Valuing Involvement

Strengthening Service User and Carer Involvement in NIMHE

Monitoring and Evaluating Service User and Carer Involvement

Tools to enable Regional Development Centres to monitor and evaluate service user and carer involvement across 3 key areas:

1. Accessing involvement including selection of service users and carers
2. Experience of being involved
3. Impact and outcomes of involvement

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 tools are designed to address some of the recommendations made within the report. They provide NIMHE and its staff with the methodology to effectively gather both the qualitative and quantitative data necessary to accurately appraise performance in relation to effective involvement.

Who are the Monitoring and Evaluation Tools for?

New NIMHE Staff and Volunteers
- All new staff should familiarise themselves with the monitoring and evaluation tools to ensure that they gain full understanding of the requirements regarding the monitoring and evaluation of involvement within their work programmes. Any queries should be discussed with their line manager.
- All new work programmes should utilise the monitoring and evaluation tools to ensure that they are gathering the information necessary to appraise their performance in relation to involvement.

Existing NIMHE Staff and Volunteers
- Existing staff members should familiarise themselves with the monitoring and evaluation tools.
- Existing staff should ensure that their work programmes are utilising the tools and gathering the data necessary to effectively monitor and evaluate their performance in relation to involvement.
- Any new work programmes should be developed utilising the tools.

People Sharing Their Expertise To Inform NIMHE’s Work
- All people involved in NIMHE should be aware of the data gathering tools and why the data is being gathered.
- All people involved should use the monitoring and evaluation tools to measure their development during their involvement with NIMHE.

NIMHE Boards, Commissioners and Performance Managers (including external stakeholders)
- All NIMHE work programmes should be expected to include plans to utilise the monitoring and evaluation tools, this should be demonstrable to any interested parties.
- All NIMHE work programmes should provide regular feedback with regard to performance related to involvement.
- All monitoring and evaluation of work programmes should be utilised to demonstrate progress to internal and external stakeholders.
Acknowledgements

The monitoring and evaluation tools were developed and written by Rob Hughes and Ian Porter on behalf of the Making a Real Difference Project.

The work was informed and overseen by the North West Making a Real Difference Work Group 7 Advisory Group.

The advisory group was made up as follows;

<table>
<thead>
<tr>
<th>Designation</th>
<th>Numbers</th>
<th>% of group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advisory group</td>
<td>11</td>
<td>100%</td>
</tr>
<tr>
<td>CSIP Staff including -</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Older Persons representative</td>
<td>3</td>
<td>27%</td>
</tr>
<tr>
<td>- Mental Health representative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- CAMHS representative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with experience of using mental health</td>
<td>5</td>
<td>45%</td>
</tr>
<tr>
<td>services including -</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Older Persons representative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mental Health representative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Making a Real Difference representative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with experience of caring</td>
<td>3</td>
<td>27%</td>
</tr>
</tbody>
</table>

The representatives came from all 3 old Strategic Health Authority areas within the North West.
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Introduction

The Making a Real Difference Report highlighted the need for NIMHE to develop a way of monitoring the process and outcomes of involvement. It is with this in mind that the following monitoring and evaluation tools have been produced.

It is expected that each Regional Development Centre will have robust and accountable systems in place for monitoring the processes and systems which embed involvement in all of the work programmes of NIMHE.

It is important that involvement is a 2 way process of development, ensuring that there are benefits for both the organisation and the people involved in the design, development and delivery of NIMHE work programmes. The monitoring and evaluation tools will enable us to compare outcomes of the involvement experience, as well as measure the impact of involving people. In other words the monitoring and evaluation tools will allow us to monitor what we do, and how we do it, whilst enabling us to evaluate how well we do it!

The data we collect needs to provide us with both qualitative and quantitative information and the tools within the monitoring and evaluation document have been designed to collect both statistics (quantitative) as well as allowing space for people to tell us their stories and experiences of being involved with NIMHE. This will allow us not only to keep track on the numbers and demographics of people involved, but also how satisfactory the experience of being involved has been.

