changes.

There were also a number of further suggestions on how to make a new National Care Service work better, including:

- services for everyone
- well-trained staff
- a cultural change within the sector
- strong, national leadership
- an evolving process with opportunities for people using the care service to feed back their opinions
- appropriate regulation.

There were also a number of barriers identified to the implementation of a National Care Service.

Attitudinal barriers

Three key attitudinal barriers were identified; a lack of confidence in the current system, the negative perception of care and support, and choice – which although often a positive, was also seen as a potential problem. There was a perception that too much choice could compromise quality and that without sufficient information, or mental capacity to make informed decisions, handing such choice to the individual could be damaging.

Structural barriers

A number of participants highlighted that failures in the current system should be addressed before a new system is implemented. Different cultures across different service providers was seen to be a barrier to joined-up working, and data protection issues, bureaucracy and concerns about existing management leading a new system were also mentioned.

Some raised the quality of the care workforce and the services provided as a barrier, noting that lack of training and regulation could be detrimental to the implementation of a new system.

Funding was also raised as an issue by many participants in responding to this question. There were concerns about how a National Care Service would be funded, and whether there would be sufficient levels of overall funding to sustain the system.

Some saw local authorities as a barrier to effective implementation because they were perceived as likely to look after their own financial interests before the care needs of the local community.

Some participants were concerned that there would be a lack of political will, and that priorities may change after the general election.

Introduction

The Green Paper proposes three changes that would be necessary to make the National Care Service a reality. The Green Paper suggests that services are better joined-up, of high quality and have an emphasis on choice. The second consultation question asked for reactions to these ideas and whether participants could identify any barriers to making it happen.

the emphasis on quality of services – an aspect which was seen by some to be more important than having a wider range of services. It was suggested that a wider range of services could potentially be confusing for some people, and may be more difficult to co-ordinate. Some national organisations noted that a National Care Service should strive for an improved quality of life for both the service user and those working in the sector or providing care for relatives or friends.

Consultation question 2

Consultation question

2. We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.
- a) Do you agree?
 - b) What would this look like in practice?
 - c) What are the barriers to making this happen?

A majority of participants agreed with the vision (16,611 participants in the open consultation simply answer 'yes' that they agree) and supported



When discussing the vision in the Green Paper, many national organisations wanted to see examples and case studies to help illustrate the key points, and bring the vision to life.

What would this look like?

A number of the issues already raised in the first part of the consultation also emerged as being important for this question, particularly joined-up working. Better communication between services was raised by 387 participants in the open consultation, with a further 128 noting that they would like to see a single agency for services and assessments. However, some local organisations felt that joining-up services would not necessarily solve core problems, and that a lack of communication to care recipients would be more of a hindrance than having two separate systems.

Some of the participants in the stakeholder events visualised a National Care Service whereby everyone works together, using many of the services that currently exist. There was a perception that there are enough care and support services at the moment, but they are not sufficiently joined up. Some participants also noted that there should be services for everyone. Others emphasised that those who are ineligible for state support should not be abandoned, but passed to other potential sources of help.

Staff training was seen to be a priority by a number of participants across all audiences (including 164 participants in the open consultation), to ensure that staff understand the care needs of those they are working with – it must be a *'stable, flexible, well trained workforce, with capacity and time to respond to individual needs, employed on decent pay and*

conditions' (National organisation). One national organisation suggested developing centres of excellence to train staff.

From the point of view of the care recipient, continuity of care was perceived as important by some; for example individuals should have the same carer all the time. The carer should also be familiar with their local community; for example a carer in a predominantly ethnic minority area should understand the needs of the local culture.

A number of stakeholders noted that if the proposals were to go ahead, alongside the structural change required, there would also be a need for cultural change within the sector – a move away from the traditional notion of 'care' towards a more personalised and joined-up approach. This was seen by some as involving wider use of voluntary organisations, encouraging more people to take on small caring roles and developing a workforce which goes beyond what is traditionally seen as 'care'. Some national organisations also stressed the importance of providing support for voluntary workers.

In order for this to work, there was a widely-held view across many audiences, particularly local organisations, that there must be strong leadership at the national level. Generally, it was thought that this is needed in order to bring together the key partners and stakeholders and ensure accountability. One local organisation suggested the introduction of a 'Minister for Older People' to give the National Care Service a political profile, although this conflicts with many of the other comments on the Green Paper, which criticised the lack of attention given to working age adults.

A number of organisations also cited the need for a National Care Service to be an evolving process. They argued that there should be feedback opportunities for individuals using care services, to give them opportunities to comment on provision as it develops, and furthermore that the system should have achievable outcomes against which its success can be measured. They noted that there should be an independent review to assess what is working well and where changes may need to be made.

Many national organisations stressed that social care must be more effectively regulated. While the Green Paper alludes to a new national agency that advises on what works best and what delivers the best value for money, there was a perception that this role should be further defined. Other national organisations noted that it is unclear how this new agency would sit alongside the Care Quality Commission.



Barriers

While the new vision of a National Care Service was supported in principle, some participants identified a number of barriers to its implementation. These barriers can be broken down into two main areas – those related to people's attitudes (eg the public, current or

potential care recipients and those who provide care), and structural barriers in terms of how services are funded, managed and delivered.

Attitudinal

Some stakeholders cited a lack of confidence in the current system, and there was therefore considerable pessimism that the three aspirations would be realised.

“We have been promised joined-up services for many years now with no significant progress apparent, so where is the evidence that this will work now?”

(National organisation)

Many participants in the open consultation felt that social services could not currently cope, and questioned how they would manage a bigger system (461).

There was also concern among some participants in the stakeholder events that while choice can be a good thing, it can also be a barrier if people do not have sufficient information about what is available, or if people do not have the mental capability to make safe and effective choices. Some participants in the general public workshops also said that not only could too much choice be overwhelming, but also that it could be difficult to regulate while also assuring the basic quality of a wide range of services.

Some participants at stakeholder events also observed that the perception of care and support needs to change in order for a National Care

Service to have credibility. There still tends to be a stigma attached to receiving social care, and there were suggestions that an education and awareness-raising campaign would be beneficial. A number of participants in the open consultation also raised this issue, noting that asking for funding rather than receiving allowances could threaten an individual's dignity.

Structural

Structural barriers in general were raised by 784 participants in the open consultation, particularly a lack of co-ordination (222) and communication (243) between organisations (typically between local health services and local authorities).

Some national organisations stressed that the Government needs to address failures in the current system and commit to meeting the shortfall in funding before a new system is implemented. Some participants at both the stakeholder events and the general public workshops expressed a concern that a National Care Service would take a long time to implement, an issue which they felt was not considered sufficiently in the Green Paper. Moving from the current system to the proposed one was seen as requiring many radical changes, not least of which was a concern that the current system is too fragmented.

Changing to complex multi-agency working was thought to be difficult by a number of participants, partly because of the different cultures that exist across different service providers as well as the different eligibility criteria that are used. Larger organisations particularly are noted as being unused to working together. There is a perceived lack of understanding and communication between health and care

services, which would need to be addressed if the proposed National Care Service were to go ahead. Many saw this disparity between health and social care as the major barrier to joined-up working between health and care services.

“One of the biggest questions the Green Paper raises, yet fails to answer, is why there is still a distinction between social care (means-tested and accommodation costs have to be paid) and health. The big care debate that needs to be had, and which the government appears to be avoiding, is why is the NHS different from a National Care Service? ”

(Local organisation)

Data protection issues were cited as a barrier – for some, particularly the general public at workshops, in terms of passing on too much personal information, and for others, in terms of not passing on vital information for fear of breaching the Data Protection Act. Alongside compatibility, data protection issues are seen as a barrier to joining up IT systems, one aspect which is seen to be essential if organisations are to work together.

A number of participants across all audiences cited bureaucracy as a barrier. For example, at stakeholder events the length of forms to be completed to apply for allowances was discussed. In the open consultation, examples included

passing responsibility between different departments or organisations and a lack of clear accountability in the system. National organisations mentioned a range of problems with bureaucracy including problems with specific issues such as assessments and means testing. There were also broader frustrations, including perceived legislative and political barriers and concerns about the number of managers in the system, which many felt should be replaced by more front-line care staff.



Some organisations and some members of the general public at workshops expressed concern that the change in culture required with the new proposals would not be implemented unless the management also changed. There was also a perception that the culture could be 'this is the way we've always done it', and that changing attitudes within the system could be much more difficult to achieve than is perceived. Some took the view that having the same management leading a new system would be ineffective. Care workers were also included in these concerns, and some national organisations noted that they may be reluctant to change and work with other services; 204 participants in the open consultation noted attitudes or mindset of those working in the industry as a barrier.

The quality of the care workforce was an issue raised repeatedly by some participants across all audiences. Carers themselves noted that high turnover of staff could be a barrier to high quality care. Lack of training and regulation was seen as a barrier to improving the quality of care services in the proposed National Care Service. Some questioned how training for the care workforce could be funded.

Many national organisations cited local authorities as a barrier to the effective implementation of a National Care Service. They were thought to have two roles – assessing people's needs and paying for services – and these were perceived as being contradictory. Some organisations felt that local authorities are likely to look after their own financial interests before the care needs of those they are assessing. Similarly, participants in the open consultation felt strongly that a National Care Service should not be run by the local authority (870), and also noted that poor administration or incompetence in local authorities could be a barrier, as could a lack of understanding of a person's needs.

Some national organisations commented that lack of attention to care charges could be a barrier to the successful implementation of a National Care Service. They felt a white paper should address the charges for care, and who pays what for them. This was raised as an issue by some people who need care, who said they did not have access to the help they needed because they could not afford to pay for care.

Funding was identified as one of the key barriers to reforming care and support. Lack of funding was raised by 554 participants in the open consultation, and a number of participants across

all audiences were unsure where the funding for the scheme would come from. Some participants in the open consultation noted the danger of having too many different funding sources, and potentially inappropriate budget management by local authorities if care funding is not ring-fenced. There were concerns among participants in stakeholder events that any funding would be biased towards towns or affluent areas, leaving those in rural areas with few services. Many national organisations emphasised that there should be some pooled funds between health and social care to ensure that the National Care Service is not saving the NHS money at its own expense, and furthermore that the way care is funded should be transparent. There was also a concern among some that no additional funding would be allocated to the transitional period, a time during which some local organisations and members of the general public at workshops were sure that costs would be incurred.

A final barrier, raised predominantly by some of the participants in the open consultation, was a lack of political will. There was a sense that reforms could not be implemented before the election, and that priorities might change afterwards.

FUNDING AND MANAGING THE NATIONAL CARE SERVICE

Summary

All three of the funding options received some support, with Partnership and Comprehensive more favoured than Insurance. In addition, some participants felt that general taxation should not have been ruled out as a funding option.

There were a number of issues raised regarding the future funding of care and support, and in particular a concern that funding should be 'fair':

- Participants were generally opposed to benefit reform.
- They were also concerned that the reforms should not penalise those who save.
- There were differing views about whether accommodation costs should be included in the National Care Service or not.

Other comments focused on broader issues such as the sustainability of the funding options, whether they would deliver reform quickly enough and the extent to which adequate funding would be realised to achieve the vision outlined in the Green Paper.

There was some support for both a fully national care and support system and a part-local, part-national model. On balance, participants tended to opt for national consistency. However, many also argued that some local flexibility would be important to ensure the system delivers high quality, tailored services.

Introduction

The third consultation question asked for responses to the Government's suggestions for how the care and support system could be funded and managed in future. In this section, the different reactions to the specific options outlined by the Government are examined, followed by a number of general issues which were raised across different consultation audiences in response to this question. Finally, views about the respective roles of local and national government are examined.

Consultation question

3. The Government is suggesting three ways in which the National Care Service could be funded in the future:

- **Partnership** – People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.
- **Insurance** – As well as providing a quarter to a third of the cost of people's care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.
- **Comprehensive** – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.

a) Which of these options do you prefer, and why?

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

Consultation question 3a

The issue of fair funding is discussed in some detail in the chapter dealing with responses to the first consultation question. Similar concerns about how the system can be equitable across the country and between different groups in society were raised in response to this question, and in particular under the main themes outlined below.

Views of the funding options

In the open consultation, there was some support for all three of the funding options. Among those participants who stated a preference, Comprehensive (41%) and Partnership (35%) were more favoured than Insurance (22%), while a small minority selected more than one option (1%).

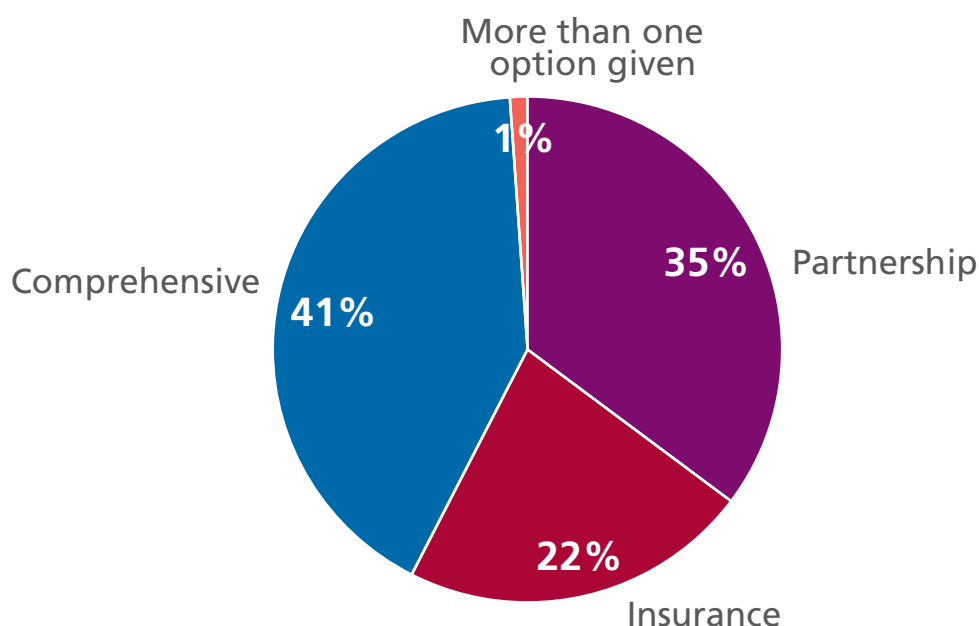
Several strands of the consultation allowed participants to explain their reasons for selecting

a particular option. In addition, many local and national organisations also discussed their funding preferences, although not all felt they could select a particular option, for reasons discussed below.

The Partnership option

The Partnership option was seen by a number of participants as closest to the current system. For some consultation participants this was an advantage, as they saw Partnership as a good first step that could be built on in future. They argued that it was the simplest and fairest of the three options because everyone is entitled to at least some help in paying for any care and support needs they may have. As such, some felt the Partnership option could provide a realistic solution to the funding gap for care and support, even if more radical change is required in the longer term.

Q How should the new system be funded?



Base: 19,255 consultation participants who gave a response

Source: Ipsos MORI

Ipsos MORI

“Your partnership system is not exactly what I would do but nearly there. The main thing is that all must pay while of working age, not by seizing assets.”

(Response to open consultation)

By contrast, others said the similarity to the current system is a weakness of the Partnership option. A number of those who wanted radical change to care funding felt this option would have many of the disadvantages of the current system, and in particular a lack of affordability for those who use services. There was a perception among some participants that the Partnership option would not release the additional funds required to achieve the high quality services described elsewhere in the Green Paper.

There was some support for the principle of sharing costs between Government and individuals, and in particular that those who can afford to pay should be expected to contribute to some extent. However, many felt that any contributions must not be prohibitive for individuals, and there was a concern that the Partnership option may be unaffordable (although this was a view echoed with reference to the other funding options as well).

“I do not want partnership of any kind because I would still worry about being able to pay my part of the funding. I do not want to worry about funding once I am old, infirm or incapacitated.”

(Response to open consultation)

There were calls for greater clarity about how the Partnership option would work in practice. Some participants pointed out that as everyone would receive a proportion of their costs paid by the state (which is not the case under the current system) it is not clear where the additional money for this option would be sourced. Others were unsure how the differing costs of care across the country would be accounted for under this option.

The general public workshops suggested that the Partnership option was preferred by those participants willing to take a risk that they may not need care and support services in the future, and therefore may not have to pay for them.

The Insurance option

There was less support for the Insurance option than for the other funding options. Those who preferred the Insurance option said they were attracted to the idea of being able to prepare for their future care needs, particularly if they could do so throughout their working life.

The Insurance option was also seen by some as offering greater flexibility and personal choice about the level of care provision people could put in place (in contrast with the compulsory Comprehensive option). As such, it was seen as a good way to voluntarily top-up care funding.

“I like the idea of being able to prepare for my old age but I don’t want my home to be taken to cover costs... An insurance based scheme is a responsible way to do this and if it is a government backed scheme I would expect it to be completely safe.”

(Response to open consultation)

However, many consultation participants were unsure about the detail of how the Insurance option would work in practice, and in particular the following queries emerged:

- If the scheme is not compulsory, there was scepticism that enough people would choose to take out this kind of insurance voluntarily to make it a viable option.
- Many were concerned that premiums would not be affordable for most people.
- Others felt that a proportion of an individual’s contributions should be refunded to their next of kin if they never needed to use care and support services.

- There were fears that those with pre-existing conditions would not be able to find insurance cover, meaning that the most vulnerable would lose out.
- Participants were worried that the Insurance option may discourage efforts to improve prevention because people would feel they are ‘covered’ for the future. Some suggested a type of ‘no claims’ benefit to avoid individuals relying on care rather than taking responsibility for their own health.
- Similarly, there was a perception that having insurance in place may reduce the willingness of family and friends to provide care.

A number of participants also drew comparisons with other countries, predominantly the United States, where they felt that insurance schemes have not been a success.

Many participants across consultation audiences stated a principled opposition to private companies making profits from care and support services. In addition, negative experiences of making a claim on other types of insurance meant some did not feel private insurance to be appropriate for something as sensitive as paying for care and support needs. Among some participants there was a general distrust of the financial sector following the recent recession, and a concern that people may not actually receive the payments they are entitled to when they develop care needs in the future. As such, for some a state-backed insurance option would be more acceptable than a private sector scheme.

“We are strongly opposed to the introduction of private insurance for funding the national care service, as the present record of private insurance in the care market is not encouraging.”

(Local organisation)

“I don’t trust private insurance. There will always be some reason why they do not pay. There are always exclusions and get-out clauses in small print.”

(Response to open consultation)

The Comprehensive option

The Comprehensive option was supported by those who wanted a system that provides universal cover to all those who require care and support, and they often said this should happen in a similar way to the NHS. Another perceived advantage of the Comprehensive system was that individuals would know well in advance what they would pay towards the costs of their care.

“Comprehensive is the fairest and covers most people. Partnership and Insurance options will exclude people who just fall below the threshold for free care and cause unnecessary financial burden.”

(Response to open consultation)

Many also pointed out that sharing the costs across society reduces the amount each individual has to contribute. They felt this would be a fairer way to deal with the funding gap than either the Partnership or Insurance options, which could still leave some people with significant costs to pay themselves.

A state-run compulsory scheme was also seen as more secure by some, and perceived as more likely to be guaranteed to pay what people expect when they need it. Similarly, some national and local organisations thought that the Comprehensive option had the benefit of being easier for the public to understand than either the current system or the alternative funding options.

In line with comments on the other options, there was some confusion about the detail of how the Comprehensive option would work. Some were unclear why only those over 65 would be expected to pay. There were also questions about whether individuals would be able to top up their contributions to get a better level of care (an approach supported by some and opposed by others).



There were some concerns about the affordability of the Comprehensive option, particularly if it involved paying a lump sum on retirement (something many people approaching retirement ruled out as unworkable). Some preferred the idea of paying during their working life. Furthermore, a number of national organisations felt that the Comprehensive option could create an incentive for people to demand services they do not need to ensure they are receiving value for money. As with the Insurance option, there were some concerns that people would feel they are 'covered' and that this could undermine efforts to promote prevention, as well as making family and friends more reluctant to take on caring responsibilities.

“Cost of the Comprehensive scheme could be prohibitive for those on a low income.”

(Response to open consultation)

The findings from the general public workshops suggested that the Comprehensive option was preferred by those who wanted greater peace of mind and were unwilling to take risks about whether they might need care in the future. They wanted to guarantee that they would

receive care and support irrespective of financial or family circumstances at the time they need care.

Other funding issues

A number of consultation responses demonstrated considerable frustration that the Green Paper ruled out funding care and support through general taxation. This was a recurring theme across consultation audiences, but many national and local organisations in particular felt this option may be the only sustainable way to meet the funding gap.

Others argued that taxation is the only fair way to pay for care and support. They felt that care and support should be funded in the same way as other key public services such as healthcare and education. Some national organisations wanted the Government to explain in more detail why a tax-funded option was ruled out ahead of the Green Paper being published.

“We think that the funding of the National Care Service via Income Tax or National Insurance has so many benefits that it should still be considered as an option and not ruled out as in [the Green Paper].”

(Local organisation)

Many national organisations were unwilling to state a preference for one of the funding options, either because they preferred a model based on general taxation or because they did not feel the Green Paper gave enough detail for them to reach a decision. There was some anger that the Government did not publish the full details of the

funding models during the consultation period, as national organisations said they wanted to scrutinise the underlying assumptions before choosing an option.

A number of national organisations also came up with suggestions as to how people could fund their care and support costs better. This included ideas such as equity release schemes, allowing home owners to pay for home-based care by deferring the costs until their home is sold, and proposals that allowed people to access their pensions, tax-free.

“By offering three options in this way, the debate is closed off, creativity is stifled and other options appear to be discounted.”

(National organisation)

In addition, there were a number of general points about funding care and support in the future raised by participants across the consultation audiences:

- There were concerns whether any of the options would be sustainable in the long term given the changing demographic pressures likely to be faced by the country.
- Many stakeholders argued that the funding crisis is urgent and were unsure that any of the suggested options would provide the additional money needed in the short term.
- There were some concerns that people in general do not understand care and support and that the public debate about future funding has been inadequate as a result.

- There were calls for greater clarity about the level of care and support people would be entitled to under each funding option.
- A desire was expressed by a number of participants for clearer proposals about how the additional funds would be spent to achieve the other reforms outlined in the Green Paper, and concerns that the options may not release sufficient money for this to happen successfully.

“It is unclear where new money necessary to boost the overall pot is coming from – everyone seems better off in this system.”

(National organisation)

Benefit reform: Attendance Allowance and Disability Living Allowance

Overall, one of the key themes that emerged from the consultation responses (and especially the open consultation) was strong opposition to the reform of benefits – in particular Attendance Allowance (AA) and Disability Living Allowance (DLA) – in order to fund care and support. This was mentioned by a large number of respondents across all audiences. Opposition to reforming DLA was mentioned by 1,811 participants in the open consultation, and against reforming AA by 933. Benefit reform was therefore one of the most consistently cited concerns across the consultation as a whole. Many were disappointed that there was not more detail given in the Green Paper about benefit reform. However, the announcement on 22 October 2009 that the Government was not considering integration of DLA for the under 65s into the National Care Service was welcomed by some stakeholders.²

² www.dh.gov.uk/en/News/Speeches/DH_107455



Those in receipt of these benefits to help with their care needs were often angry that the Government would consider taking away these payments from some possible future recipients, for a number of reasons:

- Both AA and DLA were generally seen as strengths of the current care and support system, because these benefits allow users to have choice and control over some aspects of their care.
- A number of participants pointed out that these benefits represent a source of support available to users irrespective of whether they have low, medium or high care needs, and as such were viewed by some as important to prevent greater reliance on formal care services and to enable people to stay independent for longer.

“What is important is that folk like me with limited mobility be allowed to live as

independent a life as possible. Without my DLA I will have to choose which medical appointments I go to as on pension alone I will NOT be able to afford taxis for all of them.”

(Response to open consultation)

- There was therefore some concern that removing these benefits could bring more people into the care and support system who currently manage well. Furthermore, AA and DLA were seen as representing value for money because formal care services were perceived as more expensive.
- Many participants were worried that removal of these benefits may not be balanced by equivalent or greater support on a similar basis (to all those who would currently be entitled to it), and some felt that the most vulnerable users may be harmed as a result.

“Currently the Attendance Allowance provides an easy and usually quick route for people to set up a proportion of their care needs. In many cases this may be all that is needed. Taking it away forces everyone who needs even a small amount of care to submit to a means-test.”

(Response to open consultation)

Concerns about AA and DLA were shared by most local and national organisations that represent the interests of individual care users and their carers. Many felt that removing these benefits contradicted the welcome focus on prevention in the Green Paper, whatever the advantages might be in terms of paying for care and support in the future.

Some national stakeholder organisations suggested that merging these benefits into an overall package for care funding could be done at an individual level, but only with the consent of the care user. Others argued that integrating these benefits could be part of the funding solution for care and support, but they had reservations about the impact this would have on care users in practice. At the very least, these stakeholders said that integrating benefits should not impact on independence and choice, particularly for those with lower or medium level needs who were seen as benefiting considerably from the current arrangements.

Penalising those who have saved

Many open consultation participants expressed strong concern that funding care and support should not penalise those who have saved or prepared financially during the course of their lives. It was seen as unfair by some that those who have worked hard, saved and paid taxes should be expected to pay for their own care needs when others who have not done so are supported by the taxpayer.

In particular, many felt that using housing assets to pay for care would be unacceptable, as they

felt a strong attachment to their home and saw it as something to pass on to the next generation. Furthermore, there was a strong sense among many participants that they have been paying into the general tax and National Insurance systems all their lives, and that it would be unfair to expect them to contribute further when they had not been expecting to do so.³ As a result, many consultation participants were unwilling to support any funding option that required people approaching or beyond retirement to pay for care and support services. Some were aware that current funding means many individuals pay for their own care and support; most felt this was unfair and should not continue under the new care and support system.

However, there were some comments that were in favour of people being expected to use savings or housing assets to pay for care. Many of these participants argued that the modern inheritance culture is not sustainable, and that housing assets represent an important source of funding for care that should not be discounted. A small number of national stakeholders also shared this view.

Accommodation costs

The exclusion of accommodation costs from the Green Paper's funding suggestions was another much discussed issue. Many argued that paying for accommodation represents a large proportion of the cost of care to individuals, and that this therefore should be dealt with as part of the overall package of reforms in some way.

Some national organisations in particular went further, arguing that the care system should

³ This is linked to confusion about how the current system is funded. Other surveys conducted by Ipsos MORI demonstrate that many people presume care and support services will be free and do not realise that individuals typically pay for services if they have savings or assets over a minimum threshold.

cover or include at least a proportion of the funding for an individual's accommodation. They felt appropriate housing (or residential care) is key to people having adequate care and support, and that any thorough overhaul of funding should include provision for accommodation costs. On the other hand, others acknowledged that it was not appropriate for state funding to pay accommodation costs for individuals.

Consultation question 3b

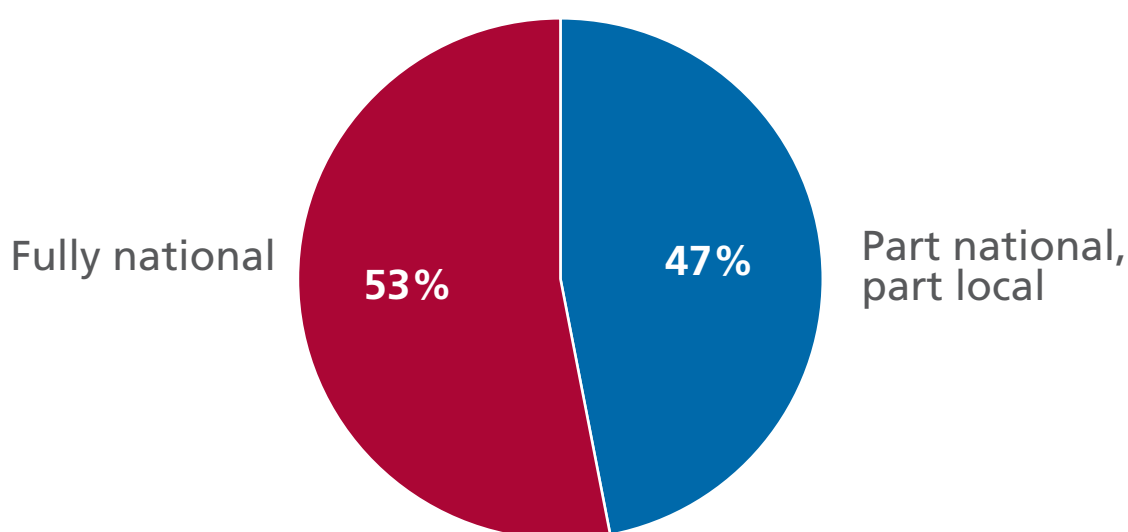
There was considerable debate about whether funding decisions in the National Care Service should be made at a local or national level, and no clear consensus emerges from the consultation responses. There was slightly more support among participants in the open

consultation for a fully national system (53% of those giving a view) rather than a part-national part-local model (47%).

Support for national government deciding

Many said achieving national consistency was the only way to ensure fairness in the care and support system. They argued strongly that the postcode lottery⁴ must not be allowed to continue – 321 participants in the open consultation said that care should not be a postcode lottery. In addition, some stakeholders felt that a nationally funded system would increase portability, giving people with care needs the confidence to move to a different area without the fear of services being reduced, or the prospect of further assessments.

Q *Should local government get a say in how much money people get depending on their area, or should national government decide?*



Base: 18,050 consultation participants who gave a response

Source: Ipsos MORI

Ipsos MORI

⁴ A situation in which the standard of public services received by the public varies from area to area, depending on the funding policies of local service providers.

“Care should be organised nationally not locally. There should be a system that does not prevent you moving house because the next local authority either won’t assess until you’re there or has different criteria.”

(Response to open consultation)

Many of those who said they supported national funding did so because of their concerns about a locally run service, rather than because of perceived benefits of a nationally run system. There was considerable scepticism about local authorities among participants in the open consultation, often based on frustrating personal experiences attempting to access funding for care and support. These participants felt that spending on care should be ring-fenced if local authorities are given control of budgets, to ensure that they do not cut spending below a nationally agreed minimum. Some claimed that local government is incompetent and wasteful, and that a local approach would not be tailored to meet the needs of the user. Others argued that the role of local authorities was confused, as they provide, commission and regulate different services. This was seen by some as unfair to private and voluntary sector service providers.

Both national and local stakeholder organisations generally supported a national system because they agreed that services should be consistent across England. Some also argued that a national system would be more efficient and cost-

effective, and that consistency would help service users to be clearer about what to expect from the care and support system.

Support for local government having a say

There was little spontaneous support for a fully local care and support system, but many participants said that a measure of local flexibility was needed to deliver the best care and support services. Some participants in the open consultation supported a combined approach, saying that care and support should be nationally controlled, as long as local conditions are taken into consideration (136).

“A fully national system would bring efficiency savings but would lose out on local flexibility and opportunities for creativity.”

(National organisation)

There was widespread agreement across audiences that service standards, entitlements and overall levels of funding should be decided nationally. However, some felt that assessments should be carried out by someone who understands the specific characteristics of the local area in which the care user lives.

Some national organisations in particular felt that local flexibility is important. They said that local agencies have an important role to play in providing guidance to individual service users, as well as being responsible for enabling an innovative and high quality care and support sector in their area.

Part 2: Consultation Evidence

Supplementary Research

Prepared for the Department of Health
by Opinion Leader

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1. EXECUTIVE SUMMARY

1.1. Introduction

In July 2009 the Green Paper 'Shaping the Future of Care Together' was published, setting out the Government's vision for the creation of a new National Care Service.

Following this the Government launched 'The Big Care Debate', with a four-month consultation component gathering the views of the public, carers and stakeholders on this vision. This report details the findings of a supplementary piece of research with 'unengaged' audiences who would be unlikely or unable to engage in the consultation through the means provided.

The research comprised the following:

- two five-hour deliberative workshops with 24 members of the public per event
- fourteen extended group discussions, each lasting two and a half hours, with ethnic minority communities (EMC) (Bangladeshi, Pakistani, Somali, Ghanaian, Nigerian and Caribbean) and gay and lesbian audiences
- seven one-to-one in-depth interviews with faith leaders representing Muslim, Hindu, Sikh, Roman Catholic, Jehovah's Witness and Jewish faiths
- two one-to-one in-depth interviews with transgender participants.

Full details of the methodology, sample, discussion guides and materials used are provided in Appendices B, C and D in the Green Paper, Volume Two (see Annexes).

1.2 Context for response

There is low awareness of the current care and support system amongst this audience generally (and particularly so amongst the youngest participants). Most do not want to think about the idea of getting older, being dependent on others or needing care and support.

There is extensive confusion about exactly what care and support is with many reverting to the term 'social care' in their discussions. It is often perceived to be part of the National Health Service (and to share many of the characteristics of the NHS such as being free at the point of use).

Although few have had any direct experience and, amongst those that have, experiences have been mixed, the overwhelming perception of the care and support system is negative. There is an assumption fuelled partially by the media that the service is slow to respond, difficult to access, provides inconsistent quality and is disjointed.

There is also some general scepticism about central Government, specifically a lack of trust in decision-making and delivery and some feeling that the proposals are more about rhetoric than substance.

1.2.1 Points specific to minority audiences

Some of the EMC participants found it difficult initially to relate to the debate having had no experience of the current care and support system. This is particularly true of those in the Somali groups who tended to have most difficulty understanding the terminology associated with the debate.

Many of those in the EMC audiences have an expectation that they will provide care and support for their families (and for some that it would bring shame onto their family not to do so). They, therefore, find it particularly difficult to relate to the current (and proposed) systems and tend to focus on how the proposals will impact on family carers.

However, some in the communities identify a change in attitudes with younger generations becoming more assimilated into Western society, with its associated model of care. Those from the Caribbean, Ghanaian and Pakistani communities in particular feel that this change is already happening and with more pressures on family life, some care will need to be provided externally in future.

1.3 Response to the case for change

Although there is some awareness of the changes in societal demographics (the ageing population and rising life expectancy), few are aware of the scale of change. They find the falling ratio of working people to those who are retired particularly concerning.

There is broad agreement that reforming the care and support system should be a key priority for

the Government. This sentiment is also expressed by communities that currently benefit from receiving care within the family or community. Despite feeling content with receiving care themselves, they nevertheless recognise that others may not, and feel it should be a priority for the sake of wider society (and for them if circumstances change and they require help in future).

The information provided on changing demographics immediately raises questions relating to funding and resourcing generally.

1.3.1 Points specific to minority audiences

EMC participants tended to have less knowledge overall of the current system and changing demographics but responses to the case for change were largely similar once information was presented.

A number of participants found it difficult to talk about making provision for care and support because of their religion. Some participants were born again Christians for whom health, life and death are believed to be in God's hands. The thought of making plans or insuring something that is in 'God's hands' is, for them, unthinkable.

1.4 Response to the vision for the National Care Service

There is a generally positive response to the vision and participants are reassured that this is an area that the Government is thinking about and prioritising. They feel that it does cover the key areas of concern and few identify gaps, although there is some call for a greater focus on quality and on carers up-front.

Having a workforce staffed by well-trained, highly qualified professionals is of pivotal importance and perceived to be crucial to the success of the National Care Service. In discussions about the provision of a 'quality' service, the quality and quantity of staff is foremost in people's minds.

The inclusion of carers is also a central theme running throughout discussions. There is a call for families and communities to be better supported to provide care and support themselves, with information provision and training for carers where appropriate.

The vision covers the key characteristics spontaneously identified when the National Care Service was first introduced to participants: joined-up services, national consistency, personalisation, prevention and education and information provision.

Most feel that the six expectations (prevention services, national assessment, a joined-up service, fair funding, personalised care and support and information and advice) work well and complement each other.

For some the introduction of the vision raises questions, including why these expectations are not already in place, is the vision possible, how will it work in practice and how much will it cost?

1.4.1 Joined-up services

Ensuring a joined-up service is felt to be key to the success of the whole system as participants feel it inter-links with all the other expectations:

- One assessment from which all services are planned.
- Services can be better personalised if all involved are aware of the individual's needs.
- Care needs can be prevented from worsening if teams work together.
- It is easier to gain information if it is all in one place.

There is a widespread and spontaneous call for the establishment of a system of 'key workers'; one point of contact for individuals who would be at the centre of this joined-up service.

They would be responsible for the assessment and then oversee and coordinate care. Ideally this key worker would be from the individual's own community or at least an appropriate gender.

Although most are wedded to the idea of having one point of contact, some are concerned whether this one person could be an expert on all aspects of care. They point to the need to have sufficient numbers of highly trained staff and a robust monitoring system to make this work. There is also some concern that joined-up working will be slower (if decisions are made by committee) and that it will cost more (as the whole system will need to be revamped).

1.4.2 National assessment

There is overwhelming support for the concept of a national assessment as long as the assessment process itself can be tailored slightly to suit the individual. Regular reassessment is felt to be extremely important and it is felt that this should be built into the process.

1.4.3 Personalisation

Most feel that the idea of personalisation is positive, although many would like to see personalisation in a limited form and equate personalisation at an individual level with high levels of expense. They suggest a menu of options rather than unlimited choice.

There is a mixed response to the idea of personal budgets, with some suspicion that money could be wasted through people not getting the most from them or abused.

1.4.4 Prevention services

Many focus on the idea of early prevention and education, for example educating people on how they might be able to avoid developing care needs and having regular check-ups. There is a tendency to see prevention exclusively in terms of healthy lifestyles.

1.4.5 Information and advice

The provision of information and advice is felt to be essential and it is expected that it would be a priority. There is a call for a system that proactively provides information, as most would not know where to access information (or that they were entitled to help and support).

Some suggest a high profile public campaign, whilst others suggest that information should be provided through a wide range of sources, including GPs surgeries, online and a telephone helpline and through community groups and organisations.

Discussions on 'fair funding' are outlined in section 1.6 below.

1.4.6 Points specific to minority audiences

Whilst those from minority audiences respond to the expectations in a similar way to the general public participants, there are differences in the extent to which some aspects resonate and the importance placed on particular elements of the vision:

- In terms of national assessment, there is a call for female assessors where appropriate and the assessment of needs on the basis of ethnicity, culture, religion and lifestyle without making assumptions about particular communities.
- Prevention services are felt to be important and are particularly popular with those communities which prefer to take on responsibility for care and support themselves, feeling that anything that would help them look after individuals at home would be beneficial.
- The concept of personalisation resonates with the minority communities particularly well. This is seen mostly in terms of enabling religious or cultural habits to continue or supplying a care worker who is a good 'fit' with the individual (i.e. from the same community or who is sensitive to their needs). They tend to focus on services being tailored at community level, for example day centres for Asian people rather than specifically for Pakistani people.
- The provision of information and outreach work is felt to be especially important for EMC communities, such as those from Bangladesh and Somalia, which do not traditionally seek external support. The Sikh faith leader felt that his culture demands that its adherents are

‘quiet and not outspoken’ which can mean that people do not ask for support when they require it.

- Some believe that their communities, in particular, should be better educated on the care and support system in general. Specifically they believe that the older generations would benefit from seeing positive images and information about nursing homes so that they are less concerned about moving into one should they need to.
- One point of contact is felt to be important to facilitate the navigation of the system for those who are not used to seeking external support. Some of the EMC participants call for literature that is translated and others point to low levels of literacy among older members of their communities.
- As mentioned, all audiences feel that the vision should explicitly mention carers but it is particularly stressed by those ethnic minority communities which tend to provide care in-home without using external support.

1.5 Response to the ways of making the vision a reality

Participants were introduced to the three ways of working: joined-up working, quality and innovation and a wider range of services. In principle all are supported although a number of barriers are immediately raised, including:

- the associated expense
- the time taken to change
- potential resistance to change from within the system.

1.5.1 Joined-up working

The idea of joined-up working is felt to be essential. It is seen in terms of the following:

- departments, agencies and individuals all talking to each other and sharing information
- staff being trained and encouraged to work in a joined-up way
- technological change allowing truly joined-up working
- the inclusion of all relevant parties (including community and religious organisations and family carers).

Some concerns are raised about the practicalities of joined-up working, including the need for cultural change within the organisations and the associated security issues with a large database of personal information.

1.5.2 Quality and innovation

Most see quality purely in terms of staff quality. They feel that staff working in the care sector need to be professional, but also sensitive to emotional and individual needs.

Innovating services is felt to be less of a priority than getting current services right, through building access to and awareness of existing services. Although some feel that sharing best practice within the UK and from international examples would be positive.

1.5.3 Wider range of services

The general consensus is that joined-up working and quality are more important than providing a wider range of services. Some feel that too much choice could be overwhelming and that it could

be difficult to regulate and assure quality of a large number of services. Moreover, some associate the provision of a wider range of services with high levels of expense.

1.5.4 Points specific to minority audiences

The concept of sharing information leads participants to assume this will be implemented through the creation of a database, which is a particular concern for some EMC audiences. They feel that using external care and support would represent a 'loss of face' within their community and who are, therefore, anxious that this information remains confidential. This is mentioned most by those from Bangladeshi and Nigerian communities.

Those from minority audiences call for reassurance that future services are able to respond to the needs of a diverse society and that professional treatment will be given with no discrimination because of ethnic origin or sexuality. Some feel that this is best guaranteed by ensuring that the care workforce is diverse with more people from LGBT and EMC communities actively recruited. There is also felt to be the need for improved training of care workers to ensure that they are sensitive to the needs of all communities.

1.6 Response to the funding options

Most of the participants have not actively considered how they will pay for care and support in the future believing that they either will not require it or that it is provided free. Some are aware of acquaintances selling assets to pay for care, but are vague about the details.

There is concern, when informed, about the (low) point at which individuals need to pay for care (the sliding scale of £23,000) and also about the fact that those on low incomes do receive free care and support. Many feel that the current system does not reward those who work hard and plan for the future.

Discontent with the current system tends to colour responses to the proposed funding options when introduced. This negative response is exacerbated by the fact that accommodation costs are not covered by any of the options. Many simply do not accept that a tax-funded option is not possible.

Responses tend to be influenced by three factors:

- perceptions of fairness (whether this is everyone contributing the same amount or everyone paying for what they use)
- attitude to risk (and how likely they feel that it is that they will require formal care and support)
- an individual's belief system about how society should behave (and fundamentally whether everyone has a responsibility to look after each other or themselves).

At the end of the sessions, participants were asked to select their preferred option. Partnership is most popular overall (with 50 of the 130 participants who selected an option choosing this). Insurance and Comprehensive were selected by 38 and 42 participants respectively.

1.6.1 Partnership

Partnership gains most support largely because it is seen as the least radical change. It is most popular amongst those who feel that they are unlikely to need support in the future and amongst those who are willing to take the risk that they will not need care or who believe that individuals should pay only for what they need. However, some feel strongly that this is a high risk and unfair system.

1.6.2 Insurance

Insurance gained least support overall, as those who want peace of mind tend to opt for the Comprehensive option and those who do not want to pay in tend to opt for the Partnership option.

1.6.3 Comprehensive

This option proves to be fairly popular, particularly amongst faith leaders, EMC males and those at the London general public deliberative workshop. Many participants liken it to a tax and feel that it is fairest if everyone pays the same. Some suggest that a system of means-testing would make this fairer, with even those on the lowest incomes contributing something.

Some reject the idea of a compulsory system outright and are concerned about the impact of the introduction of this system on those approaching retirement age who would not have been able to plan for the payment. For others, the introduction of the payment options (and particularly the ability to pay throughout one's working life) makes the Comprehensive option more acceptable generally.

Participants spontaneously raised the idea of some form of incentive for remaining healthy; this concept resonates with all audiences who discuss this in terms of a 'no-claims bonus'.

1.6.4 Points specific to minority audiences

In a similar way to the general public audiences, there are no clear patterns in terms of EMC participants from particular communities selecting specific funding options. However, their reasons for their selection are in some cases different to those of the general public as a whole:

- A relatively large number of EMC participants select the partnership option because they are certain that their family or their community will provide care and support in the future (because of convention or religious belief). Some also assume that they will return to their country of origin (or 'home' as they put it) and that they will not, therefore, need care in future.
- Some EMC participants and the Muslim faith leader are concerned about the concept of insurance, feeling that it is not appropriate for them because of their religious beliefs (either that they are forbidden to use financial products that accrue interest or that by taking out insurance that they are pre-empting God's will). Some male participants from EMC groups are also concerned about the possibility of the government making money on this sort of scheme.

There are also some particular issues associated with the comprehensive option:

- African males feel very strongly that everyone should contribute to this system and that those on low incomes should still pay something. They reference their own work ethic and are critical of policies that seem to reward those who do not work hard.
- Some EMC participants indicate that if they were to be mandated to pay into a Comprehensive scheme, they and their community would be more likely to use external services, increasing demand overall.
- When asked about the concept of a lower rate for couples, the gay men consulted rejected this option as being unfair. The majority are single and some state that they want to stay single. In contrast, more of the lesbian participants are in relationships – they will rely on their partners to provide care and support, but are sceptical as to whether the government would apply the partnership discount to gay couples.

1.7 Response to the local vs. national funding question

When asked whether funding decisions should be made on a national or local basis, many find it difficult to respond as it is not an issue that many have considered previously. The repercussions of each are hard to envisage, particularly on the local government financial system and there is some confusion over whether both systems would work with all the funding options.

The decision tends to be taken on the basis of two factors – perceptions of fairness and perceptions of the ability of individual local authorities to understand their communities' needs:

- Those participants who feel that everyone should receive the same level of care no matter where they live tend to opt for a fully national system. Those who do not trust their local authority to make decisions also opt for this system. Participants at the London general public event were more likely to choose this option than those at the Sheffield general public event (because they are more likely to feel that a national government based in London will have a good understanding of their needs).
- Those who feel more strongly that care should be tailored to local circumstances and needs tend to opt for a part-national, part-local system. This does not appear to be determined by demographic factors and is more influenced by perceptions of the performance of the individual's local authority.
- Overall the majority (79 of 132 who responded) opt for a national system.

1.7.1 Points specific to minority audiences

EMC participants respond to the options in a similar way to the general public although they tend to place a greater emphasis on the importance of local knowledge being used in decision-making (regardless of whether they opt for the fully national or part-national systems).

LGBT audiences, in particular, do not feel comfortable leaving funding decisions to local authorities as they feel that services provided are currently extremely variable and the needs of the LGBT community can be neglected in comparison to other minorities. They, therefore, all opt for a national funding system.

2. BACKGROUND AND METHODOLOGY

On 14 July 2009 the Government launched the Green Paper, Shaping the Future of Care Together, which suggests ways that the care and support system in England can be improved, both in the way it is delivered and funded. The Government wants to create a system for the future that is fairer, simpler to understand and more affordable for everyone.

A period of public consultation ran until the 13 November 2009 with responses used to inform the Government's plans to change the care and support system. These plans will be outlined in a future White Paper.

The consultation involved consulting and engaging with stakeholders and the public in a number of ways, including online, questionnaires, postcards, regional deliberative events and public road shows. This piece of research is intended to supplement this consultation activity by targeting those audiences not engaged with the debate and, specifically, members of communities who are harder to reach.

The research comprised the following:

- two five-hour deliberative workshops with 24 members of the public per event
- fourteen extended group discussions each lasting two and a half hours with ethnic minority communities (EMC) (Bangladeshi, Pakistani, Somali, Ghanaian, Nigerian and Caribbean) and gay and lesbian audiences

- seven depth interviews with faith leaders representing Muslim, Hindu, Sikh, Roman Catholic, Jehovah's Witness and Jewish faiths
- two depth interviews with transgender participants.

It should be borne in mind that this research was not a quantitative study and that the number of participants in each audience are relatively small. Whilst there are many consistent themes throughout, the findings can only give an indication of how a community feels.

Further detail on the methodology and sample is provided in Appendices B and C. Copies of the agenda, discussion guides and stimulus materials used are provided in Appendix D in Volume Two (see Annexes).

3. KEY OVERARCHING THEMES

A number of over-arching themes are evident across the audiences consulted and are outlined below.

3.1 The vision is welcomed

The vast majority of participants are positive about the overall vision for the National Care Service and the associated six expectations (prevention services, national assessment, fair funding, personalised care and support, information and advice and a joined-up service).

They concur that this should be a priority for the Government and many feel reassured that action is being taken after being presented with some of the demographic data about the ageing population.

When asked to describe the National Care Service that they would wish to see, many spontaneously mention some of the key characteristics that are included in the Green Paper. For example, allowing people to remain independent as long as possible, easy to access services, respect for people's beliefs and lifestyles and the same treatment for everyone.

However, there is some scepticism about the Government's ability to deliver. Some feel that the proposals are not particularly innovative and that many elements should be in place already.

3.1.1 A high quality workforce of pivotal importance

The success of the National Care Service is perceived to hinge on having a workforce staffed by well-trained, highly qualified professionals who are monitored closely through a robust system of regulation. In discussions about 'quality', the quality and quantity of staff is foremost in people's minds.

They equate the increasing future demand for services with a requirement for more staff and place emphasis on recruitment and retention measures. Many feel that those working in the care sector are currently under-valued and under-paid and that this has repercussions in that individuals are not attracted into the profession. Some of the faith leaders interviewed feel that provision of care to their communities would be enhanced by having a more diverse workforce and that more could be done to actively recruit from communities who are not well represented currently.

The fulfilment of many of participants' expectations for the service depends on having a high quality workforce, with an emphasis on training and development.

Joined-up working is felt to be key. Participants at all of the events and groups suggested a system with a 'key worker' at the centre; someone who would co-ordinate services and is a single point of contact for individuals requiring care. They stress that this system means that

individuals are heavily reliant on a single person and that this person, therefore, needs to be expert in dealing with people and navigating the system on their behalf. They also need to have the sensitivity to understand people's requirements, particularly those from minority audiences. There is a strong preference for having one individual as a point of contact rather than a team.

There is also recognition that it may be difficult for the workforce to change and to implement the new system, and that joined-up working may be challenging for some. They think that cultural change will be required which will need strong leadership.

3.2 Limited personalisation

There is much debate around the need for and scope of personalised services. Most feel that some tailoring of services to individual need is a positive and there is some criticism of services that are 'one size fits all'. This is particularly the case for those from ethnic minority communities (EMC) and lesbian, gay, bisexual and transgender (LGBT) groups who have specific requirements including:

- a carer of an appropriate gender (for example a woman for Bangladeshi females)
- the provision of appropriate food
- the observation of religious practices, including facilitating trips to worship
- community or day centres designed for specific communities.

However, many would like to see personalisation in a limited form and equate personalisation at an individual level with high levels of expense. They tend to focus on services being tailored at community level, for example day centres for Asian people rather than specifically for Pakistani people. They call for communities to be involved in designing these services and the development of a menu of options rather than giving individuals completely free rein. The idea of personal budgets does not resonate particularly well across all audiences and people focus on perceived negatives (older people finding these over – whelming and stressful to deal with and the potential for abuse).

Many second and third generation migrants make the point that younger people in their communities are becoming increasingly assimilated into British culture and are less likely to need specific services, like Asian daycentres, in the future.

However, there are a number of caveats to this:

- Participants were recruited on the basis that they were 'unengaged' and, therefore, tended to have little direct experience of care services. Once faced with a service that could not be individually personalised, they may feel differently about the importance of tailoring services.
- The discussion about personalisation came before the debate on funding. If individuals are faced with paying for their care through a Comprehensive scheme for example, it may be that individuals would have higher expectations of services and, therefore, expect

greater personalisation. Few made this link at the sessions, although some did select Comprehensive option as they saw it as a way of guaranteeing high quality services for all.

3.3 Involving the family in decision-making

Greater involvement of carers and family in decision-making is a central theme.

Participants wanted assurances that family and carers could have a say during the assessment process and that their wishes would also be taken into account. The idea of supporting individuals to stay at home resonated with many, particularly amongst EMC audiences. There is a call for greater information provision for carers, more financial and emotional support and for carers to receive training to allow them to provide services safely.

Among the EMC audiences, there is some recognition that the role of the family in caring is changing or is likely to do so in future. Whilst many cannot imagine a situation whereby care is provided outside of the home, there is a feeling that communities over time will become more accepting of external support. This has repercussions for information and access issues as well as data sharing; as some still see the use of external support as bringing shame on the family, security of data and confidentiality are of paramount importance.

3.4 Funding issues

There is extensive debate over the funding options with little consensus as to the best way forwards. However, there is widespread agreement as to a number of key considerations if some form of Insurance or Comprehensive scheme is introduced:

- There is a spontaneous call for the inclusion of some form of incentives for staying well and not using services (a 'no-claims bonus').
- Many feel that everyone should pay something, even those with few assets or low incomes, so as to be fairer to those who do work hard and save.
- The payment options, particularly allowing for payment during an individual's working life, do resonate well and are felt to be crucial to the acceptability of the Comprehensive option.

If a compulsory system is introduced, some EMC participants make the comment that they would be more likely to use services as they would be paying for them. They also question whether they would be able to use some of their 'pot' of money abroad if they chose to return to their country of origin when they retired.

3.5 A fourth way: tax-funded option

Many find it very difficult to accept that a tax-funded option is not a possibility.

Some (largely older participants) assume that care and support could be funded from the current tax and National Insurance system. Others do accept the need for more resources, but feel that tax should be increased to pay for the new National Care Service. They do not understand why a separate system is being created when they as individuals would find it simpler if the money was taken at source. When introduced to the idea of a Comprehensive system they rapidly liken this to a tax; a comparison which is further cemented by the option of paying during someone's working life.

3.6 Low levels of trust in private and public sector

As mentioned, many exhibit high levels of distrust of the government. However, this distrust is also evident in terms of local authorities, with many preferring a fully national system of funding so that local authorities do not have ultimate decision-making power.

Levels of trust are also low for the financial sector with the majority opting for a state run insurance scheme rather than one operated by the private sector. The latter are associated with mis-selling and high profile financial failures.

3.7 A significant communications challenge

The participants were all recruited on the basis that they are not currently engaged in the debate and most had little direct experience of care and support services. Most had not thought much about their individual or their families' need for services for a range of reasons:

- Many are in denial about the possibility of needing services in future and assume that they will remain fit and healthy.
- Younger participants find it difficult to relate to ageing and requiring support.
- Many assume that care will be provided free in a similar way to medical care.
- Some EMC participants tend to assume that they will be cared for by their family or that they will return to their country of origin (or 'home' as many put it).

The majority, unsurprisingly, have little awareness of the current system or its associated funding. Once informed about how the system works currently, many are shocked about the cost of care. This sense of outrage tends to colour their response to the new funding proposals and the message that all three options represent a better outcome than the current system is lost. The Insurance and Comprehensive systems represent a radical change and many find it difficult to digest the proposals and understand what it means for them, particularly in terms of the level of risk.

These factors combine to make a significant communications challenge:

- People do not want to think about these messages.
- They have a misguided impression of the current situation.
- The future funding options are complex and it is difficult to envisage the impact on individuals and the system as a whole.

4. GENERAL PUBLIC DELIBERATIVE EVENTS

Overview

Some key themes emerge from the events with the general public:

- Amongst members of the general public who have not had any direct contact with or have not considered care and support, awareness and knowledge of the care and support system is relatively low.
- However, when brought to their attention all believe it is an important issue for the government to prioritise, particularly given the changing demographics in England. Given these changes, there is appreciation that the care and support system will need a large-scale overhaul to make it fit for use for current and future generations. However, there is some scepticism about whether an upheaval of the system is possible or affordable.
- The vision for the National Care Service is seen as a relevant set of expectations. The ways of making the vision a reality are also supported in general. Joined-up working and high quality services are perceived as being of pivotal importance. Providing a wider range of services, although a positive step, is felt less of a priority by the general public. Staff quality and training and seen as integral for implementing the vision, as it is felt that these are the foundations on which the service will rest.

The funding issues generate heated debate, with some negative reactions to both the current system and proposed options. This is partially due to the fact that many had previously believed that care would be funded by the government. There is no strong consensus across the general public sample on the preferred option:

- The proposed options are not always instantly comprehensible. More specifically, it is not always immediately clear that each option holds a different level of risk. Participants find it difficult to envisage what each option would mean for them personally.
- Many participants simply choose the option which they believe has the potential to cost them the least – for the marginal majority this is thought to be Partnership (on the post-group questionnaire 16 chose this option). It is felt to be fairer by its supporters because those requiring care and support only pay for what they need.
- The Comprehensive option is chosen by some (14 participants) because it is closest to a tax-funded option due to its compulsory nature. It is thought to be fairer, as everybody in society contributes.

- The Insurance option was the least popular (13 participants), but is favoured by those who are risk-averse or who want peace of mind.
- A significant proportion of the sample question why the system cannot be tax – funded, as they believe it is familiar, feasible and fair. It is felt that this would be fair because it would not hit people at retirement age.

Overall, the majority favour a fully national system:

- It is felt that a fully national care service would be more easily integrated with the National Health Service for joined-up working.
- It is seen as more fair. National funding would provide consistency across the country, avoiding a 'postcode lottery'.
- Many members of the general public feel that a national system would be less expensive, as they perceive a fully national system would prevent the need for constant reassessment whenever they move area.

However, a part-local, part-national system is also popular because:

- It is thought to be the only way to address perceived wealth and demographic differences across localities.
- Local authorities are felt to be more in touch with local communities. Local knowledge is deemed critical for running care and support services effectively.

4.1 Spontaneous awareness, experiences and perceptions

Note on methodology – Participants were asked to spontaneously describe their awareness, understanding and experiences of care and support before being provided with a definition of care and support to clarify the subject for discussion.

As participants were selected to be 'unengaged', they, unsurprisingly, have low awareness of the formal care and support system in England. Many participants, particularly the younger

participants (aged 18–30), do not wish to think about future care needs and the prospect of getting older and becoming dependent naturally leads participants to feel anxious about needing help. Other participants assume that a care system will be there to look after them as a safety net. There is some awareness (generally amongst the older participants) that care and support has been more high profile in the media recently.

