Care Services Improvement Partnership CSIP

National Institute for
Mental Health in England

Valuing Involvement

Strengthening Service User and Carer Involvement in NIMHE

Communication Strategy:

Enabling and valuing the involvement of people with direct experience of mental health problems and their carers

A product of the Making a Real Difference Project (see overview for details)

Overview

The Making a Real Difference Project was undertaken in direct response to the HASCAS review of service user and carer involvement in NIMHE. This resulted in the Making a Real Difference report.

The following communication strategy is designed to address some of the recommendations made within the report. It provides the principles and values associated with effective communication with people living with mental health problems and their carers

This document provides NIMHE and its staff good practice guidelines and checklists to facilitate effective communication.

Who is the Communications Strategy for;

New NIMHE Staff and Volunteers

- All new staff should familiarise themselves with the communications strategy to ensure that they gain the full benefit of the guidelines when planning and delivering their work programmes. Any queries should be discussed with their line manager.
- All new work programmes should be designed in line with the strategy and be supported by the guidelines.

Existing NIMHE Staff and Volunteers

- Existing staff members should familiarise themselves with the communications strategy.
- Existing staff should ensure that their work is supported by the guidelines contained with the document, and should be striving to meet the values and principles within the strategy.
- Any new work programmes should be developed in line with the communication strategy, and be supported by the guidelines.

People sharing their expertise to inform NIMHE's work

- All people should be made aware of the expectations within the communication Strategy so that they are clear about what to expect when they are involved with NIMHE and its work programmes.

NIMHE Boards, Commissioners and Performance Managers (including external stakeholders)

- All NIMHE work programmes should be expected to include plans to achieve the supporting principles of the communication strategy.
- All NIMHE work programmes should provide regular feedback with regard to performance against the strategy.
- All monitoring and evaluation of work programmes should include measures of performance against the strategy.

Acknowledgements

The communication strategy was developed and written by Yvonne Pearson on behalf of the Making a Real Difference Project.

The work was informed and overseen by the East Midlands Making a Real Difference Work Group 1 Steering Group;
John Howatt
Piers Allott
Sylvia Minshull
Moira Kerr
Karen Colligan
David Gardner
Trish Crowson
Philip Douglas.

The make up of the steering group was as follows;

Designation	Numbers	% of group
Advisory group	8	100%
CSIP Staff	3	37.5%
People with experience of using mental health services including	3	37.5%
People with experience of caring	2	25%

There are so many people across the East Midlands who influenced, supported, assisted and directed the development of this strategy and my heartfelt thanks go to each of them for finding the time to become involved.

I'd particularly like to thank the following people for their detailed comments on the first draft:

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Around 430 people had the opportunity to become involved in the development of the communication strategy. (The full list is attached as appendix 1)

This work is dedicated to the memory of John Howatt, a person who touched and inspired many during his long career in mental health. John was a charismatic leader, empowering in his approach and always a joy to work with.

Contents

Introduction

The purpose of this paper is to set out a communication strategy which enables the full involvement of people living with mental health problems and those who support them, in all aspects of the work of the mental health programme (NIMHE) of the Care Services Improvement Partnership.

This strategy will focus exclusively on how NIMHE communicates with people living with mental health problems and their carers to support and enable their involvement in all aspects of its work.

The communication strategy is a clear demonstration of NIMHE’s stated commitment to putting ‘service users, families and communities’ at the centre of everything it does. It will include:

1. What it aims to achieve.
2. The principles and values which underpin the strategy and their importance and relevance.
3. A good practice guide to implementation incorporating a quality standards checklist

The aim of this strategy

The aim of this communications strategy is to enable the informed, equal, effective and inclusive involvement of people living with mental health problems and their carers in the work of NIMHE, both locally, regionally and nationally.

Chapter 1 - The principles and values underpinning this strategy

The communication strategy is based on the following values and principles:

- Using communication as a means of empowering people through developing, sharing and mainstreaming ‘expert by experience’ knowledge.
- Building capacity by supporting effective communication between service user and carer networks
- Only providing information which is relevant, timely and meaningful to people’s involvement activity.
- Promoting equal partnership by communicating in an honest, open and respectful way.
- Providing clear and relevant information to support people’s ability to participate on equal terms, in all meetings, events and conferences.
- Demonstrating the value and impact of people’s involvement.
- Proving accessible information which promotes the inclusion of people from a broad range of backgrounds, ages and experiences of living with mental distress.

