

Care Services Improvement Partnership **CSIP**

National Institute for
Mental Health in England



Valuing Involvement

**Strengthening Service User and
Carer Involvement in NIMHE**

Involvement Passport

**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 passport is designed to address some of the recommendations made within the report. It is a template for providing anyone who becomes involved in NIMHE with all of the information relevant to their role.

The passport also provides two questionnaires which will provide NIMHE with some of the information necessary to monitor and evaluate how well they are involving people.

Who is the Involvement Passport for ?

NIMHE Staff and Volunteers who have responsibility for supporting people sharing the expertise and experience of living with mental health problems.

- All staff will be responsible for developing a meaningful involvement passport with all people involved in their work programme. This could include;
 - Development Centre Directors
 - Deputy Directors
 - Work Programme Leads
 - Service Improvement Leads
 - Project Managers
 - Business Managers
 - Communications Managers
 - Events Organisers
 - Secretarial Staff
 - All Other Staff

People sharing their expertise to inform NIMHE's work

- All people involved in NIMHE should have an involvement passport as it provides a comprehensive package of information to ensure that everyone is fully informed about the organisation, the work programme or project and the needs of all parties including support and training needs.

Acknowledgements

The involvement passport was developed 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;

| Designation | Numbers | % of group |
|--|---------|------------|
| Advisory group | 11 | 100% |
| CSIP Staff including - Older Persons representative - Mental Health representative - CAMHS representative | 3 | 27% |
| People with experience of using mental health services including - Older Persons representative - Mental Health representative - Making a Real Difference representative | 5 | 45% |
| People with experience of caring | 3 | 27% |

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

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Section 1 – Information about CSIP

This section of the passport provides general information about CSIP as an organisation. It is an introduction to CSIP and should be presented in a way that would be informative to someone who is being introduced to CSIP for the first time.

This section will need to include the following information;

- A welcoming letter from the Development Centre
- Information about CSIP and the Development Centre
- An equal opportunities monitoring form

1.1 Welcoming Letter

Please follow these guidelines when developing the welcoming letter introducing the person to the organisation;

- Ensure that the letter is written in a friendly and optimistic way, making sure that the content and the format complements the friendly style.
- Write the letter in a plain English style;
 - Using Helvetica or Arial Font; size 12 (unless for a person who requires larger print)
- Ensure the letter is short and to the point, whilst remaining friendly (no more than 1 side of A4)
- Make the letter available in different formats if requested.
- State how important the involvement of people with lived experience of mental health problems and their friends and families is to the ongoing development of the organisation.
- The letter should be signed by a senior member of staff.

1.2 Information about CSIP and the Regional Development Centre

This needs to be:

- attractive and appealing in content and format
- in size 12 Helvetica or Arial
- inclusive of pictures and graphics
- relevant
- free from jargon
- not overly lengthy
- not unnecessarily complex
- not patronisingly basic
- indexed and easy to follow
- available in alternative formats on request.

1.3 Equal Opportunities monitoring form

The person involved should be asked to complete the equal opportunities monitoring form when they begin their involvement with NIMHE.

The suggested monitoring form has been developed by people with experience of living with mental health problems and people with experience of caring for someone.

Alternatively the existing CSIP staff equal opportunities monitoring form may be relevant with a few relevant adjustments.

Equal opportunities monitoring 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 the section below. This is so that the results of the monitoring and evaluation of your involvement in CSIP can be analysed in terms of relevance to such issues as people's postcode (where they live), age, race, sexual orientation, disability and gender.

(Tracking Code to be inserted before distribution which is the same code for the "Equal Opportunities monitoring form" found in the CSIP Involvement Passport)

Please allow approximately 5 minutes to complete this questionnaire.

Once completed, please post this form to:

.....
.....

Please complete this questionnaire as soon as you can after you have received the CSIP Involvement Passport.