Most are not clear about where they would go to for support; some said they would contact the voluntary sector in the first instance.

“When my Mother in Law was sick with sciatica we went to Help the Aged because we didn’t know where else to go.”

(Member of the general public, London)

There is some confusion over exactly what care and support is as ‘social care’ is a more familiar term. Participants often perceive it to be part of the government’s responsibility and they assume that the National Health Service looks after the ill and elderly. The confusion is exacerbated by people often receiving medical care and care and support at the same time. Participants feel that more clarity is needed on where ‘healthcare’ stops and ‘care and support’ begins.

The majority of participants have negative perceptions of the care and support system; they believe it is difficult to access, inconsistent and insensitive to individual needs. They also comment on the lack of joined up working, bureaucracy, form filling and the current lack of responsiveness of the system. Overall, participants’ negative perceptions are influenced by the role of the government. Those participants with indirect knowledge of the system generally express concerns about poor quality care, which are exacerbated by their recollections of stories of negligence and abuse profiled in the media. However, some participants feel that the media could contribute to enhancing the public’s perceptions of care through profiling positive messages too.

General perceptions lead participants to make assumptions on the level of pressure on both older and younger carers. They feel that there is a need to assist carers, who they feel are often left unsupported under the current system. Some fear offering support to family members as it has had detrimental impact on some of their relatives who have become sick themselves under the stress of offering care and support. Participants think that the family are only likely to play a small role in their care and support, as they feel that families are not as close knit as they used to be. They therefore expect to use the formal system if care and support is needed.

“There is a lot of pressure on the children who care for their parents, which can be unfair and stressful for those that are giving and those that are being cared for.”

(Member of the general public, Sheffield)

There is an overall lack of understanding over funding; a common concern for participants is their fear of having to sell their homes in order to fund their care. Participants are unclear about the details, for example how much the government currently contributes towards funding for care and how much is privately paid for. There is an expectation that the government pays for the most vulnerable who are not able to fund their care.

“My friend sold their home to provide for their care; even though I knew you had to take some responsibility this surprised me.”

(Member of the general public, Sheffield)

Participants are also confused over entitlements for carers. This is an area that they feel needs greater clarity as it is an important part of making the system accessible. Others highlight their perception of the lack of funding leading to inconsistent provision of care and support across the country.

“People in different parts of the country get variable levels of care, feels like a postcode lottery... it seems like Scotland has a better system.”

(Member of the general public, London)

Despite participants' lack of understanding of the system, some convey an interest in getting involved in care and support in their spare time on a voluntary basis. However they are unsure which organisations they have to go through to channel these interests into reality.

“Perhaps the local council should offer incentives to encourage people to get involved in care and support?”

(Member of the general public, London)

4.2 Response to the case for change

Note on methodology – Participants took part in a simple quiz and were presented with information about the current system and the demands that will be placed on it in future (Handout A), the aim of the quiz was to stimulate the discussion. The information used is provided in Appendix D in Volume Two (see Annexes).

The majority of the general public are aware of the changes that are expected in demographics in England, often informed by information on the news on topics like the pension debate. There is some awareness of the ageing population and increased life expectancy generally. However, the scale of change is shocking to many, particularly in terms of the changing ratios of working to non – working people. Participants quickly raise financial concerns and spontaneously want to know whether the public will be expected to pay for the huge rise in care needed.

“As years and years go on there'll be more older people and less younger people and we've still got more and more money to come out but there's the same money coming in.”

(Member of the general public, London)

Some participants question how the case for change projections was calculated. Participants want to know where the information was sourced from and on occasion question whether it is connected to the projected immigration

figures for England. Others feel that the data will be affected by changes to the retirement age and want to know if this has been factored in.

In the context of the case for change, participants indicate that they feel care will need to be delivered differently in future and they spontaneously touch on the need for innovation.

“It will need to be joined-up and someone needs to accept that people who are working stay healthier for longer, maybe work with the DWP to look at retirement and the need to help people stay on if that is what they want to do.”

(Member of the general public, Sheffield)

There is general consensus that the care and support system should be a key priority for the government. Participants feel that, regardless of circumstances all should get an equal level of care. However some participants feel that it should not be a priority area for the government because of the cost of overhaul.

“Care should be equal regardless of what you have in the bank... people are living longer and having less children, there is a gap that the government needs to think about.”

(Member of the general public, Sheffield)

4.2.1 Key characteristics of the National Care Service

Prior to being introduced to the six expectations in the Green Paper, participants were asked to discuss what they would like to see from a new National Care Service. Participants feel that currently care comes from various sources and this means that quality is variable; they think there is need for a more streamlined service.

“A lot of care comes from agencies rather than the councils – it is cheaper to use agencies, but agency nurses are not always experts, they are just someone to show a face and tick a box.”

(Member of the general public, Sheffield)

There is some consensus over what the National Care Service might look like. Participants spontaneously comment that they want a system that promotes independence for as long as possible, good quality of life, equal treatment for all, treating a person as a whole, respect for people's beliefs and lifestyles and easy to access services and information.

When discussing the key characteristics of the National Care Service participants raise questions over structure and how it will be run; this leads them to immediately make comparisons with the National Health Service.

“I like the idea of a central service, but the government has to make sure that it is run properly, not too many managerial staff. Getting the structure right in the first place is really important.”

(Member of the general public, London)

4.3 Consultation Question 1 (Vision for the National Care Service)

Note on methodology – Participants were presented with information, diagrams and examples to help explain the Government’s vision and key expectations (Handouts B, B1, B2 and B3). The information used is provided in Appendix D in Volume Two (see Annexes).

Overall, participants respond positively to the vision, they feel reassured that the government is thinking about this, especially given the case for change. They feel that these elements address the key areas of concern that they raise spontaneously, and that they would work well together in principle. However, participants quickly identify the importance of ensuring it is implemented efficiently and effectively.

“This looks like the basis of a fair system. Everything we need is in there and will ensure parity across the country.”

(Member of the general public, Sheffield)

Participants also note the capacity a new National Care Service could build through the creation of new variety of jobs.

For the majority of participants, the vision includes the key characteristics that they identify as important spontaneously. Some would like more explicit focus on the provision of high quality services and treating people with dignity, which is something they feel is missing from their perceptions and experience of the current system. The vision raises some immediate questions; participants raise the importance of ensuring that it is feasible and realistic, since it will determine the quality of a person’s life. Participants also want to know how it will be ensured that everybody gets it, they feel equitable implementation is fundamental.

“I hope they are not exaggerating what they can do because this [referring to the vision for the National Care Service] will determine the whole of someone’s life.”

(Member of the general public, Sheffield)

Participants with little or no experience of the care and support system tend to feel that the vision is not particularly radical. They assume that the things mentioned should already be in place and are disappointed that this is not the case.

“It looks comprehensive but just words that are easy to say, feels like common sense, nothing really new stands out.”

(Member of the general public, Sheffield)

“An adult with autism won’t necessarily have straight needs, they might need services from lots of different agents... they might need a number of carers.”

(Member of the general public, Sheffield)

4.3.1 A joined-up service

The idea of a joined-up service is welcomed and is felt to be of pivotal importance to ensure the system works smoothly. However, some participants are still unclear on the division between the NHS and the National Care Service. Participants feel that a joined-up service is the link, which essentially ties all other elements of the vision together. Additionally, participants refer to needs being communicated out from the concept of one assessment, which prevents needs from escalating. Joined-up services would make it easier to gain access to information and for services to be truly personalised. Some participants also link joining up services to reducing duplication of services and, therefore, costs of provision. Participants also see it as a way of emphasising communication with family and carers, thus bringing them into the care and support system.

Participants describe a joined-up service as a service where the medical and social elements of care communicate and work in a collaborative and cohesive way. They feel that this is significant as care needs are interchangeable between social and medical support. People’s needs are not always straightforward so organisations need to inform each other, and work together both efficiently and proactively for a truly joined-up service.

However, participants are realistic about implementation and identify barriers to providing a joined-up service. They recognise the need for well-trained and highly qualified staff in order for this to work efficiently. Many participants mention that ideally, there would be a ‘key worker’ who could co-ordinate the range of services on behalf of the individual in need of care and support. This key worker would be responsible for the initial assessment, act as a conduit of information and oversee care provision. However, they are unsure if it is realistic for one person to have expertise in all areas, as they might not have all the skills needed to complete the assessment on their own. Participants recognise the cultural barriers to staff from different organisations working together. They also understand that there may be issues around leadership, such as diminished authority through changing job roles and responsibilities.

Participants also think that a joined-up service could be slower as there may be more processes involved if all services are to make co-ordinated decisions. Participants are keen to highlight the importance of this way of working not translating into more bureaucracy, as this would be counterproductive and would make the process slower and less efficient. They feel that

a joined-up service should be based on a centralised secure system which would save on duplication of money and resources. This could also give an opportunity to get rid of wasteful levels of management that currently creates what participants perceive as inefficiencies in the system.

“Working in a joined-up way shouldn’t mean lots of letters, they should exchange information using email... it should be a system that everyone has access to like the police uses alongside actually talking to each other.”

(Member of the general public, Sheffield)

4.3.2 Prevention services

There is a general feeling that ‘prevention is better than cure’. Participants feel that money and resources can be saved if prevention services are implemented which would stop needs from increasing in the future. However participants are not sure how this would work. Participants mention the importance of education on healthy living, which they feel is key for prevention; they feel raising awareness in schools makes prevention easier.

Participants highlight the importance of regular reviews through reassessments to ensure that

changes in an individual’s case are recorded so that their care provision can be truly tailored to their needs. Some also comment on the importance of services, like telecare services and which would allow people to stay as independent as possible in their own homes for longer. However, they note that confidence levels are low when an individual returns from hospital and they may need emotional as well as physical support.

They feel that this and other preventative services such as regular catch ups with older vulnerable members of the public who are less likely to proactively seek help are important, if the vision is to reach a wide range of people. Promoting physical and mental wellbeing through, for example, keep fit classes is also seen as a way to prevent people developing care and support needs in the future.

Participants feel that prevention services are closely linked with assessment, which should be proactively administered to ensure it captures those who might not know they need care and support. Some feel that this should be offered to people before retirement, however, others feel that it needs to start at a younger age.

Some members of the general public suggest well qualified staff like community nurses could act as assessors and risk co-ordinators to help determine what prevention services individuals might require.

“I think compulsory assessment for all at a certain age perhaps just before retirement would be good. Otherwise how do you make sure that everyone who needs care and support gets it? Assessments should be done at home rather than at the GP.”

(Member of the general public, Sheffield)

Despite the focus on assessments from professionals, participants comment on the importance of developing relationships with the family of individuals already receiving treatment. Family members could then communicate if an individual's condition is deteriorating.

4.3.3 Information and advice

Information and advice is viewed as one of the most significant elements of making the vision a reality. Participants would like to see care and support as something that is discussed more openly in the public domain; they want to know how to access care and support services easily. Many highlight the significance of proactive information dissemination with information going to people directly rather than waiting for them to find it. This is compounded by participants suggesting that they do not know what they need until they are in the situation itself.

“People should be educated and know what's available and where to go to get it, for example you know where and how to get to a dentist – it needs to be the same for care and support services.”

(Member of the general public, London)

Currently it is felt that information and advice is difficult to access. Some participants have experienced multiple assessments before decisions are made on eligibility.

“At the moment it is an obstacle to find out anything about care and support, different people seem to have different information – you never hear the same thing twice.”

(Member of the general public, Sheffield)

It is suggested that the government needs to publicise what is available specifically targeting the most vulnerable in society, for example the elderly who are more isolated. Participants with the least knowledge about the care and support system suggest a large public communications campaign. Some also comment on the importance of reaching people just before retirement age, for example through their employers. There is also a call for more

information to be provided to carers and participants feel that information dissemination would be integral to the role of key workers.

Participants suggest multiple channels to impart information and recommend communicating through a combination of online, telephone help-lines and also having a physical point of contact where possible. Some also suggest the provision of information through local GP surgeries and existing networks.

4.3.4 Personalised care

This element of the vision is seen as important in delivering care which puts the dignity of the individual at the centre. There is a feeling that a personalised system should begin by checking what an individual's expectations are and then evaluate the care to ensure that personal needs are adequately met. The majority of participants are surprised that personalisation is not central to the current system and feel that care should be tailored around an individual's requirements. They also mentioned respecting difference and not discriminating against those with specific needs.

“This [personalised care] would benefit those less independent like the disabled and elderly members of society.”

(Member of the general public, London)

Personalised care is also seen in terms of giving those who want to be cared for at home greater scope to do so by providing more support to carers.

“You need to have the family member assessed too, as they might not be giving the care they are supposed to... they could even be abusing them. Regulation is better than letting the family member provide care on their own.”

(Member of the general public, Sheffield)

There is some recognition of the positive impact personal budgets could have upon carers in terms of relieving some of the burden from the family carer and allowing individuals to have more say over who their carer is. Using some funding to support the carer would enable individuals to feel less guilty about the burden on their family carer.

However, the general public feel that too much personalisation is not practical, as the provision of endless choices have cost implications. There is also a degree of scepticism over personal budgets; many feel that too much financial responsibility might mean that people do not spend their money efficiently or take advantage of the funds. Managing personal budgets could also be an added stress, which people might not want to take on when they are receiving care. This is felt to be particularly the case for older people who may feel overwhelmed by too much choice. Additionally they may feel nervous and uncertain about whether they are choosing the right balance of services for their specific needs. They feel that this is a particular area where the key worker could actively help the individual make these decisions which can seem daunting.

4.3.5 National assessment

Participants welcome the concept of National assessment, as long as this is available for everybody and delivered at a high standard through ensuring staff are trained adequately. During discussions participants quickly highlight the need for regular reassessments to factor in changing circumstances and requirements.

Participants feel that whilst the assessment process should be standardised, assumptions should not be made. All groups feel that the assessment should also allow for some personal preferences in terms of how it is conducted:

- For example, some people might prefer not to have a stranger in their home conducting the assessment.
- Others may prefer the assessment conducted by someone of a particular gender.
- Family carers should be able to participate in the process (but in a separate interview if appropriate).
- Some call for greater control over the timing of reassessment, i.e. some reassessments brought forward if deemed necessary in discussion with the individual receiving care and key workers.

4.4 Consultation Question 2 (Making the vision a reality)

Note on methodology – Participants were presented with additional information and examples to help explain the ways in which the vision would be implemented (Handouts C and C1). These are provided in Appendix D in Volume Two (see Annexes).

Overall, there is a mixed response to the ways of making the vision a reality. Many of those familiar with the current system view these ways of working positively, due in part to their dissatisfaction with care and support they have received in the past and the recognition of the need for change. However, whilst the three ways of working are supported, there is a widespread scepticism concerning how they can be implemented. Although good in theory, many people question whether ‘the dream can be made a reality’. Some participants suggest that requiring a complete overhaul of the current system and the installation of new joined-up systems could be expensive. Offering a wider range of services, quality and innovation, while good things to aim for sound expensive, as they will require investment to design, implement and run these services.

“To overhaul this system and make it as good as people want would cost too much money.”

(Member of the general public, London)

Many expect it to take a very long time to implement these changes. There is also a general confusion resulting from a lack of distinction between the six expectations and the three ways of achieving them: especially between ‘joined-up services’ and ‘joined-up working’. This may be because some phrases are difficult to decipher, sounding to some like ‘government speak’ or meaningless jargon. Some participants suggest making the phrases more direct and less complex, perhaps by learning lessons from

charities like Macmillan who they feel reach out to the community through clearly communicated messages. The public want to feel confident that these ways of making the vision a reality are realistic and actionable, but at present some question if they will actually happen. Some also feel there may be resistance to change within the current system.

The general public hope that the new National Care Service will decrease rather than increase inefficiency and bureaucracy. However they are concerned that this might be increased through joined-up working; for instance, if more paperwork is required for messages to be passed between a wider number of organisations.

4.4.1 Joined-up working

Despite some scepticism about the reality of this, once understood, the idea of joined-up working is deemed essential for the vision. The general public think that joined-up working should result in a simpler, more efficient and less bureaucratic system, which in turn would save time and money. A major concern for many is constant reassessment by different agencies within the system, and joined-up working is seen as a good solution to this. If this is resolved, individuals will not have to waste time being reassessed by different professionals and meeting too many strangers, which could be especially stressful for older people.

There is a feeling that individuals should be able to form personal relationships with those who provide their care and support. There is a belief therefore, that joined-up working would result in a better, simpler and less stressful experience for

those individuals who are receiving care. Also if an individual's situation changes, joined-up working would mean that everyone involved in their care would know immediately, so their needs would be better met. Younger people, in particular, expressed the hope that a joined-up service will be in place by the time they get older, as they would rather have a smoother system with fewer points of contact if they require care and support.

Some feel that if information could be placed in a central database accessible to all professionals, the system would work much more efficiently. As this would require the widespread use of modern technology, staff training should be provided for using such technology in a joined-up way to ensure that this way of working is truly embraced by everyone in the system. Additionally, they emphasise how training, cultural change and leadership embed this way of working.

“Lack of joined-up working made our experience really bad, it is something that needs to be done to make sure all receive fair and equal care on time and do not get lost in the paper work.”

(Member of the general public, Sheffield)

Conversely, some participants feel that collecting everybody's personal information in a central database would compromise security, particularly given the large number of agencies potentially involved in providing care. People are concerned

about the loss of personal data, and this is exacerbated by high profile examples of the government losing public data. Moreover, some members of the general public do not want their personal information available to all health and care and support professionals simply because they feel it would be an invasion of their privacy.

Communication between departments, agencies and individuals is seen as essential to joined-up working. However, as well as involving care and support professionals, communication should incorporate all relevant parties, from family members who have firsthand experience of their relative's care needs to community leaders and faith groups.

“Communication is a really key thing here. But it's easy to say and hard to do. It's hard to all keep in touch.”

(Member of the general public, London)

Ideally, the general public believe that for a joined-up system to work, every individual receiving care and support should have one point of contact such as a 'key-worker' or GP who can bring together all the elements mentioned above. As when discussing joined-up services, participants reiterate that joined-up working will work best if there is one person at the centre who 'manages' each individual case and makes sure the individual's needs are being met. This could link in with the assessment stage, so that the 'key-worker' is involved from the very beginning and continues to work with the individual subsequently.

Despite some initial reactions that implementing and running a joined-up service could be expensive, most come to appreciate that joined-up working could be very cost-effective by cutting out excess levels of staff and management and making communication between levels of the system easier.

“... if people are going to work in a joined-up way, maybe there won't need to be so many job roles; maybe people can concentrate on what they're doing.”

(Member of the general public, Sheffield)

4.4.2 Quality and innovation

The general public consider quality to be a fundamental consideration when reforming the care and support system. Since care users include some of the most vulnerable members of society, such as disabled people and the elderly, they emphasise that the government must ensure the quality of care is high.

The term 'quality' can be ambiguous. However, most people understand quality to be synonymous with well trained and highly qualified staff. They feel attracting and retaining high quality individuals is a real issue in terms of the successful implementation of the vision and many reference the fact that those caring profession are currently low paid.

“Really important element is staff – good quality, training – so important if this system is going to work. And if we don’t pay well we don’t get good staff.”

(Member of the general public, London)

Many believe that the care system should be constantly monitored to maintain this level of care. This would involve gaining feedback from individuals who receive care and support through the form of questionnaires or feedback calls (although this must be sensitively done, as older people may not want to be bombarded with ‘surveys’). As well as service users, feedback could be gained from service providers, since these are the people who see how the system works ‘on the ground’. To ensure that services themselves are meeting quality standards it was suggested that a system of random inspections of services should be implemented with no prior warning.

“There needs to be a feedback system that evaluates care and feeds this in – they need to ensure a quality feedback loop. Feedback from the individual being cared for is important and also some kind of supervisory check.”

(Member of the general public, London)

Although considered important, innovation is seen as a lesser priority than quality. The general attitude is that we should improve the quality of/ increase access to existing services before putting resources and funding into the development of new ones.

However, in the long run innovation is perceived to be important and should not be completely ignored. Some individuals suggest that there should be a review of how other countries provide care and support in order to take key learnings from others where appropriate. There should also be a focus on learning from any successful initiatives in our own care and support system in order to see what is working well, and use the findings to influence new innovative approaches. Additionally, they feel, innovation entails getting a deeper understanding of needs and implementing new services when there is a genuine need for this.

“Look at other countries that are doing a good job and replicate their ideas.”

(Member of the general public, Sheffield)

4.4.3 Wider range of services

In general, providing a wider range of services is felt to be an expensive and less important option than the other two ways of working. There is a sense that the current services should ‘be got right’ first before introducing lots of new ones. This is embedded in participant’s thoughts that raising awareness and access of existing services is most significant.

Introducing a large number of new services is seen as being time-consuming, as well as potentially putting quality at risk. There is a feeling that it would be hard to regulate new services as well as existing ones and it would require the introduction of new staff in new roles, complicating the system. In terms of those receiving care, too much choice for people may be seen as a negative. Firstly, it could be overwhelming, and personal budgets could be misused.

“Sometimes a wider range of services is not needed... Sometimes we’ve got too many services available. Can we make them better rather than wider – a direct and targeted service – rather than a wide service?”

(Member of the general public, Sheffield)

That said, the public recognise that there is some need for slightly more diverse services in the future and welcome a slightly wider range of services being introduced over time.

4.4.4 What is missing from the vision?

Beyond the six expectations, participants identify other areas of importance:

- speed and efficiency of the system
- ease of accessing services (not just information)
- staff quality, retention and training

- inclusion of family members in making decisions and providing care.

A minority of participants feel that the vision needs to incorporate more explicitly the concept of the family carer and specific support that they might require. This was particularly the case for those who have had some informal experience of the care and support system. Another area identified as important is involving family members in the assessment and provision of care as formal carers, if they wish to be.

4.5 Consultation Question 3a (Funding issues)

Note on methodology – Participants were presented with information about how the current system is funded (Handout D), along with three new proposed funding options; Partnership, Insurance and Comprehensive (Handout E). The information used is provided in Appendix D in Volume Two (see Annexes).

Issues relating to funding generated heated debate at the workshop sessions. Negative reactions of the current funding system (once understood) tended to colour response to the proposed options, with many questioning why the National Care Service could not be tax-funded. Although there is no clear consensus on the three proposed funding options, some clear strengths and weaknesses emerge.

4.5.1 Current perceptions

Most have not thought about paying for their future care and many feel optimistic about their individual future, believing that they will remain independent and not need care and support in their lifetime.

“I haven’t really thought too much... I feel fine at the moment so I have no cause for concerns.”

(Member of general public, London)

A number of participants believe that care and support will be provided by the government and be free at the point of delivery. They see providing care and support to those who need it as the responsibility of the state, much like the provision of medical care. A good number assume that care and support is being paid for by National Insurance contributions, and that it is covered by the remit of the NHS. Although this is a very widespread misunderstanding, it is most commonly expressed by older participants who have paid income tax and National Insurance throughout their working lives. These people feel like they have earned free care over their working lives and are often discontented to find that this is not the case.

As mentioned earlier, this is perpetuated by the fact that some participants do not understand that there is a difference between medical care and care and support, often assuming that they are part of the same system.

“It should be paid for by the government by my National Insurance and tax contributions.”

(Member of general public, London)

A few participants (typically those who are older) have greater knowledge about the funding of the care and support system. They are aware that people sometimes have to pay for their own care and support, and have often heard stories (both from personal sources and the media) about older people selling their homes to pay for their care and accommodation in a nursing home. Amongst this group, there was a good deal of negative feeling towards the idea of individuals funding their own care and support, particularly where property needs to be sold to pay for this.

4.5.2 Response to current funding system

On learning about the current funding system for care and support in England, many are surprised about how this works. As said, a good number believe that care and support is provided ‘free’ by the government to all, while others are generally surprised at the high proportion that individuals have to pay when they are on a medium or high income or have some assets. The point about tax and National Insurance contributions is raised again as a significant number (typically older participants) question why the large proportion being paid for by individuals cannot be covered by government funding.

The £23,000 figure and sliding scale stated in relation to the amount of assets and individual must have before they are expected to fund some or all of their care and support was met with a particularly negative reaction. Firstly, £23,000 is felt to be quite a low figure, which anyone owning a home would be likely to have in the value of their property. This is felt to be a particularly upsetting concept, over and above the idea of paying for care and support through other assets such as savings. For many, their property represents their family home and something they have worked towards and paid for throughout their lives, and they feel very strongly that it should belong to them for the rest of their lives. Many plan to leave their home to their children as a large part of their inheritance.

As a result, some believe the current system provides individuals with no incentive to work hard or save money throughout their lives, because those on a low income or with small assets are able to receive their care and support for free, while others have to pay for it. They believe people ‘take advantage’ of this and choose not to work, knowing that they will be looked after by the state in their older years. These comments come primarily from older participants (40 and over), many of whom own property or have a reasonable amount of assets. Younger participants tend to have less strong views on this, but on hearing the older participants comments often agree with their point of view.

“I don’t think there’s any incentive to work and save money if other people are going to get it for free.”

(Member of general public, Sheffield)

A number of older participants also believe a good deal of people who do have significant assets currently ‘play the system’ by signing their house over to their children and transferring assets.

“The current system makes me want to sign everything over to my children.”

(Member of general public, Sheffield)

There are also some comments from the general public about immigration and asylum seekers. A number, particularly in Sheffield, question whether those entering the UK (both legally and illegally) are able to receive care and support for free because they are on a low income and, if so, believe this system is unfair on the working population of England.

The proposed options are not always instantly comprehensible for the participants. There is initial confusion, with many not understanding how each would work or the differences between them. More specifically, it is not immediately clear to participants that each option holds a different level of risk, and this can sometimes skew responses, with participants simply choosing the option they believe has the potential to cost them the least – for many, this is Partnership.

“Could you join up the Comprehensive scheme with Insurance, so that if you fall out of work you have insurance to help cover you?”

(Member of general public, London)

Beyond this, participants find it hard to envisage what each option would mean for them personally. Despite the fact that estimated figures are given, they cannot always envisage at what cost this would be to them in their every day lives, particularly thinking about options like Insurance where they may be paying the £20,000 or £25,000 over a number of years. Participants over the age of 50 find the options particularly challenging and have a number of questions about how each option would affect them as they approach retirement age:

- What would they have to pay for each option to have their care and support costs covered?
- Would they be expected to pay the full amount for the Insurance or Comprehensive options?
- Would the payment options be phased in gradually or would they be expected to pay a lump sum immediately on turning 65 (for instance, in the Comprehensive option)?

“How do you pay into it if you are over 65? You might not have the money.”

(Member of general public, London)

There is also little clarity of thought on how the proposed options compare to the current funding system. It is not immediately obvious that in all of the proposed options the government pays for a larger proportion of care and support costs than in the current system. A good number assume that in the proposed options, those who can afford to pay for all of their own care and support (e.g. those who have assets over £23,000) will be worse off than currently.

On learning or comprehending that in the three proposed options a larger proportion of everyone's care will be paid for by the government, this is supported and felt to be an improvement on how the system currently works. However, it does raise questions about how the government will fund this, particularly as there is a perception that the vision and ways of making it a reality will be more expensive overall than the current system. Only a minority identify the fact that joined-up working will actually be more cost-effective in the long run and allow for cost-savings to be made.

Due to many of the reasons stated above, the proposed funding options do not receive a particularly positive response. Considering that many participants believe that care should be funded by the state, these three options can seem at a large expense to the individual. It is also noted that the three proposals continue to provide free care and support for those on a low income or with small assets, and therefore continue to provide a disincentive for individuals to earn money, save and invest in property. For many, this is a real barrier in accepting any of

the three options, particularly in Sheffield where there is believed to be a large unemployed population who are currently living off state benefits. For these participants, the inclusion of a small contribution from everyone in society (including those who are long-term unemployed) would make all options seem fairer.

“Everyone should contribute, even perhaps people that are on low incomes or not working, but everyone should be expected to contribute something so that everyone had paid towards that pot.”

(Member of general public, Sheffield)

The fact that accommodation is not covered by the funding options is also a cause for concern, particularly older participants who are approaching retirement age (50 and over).

This stems from the belief that it is ultimately the government's responsibility to ensure that people living in England are cared for and housed, and that the government is using the new funding options to push this burden back on to the individual.

Younger participants, typically, are slightly more accepting of the fact that accommodation is not covered in the free funding options. They feel that, as long as their care and support is covered by these, it is fair to be asked to cover their accommodation costs themselves. Some state that they would rather sell their homes and be able to pay for a high quality nursing home than live in a sub-standard one.

“I'd be happy to sell my house to fund my care so that I have best care possible.”

(Member of general public, Sheffield)

4.5.3 Tax-funded system

Despite being ruled out in the proposals, a significant proportion believes that a tax-funded system is both feasible and fair. A tax-funded system is seen as familiar, and as a system that would not hit those at retirement age. Again, these tend to be the older participants (40 and over) who believe the taxes and National Insurance contributions they have paid into the system for a number of years should fund care and support.

Those who see tax-funded as a strong option dismiss the argument presented that this is not feasible due to the large burden it would place on working population:

- Firstly, they argue that there is a huge amount of unnecessary spending by the government at present which, if reduced, could be used to fund the National Care Service. In particular, they mention money spent on the military and on providing immigrants and asylum seekers with housing and benefits.
- They also point out that some of the proposed funding options involve people of working age paying out a certain amount each month (e.g. Insurance, Comprehensive option if choose to pay over working life) and that paying into these would be no different than paying a small amount more tax or National Insurance.

- There is also an argument put forward that it will be easier to work in a joined-up way if both the NHS and National Care Service are funded in the same way – participants envisage that employees from both services may be working together on some cases and feel it will cause confusion if one set of workers are state-funded while others are funded by the individual.

“It shouldn’t become a burden on everybody’s wages, it should be reasonable.”

(Member of general public, London)

“Why can’t we just add a bit more to NI and tax and have done with it? We feel that that would be fairer... We’d like the government to be a little bit more efficient in other areas.”

(Member of general public, Sheffield)

There is also a sense amongst those approaching retirement age that the proposed funding options place the biggest burden of cost on the retired, particularly the Partnership and Comprehensive options (although this can be paid for over your working life, there is recognition of the fact that is, essentially, a charge on the over-65s, who may choose not to save or invest in advance). These participants (and a number of younger participants, thinking of their older relatives) feel this is unfair and that it is those who are working and earning who

should pay for the care of the older generation. There is little recognition of the fact that some of the older generation in England are wealthier and have many more assets than their younger counterparts – older people are typically seen as vulnerable and in need of looking after by the rest of society.

4.5.4 Partnership option

Overall, Partnership is the most preferred option across the two events, although only very marginally – 16 out of 43 voted for this option individually. Those who prefer this option tend to do so because they believe that it is fairest if people pay for the care they need, rather than sharing out the costs and then potentially paying for someone else’s care. It is also most popular amongst those who believe high care costs won’t be an issue for them – either because they plan to remain healthy and independent, because they have a close family who they believe would provide their care and support or because they are willing to take the risk.

“People don’t take the risk of paying and never receiving care.”

(Member of general public, London)

Some see this option as a way of rewarding people who look after their health and do as much as they can to stay independent right into their old age.

The fact that the system does not require a compulsory payment of any sort is also supported by some participants who believe that they are already paying enough to the government in taxes and National Insurance contributions.

“People aren’t forced to cover other people... It is their own responsibility.”

(Member of general public, London)

The Partnership option proved more popular in Sheffield than in London, with 11 out of 22 participants in Sheffield choosing it (compared to 5 out of 21 in London). In Sheffield there is a stronger feeling than in London that people should have to support themselves and should not be responsible for supporting others who have ‘chosen’ not to work and save money over their lives.

“I don’t appreciate paying money for people who are on a low income or unemployed for care. I would rather take my chances with the luck lottery. Life’s not fair unfortunately.”

(Member of general public, Sheffield)

Some younger participants (18–30) who believe they are currently healthy and will not need care and support for a long time, if ever, stated that they would choose this option and then just hope that they did not need any care and support.

“Everyone receives some funding and it’s like you don’t have to pay extra... we’re willing to take the risk, like if we do get sick we’re willing to pay a large amount but if we don’t then we wouldn’t have to pay.”

(Member of general public, London)

Another point worth noting is that the Partnership option is often the easiest for participants to comprehend. It is quite a simple idea that most can relate to, with people just paying a set proportion of the care and support they need. It is also the closest to the current system and the other two options can be seen as complex and radical in comparison at first glance.

Despite the relative support for this option, there are a number of criticisms of it, particularly from the London participants who are less supportive overall. Most importantly, it is the highest risk of the three options and a good number of the general public recognise that those who need a high level of care and support could end up with very high costs. Some participants do not recognise this fact at first, but following the discussion, realise that Partnership has more potential negatives than they first realised.

Some also recognise that care and support needs cannot always be predicted. Even if an individual works hard to remain healthy and independent, they may become disabled or contract an illness or condition. With the Partnership option, there is a high financial risk attached to this happening.

Some participants have a philosophy that members of society should be responsible for looking after each other and believe that the Partnership option does not fit with this belief. This tends to be based on individual personality, rather than a specific age group or gender, although the attitude is more common in London, because those in Sheffield are influenced by their stronger views about unemployed people not being supported by those who are working.

“What happens if people can’t afford it when it comes to it?”

(Member of general public, Sheffield)

4.5.5 Insurance option

This option is regularly compared to the US system for funding healthcare, although not all are actually clear on the pros and cons of this system. It raises a good deal of immediate questions, including:

- How would individuals pay into this Insurance scheme?
- Would it be run by the government or private companies?
- Would it be made available to everyone – would individuals with an underlying health issue be declined the insurance?
- What would happen if an individual required care and support before they have paid the full amount of the insurance premium?

By a marginal amount, this option was the least popular amongst the general public participants (13 of 43 voted for this individually). However, it gained more support in Sheffield (10 out of 22) than in London (3 out of 21).

The biggest strength of this option is the ‘peace of mind’ it provides to those who have taken out the insurance.

“Because it is a back up scheme available for me to access if need be.”

(Member of general public, London)

Those who prefer this option to Comprehensive feel that it is fairer for the individual, as they tend to conceptualise it as each individual paying for their own insurance and covering their own care and support, rather than paying into a large fund which supports everyone in society.

Most presume that, like other types of insurance, this could be paid for in instalments, perhaps across an individual’s working life. When worked out, a good number come to the conclusion that the £20,000 to £25,000 estimate would be relatively easy to pay if broken down over a large number of years and could be taken, in a similar way that tax or private pensions are, out of your wage slip or income on a monthly basis.

“Insurance seems the most fair but I believe the extra should be put in NI and tax to pay for future care and support.”

(Member of general public, Sheffield)

Another potential strength of the Insurance option is that it is optional rather than compulsory, so individuals can choose not to take it out if they believe they will not need care and support or already have the means to fund it. Again, some younger participants (18 to 30) believe they would take the risk and choose not to pay into it, in the hope that they would never need care and support. However, overall for this group, Partnership represents a preferred choice for them.

“The difference between the Insurance and Comprehensive don’t seem too great and I would feel resentful if the government forced people to pay for something they don’t want.”

(Member of general public, London)

“I’d go for Insurance ‘cause I like the freedom... I’d risk it.”

(Member of general public, London)

The biggest criticism of the Insurance option is the fact that, like any insurance scheme, you may pay the premium and then never need care and support, thus having ‘wasted’ your £20,000 to £25,000. A good number question whether you would be able to receive some or all of this back if you did not receive any care and support and suggested a small ‘no claims’ reward to not need care and support (thus acting as an incentive to remain healthy and independent).

Another real concern about the Insurance scheme is the fact that it is optional; particularly amongst those who take a more ‘societal’ than ‘individual’ outlook on the funding issues. There is concern amongst some that individuals may choose not to take out insurance because they feel they cannot or do not want to afford the payments at the time, but then will be left with no cover if they do develop care and support needs.

“Sounds like a good idea but worry what if I don’t take insurance out? What happens then?”

(Member of general public, London)

There is not a great deal of understanding of how the Insurance option would work (e.g. many people pay in a small amount, to fund large payouts to a small number) which leads to questions about why this option is more expensive than the Comprehensive option when, essentially, they work in the same way (e.g. pay in a set amount and then all care and support covered). However, when explained, this perpetuates the belief that this is a profitable

scheme for the government, with the understanding being that the government makes money out of all those individuals who never need to claim.

Finally, there is also a concern with the Insurance option that the premiums could vary depending on how many people are making claims. Also, some believe that individuals with existing disabilities and illnesses could be disadvantaged by this option, as they may be refused insurance or have to pay an increased premium because of their conditions.

“If people were taking out a lot of money, would that mean that premiums would have to come out?”

(Member of general public, Sheffield)

Insurance option – State-backed or private insurance

The question about who should offer this insurance scheme is spontaneously brought up by a number of participants. State-backed insurance is felt to have some advantages:

- government more trusted to offer honest and reliable insurance
- prices less likely to vary, as no market forces
- assume (and hope) that is not a profit-making scheme
- less likely to penalise those with existing disabilities or illnesses
- belief that government could take the money directly from an individual's wage, thus more convenient and easier to pay.

Advantages of a private insurance system are also identified:

- possible lower prices through competition
- the private sector has more experience of offering these types of insurance schemes
- a minority trust private companies more with money than government.

On balance, the majority feel that state-backed insurance would be the best choice, as although there are some concerns about the government's ability to deliver, they are more trusting of the government to offer a fair scheme than private companies. There is also some concern about the financial industry at present, and they believe that there are risks of mis-selling or of private companies going bankrupt.

“You'd still trust the government to put your best interests at heart, not companies looking for profit.”

(Member of general public, London)

4.5.6 Comprehensive option

For many, this option is the closest to a tax-funded option, due to its compulsory nature. It gained a fair amount of support (14 out of 43) but was far more popular in London than in Sheffield (13 out of 21 in London, 1 out of 22 in Sheffield). However, this is partly due to the fact that a number in Sheffield believe that everyone should have to contribute, not just those who have a set amount of assets, and if this were the case then the Comprehensive option would prove more popular.

The Comprehensive option proves most popular amongst those who believe that everyone in society should contribute the same amount to care and support, with those on very low incomes contributing a smaller albeit symbolic amount. This option is also popular for others who have a more general philosophy that everyone in society should look after each other.

“More people pay into the scheme, everyone gets support and will receive a fair service.”

(Member of general public, London)

The fact that everyone contributes the same amount is a real selling point of this option. This is most common amongst those in London and those who are ‘middle-aged’ (30–50); younger participants often preferring the option to ‘risk it’ with Partnership or Insurance and older participants being concerned by this option as it represents a large sum they will owe when they reach retirement age. The fact that the figure is a set amount (£17,000 to £20,000) is also a strength among supporters, as they feel this makes the option predictable and means they would be able to plan for it during their lifetime. Supporters also note that, because everyone is contributing to the scheme, it is cheaper overall for each individual, which is also seen as a positive.

“The cost is lower and with more money in the system the level of care should improve.”

(Member of general public, London)

This option also represents ‘peace of mind’ like Insurance.

“It takes the pressure off from the Partnership option of having to pay there and then.”

(Member of general public, London)

The fact that there is a range of payment options is not always picked up on at first (which can cause concern about the idea of retirement-age individuals finding they owe a lump sum to the system) – however, when realised, this is also a strength for those who support this option.

“Everyone has to pay, it costs less and there’s different payment options.”

(Member of general public, London)

As said, this option is often perceived as closest to a tax-funded system, as everyone has to pay in and then care and support is covered by the state in essence. While some individuals support this option because of this fact, it does cause a good number of others to question why the tax option is not feasible, as they believe that if everyone is able to afford to pay into the Comprehensive scheme, they should be able to afford to pay increased tax or National Insurance contributions to the same level.

“As the best of the available options and the nearest to a taxation-based system... I do not accept the government’s assertion as it is based on a selective and limited interpretation of taxation.”

(Member of general public, London)

The fact that care is offered free to those of working age is generally supported, even by those who don’t choose Comprehensive as their option of choice. It is understood that those who receive care and support at working age are generally likely to be a lower income or have smaller assets than others, so it makes sense that they would receive care and support for free, particularly if they have had care needs throughout their whole life.

Although popular with some participants, a key weakness of the Comprehensive option for many is its compulsory nature and the fact that an individual may pay into it but never need any care and support themselves. While some see it as ‘fair’ that everyone contributes, others think it is very ‘unfair’ to pay for care and support that you do not require as you are essentially paying for someone else’s care and support.

“I don’t want to put £20,000 in a pot for somebody else to have care.”

(Member of general public, Sheffield)

This is felt most keenly by those in Sheffield, who feel strongly about working hard to fund other people’s lifestyles or needs. There is a strong suggestion here that everyone should contribute something to the scheme, perhaps using a means-tested system where those who are not working only contribute a small amount of their financial benefits while those who are working contribute more.

Another strong criticism of the Comprehensive option for a minority is the perception that the burden of payment is on those of retirement age, giving the impression that people have to pay a lump sum of £17,000 to £20,000 as soon as they retire. Initial perceptions illustrate that a mix of middle-aged and older participants (30+) feel this is particularly unfair, seeing older people are some of the most vulnerable and least affluent in society. The idea of the payment options softens this criticism somewhat, but there is still an overall impression that this option places the burden on older people whereas the Insurance option puts the burden on people of working age.

Comprehensive option – Payment options

As said, there is a positive reaction to the payment options for the Comprehensive scheme and this makes the option more digestible for many. The option of payment over working life is most popular. This is felt closest to a tax-funded system and would also mean that only a small amount needs to be contributed each month, making the scheme more affordable for individuals.

The short-term payment options are less supported, as there is a feeling that they penalise those of retirement age – particularly the lump sum on retirement and deferring state pension, as there is a feeling that many of those of retirement age only have low pensions as it is.

“We liked the way that there are different options to pay in different choices, but there are quite a few people in the group who definitely preferred the option of paying within your working life.”

(Member of general public, London)

“I’d rather pay for it in instalments than in one lump sum.”

(Member of general public, London)

The idea of paying out of your estate is also met with a negative response – particularly by older participants (40 and over) who feel that your estate should be left fully to your children. Like with people’s houses, people’s estates seem to hold emotional significance. There is also a question about what would happen if someone’s estate did not hold enough to pay the set amount and whether this debt would be passed on to the children. However, as long as there are other options for payment, most agree that it is not a problem to offer this too.

Comprehensive option – Lower rate for couples

The lower rate for couples is not immediately understood with questions as to why this should be the case, with only a minority recognising that couples often provide care and support to each other for at least some part of their lifetime.

“Do they expect the couples to look after each other? That’s a bit of an assumption.”

(Member of general public, Sheffield)

It also raises a number of questions about the practicalities of this particularly around circumstances changing, for example if a couple does not stay together or one of them dies quite early in retirement.

“What if the couple don’t stay together, then it’s not fair that they’ve paid a lower rate.”

(Member of general public, London)

Others also question why those living in extended families would not receive a discount on the same basis given that they would be supported by others living with them. Therefore, on balance participants feel that it is simpler and easier to keep a consistent rate for all individuals.

4.6 Consultation Question 3b (Part-national, part-local vs. fully national system)

Note on methodology – Participants were presented with a description of national versus local control, and some of the pros and cons associated with each option (Handout F). The information used is provided in Appendix D in Volume Two (see Annexes).

There is mixed response to the question of a fully national or a part-national, part-local care and support system. Participants find it difficult to decide one way or the other, since it is an issue that many haven't considered before and thus they find it difficult to conceptualise the impact of each system. Furthermore, most people are not aware of the technicalities of government finance and the jurisdiction of local authorities. Overall, when asked to choose, 22 out of 43 participants who answered selected a fully national system, whilst 21 chose the part-national, part-local option.

4.6.1 A fully national system

Those in favour of a fully national system emphasise the point of fairness in making their choice. A system in which all localities receive the same funding from central government is seen as more equal. It is felt that a fully national care service would be more easily integrated with the National Health Service for joined-up working. National funding and guidelines are seen as providing consistency across the whole country and help avoid a 'postcode' lottery, where some areas i.e. the most affluent receive better services than others.

It is also felt that the fully national system would work better with the proposal for national assessment with the belief that a fully national system would prevent the need for the constant reassessment of individuals' needs whenever they move area, which is seen as a potential consequence of a localised system. Also the fully national option is seen by some to be less expensive, since it would cost more to have assessments for different services in different areas.

“We came down on the side of the national system, primarily because we felt it avoided the postcode lottery of services being available in one area and not in another, and also it kept the transferability of the scheme and of the initial assessment there.”

(Member of the general public, London)

Some are unsure about local authorities being responsible for the allocation of funding as it may be in their interests to allocate money to priorities other than care and support. There is a real concern that political differences and considerations of electoral popularity would have an impact on consistency of care if the local option is chosen.

“Different localities might have different priorities due to different political allegiances.”

(Member of the general public, London)

A point raised by the Sheffield audience is that only a fully national system would work with the Comprehensive payment scheme. If everybody in the country pays the same amount into the scheme, they should receive the same amount of funding for their care.

4.6.2 A part-national, part-local system

However, a part-national, part-local system is also popular, with some individuals deeming it fairer than a fully national option. This is because they feel that different local areas have different needs and it would not be fair to allocate the same amount of funding to an affluent area as to a deprived area. It would be fairer to take into account the wealth, resources and services in each locality before deciding on what to allocate there. Also different areas have vastly different populations. Most participants agreed that funding and resources must be allocated 'by head'.

“There will need to be some local tailoring in some areas, as some areas have a bigger need and it’s not fair to leave them with a deficit.”

(Member of the general public, Sheffield)

For some, part-national, part-local is a preferred option because local authorities are felt to be more 'in touch' with the local community. Local people have local knowledge about their area and can, therefore, run care and support services more effectively. There are concerns that a fully national system would not be able to offer personalised care and all people would be treated the same.

“The local authority is more in touch with the community and with the people. Whatever measures are put in place would be measured according to the needs of the people within the area.”

(Member of the general public, London)

“We’d like national government to decide how much money is spent but local authorities to decide what it is spent on.”

(Member of the general public, London)

Where people live may have an influence on their views: those who believe their local authority to be effective are more likely to support the part-national, part-local system and those who are unhappy with or have little contact with their local authority tend to lean more towards a fully national system.

Most people agree that there has to be some element of local input in the running of care and support services. Some participants questioned whether a national system would require some local tailoring. Local government would have a say in how it was allocated and national government would monitor spending and usage to ensure consistent levels of care and support. This sentiment was more prevalent among the general public in Sheffield, with 14 out of 23 participants preferring the part-national, part-local option. Conversely, the London participants leaned towards a fully national system, with 14 out of 22 participants choosing that option. These trends may reflect the probability that participants living in London are more likely to trust a national government based in London to understand their needs. For instance, one participant pointed out that because Sheffield used to be the centre of the UK steel industry, it has very specific local care needs that cannot be catered for from London and that specific illnesses and conditions that arise from a career working in the steel industry can only be supported with local knowledge.

5. SPECIFIC AUDIENCES

Overview

Some key themes emerge from the groups with Ethnic Minority Communities (EMC):

- There is a general expectation amongst EMC participants that family will be the key provider of care and support and as such they call for the vision to explicitly reference the role of family carers. They feel that prevention services are of particular importance in terms of ensuring that individuals can be cared for in-home as long as possible, as, for the majority, this fits with their current practice.
- Most feel that EMC audiences' needs are not currently well catered for, with a lack of understanding of the needs of specific communities. The proposals in terms of personalisation are therefore welcomed, with a call for greater education of care professionals on the diversity of needs.
- However, most feel that personalisation at a community rather than individual level is the way forward (fearing that a truly personalised service will be costly and overwhelming for some).
- Many groups specifically reference older generations having a strong sense of pride and a perceived shame to the family in using external care services. This has clear implications for provision of information and the identification of need in these communities. Additionally, these groups are concerned about joined-up working having inherent risks associated with data confidentiality i.e. that privacy could be lost and others in the community become aware that service users.
- Participants' responses to the funding options are coloured by their cultural frame of reference in that many select the Partnership option if they expect that future generations will continue to care for and support their extended families or that the trend of older people returning 'home' on retirement will continue.
- Others, particularly Ghanaian and Caribbean, identify changes within their communities, meaning that they believe care and support may more commonly be provided by external agencies. As a result they are more likely to select the Comprehensive option.

- Some Muslim participants and the Imam interviewed are (mistakenly) concerned that an Insurance system would not be suitable for them because of religious rules on the unacceptability of being in receipt of interest payments.
- African males, in particular, reference their own work ethic and criticise current policies and proposals which they see as rewarding those who receive benefits without providing any reward to those who work hard and pay their taxes. There is an aspiration for home ownership amongst many, particularly those communities where this is a rarity (Somali), consequently producing an emotional response to paying for care and support out of one's own estate.
- Some of the EMC participants, particularly those from less integrated communities such as the Somalis, had some difficulty understanding the terminology and concepts. This appeared to be partly because they had little experience of using external support services and so were not familiar with the jargon or terms used.
- Some of the individuals interviewed were on low incomes, but did not appear to recognise that they would be amongst those whose care and support would be paid for.

The LGBT participants raised many similar points to those at the general public workshops. Specific points include:

- A call for reassurances that that future services are able to respond to the needs of a diverse society and that professional treatment will be given with no discrimination because of sexuality. They, therefore, tend to be supportive of the concept of personalisation.
- They feel that the needs of the LGBT community can be neglected in comparison to some other minorities. In particular they feel that services provided by local authorities are extremely variable in terms of how well they cater for LGBT individuals with care and support needs so all opt for a national funding system.

5.1 Bangladeshi audiences

5.1.1 Context for response

The Bangladeshis in the groups believe they have a different culture and outlook to the ethnic majority in England, one major difference being their attitude towards family and caring responsibilities. They state that in the Bangladeshi community extended families living in England

tend to stick together, living in the same area or even living in the same house.

There is a strong feeling that looking after older relatives is part of their 'duty' and something they expect to do. They say that in their community it is expected that people will look after their relatives themselves, in their own homes, and it

would bring shame upon the family if they asked an older relative to move into a nursing home if they required care and support, as it would suggest that they are not willing or able to fulfil their family duties.

“We don’t even look in to benefits or anything, because we feel as if it’s our duty to actually do it, and I think we expect that from our kids as well.”

(Bangladeshi female, Leeds)

In general, the participants feel this is a strong cultural behaviour that will continue for generations to come, and they expect that their children will care for them and so forth. However, there is some acceptance that things may change over time and that care and support may not always be the main responsibility of the family as society changes and families become more dispersed, but they believe that family will always play a large part.

The male participants have a much more sceptical outlook on the government and their proposals. They are generally more questioning and negative about the ideas discussed, with females being much more positive and accepting of what is suggested.

“There’s a lot of political issues around the retirement age, the pension, the carers allowance and the different types of benefits that people can receive and I still think there’s a lot more that they could give, in the health service.”

(Bangladeshi male, Birmingham)

5.1.2 Spontaneous awareness, experiences and perceptions

Most of the participants have some kind of experience of care and support, having cared for a family member at some point in their lives. A good number have older relatives living with them at present for whom they provide care, including parents and grandparents. However, they have little knowledge of the formal care and support system.

“I did not really know there was a care and support system in England.”

(Bangladeshi female, Leeds)

A small number have more direct experience of the care and support system in England. These participants have relatives who receive a small amount of care and support, such as one participant’s father receiving a few hours of care in his home from care workers and another’s

father attending a day centre one day a week. One female participant works in the care system as a family support worker and so has more knowledge of this specific area, but still lacks knowledge of the system in general.

There are few clear perceptions of the care and support system, as participants feel they do not know enough to comment. One participant states that the care and support system is not particularly well tailored to older Asian people, for instance his father does not enjoy attending a day centre that is almost completely white and English, in terms of both the attendees and the staff.

5.1.3 Response to the case for change

There is surprise at the case for change, as a number of the participants assume that life expectancy is actually going to decrease in the future, as people in England are eating less healthily and there are more life-threatening illnesses being contracted. However, on learning the figures the female participants find the case for change compelling and think the care and support system should be a key priority for the government.

Whilst the males do feel that the care and support system should be a priority, they are more sceptical. They feel that the government often manipulate statistics to make the point that they want to make, so they are unsure whether they can be trusted. They believe improvements in medical technology should mean that fewer people become ill and so there will be smaller care and support requirements.

5.1.4 Consultation Question 1 (Vision for the National Care Service)

Overall, participants support the six elements of the vision in principle, although they are surprised that some of these are not happening in the care and support system at present. They note that across all six elements, service providers will need to take religious and cultural differences into consideration and be open to tailoring services towards these where possible and feasible.

Prevention services

Prevention services are seen to be an important part of the vision. Participants believe they will help prevent people's care needs from increasing and therefore mean that people can continue to be independent and live in their own or their families' homes for as long as possible (this supports their belief that older people should live with their families rather than in nursing homes).

“My grandmother can relate to prevention services. She attends these day centres and has found that they are helping her to stay independent and well for as long as possible.”

(First generation, post-task)

National assessment

This is one of the elements that participants believe should already be in place. They believe fair and equal treatment of each person being assessed is very important. However, despite its assumed uniform nature, participants believe the assessment process should also be able to take into account different ethnic and cultural needs that an individual may have. During the process, individuals should be asked, sensitively, about any cultural or religious beliefs or behaviours they may have and these should be factored in when deciding on care and support. These might include things like language constraints, dietary requirements and religious habits, such as attending a place of worship. However, there is also a strong feeling that assumptions should not be made based on someone's religion or ethnicity.

“Take their age, gender, ethnicity and background into consideration before deciding for them, also consult them – who knows them better than themselves?”

(First generation, post-task)

They believe the assessment should be done in an informal way so as not to overwhelm or intimidate the person being assessed. This will be particularly important for first generation Bangladeshis who may be suspicious of a stranger coming into their home to assess them.

“The person who is doing the assessing should not be dressed up formally in collars and cuffs, because that is automatically an authoritative figure and automatically they will have their guards up, ‘I don’t want to tell you anything’, and that’s the way they’re going to be.”

(Bangladeshi female, Leeds)

Also important is the idea that a person's family should be involved in their assessment, as the Bangladeshis believe that the family is a very important part of care and support and so decisions should not be made without them. The individual being assessed should have the opportunity to request that they are cared for by a family member rather than an unknown care worker, or that the care and support is split between the two parties in the most appropriate way.

“I would like to stay home and receive the care and support from my family. I don’t speak English and when I have any problems I can explain this easily to my family. I also think it will be better if there is a range of services to deal with my needs if my family members are busy at work.”

(First generation, post-task)

A joined-up service

The males and females have some disagreement on this element. The females are very supportive indeed, as are some first generation participants in the post-task exercise. They believe that having a joined-up service will be quicker and more efficient and will mean that individuals and their families won’t have to explain their needs repeatedly and speak to lots of different care providers.

“You get sick and tired of having people coming in and explaining, it becomes repetitive.”

(Bangladeshi female, Leeds)

Information and advice

All agree that information and advice is a key part of the vision. The most important sources of information are felt to be through one’s GP,

who should be able to advise on what care and support is available, and online. They mention the specific needs of the older generation, who may not be able to access information in the same way as everyone else. They suggest that information should be available in simple English as well as other languages and that visual aids should be provided to help communicate in addition to words, so that even those with low literacy can understand any leaflets on the subject.

“I would like to know what care and support services are out there. I don’t read, write, or speak English so it would be good if someone could explain what care is available.”

(First generation, post-task)

Personalised care and support

In general, the idea of personalised care and support resonates with the Bangladeshi participants. They believe there are some specific needs amongst their older relatives (and perhaps themselves at some point) that could be taken care of better by personalised care than a standard care package that is uniform for everyone. In particular they mention:

- sharing care between family members and professional care workers – with the family doing as much as possible (as this is what an older Bangladeshi person would generally prefer)

- having information on care and support available in appropriate languages, with care workers being able to converse with the individual in their first language where possible (this is less of an issue for the second generation)
- provision of appropriate Muslim or Asian foods in care environments
- training for staff in the care industry so that they can learn about and understand Asian and Muslim cultures.

If family members are going to be included in the care package provided, there should be some recognition of the fact that it is a difficult role and family carers can sometimes need support themselves. Participants suggest some kind of optional training for family carers.

“A lot of carers don’t know that there is this support there for them.”

(Bangladeshi female, Leeds)

However, there is a real concern amongst participants regarding the extent to which care should be personalised. They believe that if care services are forced to cater for each person’s needs on an individual level, this could make the system overly complex and expensive.

“Personalised care would not work because there are not enough resources and funds available in the local authority to support such an idea, especially in the current climate.”

(First generation, post-task)

5.1.5 Consultation Question 2 (Making the vision a reality)

The Bangladeshi participants agree with all three ways of working and feel they will ensure a well-run National Care Service if implemented successfully.

Joined-up working

Not all are instantly familiar with the term joined-up working and are not clear what this will mean. Once explained this is felt to be a good thing overall for the system but there are also a number of concerns. They feel that having one point of contact would be better for first generation Bangladeshis, who may feel overwhelmed by having to have contact with too many different people (particularly if they do not speak English particularly well).

Technology is felt to be important for joined-up working; however there are some concerns about this, particularly from older Bangladeshi people who will not like the idea of their details being kept on a database and their movements and changes being tracked.

Wider range of services

As previously mentioned, the Bangladeshi community believe there are some services that are not currently in place from which they would benefit, such as having care workers that are able to speak Bengali and the availability of appropriate Asian or Muslim foods in care environments. More Asian or Bangladeshi community centres would also be good for this community, particularly the older generation who are less comfortable mixing and conversing with the ethnic majority. However, they feel that this is somewhat of a 'wish list' and that providing services to meet everyone's specific needs should not necessarily be the priority of this system. Instead of consulting with every individual, the government could talk to representatives of each community in each area.