Chapter 2 - Why are these values and principles so important?

Principle one - Using communication as a means of empowering people through developing, sharing and mainstreaming ‘expert by experience’ knowledge.

Increasing interest in ‘evidence’ or ‘knowledge based practise’ can put user and carer led organisations who do not have real opportunity to share their ‘expert by experience’ knowledge, stories and experiences at a disadvantage. It is important that we use our communication capacity to enable this important knowledge to be gathered, developed and shared to the widest audience so it can make a real impact on health and social care policy and provision.

It is also important that people with lived experience and their supporters are enabled to take control and actively participate in the means by which their knowledge is developed, presented and shared.

Principle two - Building capacity by supporting effective communication between service users and carer networks

People with lived experience and their supporters have highlighted the importance of being able to network with each other in order to sustain a more effective voice and make a real difference. Research undertaken by Shaping our lives[1] (2006) revealed that many service user organisations and individual service users are isolated with little knowledge or contact with other service user organisations locally, regionally or nationally. This can be due to a number of factors such as:

- Problems of mobility, especially in rural areas.
- Limited capacity with a reliance on a few activists
- Inadequate or insecure funding and resources, especially compared to the resources available to large voluntary sector provider agencies, to enable them to adequately reach out to recruit other members or inform people about their activities.

Networking is central to combating isolation, institutionalisation, segregation and marginalisation. It is a key route to strengthening ‘expert by experience’ knowledge and increasing its credibility and visibility. Self organisation and ‘doing things together’ is an effective way of challenging powerlessness and exclusion. Involvement often starts at a very local level by attending a meeting. NIMHE can support this activity in two important ways; through helping to inform as wide an audience as possible about grassroots activity and by putting smaller groups in touch with other networks around the region and across the country, to allow the sharing of knowledge and capacity.

Principle three - Only providing information which is relevant, timely and meaningful to people’s involvement activity.

Providing information that is relevant.

Information is key to involvement but it can be equally disempowering to receive either too much or too little information.

The information flow to individuals needs to be actively managed by putting in systems to:

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[1] Making user involvement work –supporting service user network and knowledge (2006) F Branfield et al: funded by Joseph Rowntree Foundation email inf@jrf.org.uk tel 01904 615905

- ensure that people are not overloaded with information by the sending of indiscriminate information which is irrelevant to their particular involvement activity and
- ensure that people are provided with all the necessary information to support their full involvement.

Providing information that is timely

It is important that people receive information in time to allow them the opportunity to individually absorb it and where relevant, receive feedback from other groups and individuals. This is especially important if the involvement activity is about representing the interests of a particular group of people. People will be unable to fulfil their representative role if they do not receive their information in time to achieve this.

Providing information that is meaningful to people's situation and experience

The majority of written material relating to health and social care, from minutes of local meetings to national policy guidance is written in a way that presumes the reader has a high level of existing knowledge about current legislative and policy frameworks, management of services and working practices. Material which is written in this way makes it harder for people without a professional background in health and social care to understand what is going on and how the information they are receiving relates to their situation as a carer or past, present or potential user of services.

The government has made great strides in providing information in an easy read form but to enable full and equal involvement of people with mental health problems and their carers it is important to that all information is summarised in a way that not only explains any jargon but sets out the main issues, changes and implications from both a carer and service user perspective.

These summarises should be provided with all written material from national policies and consultations to minutes of meetings.

Principle four: Promoting equal partnership by communicating in an honest, open and respectful way.

A commitment to openness and honesty

All communication should be open and honest. This is particularly important in situations where the involvement activity has not resulted in the desired outcome. It is natural for people to be disappointed if they have been unable to influence a situation but it is very important that the organisation continues to communicate with people in an equal and honest way and takes responsibility for ensuring that people are kept informed about the impact of their involvement.

Principle five: Providing clear and relevant information to support participation in all meetings, events and conferences.

Practical information to enable attendance at meetings/events and conferences.

When people living with mental health problems and their carers are either participating in or attending any meetings or events they can expect to be informed in advance about:

The payment policy and payment of expenses

Information about meetings/conferences and events should clearly state whether attendance would attract either a payment or the payment of expenses and what arrangements will be in place on the day.