It is suggested that monitoring is best evaluated by using independent service user and carer groups, and/or buddying systems between CSIP Development Centres, to undertake external reviews on a regular basis. This method will provide the truest picture of how well NIMHE and its staff are performing in relation to the involvement of people with experience of mental ill health and their friends and families.

It is suggested that three key areas of the involvement process are monitored;

- Accessing involvement including selection of service users and carers
- Experience of being involved
- Impact and outcomes of involvement

The following chapters explore how NIMHE and its staff can achieve this by implementing the tools provided.
Chapter 1 – Accessing involvement including the selection of service users and carers

This chapter contains suggested methods for;

1. monitoring the selection process of service users and carers including;
   o the methods used to assess candidates
   o the inclusion of service users and carers in the development of role descriptions and selection criteria
   o the involvement of other service users and carers in the membership of selection panels and groups
2. monitoring the demographic characteristics of service users and carers
3. evaluating the quality of that experience for applicants.

1.1 Tools

A. Gathering data through a fair access form (See Appendix One for suggested content and format of this tool) that would be analysed quarterly to produce results that would aim to reflect the local population of the geographical area from which people were recruited.

B. Completion of the end of involvement questionnaire (included in the Involvement Passport – Making a Real Difference Resource Pack) and the later analysis of the results on a quarterly basis.

C. Analysis of audit information related to recruitment and selection to include:

   ▪ methods of “advertising” opportunities for involvement, with rationale for each choice made (minimum standard required; four different methods)
   ▪ total numbers of people who expressed an interest in becoming involved in relation to “advertising” method used and also in terms of demographic characteristics
   ▪ the types of information sent out to people with a minimum requirement being
     a. a role description
     b. an outline of the initiative or project
     c. Development Centre (DC) expectations of involvement
     d. information about the DC with relevant contact information
     e. level of formality or informality of the selection process
   ▪ selection criteria used with a minimum being by personal experience (including being a service user or carer)*
   ▪ selection methods used*
   ▪ level of training achieved by service users and carers in recruitment and selection including in the creation of role descriptions (for those involved in these processes.)*

* this information to be gathered within two weeks of the actual selection taking place
1.2 **Suggested Process of Analysis**

The process of analysing the information from the audit (as stated in the previous list) would be scrutinised by a Development Centre (DC) other than the one providing the information through the use of a “buddying” type relationship between DC’s.

The membership of the groups who would undertake this role needs to include service users and carers who have received appropriate training.

The analysis would take place quarterly and then be collated annually to make formal recommendations. As part of the annual presentation of the data this could take place at a national “showcase event” which could highlight areas of good practice, lessons learned and agreeing developments for the future.
Chapter 2 - Experience of being involved

This chapter contains methods for:

1. Monitoring the expectations of and from involvement for service users and carers
2. Evaluating how these have been fulfilled (if at all)
3. Evaluating the real “lived” experiences of people from beginning to completion.

2.1 Tools

A. Post Selection Questionnaire

The experience of the selection process to be evaluated by an audit of post-selection questionnaires (to be completed by service users and carers) that could be completed either immediately after the selection event, taken away to be completed and then returned, completed through email or through a telephone interview (choice to be made by each person.)

The minimum content of the post selection questionnaire will include:

- welcoming approach of the selection panel
- relevance and numbers of questions from the selection panel and the opportunity to ask question of the panel
- appropriateness and usefulness of the information received before and during the selection process
- perceived and actual fairness of the selection methods or process for each person and also for others
- physical environment including accessibility issues.

B. Audit of involvement plans

(See Appendix 2 for the proposed content of an involvement plan)

This would be scrutinised by a DC other than the one providing the information through the use of a “buddying” type relationship.

The membership of the group who would undertake this role needs to include service users and carers who have received appropriate training.

The analysis would take place quarterly and then collated annually to make formal recommendations. As part of the annual presentation of the data this could take place at a national “showcase event” which could highlight areas of good practice, lessons learned and agreeing developments for the future.
The Involvement Plan

Involvement plans are to be completed and agreed at the beginning of involvement and at least on one other occasion (preferably mid-way through and also at the end) and the completion of these would be a joint task for the CSIP salaried employee (or other person undertaking this mentoring-type role) and the individual service user or carer.