5.1.6 Consultation Question 3a (Funding issues)

Few are aware of the current funding system and how it works. Much like the general public, on learning about it there is concern about the fact that those on the lowest incomes and with the smallest assets receive care and support for free while those who may have some money or are on the borderline have to pay for a large proportion themselves.

“There are going to be more people that are going to want to be on benefits and now have that, and not worry about paying in to it, so I think there is going to be more people that say forget that, I’m not going to work when I get to a certain age because I don’t want to.”

(Bangladeshi female, Leeds)

On learning about the proposed funding options, there is no complete agreement across the group, but Partnership is most popular amongst the second generation participants and appears to have the most support amongst the post-task exercise participants (first generation). Partnership is the preferred option overall, but has more support from females than males.

Some of the first generation participants taking part in the post-task exercise state that they are currently receiving financial benefits and so would receive care and support for free on all three options. However, they tend to opt for the Partnership option as it is the simplest and easiest to understand.

There is little support for Insurance overall, with just one male participant preferring this option. Participants state that they do not want to pay into an individual scheme like this which they may never need. They view this as a potential waste of money.

“If I pay into an insurance scheme for 40 years of my life and I don’t have an illness at the end of life, I may have paid that money for no reason.”

(Bangladeshi male, Birmingham)

As participants do not fully understand how the system would work, they ask whether the money would accrue interest or whether they would have to pay any interest on it. If so, they believe it would not be suitable for them as Muslims, as they do not believe in the concept of paying or receiving interest and so they would need a tailored product suitable for them.

“I think from an Islamic perspective the insurance thing is not something that’s viable for Muslims.”

(Bangladeshi male, Birmingham)

The Comprehensive option is chosen by half of the males, mainly for its similarity to the tax system in their eyes; everyone paying in throughout their lives, resulting in care and support being available to everyone.

5.1.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

There is a clear split between Bangladeshi males and females on this question; all the females prefer the part-national, part-local system and all

the males prefer the fully national system. The females (and some of the participants taking part in the post-task exercise) believe that the local authorities are better placed to understand their needs in each area and provide services such as day centres and in-home care that is suitable for them. For instance, local authorities are likely to have a better understanding of language and dietary needs than the national government.

“The Bangladeshi community here has probably got different needs to down somewhere in Wales.”

(Bangladeshi female, Leeds)

In contrast to this view, the males believe that a part-national, part-local system would be complicated and local politics could get in the way of the right decisions being made on funding. They believe that funding should be controlled nationally and that this would lead to the fairest system, whereby every area gets the same amount of funding.

5.2 Pakistani audiences

5.2.1 Context for response

There is a strong sense of family solidarity amongst this group. Within the Pakistani culture it is important to look after older family relatives, including immediate and extended family, as a matter of both habit and respect. This attitude is evident in both male and female Pakistanis and it is felt to be part of what being Pakistani and Muslim is all about. Consequently, Pakistani participants indicate that they would not feel comfortable asking their elder relatives to move into a nursing home, as they feel this is against

their culture and would be shameful within their community. There is an expectation that they would care for older relatives in their own home. British nursing homes are not seen as suitable for the Pakistani first generation, because of linguistic, dietary and cultural barriers. Some older Pakistanis also go 'back home' to Pakistan to be looked after.

"As they get older, the older generation with the Muslim wives, they end up going back home to Pakistan; they go back to their roots."

(Pakistani female, Birmingham)

However, there is recognition amongst the second generation Pakistani participants that this tendency may change over time as future generations of Pakistanis grow up in England and become more assimilated into British culture.

"I think 20 or 30 years down the road, our generations, will assess in our own minds that is the best place for us to be, in a home, because we've grown up in this culture."

(Pakistani male, Leeds)

As with the Bangladeshi sample, there is some scepticism towards government proposals and decisions; this view is much stronger amongst the men, as the females are more accepting of what is being put forward.

5.2.2 Spontaneous awareness, experiences and perceptions

A large proportion of Pakistani participants provide some care and support for family members. First generation Pakistanis interviewed by their family member as part of the post-task exercise stated that care by family members is very important for their generation.

"The care family members receive is often provided by other family members and it is very vital in ensuring older people feel that they have people to care and support them to do daily tasks."

(First generation, post-task)

There is low awareness of the current formal care and support system. Those with some experience note some positives but overall the system is felt to be difficult to access, with leaflets using overly complicated language that participants and their families don't understand.

5.2.3 Response to the case for change

A good number of participants are surprised by the case for change and the figures stated, although some are already aware of population changes through the media. Pakistani participants feel that this is an important issue for the government to be tackling, given the changes in demographics. Although some of the participants expect to be cared for by their family members if they need care and support, they also want to feel that there is a formal system in place that can cope with possible demand.

5.2.4 Consultation Question 1 (Vision for the National Care Service)

Overall, the Pakistani participants (both second generation and first generation) support the vision and its six expectations, believing all the elements mentioned to be positive and necessary for a successful National Care Service. However, there are questions about how the new service will be implemented.

Prevention services

Prevention services are felt to be one of the most important parts of the vision, as this group strongly believe in keeping individuals independent for as long as possible and preventing care and support needs getting worse, particularly as older Pakistani people are keen to stay in their own homes.

Participants suggest that the best ways to prevent care needs getting worse in their community include regular socialising and seeing other people. They suggest having day centres in every community for people with care and support needs (particularly older people) to attend and socialise with people from their own area. They do not feel that these need to be exclusively Pakistani, but that it would benefit their parents' generation if there were a large number of Asian older people attending, so that they feel like they fit in and can relate to those around them.

National assessment

In general the Pakistani participants respond to the idea of national assessment in a similar way to the general public. They believe it to be a positive part of the vision and the fairest form of assessment, although some participants, particularly males, question why this is not already in place.

A joined-up service

A joined-up service is felt to follow directly on from national assessment.

“Joined-up services are very important in ensuring that you are not only relaying information to different people who work independent of each other but all services are there to help support a person wholly.”

(First generation, post-task)

Information on individuals receiving care should also be stored on a central database, so that all those working on their case can update and keep up-to-date with changes to their requirements. As long as this is well protected and sensitively handled, they believe it will benefit everyone.

Information and advice

Pakistani participants believe that people should be better educated on the care and support system in general. They feel this would help to overcome negative perceptions of care services, such as nursing homes, around. Specifically they believe that the older Pakistani generation would benefit from seeing positive images and information about nursing homes so that they are less concerned about moving into one should they need to (for instance, if their family are not able to care for them full-time).

“They think those children they don’t know how to look after their parents and they shove them into homes, because the image they’ve got of care homes is not a good one, so that’s what I’m saying they need to put more positive and exploit good images of care homes.”

(Pakistani female, Birmingham)

In terms of information sources, the dissemination of information through community and faith leaders could be a successful way of communicating with the Pakistani community. They also raise the issue of languages and suggest that in a multicultural society information needs to be presented in different languages. It must also be taken into account that some people in the older generation may not be able to read any language at all.

Personalised care and support

Personalised care and support is also very important to this group, who believe their elder relatives may want care and support which is tailored to their needs as an Asian or Pakistani, such as specific day centres or nursing homes that are able to cater for the needs of older Asian people. Ideally, people would have their religious beliefs catered for and respected, such as being given the right foods at meal times, whilst being given the opportunity to socialise with other people from similar cultures.

“They just cater for more like different communities and cultures because at the moment you do see homes, but sometimes you know with the Asians and certain communities or cultures they don’t relate themselves going there.”

(Pakistani female, Birmingham)

However, this is felt to be less important for the younger generation of Pakistanis, as they feel they are more ‘integrated’ into English society and will not need as much specific tailoring to their culture.

There is some support for the idea of personalised budgets, as the participants believe these would help Pakistanis and Muslims do the things they want to in their old age rather than having to fit in with the care services that are available, for instance, using their budget to spend time with their families, rather than going to a day centre. However, they believe there should be some limit on what personalised budgets can be spent on, ensuring that they are not abused or wasted.

5.2.5 Consultation Question 2 (Making the vision a reality)

Overall there is agreement with the three ways of working although, much like for the general public, a number of participants question why these are not already in place.

Joined-up working

Participants feel that joined-up working should cut down on bureaucracy and improve access.

Quality and innovation

Quality of services is seen as important, but the Pakistani participants believe it can only be achieved if there is something in place to monitor quality to ensure it remains high. This is important as they believe that older people are vulnerable to abuse and mistreatment if service providers are not carefully monitored. They believe older people should be entitled to the best quality service possible as in their culture it is felt they should be respected and given dignity because of their age.

Wider range of services

Having a wider range of services is felt to be key for the Pakistani community, to ensure that people who need care and support have services that suit their needs. In particular, it is suggested that the community would benefit from day care centres and nursing homes specifically for Asian people or at least tailored towards their needs in terms of languages (spoken and written) and dietary requirements (older members of the community may have preferences for South Asian foods). They note, however, that these would not need to be solely for Pakistani people, as long as there was a good sized Asian community attending or living there to ensure that their older relatives feel comfortable in the environment and feel as if they are around people who have similar beliefs and culture.

“If they did have an environment, an Asian people, you know, I think that would be a step forward in so far as care for particularly the Asian people, elderly, because traditionally they’ve all been looked after by the family.”

(Pakistani male, Leeds)

5.2.6 Consultation Question 3a (Funding issues)

Very few participants are aware of the current funding system, which comes as a surprise, particularly amongst the females who had previously believed that care and support would be free at the point of use. They are concerned by the current system, particularly the idea that you have to use your assets to pay for care and support if you need it. The vast majority would favour a tax-based system.

When the funding options are introduced it takes some time for the participants to comprehend them fully and there is concern that not everyone in society will be able to easily understand whichever option is chosen. During the post-tasks, responses show that first generation participants do not always fully comprehend how each option would work and what the risk level of each would be.

“Old people won’t ever understand this.”

(Pakistani female, Birmingham)

There is not a strong consensus of opinion on the funding options, but there is some support for Partnership amongst females and Comprehensive amongst males.

Partnership

The Partnership option receives some support (five out of thirteen participants choose this option). It is most popular amongst the females, where three out of six choose it as their option.

It is popular because it does not require any kind of up front payment. They believe that during the recession, and perhaps even after it, they will not be able to afford extra monthly payments into a scheme such as Insurance or Comprehensive.

“You would only need to make payments for this because you require the care and service and not lose out on money if not required.”

(Pakistani female, Birmingham)

Insurance

Insurance is the least preferred option with one out of seven males and two out of six females choosing it. There is some support for it by younger family members interviewed in the post-task exercise (most likely to be third generation). Of the three options, it is felt to be the most like a business proposition, with the government or private companies making money out of those paying insurance. This is based on their understanding of how insurance products normally work. For this reason it receives the least support, as the participants do not believe that funding for the care system should be like a business; instead functioning as a non-profit making scheme.

However, the minority feel it shows some potential as a way to provide people with peace of mind if they pay in a small amount each month. As said, some younger participants interviewed in the post-task exercise are more supportive of the Insurance scheme, believing it

to be a good way for people to pay into the system from a young age and then have their care and support covered in later life.

Comprehensive

The Comprehensive option is more popular with males and some first generation participants in the post-task exercise (four out of seven males). It is felt to be the closest to a tax-funded option, which is supported by the males, as it is compulsory and opportunity is given to pay over one's working life. The males believe that if the £17,000 or £20,000 is spread over someone's working life they won't notice it being taken out of their wages as it will be a relatively small amount.

Some of the second generation participants in the post-task exercise prefer the Comprehensive option as well because of the different options for paying. They feel it is going to be easier to pay for the Comprehensive scheme in instalments, rather than having to pay a large amount for their care and support upfront, as they may have to do in the Partnership option.

5.2.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

Overall, participants feel that both options have benefits and disadvantages and do not come to a consensus. Half believe the system should be fully national (more females) and half believe it should be part-national, part-local (more males). Generally those first generation participants responding to the post-task exercise

have more support for the part-national, part-local system. Most agree it is a difficult decision and there is no clear answer.

“You do want it to be fair for everyone, but then when you know you’ve got different needs for different communities and different people, especially in different communities, you’ve got different cultures and different communities, people living amongst each other so you’ve got to take that into account as well, so it’s hard to decide.”

(Pakistani female, Birmingham)

Initially the national system gains more support. It is felt that this would be fairer overall, as each area would get the same level of funding so no one area would receive better care and support than another. They also believe it would be simpler and more straightforward, with consistency across the whole country. Females, who are more supportive of this option overall, feel that local authorities are not always reliable at looking after their budgets or do not use it efficiently, so a national system would ensure there was control over this.

On further discussion of the two options, all participants raise concerns about the national system and, more specifically, that the national government may not have an understanding of local issues and needs in their area.

“I think these two parties should work alongside each other and listen to what citizens have to say and want for their communities.”

(Pakistani female, Birmingham)

This leads some participants to support the part-national, part-local system; particularly the males who have more confidence in the local authorities (perhaps as they are sceptical of national government’s ability to meet their needs).

5.3 Ghanaian audiences

5.3.1 Context for response

All Ghanaian participants highlight the importance of family in the Ghanaian culture. Many of the participants have elderly family members living at home and there is an expectation that younger family members will provide care for the older generations. Although this sentiment is prevalent within the community, it is believed that the family does not have to provide all of the care and support that family members may need – they may be involved in arranging care that they themselves cannot provide. During the course of the discussion some participants give examples of where care has been provided to family members by professionals and others from outside of the immediate family and community.

“My father... he had a stroke and he had care. He had someone who came around everyday and then his health deteriorated so he had to go into a serviced apartment where they had care there 24 hours a day.”

(Ghanaian male, London)

Participants also emphasise the significance of Ghana to many first generation and older members of the community. Some of the participants have experience of some family members returning to Ghana at the end of their lives. Many of the second generation participants refer to Ghana as ‘home’ even though they themselves were born and brought up in Britain. Due to some participants’ experiences of family members returning to Ghana they have limited knowledge of the care system in England and this led to some difficulties understanding the context of some of the discussions.

“Looking at my background, my family, not many people have been in a care home. Normally what they do is once they get to a certain age they just go back home.”

(Ghanaian female, London)

Among those who mention that their family members move 'home' to Ghana towards the end of their lives, it is seen as the natural thing to do as many still have family members there. Some also mention that although family is important in providing care, family in England often have busy lives and jobs and looking after elderly family members is not a priority. Others mention that for their family members it has always been their dream to return 'home' to Ghana where the cost of care is cheaper (if family members cannot meet all the individual's needs). Although participants recognise that there is no formal care service in Ghana they believe that the care they can receive from family and community members is often better and preferential to official care and support services in England.

"Even though you've got relatives here it's much easier because... you send them home and pay for someone to look after them."

(Ghanaian female, London)

All Ghanaians who took part in the research all demonstrate a strong work ethic. They believe in working hard, earning money and working their way up to improve their situation and quality of life. They believe that people should get what they are due and, if you have worked hard throughout your life, you should have something to show for that at the end. Some express the opinion that those who do not work hard should not be rewarded for this – many participants criticise current policies and proposals which they see as rewarding those who receive benefits

without providing any reward for those who work hard and pay their taxes.

"It seems to me that the government always 'help' those who are not able to work or low income earners as opposed to those of us who have worked hard all our lives."

(First generation, post-task)

5.3.2 Spontaneous awareness, experiences and perceptions

Many participants from this audience find it very difficult to separate care and support from medical care. Women have a better spontaneous understanding of what could be provided through care and support than men. The women mention that they are aware of such services as 'meals on wheels', adaptations to homes, home help, respite care, 24 hour support as ways of providing care and support to people. However, on reading out the definition of care and support some are surprised that their family members have been in receipt of this in the past.

5.3.3 Response to the case for change

All participants are generally aware of the changes that are expected in life expectancy and demographics in England, having seen articles in the news about the pension's debate and other issues facing society. Some participants question how these projections are calculated and whether other countries are facing similar issues and if so how they are coping with planning for the future.

5.3.4 Consultation Question 1

(Vision for the National Care Service)

Overall Ghanaian participants think that the vision for the National Care Service is not particularly 'visionary' and participants have concerns over how feasible the vision is and how it can be achieved.

Prevention services

Participants emphasise that prevention services need not only be provided by professionals but that support in the home should be provided by a family member, for example ensuring that medication is taken. Some participants think that there needs to be recognition of the role that family members often take in care and support (as this is particularly the case in their culture).

"It doesn't necessarily have to be a trained professional, family members can do this role as well."

(Ghanaian female, London)

National assessment

Some participants think that a national assessment would be useful in identifying the care needs of individuals and the approximate costs of these needs. Some participants also highlight that a national assessment should not be 'one size fits all', but rather should take into account the cultural and language needs of individuals.

A joined-up service

Many participants believe that a care co-ordinator would be best placed to ensure all organisations are working together. Some participants think that this should be the role of a professional while others think that a family member could also take on this role. If a family member is to take on this role, participants highlight that family members would need to be supported by a professional so that they have knowledge and understanding of the care system in order to fulfil their role. Second generation Ghanaians think that their parents and older Ghanaians would want a family member or someone they have a close relationship with involved in organising their care.

"I think it could be a family member supported, speaking to my mum, she'd want me to get involved... because obviously in Africa that's what they do."

(Ghanaian female, London)

Information and advice

Information and advice is seen to be very important to the person requiring care and support but also to their family members. This is paramount since Ghanaian participants mention that they currently have very little knowledge of the care system or even where they could go to get information.

Personalised care and support

Some participants like the concept of personalised care and support in theory, but believe that services are currently stretched and will not be able to cope with increased demand; they are open to fraud and would be of greater relevance to their parents rather than their generation.

5.3.5 Consultation Question 2 (Making the vision a reality)

All participants are very interested in how the vision will be made a reality. Many feel that success is more dependent upon funding than on joined-up working, quality and innovation and a wider range of services.

Joined-up working

Some participants are confused as to what joined-up working really means. They would like to know what would be done differently and to be assured that things will improve. Some participants think that this is just government jargon and that it does not state achievable goals for the future.

Quality and innovation

There is agreement that all services need to be of high quality and at the cutting edge of care and support to meet individual needs. Participants also agree that services should be adaptable; not providing what they think is needed but what is actually required. Some participants are worried that quality and innovation means bureaucracy and outside consultants being brought in to devise and consult on aspects of a national care service; they believe that this would produce

additional costs that do not provide value for money. Many Ghanaian participants also believe that unless the current system is understood, any future model may face similar problems that are present in care services today.

5.3.6 Consultation Question 3a (Funding issues)

There is surprise among the younger Ghanaian participants that care and support is not covered by National Insurance, with many feeling that care and support should be free at the point of need.

“I thought I was already in partnership and paying for my insurance because I pay my taxes. So I’m a little confused.”

(Ghanaian female, London)

Some participants are concerned that the government will step away from controlling a National Care Service, allowing other businesses to become involved in its running and this could change the values of the system – focus may shift to making a profit rather than providing compassionate care.

Although the issue of fairness was prominent in all discussions, a few participants accept that those on the lowest incomes should be able to access support to cover the cost of care. Some of these participants reference the Christian value that we should help those less fortunate than ourselves.

Partnership

None of the Ghanaian participants find the Partnership funding option appealing. Many participants think that it could be very expensive for the individual requiring care, and that overall the government may end up paying out more if people cannot afford the cost of their care.

Through analysing the post tasks it emerged that although none of the discussion group participants favour the Partnership funding option, some younger family members do. Comments from the post tasks suggest that younger family members like the fact that the government is willing to pay between a quarter and a third of the care cost and think that if information was provided to them early enough they would have time to save for the future.

Insurance

Preferences towards the funding options are clearly split by gender, with all the female and none of the male participants preferring the Insurance option. The women prefer this option as they like the fact that the cost of care and support is spread out over time and consequently they will not be faced with one large bill. The Ghanaian women also think that it will be easier to plan for the future with the Insurance option and that it will force people to seek information and learn about the care and support system. The women in the group feel that it would be easy to get people to sign up to contribute to this scheme, as many people currently pay Insurance and should be familiar with the process.

“My aunt was upset about the types of funding options that are available, as none of them seem to benefit her. Approaching 60 and a home owner that has been working for 40 years, she says that if she had to choose one it would be Insurance.”

(First generation, post-task)

Comprehensive

All of the males and none of the females in the focus group prefer the Comprehensive option. Ghanaian men think that this is the best option as it is fair and there are a number of ways in which people can pay their share of money to the government.

“Most practical, least intrusive and affordable solution for dealing with an ageing population.”

(Ghanaian male, London)

This is the least preferred option for the Ghanaian women as they feel it is unfair for those who may not require any care and support. They feel that those who have worked hard to save money should not have to cover the cost of those who cannot afford care and support.

5.3.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

As with earlier discussions, male and female Ghanaians have differing opinions on whether the National Care Service should be controlled by a fully national or a part-national, part-local system. Overall, female Ghanaians tend to prefer the option of a part-local, part-national system. They feel that in such a system the local government would be able to set the agenda for what services they need and will have a good understanding of the needs and requirements of their residents. Overall male Ghanaians prefer a fully national system.

5.4 Nigerian audiences

5.4.1 Context for responses

Within the Nigerian community, care and support is traditionally provided by the immediate and extended family. This tradition continues to be very strong with children 'expecting' to look after their parents, in the same way that their parents looked after their grandparents. There are many cultural reasons that it would not be appropriate to involve someone from outside of the family. These include ensuring the dignity of the individual by not requiring a stranger to undertake personal tasks, meeting different cultural needs and potential loss of 'face' with the rest of the family. There is also a widespread belief that if family-based support is not available, individuals will be looked after by the wider community; usually with the support of the church or mosque.

“[The church] allows you to say to the network of your people to say ‘I’m caring for...’ and when I’m going on holiday, the pastor’s wife will come and care for my dad. Or one of his children will come in because we share respite.”

(Nigerian female, Birmingham)

While there is acknowledgement that young people are less likely to care for their elders in many other communities, there is a feeling that this is not currently the case in the Nigerian community, although this could change over time.

5.4.2 Spontaneous awareness, experiences and perceptions

The perceptions of the current care and support system in England are not positive. It is felt that the system does not deliver a good service and does not take account of cultural sensitivities. There is also a feeling that care providers and the staff that work for them are only motivated by money.

In addition, it is seen to be very difficult to understand the 'system', to find out about entitlements and to know how to apply for support. These factors are particularly relevant in a community where there can be a real stigma associated with asking for care. It needs to be as easy as possible to know what support is available and access and quality of care are felt to be vital.

There is also a perception that the care system can be discriminatory against individuals and communities in that some local authorities spend more on care and support than others. There is a feeling that this could have an adverse impact on individuals that need support but that don't fit into the 'box' created by the local authority.

“And it so much depends on the local authority as to what they feel it's important to provide and if they think transport, whether it's a day centre or whatever is important, they will provide it. If they don't they'll put the money into something else.”

(Nigerian male, Birmingham)

5.4.3 Response to the case for change

Participants are well aware of the challenges faced by society relating to the ageing population, longer life expectancy and higher survival rates. Much of this knowledge has been gained from the media, in particular in relation to the publicity surrounding pensions and the need for people to work longer.

It is acknowledged that while the Nigerian community 'looks after its own', many individuals from other communities are not cared for by their families and that providing care and support should be a priority for the government. Consequently, it is appropriate to look at a vision for the future.

5.4.4 Consultation Question 1 (Vision for the National Care Service)

There is a strong feeling that adequate care and support should be made available to all those who need it and that it should be accessible, appropriate and co-ordinated.

“It should be open to every community to assess people who are having difficulty and to provide the necessary support.”

(Nigerian male, Birmingham)

Against this background, all of the elements of the vision are seen to be important. There is a particular requirement to ensure that needs are properly assessed and that support is tailored to need.

Prevention services

Prevention services are seen to be critical in reducing the need for high level care and support and to give individuals the confidence to remain independent and live with their families if they want to. However, such services would have to be tailored to cultural requirements so that minority communities can continue to live independently.

“There was a lady, she spoke no English... she was showering and the water was too hot, she was under the wrong shower and couldn't get help.”

(Nigerian female, Birmingham)

National assessment

While the concept of a national assessment is broadly welcomed, there are real concerns that it would raise the expectations of services; expectations that can never be fulfilled. There is widespread agreement that it should include not only regular reviews over time, but also reviews when someone moves to a new place to match their needs against what the area already provides.

A joined-up service

Joined-up support is seen to be essential. It is felt that it should include GPs, social services, as well as the church and other organisations. However, there are some concerns about confidentiality and the fact that certain individuals might not want their 'business' known by everyone involved in delivering care and support. This is especially true in the Nigerian community, where 'everyone knows everyone else' and there is a stigma attached to receiving statutory care.

“There can be a real stigma in asking for care. You might not want everyone to know what is wrong.”

(Nigerian male, Birmingham)

Information and advice

Appropriate and accessible information and advice is felt to be critical to the success of the vision. It needs to be tailored to the needs of the

community and disseminated through a range of gathering places. In terms of language, it is seen to be totally appropriate to have all information in English. This avoids the need to provide information in at least three Nigerian languages as well as 200 other community languages. It should be borne in mind, however, that all participants in the groups were English speakers.

Personalised care and support

Personalised care and support is seen as important in meeting different cultural needs.

“It's important for all minorities, to bring that to their home, to help learn our culture.”

(Nigerian male, Birmingham)

It was mentioned in the post-task survey that assessment of individuals should be personalised to the extent that different cultural needs are catered for. This would help avoid discrimination against minority groups. The assessor should be aware of the cultural needs of the individual requiring care. Minority communities should be taken into consideration in the development of a new care and support service in order to eliminate discrimination or exclusion. However, there is also the belief that fully personalised care would be impossible to implement. Instead, local authorities should standardise their care to national guidelines. In one participant's view, people should adapt to the system rather than vice versa.

“There is a wide range and disparity in people’s living. If African food is served to me in London and I move to Scotland what would happen? Should I not adapt? This is ‘England’.”

(First generation, post-task)

There is also some concern that support that is tailored to individuals and different communities could be seen to be discriminatory.

“Will people think she is getting that because she is white, or she’s black or she’s Asian?”

(Nigerian male, Birmingham)

Additional elements of the vision

The women emphasise the need for appropriate training and education of all those involved in delivering care and support to ensure that care is appropriate and delivered safely, including family members caring for their relatives. They see this as an additional element to the vision which could be called ‘empowering the community to care’.

“Something so that anybody who’s looking after somebody can go on a course... You can learn about manual handling, giving personal care, resuscitation, how to describe an incident to ambulance people... and at the end of the day you’ll get a qualification for it.”

(Nigerian female, Birmingham)

5.4.5 Consultation Question 2 (Making the vision a reality)

The different approaches to the vision are seen to contribute effectively to making it a reality. Both groups found it difficult to distinguish between joined-up services and joined-up working. There are considerable levels of concern relating to how joined-up working would work in reality; the main worries being that private (and financially motivated) providers would have a different motive for involvement in care and how confidentiality would be assured.

5.4.6 Consultation Question 3a (Funding issues)

There is a lack of understanding concerning how current care provision is funded and a sense of ‘outrage’ that some individuals may have to sell their house to fund their care. There is also particular anger at the thought that people who ‘can’t be bothered to work’ have their care paid for whilst those who work hard have to pay for themselves.

“It is not fair that people who work all their lives have to pay for those that don’t.”

(Nigerian male and female, Birmingham)

A number of participants find it difficult to talk about making provision for care and support because of their religion. Some participants are born again Christians for whom health, life and death are believed to be in God’s hands. The thought of making plans or insuring something that is in ‘God’s hands’ is, for them, unthinkable.

“We are brought up to trust God for some things and... it pops into my head that if I’m likely to need care when I grow old and I mean if I start to think in that direction then I’ll be thinking ‘Oh really God is not helping me’... for us, that are practical Christians, as born again Christians we believe that our health is the hands of God.”

(Nigerian female, Birmingham)

Partnership

The most acceptable of the three key solutions is felt to be the Partnership approach, which is preferred by all of the males and the majority of females. It is seen as the best approach because

individuals will only have to pay for care they need and the approach is perceived to give the individual more ‘say’ over the services that are provided. Furthermore, as the majority believe that either ‘God will provide’ or that their children will look after them, they expect the cost to be minimal.

“My children are my insurance policy.”

(Nigerian male, Birmingham)

Insurance

Insurance is not considered to be a viable option by anyone, as there is a feeling that people do not want to insure against something that might not happen. It does not make economic sense to pay for something and not use it – any money paid for insurance is potentially ‘wasted’.

Comprehensive

The Comprehensive option is considered to be the most acceptable by a couple of women, as it represents a known cost.

“For peace of mind and also the fact that it is a fixed amount would ease the burden of putting so much aside in your working years.”

(Nigerian female, Birmingham)

5.4.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

In relation to the national versus part-national, part-local debate, there are clear differences between the genders. Women feel that generic funding should be allocated nationally but that there should be local flexibility to respond to local needs. Men feel that it is important to allocate all funding at the national level because of a distrust of local authorities and a sense that they are not answerable to local residents.

“It would be fully national. Why I say that is because I don’t like the idea of it... the local authority doesn’t care, don’t take responsibility in the sense that sometimes when things that are decided by the local authorities you kind of feel that you don’t have any say.”

(Nigerian male, Birmingham)

5.5 Somali audiences

5.5.1 Context for response

Most of the participants in these groups are young men and women who lead busy and active lives and perceive themselves to be a long way off needing care and support themselves. This reflects the profile of the UK Somali community, many of whom are relatively recent arrivals. It is clear that, whilst few had given any

thought to formal care and support structures prior to the groups all have been raised to understand that if and when their parents need care they will be the ones to provide it. Those with children themselves are communicating the same messages to their children, who are learning that in adulthood they will care for family members who need their support.

“We don’t believe we should go to a care home to be treated. We believe that our children will be the ones that will look after us later on and we don’t rely on the government for them to look after us.”

(Somali female, Birmingham)

Participants in both groups stress that caring for older members of the community is an honour and believe that in adulthood they are able to repay the care given to them by their parents as infants and children. There is a strong sense that it would be disrespectful to hand over the care of one’s older relatives to an external care provider unless a situation arose where they could not meet a relative’s needs. The female group express surprise when one participant recounts the story of an older Somali woman being cared for in a local care home rather than by family members. Women suggest that should people of their parents’ generation in the Somali community not get the care they need from family members in Britain most would consider returning to relatives in Somalia to be cared for rather than going into a residential care home in the UK.

“I think it’s a cultural thing, because when you have got a baby, you’re doing everything, when you get older... like what you put in to them they help to put back in to you.”

(Somali female, Birmingham)

It is clear from the discussions that many participants in both groups do not envisage ever needing care and support from outside their family. There is, however, less clarity on exactly what leads them and others in the Somali community to feel this way; while participants refer to the cultural tradition of caring for older relatives, they also suggest that a lack of alternatives has contributed to low expectations of what could be provided outside the family. Participants in the female group explain that given the absence of stability and a functioning government in Somalia, care and support services simply do not exist there. Some are totally unaware of local care and support services and, as such, still consider the family as the only feasible provider of care for their relatives.

It should be noted that these two groups largely consist of people on low incomes or benefits. In the male group there are several students who live with their families. Whilst some may have parents who own their homes, none of these participants are homeowners and many live in rented accommodation. Women in the groups say the latter applies to the vast majority of Somalis in Birmingham.

5.5.2 Spontaneous awareness, experiences and perceptions

Several participants have noticed some service provision in their communities such as ‘meals on wheels’ and local care homes, but many do not know which services would fall within the remit of the care and support sector. When asked for their spontaneous understanding of the care and support services, young male participants assume this to be referring to youth services including youth clubs, healthy eating programmes for children and bus passes for older people.

“I actually never knew anything about the care and support system in England until reading this paper.”

(Somali female, Birmingham)

Women are largely positive about the level of care and support services available in Britain in comparison to that in Somalia where they say there is a total lack of provision in these areas. Taking facilities for people with mobility issues as an example, they explain how ramps and wheelchairs are non-existent for most disabled people in Somali and say how positive it is to see high quality facilities for young disabled people in their area.

5.5.3 Response to the case for change

Many participants are shocked by the information presented on the current system, particularly around how much people have to pay for care. Participants consider it important for a future care system to ensure a fair, affordable

and consistent service. Participants respond positively to the idea of a National Care System and consider this to be a priority issue for government to address (though some of the young men stress that other issues facing them and their community are of equal importance and mention a lack of activities for young people and high rates of youth crime in this context).

5.5.4 Consultation Question 1 (Vision for the National Care Service)

There is support for the key expectations set out in the vision, which broadly fit with participants' aspirations for a future National Care Service. They consider it important to emphasise personalised care and support, which for them is about valuing those in need of care and support as individuals rather than part of a generic group. Other elements of the vision, particularly national assessment and prevention, require some explanation for this audience.

Personalised care and support

Personalised care is the element of the vision which participants naturally focus on and they consider, in some detail, what this would mean for them and their families. As a basic premise they call for a system which respects individuals, their personal and cultural needs and interests and one which does not 'lump people together'. Young men in the London group stress that care and support must be available to all people living in England who need such services, including people born outside the UK.

For families of Somali origin, personalised care and support is also about ensuring that systems are in place to support families who want to care

for family members at home for as long as possible; the perception is that, under the current system, those caring for family members get little or no support which can make taking on this level of responsibility challenging and often stressful even though it is something which they very much want to do for their relatives.

“They [the majority of Somali families] don’t turn to the government; they look to us to help them out instead of the government. And it adds more stress, they become stressful and everything for the family, because they think that they’re by themselves just caring for the elderly, caring for them themselves.”

(Somali male, London)

Participants also place much emphasis on ensuring that older people (both those being cared for by family members and those in residential homes etc.) have appropriate opportunities for social engagement in addition to receiving any practical care and support that they may require. Thinking about the needs of older friends and relatives, women stress the need for older people to be able to reminisce and to talk through issues which are difficult for them to deal with, particularly for those who have faced real hardship, as is the case for many who have moved from Somalia to Britain. Some men and women suggest that whilst they want to

care for older family members they may also need to go out to work and would appreciate visits from outsiders to the home to give their relatives some company while their key carers are at work.

“Listen to the elderly people and respect them. You might give them the things they need, but not listen to them. I think it is important. They might want to talk about the past... their fears or their past.”

(Somali female, Birmingham)

Women state that another important aspect of personalised care and support is ensuring that women can have access to women only services and activities. Several of the women say they could envisage that older members of their communities would like to take part in regular activities with their friends/relatives, but for this to be appropriate for them as Muslims such activities would have to be exclusively for married couples or just women. In terms of more formalised care services, women in the group would want to know that were family members no longer able to care for them, they could receive care in a residential home, for example, where it could be guaranteed that those caring for them would be women. Also linked to the religious aspect of personalised care is the importance of transportation services for older people to continue to attend the mosque when they are no longer able to get out and about on their own.

“Getting them to the mosque and staying with them there and bringing them back again.”

(Somali female, Birmingham)

Information and advice

In common with other groups, information and advice are considered key to the success of a future National Care Service. As this group are likely to be providing care themselves, they assume that under the current system there is little advice for carers on how to support family members, both on an emotional and practical level. They suggest that it should be made easier for carers to complete any relevant paperwork and also request information provided in community languages.

5.5.5 Consultation Question 2 (Making the vision a reality)

Both groups broadly support the proposals for making the vision a reality. The concept of a wider range of services fits with the need they identify for services to respond to different people's needs. With some explanation, participants understand and endorse the need for quality and innovation within the future National Care Service. For them, the marker of a high quality care and support service would be one which caters for the needs of different individuals and which is easy to access both in terms of finding out about services and getting immediate support when required, to prevent people's situations from deteriorating. In care homes, high quality support means care is available 24/7, again to ensure that older people do not feel isolated.

As mentioned earlier, the young men in the London group feel that the vision needs more stress on working with families who care for older family members. This reflects their desire to ensure that, as far as possible, care continues to be provided by families but with more understanding that families need support in providing this care. The ideal National Care Service, for male and female participants, would be one which supports families in caring for family members and enabling them to remain at home for as long as possible.

“It doesn’t say anything about family. It doesn’t say what they can do to be part of this, because obviously like the way that this is being portrayed is like they’re [external services] just going to take full responsibility for that, but obviously it’s not going to be like that.”

(Somali male, London)

5.5.6 Consultation Question 3a (Funding issues)

The different models raise many questions and some participants struggle to have a clear understanding of the differences between and implications of the three options. There appeared to be more confusion than in other audiences researched. Many in these groups are in low income families who may well be entitled to higher levels of free care under all the proposed options, but do not automatically recognise this from the descriptions of the three schemes.

Participants consider the Partnership and Insurance options to be fairer than the current system. However, participants in both groups are concerned by the Comprehensive option on the basis that they understand it to mean that people are required to pay at the point when they stop earning; they envisage that people will therefore struggle to be able to afford the payments outlined in this option. Those in the male group also perceive this scheme to be unfair as people cannot opt out.

Insurance

The Insurance model is one which most participants are able to understand and they are positive about it for a range of reasons:

- Whilst it is clear that some participants would never take up the option of paying into the insurance scheme themselves, they like the idea that it is there should they or others want to do so. They also like the idea of government making it easy for people to ‘protect themselves against the future’.
- Some participants in the male group explain that whilst they envisage being cared for by family members, they cannot rule out ever needing care and support from other sources (in the event that something happens to their children or that they might develop needs their children cannot support).
- A couple of participants suggest that they might want to buy the insurance on behalf of an older relative, so that they could be assured of getting any necessary care and support paid for.

A number of the men assume that if they have paid into an insurance scheme for themselves or a family member, they would be eager to make sure that they then get value for the money that they have spent. Some envisage that whilst family members would continue to be the main carers, they would still be able to use their perceived entitlement to services through having professionals offering additional support in the family home, for example. Others recognise that the insurance is there to respond to acute and unforeseen needs that may arise.

“If my mum hasn’t got money and I’m working, I can pay for any insurance so that if anything happens to her she can be looked after in the future. I can start saving, just before anything happens. So at the end of the day if anything does happen they won’t have to fork out £20,000 to £30,000 to support her, which I don’t think you would have.”

(Somali male, London)

Partnership

Some women prefer the Partnership option as they interpret it as being the best option for people like them who are on low incomes or benefits. Whilst all three options state that the government will provide a higher proportion of care and support for people on a low income,

there appears to be an assumption that there is a greater chance of this being guaranteed under a scheme where no one is asked to invest in insurance. There is also a sense in both groups that the Partnership option makes sense for families who want to be the main providers of care for relatives in their retirement; some question why they would want to pay into an insurance scheme when they anticipate that their children will be caring for them and consequently that they will not need external care and support. However, in the male group this idea is challenged by some participants who say that the future is uncertain and no one can rule out the possibility of needing high levels of support from other services.

“I’m going for number one, because I don’t agree with two or three because the whole insurance policy, I may never need none of these costs and I’m paying £20,000 to £25,000. Does that make sense?”

(Somali male, London)

Comprehensive

Many initially consider option three to be the least fair of all the options, and also less fair than the current system and there is initial concern about being faced with a lump sum on retirement. Further explanation of the different payment options makes some participants more favourable toward the Comprehensive option. The different payment options raise various

questions including how the after death payment scheme can be enforced and whether people would have to sell holiday homes upon their death to cover payment (the background to this is that some participants would like to buy holiday homes in Somalia in the future if the country becomes stable).

Some, however, remain critical of the Comprehensive option on the grounds that for most people, there is no possibility to opt out of the proposed insurance scheme. For the young men, being able to opt out is particularly important; some clearly aspire to work hard and become high earners and are resentful at the suggestion that they may be forced to pay into a scheme which they may not need to use. Part of this is about them hoping that they will never need high levels of care and support, but it also reflects their expectation that their children will support them if and when the time comes. For some, relying on state services is a last resort. Some also stress that if they have managed to buy their own home they would want to keep it in the family so that their children and grandchildren can benefit from it.

Some men perceive this to be the option for rich people who can afford to buy peace of mind and feel that it penalises poorer groups. In the women's group it is suggested that the only members of their community would support this option would be any older people who happen to find, upon retirement, that their children are not going to care for them as expected.

“This is for people who are expecting that their children will be looking after them... and then find out their children will not be looking after them. They will go for Comprehensive because they haven't saved anything.”

(Somali female, Birmingham)

5.5.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

This debate causes some confusion in both groups and responses are mixed. The initial reaction to the proposals is to opt for the fully national model. Participants assume that this would provide for a fairer system where all people would be guaranteed the same level and quality of service across England. Women say another reason they prefer this system is that they feel they have more understanding of, and trust in, national rather than local government.

However, further discussion in the male group results in a switch of opinion and by the end of the discussion most men opt for the part-national, part-local system. They select the local option as they find the argument that local authorities can best respond to local needs of all communities a compelling one. First generation Somalis interviewed by a family member as part of the post-task added that involving local government in these decisions

should ease the burden on national government and help to ensure that services are accessible for local people.

“Fully national... because then it would be fair to everyone. They’re obviously going to make a fair amount... Everyone would be getting the same thing. No one would be different.”

(Somali male, London)

5.6 Caribbean audiences

5.6.1 Context for response

The Caribbean participants emphasise the significance of family looking after each other which is an important part of their community ethos. They believe in looking after their older relatives as they develop care and support needs as far as possible. The female participants, in particular, feel uncomfortable with the thought of a stranger looking after their relatives.

“You need your own privacy and only your family can give you that, not strangers.”

(Caribbean female, London)

However, when the Caribbean participants look to the future they are realistic about the role of the family, as families are more dispersed, and the second generation are often busy with their own priorities. Those without direct experience of

care tend to convey more of an idealistic vision for their care, which they hope will be delivered by their loved ones.

“I have two teenagers who have no interest when it comes to family support. It’s the environment and culture they are in, it’s all for themselves. I’m thinking if this is such a nightmare for my parents and I’m supporting them, then what is going to happen when it is my turn?”

(Caribbean female, London)

These individuals give examples of taking up professional help to aid them in caring for their parents. However, they feel that it is not a replacement for what they can offer as family, particularly the emotional element of care which is often felt to be missing.

“My mum has a package from the government but it is just the tip of the iceberg, it is very minimal. They have given her everything possible but it doesn’t cover everything she needs emotionally and financially.”

(Caribbean female, London)

Some participants emphasise the significance of returning home for many older members of their community. Some female participants in the group feel less confident about the support they would receive in the Caribbean, if they were without their family network. This stems from their comments around being unsure of whether they will be in England or return to the Caribbean in the future. This makes them feel uncertain about planning their future care and support needs. They recognise that there are difficulties in getting support back home.

“More and more West Indians are going back home to live there but this doesn’t suit all of them some can’t acclimatise they go back they are weak and burnt out and need support.”

(Caribbean male, London)

Going back home is also seen as a preventative measure, as it is felt that the warmer climate helps older members of the community deal with their illnesses and hence put less pressure on services here.

The second generation participants talk about the strong sense of pride which leads many of their older relatives to reject the possibility of external care and support. They believe that this stems from their background as first generation immigrants who have worked hard to establish

themselves and prove their independence. They reference the Caribbean community setting the trend for immigrants wanting to own their own properties. This strong work ethic seems to fuel their sense of wanting to stay independent. However, the second generation individuals we spoke to feel less strongly and therefore appear more similar in their responses to the general public groups than some other ethnic minority community groups consulted.

5.6.2 Spontaneous awareness, experiences and perceptions of the care and support system

Compared to other EMC groups, Caribbean participants show good spontaneous awareness of the care and support system; perhaps as they seem to have more experience of the care system than some of the other EMC groups. They are aware of day centres, home help, dial-a-ride services and personal budgets. A number of participants are providing care and support for older relatives.

5.6.3 Response to the case for change

All participants are aware of the changes that are expected in life expectancy and demographics in England. Both male and female participants agree that within the context of the projected societal changes, the care and support system will need to be a key priority area for the government. Despite the figures, some participants not surprised by the figures and hope that things in the future will work themselves out without radical action.

“We knew about unemployment, social deprivation... so it is not a surprise to me but I have got a feeling that it’s going to work out for another 25 years maybe... it depends on what the government does if they repair themselves there will be enough money and support there.”

(Caribbean male, London)

5.6.4 Consultation Question 1

(Vision for the National Care Service)

Overall participants think that the vision for the National Care Service is positive, but not particularly innovative. The male participants perceive the main difference to be the way it will be funded and feel that a lot of the elements of the vision are expected and, in some cases, already in practice. Participants feel that the system should be proactive, particularly for their parents’ generation who are unlikely to ask for help.

“Unless they are breaking down they don’t want nothing from nobody.”

(Caribbean female, London)

Prevention services

Participants recognise the importance of the re-ablement element of prevention services.

All participants think that prevention services need to be a key element of a National Care Service; they envisage it saving both time and money and ensure that the system works efficiently.

National assessment

Participants like the idea that you would be entitled to the same level of care wherever you are in the country. The greatest fear participants have is that their older relatives will miss out on care and support because they will not necessarily request help themselves. However, it is also commented that not all individuals will want strangers to come into their house and know that they are ill. In these cases it is felt important to respect the individual’s wishes and not force them to get help.

A joined-up service

Participants essentially see a joined-up service as ensuring that the various service providers communicate with each other to extent that all involved in each individual’s case are kept aware. They refer to the ‘Baby P’ case which they see as an archetypal example of the problems associated with working in a disjointed way.

Information and advice

Within the context of information and awareness, participants mention the impact of the strong sense of pride felt by the older generation. They would prefer the National Care Service to be more proactive in making information readily available, by making more suggestions. They feel that this would help improve uptake of services from the older members of their community.

“The system has a way of asking ‘We have got a lot of things for you but what would you like us to do?’ Once everyone gets on to the bandwagon of what’s available, there will be people who abuse it, but individuals who don’t know about it wouldn’t know what to ask for, it is really frustrating.”

(Caribbean female, London)

Personalised care and support

Despite recognising the merits of consistency, participants feel that there is an ultimate need to tailor services locally, especially for diverse areas like London. All participants see the benefits of the concept of having greater choice in the care and support that they receive. They recognise that other communities have different cultural sensitivities that could impact on the care required and appreciate that some communities might have more family involvement than others. Whilst they feel that the Caribbean community may require fewer tailored services than others, some participants see the benefits of more personalised care for their community.

“When her mother was dying from cancer we hired a helper who was of Caribbean origin, the benefit of that was that she cooked food in line with the food that she would eat normally... also the banter as they had things in common, that is personalising it.”

(Caribbean male, London)

5.6.5 Consultation Question 2 (Making the vision a reality)

Participants feel that funding is integral to making the vision a reality. There is some confusion over understanding ‘making the vision a reality’ as some participants feel that this is already in place now.

Joined-up working

All participants feel that joined-up working is the most important component in making the vision a reality. Both the male and female groups emphasise the significance of the need to improve the ease of sharing information through information networks. However, some participants are concerned about confidentiality, feeling that not everyone would be comfortable with their information being shared around. This sentiment stems from their strong sense of pride that leads them to keep their health business private. Analysis of the post-tasks shows that this attitude is also reiterated by some of the older participants.

“I don’t want anybody knowing my business, unless I specifically ask for this. I don’t want you knowing.”

(Caribbean female, London)

Quality and innovation

Participants feel that for all services to be of a high quality, staff training should be the main focus. There is a suggestion that something should be put in place to keep well trained staff in the system. Overall there is a sense that investing in staff needs to be a continuous and monitored process.

Wider range of services

The male participants in particular do not see a wider range of services as a priority or as a core part of achieving the vision. Participants are more inclined to focus on the need for flexibility, so that the new system would allow them to seek care and support in the Caribbean. The preference for returning to the Caribbean is mentioned by participants in the groups when they relay the preferences of their older relatives.

“It would benefit my father to live in the West Indies; his arthritis would suit the warmer climate. But there is no care there if there was a system whereby he could transfer what he has paid into the UK through a points based system there that would be good.”

(Third generation, post-task)

5.6.6 Consultation Question 3a (Funding issues)

Both the male and female participants are surprised about the funding required for care and support and this affected their response to the funding options. If they have to contribute, they all feel that it is important to contribute throughout their lives rather than facing a lump sum at retirement, or taking the money from a family’s inheritance.

Partnership

The Partnership option was not popular amongst Caribbean participants initially. However, as the discussions progressed more female participants felt that it could encourage people to be healthy. They feel that this would mean they would not necessarily need care and, therefore, not have to pay anything. It was preferred by those who might expect their families to look after them

when they are older, or those who believe they will do a good job of saving throughout their lives. The male participants tended to feel that it could leave them open to the risk of high costs in the future.

Some female Caribbean participants prefer the Partnership option because it would allow them to have the option to save independently. The female participants note that this option can be aimed at younger people and instil the idea of saving for the future in their minds by requiring them to start paying in once they are working.

“I would personally go for Partnership. I would rather save my money, but if anything happens, if I die before I get to that age, then my offspring will have that money there.”

(Caribbean female, London)

The analysis of the post-tasks shows that participants' female relatives prefer the Partnership option because they feel that it fits with their perception that all individuals have different needs. However, there are some participants that feel that this option seems fine in theory, but in practice they may have to pay more than someone in a similar situation who went for the Insurance option.

Insurance

This option received some support from some females; they see it as a way to pay in a small amount each month for 'peace of mind' in the future. However, the main concern with this option is that if the individual does not need care and support they will not get the money back. Participants want to be able to leave something for their children and do not like the idea that the government will keep it.

Despite the Insurance option not being compulsory, the male participants feel that there is not much difference between Insurance and Comprehensive.

“To me Insurance and Comprehensive are the same. Insurance like the Comprehensive will mean I pay in whether I use it or not, it is just insurance and they are calling it by a different name.”

(Caribbean male, London)

Comprehensive

Most participants in the discussion group and in the post-task prefer the Comprehensive option; they like the idea that everyone pays the same. They feel it is fair as they can pay into it steadily rather than being hit with a bill near the end of life. The male participants also feel that this option will be beneficial for the coming generations who will be accustomed to saving through the changes in the pension system.

“I think this Comprehensive one will be good for the kids coming behind. Because they can pay £17,000 from their pension which is going to become compulsory and this could come out of that so it could be a good idea.”

(Caribbean male, London)

Despite being positive about this option, participants want to know what will happen to those who might die before it matures. They want to know if there are any plans in place for the money that these individuals have contributed.

5.6.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

Both males and female support the idea of tailoring care and support to local needs. However, there is a lack of trust in local authorities. They suggest that local authorities should be able to make decisions, but be closely monitored by national government so that they have to justify their spending.

The fully national option received mixed reviews across the Caribbean groups. The female participants are initially particularly sceptical. They compare it to the National Health System and hope that a fully national system will not be bureaucratic and inefficient. However, analysis of the post group questionnaire shows that the

majority choose the fully national option as they feel it will ensure consistency across the country. The male participants feel that decisions should be made at a national level but administered through regional care offices which will ensure that care is tailored more locally.

“It will be tailored, if it is held at a national level it will automatically be tailored to individual needs because your local office will be feeding back the needs of the communities as they will get the applications.”

(Caribbean male, London)

5.7 Lesbian, gay, bisexual and transgender (LGBT) audiences

5.7.1 Context for response

Individuals express a number of significant concerns over their own future care, including how care will be provided as well as the implications of needing care. The issues include lack of trust in the system and its ability to provide care that is appropriate to the individual, as well as the legal and financial implications on partnerships:

- Some of the lesbian participants indicated an extreme position in that they would rather take their lives than have to be in a position where they need care. They do not trust the current system to take account of their needs or to provide an adequate service, a response

that is based on experiences of other statutory and voluntary sector services. In terms of statutory services they cite the failure to meet individuals' preferences, for example for a female doctor. In terms of the voluntary sector there is mention of funding being moved away from LGBT-focused services (with a consequent loss of those services) to other minority groups.

- A transgender interviewee talks of the need for people to have to divorce their spouses if they have a sex change operation. Whilst many immediately enter a civil partnership with their ex-spouse, there is always a period of time where the couple do not benefit from the legal and financial securities of being married or in a civil partnership. If one of the spouses were to die in the interim period it could have various implications for inheritance tax, care and support.
- One transgender interviewee is very aware of his own needs as he constantly lives with worry of becoming HIV positive and knows that ultimately he would require care.
- Gay males in the groups generally find it hard to look ahead.

"I just think it's very difficult for me personally to think of what I will need in another 30 years time."

(Gay male, Manchester)

5.7.2 Spontaneous awareness, experiences and perceptions

Experience varies considerably between the different groups that make up the LGBT community, with the group of lesbian participants tending to have more direct experience of being care givers and of being involved with their parents or their partners' relatives.

There is a general perception that the care and support system in England hard to access, disjointed, inefficient, bureaucratic, inconsistent, under-funded and not centred around the needs of the individual. There is also a perception that carers will not understand the needs of gay people in relation to specific illnesses and the resultant care and support needs (e.g. HIV/Aids).

5.7.3 Response to the case for change

There are high levels of understanding of the challenges faced by society as a result of the ageing population, longer life expectancy and higher survival rates. Once presented with the case for change the majority say that the issues should be prioritised, although there is some cynicism about the statistics presented and indeed that change can ever be achieved.

5.7.4 Consultation Question 1 (Vision for the National Care Service)

Overall reactions to the vision are positive and the elements are seen to incorporate many of the different aspects of care and support that they believe are critical to the future success of a National Care Service. A number of specific gaps are identified in common with other audiences, for example, greater joined-up working across

the whole of government and building systems that people can have trust and confidence in. Points specific to the LGBT audience include:

- training with a more explicit focus on improved communications, aftercare and the diversity of need
- ensuring that future services respond to the needs of a diverse society and reassurance that professional treatment will be given with no discrimination because of sexuality.

“Because you don’t conform to what the stereotype is, they might not think that you’re gay, they might presume and assume naturally that you’re straight, and I think that has an impact on the way that service and care service is delivered to people.”

(Lesbian, London)

Prevention services

There is agreement that prevention services are a critical element of the vision and individuals really like the idea of building confidence to remain independent. There is also a feeling that it is important to incorporate early prevention work to delay, where possible, the need for care and support as well as enabling those with needs to remain in their own homes. At the same time it will be important to recognise that it may be difficult to engage individuals in their own care and the effective use of prevention services.

“The person has directly got to want to do it, and you’re dealing with older people, disabled people who may not want to be involved.”

(Lesbian, London)

National assessment

The benefits of a national assessment are widely accepted. It is seen to provide a consistent and fair approach to care and support, although it is essential that regular reviews should be carried out to ensure that the level of support provided reflects need as it changes over time.

“It’s very difficult to ensure the quality of care... but maybe if you had a national assessment and you had a way of grading people and then cross-comparing what they actually receive then you could see whether there were deficiencies in certain areas, geographic areas.”

(Transgender male, London)

However, there are serious concerns over how the assessments would be carried out, by whom and how individual they would really be. The assessors will need to be ‘acceptable’ to a wide range of professionals and voluntary agencies, as will the quality of the assessment such that it will

be acted upon without question. Again there is felt to be a need for an assessor to be aware of the many issues faced by the LGBT community and especially the emotional and psychological challenges faced by individuals. Further, care needs to be taken not to stereotype individuals, something that could result in 'one size fits all' solutions.

“[There is a danger that] everyone is pigeonholed; even though they might be individually assessed they will be put in five or six categories and you can't deviate out of these categories.”

(Lesbian, London)

A joined-up service

A joined-up service is seen to be very important as there are so many different facets of care and support provided by different agencies. At the same time, there are concerns over how such a service would work in practice and in particular who would take the lead and how private and statutory sector services would work together.

Information and advice

The lack of information and advice is seen to be one of the main weaknesses of the current system and therefore it is essential that appropriate information and advice is provided for those who need care and support, as well as for their carers. Information should be tailored to the specific community group and take account

of the lifestyles and needs of different groups. This is not restricted to the LGBT community and there is agreement that the needs of all individual cultural groups should be taken into account. However, it is important to include the different LGBT communities, as they believe that all too often these groups are excluded.

Personalised care and support

Personalised care and support is key and participants feel this would meet a perceived gap in current provision. It is seen to be particularly important to ensure that personalised care and support reflects the diversity of the client group and that it takes account of all needs, including those that are a result of an individual's sexuality. This includes, for example, the need to ensure the gender of carers is appropriate for the individual.

“But I think yeah, if I'm a gay person, as I get older and in need of care support, I want to know that not only am I going to be treated professionally, and in an appropriate manner, but actually my sexuality might have some relevance to the way I'm cared for.”

(Lesbian, London)

5.7.5 Consultation Question 2 (Making the vision a reality)

While participants agree that the vision is appropriate and necessary to tackle the challenges faced by the government, the effective implementation of the vision is questioned, especially in view of increasingly limited resources.

Participants raise a number of key factors to be taken into account if the vision is to be implemented successfully. These include:

- Care and support services should be structured around a key worker model, i.e. with a single point of contact to liaise between the different services and ensure continuity.
- This individual should have in depth knowledge and understanding of the different communities that they are working with and should be in a position to facilitate the provision of both physical and emotional support.

A necessary element of delivering the appropriate care and support is the provision of training for all those involved in delivering services. These services should be delivered by professionals who are aware of the sensitivities that are experienced by the LGBT community in relation to their care. Sensitivities can include the ways in which personal care is delivered, the provision of daytime activities in appropriate settings (including the need to ensure that any group accepts fully members of the LGBT community), and an understanding of personal relationships.

“I think there is also a huge training issue, because as a gay person I don’t think sexuality even becomes visible to people in the care profession. Some might say why would it, would it be relevant?... I think there is a huge gap in the training arena for people in this profession.”

(Lesbian, London)

There is a call for greater clarity on how the assessment process will work; participants emphasise that this should be carried out by an individual who instils confidence and understands the needs of gay people. The need for a lesbian individual to be guaranteed a female assessor is given as an example.

Joined-up working

Joined-up working is considered to be an essential element of a National Care Service. The key factors of joined-up working are felt to be awareness, communication and co-operation.