Getting to and from the venue and access at the venue

People who are reliant on public transport are often disadvantaged when it comes to accessing meetings as generally more planning is required to co-ordinate transport. To support attendance, accurate and clear information about all issues to do with transport and venue accessibility should be supplied in sufficient time to enable people to make the necessary plans.

Availability of a named CSIP contact

Often unforeseen problems arise on the day and people want to be confident that they can find out information quickly or get a message to people at the meeting or event. A person who has knowledge of the meeting/event and the place where it is being held should be contactable by telephone throughout the day.

Adequate notice of meetings

People with experience of mental health problems and their carers need a reasonable period of notice of meetings/conferences and events to give them the opportunity to make the necessary arrangements to ensure their attendance. Each RDC should develop and advertise their standards relating to how much notice people can expect of events so that they can have the security of knowing that they will have the time to make any necessary arrangements to support their involvement.

The provision of information to support equal and effective involvement:

Being explicit about the purpose of involvement in all publicity materials

Beyond the important practical concerns, people want to know why their involvement is required so they can assess the likelihood that their participation will have any impact. They also need to know where their involvement activity fits within the wider context of the area, region or organisation. People can only make real choices about the proposed value and impact of their involvement activity if they in possession of all the relevant information. If people are unclear about the purpose or nature of their involvement activity, or indeed where it fits into the wider picture they are more likely to be disappointed with the outcome and less likely to continue being involved.

Relevant history and background of the matter being discussed

Many people who come into involvement activity have limited experience of services which places them at a considerable disadvantage to professional colleagues with training in health and social care.

To ensure effective involvement it is important that people are given sufficient information which directly relates to the particular involvement activity they are engaged in:

- **Information for one-off consultation events or focus groups**:

People will need to be provided with sufficient background material either prior to the event or at the event to ensure their informed participation. If information is not made available prior to the meeting it is important that enough time is devoted during the meeting to allow people to properly absorb the information before they are asked to comment. If people are expected to represent the views of others on a specific issue then information will have to be made available well in advance of the meeting.

- **Information to support ongoing participation in implementation, strategic planning, monitoring or governance.**

In order to participate fully and effectively people will require a range of information including:

a) Working knowledge of relevant legislative and policy framework and practise standards.

b) Knowledge of how the relevant organisations are structured, operate and work together.

c) Clarity about their role and responsibilities as well as any boundaries associated with their involvement.

d) Knowledge of the decision making framework they are expected to operate within.

The importance of understanding how organisations are structured and how decisions are made was highlighted in ‘Promoting Effective Citizenship and Community Empowerment[2] ‘:

“The Internet is a powerful tool for pulling together information about government, including decision-making structures. But surprisingly few councils provide simple diagrams – perhaps an organogram – to help people negotiate the complex structures of local partnership working” (2006:p.11)

It is surprising that services which are committed to offering information about such matters as the availability of services, eligibility, charging and how to make complaints, by contrast, rarely offer relevant organisational information about their structure and inter-agency decision making processes.

In the context of NIMHE work; where a person was involved as a carer representative for their locality on a CSIP Regional Implementation Group they would require information about the role of the Regional Group they sit on, the role of any national group they report up too and any local groups they are expected to consult with. This information may be more effectively presented as a series of flow diagrams but it is irrelevant how the material is presented, it is just important that the organisation which is seeking the involvement provides clear information about the full decision-making pathway to clarify what decisions people are able to make at each level.

Absorbing large amounts of policy and guidance can be overwhelming, yet in order to contribute effectively people are required to understand a large volume of information. Consideration needs to be given to the most effective way of supporting people’s learning especially in informal settings. Options could include the development of ‘learning sets’ which could be run along the lines of book clubs or the use of online chat rooms developed around a particular initiative.

Equally, people need to be given the opportunity to share lessons that can be learnt from practical experiences of getting involved in political issues, local partnership or voluntary groups. The importance of ‘reflective learning’ is discussed in Promoting Effective Citizenship and Community Empowerment (2006:p.16).

Many voluntary sector organisations offer training to support involvement and it is important that people are offered information about training opportunities and signposted to them.