You will not be asked for your name or any other personal identifying information and your responses will therefore not be attributed to you as a named individual. The tracking code on the front of this questionnaire is the means by which the results of this completed questionnaire will link with the results of a final questionnaire that you will complete once you have completed your work with CSIP. The reason for this linking is so that the relationship between the experiences that people have while working for CSIP and their personal/demographic characteristics can be usefully analysed without asking people to write their names on the questionnaire.

It is hoped that the characteristics of the types of people who are involved as service users and carers in CSIP will reflect the same characteristics as the groups of people who actually have/do use services and their carers within a specified geographical area/region. If this data is not available as a comparison, information will be used for comparative purposes about the characteristics of the general population within a region (or nationally) as appropriate, or those people who use/have used services nationally and their carers.

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 | transgender | prefer not to say |
|--------|------|-------------|-------------------|

My sexual orientation is:

| | | | |
|----------|-------------|----------|-------------------|
| bisexual | gay/lesbian | straight | prefer not to say |
|----------|-------------|----------|-------------------|

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

.....

Section 2 – Information about the involvement role

This section of the passport provides more specific information about the role being asked of the person becoming involved in NIMHE and should include the following;

- Role description
- Information about the project or work area for which the person was recruited
- Relevant maps, directions and other specific guidance related to the allocated work
- Useful contacts
- Record of meetings with nominated member of CSIP staff with agreed outcomes such as support that will be put in place

2.1 Role Description

This to include (in terms of content):

- background to project for which the work has been accepted
- purpose of involvement for the individual
- anticipated tasks
- expected outcomes of involvement as a result of service user and carer participation
- means by which personal feedback about involvement will be offered to the person within a stated time scale
- means by which the effects of involvement on the project or work area will be given to the person within a stated time scale.
- a commitment to producing this information in alternative formats on request

2.2 Information about the project or work area for which the person was recruited

This needs to be:

- attractive and appealing in content and format
- in size 12 Helvetica or Arial font
- inclusive of pictures and graphics
- relevant
- free from jargon
- not overly lengthy
- not unnecessarily complex
- not patronisingly basic
- indexed and easy to follow
- available in alternative formats on request
- specific to the project or work area and not generic.

2.3 Relevant maps, directions and other specific guidance related to the allocated work

These need to be:

- attractive and appealing in content and format
- in size 12 Helvetica or Arial font
- inclusive of pictures and graphics
- relevant
- free from jargon
- not overly lengthy
- not unnecessarily complex
- not patronisingly basic
- indexed and easy to follow
- inclusive in terms of considering all modes of transport and locations within a region
- available in alternative formats on request

2.4 Useful contacts page

To include;

CSIP people

- **Nominated support person**
Identify the nominated person who will be providing support for the individual involved. This may be the work programme lead, or another member of staff who has the relevant experience and knowledge to answer any questions, keep everyone informed and be able to communicate any issues into the piece of work to be informed.
- **Administration Support**
Identify who is the dedicated administrative officer responsible for supporting the work programme a person is becoming involved in, this will ensure they have access to all of the information relevant to meetings or events.
- **Finance Officer**
This should ensure that the person involved has the ability to bring up any queries regarding expenses and payment for their involvement with the right person.
- **In case of complaint**
Identify who the relevant person to direct complaints about any aspect of CSIP towards. This will ensure that a person is not placed in a compromised position by potentially having to ask the member of staff who the complaint may be about who they will need to make the complaint to.
- **Other relevant staff**
Identify any other relevant staff who may be useful contacts for the person who is asked to become involved in NIMHE.

People outside CSIP

- **Benefits Advisor**
If a person is on benefits they may need advice regarding how accepting payment could affect their benefits. It is important to ensure that people get the right advice and are able to access experts in this field such as Citizens Advice Bureau (CAB), Welfare Rights and Disability Advice Centre's.
It would be useful to have a nominated person within one of these organisations who was familiar with the Valuing Involvement – NIMHE Payment and Reimbursement Policy Guidelines, which is part of the Making a Real Difference Resource Pack.