Quality and innovation

To a large extent quality is dependent on those who deliver services and the continuity, consistency and competence with which these services are delivered. It is noted that quality is only as good as the weakest link; there are serious concerns due to the perceived status of the profession of carers and the lack of skills within the workforce.

“Why should an older person who is going through all the indignities of their failing bodies and their health and their confusions about everything, have to keep getting used to different people? Wouldn't it be wonderful for them to have a person who they liked, that they trusted, and who was reliable, and they could talk to? I mean, yeah, it would be phenomenal.”

(Lesbian, London)

A wider range of services

A wider range of services is seen to match with the objective of providing personalised care and support and is welcomed. However, there are a number of considerations that need to be taken into account including funding for services, the effectiveness of personal budgets in delivering a wider range of services and the need for additional training.

5.7.6 Consultation Question 3a (Funding issues)

None of the options presented are liked, as they are seen to penalise those who have worked all their lives, paid taxes and National Insurance and saved to support their retirement while supporting those who 'haven't been bothered to work but get it all paid for'. There is a call for a review of benefits alongside all of these funding options.

Partnership option

After deliberation, the majority opt for the Partnership option on the basis that it is voluntary and that people will only have to pay for what they use. It is also seen to be open to less abuse than the other options and is familiar as it most closely reflects the current system.

Insurance option

The Insurance option is not favoured by any of the participants as it is seen to be the government 'washing its hands' of the issues; it is effectively seen to be a tax that everyone would have to pay. There was a lack of trust concerning the government's motive and a belief that although the scheme is 'voluntary' this would be the case.

“To me there's very little difference... The government doesn't actually pay for anything at the end of the day, we all pay for it. So the government paying a quarter or a third, it's coming out of income tax or some other tax. It's just a question of how it's levied.”

(Transgender male, London)

Comprehensive

One transgender participant opted for the Comprehensive option as they feel it would allow for a uniform system in which all those in need would receive the care they require. LGBT participants feel that a merit of this system is that it is especially beneficial for individuals with particular care needs (for example, HIV and others) where care is not always as accessible and may be very expensive. At the same time, it is believed that this option would not work because it could be easily manipulated – especially if it involves taking payment from one's estate after death.

The majority of gay men in the group are single and some state that they want to stay single. One implication of this is that whilst they understand the rationale behind lower rates for couples, they reject this option as being unfair. In contrast, the lesbian participants are in relationships but are sceptical as to whether the government would apply the partnership discount to gay couples.

5.7.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

The majority prefer the national funding option, as this is seen to be more straightforward and fairer. They believe it also has the potential to offer a greater degree of consistency and continuity of care. These perceptions are driven largely by the fact that local authorities are seen to be untrustworthy, wasteful and most interested in funding services which gain them electoral support. There are also concerns that local authorities will invest in certain sectors of the community at the expense of others, especially those sectors that will win votes or meet high profile government agendas.

6. FAITH LEADER INTERVIEWS

Overview

Depth interviews were conducted with seven faith leaders representing the viewpoints of Muslim, Sikh, Hindu, Jewish, Roman Catholic and Jehovah's Witness faiths.

The individuals were asked to speak on behalf of the communities in which they work and live.

- All faith leaders stress the importance of family and the community in care and support provision, and so place importance on joined-up working in terms of the meaningful involvement of family members and representatives from religious communities.
- There are differences in terms of perceptions of changing attitudes of future generations. The Hindu faith leader feels that members of her community are rapidly becoming Westernised and that extended families will play less of a caring role in the future. The Sikh faith leader anticipates that this is likely to happen in future, whilst the Muslim faith leaders believe that future generations will adhere to Islamic teachings and that there will be little change in attitudes and behaviour in terms of care and support.
- Most feel that the care and support needs of their communities could be better understood and catered for; calling for improved training of care workers and more people from their communities to be actively recruited to work in care and support.
- There are mixed views on the funding options although there is a tendency to select the Comprehensive option as it is seen as one where majority contribute to help support the minority in need; a philosophy which resonates with many of the faiths. One Muslim faith leader expresses concern that under an insurance system, insurance premiums may be invested in immoral investments (such as the arms industry).
- The Muslim, Sikh and Hindu faith leaders all opt for the part-national, part-local funding option as they feel that local government has a better understanding of their communities' needs than national government. The Rabbi, Roman Catholic priest and the Jehovah's Witness all selected the national option viewing it as the fairest alternative.

6.1 Muslim faith leaders

6.1.1 Context for response

In total, two interviews with faith leaders from the Muslim community were conducted. One of these was with an Imam in Birmingham (Asian). The other was with a Somali Community Leader in London.

Both faith leaders work closely with their faith communities and provide information and advice to their local community members. This advice includes issues relating largely to housing, employment and UK settlement, particularly helping those who speak English as a second language. It can also occasionally cover health and care and support queries.

The Imam is in his early 30s; he was born and brought up in the United Kingdom and is proud of his British Muslim identity. The Somali community leader is in his 60s. He interacts with Muslim communities in the Forest Gate and Whitechapel areas of London on a weekly basis. Due to his age and experience of living in the UK for some time, he is often sought for advice on generic issues by others in the community.

6.1.2 Spontaneous awareness, experiences and perceptions

The Imam has good awareness and knowledge of current provision of care and support services in the UK. On the whole, he is very positive about the current system, and has very few concerns about it.

He says that the care and support system is in line with Islamic principles of pooling funds to help those who need it (due to old age, ill health

and disability). However, the Imam states that Islam teaches individuals to take help from others only when they cannot fully support themselves. He goes on to state that the life and teachings of the Prophet clearly encourage individuals not to take too much and forbids those who can support themselves from becoming dependent on charity and alms. Due to the Prophet exhibiting these virtues in his own conduct, the Imam is certain that this will not change and future generations will adhere to this principle. The Imam believes that the care and support system in the UK could be more proactive in recognising the risks of making recipients inadvertently dependent. He feels that the system needs to go beyond merely offering financial support to actually addressing the root causes of people becoming dependent on social security benefits (i.e. lack of educational attainment, low employment opportunities, laziness and so on).

“Social care in this country should not provide a medium to milk the system. It should provide targeted support to improve the capacity of the individual to stand up on their two feet.”

(Imam, Birmingham)

When asked about the number of people in his community getting care and support, he said that a few avail care and support services, but the majority receive the required help from their immediate family and relatives. He mentions that this is a South Asian cultural aspect. At the same

time, he thinks it is becoming more difficult for the new generation of British South Asians to look after their own because of financial constraints and wider societal change.

The Somali faith leader is less familiar with the current care and support system. Similar to the Imam, the vast majority of his community contacts rely on family support. He believes those in his community are brought up to respect those who need care; no matter how many challenges or issues an individual receiving care might face.

“The people who I know have incredibly tight-knit families. They are there with each other in good and bad times. It is what is expected in our culture. Very rarely do I see anyone asking for help from an outsider.”

(Somali male, London)

6.1.3 Response to the case for change

Both of the Muslim participants understand that the population profile and disease patterns in the UK are changing and that the government has to address these issues. The Imam feels that since 1948, vast improvements in the health and care of the British population have taken place. He notes that the same has occurred in the South Asian community settled in the country.

“Our community is increasing in size and is benefitting from the advances in health and social care. The birth rates are relatively higher than the native community, so if anything I think it [the case for change] affects us quite a bit.”

(Imam, Birmingham)

There is some scepticism from the Somali faith leader, who believes that it is difficult to predict these things and that ‘nature has its own way’ of shaping the future.

6.1.4 Consultation Question 1 (Vision for the National Care Service)

Both of the faith leaders support the vision for the National Care Service. They are especially keen on the focus on prevention. Moreover, they also stress the need for improving information.

The faith leaders believe that the assessment and provision of care should be tailored to take into account people’s religious beliefs. There was a feeling that although this is done to an extent already (i.e. around preferences for Halal and vegetarian food), it could be further improved. At the same time, both of the faith leaders also express concern about the system becoming ‘too personalised’. This is because they think it will become difficult for a lot of people (both in their community and outside) to negotiate the system (in terms of choice as well as the responsibility for planning their own care).

The Imam states that the process of assessment should be standardised across the country so that everyone should expect a similar process. There is some concern from the Somali faith leader about personal details being passed around with a national assessment, so these must be safeguarded.

6.1.5 Consultation Question 2 (Making the vision a reality)

According to the two participants, establishing joined-up working is key to making the vision a reality. This is because they feel it is important to ensure that the different parts of the system work in unison. Both individuals are aware of cases where they feel 'too many different professionals' get involved with someone receiving care. As a result, the Imam was keen on a 'one-stop shop' approach because he had met individuals in his community who were frustrated by the processes and protocols employed by different care providers. He expects non-Muslims to have similar views on the 'unnecessary duplication between providers'. Similarly, the Somali faith leader would prefer to have one key contact for each person receiving care. He thought this would make it easier for them and their family to ask questions and receive tailored support.

Having a wider range of services would be important to this community, and, in particular, the option to have funding to receive your care from a family member rather than an unknown care worker is something that would suit Muslim communities. This was strongly supported by the Imam who knows two members of his congregation that have had to leave employment to look after a parent.

“I think because our community tends to look after the elderly by themselves, it would be appropriate to ensure that the carers have the adequate financial support and recognition available in the new care service.”

(Imam, Birmingham)

Finally, the Imam also notes that any changes to the current care and support service should happen slowly and not drastically so as not to confuse those who are used to the current system.

6.1.6 Consultation Question 3a (Funding issues)

When considering the funding models, the Imam participant feels that services should be free at the point of need and use. This is because he feels strongly about the values and traditions enshrined in the National Health Service, which he relates to the care and support system. In line with this, the preferred option is Partnership, which he considers to be the fairest of the three and most in keeping with Islamic principles and values. These principles and values are thought to ensure that those who can afford to pay more also contribute towards providing care for those who are less well off.

The Imam was not in favour of the Insurance option. This is largely because he thinks that insurance premiums may be invested in immoral investments (such as the arms industry).

The Somali faith leader also believes that people should pay for care and support if they can afford it. However, he favours the Comprehensive option as the 'fairest', with everyone paying into the system and then everyone receiving care and support. The participant suggests this could be paid over their working life, in the same way as income tax and National Insurance.

6.1.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

Both participants favour the part-national, part-local option as they think national and local government need to work together. They think local control over resources would help in ensuring that they are better used and better tailored to the needs of their communities. The Imam expanded on this to observe that regional differences in services are proportional and will even out. For example, he said the costs of living in London are higher and so are the number and quality of services.

"I think local government should decide on the priorities they want to fund. But the government at the national level have a role into play in ensuring that money is well spent."

(Somali male, London)

They do not believe Islam has any specific requirement that can make one option more favourable than the other in this regard.

6.2 Sikh faith leader

6.2.1 Context for response

The faith leader from the Sikh community is actively involved in the local Gurdwara (temple) and also organises community activities (both social and sport related). While the majority of the Sikhs he interacts with are young, he also meets older members of his community. He asserts that the Sikh culture demands that its adherents are 'quiet and not outspoken' which can mean that people do not ask for support when they require it.

"Sometimes, this means that my people can be too quiet about their own needs and desires compared to others."

(Sikh faith leader, Birmingham)

The Sikh faith places an onus on a tight-knit family unit that respects and cares for the elderly and disabled. In this regard, the responsibility of looking after older, ill and disabled people is commonly taken by the children. However, he feels that this mindset is slowly changing due to the next generation of Sikhs, who are becoming relatively more 'Westernised and independent'. He also predicts that as more Sikhs immigrate to the UK, the demand for care and support services will increase.

6.2.2 Spontaneous awareness, experiences and perceptions

The faith leader knows of some people in his community who receive care and support due to old age, ill-health and disability. Many of these receive some care and support from local social services. According to him, experiences are

mixed. Although he feels that the care services are doing the best they can, he thinks those delivering such support do not understand Sikh or South Asian culture generally.

“Many people in the community are apprehensive about non-Sikhs caring for them. This is primarily because the carers are usually not aware of our religious symbols such as the wearing of the dagger, our daily washing rituals, eating habits and other preferences.”

(Sikh faith leader, Birmingham)

6.2.3 Response to the case for change

He agrees with the case for change, and is reassured that the government is keen to take action.

6.2.4 Consultation Question 1 (Vision for the National Care Service)

The Sikh faith leader feels that the vision is ‘clear cut’ and easy to understand. The most important elements are personalisation and joined-up services, because he believes everyone in the country will benefit from these two things in the National Care Service. From the point of view of his community’s needs, he believes that more Sikhs need to be recruited to work in the care sector. He believes that they are currently discouraged by the perceived low pay, lack of status and lack of training.

“Because there aren’t many Sikhs working in the social care sector, Sikhs needing care and support don’t have get many people of their own faith dealing with them. The new system being proposed needs to make the caring profession more appealing for young Sikhs to enter.”

(Sikh faith leader, Birmingham)

6.2.5 Consultation Question 2 (Making the vision a reality)

The faith leader agrees with the three key elements of making the vision a reality. However, he says that organisation culture, resistance to change, lack of financial resources and the lack of Sikhs in the care and support workforce concern him as important barriers in achieving the vision from a Sikh perspective.

6.2.6 Consultation Question 3a (Funding issues)

On the whole, he believes that there is enough money in the care system to fund it but it just needs to be used properly and not ‘wasted’.

When considering the three options, he finds it difficult to choose one that will suit his community. This is not only because all options have positives and negatives but also because he does not believe there is anything in the Sikh faith which makes one more favourable than the others.

The Comprehensive option was off-putting, as this was assumed to be a large sum that is owed once you have finished your working life. The idea of leaving it in your estate was also disliked for a similar reason; 'you may have saved to pass this sum on to your family for years'. Generally the idea of the burden of care and support being on the older and non-working generation was felt to be morally wrong. To an extent, he favours the Insurance option because this gives people the choice of opting in. He also believes that as most people pay National Insurance currently (irrespective of their income or wealth), asking the same people to pay a small amount from their income each month into this scheme could be feasible. He feels strongly that lower rates should be charged for couples, and that paying through instalments would be more affordable for all.

6.2.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

Again, he finds it difficult to choose a preference. A positive of the fully national system is that it would be fairer as everyone would know what they would receive. However, he is also keen to ensure local factors are taken into account when deciding on the provision of care and support services. Overall, part-national, part-local is the preferred option.

“I think my preferred option would allow for ground realities to be taken in to account. I also know that most people trust their local authorities to know about their area and needs than national government.”

(Sikh faith leader, Birmingham)

6.3 Hindu faith leader

6.3.1 Context for response

The faith leader from the Hindu community is actively involved in the local temple. She also participates in the organisation of community activities, including being a member of a number of committees (relating to care and support) at the local council.

The faith leader primarily interacts with older Hindus, who live not only in Birmingham but also across the West Midlands. A number of these individuals are from lower socio-economic groups and are at risk of social exclusion. Many face difficulties in interacting with other members of their community due to a lack of adequate transport facilities to local care services. She mentions the closure, due to a lack of funding, of a day centre, which she feels is affecting the quality of life of many Hindus she knows.

The participant regularly gives advice about issues relating to health and care and support, housing and transport to the Hindu community. She feels strongly that care and support needs to be about delivering quality of life and compassion to the person receiving care.

“I think social care should go beyond merely fulfilling materialistic needs such as shelter or food. People deserve a lot more than this. They have other intangible needs like social interaction and personal satisfaction that have to be met.”

(Hindu faith leader, Birmingham)

The faith leader states that a number of older generation Hindus are living on their own as their children are becoming increasingly Westernised and independent. She feels that the speed at which this is happening is much faster than that taking place in the Muslim and Sikh communities.

6.3.2 Spontaneous awareness, experiences and perceptions

Through her role, the faith leader is aware of current services. She is fairly negative and is particularly concerned about the lack of funding that is adversely affecting day centre facilities and transport.

She says that the Hindu faith teaches its followers to provide for the elderly and those in need. The faith leader thinks the provision of care services in Birmingham is not adequately meeting this need. Moreover, she observes that the available services are often insensitive to the religious practices of her community members. For example, current provision of the ‘Meals on Wheels’ does not fully recognise the eating requirements (i.e. vegetarian food) and preferences (i.e. salt and pepper content) of Hindus.

“Our religion is very prescriptive about what is allowed [food wise] depending on the festival or day of the week.”

(Hindu faith leader, Birmingham)

6.3.3 Response to the case for change

The facts presented in the case for change handout surprised and worried the faith leader. She is of the view that something needs to be done about the trends outlined.

6.3.4 Consultation Question 1 (Vision for the National Care Service)

The faith leader supports the vision for the National Care Service, especially the focus on personalisation. She believes this will allow the needs and expectations of Hindus to be better identified and catered for. The participant also adds that Hindu recipients of care will benefit from the increased autonomy and choice of having a monetary budget at their disposal.

“I am sure most will spend it on hiring appropriate transport... this will increase their mobility and inclusion in to wider society.”

(Hindu faith leader, Birmingham)

She thinks there is a lack of translated materials for her community and would like more advice for Hindus in Gujarati, Hindi and Bengali. She also believes that a standardised national assessment would be advantageous as long as it was undertaken by local people who understand the Hindu faith.

6.3.5 Consultation Question 2 (Making the vision a reality)

Establishing joined-up working is seen to be a key prerequisite to making the vision a reality. At the same time, the participant is concerned about the possibility of one care professional carrying out the assessment. This is because she feels that that person may not be an expert in picking up all the needs. The risk of abuse and neglect by the sole assessor is also raised. The faith leader would like every individual in the country to receive information on the vision and the way it will be implemented. She would like it to be sent in different languages. She also suggests that any proposed alterations to the system should be piloted before wholesale changes are introduced.

6.3.6 Consultation Question 3a (Funding issues)

In considering the funding models, the participant strongly advocates that care and support should be free at the point of need, and should be funded by the state. She is of the view that the Hindu community she interacts with will not be happy with any of the proposed funding options, particularly the notion of having to sell part of one's estate or using personal savings (here the £23,000 figure was particularly upsetting for the participant). As a result, she was reluctant to choose a funding option on behalf of her community.

“It does not feel right for me to choose one option over another when the community is going to oppose each one.”

(Hindu faith leader, Birmingham)

6.3.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

The faith leader favours the part-national, part-local option as she thinks local authorities with larger Hindu populations would then be better placed to cater for their needs than national government.

6.4 Roman Catholic faith leader

6.4.1 Context for response

This priest's role involves being in touch with members of his community, providing emotional support to them and ensuring they are receiving the practical support they need. He states that the Catholic community believes in helping those who are less fortunate than oneself, and also that every individual should have the right to the same treatment and same level of care.

6.4.2 Spontaneous awareness, experiences and perceptions

The priest is aware of a number of people in his community who require care and support. His role involves a degree of counselling and the Catholic church provides a range of emotional support services for such people, including the St Vincent de Paul society, in which individuals from the parish visit those who are in need, and a bereavement service, which supports grieving individuals.

However, practical support is provided through the formal care and support system, not through the church. He believes there are legal and health and safety issues with individuals providing unpaid practical support to those in their faith community. For example, parishioners may need to be police-checked and carefully monitored if working with vulnerable adults.

“I would see myself as being like a referral agency. These days you have to be so careful with vulnerable adults, and people who are elderly would come under that category.”

(Priest, Manchester)

The priest and his church act as a referral agency to the formal care and support system; if members of the community need care he will help contact and direct them to the right services.

“The parishioners don't actually do those practical things like helping people get dressed and things like that, but they would be sensitive enough to make referrals if they thought that somebody was not able to look after themselves or something like that.”

(Priest, Manchester)

6.4.3 Response to the case for change

He is not particularly surprised by the demographic information presented, as he knows that there is an ageing population in England. He does believe that this is a key priority area for the government.

“The bottom line all the time is how much will it cost and how are we going to pay for it.”

(Priest, Manchester)

6.4.4 Consultation Question 1 (Vision for the National Care Service)

The priest supports the vision and feels strongly that care and support should be fairly and consistently provided across the whole of the country. He believes that the key to having the service working well is having a joined-up system, particularly for old and vulnerable adults who do not want to have to deal with lots of different assessors and care workers.

“All the different agencies that an individual is involved with, they should communicate with each other... If agencies can co-ordinate their services between themselves then I’m sure that people will find that very helpful and less tedious.”

(Priest, Manchester)

His opinion is that when assessed, people’s religious beliefs should be taken into account, but that Catholic users of care will not require specifically tailored care packages because of their faith. Transport to and from place of

worship is the only key service he identifies they might require that is different from the rest of the general public.

“It would be nice if every elderly person’s home had a little chapel but, I mean, that’s not realistic and if people do want to get to church, who are elderly and infirm, we try to make arrangements that can happen through people giving them lifts and things in their cars.”

(Priest, Manchester)

6.4.5 Consultation Question 2 (Making the vision a reality)

The priest agrees with all three ways of working in principle, although he assumes that it is likely to take a large amount of funding to change the system in this way.

“Certainly in principle it’s a good idea, but the whole of this is going to cost millions, so where is it coming from?”

(Priest, Manchester)

In his opinion, joined-up working will allow the individual to be treated as a whole person and this reflects his belief on how human beings should be considered. Quality and innovation are

also important and he believes this will be more easily monitored within the new system, if everyone is supposed to be getting the same, consistent level of care. A wider range of services should be considered, but only if it is affordable and not going to put a huge burden on the cost of care and support to the nation.

6.4.6 Consultation Question 3a (Funding issues)

He considers funding to be 'the crux of the matter'. He believes that care should not necessarily be free; those who can afford it should pay something towards it and those who are unable should have help with it. His attitude is 'if you've got the money, then you should pay for it'.

He prefers the Insurance and Comprehensive options, as they seem like a 'fairer' way of doing things with everyone paying something into the system. He would choose the Insurance option if it had a 'no claims bonus' attached, so that people who never have to receive care get something back. This would encourage people to remain healthy – the participant disagrees with people who do not take care of their health abusing the system at the expense of the healthy. On balance, he feels that the Comprehensive option is the most appealing, as it is compulsory, but he suggests making it 'means-tested'.

"I think that wealthier people should pay more... If you've got plenty of assets and everything then you should be expected to pay more."

(Priest, Manchester)

6.4.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

The national system is preferred as a 'fairer' and 'more consistent' way of making decisions. He feels that there may be too much inconsistency between how local authorities make decisions and how effective they are, which could lead to some areas providing better care and support than others. He also feels that money can be wasted or misused at the local level.

"I've a thing about too many people with their fingers in the pot, like the local authorities, then there is always a danger of at worst corruption and at best the money being – instead of being ring-fenced for a specific task it gets used for other things. So I think that the national option is better."

(Priest, Manchester)

Finally, the priest suggests that national government should make decisions on funding, but provide money on a 'needs basis' so that the areas with the most people with care needs get more funding.

6.5 Jehovah's Witness faith leader

6.5.1 Context for response

The participant has been an Elder for 16 years. He stresses that the Jehovah's Witness community will support any proposals driven by government without any objection, as they are politically neutral for religious reasons.

"Our religious beliefs say that whatever the government decides we will go along with."

(Elder, Manchester)

In his congregation there is a strong tradition of members helping each other in times of need. Jehovah's Witnesses place a heavy emphasis on family solidarity. He, therefore, believes that an individual should always help those less fortunate than him or herself and this influences his views on care and support. If an individual finds themselves in a position where they and their family cannot provide adequate care, other members will take on support responsibilities for as long as they are able to do so. He and other members of his congregation often work alongside the NHS and care and support services.

"The principle that guides us is the family do it and when the family can't do it then the congregation help out, but usually if the family can't do it then the State's got to do it."

(Elder, Manchester)

6.5.2 Spontaneous awareness, experiences and perceptions

The Elder's family has frequent contact with local care and support services as his two children are disabled and receive Disability Living Allowance. He has a comprehensive knowledge of current care and support provision, much of which he feels positively about. However, he is concerned about inconsistencies in the quality of care available in different areas.

6.5.3 Response to the case for change

He considers it a priority for the government to address these issues, but says that prior to reading the various documents provided he 'hadn't realised the enormity of the problem'. He fully supports and trusts the government's initiative for change in the care and support system.

6.5.4 Consultation Question 1 (Vision for the National Care Service)

The Elder supports these principles but would like to see some more elements incorporated into the vision, such as a system which is simple to understand and use. He would also like a system which is proactive in offering information and support. In his experience, sometimes it is difficult to access all relevant information and in a new system it should be easier to access.

“It’s always a bit challenging getting information and advice; you’ve got a lot of hoops to jump through... it would be nice if there was one webpage and you could just click, click and you’d get the answers that you needed.”

(Elder, Manchester)

In an ideal world, personalised services would include more spaces in residential homes led by Jehovah’s Witnesses. As followers of this faith do not celebrate religious holidays, such as Christmas and Easter, he feels it would be preferable for them not to be living in care homes where these events are celebrated. He recognises, however, that this would be a difficult policy to implement.

6.5.5 Consultation Question 2 (Making the vision a reality)

Establishing joined-up working is the most important aspect of the vision for this faith leader, who is largely satisfied with the services his family and members of his congregation receive but feels that they can be disjointed. He says steps could be taken to simplify relationships between those ‘representing’ people in his congregation who need services and those providing them.

6.5.6 Consultation Question 3a (Funding issues)

The Elder accepts that care and support can cost a lot and that the burden falls partly on the

individual. His preferred payment option is Comprehensive, which he considers to be the fairest of the three and most in keeping with his personal and religious values. He believes that ‘we should all help those not as fortunate as us’.

“My personal view is that we should all help those not as fortunate as us. To me it seems fairer if 1000 of us pay for the 100 of us that need help, rather than those poor 100 getting stuck with something they can’t pay for.”

(Elder, Manchester)

6.5.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

The Elder feels a fully national system would be fairer. He thinks it would provide a better system for delivering consistently high quality services across different communities. He conveys that there is a ‘massive demographic’ of people in the Jehovah’s Witnesses, and a national system would be fairer in provisioning standardised care across this diverse range.

Furthermore, the Elder anticipates it would be easier to increase and improve the number of residential homes run by Jehovah’s Witnesses if decisions were to be made at a national level. This is because he feels that some local authorities may not want new Jehovah’s Witness institutions in their area and deny them planning permission and so on.

6.6 Jewish faith leader

6.6.1 Context for response

The interview was conducted with the Rabbi of a synagogue in a Jewish reform community. He states that Jewish congregations have a strong sense of community care and if a member of the community is in need, they will be helped and comforted. He sees spiritual care as an integral part of care and support, especially in end of life situations. It is the role of the community as a whole to look after each other, not specifically of the Rabbi.

“Visiting somebody who’s ill, or comforting the bereaved, those are all Jewish values and Jewish practices.”

(Rabbi, London)

6.6.2 Spontaneous awareness, experiences and perceptions

The Rabbi has a high awareness of the existing care and support system as there is a Welfare Co-ordinator at the Synagogue who is responsible for identifying and co-ordinating support for community members. In similar communities, paid care workers are provided. These support roles are supplementary to the statutory system, as sometimes this does not meet individual needs.

“It’s what people get from being part of the community. Perhaps we’re supplementing the care that we’re talking about, the state care, and we’re replacing what people probably got more of when everyone knew everyone else in the street.”

(Rabbi, London)

6.6.3 Response to the case for change

The Rabbi feels that the statistics give powerful backing to the case for change and make the care and support system a key priority for the government. In his opinion, a key objective should be for individuals to be treated equally irrespective of where they live.

6.6.4 Consultation Question 1 (Vision for the National Care Service)

He feels that all of the elements of the vision are essential, but thinks they are what one would hope to be already in place and provided as a norm. In his opinion, a joined-up service is an important aspect of the vision. Although he feels services are joined-up to a certain extent already, he stresses that they should be more so. There was concern over the fact that there is no obvious element that interfaces with hospital care and bridges the gap.

The Rabbi also feels that there should not be a separation between State-provided care and the role of the religious community – the interface between the two should be merged. The supplementary work done by the community is critical for the smooth running of the overall statutory system.

He feels that the title 'prevention services' is misleading. He believes that they should not only be in place to prevent an individual's care and support needs increasing, but also to avoid individuals needing care and support in the first place.

The Rabbi is unsure about national assessment. He feels that constant reassessment is a hindrance to the system and the individual. Whilst a certain amount of assessment is required, overall there should be fewer assessments which are more relevant. The assessment needs to include an exploration of the individual's spiritual needs (whatever they might be) so that the necessary groups can be involved in care (in the Jewish community this would be the Care Link Committees).

“You don't need reassessing if you move to another authority and you also don't need reassessing when you walk from your doctor to Age Concern to the dementia unit in the hospital... That should mean there's less assessment. On the other hand, to keep that individual care package tailored and personalised actually means reassessing frequently, which should be the other side of the seesaw.”

(Rabbi, London)

6.6.5 Consultation Question 2 (Making the vision a reality)

The Rabbi agrees with the three ways of making the vision a reality and thinks they flow naturally from the six elements. For joined-up working to be effective he believes there will need to be a single point of contact to co-ordinate effectively the many different services. Co-ordinating the mix of statutory, private and voluntary sector agencies and the NHS will be challenging, especially ensuring the free flow of information while protecting confidentiality. It will be important to include faith communities as part of the core mix of agencies involved in delivering care as they have a vital practical and spiritual role to play.

“I would actually like to see it joined up with how we work as a society for medical needs and indeed for pension living. They’re not completely different... The voluntary sector, the statutory sector and the faith communities are actually all part of society’s provision and that needs some joining up as well.”

(Rabbi, London)

6.6.6 Consultation Question 3a (Funding issues)

He would like to see any funding option ‘joined-up’ with medical care and pension payments so that those elements are ‘joined-up’ for the individual. He believes that the Insurance option would be the one that would be most fully understood by members of the community as it is something they will ‘recognise’ while the others are outside their sphere of knowledge. Whatever the option, it is preferable for the individual to be able to contribute while they are working on the basis of ‘pay when you can afford it; get the benefit when you need it’. He also feels it should be means-tested.

From a values point of view, Comprehensive is the one he considers most appropriate to the community’s values, as those who have sufficient means pay for themselves and also contribute towards the needs of others who are ‘less fortunate’.

“The balance is how well it’s funded, and you want it to be quality provision, not basic second class poorly funded provision.”

(Rabbi, London)

6.6.7 Consultation Question 3b (Part-national, part-local vs. fully national system)

The Rabbi strongly feels that funding should be allocated nationally to ensure a consistent approach across the country and to reduce existing inequalities. He feels that the danger of local authorities deciding is that other priorities can ‘get in the way’. However, he recognises that local differences will have to be catered for in order to allocate funding and resources fairly, but believes this can be achieved under a national system.

“My initial preference is for national, so you don’t get these discrepancies moving over a local authority border. It’s not one size fits all, so national provision should mean that if there are more social care needs in one particular geographical area then more money goes to that area for that purpose.”

(Rabbi, London)

Stakeholder Events Summary Report

Prepared for the Department of Health
by COI

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1. INTRODUCTION

In the summer and autumn of 2009, the Central Office of Information (COI) was asked to provide support to the Department of Health (DH), on behalf of the Government, in developing and running elements of a consultation on a wide ranging and radical set of proposals around the future of care and support services in England.

A significant part of COI's role was to deliver a comprehensive programme of stakeholder engagement events across all nine English regions. Following that programme, 10 reports were prepared for DH, outlining the key findings and issues that arose. All but the final report in this series presented the findings from a group

of three or four events held in a given region. The final report was based on a single event only (Brighton).

This document provides a compiled summary of the findings presented in these reports.

2. BACKGROUND

In July 2009, the Government published its Green Paper *Shaping the Future of Care Together*. This document set out the Government's vision to build a new National Care Service for all adults in England that is fair, simple and affordable. Its publication also marked the beginning of the Big Care Debate.

2.1 *Shaping the Future of Care Together*

The Green Paper was divided into four broad areas:

1. The case for change
2. The vision for a National Care Service
3. Making the vision a reality
4. Funding choices and options.

In sections 2, 3 and 4 of the Green Paper a number of questions were posed. Responses and views were sought on some difficult choices around what people should be able to expect from a National Care Service, on how we should ensure that the vision of a National Care Service can become a reality, and on meeting the challenge of funding and delivering a care and support system that will meet the demands of a changing society in the future.

2.2 The Big Care Debate

To accompany this Green Paper, from 14 July until 13 November 2009, the Department of Health held a wide ranging consultation on behalf of the Government, entitled the Big Care

Debate. The aim of the consultation was to stimulate the highest possible level of engagement with the issues raised in the Green Paper, to boost responses to its proposals and to capture views effectively.

This consultation used several engagement channels in order to reach the widest possible cross-section of interested and involved audiences, including:

1. 37 regional stakeholder engagement events to give in-depth information to stakeholder organisations and to seek their detailed views.
2. An extensive roadshow programme in 80 different locations around England, to provide large numbers of the general public with a chance to engage interactively with the issues raised in the Green Paper.
3. Online resources including downloadable toolkits, online questionnaires and social media links, to support stakeholders in engaging their own networks, members and associates in the debate.
4. Wider communications and engagement material to boost awareness and gain further responses. These included leaflets, booklets, postcards and questionnaires, which were distributed through magazines, cinemas, shops, universities, workplaces, doctors surgeries and by stakeholder organisations.

5. Supplementary research to ensure that specific population groups who might otherwise be unlikely to respond to the consultation, or who might be disproportionately affected by policy changes, could get involved and have their say.

This report provides a summary of the findings from the stakeholder engagement events (part 1). The findings from the other consultation strands can be found in the associated reports produced by MORI (parts 2–4) and by Opinion Leader (part 5).

2.3 Stakeholder engagement events

As outlined above, COI worked with DH to deliver stakeholder events across England. A total of 37 events were held, four in each of the Government regions, apart from London where there were 5 events. Please see Annex 1 for a list of the locations and dates of these events.



The aim of the events was to provide in-depth information to interested parties on the proposals outlined in the Green Paper, and to elicit their

detailed responses to these. Discussions were preceded by an explanatory film and a series of presentations setting out the issues, the options under consideration and the consultation process.

The events were designed to be interactive and to enable people to understand the key issues raised in the Green Paper so that they could contribute to the wider debate. As well as presentations and discussions, participants also had opportunities to review and comment on each other's work during 'critical friends'¹ sessions, and to ask questions of DH ministers and officials.

These events were attended by 1,540 people, who were grouped in the following categories:

1. members of the general public with an interest in care and support;
2. professional workers and managers;
3. representatives from groups supporting carers and care users;
4. representatives of commissioners and deliverers of care and support;
5. central government representatives; and
6. other representatives, including academics, researchers or representatives from standards agencies.

A full recruitment campaign took place to identify interested and relevant parties and to make them aware of the events taking place in their area. This campaign included a direct marketing campaign using COI's Publicity

¹ During their discussions participants were encouraged to produce flipcharts outlining the key aspects of their discussion. These were pinned up around the room and during the critical friends session, participants had an opportunity to review, comment on and endorse or critique the work of other groups.

Register,² and a town by town purposive recruitment programme to raise awareness and ensure attendance by relevant local organisations.

2.3.1 Event structure

During the events participants took part in four separate discussion sessions. The first two of these were run as 'World Café'³ sessions, with participants asked during registration to select their preferred topic for discussion from a list of key areas outlined in the Green Paper. Please see Annex 2 for an example of the selection sheet used by participants to select their discussion topics. During the third and fourth sessions, everyone talked about the same topic.

The options and content for discussion during each session were as follows:

1. The Vision. After discussing their overall impressions each table of participants went on to discuss one of following five components of a new National Care Service: Prevention Services; National Assessment; Joined-up Services; Information and Advice; Personalised Care and Support.
2. Vision to reality. Participants took part in discussions on one of three topics: More joined-up working; Ensuring a wide range of care and support services, or: better quality and innovation.
3. Funding.
4. National or national/local.

Each session was designed to build on the information presented in the Green Paper, and closely followed the questions and discussion points as presented in that document. Please see Annex 3 for an example of the pro-forma used to capture information from the sessions.

At the start or the end of each event, participants were given an opportunity to pose questions to a panel of DH Ministers and officials on the Green Paper and the consultation process. These questions tended to reflect the content of the group discussions or to seek clarification of points of particular note. A brief summary of the issues raised during this session, as well as a list of the DH Ministers and officials who sat on the panels, can be found at the end of the main body of this report.

At the end of the events participants were invited to provide their views on the events by completing an evaluation questionnaire.

The remainder of this report provides a summary of the discussions that took place under each of these four sessions and during the Q&A, as well as the results of the evaluation questionnaires.

2.3.2 Participant profile

The mean average attendance in each region was 176 participants.

On registration, participants were invited to identify the category they felt best fitted their main involvement in the area of care and

² A cross-government initiative, the COI Publicity Register is a database of 'high street' intermediaries, for example libraries, GP surgeries or Citizens Advice Bureaux, that have expressed an interest in being informed about different categories of Government activity and which accept materials to display or to pass on to the public.

³ World Café is a type of deliberative method that allows participants to choose which topics they wish to discuss, and to circulate around the room engaging with the work of other groups.

support. The best represented category in total was professional workers and managers, while the least represented category was central government, agencies and NDPBs.

The below table provides details of the number of participants attending the event series, broken down by region and by participant category.

A list of all the organisations represented at the events is provided in Annex 7.

	Total number per region	General Public	Professional Managers and Workers	Representative groups for Carers and Care Users	Representing Commissioners and Deliverers of Social Care	Central Government/ Agencies/ NDPBs	Other
East Midlands	155	17	69	16	20	12	21
East of England	164	39	51	23	14	6	31
London	219	39	64	38	17	12	49
North East	175	23	49	27	16	27	33
North West	216	48	78	13	40	16	21
South East inc Brighton	120	17	46	12	8	18	19
South West	205	35	75	25	32	14	24
West Midlands	126	26	52	17	17	7	7
Yorkshire and the Humber	160	25	56	23	19	16	21
Total number per category	1540	269	540	194	183	128	226
% of total number per category	100%	17%	35%	13%	12%	8%	15%

3. THE VISION

Each discussion on the vision for a National Care Service was divided into two broad sections:

1. Participants' responses to the overall vision outlined in the Green Paper.
2. Their detailed views on the topic they had selected to focus on from the five key areas outlined in the Green Paper (Prevention Services; National Assessment; Joined-up Services; Information and Advice; Personalised Care and Support).

In this section responses to each of these sections are summarised.

3.1 The overall vision



Participants expressed broad support for the vision for the National Care Service set out in the Green Paper. They were particularly in favour of proposals around:

1. prevention services that maintain the care user's independence;
2. the need for high quality, accessible and consistent information and advice;

3. a national assessment that is truly portable;
4. personalised services that put the individual at the centre of care; and
5. a joined-up approach to planning and delivery of care and support services.

Six key areas were highlighted within the overall vision where participants feel that further clarification or consideration is required:

1. Participants believed that the vision must clearly state a **broad, easy to understand and universal definition of care** that explicitly consider the holistic needs and wellbeing of the individual in addition to more traditional 'social care' and medical needs.
2. Building on this point, some participants requested more explicit **recognition, inclusion and equality for adults of working age** with care and support needs, expressing concerns that the Green Paper focused excessively on the needs of elderly people.
3. A provision for **strategic vision and leadership** in the Green Paper proposals was expressed. Participants suggested that gaining wide buy-in for the proposals will be vital for the success of the approach, which they believe will require a shift towards a culture of working in a flexible and collegiate manner. Many participants suggest that a single agency should be given responsibility for overseeing the

transition to the proposed new system, which is seen as likely to help in defining the various roles and responsibilities of those who contribute to the care and support system.

4. Many participants asked for further **clarification on the role of the third sector** in the proposals. They suggested that this sector is often expected to 'react' to issues and to 'plug the gaps.' It was argued that outlining a strategic role for the third sector within the National Care Service would help to address this, with the possibility of a clearly defined partnership with the Government suggested by many.
5. Participants highlighted the need for **significant investment in workforce development and training** to deliver the vision for a National Care Service. High quality training and satisfactory remuneration for both formal and informal carers were argued to be essential to raise standards in the care and support sector and to improve recognition and the perceived societal value placed on this work.
6. Participants also called for **clearer recognition of the role of informal carers** in supporting those with care and support needs. The support given by families and communities was seen as integral to the existence and effectiveness of the care and support system, and as such participants believed that it should be acknowledged more clearly in the strategy. Many felt that alongside investment in workforce training and development, this

should come as part of a wider goal to improve attitudes towards care and support in general.

3.2 Topic discussions

Following their brief discussion of the vision overall, participants focused on the area of the vision they had selected at registration. The key issues raised during these discussions are outlined below.

3.2.1 Prevention services

All the elements of prevention services were well supported. In particular, many participants felt that such services could offer a way of reducing the need for the provision of much more expensive and time consuming services later on.

Key points raised were as follows:

1. Many participants expressed a desire for more **clarity over what prevention comprises** and as with definitions of care, they were keen to have a broad definition of prevention that is capable of picking up on the range of triggers that could precipitate a need for care before people's conditions deteriorate or become critical. Some participants went further, arguing that prevention should focus more explicitly upon people with low levels of need.
2. Participants strongly supported the use of **telecare**, provided that it is not employed as a substitute for face-to-face services and that the right support is provided for users. They also suggested that telecare services should be joined-up with wider information and advice services.

3. Participants also suggested that a more **holistic view of prevention** should be taken. Above all, it was argued that the holistic approach would support the design and commissioning of prevention services focused on the needs of the individual. Participants suggested that third sector expertise should be considered more explicitly in the proposals as a means of delivering this.
4. Two related **considerations around housing** were proposed as key elements of prevention. Participants argued that a combined approach of providing effective housing support on the one hand, and offering people adaptations to their homes on the other, could help them retain their independence for longer.

3.2.2 National assessment

Overall, participants welcomed the proposals for national assessment, particularly as a means to ensure consistency between different Local Authority areas. They felt that national assessment could also increase the geographical mobility of people with care needs, seen as particularly beneficial to younger people.

Participants identified four key issues around national assessment where they believed further consideration or clarification will be necessary in developing the vision:

1. Participants identified a number of potential risks to an effective and consistent system of national assessment:
 - a. The **varying opinions, working practices and expertise** of the range

of different professionals that would need to be involved in a national assessment regime, which could lead to individual interpretation of the formulae in different locations or parts of the system

- b. **Variability in the local provision of services**, which might mean variation in the quality and choice of services that people receive in different areas, even where their assessment is consistent
- c. Data management systems acting as **barriers to necessary data** sharing between the relevant parties.

Many participants highlighted the need for strategic leadership from central government in order to address these issues. In particular, they call for the provision of clear training and guidelines to ensure consistency, and the establishment of robust assessment frameworks and monitoring systems. There was also a request for greater clarity around who will be delivering and monitoring assessments, as well as how support might be provided to ensure effective information-sharing between agencies.

2. Some participants were concerned that a national assessment regime could restrict **the flexibility of different providers** to take account of individual needs, and would therefore restrict the choices open to individuals. An assessment system that turned into a depersonalised 'tick-box' approach was therefore seen as contradictory to the aim of increasing individual choice within the care and support system.

3. Participants were worried that **sufficient funding would not be available** to deliver an effective system of national assessment. As a means of addressing this concern, participants supported the idea of ensuring strong separation between assessment of care needs and wider funding concerns. They also strongly supported the idea of funding following individuals in a seamless fashion.
4. Effective **support, guidance and advocacy services** were identified as a necessary accompaniment to a potentially complex national assessment system, to ensure service users understood and could effectively navigate it. In particular, participants raised the question of whether without such support, re-assessment could cause stress to those who were afraid of losing their entitlements.
2. The proposals acknowledging the **important role played by both formal and informal carers** were well supported. Some participants did note that it may prove to be complicated to reconcile the range of different needs that are likely to exist, particularly across the divide between formal and informal care providers.
3. The need to create a **collaborative and cooperative working culture** between organisations involved in delivering social care was highlighted as vital in providing joining up services. Participants strongly emphasised the need for clear leadership, guidance and support to help organisations through this period of transition.
4. Participants also highlighted the need for **improved systems for collecting and sharing information** between organisations with different working practices and data systems.

3.2.3 Joined-up services

Participants strongly support most elements of the vision around joined-up services. Current divisions between health and social care were emphasised in particular as a cause of many problems in the existing care and support system.

Further detailed consideration and discussion took place around the following points:

1. Some questioned **whether local authorities are best placed to take responsibility** for reassessments, as great variation is believed to exist between different authorities in terms of quality, resources and attitudes.
5. The proposal for a **single assessment to access a wide range of care and support services** was widely supported. However, some participants were unsure how this would work in practice, given the range of professionals that they thought would be required to appraise the potentially wide variety of needs that an individual might have. In relation to this, some participants advocated the inclusion of an appeals mechanism.

3.2.4 Information and advice

Participants cited a lack of awareness and understanding about existing services as a key barrier to the provision of high quality care and support. As such the proposals around the provision of high quality, accessible and timely information and advice were widely supported by participants.

Key points raised by participants during discussions were as follows:

1. The importance of information services in **improving access to care and support services** was highlighted. It was pointed out that too many sources of possibly contradictory information can be as problematic as too few sources, and a single information portal for accessing information on a National Care Service would therefore be welcomed.
2. As such, a **National Care Service brand** was seen as likely to be effective in disseminating clear, structured and consistent information. Participants believed that this would boost awareness of the available services in a way less likely to confuse service users, as well as stimulating buy-in and support.
3. Some **potential distribution points** for the provision of high quality information and advice were identified. GP surgeries were highlighted in particular here. Many participants also stressed the likely benefits of working closely with third sector

organisations, as these are seen as likely to be better placed to provide information and advice through closer and better contact with vulnerable audiences.

4. Participants emphasised the need for **advocacy and guidance** services to supplement the provision of information and advice. This was seen as particularly the case where informal carers, older people and those with mental health problems are concerned.

3.2.5 Personalised care and support services



Participants expressed strong support for proposals in the Green Paper for care and support services that are built around individual needs. It was argued that placing the needs and aspirations of the individual at the centre of service planning and provision will be key to the success of the Green Paper's proposals. A system where the care user is involved as much as possible in the design of their own care packages was seen as likely to be most successful.

Participants put forward recommendations for how this might be achieved in the following four areas:

1. Strong support was expressed for **personal budgets**, particularly where younger people with care and support needs are concerned. However, participants felt that personal budgets could be challenging for older people and people with certain specific care and support needs. The need to accompany these with independent information and advice services, brokerage services and where necessary personal assistants to support those who need help in designing and managing their budget was highlighted. Others also noted that personal budgets will have to be backed-up with effective safeguarding to prevent misuse or any risk to vulnerable benefit recipients.
2. Participants also argued strongly for improvements to **conditions for carers** as part of the personalisation of care and support services. Accommodating the needs and wishes of carers alongside care users was seen as likely to create far more effective care packages overall, subject to clarification on who counts as a person's carer.
3. The perceived **inflexibility of local authorities** in providing services was seen as a barrier to the implementation of proposals around personalisation, especially where shortages of skilled staff are concerned. Some participants claimed that third sector and community-based organisations should be brought closer to the heart of the proposed vision. They were seen as more flexible than local authorities in providing user-centred services, and providing the sector is properly supported, were thought to have better capacity for fielding appropriate specialist staff at short notice.
4. Many participants warned that there might be some issues around **funding and provision of specialist services** for which there is low demand.

4. MAKING THE VISION A REALITY



In their discussion on making the vision a reality, participants selected one of the three key principles upon which any future National Care Service must be based laid out in the Green Paper. These were:

1. more joined-up working
2. ensuring a wider range of care and support services
3. better quality and innovation.

Across the three discussion areas, strong and consistent themes emerged around the need for clear definitions, robust and strategic leadership,

flexible, accessible and relevant services designed around the needs of the individual, and the importance of ensuring capacity exists in the workforce.

Discussions in each of these sections are summarised below.

4.1 More joined-up working

Participants were strongly in favour of improvements to the system that would encourage more joined-up working. They expressed a desire to see a multi-agency and collegiate approach to service commissioning and delivery, particularly where health and social care services are concerned, although they also request more detail on how the different funding models will affect this.

Participants believe that in many cases good practice in joined-up working is already emerging, both formally and informally, and the need to build on this existing good practice was highlighted.

The following key themes emerged from participants' discussions:

1. The **need for culture change** to encourage increased cooperation between different parties was highlighted and to deliver a single point of access to the proposed National Care Service. Participants argue that there should be a collegiate and flexible approach across all the relevant parties. Working to change the culture

among staff responsible for delivering services was seen as particularly important here.

2. Some participants felt **more fundamental changes, instigated by central government** may be necessary to remove structural and institutional barriers to joined-up working between different organisations. In these cases, culture change alone may not always be enough. The divisions between health, social care, housing and benefits services were highlighted among others here.
3. In particular around the cultural and organisational change needed to ensure effective joined-up working, the need for **increased strategic leadership and direction** was emphasised. In particular, participants argued that clear lines of accountability will be needed to provide the necessary harmonisation of commissioning frameworks, budgets, targets, impact assessments, remits and workforces.
4. As a function of the need for strategic leadership, participants also emphasised the need for **universal definitions of care** that the broad range of organisations involved in the care and support system can buy in to and use. The need for clearer definitions of outcomes for users was emphasised in particular.
5. Participants also discussed the need for **closer definition of roles and responsibilities** in ensuring more joined-up working. Specifically, they emphasised the need for clear delineation between the roles of Local Authorities, private providers and the third sector in managing and

delivering care and support services.

Participants again stressed the need for a flexible and collegiate approach, often highlighting local authorities in particular as needing to change.

6. Participants also suggested that encouraging and supporting **information sharing** between different services and organisations will be essential for effective joined-up working. This was particularly highlighted in terms of data sharing and sharing IT systems.

4.2 Ensuring a wider range of care and support services

Participants agree that a wider range of care and support services is essential if the aim of offering choice and individualised care packages to care users is to be realised.

Their discussions focused particularly on the following aspects:

1. Again, participants sought a **clearer and more universal definition of care**. Relating to the discussion of prevention services, some felt that not enough clarity has been provided on which services will be included as care and support services, particularly at the lower end of the spectrum of care needs.
2. **Strategic leadership and direction** were felt to be crucial to the delivery of a wider range of care and support services. In particular, participants emphasised the importance of ensuring consistency between different local authorities in the range of care and support services that are available, to prevent a 'postcode lottery' in terms of the services available.

3. Participants emphasised the need to ensure **services are flexible, appropriate to need and accessible to all**. They also stressed the importance of focusing service commissioning and delivery on the needs and choices of the user, and recommended the inclusion of communities and families in the development of care and support services.
4. Participants argued that **workforce development and training** should be more explicitly addressed in the vision, to make sure that the services are flexible enough to meet needs. For many, there is a need to increase investment in training and development to create a highly skilled care workforce. Participants also welcomed steps to take into account the needs of informal carers, noting that families and communities need to be explicitly acknowledged in any consideration of the range of care and support services that need to be provided.
5. Participants also emphasised the importance of ensuring that **information, advice and guidance services keep pace** with the range of services on offer.
6. Participants felt that more work has to be done to overcome **the stigma associated with having care needs**. They suggested that further consideration is also needed to understand the range of needs that exists. It was also noted that keeping expectations of the proposed National Care Service realistic is important, as concerns were expressed that there will not be sufficient funding to deliver a range of care and support services truly wide enough to meet everyone's needs.

7. The need to **measure outcomes**, such as whether individual's needs are being met, rather than examine the variety of services available was also highlighted by some.

4.3 Better quality and innovation

Participants discussing better quality and innovation were strongly in favour of an independent body to regulate and monitor a care and support service and clarify the roles and responsibilities of those who contribute to the system. They also call for the collection and effective dissemination of best practice where it exists, to tackle the 're-inventing the wheel' that can characterise the sector at present.

The discussion focused upon the following areas:

1. Participants felt that there is a need for a **clear definition of quality** in the context of care and support. Some argued that this definition should explicitly take into account the perspective of service users, and warned that this is currently lacking from the Green Paper's vision.
2. Ensuring that there is **strategic leadership, oversight and monitoring** of any future system was important for many. Building on the discussion of definitions, some advocated the development of guidelines and delivery frameworks to specify quality. It was suggested that this process should be informed by collecting and disseminating examples of best practice, with discussion around the development of an independent body to carry this out as well as to regulate and monitor care and support services.

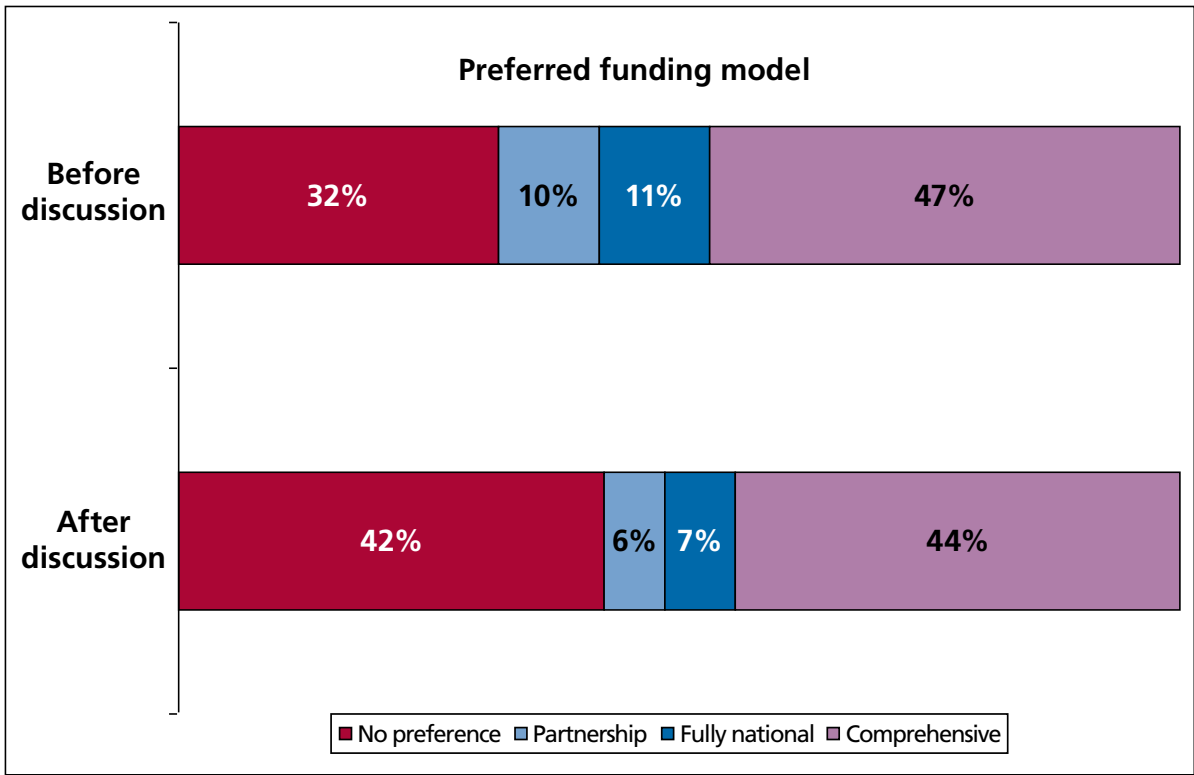
3. Many participants stressed the need to recognise in the strategic vision the fact that innovation and high-quality services are most often found in the **third sector**. The need to outline a clear role for the third sector in the strategic vision was therefore emphasised again.
4. The need to **stimulate and create the right conditions for a culture of innovation** was emphasised by many participants. For some, this would only be achieved with more fundamental organisational and structural change, perhaps through the introduction of an independent regulator.
5. Making sure that quality and innovation in service development is focused on the **needs of the user** was a recurrent theme in several discussions. In order to achieve this, the need to involve care users and carers in the delivery of services in a systematic way was stressed.
6. There was much emphasis on **investment in workforce development** to improve the quality of staff. Investing in workforce development was argued to be a key route to driving up quality, and was also seen as likely to improve the status of care work as a profession, which in turn would improve wider perceptions and societal attitude towards care.
7. **Advocacy and safeguarding** for the most vulnerable care and support service users were seen as vital in ensuring they would also benefit from better quality and innovation.

5. FUNDING

Despite their general support for the vision, throughout all their discussions participants express concern about whether sufficient funding will be available to make it happen. Many are worried that the Green Paper will raise expectations unfairly, if it cannot be backed by the funding needed to make it happen. They are clear in their view that how the proposed National Care Service is funded will have a major impact on the success any future scheme.

Participants were offered two opportunities to vote on which funding model they thought would be preferable, both before and after round table discussions. Please see Annex 4 for a copy of the preference sheet used by participants.

The results were as follows:



Before the discussion the comprehensive option was the most popular of the options on offer, with almost half of the votes cast being in favour of this option (47%). Around one in ten participants voted for the partnership and insurance models (10% and 11% respectively). Around a third of the participants declined to state a preference.

The second round of voting following the discussions shows some slight changes. There was a general decrease in support for all the funding options on offer and an increase in the number of participants unwilling to state a preference.



Of the funding models on offer, therefore, the comprehensive model received the strongest support from participants. During their discussions, participants noted that it is the fairest option in the sense that everyone would make contributions and everyone would receive care, and as such embodies the value of reciprocity. Furthermore, they believed it would be the cheapest, and most similar to an NHS style of provision. The partnership and insurance models received much less support, as they were felt to be less fair and more risky options.

While participants felt that on balance the choice about whether or not to pay into the insurance model was a positive, significant concerns were expressed about what would happen to people who chose to opt out of the scheme, and who would subsequently face high care costs. Concerns were also expressed about insurance schemes run by private companies, and

participants often stipulated that this model would have to be based on a state run scheme.

Anxieties were also expressed that the partnership option could replicate current inequalities and leave some people vulnerable to very high costs for meeting their care needs. It was also noted that this option would be unlikely to boost understanding of and engagement with the care and support system moving forwards.

A substantial number of participants remained unwilling to express a preference at the events. This partly reflects the complexity of the debate and the difficulty of understanding the differences between the models, with participants feeling they need more time to reflect and consult with colleagues before expressing an opinion.