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[2] ‘Promoting Effective Citizenship and Community Empowerment – A guide for local authorities on enhancing capacity for public participation’ :R Andrews et al Feb 2006 Office of Deputy Prime Minister: London

Principle six: Demonstrating the value and impact of people’s involvement.

The provision of full and timely feedback is the most positive way for an organisation to demonstrate that it places a high value on involvement.

A SCIE review (2004)[3] looking into the effectiveness of service user participation highlighted the importance of feedback as an integral part of the participation process and stated that “*agencies should see monitoring of impact and meaningful feedback as a vital constituent of the user participation initiative, as it is related to engagement and commitment” (2004:p.9).*

The SCIE study also reported that the failure to provide any or sufficient feedback had a negative effect on people’s motivation and confidence. Frequent consultations without adequate feedback can lead to a continued feeling of disempowerment, cynicism and disengagement.

It is equally important that organisations take responsibility for the widest dissemination of feedback instead of relying on individuals to feed back to their communities of interest. This processes can be supported by ensuring that information in delivered in a variety of formats relevant to the diverse audiences.

Principle seven: Providing accessible information which promotes the inclusion of people from a broad range of backgrounds, ages and experiences of living with mental distress.

Information that is accessible

Please cross reference with: Guidelines for supporting communication with Diverse Groups’ – Making a Real Difference Involvement Resource Pack.

Please cross reference with minimum standards for engaging diverse groups and communities – Making a Real Difference Involvement Resource Pack.

Different methods

Information can be given out and received in a wide variety of ways through the internet by the use of; chat rooms, web-casting meetings so people do not have to attend, online discussion groups, bulletin boards, NIMHE knowledge community, Wiki’s, pod casts as well as the production of DVD’s and video’s,

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[3] ‘Has service user participation made a difference to social care services?: SCIE: Position Paper No.3 March 2004

Information can be sent out and targeted to certain communities through the use of leaflets, newsletters, posters, displays and the use of other promotional material at community events.

Information can often be most effectively delivered in person through attendance at community groups, by presentations at meetings, conferences and forums.

The media can be utilised through the development of 'special interest reports', local radio and television.

Different approaches to communication:

For examples of different ways of communicating with people with dementia and the people who support them please see:

- 'Talking point' an online discussion board for people with dementia and their carers and friends on www.alzheimers.org.uk/talkingpoint

- 'Listen to us: Involving people with dementia in planning and developing services' Caroline Cantley, Janet Woodhouse and Monica Smith: Dementia North Northumbria University 2005:

For discussion around effective communication with young people please see:

- Promoting Participation in CAMHS Child and Adolescent Mental Health Services) Good Practice DVD produced by YoungMinds www.youngminds.org.uk

- Conference Report of 'Exploring Participation in CAMHS' July 2005 Hosted by National CAMS support services (NCSS) in association with YoungMinds Available on http://www.camhs.org.uk or www.youngminds.org.uk

For examples and guidelines regarding communication with Diverse and often marginalised groups and communities please see;

- 'Guidelines for supporting communication with Diverse Groups' – Making a Real Difference Involvement Resource Pack.

Chapter 3 - Implementing the Communications strategy – Good practice guidance and checklist

Principle 1 - Using communication as a means of empowering people through developing, sharing and mainstreaming 'expert by experience' knowledge.

Do you ensure there are opportunities for lived experiences to be gathered and shared on all your publications and at all your events? At training events, conferences and newsletters are there spaces and opportunities provided for lived experiences to be gathered, promoted and shared?

Good practice checklist:

Does your newsletter and website provide opportunities for expert knowledge to be shared and used?

At all conferences, events and training do you maximise on opportunities to gather, share and publicise expert knowledge.

Do you have a systematic way of facilitating the gathering and sharing of expert knowledge.

Is the system of gathering and sharing of expert knowledge led by experts by experience?

Principle 2 - Building capacity by supporting effective communication between service user and carer networks

Do you promote contact between local networks through the provision of accurate information? Have you got ready access to a database of local and national service user and carer organisations and groups both locally and nationally? Can people access this information through you? Is it reliable and kept up to date?

Good practice checklist:

Do you have an accurate and reliable database of local, regional and national 'expert by experience' groups, networks and organisations?

Do you have an accurate and reliable database of all relevant training which is available to support involvement work?