This involvement plan would need to explicitly include the expectations of both parties and how these have or have not been met at the different stages of completion of the plan (with a section on the reasons for the result). This will need to include training needs of service user and carers and how well these have been met, if at all.

The completion of the audit at the end of involvement would lead to an analysis of those expectations that were met and not met and then lead to a determination of the reasons behind the results. The audits would be analysed and could be by types of programmes, types of involvement or other agreed variables.

C. End of involvement questionnaire

(See Involvement Passport)

The completion of the end of involvement questionnaire will provide qualitative comments and testimonial-like statements about people’s experiences.

D. Individual Testimonial Forms

- Completion of an individual testimonial form for service users and carers (See Appendix 3 for suggested content of this tool) that would be given to people at the beginning of their involvement and that could be completed and submitted at a time of their own choice with the option of this being anonymous.

- Completion of an individual testimonial form for salaried members of CSIP (to follow a similar format as the one stated above for service users and carers) that could be completed and submitted at a time of their own choice with the option of this being anonymous.

E. Service user and carer network event

To focus on a comparison between different experiences throughout a region and/or nationwide and in particular the achievement of expectations and the lessons learned for all parties.
Chapter 3 – Impact and outcomes of involvement

This Chapter contains methods for monitoring and evaluating the impact and outcomes of service user and carer involvement.

3.1 Tools

A. Involvement Plans

The audit of involvement plans (See Appendix 2) and more specifically, the audit of the last entries into these plans.

This would be a joint task at the final meeting of the CSIP salaried employee (or other person undertaking this mentoring-type role) and the service user or carer. The results of the audit would need to be analysed as stated previously.

B. End of Involvement Questionnaire

Completion of the end of involvement questionnaire and the later analysis of the results on a quarterly basis.

C. Individual Testimonial Forms

- Completion of an individual testimonial form for service users and carers (See Appendix 3 for suggested content of this tool) that would be given to people at the beginning of their involvement and that could be completed and submitted at a time of their own choice with the option of this being anonymous.

- Completion of an individual testimonial form for salaried members of CSIP (to follow a similar format as the one stated above for service users and carers) that could be completed and submitted at a time of their own choice with the option of this being anonymous.

D. Specific requests to service users, carers and salaried members of CSIP staff (including other people undertaking the mentoring-type role as already stated) to expand on issues raised through other methods (such as questionnaires) to then be used in promotional materials, reviews and other publications. This could be through the use of the written word, spoken word or in diagrams.
E. Follow up interview with a stated proportion of service users and carers 3-6 months after their involvement has ended and these interviews to include the following issues:

- personal achievements since involvement
- information about the progress of work undertaken including the sustainability resulting from the impact of involvement
- opportunities for further involvement in CSIP.

F. Follow up questionnaire

A follow up questionnaire will be sent to all people who have been involved (by email and post), followed by a quarterly analysis of the results and then by an annual review.

G. Staff Appraisals

Inclusion of the need to reflect and evaluate the impact of service user and carer involvement in NIMHE work within CSIP staff appraisals and the subsequent analysis of and response to this information (without breaking confidentiality).

It is recommended that staff appraisals include the involvement of appropriately experienced and qualified service users and carers.

H. An analysis of other achievements achieved by people who had been involved and this information could be derived from one or more of the above sources of information and would include certificated learning (formal and experiential) and requests for references for other work.
## Glossary

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

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer</td>
<td>Anyone who has a significant role in supporting a friend or family member in managing or overcoming their mental health problems.</td>
</tr>
<tr>
<td>Care Services Improvement Partnership (CSIP)</td>
<td>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.</td>
</tr>
<tr>
<td>Experts by Experience (EbE)</td>
<td>A national service user and carer group which was part of NIMHE.</td>
</tr>
<tr>
<td>Local Implementation Team (LIT)</td>
<td>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.</td>
</tr>
<tr>
<td>National Institute for Mental Health England (NIMHE)</td>
<td>Part of the Department of Health, NIMHE was established to support the implementation of mental health policy.</td>
</tr>
<tr>
<td>PCT (Primary Care Trust)</td>
<td>Organisations which are based in primary care and responsible for commissioning health services for the local population.</td>
</tr>
<tr>
<td>Programme Lead</td>
<td>A member of NIMHE staff responsible for leading a programme of NIMHE’s work either at a national or a regional level.</td>
</tr>
<tr>
<td>Regional Development Centre (RDC)</td>
<td>NIMHE has eight regional development centres.</td>
</tr>
<tr>
<td>Service user</td>
<td>Someone who uses mental health services or has lived experience of managing or overcoming their mental health problems.</td>
</tr>
</tbody>
</table>
Other Terms used within this report include:

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

DATE RATIFIED ......................................................................