Many participants also expressed support for a tax-funded option, and argued that this should not have been ruled out of the Green Paper or the discussion events. This is especially true of those who believe they have made contributions to the state throughout their working lives and feel that the state should deliver care and support in return.

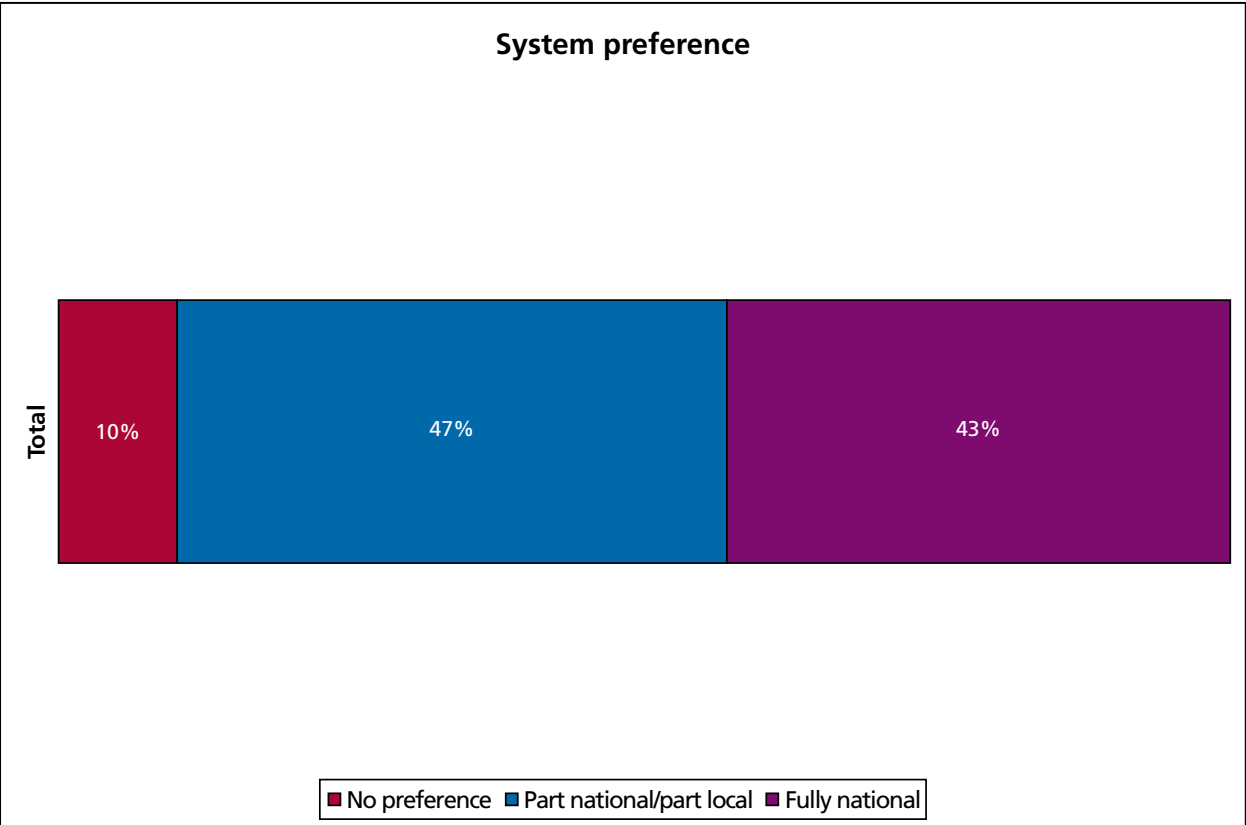
Many participants also stated that they did not wish to make a firm choice until they receive further clarification on how the proposed models will affect current benefits and allowances, for example, Attendance Allowance and the Independent Living Fund. Many participants expressed strong support for these benefits, and were adamant that these resources should not be reduced or abolished.

6. NATIONAL OR NATIONAL / LOCAL

In the final discussion session, participants discussed the extent to which there should be local or national control over a National Care Service. They were offered the opportunity to vote on which they preferred following table

discussions on this topic. Please see Annex 5 for a copy of the preference sheet used by participants.

The results were as follows:



Overall, a slim majority expressed a preference for the mixed part national, part local system (47% against 43% in favour of a fully national system). Strong feelings were expressed on both sides of the debate.

Supporters of the national/local approach argued that this system:

1. would allow for more flexibility to adapt to local circumstances. The distinct differences between rural and urban needs, as well as local variations in the care and support market were cited as examples of the kind

of variation to which the system would need to be able to respond;

2. would mean that services can be more easily personalised, because local authorities will be better placed to respond to local need and to develop local service markets; and

3. would ensure that services are more accountable to local people, through placing responsibility for delivering services in the hands of local authorities. Participants believed this will give carers and care users more influence over their local services.

Supporters of both systems made it clear that inequitable 'postcode lotteries' must not be tolerated, however the care and support system is constructed and managed. Many from both sides also express support for the idea of an independent body to monitor and regulate assessment and allocation of funding.

On the other hand, supporters of a fully national system thought this system:

1. would be much more likely to deliver nationwide consistency, making the system fairer, more predictable and both easier and cheaper to administer;
2. would challenge the hegemony of local authorities, who participants did not believe were capable of fulfilling the role of local lead in the care and support system; and
3. would also enhance people's mobility through removing further structural barriers to people's movement.

7. Q&A SESSIONS



At the start or the end of each event, participants were given an opportunity to pose questions or make observations to a panel of DH Ministers and officials on the Green Paper and the consultation process. Over the course of the series, this panel included the Rt Hon. Andy Burnham MP, Secretary of State for Health, Phil Hope MP, Minister for Care Services, David Behan, Director General of Social Care, Alexandra Norrish, Head of Social Care Strategy, Catherine Davies, Head of Stakeholder Engagement in the Green Paper team, and Richard Simper, Strategic Advisor, Green Paper team.

These questions and observations tended to reflect the content of the group discussions or to seek clarification of points of particular note. In responding, the panel emphasised that the detail of any future White Paper cannot be pre-empted before the consultation process has been completed, and that the feedback from these events will contribute to this.

Key questions and observations raised during the Q&A sessions were as follows:

1. **The likely timescale for phasing in a new National Care Service.** In particular, participants were keen to hear the panel's views on the likely impact of the forthcoming general election.

In their responses, the panel stressed the importance of the issues attached to the consultation, and noted that waiting until an election had taken place would leave many people continuing to struggle with the problems that the consultation sought to address. The panel also pointed out that the views gathered during the consultation would be relevant and useful to addressing these issues, whichever administration took the proposals forward after an election.

2. **The role of taxation.** Participants were keen to hear more about the thinking behind ruling out funding a National Care service out of general taxation, and raised several points about the varying impact on different groups in society that taxation might have, in particular where disabled people of working age are concerned.

In their responses, the panel reiterated their view that the financial modelling carried out as part of the preparation of the Green Paper suggested that funding a National Care Service from general taxation would ultimately place an unsustainable burden on younger generations. They also noted that where necessary, the varying burden placed on different groups in society by the

funding models under consultation would be examined further.

3. **Links between social care, health care and other related services.** Participants re-emphasised the points raised during discussions about the importance of establishing new and better links across these services, including local authority housing services, benefit, employment and leisure services. In particular, a desire was expressed to hear more about the Government's thinking on an infrastructure for ensuring this happened.

In their responses, the panel agreed that in order to realise many of the proposals around a National Care Service, closer and more effective integration of different services will be vital. They reassured participants that the precise form this integration might take was dependent on the outcomes of the consultation, as well as on discussions with other service providers, and that no decisions had been taken yet.

4. **Benefits, in particular Attendance Allowance and Disability Living Allowance.** Participants attending many of the events requested further clarity on the Government's intentions for these. A great many also stressed the value of these benefits to service users and requested reassurance that these benefits would not be withdrawn.

In their responses, the panel stressed that although changes to Attendance Allowance had been factored into the modelling as part of the Green Paper development, no decisions had been taken,

or would be taken before the consultation was complete. They also sought to reassure participants that any changes to Attendance Allowance that were made would not curtail or restrict entitlements or benefits currently received. It was also noted that changes to Disability Living Allowance had not been factored into the modelling and were therefore unlikely at this stage.

5. **Delivering care and support in border areas.** Many participants from regions sharing borders with other UK nations questioned how the delivery of services might work in Local Authority areas on the border. The intention of offer personalised services was raised in particular here, with participants questioning what might happen if particular services were offered only in Local Authority areas outside England. The need to learn from good practice in other UK nations was also highlighted, in particular from Scotland where free personal care is already being offered.

In their responses the panel agreed strongly that best practice should be examined and built upon wherever it exists. In re-emphasising that no firm decisions had yet been taken on managing cross-border issues, the panel also noted that the consultation represented a good opportunity for best practice to be flagged to the Government for inclusion in the evidence base on which detailed policy would be built. In acknowledging the issues that participants suggested might arise in border areas, particularly around the delivery of personalised services, the panel

therefore encouraged participants to raise these issues in detail in their written consultation responses.

6. **The importance of considering the workforce, in particular informal carers.**

Some participants felt that the workforce should be more explicitly considered, and reiterated their calls for a concerted effort to improve the profile of the workforce and the financial and other support that carers and other members of the workforce receive.

In their responses, the panel agreed that the workforce is critical to the success of a National Care Service, and stressed that they would be paying close attention to the issues raised in consultation responses in this area, in particular where informal caring was concerned.

7. **Other general points** that participants highlighted for particular consideration were as follows:

a. The impact of the consultation in terms of raised expectations among the population, and the need to be clear about what changes people could expect, and when.

- b. The importance of thinking carefully about information, advice and in particular guidance and advocacy for disadvantaged groups.
- c. The links between the proposed National Care Service and other strategies. This was particularly highlighted in terms of other work currently being carried out by the Department of Health, but was also seen as applying to related work being carried out by other government departments.
- d. The need for more detailed modelling on technological advances and the likely impacts these could have on a National Care Service.
- e. The need for close and effective monitoring, evaluation and assessment within a National Care Service, in particular in the early years of its operation.

8. EVALUATION

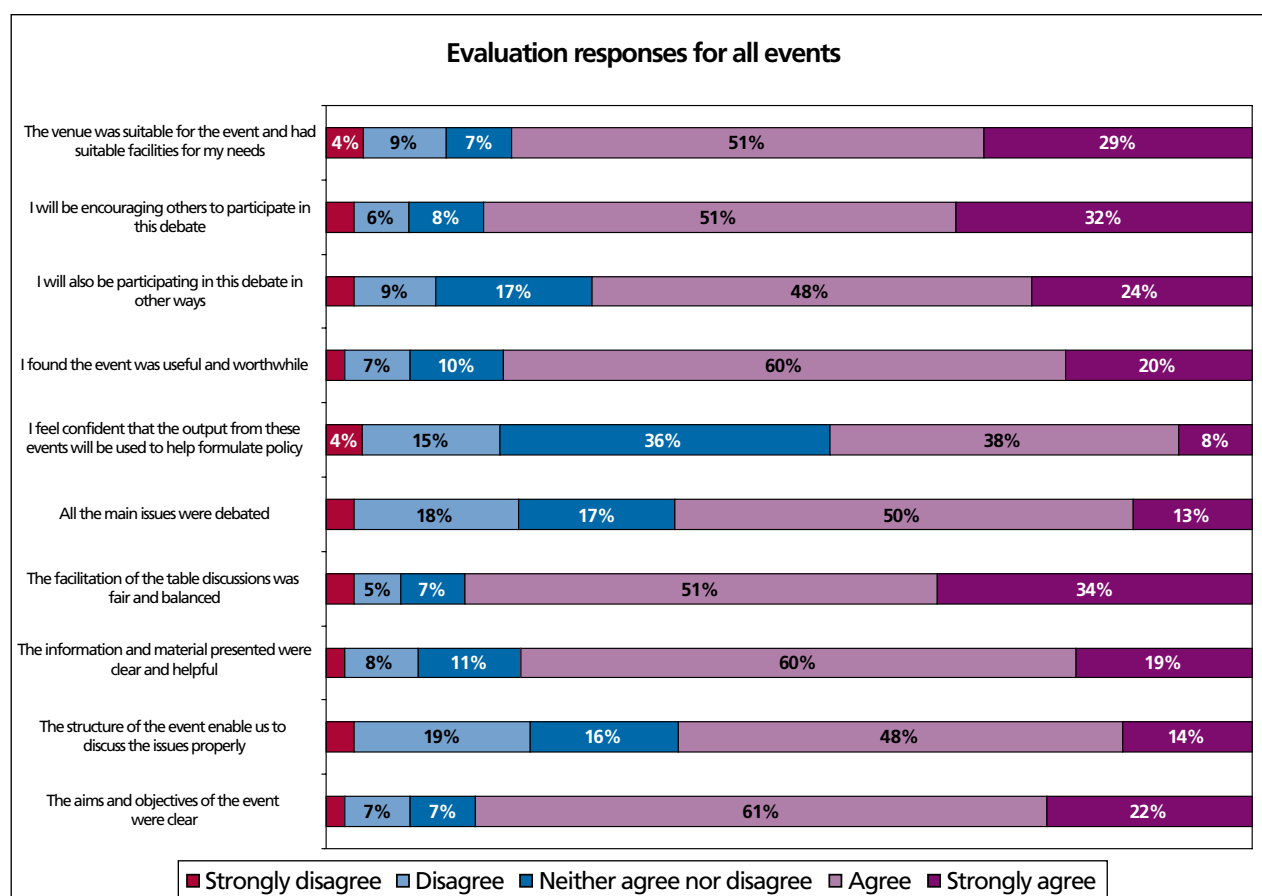
At the end of the event participants were invited to give their feedback on the event they had attended by filling in a short evaluation questionnaire. Please see Annex 6 for an example of this questionnaire.

Overall, participants viewed the event as highly successful.

As can be seen from this chart:

1. 80% of participants agreed or strongly agreed that the events were useful and worthwhile;

2. 83% agreed or strongly agreed that the aims and the objectives of the event were clear;
3. 79% agreed or strongly agreed that the information and materials presented were clear and helpful; and
4. 85% agreed that the table facilitation was fair and balanced.



Qualitative feedback in post event questionnaires shows that participants strongly welcomed the opportunity to discuss the issues and also to hear first hand the views of the Government as well as a cross section of stakeholders. They also welcomed the opportunity to have face to face discussions with DH representatives.

Many were also pleased to have the opportunity to contribute to an important national debate and to make a meaningful contribution to shaping the future of the care and support system.

Part 3: Annexes

Technical Annex

Prepared for the Department of Health
by Ipsos MORI

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INTRODUCTION

This document details the methodological approach to the Government's consultation on the *Shaping the Future of Care Together Green Paper*. This should be read alongside the document *Shaping the Future of Care Together Consultation Report*, which summarises the key findings from the consultation.

The context and the challenges

The demographic profile of Britain is changing. An ageing population is causing a rise in the number of people with care and support needs, which will place increasing pressure on both services and financial support. This is exacerbated by other factors such as rising expectations of potential or actual care recipients, a perceived lack of fairness in distribution of care services and a lack of clarity in the current system.

Therefore, in 2008, the Department of Health ran a six month engagement programme on the future of the care and support system in England. Ipsos MORI was heavily involved in this process, conducting four workshops and a reconvened national summit exploring these issues with the general public across England.

The conclusions from this engagement process helped inform the development of the *Shaping the Future of Care Together Green Paper* launched in July 2009. The Green Paper includes proposals to reform the care and support system for adults in England. To identify the views of the general public and other stakeholders across England upon these proposals, the Department

of Health conducted a comprehensive and wide-ranging consultation known as the Big Care Debate.

Lasting from 14 July to 13 November 2009, the Big Care Debate consisted of a number of activities designed to maximise awareness among stakeholders and the public on the need for change and the consequence of the proposals; generate optimum response levels to the consultation; and capture effectively stakeholder and public views on the key policy issues emerging.

The responses to the consultation helped the Department of Health produce evidence-based policy decisions that reflect the outcomes of the consultation.

Partners

The Department of Health have conducted a multi-strand full-scale consultation exercise to investigate the views of the general public and stakeholders towards the Big Care Debate proposals. Ipsos MORI was commissioned to undertake the analysis of this consultation as an independent body. Ipsos MORI was not involved in the design and content of the consultation materials, which was led by the Department of Health and the Central Office for Information (COI).

Central Office of Information

The Department of Health Green Paper team appointed COI to work closely with them

throughout the consultation process. Building on its close involvement in the engagement that took place in 2008, COI supported the Department of Health in developing the consultation and engagement campaign that included:

- Strategic development work around consultation audiences and content, including stakeholder and public segmentation, citizen journey mapping and social care message testing with key audiences.
- Strategic communications work around the development and delivery of an engaging brand proposition 'The Big Care Debate' and visual identity.
- An innovative engagement approach including two models of engagement never previously used by Government on this scale – 'world café' style events for stakeholder audiences and an extensive road show programme to reach out to the public.
- COI worked with the Department of Health to develop the stakeholder campaign, including:
 - Running the 37 World Café style face-to-face regional engagement events
 - Carrying out a full recruitment campaign to recruit stakeholders to events, including a direct marketing campaign using COI's Publicity Register to identify interested and relevant parties, and a town by town purposive recruitment programme to raise awareness and ensure attendance by relevant local organisations
 - The development of online resources including downloadable toolkits, online questionnaires and social media links allowed stakeholders to run their own events
 - Providing accessibility guidance for all elements of the stakeholder engagement campaign, to ensure that all those who wished to contribute could do so.
- COI worked with the Department of Health on several key elements of the public consultation, including:
 - Procuring and managing the extensive road show programme, including training and briefing the road show team on techniques for engaging ordinary citizens in the debate in a fair and consistent way
 - The development and deployment of a comprehensive communications and engagement campaign to encourage the public to join the debate, through cinemas, shops, universities, workplaces, doctors surgeries and stakeholder organisations.

COI also procured Opinion Leader Research (OLR) to carry out supplementary research, and Ipsos Mori to conduct the analysis and reporting of the responses to the consultation, on behalf of the Department of Health.

The consultation process

The Big Care Debate set out to be the largest ever consultation on care and support. One of the priorities was to ensure that those who wanted to contribute to the consultation were

able to do so and therefore the Department of Health offered many different ways to engage and debate the issues outlined in the Green Paper. These ranged from completing a postcard at a public road show to spending an afternoon in a workshop discussing all the issues in detail. People could respond online or by postal questionnaire, or comment on the website.

There were five main channels through which participants could respond, all of which are listed below:

1. The written consultation process:

Online short questionnaire (Strand 1) – responses to specific questions on the Big Care Debate website

Online long questionnaire (Strand 2) – responses to specific questions on the Big Care Debate website

Short paper questionnaire (Strand 3) – distributed primarily to members of the general public through GP surgeries and direct marketing via COI's publicity list (organisations and individuals who have said they are interested in care and support) (attached as Appendix C)

Long paper questionnaire (Strand 4) – distributed predominantly to stakeholders at stakeholder events and with stakeholder toolkits (Appendix D)

Postcards (Strand 5) – distributed to members of the general public through cinemas, health clubs and playhouses (Appendix E)

Written comments (Strand 6) – letters sent to the Department of Health

Written comments (Strand 7) – emails sent to the Department of Health

'Q&A' feedback pages (Strand 8) – feedback pages from the easy-read version of Green Paper (Appendix F)

Questionnaires printed in *Saga* and *Take a Break* magazines (Strand 9) – in partnership with the Department of Health these magazines ran competitions for people taking part in a short questionnaire about care and support (Appendix G and H).

2. Website comments:

Online comments on the Big Care Debate website (Strand 10) – there was the opportunity to comment on each aspect of the Green Paper

Comments on David Behan's blog (Strand 11) – David Behan (Director General of Social Care at the Department of Health) wrote a blog which detailed the progress of the care and support debate. Participants could make comments on this blog.

3. Stakeholder events:

Regional stakeholder events (Strand 12) – workshop-style events were held at different locations geographically spread around England, where up to 100 stakeholders per session were presented with information about the proposals and then given the opportunity to discuss and comment upon the various aspects in detail (see Appendix I for further details)

Feedback forms from events held by stakeholders (Strand 13) – toolkits were also produced to allow stakeholders to run their own events following the same structure as the regional events. Conclusions were fed back by the organising stakeholder via a feedback form (Appendix J).

4. Public road shows:

Eighty public road shows were run and co-ordinated by COI and held in locations geographically spread around England, from city centres to county fairs, providing information on the Green Paper and giving people the opportunity to complete the following:

Short questionnaire on handheld PDA device (Strand 14) (Appendix K)

Short questionnaire on touch screen (Strand 15) (Appendix L)

Long questionnaire on touch screen (Strand 16) (Appendix M)

Write comments on **interactive whiteboards (Strand 17)**.

5. Supplementary qualitative research:

Supplementary research (Strand 18) – supplementary qualitative research with the general public, specific ethnic minority communities and faith leaders, which was designed to ensure that the opinions of under-represented groups would be taken into account. This included 2 deliberative workshops, 14 group discussions and 9 interviews, and were run by Opinion Leader Research. While some of the key themes from this research are included in this report, the overall results of the supplementary

qualitative research are detailed in a separate report (published by the Department of Health). (See also Appendix N.)

Throughout this document, we talk about ‘strands’ of response. By strand, we mean each of the different ways in which people could respond. Each strand generated a substantial amount of data that was collated and analysed throughout the consultation period.

The consultation ran for 18 weeks from 14 July to 13 November 2009. All responses dated and received within these dates were treated as valid consultation responses. In addition, to make allowance for any potential delays within the post, all those received through the post on or before 20 November 2009 were accepted as ‘on time’. All these responses were sent to the Department of Health and forwarded to Ipsos MORI for analysis.

The consultation in context

Consultation with the general public and stakeholders is now a common feature in major policy-making decisions. It allows those most affected by proposed policies an opportunity to express their views on the proposals, and to have an input into the decision-making process. Every consultation is different, since the nature of the issues involved and the way in which they affect those being consulted will be specific to the proposals being considered. Consultations can take place at various stages of the decision-making process and involve various degrees of detail. Direct comparisons between different consultations can, therefore, be misleading.

One of the factors making comparisons across different consultations difficult is that few reports on consultations provide full details of the consultation processes undertaken – this makes direct comparisons on, for example, differing response rates almost impossible.

Responses to the consultation

There were a total of 28,188¹ direct responses to the consultation, plus 107 dedicated stakeholder events, 25 general public events, interviews and discussion groups, 7 outputs of comments from public road shows and a further 40,619 indirect responses – from those who were consulted by stakeholder organisations who responded on their behalf. The number of responses via each means is shown in Table 1.

Table 1

Direct Responses to the Big Care Debate Consultation – by strand		
Strand	Description	No. of responses
Online questionnaire	Short questionnaire (strand 1)	5,116
	Long questionnaire (strand 2)	1,371
Paper questionnaire	Short questionnaire (strand 3)	7,470
	Long questionnaire (strand 4)	991
Touch screen questionnaire at road shows	Short questionnaire (strand 15)	656
	Long questionnaire (strand 16)	231
PDA questionnaire	Short questionnaire (strand 14)	4,811
Postcard	(strand 5)	665
Completed Q&A pages from 'easy-read' version of Green Paper	(strand 8)	45
Interactive whiteboard comments	(strand 17)	7 printouts (attendees to road shows who posted comments on whiteboards)
Online comments	On the Green Paper (strand 10)	3,257
	On David Behan's blog (strand 11)	465
Additional questionnaires, printed in magazines as competitions	<i>Saga</i> magazine (strand 9)	218
	<i>Take a Break</i> magazine (strand 9)	761
Open written responses (including detailed reports from stakeholders)	By letter (strand 6)	722
	By email (strand 7)	1,409
Stakeholder events	Regional events run by COI (strand 12)	37 events
	Run by stakeholders using 'toolkits' (strand 13)	70 events

¹ Table 1

Direct Responses to the Big Care Debate Consultation – by strand		
Strand	Description	No. of responses
Supplementary research among general public	(strand 18)	2 deliberative events, 14 group discussions, 9 depth interviews
TOTAL		28,188 individuals/ stakeholders (plus 107 dedicated stakeholder events, 25 general public events/interviews and 7 printouts from road shows)

Source: Ipsos MORI

The consultation sought to reach a wide-ranging audience and responses came from both the general public and various stakeholders. Throughout the report, key themes are broken down by audience where appropriate. The total number of participants by audience group is shown in Table 2, and further descriptions of each audience group are given below.

Table 2

Response to the Big Care Debate Consultation – by audience		
Audience group	Breakdown of group	Number of responses
Stakeholders	National organisations (responses from strands 6 and 7)	234
	Local organisations (responses from strands 6 and 7)	420
	Individuals (responses from strands 6, 7 and 8)	60
	Stakeholder regional events (run by COI) (strand 12)	37 events
	Stakeholder-organised events (strand 13)	70 events
	TOTAL STAKEHOLDERS	714 (plus additional participants who attended the 107 events)
Open consultation	Responses from strands 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 14, 15, 16, 17	27,474
General public	Responses from strand 18	2 deliberative events, 14 group discussions, 9 depth interviews (a total of c.135 participants)
Indirect respondents	Represented by stakeholders	40,619

Source: Ipsos MORI

Open consultation

The largest group, 27,474² participants, responded to the open consultation, via various means. This group comprises both the general public and individuals who may be engaged with the care and support system in some way – they may care for a friend or family member, work in the sector, receive care and support or have an interest in the sector for other reasons.

Stakeholders may also have responded via this means. Unfortunately it was not always clear what category consultation participants fell into, e.g. whether they were a stakeholder or general public, therefore we are unable to break this audience down any further. There may also be participants who responded on more than one occasion and there is no way of identifying such duplication of response.

While we know that people who responded via the different strands of the Big Care Debate received differing levels of information about the consultation, what we do not know, is the extent of their knowledge about the care and support system to start with. It is therefore important to bear in mind that responses are likely to be based on differing levels of knowledge.

General public

Supplementary qualitative research was held with the general public, specific ethnic minority communities and faith leaders, which was designed to ensure that the opinions of under-represented groups would be taken into account. These participants were provided with information and opportunities to discuss the proposed reforms through workshops, group discussions and depth interviews.

Stakeholders

A wide range of stakeholders contributed to the consultation, many of whom had extensive knowledge and/or expertise in care and support.

There were 234 submissions from **national organisations**. These stakeholders are more likely to be engaged with or be more knowledgeable about the subject area, and as a result, many of the submissions comprised detailed, well-researched reports. Many organisations had conducted their own research among those in or associated with their organisation, via surveys, focus groups, meetings etc. Those within these stakeholder groups were able to put forward their points of view on behalf of the organisation.

There were a further 420 responses from those within **local organisations** – some of which were regional branches of national organisations. Again, many of these submissions included the points of view of those in or associated with the organisation, gathered via their own investigations and/or discussions.

While local and national organisations have been classified as such, we cannot always know that a response is that of the organisation rather than the individual response of the representative.

Some **individuals** (60) also responded in a professional capacity. These individuals have therefore been classified as stakeholder. Given the nature of their role, they appear to be more informed about the care and support system than many of those responding in the open consultation.

² Table 2

Many stakeholders contributed to the debate through regional **stakeholder events** (37 separate events were held across England). During these events, stakeholders were informed of the proposals in detail, by representatives from the Department of Health and afterwards discussed various aspects of the consultation at table discussions. COI reported back on these events and key themes captured are incorporated in the main report.

Some stakeholders (70) held their own events. 'Stakeholder toolkits' were produced by the Department of Health to provide these people with further information about the Green Paper and provided advice on how to hold their own events. This included advice on how to hold such an event, further background information on the proposals and suggested areas for discussion.

Indirect responses

Many thousands more people may have contributed to the Big Care Debate. We know that at least 40,619 more people contributed through further research or events organised by stakeholders, which includes 32,742 via national organisations, 7,362 via local organisations and 515 through events organised by stakeholders.

Reporting participant views

It must be borne in mind that a consultation such as this does not comprise the responses of a representative sample of the general public and stakeholders, only of those who chose to respond to the Big Care Debate consultation. In consequence, it may over-represent particular points of view if those people holding them were disproportionately likely to respond. In particular,

demographic groups or those who are particularly engaged with the care and support system may be over-represented or under-represented.

It must also be understood, that the consultation as summarised within the main report can merely aim to catalogue the type of themes and opinions emerging from the general public, stakeholders and open consultation with regard to the Big Care Debate proposals; it cannot measure in fine detail the exact strength of particular concerns.

While every attempt has been made to classify each participant into the correct category, it is not always clear from the response exactly who is responding or in what capacity – several strands of response did not ask for stakeholder or demographic information, and others that do are self-completion, meaning that this information is often incomplete. The data is also self-classified.

While attempts are made to draw differences between the views and opinions across the different audiences, it is important to note that responses are not directly comparable. Across the different strands of the consultation, participants received differing levels and amounts of information about the proposals, ranging from several sentences of description on a postcard, to several hours at a regional event, where various aspects of the Green Paper were highlighted, scrutinised and discussed. Responses are therefore based on varying levels of information and may also reflect differing degrees of interest and prior knowledge. Each of the strands included in the consultation can be found in Appendices C–N.

The lack of available demographic information for participants also means that it is not possible to give a clear demographic profile of who responded, and compare with the population as a whole. Nor is it feasible to reliably analyse results by demographic group. Demographic information, where this information has been recorded, is given in Appendix B.

The consultation questions

The *Shaping the Future of Care Together* consultation document poses three broad questions, which form the crux of the consultation. However, within each broad question area, the precise wording of the questions differed across the strands. These are all fed back together underneath the core consultation questions in the report.

The consultation questions are detailed below, along with the related questions as asked on the various strands. The original consultation materials can be seen in Appendices C–N.

Consultation question 1 – taken from the Green Paper

We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- prevention services
- national assessment
- a joined up service
- information and advice
- personalised care and support
- fair funding.

a) Is there anything missing from this approach?

b) How should this work?

Table 3

Consultation question 1 – wording by strand	
Strand	Question wording
Long questionnaire: – Online (strand 2) – Paper (strand 4) – Touch screen (strand 16)	We have suggested six key things that everyone should expect from a National Care Service and we want your views on them. Prevention services You will receive the right support to help you stay independent and well for as long as possible and to stop your care and support needs getting worse. National assessment Wherever you live in England, you will have the right to have your care and support needs assessed in the same way and you will have a right to have the same proportion of your costs paid for. A joined-up service All the services you need will work together smoothly, particularly when your needs are assessed. You will only need to have one assessment of your needs to access a whole range of care and support services. Information and advice If you need care and support, or you are preparing for it, you will find it easy to get information about who can help you, what care and support you can expect, and how quickly you can get it. Personalised care and support Your care and support will be designed and delivered around your individual needs. As part of your care and support plan, you will have much greater choice over how and where you receive support, and the possibility of controlling your own budget wherever appropriate. Fair funding Everyone who qualifies for care and support from the state will get some help meeting the cost of their care and support needs. Your money will be spent wisely to fund a care and support system that is fair and sustainable. a) Is there anything missing from this list? b) How should this work?
Short questionnaire: – Online (strand 1)	We want a National Care Service that helps you stay independent and well for as long as possible. We have suggested six key things that everyone should expect from a National Care Service: – help to stay independent and well for as long as possible – assessments that are the same in every region – services that work together smoothly – clear information and advice – services designed and delivered around people's needs – wise and fair spending of taxpayers' money. Is there anything missing from this list?
Short questionnaire: – Paper (strand 3)	We want to build a fair, simple and affordable National Care Service. It should help you to stay independent and well, offer the same support and assessment in every part of the country, be easy to understand, offer you care and support fitted to your wants and needs, and spend money wisely. Is there anything missing from this?

Consultation question 1 – wording by strand	
Strand	Question wording
Short questionnaire: – PDAs (strand 14)	We want to build a fair, simple and affordable National Care Service. It should help you to stay well and independent, assess your needs in the same way in every region, have services working together smoothly, be easy to understand, offer you care and support designed around your needs, and spend money wisely. Is there anything missing from this? Yes/No If 'yes' please give details
Short questionnaire: – Touch screens (strand 15)	We want to build a fair, simple and affordable National Care Service. It should help you to stay well and independent, assess your needs in the same way in every region, have services working together smoothly, be easy to understand, offer you care and support designed around your needs, and spend money wisely. Is there anything missing from this list?

Source: Department of Health

Consultation question 2 – taken from the Green Paper

We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.

- a) Do you agree?
- b) What would this look like in practice?
- c) What are the barriers to making this happen?

Table 4

Consultation question 2 – wording by strand	
Strand	Question wording
Long questionnaire: – Online (strand 2) – Paper (strand 4) – Touch screen (strand 16)	We think that to deliver this vision three main changes are required to the care and support system. More joined-up working between health, housing, social care and benefits systems. A wider range of care and support services, so people have a greater range of services to choose from. Better quality and innovation. Staff must have the right training and skills, and services should be based on the best and most recent information about what works well in providing care. a) Do you agree? b) What would this look like in practice? c) What are the barriers to making this happen?
Short questionnaire: – Online (strand 1)	We think that to deliver the vision, three main changes are required to the care and support system: 1. More joined-up working between health, housing, social care and benefits systems. 2. A wider range of care and support services, so people have a greater range of services to choose from. 3. Better quality and innovation. Staff must have the right training and skills, and services should be based on the best and most recent evidence. Do you agree? Yes/No If no, what else do you think is needed?
Short questionnaire: – Paper (strand 3)	Do you think that a wider range of better joined-up and higher-quality services will make a better care and support system? If not, what else do you think is needed?
Short questionnaire: – PDAs (strand 14) – Touch screens (strand 15)	Do you think a wider range of better joined-up and high-quality services will improve the care and support system? Yes/No If no, what else do you think is needed?

Source: Department of Health

Consultation question 3 – taken from the Green Paper

The Government is suggesting three ways in which the National Care Service could be funded in the future:

Partnership: People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.

Insurance: As well as providing a quarter to a third of the cost of people's care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.

Comprehensive: Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.

- a) Which of these options do you prefer, and why?
- b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

Table 5

Consultation question 3 – wording by strand	
Strand	Question wording
Long questionnaire: – Online (strand 2) – Paper (strand 4)	We will achieve this vision by making better use of taxpayers' money so funding is focused on people who can benefit from it and need it most. But the money in the system at the moment won't pay for all of everyone's care in the future. In deciding how to fund care and support, there are some very difficult decisions to make. Funding options We have therefore proposed three options for funding a National Care Service. Partnership: The responsibility for paying for care and support would be shared between the Government and the person who has the care and support needs. The Government provides between a quarter and a third of the cost of care and support, more for people on a low income. Today's 65-year-olds will need care and support costing on average £30,000. The Partnership system would work for adults of all ages. Under this system we expect many people born with a care and support need to qualify for free care, as they do under the current system. Those working-age adults who do not qualify for free care (those who are better off) would have the same offer around funding as people over 65. Insurance: The same as Partnership, but the Government could help people prepare to meet the costs that they would have to pay for themselves through an insurance-based approach. As well as providing people with between a third and a quarter of the cost of care and support, the Government would make it easier to take out insurance to cover care and support costs if they want it. It is estimated that the cost of insurance could be around £20,000 to £25,000. The Insurance part of the second option would be likely to be less relevant to people who have been born with a care and support need, since people cannot insure against the risk of something that has already happened. However, many people born with a care and support need are likely to qualify for free care under the Partnership element of the system. Comprehensive: Everyone over retirement age who can afford it would pay into a state insurance system, so that everyone who needs care and support will receive it free. It is estimated that the cost of being in the system could be between £17,000 and £20,000. The Comprehensive system would be for people over retirement age, but we would also look at having a free care and support system for people of working age alongside this. a) Which of the three funding options do you prefer? Why is this your preference? We believe that the care and support system should be fair and universal. But we also need to ensure that the system is flexible enough to respond to local circumstances and encourage innovative approaches. There could be two different approaches to how the system works – either a part-national, part-local system or a fully national system. The two approaches have different implications for the way money is raised and distributed around England. b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

Consultation question 3 – wording by strand	
Strand	Question wording
Short questionnaire: – Online (strand 1)	The money in the system at the moment won't pay for all of everyone's care in the future so we have suggested three options for funding a National Care Service: (i) Partnership: The Government covers some care and support costs, for example a quarter to a third. More if you have a lower income. This would apply to all adults. (ii) Insurance: The Government covers some care and support costs, for example a quarter to a third. More if you have a lower income. And, helps you to take out insurance for the rest, if you want it. This would apply to adults of retirement age. (iii) Comprehensive: Everyone over retirement age who could afford it would pay into a state insurance scheme, which covers everybody's care costs. For people of working age we would look at having a free care and support system alongside this. How should the new system be funded? Partnership Insurance Comprehensive We believe that the care and support system should be fair and universal but needs to be flexible enough to respond to local circumstances. There could be two different approaches to how the system works, each has different implications for the way money is raised and distributed around England. Should local government say how much money people get depending on the situation in their area (part national, part local), or should national government decide? Part national, part local Fully national
Postcard (strand 5)	We want to build a fair, simple and affordable National Care Service. How should a new system be funded? Partnership: The Government covers some care costs, more if you have a low income. Insurance: The Government covers some care costs, and helps you take out insurance for the rest, if you want it. Comprehensive: Everyone pays into a state insurance scheme, which covers everybody's care costs.
Short questionnaire: – Paper (strand 3)	We want to build a fair, simple and affordable National Care Service. How should a new system be funded? Partnership: The Government covers some care costs, more if you have a low income. Insurance: The Government covers some care costs, and helps you take out insurance for the rest, if you want it. Comprehensive: Everyone pays into a state insurance scheme, which covers everybody's care costs. Should local government say how much money people get depending on the situation in their area, or should national government decide? National Local

Consultation question 3 – wording by strand

Strand	Question wording
Short questionnaire: – PDAs (strand 14) – Touch screens (strand 15)	We want to build a fair, simple and affordable National Care Service. How should a new system be funded? Partnership: The Government covers some care and support costs, more if you have a low income. Insurance: The Government covers some care and support costs, and helps you take out insurance for the rest, if you want it. Comprehensive: Everyone pays into a state insurance scheme, which covers everybody's costs. Should local government say how much money people get depending on the situation in their area, or should national government decide? Part national, part local Fully national
Long questionnaire: – Touch screen (strand 16)	We will achieve this vision by making better use of taxpayers' money so funding is focused on people who can benefit from it and need it most. But the money in the system at the moment won't pay for all of everyone's care in the future. In deciding how to fund care and support, there are some very difficult decisions to make. Funding options We have therefore proposed three options for funding a National Care Service. Partnership: The responsibility for paying for care and support would be shared between the Government and the person who has the care and support needs. The Government provides between a quarter and a third of the cost of care and support, more for people on a low income. Today's 65-year-olds will need care and support costing on average £30,000. The Partnership system would work for adults of all ages. Under this system we expect many people born with a care and support need to qualify for free care, as they do under the current system. Those working-age adults who do not qualify for free care (those who are better off) would have the same offer around funding as people over 65. Insurance: The same as Partnership, but the Government could help people prepare to meet the costs that they would have to pay for themselves through an insurance-based approach. As well as providing people with between a third and a quarter of the cost of care and support, the Government would make it easier to take out insurance to cover care and support costs if they want it. It is estimated that the cost of insurance could be around £20,000 to £25,000. The Insurance part of the second option would be likely to be less relevant to people who have been born with a care and support need, since people cannot insure against the risk of something that has already happened. However, many people born with a care and support need are likely to qualify for free care under the Partnership element of the system. Comprehensive: Everyone over retirement age who can afford it would pay into a state insurance system, so that everyone who needs care and support will receive it free. It is estimated that the cost of being in the system could be between £17,000 and £20,000. The Comprehensive system would be for people over retirement age, but we would also look at having a free care and support system for people of working age alongside this. a) Which of these options do you prefer? We believe that the care and support system should be fair and universal. But we also need to ensure that the system is flexible enough to respond to local circumstances and encourage innovative approaches. There could be two different approaches to how the system works – either a part-national, part-local system or a fully national system. The two approaches have different implications for the way money is raised and distributed around England. b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

Source: Department of Health

Methodology of analysing responses

Analysis of the consultation responses required coding of the data. Coding is the process by which responses are matched against standard 'codes' from a coding frame Ipsos MORI compiled (with sign-off from the Department of Health) so that their content can be classified and tabulated. These codes were developed from an initial selection of responses, and were added to and updated throughout the duration of the consultation period.

Each of these codes represents a discrete 'theme' raised in a number of responses; the complete coding frame should be comprehensive in representing the whole range of opinions and 'themes' given in the responses. It was continually developed throughout the duration of the consultation. As further responses were received, they were coded to ensure that any new themes that emerged were captured, and that no nuances were lost. Any one response received from an individual may have had a number of codes applied to it if they make more than one point, or address more than one theme.

The coding was conducted by Ipsos MORI coders, using the web-based 'Ascribe' coding system – a secure Internet platform.

For responses where more detail was provided, and where categorising the response into codes would lose much of the meaning of the response, a qualitative-type content analysis was carried out. This involved all responses being read, and the identification of key themes and issues emerging. Qualitative-type analysis was undertaken for submissions from national organisations, local organisations, stakeholders and letters and emails from the general public.

Below we outline how responses to each strand were recorded and analysed.

Online short and long questionnaires

(strands 1 and 2) – these email responses were transferred to an Excel file. All responses were logged and loaded into the Ascribe system to be coded.

Short (paper) questionnaire (strand 3) –

responses were logged and scanned electronically. 'Tick box' responses were captured and verbatim comments loaded into Ascribe to be coded.

Additional comments written on the questionnaires were also captured and loaded into Ascribe. Damaged questionnaires were transferred manually on to clean questionnaires.

Long (paper) questionnaire (strand 4) –

responses were logged and scanned electronically. 'Tick box' responses were captured and verbatim comments loaded into Ascribe to be coded.

Additional comments written on the questionnaires were also captured and loaded into Ascribe. Damaged questionnaires were transferred manually on to clean questionnaires. Some questionnaires were sent as printed PDFs from the Big Care Debate website. These were unable to go through the scanning machines and were often printed a larger size than the original questionnaire (A4 rather than A5). This meant that transcribing responses to an original was not feasible as responses were often longer than the space given on the A5 questionnaire. In these instances, responses were manually typed into an Excel file, and loaded into Ascribe to be coded.

Postcards (strand 5) – were logged and scanned electronically, to pick up the ‘tick box’ responses. Any additional comments written on the postcards were also captured and uploaded into the Ascribe system to be coded.

Where postcards were damaged, and unable to pass through scanning machines, responses were manually transferred on to clean postcards, which were then scanned.

Letters and emails sent to the Department of Health (from both stakeholders and the general public) (strands 6 and 7) – responses were divided into national and local organisational responses, other stakeholder responses, and personal submissions. Each of these responses was read by a member of the core research team and a qualitative-type content analysis was carried out.

‘Easy read’ Q&A pages (strand 8) – responses were divided into stakeholder and public responses. Stakeholder responses were included in the appropriate qualitative content analysis, and public responses were loaded into Ascribe to be coded.

Questionnaires in *Saga* and *Take a Break* magazines (strand 9) – all responses were loaded into an Excel file by COI and sent to Ipsos MORI, where they were loaded into Ascribe to be coded.

Online comments on the Green Paper (strand 10) – all responses were loaded into an Excel file by COI and sent to Ipsos MORI, where they were loaded into Ascribe to be coded.

Online comments on David Behan’s blog (strand 11) – all responses were loaded into an Excel file by COI and sent to Ipsos MORI, where they were loaded into Ascribe to be coded. Where possible, duplicated responses were removed, with the aim of counting each response once only.

Regional events (strand 12) – responses received at these events were summarised into a series of ten regional, qualitative reports by COI, the results of which were incorporated into Ipsos MORI’s overall report.

Feedback forms from stakeholder toolkits (strand 13) – all responses were read and included in the qualitative-type content analysis of local organisational responses.

Questionnaires via touch screen and PDA (strands 14, 15 and 16) – all responses were loaded into Ascribe to be coded.

Interactive white board printouts (strand 17) – these responses were loaded into Ascribe to be coded.

Supplementary qualitative research (strand 18) – the responses to these events were written up into a qualitative report by OLR, the results of which were incorporated into Ipsos MORI’s overall report.

Hard copies of responses remained securely stored in Ipsos MORI’s Harrow offices. Answers to the ‘tick box’ questions on the questionnaires were also recorded and matched to the coded data by serial numbers, enabling a more detailed breakdown of data at the final analysis stage.

All open ended responses were coded twice, to verify that the correct code or codes had been applied (and to make amendments as necessary). Once coding was complete, a further series of checks was carried out to ensure that no responses had either been omitted from the analysis or inadvertently double-counted.

The coding and data handling procedures, and the working of the Ascribe software, are set out in more detail in Appendix A.

Throughout the main body of the report, reporting of the consultation responses received is based upon this classification. It will be understood that because people often express the same idea in different ways, the codes must be wide enough in their scope to draw together those responses that are making the same point in different ways. It is also sometimes inevitably the case that responses are sometimes ambiguous and might be intended to put across any one of a number of related but distinct points. Therefore, it is sometimes necessary when reporting the number of responses making a particular point to express it in somewhat vague terms. This is simply because the coding must ensure that broadly similar responses are not sub-divided too finely if it is to be useful in helping understand what those replying to the consultation have said.

Interpreting the consultation responses

It is important to bear in mind the limitations of this form of consultation in measuring the detailed views of the general public and stakeholders. A consultation in which the whole population is offered an opportunity to take part has some obvious advantages over opinion polls and similar exercises as a democratic tool

allowing everybody a voice in the decision-making process. However, it is less effective at measuring how widely held particular opinions are, and while some people comment on issues not directly asked in the consultation, it cannot be assumed that others do not hold these opinions.

As noted above, the consultation does not comprise the responses of a representative sample of those in the target audience, only of those who chose to respond to the consultation. It over-represents some demographic groups who were disproportionately likely to respond, and may also over-represent particular points of view in the same way. For a strictly representative view, well-conducted representative sample surveys are more likely to be reliable. Moreover, many consultation responses consisted of a brief free-form response to the proposal document, and will naturally not have expressed in the fullest detail participants' views on every point in question.

It must be understood, therefore, that the consultation as reflected through the report should not be interpreted as if it were a survey or opinion poll. Its function is very different, and is predominantly qualitative in nature. Findings emerge as a number of themes and ideas. Therefore, while some figures are given in the report, these are to illustrate the relative importance of particular themes. The core focus is on the themes emerging, and no reliable statistical analysis can be undertaken with the data produced.

Some figures are reported in the report, although they must be treated with caution. While some figures may seem small given the scale of the

overall consultation, all those reported on have been highlighted due to their importance relative to other themes, and small figures can reflect important themes. The vast majority of responses are spontaneous in nature and as a result, there are a wide range of themes emerging from the consultation. The spontaneous nature of the comments also means that the absolute numbers mentioning a particular theme can be small compared to the total number of responses to the consultation. There are also many blank responses to certain questions, where participants chose not to answer. Often they had a strong view on one aspect of the consultation, and made their views on this clear, but left other questions blank.

A great deal of time and effort has been put into the responses by contributors to the consultation. For example, many individuals described their personal experiences and national and local organisations discussed in detail the specific issues relevant to their organisation and members. All of these responses have been read and analysed by the Ipsos MORI research team.

The report includes responses from stakeholders. It is, however, not possible to subsume all the important and detailed issues from stakeholder responses and do justice to the amount of work that has been put into many of the responses in this summary document. Throughout the report, we have sought to include recurring themes emerging from stakeholder responses, rather than detailing specific, individual issues or outlining every point of view. The list of stakeholders who responded is appended to this document as Appendix O.

Furthermore, through various forms of engagement with stakeholders and members of the public, the Department of Health has been able to hear first hand many different perspectives on care and support. There are a large number of specific, detailed points which the Department has noted and taken forward in developing the White Paper, but which due to the nature of this document could not be included. This document is one of a number which informed the Government's White Paper.

APPENDICES

The **appendices** to this report are as follows:

Appendix A: Technical note on the coding process

Appendix B: Demographic information

Appendices C–N: Consultation materials:

Appendix C: Strand 3 – Short paper questionnaire

Appendix D: Strand 4 – Long paper questionnaire

Appendix E: Strand 5 – Postcard

Appendix F: Strand 8 – Q&A feedback pages

Appendix G: Strand 9 – Questionnaire in *Saga* magazine

Appendix H: Strand 9 – Questionnaire in *Take a Break* magazine

Appendix I: Strand 12 – Regional stakeholder events

Appendix J: Strand 13 – Stakeholder toolkit and feedback form

Appendix K: Strand 14 – Short questionnaire on handheld PDA device

Appendix L: Strand 15 – Short questionnaire on touch screen

Appendix M: Strand 16 – Long questionnaire on touch screen

Appendix N: Strand 18 – Supplementary qualitative research

Appendix O: List of stakeholder respondents

APPENDIX A: TECHNICAL NOTE ON THE CODING PROCESS

Development of initial coding frame

Coding is the process by which open ended responses are matched against standard 'codes' from a coding frame compiled by Ipsos MORI and approved by the Department of Health to allow systematic statistical and tabular analysis. The codes within the coding frame represent an amalgam of responses raised by those registering their view and are comprehensive in representing the range of opinions and 'themes' given.

The Ipsos MORI coding team drew up an initial code frame using a selection of the first responses. An initial set of codes was created by drawing out the common 'themes' and points raised. Each code thus represents a discrete view raised. The draft coding frame was then presented to the Ipsos MORI project team and Department of Health project team and fully approved before the coding process continued. The code frame was continually updated throughout the analysis process to ensure that newly emerging 'themes' were captured throughout the duration of the consultation.

Coding using the Ascribe package

Given the scale and complexity of the consultation, Ipsos MORI used the web-based Ascribe coding system to code all open ended responses found within completed questionnaires and other free form responses. Ascribe is a proven system which has been used on numerous large scale projects. The scanned and

electronic verbatim responses were uploaded into the Ascribe system, where the coding team worked systematically through the verbatim comments and applied a code to each relevant part(s) of the verbatim comment.

The Ascribe software has the following key features:

- accurate monitoring of coding progress across the whole process, from scanned image to the coding of responses;
- an 'organic' coding frame that can be continually updated and refreshed; not restricting coding and analysis to initial response issues or 'themes' which may change as the consultation progresses;
- resource management features, allowing comparison across coders and question areas. This is of particular importance in maintaining high quality coding across the whole coding team and allows early identification of areas where additional training may be required; and
- a full audit trail – from verbatim response to codes applied to that response.

Coders were provided with an electronic file of responses to code within Ascribe. Their screen was split, with the left side showing the response along with the unique identifier, while the right side of the screen showed the full code frame. The coder attached the relevant code or codes to

these as appropriate and, where necessary, alerted the supervisor if they believed an additional code might be required.

If there was other information that the coder wished to add they could do so in the 'notes' box on the screen. If a response was difficult to decipher the coder would get a second opinion from their supervisor or a member of the project management team. As a last resort, any comment that was illegible was coded as such and reviewed by the Coding Manager.

Briefing the coding team and quality checking

A dedicated core team of coders worked on the project, all of whom were fully briefed and were conversant with the Ascribe package. This team also worked closely with the project management team.

In addition to the core coding team, a number of senior coders also took a supervisory role throughout and undertook the quality checking of all coding. Using a reliable core team in this way minimises coding variability which retains data quality.

The Ascribe software was controlled on a secure Internet platform, making it totally secure and, at the same time, easy to administer for joint site working.

To ensure consistent and informed coding of the verbatim comments, all coders were fully briefed prior to working on this project. During the first week of starting work, coding was carefully monitored to ensure data consistency and to ensure that all coders were sufficiently competent to work on the project.

The coder briefings included background information and presentations covering the Green Paper proposal, the consultation process and the issues involved; discussion of the initial coding frame; and an exercise testing consistency of coding, using photocopies of actual verbatim responses and a 'test' coding exercise to ensure the coder was fully up to speed on the requirements of the task. The briefings were carried out by one of Ipsos MORI's executive team members.

The Ascribe package also afforded an effective project management tool, with the coding manager reviewing the work of each individual coder, having discussion with them where there was variance between the codes entered and those expected by the coding manager.

To check and ensure consistency of coding, coded responses were validated by the coding supervisors, who checked that the correct codes had been applied and made changes where necessary.

Coding additional comments and damaged questionnaires

The scanning machines are programmed to capture responses written in the spaces dedicated to each question on the questionnaires. In some instances, participants had written comments on the questionnaires outside of the scanned areas. In these cases, the additional comments were transcribed manually into Excel and fed into Ascribe.

Similarly, some questionnaires were unable to pass through the scanners due to being damaged. Responses were transferred manually on to blank questionnaires and fed through the

scanners. In some instances, PDF versions of the long questionnaire had been downloaded from the Big Care Debate website, completed and sent to Ipsos MORI (via the Department of Health). Where this occurred, responses were transcribed into Excel as printouts, often larger than the A5 questionnaires, and therefore contained too much information to be transcribed on to blank questionnaires.

Updating the coding frame

An important feature of the Ascribe system is the ability to extend the code frame 'organically' direct from actual verbatim responses throughout the duration of the consultation coding period.

The coding teams raised any new codes during the coding process when it was felt that new themes were being registered. In order to ensure that no detail was lost, coders were briefed to raise codes that reflected the exact sentiment of a response, and these were then collapsed into a smaller number of key themes at the analysis stage. During the initial stages of the coding process, meetings were held between the coding team and Ipsos MORI executive team to ensure that a consistent approach was taken to raising new codes and that all extra codes were appropriate and correctly assigned. In particular, the coding frame sought to capture precise nuances of participants' comments in such a way as to be comprehensive.

A second key benefit of the Ascribe system is that it provides the functionality of combining codes, revising old codes and amending existing ones, as appropriate. Thus, the coding frame grew organically throughout the coding process to ensure it captured all of the important 'themes'.

Checking the robustness of the datasets

As already stated, all open ended responses were coded twice. The first time was by the coder and the second time by a senior coder to verify that the correct code or codes had been applied to the open ended responses and to make amendments as necessary. This second verification occurred once the coding frame had been extensively developed, enabling the most appropriate codes to be applied and back-coding of 'other' codes into newer codes where appropriate, using codes which may have not existed at the time the response was originally coded.

Once coding was complete, and all data streams combined, a series of checks were undertaken to ensure that the data set was comprehensive and complete.

APPENDIX B: DEMOGRAPHIC INFORMATION

Demographic information, where this information has been recorded, is given below, although it is important to bear in mind that this is just a subset of the consultation participants and cannot be taken to be representative of the consultation participants in general. (It should be noted that all percentages referred to below are rounded to the nearest whole number, and that when

two or more such figures are added, it can create rounding error; the rounded figures given in a column, therefore, may not sum to exactly 100%.)

As demographic questions were not asked on all strands, the totals in the tables below do not add to the total number of responses received.

Table A1

Consultation responses by gender		
Gender	Number of responses	% of responses giving gender
Male	6,332	40%
Female	9,681	60%
<i>Stating gender</i>	16,013	
<i>Not stated (where question asked)</i>	496	
Total	16,509	100%

Source: Respondents to long online questionnaire, long paper questionnaire, short paper questionnaire, PDA and touch screen long and short questionnaires, *Saga* and *Take a Break* questionnaire

Table A2

Consultation responses by age		
Age	Number of responses	% of responses giving age
Under 18	469	3%
18–24	1,134	7%
25–34	1,735	11%
35–44	2,575	16%
45–64	6,076	38%
65–79	3,308	20%
80+	842	5%
<i>Stating age</i>	16,139	
<i>Not stated (where question asked)</i>	370	
Total	16,509	100%

Source: Respondents to long online questionnaire, long paper questionnaire, short paper questionnaire, PDA and touch screen long and short questionnaires, *Saga* and *Take a Break* questionnaire

Table A3

Consultation responses by region		
Region	Number of responses	% of responses giving region
London	979	6%
South East	2,142	14%
East	1,295	9%
South West	1,724	11%
East Midlands	1,868	12%
West Midlands	1,874	12%
North East	1,128	7%
North West	2,130	14%
Yorks and Humber	1,961	13%
<i>Stating region</i>	15,101	
<i>Not stated (where question asked)</i>	429	
Total	15,530	100%

Source: Respondents to long online questionnaire, long paper questionnaire, short paper questionnaire, PDA and touch screen long and short questionnaires

Table A4

Consultation responses by carers		
Carer	Number of responses	% of responses stating whether carer
Yes	3,132	26%
No	8,738	74%
<i>Stating whether carer</i>	11,870	
<i>Not stated (where question asked)</i>	1,067	
Total	12,937	100%

Source: Respondents to short paper questionnaire, PDA and touch screen short questionnaires

Table A5

Consultation responses by recipients of care and support		
Receive care and support	Number of responses	% of responses stating whether receive care and support
Yes	1,635	14%
No	10,120	86%
<i>Stating whether receive care and support</i>	11,755	
<i>Not stated (where question asked)</i>	1,182	
Total	12,937	100%

Source: Respondents to short paper questionnaire, PDA and touch screen short questionnaires

Table A6

Consultation responses by involvement in care and support system		
Involvement	Number of responses	% of responses stating involvement*
Member of public with interest in care and support issues	945	41%
Care user	330	14%
Informal carer	408	18%
Professional worker in the sector	450	20%
Representing individual carers and care users	125	5%
Representing other organisations supporting carers and care users	105	5%
Representing managers and professional workers in the social care sector	28	1%
Representing individuals and organisations responsible for commissioning or delivering social care	71	3%
Academic/research organisation/think tank	45	2%
Central government department/agency/non-departmental public body	66	3%
Other	60	3%
None	6	<1%
<i>Stating involvement</i>	2,279	
<i>Not stated (where question asked)</i>	314	
Total	2,593	

Source: Respondents to long online questionnaire, long paper questionnaire and touch screen long questionnaire

* These totals add to more than 100% as some participants have selected more than one option

Table A7

Consultation responses by ethnicity		
Ethnicity	Number of responses	% of responses stating ethnicity*
White	8,611	93%
British	7,030	76%
Irish	136	1%
Other White background	1,470	16%
Mixed	58	1%
White and Black Caribbean	15	<1%
White and Black African	8	<1%
White and Asian	11	<1%
Other mixed background	26	<1%
Asian or Asian British	273	3%
Indian	111	1%
Pakistani	43	<1%
Bangladeshi	5	<1%
Other Asian background	115	1%
Black or Black British	181	2%
Caribbean	66	1%
African	78	1%
Other Black background	42	<1%
Chinese or other ethnic group	206	2%
Chinese	30	<1%
Other ethnic group	176	2%
<i>Stating ethnicity</i>	9,266	
<i>Not stated (where question asked)</i>	6,482	
Total	15,748	

Source: Respondents to long online questionnaire, long paper questionnaire, short paper questionnaire, PDA and touch screen long and short questionnaires and Saga questionnaire

* These totals add to more than 100% as some participants have selected more than one option

Table A8

Consultation responses by disability		
Disability	Number of responses	% of responses stating disability
No disability	1,668	72%
Hearing	134	6%
Vision	83	4%
Speech	33	1%
Mobility	402	17%
Learning	59	3%
Mental health	99	4%
Physical disfigurement	23	1%
Illness	320	14%
Other	30	1%
<i>Stating involvement</i>	2,308	
<i>Not stated (where question asked)</i>	285	
Total	2,593	

Source: Respondents to long online questionnaire, long paper questionnaire and touch screen long questionnaire

* These totals add to more than 100% as some participants have selected more than one option

APPENDIX C: STRAND 3 – SHORT PAPER QUESTIONNAIRE



**Care
Support
Independence**



... help shape the
future of care together

A quick guide to the reform
of the adult care and support
system in England.