Are these information databases easily accessible to the public, workers within the organisation and outside agencies and workers?

Is this database publicised so people can make use of it?

Do you provide the facilities for groups to advertise their activities, publish minutes of meetings and share information?

Do you offer internet access to community groups?

Principle 3 - Providing information which is relevant, timely and meaningful to people's involvement activity.

Does each project or programme have an agreed communication plan developed with the project's stakeholders?

Have you got an 'involvement database' which informs you about the information requirements of each involved individual?

As a minimum this should be able to capture details such as:

a) The person's background, experience or the group they are representing through their involvement such as: carer of someone with mental health problems, young carer, young person experiencing mental distress, older person with depression, adult with dementia, carer of young person with eating disorders, adult with diagnosis of personality disorder.
b) The particular service area or programme which is relevant to their involvement activity such as: acute care, community mental health teams, social inclusion, older people services, recovery, dual diagnosis, social inclusion, employment, benefits, health and well being.
c) Any particular area they are associated or working in ie Nottingham City, South Derbyshire, Leicestershire and Rutland MHT, East Midlands, or national.
d) List of meetings which the person would expect to receive information about.
e) Whether the person would wish to be informed about conferences and what their areas of interest are. Whether they have any preferences with regard to location of conferences.
f) What either local or national related policy, guidance or good practice guides they would wish to receive.
g) What training they require and is available locally.
h) What format the person would like to receive the information in, any specific translation or language requirements.
i) The time scale for the receipt of key information such as the agenda and minutes for key meetings.
j) How the person would like to receive the information whether they would like to receive the information electronically, by post or both.

Equally which documents they would require multiple copies of for dissemination to groups.

Have you an identified worker who is responsible for entering information on the database, updating people's information and ensuring people's specific information requirements are adhered too.

Good practice checklist:

Has each project, meeting or programme developed a clear communication plan which sets out any reporting responsibilities and describes what information each person involved in the project can expect.

Do you have an accurate and reliable 'involvement database' which informs the type, timing, format and level of information each person would like to receive?

Do you have a named individual who holds responsibility for actively managing and updating this database and who also ensures that people's requests are adhered too?

Develop an individual information agreement at the onset of all involvement activity.

At the beginning of any involvement activity an 'information agreement' should be developed which sets out the nature, type, level, timing and format of any information the person will require to effectively fulfil their role. You will also need to include in this agreement a time frame detailing when the person will receive any information to allow them the opportunity to absorb the information and/or consult and receive feedback from any group or individuals whose interests they are expected to represent.

This information will be used to form an information agreement which should be signed by the worker who is responsible for the involvement activity and should be regularly reviewed to reflect any change in involvement activity. The Information Agreement should be counter-signed by the relevant information officer who is responsible for managing the involvement database.

Good practice checklist:

Do you develop an information agreement which clearly sets out each individual's specific information requirements at the start of any involvement activity?

Providing information that is meaningful to people's situation and experience

Do you check to see whether the information provided from minutes of meetings to consultation documents and policy papers are readily understandable and meaningful to the individual's involvement activity?
Do you have systems in place to deal with information which is not meaningful or understandable i.e if minutes are incomplete or full of jargon would you raise this with the Chairperson of the meeting?
If Government policy or guidance documents are not meaningful to the service user or carer's perspective do you provide a summary outlining major implications or discussion points from their perspective?

Good practice checklist:

Do you routinely check whether the information people receive is understandable and meaningful? Do you have a system to deal with a situation where inadequate information is produced?

Do you ensure that there is an opportunity before every meeting for the service user and carer member of the group to discuss the agenda of the meetings go through the minutes?

Do you regularly provide summaries of key policy documents to highlight important issues from the service user or individual's perspective?

Do you link up with other organisations which produce such summaries to ensure there is not duplication of effort? (should we be encouraging the Department of Health to offer this service?)

Principle 4 - Promoting equal partnership by communicating in an honest, open and respectful way.

Good practice checklist:

Do you fully explain when either no action has been taken or the outcome is different than the person or group expected?

Principle 5 - Providing clear and relevant information to support people’s ability to participate on equal terms, in all meetings, events and conferences.

All publicity materials or advertisements informing people about meetings/conferences or events should offer a clear description of why people should be involved and what their involvement would either influence or change.
At the event people should be provided with a clear feedback process with an indication of when the feedback would be made available.