NEXT REVIEW DATE .............................................................

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

Monitoring and Evaluating Service User & Carer Involvement
March 2007
Fair Access Form

Monitoring and Evaluation of Service User and Carer Involvement in Development Centres

In order for CSIP to monitor the fairness of its involvement of service users and carers from all groups in the community please tell us a little about yourself by completing this form.

Please allow approximately 5 minutes to complete this questionnaire.

Once completed, please return this form to:

Please tick the relevant boxes:

My age is:
- upto 18
- 19 - 25
- 26 - 45
- 46 - 65
- over 65
- prefer not to say

My gender is:
- female
- male
- other
- prefer not to say

My sexual orientation is:
- bisexual
- homosexual
- heterosexual
- prefer not to say

I have been involved with CSIP before on:
- no other occasion
- on one previous occasion
- on two or more occasions

If you are disabled, and are happy to do so, please write below how you would describe your disability:

....................................................................................................................................................

If you are happy to do so, please write below your race/nationality

....................................................................................................................................................

If you are happy to do so, please write below the first three digits of your home postcode (e.g. WA8)

....................................................................................................................................................

Please write below if you are or have been in the past a carer, service user or both

....................................................................................................................................................
Involvement Plan

This document would have an introductory front page and then three identical pages (each one to be produced in duplicate - one copy to be retained by CSIP staff and the other to be retained by the service user or carer)

- the first page to be completed with the service user or carer and the nominated CSIP mentor (salaried staff, volunteer or allocated other service user or carer) at the beginning of their involvement
- the second page to be completed with the service user or carer and the nominated CSIP mentor (salaried staff, volunteer or allocated other service user or carer) at some point in the middle of their involvement
- the third page to be completed with the service user or carer and the nominated CSIP mentor (salaried staff, volunteer or allocated other service user or carer) at the end of their involvement.

Proposed content of the three pages after the front page:

Name of service user or carer
Name of CSIP mentor
Contact details of both parties listed above
Signature of both parties listed above agreeing that the content is correct
Agreed proposed dates for further completion of the document and the actual date that the document was completed

Project name
Proposed and actual start date of involvement
Proposed and actual date of completion of involvement

Who to contact if the service user or carer has a concern, complaint or would like to make a compliment

Support needs of the service user or carer (personal, financial information, training etc)

Personal expectations from the service user or carer for their involvement

CSIP expectations from the service user or carer in terms of:
- expertise
- skills
- dates of involvement (if known)
- total time commitment and frequency of activities requiring involvement
- anticipated impact of service user or carer involvement.
Testimonial form

Monitoring and Evaluation of Service User and Carer Involvement in CSIP

Please indicate below either in words, pictures or diagrams your experience of service user and carer involvement in CSIP which will be used as one of the means of evaluating the success or otherwise of the organisation to work with people who use services and their carers. The topics within your personal testimony may be positive or negative and either reflective of your own or the experiences of others or a mixture of both.

It is your choice to write your name or not at the end of the statement as all statements will be considered and it is not necessary for us to identify everyone who has submitted these testemonies. Please continue on the reverse of this sheet of paper or on additional pages if necessary. If you need assistance or have questions about completing this form please contact;

........................................................................................................... on ................................................

All or parts of your testimonial may be seen by others both within and also outside CSIP but only as part of the evaluation process and the publication of results.

Subsequent pages following this initial introductory page will include:
1. Guidelines on how to complete and what to include
2. Quotes from other people to offer examples to encourage completion
3. Graphics and other images to encourage completion (these could also go on the front page)