Find out more at
www.careandsupport.direct.gov.uk

What is care and support?

Care and support helps people do everyday things like living in their own homes, working, shopping and caring for their family.

It includes:

- benefits for disabled people
- occupational therapy
- day care
- care homes
- support for carers
- housing support services.

Public, private and charitable organisations provide care and support, as well as friends, family and community groups.

The main users are:

- people who have a long-term illness
- disabled people
- older people.

It is paid for by individuals and a mixture of general and local taxes.



Why do we need change?

Society is changing

- People are living longer and we know there will be more people with care and support needs in the future.
- The number of people of retirement age is growing much faster than the number of people working.

Expectations are higher

- People want care and support that is designed around their needs.
- People want a greater say in the care and support they receive.

Problems in the current system

- The system is too complicated.
- The system does not always give value for money.
- Levels of care and support are different in different parts of the country.

A National Care Service

The Government wants to create a **National Care Service** that is **fair, simple** and **affordable** for all adults in England.

We think everyone should be able to expect a system that:

- helps you to stay well and independent for as long as possible
- assesses your care and support needs in the same way in every region
- has care and support services working together smoothly
- provides you with clear information and advice
- offers services that are designed and delivered around your needs
- spends taxpayers' money wisely and fairly.

For a National Care Service to work, the Government believes it must offer:

- joined-up services
- a wider range of services
- high-quality services that are based on evidence of what works.



The funding question

The Government has published *Shaping the Future of Care Together*, a public consultation document or Green Paper, which spells out the options for reform. It asks which options you think would best deliver the new National Care Service, and how you think it should be funded.

The Green Paper suggests three ways of funding the National Care Service:

Partnership

The Government covers some care and support costs, more if you have a low income.

Insurance

The Government covers some care and support costs, and helps you take out insurance for the rest, if you want it.

Comprehensive

Everyone pays into a state insurance scheme, which covers everybody's care costs.

We also need to decide if local authorities or central Government determine how much funding people will receive.

How to join the Big Care Debate

Answer the questions attached to this leaflet and post it to us. No stamp required.

Visit www.careandsupport.direct.gov.uk to read more, watch videos and have your say.

To order copies of the Green Paper, go to www.orderline.dh.gov.uk, and quote 295936, phone **0300 123 1002**, or download it from www.careandsupport.direct.gov.uk

The Big Care Debate runs until 13 November 2009.

Contact us by email:

careandsupport@dh.gsi.gov.uk

Or by post:

Green Paper Team

Room 149
Richmond House
79 Whitehall
London SW1A 2NS

We are also on Facebook and Twitter as 'Care and Support'.



1. We want to build a fair, simple and affordable National Care Service. It should help you to stay well and independent, assess your needs in the same way in every region, have services working together smoothly, be easy to understand, offer you care and support designed around your needs, and spend money wisely.

Is there anything missing from this?

2. Do you think a wider range of better joined-up and high-quality services will improve the care and support system?

☐ Yes ☐ No

If no, what else do you think is needed?

3. We want to build a fair, simple and affordable National Care Service.

How should a new system be funded?

- ☐ **Partnership:** The Government covers some care and support costs, more if you have a low income.
- ☐ **Insurance:** The Government covers some care and support costs, and helps you take out insurance for the rest, if you want it.
- ☐ **Comprehensive:** Everyone pays into a state insurance scheme, which covers everybody's care costs.

Should local government say how much money people get depending on the situation in their area, or should national government decide?

- ☐ Part national, part local
- ☐ Fully national

About you

We'd like to ask you some questions about yourself to help us understand and analyse responses in a more effective manner.

What gender are you?

- ☐ Male
- ☐ Female

What age range do you fall into?

- ☐ Under 18
- ☐ 18–24
- ☐ 25–34
- ☐ 35–44
- ☐ 45–64
- ☐ 65–79
- ☐ 80+

What region do you live in?

- ☐ London
- ☐ South East
- ☐ East of England
- ☐ South West
- ☐ East Midlands
- ☐ West Midlands
- ☐ North East
- ☐ North West
- ☐ Yorkshire and Humberside

What is your marital status?

- ☐ Single
- ☐ Married/living as married/civil partnership
- ☐ Divorced/separated/widowed

What is your current working status?

- ☐ In work
- ☐ Unemployed
- ☐ Retired
- ☐ Student

Do you have any children in your household?

- ☐ Yes
- ☐ No

Do you own your home?

- ☐ Yes
- ☐ No

Do you act as a carer for a family member or friend?

- ☐ Yes
- ☐ No

Do you receive care and support?

- ☐ Yes
- ☐ No

Which ethnic group do you belong to?



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APPENDIX D: STRAND 4 – LONG PAPER QUESTIONNAIRE



**Care
Support
Independence**



... help shape the
future of care together

The Big Care Questionnaire

visit www.careandsupport.direct.gov.uk

Join the Big Care Debate and help shape the future of care and support

The Government's new Green Paper **Shaping the Future of Care Together** sets out a vision for a **National Care Service for all adults in England**. A service that is fair, simple and affordable for everyone, underpinned by national rights and entitlements and personalised to individual needs. It asks for your views on some difficult choices that we need to make for this vision to become a reality. The proposals in this Green Paper are some of the most fundamental reforms ever in this area.

Why do we need a debate

We are an ageing society. For the first time ever there are more people over the age of 65 than there are under the age of 18. Life expectancy is going up and advances in medical science mean that people with a disability are living longer. This is worth celebrating but it does mean we need to radically change the way care and support is provided and paid for. The current system has its basis in the 1940s and there have been huge social changes in terms of what we value and what we want from public services. People now want more independence, choice and control, and we need to reflect these demands.

As a society we will have to spend more on care and support in the future. One of the most important issues we want your views on is what is fair to ask people to pay for themselves, and how we protect people from having to pay a huge bill if they need long-term residential care.

The process

The Green Paper has been informed by a six-month engagement process that took place in 2008 in which thousands of people were asked about their views on the challenges that we face for the future and the problems with the current system.

The debate questions

We'd like you to answer as many of these as you can, but don't worry if there are some you don't have a view on, just leave them out.

When answering these questions you may want to consider any impact our proposals may have on race, disability, gender, sexual orientation, religion, belief or age equality for you or your service users.

1 The vision for the future

We have suggested six key things that everyone should expect from a National Care Service and we want your views on them.

- **Prevention services**

You will receive the right support to help you stay independent and well for as long as possible and to stop your care and support needs getting worse.

- **National assessment**

Wherever you live in England, you will have the right to have your care and support needs assessed in the same way and you will have a right to have the same proportion of your costs paid for.

- **A joined-up service**

All the services you need will work together smoothly, particularly when your needs are assessed. You will only need to have one assessment of your needs to access a whole range of care and support services.

- **Information and advice**

If you need care and support, or you are preparing for it, you will find it easy to get information about who can help you, what care and support you can expect, and how quickly you can get it.

- **Personalised care and support**

Your care and support will be designed and delivered around your individual needs. As part of your care and support plan, you will have much greater choice over how and where you receive support, and the possibility of controlling your own budget wherever appropriate.

- **Fair funding**

Everyone who qualifies for care and support from the state will get some help meeting the cost of their care and support needs. Your money will be spent wisely to fund a care and support system that is fair and sustainable.

1a) Is there anything missing from this list?

1b) How should this work?

2 Making the vision a reality

We think that to deliver this vision three main changes are required to the care and support system.

- **More joined-up working** between health, housing, social care and benefits systems.
- **A wider range of care and support services**, so people have a greater range of services to choose from.
- **Better quality and innovation**. Staff must have the right training and skills, and services should be based on the best and most recent information about what works well in providing care.

2a) Do you agree?

2b) What would this look like in practice?

2c) What are the barriers to making this happen?

3 Funding care and support in the future

We will achieve this vision by making better use of taxpayers' money so funding is focused on people who can benefit from it and need it most. But the money in the system at the moment won't pay for all of everyone's care in the future.

In deciding how to fund care and support, there are some very difficult decisions to make.

Funding options

We have therefore proposed three options for funding a National Care Service.

- (i) Partnership:** The responsibility for paying for care and support would be shared between the Government and the person who has care and support needs. The Government provides between a quarter and a third of the cost of care and support, more for people on a low income. Today's 65-year-olds will need care and support costing on average £30,000. The Partnership system would work for adults of all ages. Under this system we expect many people born with a care and support need to qualify for free care, as they do under the current system. Those working-age adults who do not qualify for free care (those who are better off) would have the same offer around funding as people over 65.
- (ii) Insurance:** The same as Partnership but the Government could help people prepare to meet the costs that they would have to pay for themselves through an insurance-based approach. As well as providing people with between a third and a quarter of the cost of care and support, the Government would make it easier for people to take out insurance to cover care and support costs if they want it. It is estimated that the cost of insurance could be around £20,000 to £25,000. The Insurance part of the second option would be likely to be less relevant to people who have been born with a care and support need, since people cannot insure against the risk of something that has already happened. However, many people born with a care and support need are likely to qualify for free care under the Partnership element of the system.

(iii) Comprehensive: Everyone over retirement age who can afford it would pay into a state insurance scheme, so that everyone who needs care and support will receive it free. It is estimated that the cost of being in the system could be between £17,000 and £20,000.

The Comprehensive system would be for people over retirement age, but we would also look at having a free care and support system for people of working age alongside this.

We have ruled out a system based on tax funding, because it would put a large burden of paying for care and support on people who are working. Given demographic changes, there will be an increasing pressure on a shrinking proportion of working-age people. In 2007, the number of people aged over 65 became greater than the number of people under 18 for the first time. Because the majority of people benefiting from a reformed care and support system will be pensioners, it is fairer to think about more targeted ways of bringing in extra funding, rather than placing a lot of the burden of the system on people of working age.

Disabled people of working age

At the moment, people who are disabled when they are born, or who become disabled during their working lives, are likely to have lower incomes and so will struggle to meet the cost of their care and support. In the future, more disabled people will be working, but those who are on low incomes will have their care and support funded by the state.

What about accommodation costs?

It is important to note that these options consider only the cost of people's care and support. People entering a care home would have to pay for their accommodation costs, such as the costs of food and lodging. This is because the state would not pay for people to buy their food or pay their mortgage or rent if they were living at home.

Of course, the state will always have a role in supporting people who are in a care home who cannot afford these costs.

3a) Which of the three funding options do you prefer and why?

A national or local system?

We believe that the care and support system should be fair and universal. But we also need to ensure that the system is flexible enough to respond to local circumstances and encourage innovative approaches. There could be two different approaches to how the system works – either a part-national, part-local system or a fully national system. The two approaches have different implications for the way money is raised and distributed around England.

3b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

If you want to learn more or run your own Big Care Debate and tell us about it, there are some materials that can help you and can be downloaded at www.careandsupport.direct.gov.uk

The Big Care Debate lasts until 13 November 2009.

About you

Please provide us with some information about yourself. This will help us to determine whether we have captured the views of everyone. All the information you provide will be kept completely confidential. No identifiable information about you will be passed to on to any other bodies, members of the public or press.

What is your sex?

- ☐ Male ☐ Female

Which age group do you belong to?

- ☐ Under 18 ☐ 35-44 ☐ 65-79
☐ 18-24 ☐ 45-54 ☐ 80 yrs and over
☐ 25-34 ☐ 55-64

What region do you live in?

- ☐ London ☐ West Midlands
☐ South East ☐ North East
☐ East of England ☐ North West
☐ South West ☐ Yorkshire and Humberside
☐ East Midlands

What is your marital status?

- ☐ Single ☐ Married/living as married/civil partner
☐ Divorced/separated/widowed

What is your current working status?

- ☐ In work ☐ Retired
☐ Unemployed ☐ Student

Do you have any children in your household?

- ☐ Yes ☐ No

Do you own your home?

- ☐ Yes ☐ No

Which of the following descriptions best reflects your involvement in the care and support system at the moment?

- ☐ A member of the public with an interest in care and support issues
 - ☐ Care user
 - ☐ Informal carer
 - ☐ Professional worker in the sector
 - ☐ Representing individual carers and care users
 - ☐ Representing other organisations supporting carers and care users
 - ☐ Representing managers and professional workers in the social care sector
 - ☐ Representing individuals and organisations responsible for commissioning or delivering social care
 - ☐ Academic/research organisation/think tank
 - ☐ Central government department/agency/non-departmental public body
 - ☐ Other (please specify)
-

What is your ethnic group?

White

- ☐ British ☐ Irish
 - Any other White Background, please write below
-

Mixed

- ☐ White and Black Caribbean ☐ White and Black African
 - ☐ White and Asian
 - Any other Mixed Background, please write below
-

Asian or Asian British

- ☐ Indian ☐ Pakistani ☐ Bangladeshi
 - Any other Asian Background, please write below
-

Black or Black British

- ☐ Caribbean ☐ African
 - Any other Black Background, please write below
-

Chinese or other ethnic group

☐ Chinese

Any other, please write below

Do you have a disability as defined by the Disability Discrimination Act (DDA)?

☐ Yes

☐ No

The Disability Discrimination Act (DDA) defines a person with a disability as “someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day to day activities”.

If yes, please tick all which apply

☐ Partial or total loss of hearing

☐ Partial or total loss of vision

☐ Speech impediment or impairment

☐ Mobility impairment or difficulty moving around

☐ Learning difficulty or learning disability

☐ Mental health condition or disorder

☐ Severe physical disfigurement

☐ A longstanding illness or disease

☐ Other medical condition or impairment (please specify)

Do you consider yourself as belonging to any particular religion or belief?

☐ Christian

☐ Buddhist

☐ Hindu

☐ Jewish

☐ Muslim

☐ Sikh

☐ Atheist

☐ No religion
or belief

☐ Other
(please write below)

Which of the following best describes your sexual orientation?

Only answer this question if you are aged 16 years or over.

☐ Heterosexual/Straight

☐ Lesbian/Gay

☐ Bisexual

☐ Other

☐ Prefer not to answer

Find out more

Building a new system for care and support is not a simple task. It is vital we get the views of everybody affected, and that is why we're inviting and encouraging everyone to participate in the debate.

- ☐ If you are interested in receiving materials to help take this important debate forward, please tick this box and complete your details below.
- ☐ If you would like to receive further communications from the Department of Health on care and support, please tick this and complete your details below.
- ☐ If you would like to receive further communications from the Department of Health on wider policy areas, please tick this box and complete your details below.

Title _____

First name _____

Surname _____

Email address _____

Telephone _____

Postal address _____

The Department of Health will not share your details with any third parties.

Confidentiality of information

Please be aware that under the Freedom of Information Act 2000, we may be asked to share the information we receive as part of this consultation.

If you would like your response to remain confidential, it would be helpful if you could explain why. If we receive a request to disclose the information, we will take full account of your explanation but we cannot guarantee that confidentiality can be maintained in all circumstances. Your name, address and any other personal data as defined under the Data Protection Act is exempt from disclosure.

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If you require further copies of this title visit

www.orderline.dh.gov.uk and quote 297528/The Big Care Questionnaire

Email: **dh@prolog.uk.com**

Tel: 0300 123 1002

Minicom: 0300 123 1003 (8am to 6pm Monday to Friday)

Gateway reference 12462

APPENDIX E: STRAND 5 – POSTCARD



Care
Support
Independence



We want to build a **fair, simple** and **affordable National Care Service**.

How should a new system be funded?

- ☐ **Partnership**
The Government covers some care costs, more if you have a low income.
- ☐ **Insurance**
The Government covers some care costs, and helps you take out insurance for the rest, if you want it.
- ☐ **Comprehensive**
Everyone pays into a state insurance scheme, which covers everybody's care costs.

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SE1 7DU

The Big Care Debate runs until 13 November 2009.

APPENDIX F: STRAND 8 – Q&A FEEDBACK PAGES – EASY READ

Shaping the Future of Care Together Tell us what you think

Care and support consultation

Question and answer pages

Please tell us your name, address and how to contact you.

We want this in case we need to ask more questions. But you don't need to tell us all these details if you don't want to.

Your name.....

Your address.....

.....

.....

.....

Please tick (✓) a box to show how you want us to contact you.

☐

by post at the above address

☐

by email. My email address is

@

☐

by telephone. My telephone number is

If you do not want us to tell other people about what you tell us, please tell us why. Even then, unless you have a good reason, the Freedom of Information Act may mean that we have to tell people.

.....

.....

Question 1

Information about this question is on pages 15 to 22 in this booklet.

Standard words

We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- prevention services
- national assessment
- a joined-up service
- information and advice
- personalised care and support
- fair funding.

(a) Is there anything missing from the approach?

(b) How should this work?

Easy-read words

Chapter 3 talked about the 6 things you can expect from a National Care Service. Have we missed anything? Do you have any ideas for how we could make these things happen?



Shaping the Future of Care Together Tell us what you think

Tell us what you think

[illegible]

Question 2

Information about this question is on pages 23 and 26 in this booklet.

Standard words

We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.

- (a) Do you agree?
- (b) What would this look like in practice?
- (c) What are the barriers to making this happen?

Easy-read words

We think the National Care Service should have first-class **joined-up services** where people can choose the services they want to use

- Do you agree?
- How could we set this up?
- What things might make it hard for us to make this happen?

Tell us what you think

.....

.....

.....

.....

You can write more on the next page if you need to.

Shaping the Future of Care Together **Tell us what you think**

This image shows a full page of white paper with horizontal dashed lines, typical of primary school handwriting practice paper. The lines are evenly spaced and run across the entire width of the page. There are no margins, text, or other markings present.

Question 3

Information about this question is on pages 31 and 47 in this booklet.

Standard words

The Government is suggesting three ways in which the National Care Service could be funded in the future:

- **Partnership** – People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.
- **Insurance** – As well as providing a quarter to a third of the cost of people's care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.
- **Comprehensive** – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.

(a) Which of these options do you prefer, and why?

(b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

The easy-read question is on the next page.



Shaping the Future of Care Together Tell us what you think

Easy-read words

The government thinks there are 3 ways the **care and support** system could be paid for in the future.

- **Partnership.** Costs are shared so that everyone pays a bit. People who need care must pay some of the costs themselves if they can afford it.
- **Insurance.** Costs are shared so everyone pays a bit. If they want to, people can buy **insurance** to pay their share of the cost of **care and support** if they need it in the future.
- **Comprehensive.** Costs are shared by everyone. This means everyone pays into the system whether or not they need care. In return, everyone gets their **care and support** services free if they need them in the future.

Which system do you think is best, and why you think so?

Should decisions about how much money people get be made locally or by the government?

Tell us what you think

.....

.....

.....

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.....

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You can write more on the next page if you need to.

APPENDIX G: STRAND 9 – QUESTIONNAIRE IN SAGA MAGAZINE

Question wording

HAVE YOUR SAY AND JOIN THE BIG
CARE DEBATE

Question 1

The Government believes that everyone in England should be able to expect a system that:

- helps you to stay well and independent for as long as possible
- assesses your care and support needs in the same way in every region
- has care and support services working together smoothly
- provides you with clear information and advice
- offers services that are designed and delivered around your needs
- spends taxpayers' money wisely and fairly.

Is there anything missing from this?

Question 2

Do you think a wider range of better joined-up and high-quality services will improve the care and support system?

☐ Yes

☐ No

Question 3

Care and support is not free, it can cost as much as £200k per person. Shaping the Future of Care Together suggests three possible ways of finding the money for the new National Care Service.

Tick the box beside the one you prefer:

1. **Partnership** The government covers some care costs, more if you have a low income.
2. **Insurance** The government covers some care costs and helps you take out insurance for the rest.
3. **Comprehensive** Everyone pays into a state insurance scheme, which covers all costs.

Question 4

Should local government say how much money people get depending on the situation in their area, or should national government decide?

Part national, part local

Fully national

APPENDIX H: STRAND 9 – QUESTIONNAIRE IN *TAKE A BREAK* MAGAZINE

Question wording

QUESTION 1

The Government believes that everyone in England should be able to expect a system that:

Please tick one:

- ☐ Helps you to stay well and independent for as long as possible
- ☐ Assesses your care and support needs in the same way in every region
- ☐ Has care and support services working together smoothly
- ☐ Provides you with clear information and advice
- ☐ Offers services that are designed and delivered around your needs
- ☐ Spends taxpayers' money wisely and fairly.

QUESTION 2

Do you think a wider range of better joined-up and high-quality services will improve the care and support system?

- ☐ Yes ☐ No

QUESTION 3

Care and support is not free, it can cost as much as £200k per person. *Shaping the Future of Care Together* suggests three possible ways of finding the money for the new National Care Service.

Tick the box beside the one you prefer:

☐ PARTNERSHIP

The government covers some care costs, more if you have a low income

☐ INSURANCE

The government covers some care costs and helps you take out insurance for the rest

☐ COMPREHENSIVE

Everyone pays into a state insurance scheme, which covers all costs.

QUESTION 4

Should local government say how much money people get depending on the situation in their area, or should national government decide?

- ☐ Part national, part local
- ☐ Fully national

APPENDIX I: STRAND 12 – REGIONAL STAKEHOLDER EVENTS

Total attendance by region

Four events per region unless stated otherwise

Date	Region	Location	Attendees
23–25 July 2009	South East (3 events)	Reading/Tonbridge	82
30 July–1 August 2009	West Midlands	Telford/Birmingham	126
3–5 September 2009	North East	Darlington/Newcastle	175
10–12 September 2009	East Midlands	Nottingham/Leicester	155
17–19 September 2009	North West	Carlisle/Manchester	216
24–26 September 2009	East of England	Peterborough/Norwich	164
1–3 October 2009	Yorks & Humber	Hull/Leeds	160
8–10 October 2009	South West	Exeter/Bournemouth	205
15–17 October 2009	London	London	179
03 November 2009	Brighton (1 event)	Brighton	38
04 November 2009	London (1 event)	London	40
		TOTAL	1540

APPENDIX J: STRAND 13 – STAKEHOLDER TOOLKIT AND FEEDBACK FORM



**Care
Support
Independence**



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Big Care Debate**

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DH INFORMATION READER BOX

Policy	Estates
HR/Workforce	Commissioning
Management	IM & T
Planning	Finance
Clinical	Social Care / Partnership Working

Document Purpose	Consultation/Discussion
Gateway Reference	12426
Title	Running your own Big Care Debate
Author	HM Government
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Superseded Docs	
Action Required	N/A
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For Recipient's Use	

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Part 1 Introduction

The Government's new Green Paper **Shaping the Future of Care Together** sets out a vision for a **National Care Service for all adults in England** – a service that is fair, simple and affordable for everyone, underpinned by national rights and entitlements and personalised to individual needs. It asks for your views on some difficult choices that we need to make for this vision to become a reality. The proposals in the Green Paper constitute some of the most fundamental reforms ever in this area.

Why do we need a debate?

We are an ageing society. For the first time ever there are more people over the age of 65 than there are under the age of 18. Life expectancy is going up and advances in medical science mean that people with a disability are living longer. This is worth celebrating but it does mean we need to radically change the way care and support is provided and paid for. The current system has its basis in the 1940s and there have been huge social changes in terms of what we value and what we want from public services. People now want more independence, choice and control, and we need to reflect these demands.

As a society we will have to spend more on care and support in the future. One of the most important issues we want your views on is what is fair to ask people to pay for themselves, and how we protect people from having to pay a huge bill if they need long-term residential care.

The process

The Green Paper has been informed by a six-month engagement process, which took place in 2008 in which thousands of people were asked about their views on the challenges that we face for the future and the problems with the current system.

Why this debate matters to you

Everyone will be affected by the proposed changes: stakeholders, people who care for friends and family, people who use the care and support system and all of us who pay for care and support services through taxes.

With your help we can raise awareness of the Green Paper, promote the Big Care Debate and get the views and opinions of as many people as possible.

This is your opportunity to take part and shape the future of the care and support system for all adults in England.

Running your own Big Care Debate

Organisers' guide

... help shape the **future of
care and support** together

Part 2 Running your own Big Care Debate

We'd like you to hold a Big Care Debate within your organisation, then feed back your group's conclusions to us. We've included some guidance below on how to use this document to assist you in running a debate. Copies of all the materials listed in sections (a) and (c) below can be downloaded online at www.careandsupport.direct.gov.uk.

a) How to set up your own Big Care Debate

Set up a group to debate the big questions

Promote the fact that you are holding your own Big Care Debate using the A3 posters and/or the invitation template provided.

Use this guide to help organise your debate on the day

On the day, use Parts 2d and 3 of this guide to help you organise discussions and stimulate debate around the key questions.

Send us your feedback

We've included a feedback form (Part 4) for you to set out the views from your debate. Please complete this form during your debate and make sure it is sent to the Department of Health by **13 November 2009**. **Important: please do not attribute feedback on the form to specific individuals.**

b) The questions for your own Big Care Debate

When you are discussing **Shaping the Future of Care Together** at your Big Care Debate there are a series of questions the Government would like you to feed back on. These are summarised below.

When answering the consultation questions you may want to consider any impact our proposals may have on race, disability, gender, sexual orientation, religion, belief or age equality for you or your service users.

Topic 1 for discussion: The Government's vision for the future

The Government wants to build a National Care Service that is fair, simple and affordable. The Government thinks that in this new system there are six things that you should be able to expect:

- **Prevention services:** you will receive the right support to help you stay independent and well for as long as possible and to stop your care and support needs getting worse.

Running your own Big Care Debate

- **National assessment:** wherever you are in England, you will have the right to have your care and support needs assessed in the same way. And you will have the right to have the same proportion of your care and support costs paid for wherever you live.
- **A joined-up service:** all the services you need will work together smoothly, particularly when your needs are assessed.
- **Information and advice:** you can understand and find your way through the care and support system easily.
- **Personalised care and support:** the services you use will be based on your personal circumstances and need.
- **Fair funding:** your money will be spent wisely and everyone who qualifies for care and support from the state will get some help meeting the cost of their care and support needs.

Consultation questions

- Is there anything missing from this approach?
- How should this work?

Topic 2 for discussion: Making the vision a reality

The Government thinks that in order to make the vision of a National Care Service a reality, there are three key changes we will need to make to the care and support system. We need:

- **more joined-up working** between health, housing and social care services and between social care and the disability benefits system
- **a wider range of care and support services** so that people have a greater range of services to choose from
- **better quality and innovation.** Staff must have the right training and skills, and services should be based on the best and most recent information about what works well in providing care.

Consultation questions

- Do you agree?
- What would this look like in practice?
- What are the barriers to making this happen?

Topic 3 for discussion: Funding options

The Government is suggesting three ways in which the National Care Service could be funded in the future:

- **Partnership:** the responsibility for paying for care and support would be shared between the Government and the person who has care needs. The Government would provide between a quarter and a third of the cost of care and support, with more for people on a low income. Today's 65-year-olds will need care and support costing on average £30,000.

The Partnership system would work for adults of all ages. Under this system we expect many people born with a care and support need to qualify for free care, as they do under the current system. Those working-age adults who do not qualify for free care (those who are better off) would have the same offer around funding as people over 65.

- **Insurance:** the same as Partnership, but the Government would help people prepare to meet the costs that they have to pay for themselves through an insurance-based approach. As well as providing between a quarter and a third of the cost of care and support, the Government would make it easier for people to take out insurance to cover care and support costs. It is estimated that the cost of insurance would be around £20,000 to £25,000.

The Insurance part of the second option would be likely to be less relevant to people who have been born with a care and support need, since people cannot insure against the risk of something that has already happened. However, many people born with a care and support need are likely to qualify for free care under the Partnership element of the system.

- **Comprehensive:** everyone over retirement age who could afford it would pay into a state insurance scheme, meaning that everyone who needs care and support would receive it free. It is estimated that the cost of being in the system would be between £17,000 and £20,000.

The Comprehensive system would be for people over retirement age, but we would also look at having a free care and support system for people of working age alongside this.

People with disabilities

At the moment, people who are disabled when they are born, or who become disabled during their working lives, are likely to have lower incomes and so will struggle to meet the cost of their care and support. In the future, more disabled people will be working, but those who are on low incomes will have their care and support funded by the state.

A nationally or locally determined funding scheme?

The Government is also seeking your views on whether the funding scheme should be determined at a national or local level.

The Government believes that the care and support system should be fair and universal. This means that everyone who needs care and support will receive it, regardless of where they live. But we also need to ensure that the system is flexible enough to respond to local circumstances and encourage innovative approaches. There are two different approaches to how the system could work:

- a part-national, part-local system – local authorities decide how much is to be spent on care and support, or
- a fully national system – government decides how much is to be spent on care and support.

These two approaches have different implications for the way money is raised and distributed around England.

Consultation questions

- a) Which of these options do you prefer, and why?
- b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

c) Materials you can use to stimulate the debate

1. A3 poster

Use this to promote your debate to your members/associates, and raise the profile of the Big Care Debate.

2. Film

The film talks about why the Big Care Debate is important. It may help to stimulate debate and provides a valuable context for the discussions. We recommend that you use this where possible.

3. Guide for people attending your Big Care Debate

The questions for debate are printed on A4 pages for distribution to your participants.

4. Feedback form to fill in to tell us your views

Record your conclusions to each of the questions on this form. The form should also include the names of the participants.

Important: please do not attribute feedback on the form to specific individuals.

Need more copies?

- Visit www.careandsupport.direct.gov.uk to download the materials which include
 - a step-by-step guide to running your own Big Care Debate
 - guide for people attending your Big Care Debate
 - feedback form
 - A3 poster to advertise your debate
 - invitation template for you to use to invite people to your Big Care Debate
 - a film which explains the issues under discussion in the Big Care Debate
 - the full Green Paper, **Shaping the Future of Care Together**.
- Or visit www.orderline.dh.gov.uk
- Or telephone 0300 123 1002, or fax 01623 724 524.

d) A step-by-step guide to running your Big Care Debate

Step 1 When you've got your group together you might find it a good idea to set the scene for the debate and share some background facts.

The facts: Why we need to change

- **Increased life expectancy:** when the current system was designed in the 1940s, life expectancy was 66 for men and 71 for women. Today it is 77 for men and 82 for women.
- **We are an ageing society:** there are now more people over the age of 65 than under the age of 18.
- **People are living longer with disabilities:** life expectancy for people with Down's syndrome has almost doubled in recent years.
- **The demand for services is increasing:** by 2026, we expect over 1.7 million more adults to have a need for care and support. This is at least double the number of people who received care and support last year.
- **Economic impact:** there are currently around four people of working age for every retired person. By 2059, this ratio will almost halve.
- **Social change and rising expectations:** there have been huge social changes in terms of what we value and what we want from public services. People want more independence, choice and control and our system needs to reflect these demands.

Need more information? The Green Paper explains these points in more detail.

Step 2 Hand out the guide for people attending the Big Care Debate. This is Part 3 of this guide and is also available to download online from: www.careandsupport.direct.gov.uk.

Step 3 Using the participants' guide, begin discussing Topic 1: The Government's vision for the future.

- Step 4** Record the group's responses to Topic 1: The Government's vision for the future on the feedback form, specifically the consultation questions:
- a) Is there anything missing from this approach?
 - b) How should this work?
- Step 5** Using the participants' guide, begin discussing Topic 2: Making the vision a reality.
- Step 6** Record the group's responses to Topic 2: Making the vision a reality on the feedback form, specifically the consultation questions:
- a) Do you agree?
 - b) What would this look like in practice?
 - c) What are the barriers to making this happen?
- Step 7** Using the participants' guide, begin discussing Topic 3: Funding options.
- Step 8** Record the group's responses to Topic 3: Funding options on the feedback form, specifically the consultation questions:
- a) Which of these options do you prefer, and why?
 - b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

Running your own Big Care Debate

Participants' guide

... help shape the **future of
care and support** together

Part 3 Guide for people attending your Big Care Debate

Hand this out to the people who attend your Big Care Debate. It will give them the background to the consultation, and some guidance notes on each of the consultation topics. It will also give them space to jot down their own thoughts as you debate the issues. More copies are available to download online at: www.careandsupport.direct.gov.uk.

Introduction

The Government's new Green Paper **Shaping the Future of Care Together** sets out a vision for a **National Care Service for all adults in England** – a service that is fair, simple and affordable for everyone, underpinned by national rights and entitlements and personalised to individual needs. It asks for your views on some difficult choices that we need to make for this vision to become a reality. The proposals in the Green Paper constitute some of the most fundamental reforms ever in this area.

Why do we need a debate?

We are an ageing society. For the first time ever there are more people over the age of 65 than there are under the age of 18. Life expectancy is going up and advances in medical science mean that people with a disability are living longer. This is worth celebrating but it does mean we need to radically change the way care and support is provided and paid for. The current system has its basis in the 1940s and there have been huge social changes in terms of what we value and what we want from public services. People now want more independence, choice and control, and we need to reflect these demands.

As a society we will have to spend more on care and support in the future. One of the most important issues we want your views on is what is fair to ask people to pay for themselves, and how we protect people from having to pay a huge bill if they need long-term residential care.

The process

The Green Paper has been informed by a six-month engagement process, which took place in 2008 in which thousands of people were asked about their views on the challenges that we face for the future and the problems with the current system.

Why this debate matters to you

Everyone will be affected by the proposed changes: stakeholders, people who care for friends and family, people who use the care and support system and all of us who pay for care and support services through taxes.

With your help we can raise awareness of the Green Paper, promote the Big Care Debate and get the views and opinions of as many people as possible.

This is your opportunity to take part and shape the future of the care and support system for all adults in England.

Topic 1 for discussion: The Government's vision for the future

The Government wants to build a National Care Service that is fair, simple and affordable. The Government thinks that in this new system there are six things that you should be able to expect:

- **Prevention services**

You will receive the right support to help you stay independent and well for as long as possible and to stop your care and support needs getting worse.

- **National assessment**

Wherever you live in England, you will have the right to have your care needs assessed in the same way. And you will have a right to have the same proportion of your costs paid for wherever you live in England.

- **A joined-up service**

All the services you need will work together smoothly, particularly when your needs are assessed. You will only have to have one assessment of your needs to access a whole range of care and support services.

- **Information and advice**

If you need care and support, or you are preparing for it, you will find it easy to get information about who can help you, what care and support you can expect, and how quickly you can get it.

- **Personalised care and support**

Your care and support will be designed and delivered around your individual needs. As part of your care and support plan, you will have much greater choice about how and where you receive support, and the possibility of controlling your own budget wherever appropriate.

- **Fair funding**

Everyone who qualifies for care and support from the state will get some help towards meeting the cost of their care and support needs. Your money will be spent wisely to fund a care and support system that is fair and sustainable.

For the consultation questions, and a space to jot down your thoughts, please turn over.

Running your own Big Care Debate

Topic 1: Consultation questions:

a) Is there anything missing from this approach?

b) How should this work?

Topic 2 for discussion: Making the vision a reality

The Government thinks that, in order to make the vision of a National Care Service a reality, there are three key changes we will need to make to the care and support system. We need:

- **More joined-up working**

We need services that will keep people independent and well for longer. They should also help people with ongoing care and support needs to stay at home, if this is what they want, and maintain their independence. One way of doing this is through better joined-up working between health, housing and social care services and between the care and benefits systems.

- **A wider range of care and support services**

As people begin to have greater choice over the care and support they receive, they will need to have a range of services to choose from. The Government believes local authorities are best placed to manage this. We need to help local authorities make sure that the services and ways of working in their area support innovative and high-quality care and support.

- **Better quality and innovation**

Everyone who uses care and support services has a right to expect high-quality services and to be treated with respect and dignity. There are many ways of improving quality, but the most vital is through the people who deliver the services. Staff must have the right training and skills to provide the care and support that people want. We also need to make sure that the services that are available are based on the best and most recent information about what works in providing care and support. We think that we should have an independent body to provide advice on what works best in care and support.

For the consultation questions, and a space to jot down your thoughts, please turn over.

Running your own Big Care Debate

Topic 2: Consultation questions:

a) Do you agree?

b) What would this look like in practice?

c) What are the barriers to making this happen?

Topic 3 for discussion: Funding options

We will achieve this vision by making better use of taxpayers' money so funding is focused on people who can benefit from it and need it most. But the money in the system at the moment won't pay for all of everyone's care in the future.

In deciding how to fund care and support, there are some very difficult decisions to make.

The current system

In the current system, people who have the highest needs and lowest means get some help through the social care system, and some people get help through disability benefits. But many people, including some with high needs, get no help at all with paying for care. Twenty per cent of people will need care that costs less than £1,000 – but 20 per cent will need care that costs more than £50,000. And someone who is in a care home for years could have costs of more than £100,000. If someone is in a care home and their house is empty, they are expected to use their savings and the value of their house to pay for care and accommodation, until they have used up almost all their money.

The future funding options

The Government is suggesting three ways in which care and support could be funded in the future.

It is important to note that these options consider only the cost of people's care and support. People entering a care home would also have to pay for their accommodation costs, such as the costs of food and lodging. This is because the state would not pay for people to buy their food or pay their mortgage or rent if they were living at home. Of course, the state would always have a role in supporting people who are in a care home who cannot afford these costs.

- **Partnership**

The responsibility for paying for care would be shared between the Government and the person who has care and support needs. The Government provides between a quarter and a third of the cost of care and support, more for people on a low income. Today's 65-year-olds will need care and support costing on average £30,000.

The Partnership system would work for adults of all ages. Under this system we expect many people born with a care and support need to qualify for free care, as they do under the current system. Those working-age adults who do not qualify for free care (those who are better off) would have the same offer around funding as people over 65.

Running your own Big Care Debate

- Everyone who qualified for care and support would be entitled to have a set proportion – for example, between a quarter and a third – of their basic care and support costs paid for by the state.
- People who were less well off would have more care paid for.
- The least well off people would continue to get all their care free.
- This system would work for people of all ages.

An **advantage** of the Partnership option is that people only have to pay for their own care and support costs, and if they don't develop a care need they don't have to pay anything (beyond the contribution that they have already made through general taxation).

A **disadvantage** is that people who have really high care and support costs and own their own homes or have savings might still have to pay very high contributions.

- **Insurance**

This option is the same as the Partnership option but the Government could help people prepare to meet the costs that they would have to pay for themselves, through an insurance-based approach. As well as providing between a quarter and a third of the cost of care and support, the Government would make it easier for people to take out insurance to cover care and support costs. It is estimated that the cost of insurance could be around £20,000 to £25,000.

The Insurance part of the second option would be likely to be less relevant to people who have been born with a care and support need, since people cannot insure against the risk of something that has already happened. However, many people born with a care and support need are likely to qualify for free care under the Partnership element of the system.

- Like the Partnership model, everyone would be entitled to have a share of their care and support costs met.
- This system would go further to help people cover the additional costs of their care and support through insurance, if they wanted to.
- The state could play different roles to enable this – it could work more closely with the private insurance market or the state could create its own insurance scheme.
- If people decided to pay into the scheme, they would get all their basic care and support free if they needed it.
- People could pay in several different ways.
- This system would work for people over retirement age.

An **advantage** of the Insurance option is that people would have a choice and flexibility over whether they wanted to insure themselves.

A **disadvantage** is that people who chose not to take out insurance would still face the risk of potentially high costs later on in life. If they needed residential care, they would be likely to have to use their savings or their assets to pay for care and support.

- **Comprehensive**

Everyone over retirement age who could afford it would pay into a state insurance scheme, meaning that everyone who needs care and support would receive it free. It is estimated that the cost of being in the Insurance system could be between £17,000 and £20,000.

The Comprehensive system would be for people over retirement age, but we would also look at having a free care and support system for people of working age alongside this.

- Everyone over retirement age would be required to pay into a state insurance scheme if they had the resources to do so.
- Everyone whose needs meant that they qualified for care and support would get all of their basic care and support for free when they needed it.
- It would be possible to vary how much people had to pay according to what they could afford. The size of people's contribution could be set according to what savings or assets they had, so that the system would be more affordable for people who are less well off.
- Alternatively, people could pay a single, set figure, so that they would know how much they would have to save.
- People could pay in several different ways.
- The Government will also look at having a free care system for people of working age alongside this.

An **advantage** of this Comprehensive option is that once people had paid their contribution they would know that they would receive the care and support they needed.

A **disadvantage** of the system would be that everyone would have to pay in, whether or not they actually needed care and support themselves.

Ways to contribute

In the long term, we could have a system that would enable people who are still working to make regular contributions so that they could save up and pay their contributions to the Insurance or Comprehensive system by the time they had retired. In the short term, we could have a menu of different ways in which people could choose to contribute – for example, by a lump sum on retirement, by deferring their state pension, by paying in instalments throughout retirement, by paying out of their estate (defer until death) or a mixture of these options.

Why not a tax-funded system?

The Government has ruled out a system based on tax funding because it would put a large burden of paying for care on people who are working. Given demographic changes, there will be increasing pressure on a shrinking proportion of working-age people. In 2007, the number of people aged over 65 became greater than the number of people under 18 for the first time. Because the majority of people benefiting from a reformed care and support system will be pensioners, it is fairer to think about more targeted ways of bringing in extra funding, rather than placing the burden of the system on people of working age.

A nationally or locally determined funding system?

The Government is also seeking your views on whether the funding system should be determined at a national or local level.

The Government believes that the care and support system should be fair and universal. This means that everyone who needs care and support will receive it, regardless of where they live. But we also need to ensure that the system is flexible enough to respond to local circumstances and encourage innovative approaches. There are two different approaches to how the system could work:

- a part-national, part-local system – local authorities decide how much is to be spent on care and support, or
- a fully national system – government decides how much is to be spent on care and support.

These two approaches have different implications for the way money is raised and distributed around England.

For the consultation questions, and a space to jot down your thoughts, please see opposite.

Topic 3: Consultation questions:

a) Which of these options do you prefer, and why?

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

Running your own Big Care Debate

Feedback form

... help shape the **future of
care and support** together

Part 4 Feedback form

Thank you for contributing to the Big Care Debate and responding to the consultation questions in the Green Paper **Shaping the Future of Care Together**.

Please use this form to record your group's conclusions to each of the questions. This form should be used in conjunction with stimulus material, which includes more detail about each of the questions.

Please complete only **one** feedback form for each group debate. Make a note of answers where there was agreement in the group, and where there were differences. Do add pages if you need more space.

This form should also include the names of the participants. **Important: please do not attribute feedback on the form to specific individuals.**

Once completed, please return this document by 13 November 2009:

- **via email to** careandsupport@dh.gsi.gov.uk
- **or by post to** Care and Support Team, Room 149, Richmond House, 79 Whitehall, London SW1A 2NS

Organiser contact details:

Name _____

Organisation _____

Address _____

Email _____

Telephone _____

About your debate:

When was the discussion held? _____

How many people took part? _____

What groups of people took part (e.g. care workers, disabled people, staff) _____

Please list the names of people who took part _____

Confidentiality of information

Please be aware that under the Freedom of Information Act 2000, we may be asked to share the information we receive as part of this consultation. If you would like your response to remain confidential, it would be helpful if you could explain why. If we receive a request to disclose the information, we will take full account of your explanation but we cannot guarantee that confidentiality can be maintained in all circumstances. Your name, address and any other personal data as defined under the Data Protection Act is exempt from disclosure.

Running your own Big Care Debate

Topic 1: The Government's vision for the future

The Government wants build a National Care Service that is fair, simple and affordable. The Government thinks that in this new system there are six things that you should be able to expect:

- prevention services
- national assessment
- a joined-up service
- information and advice
- personalised care and support
- fair funding

a) Is there anything missing from this approach?

b) How should this work?

Topic 2: Making the vision a reality

The Government thinks that, in order to make the vision of a National Care Service a reality, there are three key changes we need to make to the care and support system. We need services which are joined up, a wider range of care and support services and better quality and innovation.

a) Do you agree?

b) What would this look like in practice?

c) What are the barriers to making this happen?

Running your own Big Care Debate

Topic 3: Funding options

The Government is suggesting three ways in which care and support could be funded in the future:

- **Partnership:** People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.
- **Insurance:** As well as providing a quarter to a third of the costs of people's care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.
- **Comprehensive:** Everyone gets care and support free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.

a) Which of these options do you prefer, and why?

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

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Fax: 01623 724 524
Minicom: 0300 123 1003 (8am to 6pm, Monday to Friday)
www.dh.gov.uk/publications

APPENDIX K: STRAND 14 – SHORT QUESTIONNAIRE ON HANDHELD PDA DEVICE



1. We want to build a fair, simple and affordable National Care Service. It should help you to stay well and independent, assess your needs in the same way in every region, have services working together smoothly, be easy to understand, offer you care and support designed around your needs, and spend money wisely.

Click Next for answer fields

Reset	Next	Previous	Next

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Is there anything missing from this?

☒ Yes ☐ No

If 'Yes' please give details

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2. Do you think a wider range of better joined-up and high-quality services will improve the care and support system?

☒ Yes ☐ No

If no, what else do you think is needed?

123	1	2	3	4	5	6	7	8	9	0	-	=	←
Tab	q	w	e	r	t	y	u	i	o	p	[	]	
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3. We want to build a fair, simple and affordable National Care Service.
How should a new system be funded?

- ☐ Partnership: The Government covers some care and support costs, more if you have a low income.
- ☒ Insurance: The Government covers some care and support costs, and helps you take out insurance for the rest, if you want it.
- ☐ Comprehensive: Everyone pays into a state insurance scheme, which covers everybody's costs.

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About you

We'd like to ask you some questions about yourself to help us understand and analyse responses in a more effective manner.

What gender are you?

- ☒ Male ☐ Female

What age range do you fall into?

- ☐ Under 18 ☐ 18-24yrs
- ☒ 25-34yrs ☐ 35-44yrs
- ☐ 45-64yrs ☐ 65-79yrs
- ☐ 80yrs+

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Should local government say how much money people get depending on the situation in their area, or should national government decide?

- ☐ Part national, part local
- ☒ Fully national

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What region do you live in?

- ☐ London
- ☐ South East
- ☒ East of England
- ☐ South West
- ☐ East Midlands
- ☐ West Midlands
- ☐ North East
- ☐ North West
- ☐ Yorkshire and Humberside

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What is your marital status?

- ☒ Single
☐ Married/live as married/civil partnership
☐ Divorced/separated/widowed

What is your current working status?

- ☒ In Work ☐ Unemployed
☐ Retired ☐ Student

Do you have any children in your household?

- ☐ Yes ☒ No

Do you own your home?

- ☐ Yes ☒ No

Do you act as a carer for a family member or friend?

- ☐ Yes ☒ No

Do you receive care and support?

- ☐ Yes ☒ No

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Which ethnic group do you belong to? (optional)

British - White

Find out more at
www.careandsupport.direct.gov.uk

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Menu

Which ethnic group do you belong to? (optional)

British - White

Find out more at
www.careandsupport.direct.gov.uk



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Submit

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APPENDIX L: STRAND 15 – SHORT QUESTIONNAIRE ON TOUCH SCREEN



Join the **big**

care

debate

...help shape the **future of care** together

www.careandsupport.direct.gov.uk

[Click to start short questionnaire](#)

[Click to start long questionnaire](#)



Care
Support
Independence

What is care and support?

Care and support helps people do everyday things like living in their own homes, working, shopping and caring for their family.

It includes:

- benefits for disabled people
- occupational therapy
- day care
- care homes
- support for carers
- housing support services.

Public, private and charitable organisations provide care and support, as well as friends, family and community

The main users are:

- people who have a long-term illness
- disabled people
- older people.

It is paid for by individuals and a mixture of general and local taxes.

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Care
Support
Independence

Why do we need change?

Society is changing

- People are living longer and we know there will be more people with care and support needs in the future.
- The number of people of retirement age is growing much faster than the number of people working.

Expectations are higher

- People want care and support that is designed around their needs.
- People want a greater say in the care and support they receive.

Problems in the current system

- The system is too complicated.
- The system does not always give value for money.
- Levels of care and support are different in different parts of the country.

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A National Care Service

The Government wants to create a National Care Service that is fair, simple and affordable for all adults in England.

We think everyone should be able to expect a system that:

- helps you to stay well and independent for as long as possible
- assesses your care and support needs in the same way in every region
- has care and support services working together smoothly
- provides you with clear information and advice
- offers services that are designed and delivered around your needs
- spends taxpayers' money wisely and fairly.

The main users are:

- joined-up services
- a wider range of services
- high-quality services that are based on evidence of what works.

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The funding question

The Government has published *Shaping the Future of Care Together*, a public consultation document or Green Paper, which spells out the options for reform. It asks which options you think would best deliver the new National Care Service, and how you think it should be funded.

The Green Paper suggests three ways of funding the National Care Service:

Partnership

The Government covers some care and support costs, more if you have a low income.

Insurance

The Government covers some care and support costs, and helps you take out insurance for the rest, if you want it.

Comprehensive

Everyone pays into a state insurance scheme, which covers everybody's care costs.

We also need to decide if local authorities or central Government determine how much funding people will receive.

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The Debate Questions

1. We want to build a fair, simple and affordable National Care Service. It should help you to stay well and independent, assess your needs in the same way in every region, have services working together smoothly, be easy to understand, offer you care and support designed around your needs, and spend money wisely.

Is there anything missing from this list?

Test...

2. Do you think a wider range of better joined-up and high-quality services will improve the care and support system?

☐ Yes
 ☐ No

If no, what else do you think is needed?

Test...

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The Debate Questions

3. We want to build a fair, simple and affordable National Care Service.

How should a new system be funded?

☐ Partnership: The Government covers some care and support costs, more if you have a low income.
☐ Insurance: The Government covers some care and support costs, and helps you take out insurance for the rest, if you want it.
☒ Comprehensive: Everyone pays into a state insurance scheme, which covers everybody's care costs.

Should local government say how much money people get depending on the situation in their area, or should national government decide?

☐ Part national, part local
☒ Fully national

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About you

Please provide us with some information about yourself. This will help us to determine whether we have captured the views of everyone. All the information you provide will be kept completely confidential. No identifiable information about you will be passed to on to any other bodies, members of the public or press.

What is your sex?

- ☒ Male ☐ Female

Which age group do you belong to?

- ☐ Under 18 ☐ 18 – 24 ☒ 25 – 34 ☐ 35 – 44
☐ 45 – 54 ☐ 55 – 64 ☐ 65 – 79 ☐ 80 yrs and over

What region do you live in?

- ☐ London ☐ South East ☐ East Midlands ☐ South West ☒ East of England
☐ West Midlands ☐ North East ☐ North West ☐ Yorkshire and Humberside

What is your marital status?

- ☐ Single ☐ Married/living as married/civil partner
☐ Divorced/separated/widowed

What is your current working status?

- ☐ In work ☐ Unemployed ☐ Retired ☐ Student

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About you

We'd like to ask you some questions about you to help us understand and analyse responses in a more effective manner.

Do you have any children in your household?

- ☐ Yes ☒ No

Do you own your home?

- ☐ Yes ☒ No

Do you act as a carer for a family member or friend?

- ☐ Yes ☒ No

Do you receive care and support?

- ☐ Yes ☒ No

Which ethnic group do you belong to?

British

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Finish

APPENDIX M: STRAND 16 – LONG QUESTIONNAIRE ON TOUCH SCREEN



Join the Big Care Debate and help shape the future of care and support

The Government's new Green Paper **Shaping the Future of Care Together** sets out a vision for a **National Care Service for all adults in England**. A service that is fair, simple and affordable for everyone, underpinned by national rights and entitlements and personalised to individual needs. It asks for your views on some difficult choices that we need to make for this vision to become a reality. The proposals in this Green Paper are some of the most fundamental reforms ever in this area.

Why do we need a debate

We are an ageing society. For the first time ever there are more people over the age of 65 than there are under the age of 18. Life expectancy is going up and advances in medical science mean that people with a disability are living longer. This is worth celebrating but it does mean we need to radically change the way care and support is provided and paid for. The current system has its basis in the 1940s and there have been huge social changes in terms of what we value and what we want from public services. People now want more independence, choice and control, and we need to reflect these demands.

As a society we will have to spend more on care and support in the future. One of the most important issues we want your views on is what is fair to ask people to pay for themselves, and how we protect people from having to pay a huge bill if they need long-term residential care.

The process

The Green Paper has been informed by a six-month engagement process that took place in 2008 in which thousands of people were asked about their views on the challenges that we face for the future and the problems with the current system.

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The debate questions

We'd like you to answer as many of these as you can, but don't worry if there are some you don't have a view on, just leave them out.

When answering these questions you may want to consider any impact our proposals may have on race, disability, gender, sexual orientation, religion, belief or age equality for you or your service users.

1 The vision for the future

We have suggested six key things that everyone should expect from a National Care Service and we want your

- **Prevention services** You will receive the right support to help you stay independent and well for as long as possible and to stop your care and support needs getting worse.
- **National Assessment** Wherever you live in England, you will have the right to have your care and support needs assessed in the same way and you will have a right to have the same proportion of your costs paid for.
- **A joined-up service** All the services you need will work together smoothly, particularly when your needs are assessed. You will only need to have one assessment of your needs to access a whole range of care and support services.
- **Information and advice** If you need care and support, or you are preparing for it, you will find it easy to get information about who can help you, what care and support you can expect, and how quickly you can get it.
- **Personalised care and support** Your care and support will be designed and delivered around your individual needs. As part of your care and support plan, you will have much greater choice over how and where you receive support, and the possibility of controlling your own budget wherever appropriate.
- **Fair Funding** Everyone who qualifies for care and support from the state will get some help meeting the cost of their care and support needs. Your money will be spent wisely to fund a care and support system that is fair and sustainable.

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HM Government

Care Support Independence

The Debate Questions

1a) Is there anything missing from this list?

Test...

1b) How should this work?

Test...

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HM Government

Care Support Independence

The Debate Questions

2 Making the vision a real

We think that to deliver this vision three main changes are required to the care and support system.

- **More joined-up working** between health, housing, social care and benefits systems.
- **A wider range of care and support services**, so people have a greater range of services to choose from.
- **Better quality and innovation**. Staff must have the right training and skills, and services are based on the best and most recent information about what works well in providing care.

2a) Do you agree?

Test...

2b) What would it look like in practice?

Test...

2c) What are the barriers to making this happen?

Test...

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The Debate Questions

3 Funding care and support in the future

We will achieve this vision by making better use of taxpayers' money so funding is focused on people who can benefit from it and need it most. But the money in the system at the moment won't pay for all of everyone's care in the future.

In deciding how to fund care and support, there are some very difficult decisions to make.

Funding Options

We have therefore proposed three options for funding a National Care Service.

(i) Partnership: The responsibility for paying for care and support would be shared between the Government and the person who has care and support needs. The Government provides between a quarter and a third of the cost of care and support, more for people on a low income. Today's 65-year-olds will need care and support costing on average £30,000.

The Partnership system would work for adults of all ages. Under this system we expect many people born with a care and support need to qualify for free care, as they do under the current system. Those working-age adults who do not qualify for free care (those who are better off) would have the same offer around funding as people over 65.

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The Debate Questions

(ii) Insurance: The same as Partnership but the Government could help people prepare to meet the costs that they would have to pay for themselves through an insurance-based approach. As well as providing people with between a third and a quarter of the cost of care and support, the Government would make it easier for people to take out insurance to cover care and support costs if they want it. It is estimated that the cost of insurance could be around £20,000 to £25,000.

The Insurance part of the second option would be likely to be less relevant to people who have been born with a care and support need, since people cannot insure against the risk of something that has already happened. However, many people born with a care and support need are likely to qualify for free care under the Partnership element of the system.

(iii) Comprehensive: Everyone over retirement age who can afford it would pay into a state insurance scheme, so that everyone who needs care and support will receive it free. It is estimated that the cost of being in the system could be between £17,000 and £20,000.

The Comprehensive system would be for people over retirement age, but we would also look at having a free care and support system for people of working age alongside this.

We have ruled out a system based on tax funding, because it would put a large burden of paying for care and support on people who are working. Given demographic changes, there will be an increasing pressure on a shrinking proportion of working-age people. In 2007, the number of people aged over 65 became greater than the number of people under 18 for the first time. Because the majority of people benefiting from a reformed care and support system will be pensioners, it is fairer to think about more targeted ways of bringing in extra funding, rather than placing a lot of the burden of the system on people of working age.