Good practice checklist:

For events and meetings do you routinely provide at least two weeks in advance: clear information about whether involvement will attract payment of a fee, a named person to deal with any concerns, details about how to get to the venue by public transport or car, details about whether expenses will be paid in cash on the day, details about facilities for disabled people?

Do you clearly state in all publicity why you want people to become involved in that activity?

Do you offer opportunities for groups of service users and/or carers to go through major policy documents, legislation, practice standards and discuss them?

Do you offer people the opportunity to reflect on their experiences of involvement and learn from each other?
Do you routinely offer people background information about how local organisations are structured, operate and work together or signpost them to relevant local training.

Do you provide clear information about decision making processes associated with the meeting which the person attends?

Principle 6 - Demonstrating the value and impact of people's involvement.

Good practice checklist:

Do you routinely inform people about; the results, if any, of each involvement activity with a clear timescale for feedback.

Do you use a range of methods to give people feedback beyond posting information on your website?

Do you ensure equal access to feedback for people who do not have access to the internet?

Principle 7 - Providing accessible information which promotes the inclusion of people from a broad range of backgrounds, ages and experiences of living with mental distress.

Good practice checklist:
Please refer to the minimum standards for working with diverse groups and communities

Glossary

The Glossary of terms used within the Making a Real Difference Report is;

Carer	Anyone who has a significant role in supporting a friend or family member in managing or overcoming their mental health problems.
Care Services Improvement Partnership (CSIP)	An organization formed in April 2005 to bring together NIMHE with other Department of Health Groups which cover people with learning disabilities, older people and children and young people.
Experts by Experience (EbE)	A national service user and carer group which was part of NIMHE.
Local Implementation Team (LIT)	An organisation made up of stakeholders from different organisations including service users, carers, health and social services staff. Responsible for agreeing the direction for mental health services locally and for implementing national mental health policy.
National Institute for Mental Health England (NIMHE)	Part of the Department of Health, NIMHE was established to support the implementation of mental health policy.
PCT (Primary Care Trust)	Organisations which are based in primary care and responsible for commissioning health services for the local population.
Programme Lead	A member of NIMHE staff responsible for leading a programme of NIMHE's work either at a national or a regional level.
Regional Development Centre (RDC)	NIMHE has eight regional development centres.
Service user	Someone who uses mental health services or has lived experience of managing or overcoming their mental health problems

Other Terms used within this report include;

HASCAS – Health and Social Care Advisory Service	An advisory service working in all aspects of mental health and older peoples services – HASCAS wrote the Making a Real Difference Report
Directors	The senior managers in each CSIP Development Centre
Products	The policies, procedures, guidelines and systems developed during the Making a Real Difference project.
PRINCE2	Projects IN Controlled Environments, a structured way of managing projects.
Work Group	One of the seven groups that were tasked with developing the Making a Real Difference products.
Project Governance	A term to describe how the whole project was monitored and managed.
Terms of Reference	A description or the responsibilities and purpose of a group – used in reference to the national Making a Real Difference Steering Group.

RATIFYING BODY ……………………………………………………………….

DATE RATIFIED ………………………………………………………………….

NEXT REVIEW DATE ……………………………………………………………

TO BE APPROVED BY…………………………………………………………….

Appendix 1 - Acknowledgements

Individual interviews:

Individual interviews about both the purpose of involvement and good practices in communication were undertaken with:

- 10 East Midlands CSIP programme leads,
- 2 communications managers of National Voluntary Organisations,
- 1 national Voluntary Sector head of user and carer involvement, along with their regional involvement worker.
- 1 Local Authority manager of user and carer involvement,
- 2 Mental Head Trust leads for User and Carer Involvement.
- 1 Policy lead responsible for developing the involvement strategy for a City community partnership
- 2 long standing service user activists
- 4 managers of local BME agencies

Meetings, forums, networks and events

The purpose of involving people and how communication can strengthen involvement were discussed at the following events, forums and meetings:

- East Midlands Carer Support worker Network 9th May 2006 attended by 32 mostly voluntary sector carer support workers covering the East Midlands area.
- East Midlands Mental Health Network event for people with direct or indirect lived experience of mental health held in Northamptonshire on 23rd May 2006 with around 80 service users and carers
- Nottinghamshire Carer Link workers 24th May 2006, around 10 workers across a range of mental health settings.
- Carers Council Nottinghamshire Open evening on 7th June with around 10 carers.
- Carers Group in Nottingham in evening on 12th June at an outer city estate arranged by RETHINK with 6 carers
- Evening meeting with 4 young carers from 11 to 15 years in Derby 3rd July arranged by Derbyshire NCH Young Carers Project
- Focus group of 2 carers and 7 service users from Lincolnshire, Nottinghamshire, Northamptonshire held in Sleaford 4th July arranged through CSIP
- Focus group of 4 African Caribbean service users in Nottingham Tuesday 11th July arranged by Amaani Tallawah Nottingham
- Meeting with 9 older people with dementia and their carers at Alzheimer's Café 20th July 2006 in Ripley, Derbyshire arranged by the Alzheimers Society.

- Meeting with group of 10 people with early onset dementia and their carers in Derbyshire 27th July 2006 to look at purpose of involvement and involvement toolkit arranged by Alzheimer's Society
- Meeting in Leicester at African Caribbean Centre with approx 60 African, African-Caribbean and Asian carers and service users organised by,Akwaaba Ayeh, the East Midlands Carer Development worker for Afiya Trust, SAVA and LAMP.
- Nottingham City BME woman and mental health group - 11th August 2006 organised by Nottingham City CMHT with 7 BME service users.
- Younger people with dementia and their carers across Derbyshire organised through Alzheimer's Society 14th September 2006 attended by 14 people with dementia and their partners.
- Rural carers from Rutland and Leicestershire organised through Leicestershire RETHINK 15th September 2006 with10 carers
- Members of the Alzheimer's Café in Ripley, Derbyshire 18th September 2006 with 17 people with dementia and their carers from a rural setting.
- East Midlands Mental Health Network event for people with direct or indirect lived experience of mental health in Sleaford Lincolnshire on 4th October 2006 – around 50 service users and carers.

In mid October a substantive draft of the involvement statement was circulated by post and email to around 70 service users, carers and workers in both the statutory and voluntary sector who had been actively involved in its development.

After redrafting the policy and statement was discussed further at:

- Derbyshire/Derby City Carers Strategy Group 17th October 2006 which included 8 carers, PCT commissioning lead, Derbyshire CPA Coordinator, Service Manager Derbyshire Mental Health Trust, Local Authority Carer Lead and voluntary sector provider agencies
- Nottingham City African Caribbean Carers Group 19th October 2006 attended by 7 African Caribbean Carers and supported by the City Community Mental Health Team.
- Members of the Alzheimer's Café in Ripley, Derbyshire 19th October 14 people with dementia and their carers from a rural setting.
- Leicestershire and Rutland carers group 20th October organised by RETHINK with 10 carers from a rural area.
- North Derbyshire Carers Forum 25th October 2006 attended by 25 carers
- Younger people with dementia and their carers across Derbyshire organized through Alzheimer's Society 30th October 2006 – 10 people with dementia and their partners.

- Amber Valley Carers Group supporting older people with dementia organised by Amber Valley CMHT 1st November 11 carers of older people.

The first draft was submitted to the national Making a Real Difference steering group on 3rd November 2006 and following minor amendments was resubmitted to the 7th December steering group for sign off.

Summary of involvement activity.

The East Midlands adopted a policy of trying to attend existing community groups, forums and meetings rather than expecting people to travel to a new event. This policy worked well in reaching BME communities. In terms of ‘out of reach’ communities a great deal of effort was made in the planning of the major Regional Mental Health Network events to attract local users and carers who were not part of any local groups.

A small social meeting was arranged specifically for the project on only two occasions in order to meet with young carers and African Caribbean service users.

Around 430 people had the opportunity to become involved in the development of the involvement and/or the communication policy.

- In all, around 360 people with a direct or indirect experience of managing mental health problems were involved across the East Midlands. Interestingly, of this group of 360 people, almost half were service users and the other half carers. Despite the fact that more of the community meetings were with carers, a high proportion of service users attended each of the main East Midlands Network events.

- Around 70 workers were also informed and consulted about the two policies.

Of the 430 people who were involved some 22% (around 100) were from BME communities