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The Debate Questions

Disabled people of working age

At the moment, people who are disabled when they are born, or who become disabled during their working lives, are likely to have lower incomes and so will struggle to meet the cost of their care and support. In the future, more disabled people will be working, but those who are on low incomes will have their care and support funded by the state.

What about accommodation costs?

It is important to note that these options consider only the cost of people's care and support. People entering a care home would have to pay for their accommodation costs, such as the costs of food and lodging. This is because the state would not pay for people to buy their food or pay their mortgage or rent if they were living at home.

Of course the state would always have a role in supporting people who were in a care home who were in a care home who could not afford these costs.

3a) Which of these options do you prefer

Test...

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The Debate Questions

A national or local system?

We believe that the care and support system should be fair and universal. But we also need to ensure that the system is flexible enough to respond to local circumstances and encourage innovative approaches. There could be two different approaches to how the system works – either a part-national, part-local system or a fully national system. The two approaches have different implications for the way money is raised and distributed around England.

3b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

Test...

If you want to learn more or run your own big care debate and tell us about it, there are some materials which can help you and you can download at www.careandsupport.direct.gov.uk

The big care debate lasts until 13 November 2009

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About you

Please provide us with some information about yourself. This will help us to determine whether we have captured the views of everyone. All the information you provide will be kept completely confidential. No identifiable information about you will be passed to on to any other bodies, members of the public or press.

What is your sex?

- ☐ Male ☐ Female

Which age group do you belong to?

- ☐ Under 18 ☐ 18 – 24 ☐ 25 – 34 ☐ 35 – 44
☐ 45 – 54 ☐ 55 – 64 ☐ 65 – 79 ☐ 80 yrs and over

What region do you live

- ☐ London ☐ South East ☐ East Midlands ☐ South West ☐ East of England
☐ West Midlands ☐ North East ☐ North West ☐ Yorkshire and Humberside

What is your marital status?

- ☐ Single ☐ Married/living as married/civil partner
☐ Divorced/separated/widowed

What is your current working status?

- ☐ In work ☐ Unemployed ☐ Retired ☐ Student

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About you

We'd like to ask you some questions about you to help us understand and analyse responses in a more effective manner.

Do you have any children in your household?

- ☐ Yes ☐ No

Do you own your home?

- ☐ Yes ☐ No

Which of the following descriptions best reflects your involvement in the care and support system at the moment?

- ☐ A member of the public with an interest in care and support issues
☐ Care user
☐ Informal carer
☐ Professional worker in the sector
☐ Representing individual carers and care users
☐ Representing other organisations supporting carers and care users
☐ Representing managers and professional workers in sector
☐ Representing individuals and organisations responsible for commissioning or delivering social care
☐ Academic/research organisation/think tank
☐ Government department/Agency/NDPB
☐ Other (Please specify) None

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About you

Which ethnic group do you belong to (optional)

White

☒ British
 ☐ Irish
 ☐ Any other White background, please write below

Mixed

☐ White and Black Caribbean
 ☐ White and Black African
 ☐ White and Asian
 ☐ Any other Mixed background, please write below

Asian or Asian British

☐ Indian
 ☐ Bangladeshi
 ☐ Pakistani
 ☐ Any other Asian background, please write below

Black or Black British

☐ Caribbean
 ☐ African
 ☐ Any other Black background, please write below

Chinese or Other Ethnic Group

☐ Chinese
 ☐ Any other, please write in below
 ☐ Refused

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About you

We'd like to ask you some questions about you to help us understand and analyse responses in a more effective

What is your religion or belief?

- ☐ Christian ☐ Buddhist ☐ Hindu
☐ Jewish ☐ Muslim ☐ Sikh
☐ Other, please write in below

Which of the following best describes your sexual orientation?

Only answer this question if you are aged 16 years or over.

- ☒ Heterosexual/Straight ☐ Lesbian/Gay ☐ Bisexual
☐ Other ☐ Prefer not to answer

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Find out more

Building a new system for care and support is not a simple task. It is vital we get the views of everybody affected, and that is why we're inviting and encouraging everyone to participate in the debate.

- ☒ If you are interested in receiving materials to help take this important debate forward, please tick this box and complete your details below.
☐ If you would like to receive further communications from the Department of Health on care and support, please tick this box and complete your details below.
☒ If you would like to receive further communications from the Department of Health on wider policy areas, please tick this box and complete your details below.

Title	MR
First Name	TRO
Surname	TEST
Email address	test@tro-group.co.uk
Telephone	0123456789
Postal address	TRO

The Department of Health will not share your details with any third parties.

Confidentiality of Information Please be aware that under the Freedom of Information Act 2000, we may be asked to share the information we receive as part of this consultation. If you would like your response to remain confidential, it would be helpful if you could explain why. If we receive a request to disclose the information, we will take full account of your explanation but we cannot guarantee that confidentiality can be maintained in all circumstances. Your name, address and any other personal data as defined under the Data Protection Act is exempt from disclosure.

Email: dh@prolog.uk.com
Tel: 0300 123 1002
Fax: 03023 774 524
Minicom: 0300 123 1003 (Open to 6pm Monday to Friday)

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APPENDIX N: SUPPLEMENTARY QUALITATIVE RESEARCH

The following research was conducted by Opinion Leader Research:

- 2 deliberative workshop events
- 14 extended group discussions
- 9 depth interviews.

Deliberative events

Two five-hour deliberative workshop events were conducted, each with 24 participants. One was held in Central London on 21 October 2009 and one in Sheffield on 23 October 2009.

The sample for each event was as follows:

- Not 'engaged' with care (i.e. little knowledge of current care and support system; not formally involved in current care and support system; not involved in 'The Big Care Debate')
- Informal carers (unpaid, no more than 20 hours/week)
- 12 x males, 12 x females
- Social classifications – 4 x AB, 10 x C1C2, 5 x D, 5 x E and socially excluded
- Mix of income levels
- 10 x 18–29, 10 x 30–59, 4 x 60 and over
- Mix of family and lifestages
- Spread of ethnicity to reflect the locality.

Health professionals, those working in the formal care industry and those working in market research, marketing, PR, national government and journalism were specifically excluded.

Group discussions

Fourteen extended group discussions, each lasting two and a half hours, were conducted as detailed in the table below.

Group	Audience	Location	Date
1	Bangladeshi men	Birmingham	15 October 2009
2	Bangladeshi women	Leeds	14 October 2009
3	Somali men	London	20 October 2009
4	Somali women	Birmingham	20 October 2009
5	Pakistani men	Leeds	14 October 2009
6	Pakistani women	Birmingham	15 October 2009
7	Caribbean men	London	20 October 2009
8	Caribbean women	London	20 October 2009
9	Ghanaian men	London	26 October 2009
10	Ghanaian women	Manchester	19 October 2009
11	Nigerian men	Birmingham	20 October 2009
12	Nigerian women	Birmingham	20 October 2009
13	Homosexual men	Manchester	15 October 2009
14	Homosexual women	London	14 October 2009

Depth interviews

Nine depth interviews, each lasting around one hour, were also conducted as shown below.

Depth	Audience	Location	Date
1	Muslim faith leader	London	26 October 2009
2	Muslim faith leader	Birmingham	26 October 2009
3	Sikh	Birmingham	26 October 2009
4	Rabbi	Hertfordshire	14 October 2009
5	Hindu	Birmingham	26 October 2009
6	Roman Catholic	Manchester	26 October 2009
7	Jehovah's Witness	Manchester	15 October 2009
8	Transgender man	Manchester	15 October 2009
9	Transgender man	London	15 October 2009

APPENDIX O: LIST OF STAKEHOLDER RESPONDENTS

National stakeholders

25% ME Group

Abbeyfield Society

ABDO, AOP, the College of Optometrists and FODO

ABI

Action for M.E.

ADASS

Adfam

Age Concern and Help the Aged

Allied Health Professions Federation

Alzheimer's Society

Anchor Trust

The Parliamentary & Health Service Ombudsman

Arthritis Care

Association for Real Change

Association of Directors of Public Health

Association of Directors of Social Work

Association of Disabled Professionals

Audit Commission

Barchester Healthcare

Blue Ribbon for the Awareness of Myalgic Encephalomyelitis

BME Elders Forum

Breast Cancer Care

British Association and College of Occupational Therapists

British Association of Social Workers

British Geriatrics Society

British Insurance Brokers' Association

British Lung Foundation

British Medical Association

British Society of Rehabilitation Medicine

Brittle Bone Society

Bupa Group

Care Quality Commission

Care UK

Careforce Group

Carer Watch

Carers UK

Centre for Policy on Ageing

Chartered Institute of Housing

Chartered Society of Physiotherapy

Child Poverty Action Group

Chill 4 Us

Church of England – Mission and Public Affairs Council

CIPFA

CIPFA CJC

Citizens Advice

Civil Service Pensioners' Alliance

Coalition for Quality in Care

Coalition on Charging

Commission for Rural Communities

Commission for the Compact

Community Support

Compassion in Dying

Consumer Focus
Contact a Family
Continuing Care Conference
Council for Disabled Children and the Transition Information Network
Council of Ethnic Minority Voluntary Sector Organisations
Counsel and Care
County Councils Network
CSPA
Cystic Fibrosis Trust
DeBRA
Department of Health (End of Life Care Team)
Diabetes UK
Dimensions
Disability Alliance
Disability Benefits Consortium
Disability Charities Consortium
Disability Law Service
Disabled Living Foundation
Down's Syndrome Association
Dystonia Society
English Community Care Association
Epilepsy Action
Equality 2025
Equality and Human Rights Commission
Foundations
fpa
General Social Care Council
GMB

Grace Consulting
Grandparents Plus
Green Party of England and Wales Regional Council
Hanover
Help the Hospices
Hempsons
Home Care 2 3 4
Homeless LINK
Housing 21
ILAG
Improving and Integrating Respiratory Services in the NHS
In Control Partnerships
Independent Age
Independent Living Funds
Inter Agency Group
Joint Committee on Mobility for Disabled People
Joint Epilepsy Council
Joint response from Leonard Cheshire Disability, Mencap and MS Society
Joint response from Leonard Cheshire Disability, MS Society, Mencap, National Centre for Independent Living, Counsel and Care, Disability Alliance, Motor Neurone Disease Association, Parkinson's Disease Society, Sue Ryder Care, In Control
Joint response from Mind, Rethink, the Mental Health Foundation and Sainsbury Centre for Mental Health
Joint response from National Centre for Independent Living and the Royal Association for Disability Rights

Joint response from The Royal National Institute of Blind People; Action for Blind People; The Guide Dogs for the Blind Association; The National Association of Local Societies for Visually Impaired People; Deafblind UK	National Association of Care Catering
Joseph Rowntree Foundation	National Association of Deafened People
KeyRing Living Support Networks	National Association of Laryngectomee Clubs
Leadership Group of the Employers for Carers	National Association of LINKs Members
Learning Disability Coalition	National Association of Welfare Rights Advisers
Legal & General	National Autistic Society
Leonard Cheshire Disability	National Care Association
Livability	National Care Forum
Lloyds Pharmacy	National Deaf Children's Society
Local Government Association	National Family Carer Network
Look Ahead Housing and Care	National Housing Federation
Macmillan Cancer Support	National Information Governance Board
ME Association	National Network for Volunteer Involving Agencies
Mencap	National Osteoporosis Society
Mental Health Foundation	National Pensioners Convention
Mentoring and Befriending Foundation	National Valuing Families Forum
Methodist Homes for the Aged	National Voices
Mind	NAVCA and Regional Voices
Motor Neurone Disease Association	NCB and National Voices
MS Society	NHS Confederation
MS Trust	Offender Health
Muscular Dystrophy Campaign	Older People's Advocacy Alliance
Myeloma UK	Older Prisoners Action Group
Nacro	Opportunity Links
NASS	Papworth Trust
NAT and George House Trust	Parkinson's Disease Society
National Association for Colitis and Crohn's Disease	Places For People
	PMLD Network
	Poverty Alliance
	Prudential

Public and Commercial Service Union
Race Equality Foundation
Registered Nursing Home Association
Relative Care
Relatives & Residents Association
Resolution Foundation
Rethink
Retirement Housing Group
RNID
Royal College of Nursing
Royal Pharmaceutical Society of Great Britain
Safe Home Income Plans
Saga Group
Sanctuary Group
Scope
Secular Medical Forum
Self Unlimited
Sense
Service Users' Networking Association Committee
Skill
Skills for Care
Social Care Association
Social Care Institute for Excellence
Society of County Treasurers
Society of Later Life Advisers
Southern Cross Healthcare
Spinal Injuries Association
Stonewall
Sue Ryder Care
Terrence Higgins Trust

ThCell
The Actuarial Profession
The Afiya Trust/National Black Carers & Carers Workers Network
The Association of Charity Officers
The British Association for Counselling and Psychotherapy
The Challenging Behaviour Foundation
The Children's Society
The Disabled Persons Liaison Committee
The Hyde Group
The King's Fund
The Law Society
The Leaders of Worship and Preachers Homes
The LIFT Council
The National Council for Palliative Care
The National Council of Women of Great Britain
The Princess Royal Trust for Carers and Crossroads Care
The Royal British Legion
The Salvation Army
The Society of Later Life Advisers
The Stroke Association
The Wheelchair Users Group
Tourettes Action
TreeHouse
TUC
Turning Point
UNISON
Unitarian Church Movement

Unite (The National Federation of Royal Mail and BT Pensioners)

Unite the Union

United Kingdom Disabled People's Council

United Kingdom Homecare Association

United Response

Values Into Action

Voluntary Organisations Disability Group

Volunteering England

Which?

WRVS

Local and other stakeholders

Adult Care and Support, Cornwall

Age Concern Blackburn with Darwen

Age Concern Brighton, Hove, Portslade

Age Concern Central Lancashire

Age Concern Cheshire

Age Concern Dacorum

Age Concern Dorchester

Age Concern East Sussex

Age Concern Haringey

Age Concern Lambeth

Age Concern Lewisham and Southwark

Age Concern Liverpool

Age Concern Newham

Age Concern North East

Age Concern North Staffordshire

Age Concern Norwich

Age Concern Oxfordshire

Age Concern Redbridge

Age Concern Sandwell

Age Concern Sheffield

Age Concern Shropshire Telford & Wrekin

Age Concern South Lakeland

Agewell Bromwich

Agewell Sandwell

Agewell Wednesbury

Alzheimer Scotland

Autism Rights

Avante Partnership

Barnet 55+ Forum

Barnet and Enfield Local Involvement Networks

Barnsley Metropolitan Borough Council

Bath and North East Somerset Council

Bedford Borough Council

Benefits Network Group

Bexley Down's Syndrome Group

Bexley Mencap

Bideford on Avon SCAN

Birmingham City Council

Birmingham Older Peoples Reference Group

Blackburn and District Trades Union Council

Blackburn with Darwen Borough Council

Blackpool Senior Voice Forum

Bolton Council

Borough of Poole

Bracknell Forest Council

Bradford Adult and Community Services

Bradford Alliance on Community Care

Brighton & Hove City Council Green Party councillors' group

Brighton & Hove Unwaged, Advice & Rights Centre
Brighton and Hove Older People's Council
Brighton and Hove Pensioner Forum
Bristol Disability Equality Forum
Bristol LINK
Bristol Older People's Forum
Bromley Mencap
Browne Jacobson LLP
Brunel University
Buckinghamshire County Council
Buckinghamshire Partnership Boards
Bury Borough Council
Camborne & Redruth Labour Party
Cambridgeshire Charity Care Network
Cambridgeshire County Council
Cambridgeshire LINK
Cambridgeshire Older People's Enterprise
Camden LINK
Canterbury and District Pensioners Forum
Carers in Hertfordshire
Carers Network Westminster
Carers Northumberland
Carers Outreach Service
Carers Strategy Group in Southampton
Carers UK, Hounslow
Cares Sandwell
Caroline Walker Trust
Central Bedfordshire Council
Central Bedfordshire OPRG
Centre for Housing and Support

Centre for Inclusive Living
Charles Wilkinson Financial Planning
Chelmsford Local Action Group
Cheshire Fire & Rescue Service
Chichester District Council
Chorley and South Ribble Disability Forum
Chorley Pensioners Association
Church of God of Prophecy
CIL Kent
Circle Anglia
City LIT
City of Bradford Metropolitan District Council
City of Durham Constituency Labour Party
Cleveland Trade Unionists & Unemployed Workers Resource Centre
Coalition of Carers in Scotland
Community Care Services, Bournemouth BC
Community to the Government
Connect Advocacy
Conservative Administration of Brighton & Hove City Council
Cornerstone
Coventry and Warwickshire Partnership for Care
Coventry City Council
Coventry Teaching Primary Care Trust
COVER
Crawley Borough Council
Croydon Council
Cumbria County Council
CVS Hounslow
Darlington Association on Disability

Derby City Council	Foggy Friends
Derbyshire County Council	Folkestone Hythe & District Mencap
Derbyshire LINK	Forest Heath District Council
Devon County Council	Forest Seniors Network
Devon Pensioners' Action Forum	Gateshead Advocacy and Information Network (GAIN)
DHHG, Diocese of Worcester	Gateshead CAB
Director of Policy and Development ECDP	Gateshead Council
Directors of Public Health in Lancashire	Getting Involved
Disability Action	Gloucestershire County Council
Disability Wales/Anabledd Cymru	Gloucestershire Older Persons' Assembly
Doncaster Metropolitan Borough Council	Goostrey WI
Dorset Blind Association	Gradus Consulting
Dorset County Council	Great Budworth WI
Dudley MBC	Greater London Forum for Older People
Durham County Council	Greenwich Council
Ealing LINK	Greenwich Pensioners Forum
East Midlands Older People Advisory Group	Greenwoods Solicitors' Care Project Group
East Midlands UNISON Regional Centre	Hackney LINK
East Riding of Yorkshire Council	Halton Borough Council
East Sussex Disability Association	Halton LINK
East Sussex Seniors' Association	Halton Voluntary Action
Eastern Region Age Concern and Help the Aged	Hampshire Centre for Independent Living
Ecas	Hampshire County Council
Eden Community Alarms	Hampshire-wide Carers Network
Ehlers-Danlos Support Group	Haringey LINK
Elders Council of Newcastle	Haringey Forum for Older People
EPIC Trust	Harrow Association of Disabled People, Harrow Mencap, Mind in Harrow, Harrow Carers, and Age Concern Harrow
Essex and Southend LINK	Harrow Council
Essex County Council	
Essex Independent Care Association	

Hartlepool Borough Council
Hartlepool Carers
Hartlepool LINK
Hartrigg Oaks, York
Haslemere U3A
Headway
Health and Care Together, Bolton
Hereford Carers Support
Hertfordshire County Council
Hillingdon Association of Voluntary Services
Hillingdon LINK
Home Group Ltd
Hounslow Pensioner's Forum
Hounslow Welfare Benefits and
Money Advice Unit
Hull City Council
Hutton Rudby WI
Inclusion London
Inclusive Living Sheffield
Independent Living Alternatives
Independent Living Kent
Island Healthcare
Isle of Wight Council
Islington Council
Islington Deaf Campaign
Joint Commissioning Group for Mental Health
Joint response from David Kidney MP for
Stafford, Centre for Ageing and Mental Health,
Staffordshire University, Staffordshire County
Council, South Staffordshire NHS PCT

Joint response from Scottish Association for
Mental Health; Depression Alliance Scotland;
Penumbra; Scottish Development Centre for
Mental Health; Bi-Polar Fellowship Scotland;
NSF Scotland; Highland Users Group;
Renfrewshire Association for Mental Health
and Glasgow Association for Mental Health
K&C Forum for Older Residents
Kensington & Chelsea Local Involvement
Network (K&C LINK)
Kent Adult Social Services
Kent Community Care Association
Kent County Council
Kent Local Involvement Network (LINK)
Knowle WI Bristol & Avon
Knowsley LINK and Knowsley Older
People's Voice
Knowsley Metropolitan Borough Council
Colne Valley Labour Party
Lambeth Elfrida Rathbone Society
Lancashire Association of Trade Union Councils
Lancashire County Council
Laura Moffat MP – constituency response
Learning Disability Alliance Scotland
Learning Disability Parliament
Leeds & District branch of the National
Federation of the Blind
Leeds City Council
Leeds Jewish Blind Society
Leicester City 50+ Network
Leicester City Council
Leicestershire County Council

Leicestershire LINK	Medway Older People Communication Network
Lewisham LINK	Merseyside Pensioners Association
Lewisham Mencap	Middlesbrough Welfare Rights Unit
Lewisham Pensioners' Forum	Middlesbrough Senior Citizens Forum
LINK Hillingdon Local Involvement Network	Midland Hearts
LINK in Cornwall	Mid-Sussex Older People's Council
Liverpool Getting Involved Group	Mind in Croydon
Liverpool Mental Health Consortium	Multiple Sclerosis Society Cheshire & Merseyside
London Borough of Barking and Dagenham	Muswell Hill & Highgate Pensioners Action Group
London Borough of Barnet	Neighbourhoods and Adult Services Directorate
London Borough of Brent	Newcastle and North Tyneside Learning Disability Partnership Boards
London Borough of Camden	Newcastle Health and Community Care Forum
London Borough of Hackney	NHS Bradford and Airedale
London Borough of Hammersmith & Fulham	NHS North West
London Borough of Haringey	NHS South Central Strategic Health Authority
London Borough of Lambeth	NHS South East Essex Patient and Public Voice
London Borough of Lewisham	NHS South Gloucestershire
London Borough of Merton	Norah Fry Research Centre, University of Bristol
London Borough of Newham and NHS Newham	Norfolk County Council
London Borough of Redbridge	Norfolk County Council Green Party Group
London Borough of Richmond	Normanton and Altofts Senior Citizens Association
London Borough of Sutton	North Derbyshire Voluntary Action
London Councils	North East Local Authorities
London Older People's Strategies Group	North East Primary Care Organisations' Chief Executives and the Chief Executive of North Tees and Hartlepool NHS Foundation Trust
Mablethorpe and District Seniors' Forum	North Eastern Association of Women Graduates
MACS	North Lancashire NHS
Maidstone Carers Project	North Somerset Crossroads
Manchester LINK	
Maureen and friends	
Mayor of London	

North Staffs Pensioners Convention
North Yorks
North Yorks LINK
North Yorkshire County Council
Northgate Public Services
Northumberland Care Trust
Northumberland LINK
Nottingham City Council
Nottinghamshire County Council
Nottinghamshire County LINK
Nuffield Council on Bioethics
Oadby & Wigston Community Action
Older People in Action in Warwick District
Older People's Advocate for Northern Ireland
Older Peoples Advocate
Older People's Commissioner for Wales
Older Persons' Advisory Forum for the Royal
Borough of Windsor & Maidenhead
Oldham Partnership
One East Midlands
One Voice
OPeN
Open Sight
Orbit Group
Orbit Heart of England
Oxfordshire County Council
Oxfordshire Direct
Parliament Group
Partnership Life Assurance Company
Pembrokeshire Association of Voluntary Services
People's Voices

Peterborough City Council & NHS Peterborough
Peterborough Community Services
Pewsey Community Area
Plaid Cymru – The Party of Wales
Planning & Service Development, Adults
and Housing
Porchlight
Quarriers
Radstock WI
RAISE
Redcar and Cleveland Older Peoples Partnership
Rescare the Society for Children and Adults with
Learning Disabilities and Their Families
Richmond & Kingston ME Group
Richmond AID
Richmond Fellowship
Richmond upon Thames Local Involvement
Network
Ridgeway Partnership
RNIB
Rochdale MBC
Rotherham Fibromyalgia Group
Rotherham Pensioners Action Group
Rowley Reigs Agewell
Royal Borough of Windsor and Maidenhead's
Access Advisory Forum
Royal College of General Practitioners
Royal College of Physicians
Royal College of Physicians Edinburgh
Royal College of Psychiatrists
Royal Society of Arts, London Region

Runnymede Borough Council	South Yorkshire Centre for Inclusive Living
Salford City Council	Southampton Local Involvement Network
Salford Residents	Southampton Pensioners Forum
Sandwell Council Adult and Community Services	Speak Up Sutton
Sandwell Local Involvement Network	St Andrew's Healthcare
Scottish Ministerial Strategic Group on Health and Community Care	St Anne's Community Services
Sefton Carers Centre	St Helens Council
Selby Carers Centre	St Helens LINK
Senior Citizens Open Forum for the Northern Parishes	St Mungos
Senior Council for Devon Exeter Area	St Vincents Housing Association
Sheffield Learning Disability Partnership Board	St John Somerset
Shropshire Association of Senior Citizens Forums	Staffordshire County Council
Shropshire Disability Network	Stockport Advice
Signposts/Cumbria County Council Working Together	Stockport Council Adults and Communities Directorate
Sitra	Stockton Borough Council/NHS Stockton
Skillnet Group	Stoke on Trent Fifty+ Forum
Skills for Care	Stoke on Trent LINK
S-LINK	Suffolk County Council, NHS Suffolk, NHS Great Yarmouth and Waveney, Optua, Suffolk Family Carers and Age Concern Suffolk
Somerset Community Health	Suffolk Supporting People
Somerset County Council	Sunderland Carers' Centre
Soroptimist International Blackburn	Sunderland City Council
Soroptimist International of Central Birmingham	Supporting People Eastern Regional Group
Soroptimist International of Northern England	Surrey Coalition of Disabled People
Soroptimist International, Plymouth	Surrey County Council
South East County Chief Executives group	Surrey County Council Action for Carers and Surrey Coalition of Disabled People
South Gloucestershire Council	Sutton on Sea WI
South Tyneside Central Organisation on Disabilities	Swindon Borough Council/NHS Swindon

Tameside Local Involvement Network	Wandsworth Borough Council
Tameside Third Sector Coalition	Wandsworth Older People's Forum
Tendring Pensioners' Action Group	Warrington Borough Council
The Access Group Tunbridge Wells Borough Area	Warrington LINk and Speak Up group
The Action Group	Warwickshire County Council
The Carers Centre	Warwickshire Local Involvement Network
The Community Voice	Washington Age Concern
The Midlands TUC Pensioners Network	Watford & Three Rivers Health & Social Care Group
The Princess Royal Trust for Carers	Weavers Care Home
The Ridgeway Partnership (Oxfordshire Learning Disability) NHS Trust	Wellington Eve Town's Women's Guild
The Saltbox Christian Centre	West Berkshire Disability Alliance
Thurrock Council	West Berkshire District Council
Trowers & Hamlins LLP	West Lancs Peer Support Group
Trustee of the Royal Mail Pension Plan	West Sussex County Council
Tunstall Healthcare (UK) Ltd	Western Super Care Group
Turning Point Scotland	Westminster City Council
UNISON Devon County Branch	Westminster Health and Wellbeing Board
UNISON Stoke on Trent	Wigan Council
Unite the Union's London and Eastern Disabled Members' Committee	Wiltshire & Swindon Users' Network
University of Huddersfield	Wiltshire Involvement Network
University of Nottingham	Wirral Council
Voices 4 Wellbeing	Wirral LINK
Voluntary Action Sheffield	Wirral Older People's Parliament
Voluntary Organisations' Network North East	Wolverhampton Black Strategic Health Group
Voluntary Sector North West	Wolverhampton City Council
Wakefield District LINK	Worcestershire County Council
Walsall Borough Labour Party	Wragge & Co LLP
Walsall Pensioners Convention	York Carers Centre
Walsingham – Supporting people with learning difficulties	York CVS
	York Older People's Assembly

Supplementary Research Report Annex

Prepared for the Department of Health
by Opinion Leader

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APPENDIX A:

QUESTIONNAIRE RESULTS

The results from the questionnaire completed at the end of the discussions are shown below. In a minority of cases participants refused to select an option or selected two options. The latter cases have not been included in the tables below, for example one of the faith leaders declined to select a funding option.

Funding Options

Group	Partnership	Insurance	Comprehensive	Total
Ghanaian	0	6	5	11
Bangladeshi	8	1	3	12
Pakistani	5	3	5	13
Somali	1	11	0	12
Caribbean	6	0	5	11
Nigerian	8	0	2	10
LGBT	5	3	3	11
General Public	16	13	14	43
Transgender	0	0	1	1
Faith Leaders	1	1	4	6
Total	50	38	42	130

National/Local

Group	Fully National	Part Local/Part National	Total
Ghanaian	5	5	10
Bangladeshi	6	6	12
Pakistani	6	7	13
Somali	5	7	12
Caribbean	7	5	12
Nigerian	7	3	10
LGBT	11	0	11
General Public	22	21	43
Transgender	1	1	2
Faith leaders	3	4	7
Total	72	59	132

APPENDIX B: FULL BACKGROUND AND METHODOLOGY

Background

In 2008, the Government undertook a six-month public engagement programme to get the views of the public and stakeholders on the principles on which a new system should be built as part of the Green Paper development.

Formal consultation on the Green Paper took place between July and November 2009.

Consultation involved a number of activities to help raise awareness of the issues, along with a broad range of ways to feedback, all designed to make it as easy as possible for people to respond. These included:

- Online for responses to the key questions – www.careandsupport.direct.gov.uk
- Questionnaires
- Leaflets
- Postcards
- Roadshows
- Market research with specific groups
- Toolkit – for stakeholders to continue the debate with their networks
- 36 regional ‘deliberative’ events with stakeholder audiences (local carers/care users to delivery professionals and Directors of Adult Social Services).

The information gathered during the consultation will feed into the next stage of the process – the production of a White Paper in which the government will make a statement of the proposed policy, and within that framework will set out proposals for legislative changes or the introduction of new laws.

Our research

While this consultation period aimed to engage people from all groups in society and ensure their views are heard, it was felt that some audiences may be unlikely or unable to engage in the debate via the means provided. Therefore, supplementary market research was commissioned to reach out to these additional audiences.

The overall aim of the research was:

- To gather views on the range of options for the future design of the National Care System in England from those groups who may be unlikely or unable to engage with ‘The Big Care Debate’.

The sample

In total, 2 deliberative workshop events, 14 extended group discussions and 9 depth interviews were conducted. Participants at the groups and events were all asked to complete a short pre-task, prior to attending the research. This provided some limited information on the consultation and asked them to consider their experiences of the current care and support system and any plans for funding care and support in future.

The events, group discussions and depth interviews all followed the same broad discussion guide and participants were presented with the same stimulus materials. These are provided in Appendix D.

The ethnic minority communities (EMC) selected were chosen on the basis of a combination of a number of factors:

- the size of the community in England
- how well assimilated the community is generally
- the presence of health inequalities among the community.

For example, we did not include participants from an Indian background as, although it has the highest population of any EMC in England, it is fairly well assimilated into the population as a whole.

Deliberative events

Two five-hour deliberative workshop events were conducted; each with 24 participants. One was held in Central London on 21 October 2009 and one in Sheffield on 23 October 2009.

The sample for each event was as follows:

- None to be 'engaged' with care. This was defined as:
 - Little knowledge of current care and support system
 - Not formally involved in current care and support system
 - Not involved in 'The Big Care Debate' (for example public road shows)
 - Can include carers (unpaid, no more than 20 hours/week)
- 12 x men, 12 x women
- 4 x AB, 10 x C1C2, 5 x D, 5 x E and socially excluded
- Mix of income levels: Household income of <£15K, £15-25K, £25K+
- 10 x 18-29, 10 x 30-59, 4 x 60 and over
- Mix of family and lifestages
- Spread of ethnicity to reflect the locality
- To fall out naturally (no quota): disability, sexuality, religion/faith.

Health professionals, those working in the formal care industry and those working in market research, marketing, PR, national government and journalism were specifically excluded.

Group discussions

14 extended group discussions, each lasting two and a half hours, were conducted as detailed in the table below.

Group	Audience	Location	Date
1	Bangladeshi men	Birmingham	15 October 2009
2	Bangladeshi women	Leeds	14 October 2009
3	Somali men	London	20 October 2009
4	Somali women	Birmingham	20 October 2009
5	Pakistani men	Leeds	14 October 2009
6	Pakistani women	Birmingham	15 October 2009
7	Caribbean men	London	20 October 2009
8	Caribbean women	London	20 October 2009
9	Ghanaian men	London	26 October 2009
10	Ghanaian women	Manchester	19 October 2009
11	Nigerian men	Birmingham	20 October 2009
12	Nigerian women	Birmingham	20 October 2009
13	Gay men	Manchester	15 October 2009
14	Gay women	London	14 October 2009

The sample for each of the groups with Ethnic Minority Communities (EMC) was as follows:

- All participants were second generation and born in England
- They all spoke and read English to a reasonable level
- With older relatives (parents/grandparents/aunts/uncles) living in England
- 2 engaged with care and 4 not engaged as per definition above
- Mix of key demographics (age, socio-economic group).

The research with EMC participants was conducted in two parts:

- Part one was to attend the group
- Part two was to complete a simple post-task involving interviewing older members of their family and sending back a completed proforma, documenting their views. Participants were given a pack including a pre-paid envelope. Their incentive was weighted, with some of the payment following the post-task, to encourage completion. In total 72 post-tasks were distributed and 42 received back.

A copy of the post-task proforma is provided in Appendix D.

In total, 44 post-task questionnaires were returned by participants for analysis.

Post-task return rates by audience

Group	Dispatched	Returned
Ghanaian	11	8
Bangladeshi	12	9
Pakistani	13	12
Somali	13	1
Caribbean	12	8
Nigerian	11	6
Total	72	44

Depth interviews

Nine depth interviews, each lasting around one hour, were also conducted as shown below.

Depth	Audience	Location	Date
1	Muslim faith leader	London	26 October 2009
2	Muslim faith leader	Birmingham	26 October 2009
3	Sikh	Birmingham	26 October 2009
4	Rabbi	Hertfordshire	14 October 2009
5	Hindu	Birmingham	26 October 2009
6	Roman Catholic	Manchester	26 October 2009
7	Jehovah's Witness	Manchester	15 October 2009
8	Transgender man	Manchester	15 October 2009
9	Transgender man	London	15 October 2009

APPENDIX C: PARTICIPANT DEMOGRAPHICS

The tables below detail the key demographics of the participants at the two general public events and the 14 extended groups. Detailed demographic information for the depth interviews with faith leader and transgender participants was not captured in the same way.

Gender

Group	Male	Female
Ghanaian	7	4
Bangladeshi	6	6
Pakistani	7	6
Somali	8	4
Caribbean	6	6
Nigerian	5	5
LGBT	6	5
Transgender	2	0
General Public	21	24
Total	66	60

Age

Group	18–29	30–59	60–65	65+	Total
Ghanaian	5	5	0	0	10
Bangladeshi	7	3	0	0	10
Pakistani	3	10	0	0	13
Somali	11	0	0	0	11
Caribbean	3	9	0	0	12
Nigerian	1	8	0	0	9
LGBT	3	7	1	0	11
Transgender					
General Public	18	18	6	1	43
Total	51	60	7	1	119

Life Stage

Group	Single, no children	Married, no children	Married, living with children	Single, living with children	Married, children but not living with them	Single, children but not living with them	Other
Ghanaian	5	1	2	1	1	0	0
Bangladeshi	3	2	4	1	0	0	1
Pakistani	0	0	12	0	0	1	0
Somali	0	7	3	2	0	0	0
Caribbean	3	0	6	1	2	0	0
Nigerian	1	0	8	1	0	0	0
LGBT	5	4	1	0	0	0	1
General Public	15	3	17	2	4	2	1
Total	32	17	53	8	7	3	3

Area

Group	Urban	Suburban	Rural
Ghanaian	7	3	0
Bangladeshi	10	1	0
Pakistani	7	6	0
Somali	6	5	0
Caribbean	11	1	0
Nigerian	2	5	2
LGBT	7	4	0
General Public	12	30	2
Total	62	55	4

Salary

Group	Less than £15,000	£15,000–£24,999	£25,000–£49,999	£50,000–£74,999	£75,000 and above
Ghanaian	0	0	8	1	1
Bangladeshi	5	2	4	0	0
Pakistani	9	2	0	0	0
Somali	10	0	0	0	0
Caribbean	7	3	0	1	0
Nigerian	1	6	3	0	0
LGBT	1	3	2	2	3
General Public	8	11	15	3	2
Total	41	27	32	7	6

Sexuality

Group	Hetero	Gay male	Lesbian	Bi-sexual male	Bi-sexual female	Don't wish to answer	Other
Ghanaian	10	0	0	0	0	0	0
Bangladeshi	9	0	0	0	0	0	0
Pakistani	10	0	0	0	0	2	0
Somali	11	0	0	0	0	0	0
Caribbean	10	0	0	0	1	1	0
Nigerian	9	0	0	0	0	0	0
LGBT	0	6	4	0	0	0	0
General Public	37	0	0	0	0	3	0
Total	96	6	4	0	1	6	0

Religion

Group	Catholic	Protestant	Christian other	Hindu	Muslim	Jewish	Buddhist	No religion	Don't wish to answer
Ghanaian	0	1	6	1	0	0	0	0	0
Bangladeshi	0	0	0	0	11	0	0	0	0
Pakistani	0	0	0	0	12	0	0	0	0
Somali	0	0	0	0	11	0	0	0	0
Caribbean	2	0	6	0	0	0	0	1	1
Nigerian	0	2	6	0	1	0	0	0	0
LGBT	0	1	0	0	0	4	0	4	0
General Public	8	7	8	0	2	0	2	12	3
Total	10	11	26	1	37	4	2	17	4

APPENDIX D: RESEARCH MATERIALS

Copy of deliberative event agenda/discussion guides

Copy of stimulus materials

Copy of post-task proforma

Green Paper – Shaping the Future of Care Together

Agenda, event (10am–3.30pm)

SUMMARY AGENDA		
Timings	Activity	What is needed/ Stimulus
9.45 – 10.00am	Arrival and registration	
10.00 – 10.15am	Introductions Welcome, introduction and housekeeping by Opinion Leader Brief explanation that the research is about a new National Care Service and what their input will be Table introductions	
10.15 – 10.30am	Initial discussion <i>Objectives</i> <i>To explore spontaneous awareness, experiences and perceptions of care & support system. To warm up participants to subject and allow them to get any issues with care and support off their chest in advance of the full discussions.</i> <i>Table discussion (participants can refer to pre-task):</i> • Is care and support a topic they are interested in? • Current awareness and knowledge of the care and support system in England – What care and support is available and to whom? – How is it accessed? • Experiences of care and support system (keep brief) – Have they ever experienced the care and support system? – Have their family members? • Perceptions of care and support system in England – what do they think the system is like? <i>Capture spontaneous responses.</i>	
10.30 – 10.45am	Plenary: Presentation of case for change <i>Objectives</i> <i>To inform participants of the need for change and the key demographic, social and economic factors influencing this.</i> Participants will take part in the short quiz based on stats and info about population demographics. Multiple choice questions – participants to vote by deciding as a table and then putting their hands up. Once quiz completed, participants given hand out summarising key facts from quiz (can refer back to in later discussions). Facilitator to discuss briefly: • Do they feel tackling these issues should be a key priority for the Government? Why/why not?	Table quiz HANDOUT A (Key Facts)

SUMMARY AGENDA

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SUMMARY AGENDA		
Timings	Activity	What is needed/ Stimulus
1.15 – 1.30pm	Plenary: Introduction of funding issues <i>Objectives:</i> <i>Introduce funding issues and get participants warmed-up to discussing funding options.</i> Participants given a one-page handout showing the average costs of care. <i>Brief table discussion</i> • Explore initial reactions to cost information – What do they think of this? – What they expected or not?	HANDOUT D (Costs)
1.30 – 2.30pm	Plenary: Presentation of funding options <i>Objectives</i> <i>To explore consultation question 3</i> Participants given a handout explaining the 3 funding options. Facilitator to go through verbally again. <i>Table discussion</i> • Which of these options do you prefer, and why? Each table then to discuss the pros and cons of each funding options and think about the principles behind it e.g. comprehensive everyone looks after one another • Facilitator prompt using the guiding vision principles: Fair, Simple, Affordable and Sustainable, Universal, Help people live their lives the way they want to Open up discussion to talk about all 3 options • Which option is their preference and why – How would others in their family/community feel? • Probe on specific points about the funding options: – Private vs. state insurance – Different ways to pay e.g. instalments, lump sum, estate – Free care for people of working age vs. same system for everyone – Accommodation costs excluded (but can defer) – Lower rate for couples <i>Summary</i> • Plenary feedback session	HANDOUT E (Funding options)

SUMMARY AGENDA

Timings	Activity	What is needed/ Stimulus
2.30 – 3.00pm	Plenary – presentation of national vs national-local <i>Objectives</i> <i>To explore consultation question 3b</i> Participants given a handout explaining the 2 options and outlining the pros and cons of each (second sheet) <i>Table discussion</i> • Should local government say how much money people get depending on the situation in their area, or should national government decide? • Discuss in more detail: – What do they think of the pros and cons of each option? (explain this is not an exhaustive list) – Can they add any more pros and cons? – Is either option more appealing to them? Why? – Who would benefit from each option? How? – Any reasons they wouldn't work? <i>Summary</i> • Plenary feedback session	HANDOUT F (National/Local)
3.00 – 3.10pm	Individual feedback • Fill in individual questionnaire (including questions on funding options, national/ local option and demographics) • Also space to write final thoughts for those writing the White Paper to consider (5 mins)	Individual questionnaire
3.10 – 3.30pm	Feedback presentations Thanks and close Housekeeping Handout copies of Exec Summary to those who want it.	

Group guide

Introduction (10 mins)

- Welcome and introduce Opinion Leader
- The research is being done on behalf of the Department of Health about the care and support system in England
- Explain purpose of research and their input – their feedback will feed into a final report on the consultation as a whole
- Assure confidentiality
- Ask permission to record interview
- No right or wrong answers, they are not expected to be an expert on care and support
- Respondents to introduce themselves:
 - Name, work, family.

Awareness of care and support system (10 mins)

- Explain that we are going to start by talking about the care and support system and what they know of it. Re-iterate that this is not a test – just want to know what they know
- Ask participants to refer back to their pre-task documents as and when they want to
- Read out definition of care and support to them again.

Definition

Care and support is the mixture of financial, practical and emotional support that helps people to do everyday things that most of us take for granted:

- *Getting out of bed, dressed and into work, choosing what and when to eat, getting out of the house, being able to see friends, being able to care for our families.*

Public, private and charitable organisations provide care and support, as well as friends, family and community groups.

The main users are: people who have long-term illnesses, disabled people, older people.

It is paid for by individuals and a mixture of general and local taxes

- Current awareness and knowledge of the care and support system in England
 - What do you know about the care and support system in England?
 - Is it a topic you are interested in, in general? Why/why not? Do you pay attention to media coverage about it? Why/why not?
 - What care and support is available in England?
 - Who is it available to?
 - How do people receive care and support? Is there anything they have to do?
- Experiences of care and support system
 - Brief review of any experiences or family experiences of care and support (allowing participants to get any issues off their chest and then move on)
- Perceptions of care and support system in England
 - What do they think the care and support system is like in England? Good/poor? Why?
 - Capture spontaneous responses.

Presenting the case for change (10 mins)

- Now we're going to talk a bit about society as a whole. I'm going to ask you some questions about the population of England and see what you think. Remind again that this is not a test.
- Informally go through the 'quiz' questions, see what they think the answers are, and then reveal the answers
- Then give out HANDOUT A summarising key facts from 'quiz' (can refer back to in later discussions) and briefly probe:
 - Do they feel that tackling these issues should be a key priority for the Government? Why/why not?

Response to key principles (35 mins)

- Moderator to introduce the idea of a new National Care Service. Explain, in suitable language for the group that:
- *1948 the NHS was established - universal health care service paid for by central government and free at the point of need. This was in stark contrast to the 1948 National Assistance Act – social care services provided by the Local Authorities, funded by local tax, means tested, and only offered to the really needy. The system hasn't changed from this, and no longer fits the needs of modern society*
 - *Many people do not get help from the state towards paying for their care and support*
 - *People with the same needs receive different levels of care depending where they live*
 - *The different parts of the care and support system do not work together*
 - *The system is not tailored to people's needs*

- *The Government wants to build a new National Care Service for everybody, and has set out a vision to build a National Care Service which is fair, simple and affordable for all adults in England.*
- Moderator to give out HANDOUT B on the six things that people should be able to expect from the National Care Service. Then read out loud for the group to follow.
- Allow a few minutes for participants to read over, then discuss.
- **Is there anything missing from the vision?**
- **How should this work?**
- Then quite move on quite quickly to probe each principle in more detail one-by-one:
 - What does this mean to them? How would it feel?
 - Have they got any examples of this from other businesses/organisations e.g. local council, service or retail organisations?
 - Who do you think would benefit from these principles? How?
 - Are there any people that wouldn't benefit?
 - Are there any reasons that this idea wouldn't work in practice?
 - Anything off-putting here?
- Ask them to think about a member of their family who might need care and support in the near future... Would this idea be suitable for them? How would it work for them?

- If participants struggling to understand Prevention Services, a Joined-up Service and Personalised Care and Support show HANDOUT B1, 2 or 3.
- Specific probes when going through Principles:
 - What do they understand by a joined-up service? Probe: people talking to each other? Systems talking to each other? Making it easier to individuals to access services? Something else?
 - What kind of information might they want on care and support?
 - What do personalised services truly mean to them?

(Moderator to listen out for comments based on ethnicity or religious beliefs and probe fully on reasons behind these)

Response to ways of making the vision a reality (20 mins)

- Moderator to give out HANDOUT C on ways of making the vision a reality. Then read out loud for the group to follow.
- Allow a few minutes for participants to read over, then discuss.
- **Do you agree?**
- **How could we set this up?**
- **What things might make it hard for us to make this happen?**
- Then probe each way in more detail one-by-one:
 - How do you respond to this?
 - Do you agree with these ideas?
 - How do you imagine this working in real life?
 - What would they mean for you?

- Anything that might be off-putting about them?
- Ask them to think about a member of their family who might need care and support in the near future... Would this be suitable for them? How would it work for them?
 - What would joined-up working mean for them?
 - What range of services would they need/want?
 - What would be good quality service for them?
- If participants struggling to understand Joined-up Working show HANDOUT C1.

(Moderator to listen out for comments based on ethnicity or religious beliefs and probe fully on reasons behind these)

Funding issues (10 mins)

- Moderator to give out HANDOUT D showing the average costs of care. Read out loud for the group to follow.
- Allow a few minutes for participants to look at, then discuss.
- Initial reactions to the cost of care:
 - What do they think of this?
 - What they expected or not?
 - Would they expect to need care and support that cost this amount? Would their parents/older family expect to?

(Moderator to listen out for comments based on ethnicity or religious beliefs and probe fully on reasons behind these)

Funding options (35 mins)

- Moderator to give out HANDOUT E explaining 3 funding options. Read out loud for the group to follow.
- Explain that this shows an overview for each option, but the exact details have not been decided on yet. It will be a difficult decision for everyone, as there is unlikely to be one option that works best for everyone. This is the first debate on these three options and we want to hear their views on them.
- Allow a few minutes for participants to read through.
- Which of these options do you prefer, and why?
- Are any of these options better than what we have now?
- Are any fairer than what we have now?
- (refer participants to back of Handout E, which shows comparison to current system)
- Then split group into pairs and ask each one to think about the pros and cons of one of the funding options. Read out and lay out sheet with the follow prompts to help them think about it and think about the principles behind it e.g. in Comprehensive everyone looks after one another:
 - *Is it fair?*
 - *Is it simple to understand?*
 - *Is it affordable for people, now and in the future?*
 - *Will it work for everyone?*
 - *Will it help people live their lives the way they want to?*
- Discussion around their own preferences
 - Which option do they prefer and why?
 - How would other people in their family feel?
 - How do they think other people in the wider community would feel?
 - (focus on the 3 preferred options, but if people talk about tax-funded option capture their thoughts and then move on)
- Moderator to discuss their thoughts on some of the specific points about the funding options:
 - Private vs. state insurance (Comprehensive option)
 - Different ways to pay e.g. instalments, lump sum, estate (Comprehensive option)
 - Free care for people of working age vs. same system for everyone
 - Accommodation costs excluded (but can defer)
 - Lower rate for couples (Comprehensive option)
 - o What do they think about this?
 - o How could this affect them in the future?
 - o What would their other family members think about this?

(Moderator to listen out for comments based on ethnicity or religious beliefs and probe fully on reasons behind these)

National vs. national-local (10 mins)

- Moderator to give out HANDOUT F explaining 2 options and, on second sheet, outlining pros and cons. Read out loud for the group to follow.
- Allow a few minutes for participants to read through.
- **Should local government say how much money people get depending on the situation in their area, or should national government decide?**
- Discuss their responses to the national/local options:
- What do they think of the pros and cons of each option? (explain this is not an exhaustive list)
- Can they add any more pros and cons?
 - What do you think of each option?
 - What difference do you think it would make?
 - Do you think one of the options sound better than the other? Why?
 - Who do you think would benefit from each option? How?
 - What would other people in your family think?
 - What would people in your wider community think?

(Moderator to listen out for comments based on ethnicity or religious beliefs and probe fully on reasons behind these)

Questionnaire and summary (10 mins)

- Participants to be given questionnaire to fill in on their thoughts re. funding and local/national, as well as demographic questions
- Also postcard to write final thoughts for those writing the White Paper to consider

Thanks & Close

- If they want to find out more about The Big Care Debate they can go to:
- <http://careandsupport.direct.gov.uk/>

Depth guide

Introduction (5 mins)

- Introduce Opinion Leader
- The research is being done on behalf of the Department of Health about the care and support system in England
- Explain purpose of research and their input – their feedback will feed into a final report on the consultation as a whole
- Assure confidentiality
- Ask permission to record interview
- No right or wrong answers, they are not expected to be an expert on care and support
- Respondent to introduce themselves:
 - Name, role as Faith Leader – what does this involve, how long have they been a Faith Leader, number in their community

Care and support in their community (10 mins)

- Explain that we are going to start by talking about the care and support system and what they know of it. Re-iterate that this is not a test – just want to know what they know
- Read out definition of care and support to them.

Definition

Care and support is the mixture of financial, practical and emotional support that helps people to do everyday things that most of us take for granted:

- *Getting out of bed, dressed and into work, choosing what and when to eat, getting out of the house, being able to see friends, being able to care for our families*

Public, private and charitable organisations provide care and support, as well as friends, family and community groups.

The main users are: people who have long-term illnesses, disabled people, older people.

It is paid for by individuals and a mixture of general and local taxes.

- Lets start by talking about care and support in your faith community
 - What is the general view of care and support in your faith community?
 - Do you hold any particular beliefs around illness, disability or old age?
 - What aspects of your faith do these views tend to be based on?
 - Does your faith community have a particular approach to these people?
- Do there tend to be any particular systems or services in place in your community for providing care and support?
 - What kinds of systems or services are these?
 - Are they available to all in society or those in your community specifically?
 - Are these systems formal or informal? How, if at all, are they funded?
 - Who provides them?

- Where / How can they be accessed?
- Now thinking about the care and support system in England provided by the Government, local councils, voluntary groups and businesses
 - Do you have any experience of this system as a Faith Leader? If so...
 - Does it work with or against the systems and services in place in your faith community?
 - Do they work together at all, or always separately?

Response to key principles (10 mins)

- Moderator to briefly recap on the case for change and the key principles (Faith Leaders will have been tasked to read the Exec Summary of the Green Paper before the interview)
- Show handout on 6 principles. Then discuss.
- **Is there anything missing from the vision?**
- **How should this work?**
- Then probe in more detail...
- How do you feel about these ideas as a leader of your faith?
 - Do these fit with the beliefs and behaviour of your faith community? If not, why not?
 - Is there anything here that would benefit your community particularly?
 - Is there anything missing?
- Then probe each principle in more detail one-by-one:
 - What would this mean to your community?
 - Who do you think would benefit from these principles? How?

- Are there any people that wouldn't benefit?
- Are there any reasons that this idea wouldn't work for your community in practice?
- Anything off-putting to your community here? If so, how could it be made better?
- Specific probes:
 - What would you understand by a joined-up service? Probe: people talking to each other? Systems talking to each other? Making it easier to individuals to access services? Something else?
 - What kind of information might their community want on care and support?
 - What would personalised services mean to their community?

Response to ways of making the vision a reality (10 mins)

- Moderator to give out handout on ways of making the vision a reality.
- Allow a few minutes for participants to read over, then discuss.
- **Do you agree?**
- **How could we set this up?**
- **What things might make it hard for us to make this happen?**
- Further discussion about ways of making the vision a reality
 - Do these fit with the beliefs and behaviour of your faith community?
 - How do you imagine these working in real life?
 - What would they mean for your community?
 - Is there anything that might be off-putting about them?

Funding issues (10 mins)

- Moderator to briefly recap on funding options. Show handout explaining 3 funding options.
- Which of these options do you prefer, and why?
- In more detail – What impact might each of these funding options have on your faith community?
 - Go through each one individually
 - Ask for specific examples of how this might impact the community. Probe for things like language and understanding
- Is there one option that would be preferable? Why?
 - How would this suit the needs of your community better?
 - Is there one option that would suit everyone, or would it be a mixture?
- Discuss their thoughts on some of the specific points about the funding options:
 - Private vs. state insurance
 - Different ways to pay e.g. instalments, lump sum, estate
 - Free care for people of working age vs. same system for everyone
 - Accommodation costs excluded (but can defer)
 - Lower rate for couples

National vs. national-local (10 mins)

- Moderator to briefly recap on local/national options.
- Should local government say how much money people get depending on the situation in their area, or should national government decide?
- What are the pros and cons of each options for your faith community?
- What impact might each of these options have on your faith community?
 - Go through both individually
 - Ask for specific examples of how this might impact the community
- Is there one option that would be preferable? Why?
 - How would this suit the needs of your community better?
 - Is there one option that would suit everyone, or would it be a mixture?
 - (Moderator to note any comments on trust around National vs. Local government)

Final comments (5 mins)

- Do you have any final thoughts for those writing the White Paper to consider about your faith community?
- What specific factors about your faith community should they bear in mind when making decisions?

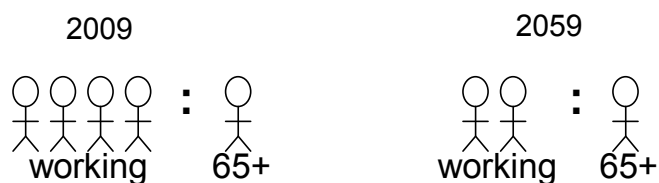
Thanks & Close

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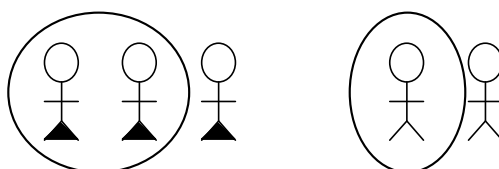
A

England in 2009 and beyond...

- People are living 11 years longer today than in 1948
- There are currently 4 people working to every 1 aged 65 years or over. But because people are living longer, by 2059 there will be around 2 people working to every 1 aged 65 or over



- Two in three women and 1 in 2 men will need high levels of care and support in their life

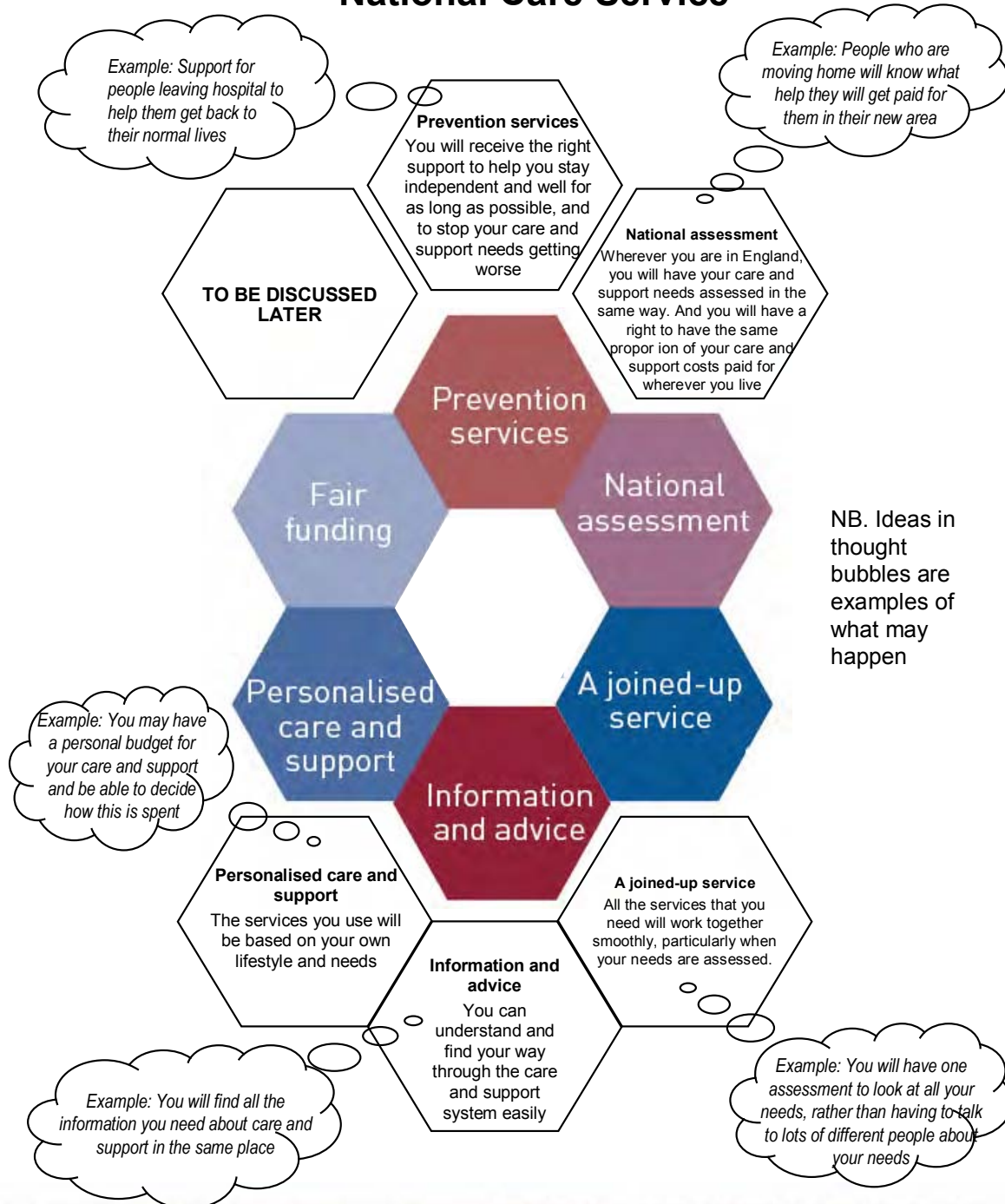


- There are more people with care and support needs – an increase of 1.7 million from the current number is expected by 2026
- People with disabilities and long-term illnesses are living longer
- Our expectations of the range, type and quality of care and support that should be available are increasing

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B

What people should be able to expect from a National Care Service



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B1

What are prevention services?

If we can do things now so people need less care and support in the future, they will enjoy a better life and money will be spent more effectively. Here are some of the ways we will do this:

Re-ablement:

This is about helping people to get back some of the skills and confidence they may have lost through poor health, a disability or going into hospital or residential care.

For instance, people who are leaving hospital and need care and support for the first time should have the right to the re-ablement help they will benefit from at home, for example for six weeks.

Telecare:

These are services that bring technology-based care and support directly into a person's home. These can range from a basic community alarm service to more complex systems with sensors that detect motion, falls, fire or gas and let a response centre know when somebody needs help.

Housing support:

A range of housing support options, which will include supported living (care in a person's own home), extra care housing (accommodation with design features and support to help people live independently), changes to homes or workplaces that make it easier for people to move about, and designing new homes.

Information:

We will make sure that everyone can easily get hold of information about prevention and early intervention.

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B2

What is a joined-up service?

Whatever your care and support needs are, services will work around you and be better joined up. You will only need to have one assessment of your needs to gain access to a whole range of care and support services. This will involve:

- One assessment process that considers people's individual needs, means and eligibility for all forms of support in a more joined-up way. This will minimise multiple questioning of the same people for the same information.
- Carers who are providing, or who intend to provide, a substantial amount of care on a regular basis will also be entitled to an assessment. And this assessment would be conducted at the same time as the person needing care and support.
- People will have ongoing support, so that if their needs change over time or something goes wrong, support is still available. For example, if a care worker becomes ill or a family member is called away, a person should not be left without care and support
- Local authorities will ensure that reassessment takes place on an ongoing basis. Reassessment should not just aim to confirm that someone's package should continue – the assessor should discuss with the individual whether they would prefer a different way of meeting their needs.

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B3

What is Personalised Care and Support?

Care and support services will be built around the person's needs shown in their care plan. We want people to be able to choose and control their care and support services if they want to. This is because they, more than anyone else, know what their needs are. We will also make sure people get the help they need to choose their care and support services.

Here are some of the ways we will do this:

Supporting carers: A carer is someone who (without payment) looks after a family member, partner or friend who needs help because of their age or physical or mental disability.

We want people to choose how much support they get from carers, and for carers to choose how much support they give. We do not want carers to become ill after trying to do too much.

Personal budgets: Under the new care and support system, once people are assessed, everyone who is entitled to a personal budget will get one, rather than being told what services they should receive. They will have as much support as they want in using this resource. Some people will choose to take their budget as cash and pay for everything directly themselves.



C

Making the vision a reality

Joined-up working

For the new care and support system to work at its best, we need more joined-up services to keep people well for longer and to help people live at home for longer, if that is what they want.

Example: Everyone who provides your care and support will work together, such as social workers and physios, GPs and nurses.



Quality and innovation

People want first class and safe services when they need them. And this is also a good use of tax money.

This is because it is better to have a high quality services which keeps people well and able to look after themselves for longer than to have second-class services which mean people need more support later.

Example: Experts to build up evidence and give advice about which care and support services work best.

Wider range of services

Society is changing and people have more diverse needs these days. Also people want more choice and control over the services they use. People will be able to use their care and support money in new and different ways.

Example: Someone might want to spend time on their hobbies or leisure activities, instead of going to a day centre.

NB. Ideas in thought bubbles are examples of what may happen

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C1**What is joined-up working?****CASE STUDY**

Freda lives alone in a second-floor flat. She has short-term memory loss and is registered as partially sighted. Several months ago she fell and injured her leg, which needed regular dressing by the district or practice nurse.

Due to her memory loss, Freda did not always remember to go to the surgery or that the nurse was supposed to be coming to visit. As a result, her leg got so much worse that it was looking likely that she would need to be admitted to hospital for a skin graft.

The nurse arranged for George, a Help and Care volunteer driver, to come and pick up Freda and take her to the surgery, which meant she was able to get to her appointments.

Her leg has now healed and Freda has not needed to go into hospital for a skin graft.



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D

Paying for care and support

- People who need care and support can face very high costs
- The average 65-year-old in England can expect to need care and support that costs **£30,000** during their retirement years
- Care and support needs can vary greatly between individuals and people have no way of knowing what costs they personally will face during their lives...
 - 1 in 5 people can expect to need care and support costing **less than £1,000** during their retirement
 - But 1 in 5 people can expect to need care and support costing **more than £50,000** during their retirement
- Currently people have to **pay for all of their care and support themselves unless they have assets worth less than a set amount**
 - For example, when people start to get their care and support paid for in a nursing home they will have to pay all of this themselves if they have assets worth over £23,000.



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E

Funding options

1) Partnership

The responsibility for paying for care and support would be shared between the Government and the person who has care and support needs. The Government provides between quarter and a third of the cost of care and support, more for people on a low income. Today's 65 year olds can expect to need care and support costing £30,000 during retirement.

2) Insurance

As well as receiving between a third and a quarter of the cost of care and support, more for people on low incomes, the Government would make it easier for people to take out insurance to cover care costs. It is estimated that the cost of insurance could be around £20,000 to £25,000.

3) Comprehensive

Everyone over retirement age who can afford it would pay into a state insurance scheme, so that everyone who needs care and support will receive it free. It is estimated that people might need to pay between £17,000 and £20,000. People could pay in several different ways.

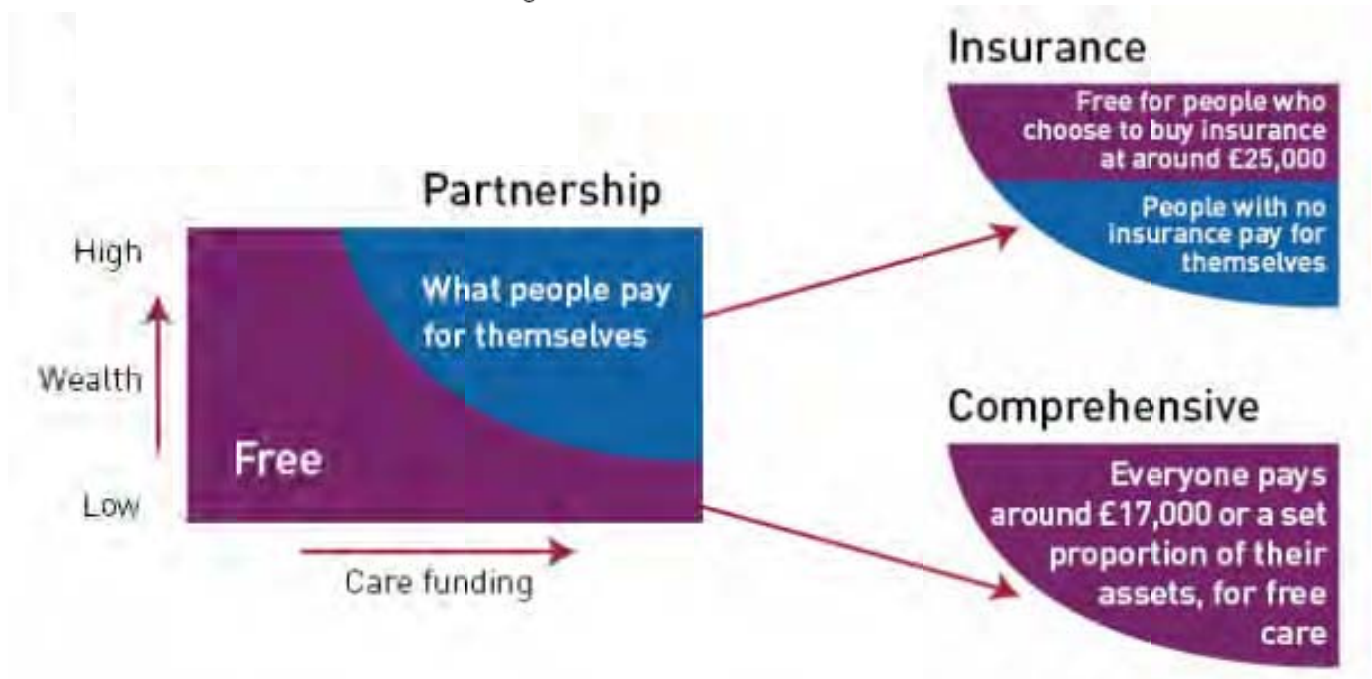
There would be a free care and support system for people of working age alongside this.

Accommodation costs:

- It is important to note that these options consider only the costs of people's **care and support**. People entering a care home would also have to pay for their **accommodation**.
- Accommodation costs, such as the costs of food and lodging, are not paid for by the Government. This is because the Government would not pay for people to buy their food or pay their mortgage or their rent if they were living at home.
- Of course the Government would always have a role in supporting people who could not afford these costs.

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Current system



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F

Everyone who needs care can get it regardless of where they live

Through:

- A national and portable assessment
- Same proportion of care costs will be paid for wherever you live in England

Options

- Part national/part local
 - Local Authority would decide how much to be spent on care and support
- Fully national system
 - Government would decide how much to be spent on care and support



Pros and cons of each system

Part national / part local

Local Authority decides how much to be spent on care

Positives:

- ☑ Local authorities have the flexibility to encourage new kinds of care in their area
- ☑ Delivering services that are focused on people's needs in that area e.g. people might have different needs in city vs. countryside

Negatives:

- ☒ People get different amounts of funding in different places, which might be seen as unfair

Fully national

National government decides how much to be spent on care

Positives:

- ☑ Easy for people to understand and plan for
- ☑ Could be seen as fairer, as everyone gets the same amount of money

Negatives:

- ☒ More difficult to tailor care and support to respond to local circumstances
- ☒ Likely to mean major changes to the way that money for care and support is raised and spent

e.g. Local Authorities might not be able to raise extra money for care and support through Council tax

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Big Care Debate questionnaire

We would be grateful if you could help us by completing this questionnaire so that we can find out your views.

- 1 The Government is suggesting three ways in which care and support could be funded in the future. Which of these options do you prefer?

Please tick one

Partnership The responsibility for paying for care and support would be shared between the Government and the person who has care and support needs. The Government provides between quarter and a third of the cost of care and support, more for people on a low income. Today's 65 year olds will need care and support costing on average £30,000.	
Insurance The same as Partnership but the Government could help people prepare to meet the costs that they would have to pay for themselves, through an insurance-based approach. As well as receiving between a third and a quarter of the cost of care and support, more for people on a low income, the Government would make it easier for people to take out insurance to cover care and support costs. It is estimated that the cost of insurance could be around £20,000 to £25,000.	
Comprehensive Everyone over retirement age who can afford it would pay into a state insurance scheme so that everyone who needs care and support will receive it free. It is estimated that people might need to pay between £17,000 and £20,000. People could pay in several different ways. There would be a free care and support system for people of working age alongside this.	

Why do you prefer this option?

- 2 Should local government say how much money people get depending on the situation in their area, or should national government decide?

Part national, Part local Local Authority would decide how much to be spent on care and support	
Fully National Government would decide how much to be spent on care and support	

Why do you prefer this option?

- 3 Based on your experience of this research event, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree** with each of the following statements (by placing a tick in the relevant box)

PLEASE TICK ONE BOX ON EACH LINE	Strongly Agree	Agree	Neither agree or Disagree	Disagree	Strongly Disagree	Don't know
a. I enjoyed taking part in the event	☐	☐	☐	☐	☐	☐
b. There was not enough time to fully discuss the issues properly	☐	☐	☐	☐	☐	☐
c. The event was well organised and structured	☐	☐	☐	☐	☐	☐
d. The information that was given to me was fair and balanced	☐	☐	☐	☐	☐	☐
e. I think events like this are a good way of engaging with the public about things that matter	☐	☐	☐	☐	☐	☐
f. The information that was given to me was easy to understand	☐	☐	☐	☐	☐	☐

-
- 4 Now you have taken part in the research, please tell us how you feel about the subject of care and support.

I feel much more interested in the subject of care and support than I did before	
I feel a little more interested in the subject of care and support than I did before	
I feel about as interested in the subject of care and support as I did before	
I feel a little less interested in the subject of care and support than I did before	
I feel much less interested in the subject of care and support than I did before	

<u>If you have said you feel much more or a little more interested in the subject of care and support than you did before, please explain why below. What has made you more interested?</u>

About you

5 Please tick which box applies to you.

Male	1
Female	2

6 What age did you turn on your last birthday?

7 Which of the following best describes you?

Single, no children	1
Married/co-habiting, no children	2
Living with children, married/co-habiting	3
Living with, single/divorced/widowed	4
Have children but do not live with them / children have left home, married/co-habiting	5
Have children but do not live with them / children have left home, single/divorced/widowed	6
Other. Please write in:	7

8 Which statement best describes the area you live in?

Urban – city centre or built up area	1
Suburban – in the suburbs or outskirts of a city or town	2
Rural – outside of a city or town e.g. in a village, hamlet or in the countryside	3

9 Which of the following best describes your ethnic background?

White		Black or Black British	
White British	1	Caribbean	9
White Irish	2	Ghanaian	10
Eastern European	3	Nigerian	11
Any other white background	4	Somali	12
		Any other African background	13
		Any other Black background	14
Asian or Asian British		Mixed (other in specification)	
Indian	5	Mixed - White and Black Caribbean	15
Pakistani	6	Mixed - White and Black African	16
Bangladeshi	7	Mixed - White and Asian	17
Any other Asian background	8	Any other mixed background	18
		Chinese or other ethnic group	
		Chinese	19
		Other (please state): 20	

10 What is the occupation of the chief income earner in your household (the person who brings in the most money to the household)?

11 Please tick which option describes your yearly household income (before tax). This information will not be passed on to anyone; it is purely being recorded for research purposes.

Less than £15,000	1
Between £15,000 and £24,999	2
Between £25,000 and £49,999	3
Between £50,000 and £74,999	4
£75,000 and above	5

12 Which of the following statements best describes you?

Heterosexual	
Gay male	
Lesbian	
Bi-sexual male	
Bi-sexual female	
Do not wish to answer	
Other, write in:	

13 Do you consider yourself as belonging to any particular religion or denomination?

Catholic		Sikh	
Protestant		Buddhist	
Christian other		Humanist	
Hindu		No Religion	
Muslim / Islam		Do not wish to answer	
Jewish		Other, write in:	

14 Are you happy for Opinion Leader to contact you from time to time about other research?

Yes	1
No	2

If yes, please write in your contact details here

FULL NAME:

ADDRESS:

POSTCODE:

TEL NO:

MOBILE NO:

Email address:

Stakeholder Event Summary Report Annex

Prepared for the Department of Health
by COI

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ANNEX 1: EVENT LOCATIONS AND DATES

Care and Support Green Paper Consultation Events

Locations, Dates, Times

Region	Location	Suggested Dates	Time
South East	Reading	23-Jul	13:00 - 16:30
South East	Tonbridge	24-Jul	13:00 - 16:30
South East	Tonbridge	25-Jul	09:30 - 13:00
West Midlands	Telford	30-Jul	13:00 - 16:30
West Midlands	Telford	30-Jul	17:00 - 20:30
West Midlands	Birmingham	31-Jul	13:00 - 16:30
West Midlands	Birmingham	01-Aug	09:30 - 13:00
North East	Darlington	03-Sep	13:00 - 17:00
North East	Darlington	03-Sep	17:00 - 21:00
North East	Newcastle upon Tyne	04-Sep	13:00 - 17:00
North East	Newcastle upon Tyne	05-Sep	09:30 - 13:30
East Midlands	Lincoln	10-Sep	13:00 - 17:00
East Midlands	Lincoln	10-Sep	17:00 - 21:00
East Midlands	Leicester	11-Sep	13:00 - 17:00
East Midlands	Leicester	12-Sep	09:30 - 13:30
North West	Carlisle	17-Sep	13:00 - 17:00
North West	Carlisle	17-Sep	17:00 - 21:00
North West	Manchester	18-Sep	13:00 - 17:00
North West	Manchester	19-Sep	09:30 - 13:30
East of England	Bedford	24-Sep	13:00 - 17:00
East of England	Bedford	24-Sep	17:00 - 21:00
East of England	Norwich	25-Sep	13:00 - 17:00
East of England	Norwich	26-Sep	09:30 - 13:30
Yorkshire and the Humber	Hull City	01-Oct	13:00 - 17:00
Yorkshire and the Humber	Hull City	01-Oct	17:00 - 21:00
Yorkshire and the Humber	Leeds	02-Oct	13:00 - 17:00
Yorkshire and the Humber	Leeds	03-Oct	09:30 - 13:30
South West	Exeter	08-Oct	13:00 - 17:00
South West	Exeter	08-Oct	17:00 - 21:00
South West	Bournemouth	09-Oct	13:00 - 17:00
South West	Bournemouth	10-Oct	09:30 - 13:30
London	London	15-Oct	13:00 - 17:00
London	London	15-Oct	17:00 - 21:00
London	London	16-Oct	13:00 - 17:00
London	London	17-Oct	09:30 - 13:30
South East	Brighton	03-Nov	13:00 - 17:00
London	London	04-Nov	13:00 - 17:00

ANNEX 2: TOPIC CHOICES

Big Care Debate Discussion Topics – Your Choices

Our aim is to ensure that your views are heard and your opinion is captured. As much as possible, the event will be structured around the issues you wish to discuss.

The event will begin with a series of presentations on the Green Paper options. These will be followed by discussions at your table on your selected topics across the three areas noted below.

At registration, we will be asking you to select one topic you wish to discuss from session one, and one topic from session two. **Please come ready to let us know which topics you wish to discuss.**

Session 1: The vision for care and support

You can choose **one** of the following options:

- a. **Prevention:** *The right support to help you stay independent and well for as long as possible*
- b. **National assessment:** *Wherever you live in the country, your care needs will be worked out in the same way*
- c. **A joined-up service:** All the services you need will work together smoothly
- d. **Information and advice:** *Being able to understand and find your way through the care system easily*
- e. **Personalised care and support:** Services built around your needs and the way you live

Session 2: From vision to reality

You can choose **one** of the following options:

- a. **More joined-up working:** *More joined-up services*
- b. **Wider range of care and support services:** *More and different care and support services*
- c. **Better quality and innovation:** Better care and support services we know work well

Session 3: Funding options

All delegates will be discussing this topic.

We will do our best to ensure your preferences are accommodated. If you are not able to join your first choice group, there will other opportunities to comment on these issues during the event.

ANNEX 3: DATA CAPTURE PRO-FORMA



Care and Support Big Care Debate Events Pro Forma

The pro forma, as per the discussions on the day, is split into three core topic areas:

SESSION 1 WORLD CAFÉ: VISION (*WHERE WE WANT TO GET TO*)

- 1a [Prevention services](#)
- 1b [National assessment](#)
- 1c [Joined-up services](#)
- 1d [Information and advice](#)
- 1e [Personalised care and support services](#)

SESSION 2 WORLD CAFÉ: VISION TO REALITY (*HOW WE GET THERE*)

- 2a [More joined up working](#)
- 2b [Ensuring a wide range of care and support services](#)
- 2c [Better quality and innovation](#)

SESSION 3 WORLD CAFÉ: FUNDING

- 3a [Funding options](#)
- 3b [National vs local](#)

In the earlier part of the day tables will be listening to presentations and table facilitators will not be required to do any facilitation at these points.

[Table names and numbers and colour coding](#)

[Principles](#)

Time	Activity	Roles	Questions and notes
30 mins before event start	Refreshments and registration	-	-
15 mins before event start	Delegates take seat	-	Accessibility It is likely that there will be people with specific accessibility requirements on your table. Please ensure that you have made sure they are comfortable and have a clear line of sight etc. to the speakers. All materials should be available in large print, if this is not the case, please speak immediately to one of the COI team. Raise your red card to get attention. The film shown will have subtitles, but those who are visually impaired may appreciate it if you would talk them through the images on the screen. Please check with them in advance. There are hard copies of the slides in large font in your table packs, and any presenters have been briefed to ensure they read out the content of the slides in their presentations. Although there are a couple of scheduled breaks throughout the day, please do ensure your table understands that people should stop for a break when they require it, and help themselves to tea and coffee etc.
3 mins	Event start	-	On stage

Time	Activity	Roles	Questions and notes
6 mins	Film		
4mins	Welcome and case for change	DH official / DRD	
12 mins	Overview of GP/ Consultation	DH Official	Presentation
6 mins	Objectives, agenda and approaches for the day	Lead facilitator	
25 mins	Discussion 1 - Vision	Table facilitators	Discussion 1: The 6 Principles Introductions - Facilitator introduction - Trained, independent facilitator - Here to keep discussion moving and to time and to ensure everyone has a fair opportunity to contribute

Time	Activity	Roles	Questions and notes
			- Ground rules ▪ Participant introduction - Name, organisation Throughout the day please capture speakers to allow for analysis of responses by participant type where possible. Setting the scene – PLEASE READ OUT All tables to review the 6 principles and discuss briefly whether they believe anything is missing NO LONGER THAN 5 MINS. Tables to then look at specific elements of 'the package to deliver the vision' and suggest ways in which they could work. Tables to then look at specific elements of 'the package to deliver the vision' and suggest ways in which they could work. To include: <i>The government wants to build a National Care System that is fair, simple and affordable. They think that in this new system there are six things that you should be able to expect:</i> 1a Prevention 1b National assessment 1c Joined up services 1d Information and advice 1e Personalised care and support Key issues and recommendations agreed by group written up on flip chart paper Facilitator to keep discussion focused and prompt comments to be recorded <i>Lead facilitator to end discussions</i>

Time	Activity	Roles	Questions and notes
			Refer to handout Notes <i>Reference handout with 6 principles</i> <i>Facilitators to keep the discussion short and topline.</i> <i>Facilitators to focus on what is missing (i.e. any additions to the outlined vision.)</i> Key Question for discussion: 1. Is there anything missing from this approach? 2. How should this work? PROBE • Do you agree with the approach? • Has everything been captured? • What is positive about it?
15mins		Critical friend additions	Participants move around the venue to read through flipcharts on walls/screens. Chair/Lead facilitator to start and end discussions
5 mins		Changing groups	
25 mins	Discussion 2 – The new system	Table facilitators	Discussion 2: <i>Chair/Lead facilitator to start and end discussions</i> Table topics will be divided into:

Time	Activity	Roles	Questions and notes
			2a More joined-up working 2b Wider range of care and support services 2c Better quality and innovation ...to look at specific elements of ways to deliver the vision. "We think that in order to make the National Care Service work, we will need services which are joined up, give you choice around the kind of care you get, and are high quality." Consultation questions: – Do you agree? Does anyone disagree? – Focusing on the specific element you have chosen, in 2020 what would this look like in practice? – What would this look like in practice? – What are the barriers to make this happen? (What needs to be done to make this happen?) Key issues and recommendations agreed by group written up on flip chart paper • Facilitator to keep discussion focused and prompt comments to be recorded
		2a More joined-up working	
		2b Wider range of care and support services	

Time	Activity	Roles	Questions and notes
		2c Better quality and innovation	
10mins		Critical friend additions 2	Participants move around the venue to read through flipcharts on walls/screens. Chair/Lead facilitator to start and end discussions
		Return to Groups	
			SAVE WORK
15 mins	Presentation on funding	DH	
30 mins	Discussion 3 – funding	Table facilitators	Open the discussion reviewing the different options in the GP. Use personal preference sheets and fill in 'before' side. Key thoughts issues. Participants to complete preference sheets selecting their preferred option/best fit and saying why – pre and post discussion. It would be really helpful if they put their coloured sticker on their sheet to help us analyse whether your view is endorsed by others with your background and experience and/or across all involved in care and support in different ways.

Time	Activity	Roles	Questions and notes
			To discuss: The Government is suggesting three ways in which the National Care Service could be funded in the future: Partnership Insurance Comprehensive Consultation question: Which of these options do you prefer, and why?
			SAVE WORK
10 mins	Presentation on national/local	DH	
20 mins	Discussion 4 – national/local	Table facilitators	Participants identify advantages and disadvantages of national option (can discuss part national part local as well if this helps their thinking). Participants to fill in proforma on national vs local.

Time	Activity	Roles	Questions and notes
		Advantages	
		Disadvantages	
10 mins	Q&A	DH official/Minister	On stage. Roving mic
5 mins	Summary and close		On stage
	Event ends	Table facilitators	Please ask delegates to complete evaluation forms
			SAVE WORK

ANNEX 4: FUNDING OPTIONS

VOTING SHEET

Big Care Debate – Funding Options

Location: _____

Put your
coloured
sticker here:

Time (please circle): Morning / Afternoon / Evening

**PLEASE COMPLETE THIS SIDE OF THE HAND OUT BEFORE
UNDERTAKING THE DISCUSSION ON FUNDING OPTIONS**

The Government is suggesting three ways in which care and support could be funded in the future.

Which of these options do you prefer?

- ☐ **Partnership:** the responsibility for paying for care would be shared between the Government and the person who has care needs. The Government provides between quarter and a third of the cost of care, more for people on a low income. Today's 65 year olds will need care costing on average £30,000
- ☐ **Insurance:** the same as Partnership but the Government could help people prepare to meet the costs that they would have to pay for themselves, through an insurance-based approach. As well as receiving between a third and a quarter of the cost of care, the Government would make it easier for people to take out insurance to cover care costs. It is estimated that the cost of insurance could be around £20,000 to £25,000.
- ☐ **Comprehensive:** everyone over retirement age who can afford it would pay into a state insurance scheme meaning everyone who needs care will receive it free. It is estimated that the cost of being in the system could be between £17,000 and £20,000.

Please explain your choice.

PLEASE COMPLETE THIS SIDE *AFTER* YOUR DISCUSSION ON THE FUNDING OPTIONS

The Government is suggesting three ways in which care and support could be funded in the future.

Which of these options do you prefer?

- ☐ **Partnership:** the responsibility for paying for care would be shared between the Government and the person who has care needs. The Government provides between quarter and a third of the cost of care, more for people on a low income. Today's 65 year olds will need care costing on average £30,000
- ☐ **Insurance:** the same as Partnership but the Government could help people prepare to meet the costs that they would have to pay for themselves, through an insurance-based approach. As well as receiving between a third and a quarter of the cost of care, the Government would make it easier for people to take out insurance to cover care costs. It is estimated that the cost of insurance could be around £20,000 to £25,000.
- ☐ **Comprehensive:** everyone over retirement age who can afford it would pay into a state insurance scheme meaning everyone who needs care will receive it free. It is estimated that the cost of being in the system could be between £17,000 and £20,000.

Please explain why your choice has/has not changed.

Optional information

Name: _____

Organisation: _____

Job Title: _____

ANNEX 5: NATIONAL/LOCAL OPTIONS VOTING SHEET

Big Care Debate – National / Local

Location: _____

Put your
coloured
sticker here:

Time (please circle): Morning / Afternoon / Evening

Should local government say how much money people get depending on the situation in their area, or should national government decide?

Which of these options do you prefer?

☐

Part national/part local

Local Authority decide how much to be spent on care

☐

Fully national system

Government would decide how much to be spent on care

Please explain your choice.

Optional information

Optional information

Name: _____

Organisation: _____

Job Title: _____

ANNEX 6: EVALUATION QUESTIONNAIRE

Big Care Debate: Event Evaluation

Thank you for participating in the Big Care Debate event today. Please take the time to complete this evaluation form. Your feedback on the event is important to us.

Location: _____

Time (please circle): Morning / Afternoon / Evening

To what extent **do you agree or disagree** with the following statements?

Please tick ONE box in each line	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
The aims and objectives of the event were clear					
The structure of the event enabled us to discuss the issues properly					
The information and material presented was clear and helpful					
The facilitation of the table discussions was fair and balanced					
All the main issues were debated					
I feel confident that the output from these events will be used to help formulate policy					
I found the event was useful and worthwhile					
I will also be participating in this debate in other ways (e.g. online)					
I will be encouraging others to participate in this debate					
The venue was suitable for the event and had suitable facilities for my needs					

PTO

What topics did you discuss in session 1? (please circle)

Prevention Services	National Assessment	Joined-up Services	Information and Advice	Personalised Care and Support

What topics did you discuss in session 2? (please circle)

More joined-up working	Wider range of care and support services	Better quality and innovation

What were the best / most useful aspects of the event?

Where there any aspects of the day you felt did not work well? If yes, what could be changed?

Has your opinion on anything related to care and support changed throughout the course of the day? If so, please provide details.

Do you have any other comments?

Thank you very much for taking the time to complete this questionnaire.
Please leave it on your table or registration desk before you leave.

ANNEX 7: ATTENDING ORGANISATIONS

Care and Support Green Paper Consultation Events

Organisations represented by region

East Midlands

Action for Blind People	East Midlands JIP	Parkinson's Disease Society
Age Concern and Help the Aged	Grantham Deaf Children's Society	Pat Clarke Qualifications
Age Concern Kesteven	Guardian Care Homes	PDCS
Age Concern Lincoln	Leicester City Council	Radford Care Group
Age Concern Spalding & District	Lincolnshire County Council	RNIB
Allied Healthcare Group	Lings Bar Hospital	Rural Community Council (Leics & Rutland)
Alzheimer's society	Local Involvement Network	Rutland County Council
Business Link	Mencap	Sheffield City Council
Carers Forum, Nottingham	North East Lincolnshire LINK	Skills for Care
Coventry Carers' Centre	North East Lincs Care Trust Plus	Spalding & District Age Concern
Crossroads Care - East Midlands	Northamptonshire LINK	The Carers Federation
Department for Work and Pensions	Nottingham Community Housing Association	The Stroke Association
Derby City Council	Nottingham Trent University	UNITE Trade Union
Derbyshire LINK	Nottinghamshire County Council	Voluntary Action-Leeds
Dorset Community Health Services		Wren Hall Nursing Home

East of England

Adult & Community Services	Allied Healthcare Group Ltd	ASSOCIATION OF DISABLED PROFESSIONALS
Adult Day Care Ltd	Alzheimer's Society	Bedford Borough Council
Adult Social Services	Anglia Region Pensioners Association	BAME
Age Concern & Help the Aged	NPC	British Polio Fellowship
Age Concern (NOPIP)	Ann James Ltd	Broadland Housing Association
Age Concern North Norfolk	Asperger East Anglia Association for Spina Bifida & Hydrocephalus (ASBAH)	Bucks County Council
Age Concern Norwich		

Cam Sight (Cambs. Society for the Blind & Partially Sighted)	Hightown Housing Association	Norfolk Coalition of Disabled People
Cambridgeshire County Council	Housing21	Norfolk County Council
Care and Repair England	HPFT	Norfolk County Council, Adult Social Services
Care Quality Commission	Hugh Gault	Norfolk Learning Difficulties Service
Care Solutions Group	Huntingdonshire Society for the Blind	Norfolk Links
Care UK	Hunts Care	Norfolk Older Peoples Forum
Central Bedfordshire Council	Joint Learning Disability Service	Norfolk Probation
Cephas Care	KIDS West Midlands Orchard Centre	Norfolk Supporting People
Chill4usCarers	Kinexus Consulting Inc	North Hertfordshire Homes
Christies Care Ltd	Leonard Cheshire Disability	Norwich and District Carers Forum
Citizens Advice	LiNK	Norwich Old People Insertion Project (NOPIP)
Civil Service	Lockwood Hall Associates Ltd	Opportunity Links
Pensioners' Alliance Norfolk Group	London Borough of Sutton	Optua UK
Coalition of Elderly People	Luton Borough Council	Orbit East
CSV	Norfolk Coalition of Disabled People	Papworth Trust
DIAL Great Yarmouth	Mencap	Parker Castle (Financial Management) Ltd
Douglas Campbell Consulting Ltd	Mentoring and Befriending Foundation	Parkinson's Disease Society
Dudley MBC	Mid Norfolk Mencap	PCVS
DWP	Mobilise	Peterborough Community service
Equality and Human Rights Commission	MS Society	Peterborough Council for Voluntary Service
Essex County Council	National Pensioner Convention Anglia	Rethink Bedfordshire Carer Support
Essex Independent Care Association	National Union of Journalists	Royal College of Nursing
Great Yarmouth Visually Impaired User Group	NCC ASSD	Self Unlimited
Hertfordshire Care Providers Association Ltd	NHS Norfolk	Skills for Care
Hertfordshire Community Healthcare Services	Norfolk & Waveney Mental Health MHS FT	South Norfolk Older People's Forum
Hertfordshire County Council	Norfolk & Norwich University Hospital	Southend Borough Council
Hertfordshire LiNK	Norfolk Adult Social Services	
	Norfolk and Waveney Mental Health NHS Foundation Trust	

Spinal Injuries
Association
St Matthew Housing
Stowcare Ltd.
SUF
Suffolk County Council

Suffolk Family Carers
Suffolk Independent
Living
Suffolk LINK
Suffolk Supporting
People

The Abbeyfield Society
The Benefits Shop
The Thalidomide
Society
Thurrock Council
Voluntary Norfolk

London

Action for Advocacy
Advocacy in Barnet
Affinity Trust
Age Concern
Age Concern
Kensington & Chelsea
Age Concern Kingston
upon Thames
Age Concern London
AgeCare
Apetito
Area Benefit Team
Association of British
Insurers
Barnet Carers Centre
Benevolence Today
British Association of
Social Workers
British Heart
Foundation
Canterbury Oast Trust
Care Quality
Commission
Carer end of life
Carers Action Group
Caretrak
CaVSA H&F
(Community and
Voluntary Sector
Association)
CEMVO (Essex and
Southend LINK project)
Central and Cecil
Centre of Excellence in
Interdisciplinary Mental
Health

CNRT
CNWL NHS
Foundation
Trust/SLAM
College of
Occupational Therapy
Compassion in Dying
Consultancy Services
Contact a Family
Crossroads Lea Valley
Crunch Consulting Ltd
Disability Law Service
Disability Voice
Bromley
DK Maslyn Ltd
DWP
Ealing LINK
East and Coastal Kent
Primary Care Trust
East Living (previous)
East Sussex County
Council
Epsom & St Helier
NHS Trust
Essex and Southend
LINK
FirstStop Advice
GCPA
Greater London Forum
for Older People
Greenwich Council
Guinness Care &
Support
Hampshire County
Council

Harringay Learning
Disabilities Partnership
Board
Harrow Carers
Harrow Council
harrow mental health
services
Headway - The Brain
Injury Association
Heritage Care
Hertfordshire Money
Advice Unit
Hft
Hillingdon Carers
Home Instead Senior
Care
ILAG
Independent Age
ISLINGTON
DISABILITY
NETWORK
Jewish Care
John Lewis Partnership
John Lewis PLC
Kent County Council
KINGSTON LINK
Lambeth Link
Lawns NCC LLP
LB Hillingdon/NHS
Hillingdon
LB Richmond upon
Thames
Leonard Cheshire
Disability Service User
Support

Linkline Telecare Service
LONDON & ANGLIA REGION 10 RMA
London Borough of Barnet
London Borough of Croydon
London Borough of Enfield
London Borough of Greenwich
London Borough of Haringey
London Borough of Hounslow
London Borough of Lambeth
London Borough of Richmond upon Thames
London Borough of Southwark - Health and Social Care Dept
London South Bank University
Look Ahead Housing and Care
Macmillan Cancer Support
Maidstones Carers Project
Mental Health Foundation
Mental Health Foundation
MoJ

Motor Neurone Disease Association
National Society for Epilepsy
NCC
Neighbours in Poplar
Nestor plc
NHS Camden Provider Services
NHS Eastern and Coastal Kent
Norfolk Learning Difficulties Officer
NUS HQ
Opportunity links
Pure Innovations Limited
RAISE
Richmond AID
Richmond upon Thames LINK
Royal Borough Windsor & Maidenhead
Royal Mencap
RSI Action
Saga Health
Scope
Self
SENPeC
Service User and Croydon LINKs
Skills for Care
Slough Borough Council
St Dunstons

Surrey Care Association
Systems 4
Systems 5
The Encephalitis Society
The King's Fund
The Princess Royal Trust Salford Carers Centre
The Resident's and Relatives Association
The Social Security Advisory Committee
Thurrock Council
Tower Hamlets LINK TUC
Tunstall Healthcare (UK) Ltd
University of Brighton
Walsingham
Wandsworth Borough Council
Warwickshire Association for the Blind
West Sussex County Council
Willow Housing & Care
Wimbledon Guild
WinVisible (women with visible & invisible disabilities)
WSCC

North East

Action for Blind People
Action for Health - Senior Citizens in Newcastle
Adapt

Adult Wellbeing and Health
Advocacy Together Darlington
Age Concern Gateshead

Age Concern North East
Age Concern North Tyneside
Autism-in-Mind
Newcastle City Council

Care UK	HQN / PFA	Parkinson's Disease Society
Carers Centre Newcastle	John Lewis Partnership Links	PCS Arms Group
Carers Federation	MENCAP	Quality of Life Partnership
Carers Northumberland	Mental Health Concern	Real Life Options
Carers UK	Mental Health North East	Redcar and Cleveland Borough Council
Centre Against Unemployment	Middlesbrough Council	Redcar and Cleveland LINK
Community Integrated Care	Middlesbrough Council Dept Social Care	Redcar and Cleveland Welfare Rights Unit
DAMHA	Motor Neurone Disease Association	Rochdale MBC
Darlington Adult Learning Disabilities Carers Group	MS Society	Self Unlimited
Darlington Association on Disability	NEMH DU	Sight Service
Darlington Borough Council	Newcastle City Council	Sitra
Darlington LINK	Newcastle University	Skills for Care
Darlington PCT	NHS	South Tyneside Council
DH	NHS Alliance	St Anne's Community Service
Disability Inclusion Tyneside	NHS Middlesbrough	Stockton Borough Council
Disability North	North Tyneside LINK	Stockton Borough Council/ Stockton on Tees PCT
Durham County Council	North East Mental Health Development Unit	Stockton-on-Tees Borough Council
DWP	North East PCOs Policy Unit	Stockton-on-Tees LINK
Edward Lloyd Trust	North Tyneside	Sunderland City Council
Elders Council of Newcastle	Coalition of Disabled People	Sunderland City Hospitals
Epilepsy Action	North Tyneside Council	Sunderland LINK
Gateshead Community Care Forum	North Tyneside Learning Disability Partnership Board	Tees Valley Alliance
Gateshead Advocacy Information Network	North Yorkshire County Council	Teesside University
Gateshead Council	Northern Housing Consortium	The Princess Royal Trust for Carers
Gateshead LINK	North Tyneside Council	The Social Security Advisory Committee
Gentoo	Northumberland Care Trust	The Stroke Association
Hartlepool Borough Council	Northumberland County Council	Tyne and Wear Care Alliance
Health, Housing & Adult Services, Sunderland City Council	Northumberland LINKs & Northumbria NHS. Foundation Trust	Wales Asbestos Victims' Support Group
		Wear Valley Women's Aid

North West

Action for Blind People
Adult & Cultural
Services Directorate,
CCC
Adult Care Services,
Bury Council
Adult Social Care,
Adult & Cultural
Services, Cumbria
County Council
Age Concern
Age Concern Carlisle
and Eden
Age Concern South
Lakeland
AgeConcern +
CUMBRIA LINK
[Chairman]
Alzheimers Society
Carlisle Branch
APETITO
Blackburn Diocese
Blackburn with Darwen
Adult Social Care
Blackburn with Darwen
Borough Council
Blackburn with Darwen
LINK
Blackpool Council
Bolton Welfare Rights
British Polio Fellowship
Bunley PDS Branch
Care Quality
Commission
Carers Action Forum
Carers Federation/Host
Carers Link
Carers Resource
Carlisle Carers
Carlisle MIND
Changingtogether

Cheshire Centre for
Independent Living
Cheshire West and
Chester Borough
Council
Cheshire West and
Chester Council
Civil Service Pensioner
Alliance/National
Pensioners Convention
CLS Care Services Ltd
Community Integrated
Care
Contour Homes
Copeland Disability
Forum
Craegmoor
Croftlands trust
Crossroads Care Bury
Crossroads Care,
Cumbria
Cumbria Adult and
Cultural Services
Cumbria County
Council
Cumbria County
Council - Adult Social
Care
Cumbria County
Council - Cumbria
Care
Cumbria County
Council/NHS Cumbria
Cumbria CVS
Cumbria Partnership
NHS Foundation Trust
Cumbria Strategic
Partnership
Cumbria View care
Services
DH
Dial

Disability Advice &
Information St Helens
Disability Association
Carlisle & Eden
Disabled Parent
Network
DMBC - Directorate of
Adult and Community
Housing Services
DWP
Eden Carers
Eden Community
Alarms
Eden Mencap Society
Eden Valley Hospice
Finegan Consulting Ltd
Foundations, the
National Body for
Home Improvement
Agencies
Gateshead Carers
Association
Greater Manchester
Asbestos Victims
Support Group
Halton Borough
Council
Halton Voluntary
Action
Health & Care
Together
Heathlands Village
HMT
Home Instead Senior
Care
Housing 21
Hyndburn Crossroads
IDeA
Impact Housing
Association
In Control User
Consortium

Independent Direct
Payment Forum
Knowsley LINK Support
Knowsley MBC
Lancashire County
Council
LINK
Liverpool Charity and
Voluntary Services
Liverpool Crossroads
Liverpool Local
Involvement Network
(LINK)
Manchester Advice
Manchester City
Council
Manchester LINK -
Black Health Agency
Mentoring +
Befriending Foundation
Merseyside Asbestos
Victims Support Group
Merseyside Coalition of
Inclusive Living
MND Association
MS Society
NHS
NHS Cumbria
NHS Sefton
North West Joint
Improvement
Partnership
NWJIP
Oaklea Trust
Oldham Council
One Vision Housing

South East

Advocacy Partners
Age Concern
Maidstone
Allied Healthcare

Owls
Parkinson's Disease
Society
Pennine Care NHS
Foundation Trust
Penrith Hospital
League of Friends
Personalisation 4 You
Pilkington family trust
funds
Princess Royal Trust
Salford Carers Centre
Prospect House
Rescare
RNIB
Rochdale and District
Mind
Rochdale Metropolitan
Borough Council
Royal College of
Nursing
Salford City Council
Salford Welfare Rights
and Debt Advice
Service
SANDWELL MBC
Sefton Carers Centre
Sheffield City Council
Shipley College
Speak Up Group
St Gregory's House
St Helens Council
St Mary's Carers Ltd
St Vincent's Housing
Association
Stockport Advice

Stockport Council
Stockport Hospital
Sue Ryder Care
Sunshine Care
Tameside MBC
Tameside MBC Adult
Services
TAMESIDE
METROPOLITAN
BOROUGH COUNCIL
The Generation project
The Mentoring +
Befriending Foundation
The Regenda Group
Together
Trafford Council
Trafford Housing Trust
Vegetarian for Life
Voices 4 Wellbeing
(Rochdale Borough
Local Involvement
Network)
Warrington Carers
Centre
West Cumbria Carers
West House
WESTMORLAND
COURT
Wirral Partnership
Homes
Worcestershire
Association for the
Blind
Wyre Strategic
Partnership

Brighton and Hove City
Council
Brighton and Hove
Reform Synagogue
Carers Forum
Chapter 1

Cherchefelle Housing Association
 Citizens Advice
 Coate Water Care Co. Ltd
 Department of Community Care
 Disability Croydon
 Downland Housing Association
 East Sussex County Council
 East Sussex County Council Supported Accommodation Team
 Folkstone Methodist Church
 GP Practice
 Greensleeves Homes Trust
 Hampshire County Council
 Hasting Borough Council
 Hertsmere Borough Council
 Hospice in the Weald
 Housing 21
 Hurman Management Consulting
 Independent Age
 Islington council

Kent and Medway Care Alliance
 Kent County Council - Adult Services
 Kent Social Services
 LB Hillingdon
 LDPB
 London Borough of Bexley
 London Borough OF Hillingdon
 London Borough of Richmond
 Maidstone Child Development and Therapy Centre
 Medway Council
 Mentoring and Befriending Foundation
 Michael Yoakley's Charity
 National Mencap
 New Downland Housing Association
 NHS
 NHS Berkshire West
 Open Sight (and National Association of Local Societies for the Visual Impaired)
 Oxfordshire County Council

Prestige Nursing Ltd
 Regal care homes
 Royal Borough of Windsor and Maidenhead
 Royal British Legion
 Social Care Institute for Excellence
 Somerset Day Centre
 Surrey Coalition of Disabled People
 Surrey County Council
 Surrey Heath and NE Hants Mental Health Forum
 TESTWAY HOUSING
 Together: 'Working for Wellbeing'
 Topaz Community Ltd
 Tribal Consulting
 West Kent Community Health
 West Kent Community Trust
 West Kent Housing
 West Sussex County Council
 Wokingham Borough Council
 WRVS

South West

Abilink
 Accessible Transport (South Coast) UK
 ACTAN
 Action for Blind People
 Action for M.E.
 Adult Social Care, Somerset County Council
 Advice Network

Age Concern Blandford Forum Dorset
 Age Concern and Help the Aged
 Age Concern Bournemouth
 Age Concern Brighton Hove Portslade
 Age Concern Hampshire
 Age Concern Somerset

Age Concern Torbay
 Allied Healthcare
 Altogether Care
 Alzheimer's Society
 Associate and Retired Members of the Public and Commercial Services Union
 BANES Council

BANES Local Involvement Network	Drake Family Care Services Ltd t/a Carewatch	NHS Bournemouth and Poole
Barnhaven Community Care	DWP	NHS Dorset
Borough of Poole	EXETER BRANCH	North Somerset Council
Bournemouth Borough Council	PDS	NovasCarman
Bournemouth Council	Exeter Senior Council for Devon	Nurse Plus and Carer Plus
Bristol City Council	Free Lance	Ophira Ltd
Bristol City Council Welfare Rights and Money Advice Service	Gloucestershire County Council	Ottery Locality Health and Care Team and Devon Health and Social Care Forum
Bristol Community PCT	GMB	Partners in Care
Broadstone Access Group	Guinness Care and Support	Plymouth City Council
Candlelight Homecare Services Ltd	Hampshire Community Health Care	Poole Borough Council
Canine Partners	Hampshire LINK	Poole Forum
Care Focus Somerset	Hampshire Local Involvement Network	Poole LINKs
Care Learning	Hanover Housing Association	Stewardship Group
CARE SOUTH	Headway Devon	Poole Mental Health Forum
Carers Together	Headway Dorset	Poole NHS Foundation Trust
Commission for Rural Communities	Help and Care	Portsmouth Pensioners Association
Cornwall Council	HFT	Princess Royal Trust for Carers
Crossroads - North Somerset	Home Instead Senior Care	RAISE
DCAB	Alstrom Syndrome UK	Registered Care Providers Assoc Ltd Somerset
Department for Work and Pensions	In.S.P.I.R.E Ltd	RNIB
Devon County Council	Independent	ROCC
Devon PCT	Island Healthcare Ltd	Self Direct Support
Devon Welfare Rights Unit Citizens Advice	John Lewis Partnership	Self Unlimited
Disability Action	Knightstone Housing Association	Self Unlimited Choice
Network of Plymouth	LINK in Cornwall	Senior Council Health and Safety Forum for Devon
Do Care Ltd	Living Options Devon	Sherborne Cab
Dorset Blind Association	Local Involvement Network BANES	Skills for Care South West
Dorset PCT	Lyndridgecare	Somerset Care at Home
DOTS	Mendip Housing Ltd	Somerset Care Ltd
Down's Syndrome Association	Moorcare Devon Its	
	Motor Neurone Disease Association	
	MS Society	

Somerset County Council
Somerset Sight
South Gloucestershire LINKs
South West Social Care Team
Department of Health
Southampton City Council
Spinal Injuries Association
St Dunstan's
St John Ambulance

Teignbridge Access Group
Teignbridge Access Group
The Koppers
The Macular Disease Society
The Princess Royal Trust Carers Centre - Bristol & South Glos
The PSP Association
The Wealth Care Partnership
Torbay Care Trust

Torbay Council
West Somerset Senior's Forum
West Sussex County Council
West Sussex PCT
Westlea Housing Association
Wiltshire Council
Wiltshire Involvement Network(Links)

West Midlands

ACCI
Adelaide House
Adult Services
Sandwell M B C
Advance Housing & Support LTD
Age Concern
Age Concern and Help the Aged
Age Concern Birmingham
Aim 4 (Warwickshire CC)
All Seasons Care Ltd
Alzheimer's Society
Asbestos Support West Midlands
Asha Women's Centre
Aston University
Base 25
BBT
Belle Vue Medical Centre
BID Services
Birmingham and Solihull Mental Health Trust

Birmingham Carers Association
Birmingham Centre For Inclusive Living
Birmingham City Council
Birmingham City Council adults and Communities Directorate
Birmingham Crisis Centre
Birmingham Resource Disability Centre
Birmingham St Mary's Hospice
BITA Pathways
Bourneville Village Trust
British Red Cross
BSMHFT NHS
CARES
CWPCT
Cannock Road Surgery
Cape Road Clinic
Carers Association
Southern Staffordshire

Cerebral Palsy Midlands
CHADD
Charnwood Residential Home
Citizens Advice Bureau
Community Involvement in Care and Health (Shropshire LINK)
Confederation of Bangladeshi
Coventry City Council
Coverage Care Services
Crossroads Care
Crossways Home
Cruise Birmingham
Department of Health West Midlands
Dudley CiP
Dudley Council
Dudley CVS
Dudley MBC
Dudley Metropolitan Borough Co
DWP

E R MASON Youth Centre	MS Society	Sandwell West Birmingham Hospitals NHS Trust
Education Welfare Service	My Life (Wolverhampton) Ltd	Scott Atkinson Centre
ELITE	National Probation Service	Sefton Health and Social Care Directorate
FCH	NHS Herefordshire	Self Unlimited
Foreign Office	Nuneaton Training Centre	Shree Vishwa Karma Association
Future Health & Social Care	Old Ben Homes	Shropshire Council
George Elliot Hospital	Orchard Service	SI of Central Birmingham
Greville House	Park Attwood Clinic	Simon Stevens
Harmony Care	Park Attwood Clinic	Sir Josiah Masons Trust
Hartlands Hospital	PARKINSON DISEASE SOCIETY	Sisters Hospitallers of the sacred heart of Jesus - Fotherly Hall
Health & Well-being Unit	Parkinson's Disease Society	Sitra
Hillcroft Nursing Home	PCT	Skills for Care
Hollyoaks Medical Centre	Priory Road family Health Centre	Social Care & Health
Housing 21	Radnor House	Social Services
INDEPENDENT	Radnor House	Solihull Care Ltd
IRC (Islamic Resource Centre)	Redditch YMCA	Solihull Carers Centre
Jubilee Citizens U.K. (Age Concern)	Redditch YMCA	Solihull Hospital
LGBT Women Against Anti Social Persecution	regional driving assessment centre	Solihull Local Involvement Network
Life Path Trust	Residential Administration	Solihull NHS Care Trust
Litchfield CAB	RNIB	Somerset County Council
Lobby. Central Birmingham	roshni	Soroptimist
Soroptimists	SSAFA	International of Central B'ham
M.E Staffordshire Support Group	Saltley and Nechalls Law Centre	South Warwickshire Care and Support Service
Malvern Health Centre	Sandwell Borough Council	St Chads Health Centre
Maypoles Children Centre	Sandwell Homes	St Mary Magdalene Church
MECC	Sandwell LINK (BCHG)	Staffordshire County Council
Mencap	Sandwell MBC	
Mencap Midland	Sandwell Mental Health and Social Care Foundation NHS Trust	
Mental Welfare Society	Sandwell Metropolitan Borough Council - Adult Services	
Mentoring & Befriending Foundation		
Midland Heart		
Morcom House		

Staffordshire County
Council Social
Services
Staffordshire JCU
Staffordshire Social
Care & Health
Stonham
Supporting People
Telford & Wrekin
Council
Telford VIP Group
Terrence Higgins Trust
The Homecare
Partnership
The Benefits Shop
The Haven
The Mentoring and
Befriending Foundation

The Myton Hospice
The Social Security
Advisory Committee
The Stroke Association
Transform Sandwell
Tunstall Healthcare
(UK) Ltd
UHCW
United Reformed
Church
University Hospital
WCC
Walsall Black Sisters
Collective
Walsall Borough
Council
Walsall Council

Walsall M B C
(Revenues and
Benefits)
Walsall M B C (Welfare
Rights and Fairer
charging)
Walsall Social Care
Walsall SUE
Welford House
WELSH ASSEMBLY
GOVERNMENT
West Midlands
Pensioners Convention
Worcestershire Care
Group Ltd
Worcestershire County
Council
Yardley Office

Yorkshire and the Humber

Age Concern and Help
the Aged
Age Concern Bradford
& District
Age Concern
Calderdale and
Kirklees
Age Concern Hull
Age Concern Leeds
Alliance of Service
Users and Carers
Alzheimer's Society
Ancholme Branch
Seniors Forum
ARC
Asp-ect
Aston Court
Autism Plus
Barnsley MBC
Barnsley Sexual Abuse
and Rape Crisis
Helpline
Blackburn with Darwen
Adult Social Services

BOPA - Bradford Older
Peoples Alliance
Bradford Adult
Services
Bradford Council
Bradford District Care
Trust
Bradford Primary Care
Trust
C4C
Calderdale Health and
Social Care
Calderdale LINK
Calderdale MBC
Carers Leeds
City of York County
council
Cloverleaf Advocacy
Community Action For
Roundhay Elderly
Community Care
Services
Connect in the North
Connections

Darlington Association
on disability
Department of Health
Dial Doncaster
Disability Advice
Bradford
Doncaster 50+
Doncaster LINK
DWP
E G Corbett consulting
East Riding of
Yorkshire Council
East Riding Quality
Homecare
Gloucestershire
County Council
Goodwin Development
Trust
Guardian Care Ltd
H3Plus PPAG
Halifax & District Irish
Society
Home Instead Senior
Care

Housing 21	Leeds Older People's Forum	Royal British Legion
Housing and Adult Social Services City of York Council	Leeds University	Royal College of Nursing
Hull and Yorkshire Coast Cancer Network	Leeds Adult Diabetes Consultative Group	Selby Carers Centre
Hull Churches Home from Hospital	LINK Wakefield District	Self Direct
Hull City Council	LINKS	Seniors Forum
Hull City Council, Community Care Services	Lives Unlimited	Shaw Trust - LINKs
Hull Council of Disabled People	Mencap	Sheffield City Council
Hull LINK	Mentoring and Befriending Foundation	Sheffield Hallam University
Hull Social Services	MND Association	Sheffield Local Involvement Network
Humber Mental Health (NHS Trust)	Multiple Sclerosis Society	Sheffield Hallam University
Independent Care Group	NHS Central Lancashire	Skills for Care
Independent Living Fund	NHS Leeds	Skills for Care Y&H
Joseph Rowntree Foundation	North Bank Forum	South Yorkshire Housing Association
Judith Cork Consulting	North East Lincs Council	St. Anne's Community Services
KEIGHLEY VOLUNTARY SERVICES	North Lincolnshire Council	Stockport MBC
Kirklees Education	Northbank Forum	The Disabilities Trust
Kirklees Neighbourhood Housing	Orchard Care Homes	The Wilf Ward Family Trust
Leeds Care Association	Parkinson's Disease Society	UKHCA
Leeds City Council	Passion for Support	Unison
Leeds City Council - Adult Social Care	Pensioner's Action Group East Riding	University of Leeds
Leeds Irish Health & Homes	Quality Care Partnership	Wakefield District LINK
	RAP	Walker Morris
	Rethink	Welfare Benefits Office
	Rotherham Crossroads	YHIP
	Caring For Carers	York Welfare Benefits Unit
	Rotherham General Hospital	Yorkshire & Humber Pensioners Convention
	Round Hay Care	Yorkshire Metropolitan Housing

Brighton

40-70 Tomorrow's Workforce	Brighton & Hove City Council	Brighton and Hove Impetus
Adur District Council	Brighton & Hove Older People's Council	

Brighton and Hove
Unwaged Advice and
Rights Centre
Brighton Unemployed
Centre
Carewatch Lewes and
Mid Sussex
Direct Payment
Employer
East Sussex Research
Associates
East Sussex, Brighton
& Hove Crossroads
Essex Independent
Care Association

Federation of Disabled
People for Brighton &
Hove
Headway
Lewis Elderly Forum
Mearsgroup
Money Advice and
Community Support
NHS Brighton & Hove
Novas Scarman
OPCAT
People's Engagement
and Development
Network NHS South
East Coast

Royal Ballet
Benevolent Fund
SASH - Sussex
Aphasia Self-Help
Service User
Southdown Housing
Association
SPIN / TDC
The Carers Centre for
Brighton and Hove
THE PINES NURSING
HOME
West Sussex County
Council
York House and
Aldemore



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