2.5 Record of meetings

This record needs to provide space and an easy to follow format which can record information from meetings with a persons' nominated member of CSIP staff.

It needs to include agreed outcomes to these meetings such as support that will be put in place.

The record sheet section of the passport should be;

- presented in easy to follow language
- not always in the written word especially when diagrams and pictures can be equally effective
- in duplicate so that neither party forgets the content of what has been agreed
- inclusive of what is impossible or unlikely as well as what is possible
- agreed, dated and signed by both parties
- inclusive of the next agreed meeting date

Section 3 – After the involvement has ended

3.1 End of Involvement Questionnaire

The end of involvement questionnaire will provide both quantitative and qualitative information to NIMHE to monitor and evaluate the effectiveness of the involvement.

This is a two way process and helps us to track both the benefits of involvement to the organisation and to the individual.

The questionnaire should be completed at the end of each and every involvement experience.

The questionnaire has been developed and produced by people with experience of living with mental health problems and people with experience of caring for someone. However it may be necessary to check the format and style with the Development Centre Research and Development Lead before use.

The End of Involvement questionnaire can be found as appendix 1.

3.2 Useful Contacts

During a period of involvement with NIMHE a person may have developed useful contacts within the organisation and with external stakeholders. It is worth including a useful contacts section in the passport to note down those relevant details.

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..... |



End of Involvement Questionnaire

**Monitoring and Evaluating
Service User and Carer
Involvement in NIMHE and CSIP**

Tracking Code

This Questionnaire is to be completed by service users and carers who are involved in working with CSIP

Please allow approximately 15 minutes to complete this questionnaire.

You will not be asked for your name or any other personal identifying information and your responses will therefore not be attributed to you as a named individual. The tracking code above is the means by which the results of this completed questionnaire will link with the Equal Opportunities monitoring form that you completed when you were first given this CSIP Involvement Passport. The reason for this linking is so that the relationship between the experiences that people have while working for CSIP and their personal characteristics can be usefully analysed without asking for people to write their names on the questionnaire.

Once completed, please post this form to:

.....
.....

Please complete this questionnaire as soon as you can once you have finished this current period of work with CSIP.

We will greatly value your feedback on your experience of working with CSIP.

1. Please circle the box that best describes your belief in the statement below.

| | | | |
|--|-----------|------------|---------------|
| The work of CSIP will have benefited from me being involved. | √ True | X False | ? Not sure |
|--|-----------|------------|---------------|

Please write down below up to three reasons for your choice of circling the above box.

.....

.....

.....

2. Please circle the box beside each statement that best describes your belief about each one.

At the beginning of my involvement...

| | | | |
|--|-----------|------------|---------------------|
| Time was spent on welcoming me | √ True | X False | ? Can't remember |
| I was not asked about my training needs | √ True | X False | ? Can't remember |
| I was not asked about my support needs | √ True | X False | ? Can't remember |
| I was asked how I would like to be involved | √ True | X False | ? Can't remember |
| I was asked how I would like to be supported | √ True | X False | ? Can't remember |

Please add any comments below about what it was like to begin getting involved and what was helpful or not:

3. Please circle the box beside each statement that best describes your belief about each one.

Information

| | | | |
|--|-----------|------------|--------------------|
| I was not given adequate information throughout my involvement | √ True | X False | ? No opinion |
| I knew who to ask for help and advice | √ True | X False | ? No opinion |
| Information was not easy for me to access | √ True | X False | ? No opinion |
| Information was not easy to understand | √ True | X False | ? No opinion |
| I found the use of jargon unhelpful | √ True | X False | ? No opinion |

Please add any comments below about the information you received and what was helpful or not:

4. Please circle the box beside each statement that best describes your belief about each one.

Feeling valued

| | | | |
|--|-----------|------------|---|
| My input was valued by CSIP staff | √ True | X False | ? Only some of the time |
| My opinions and ideas were accepted as valid and important by CSIP staff | √ True | X False | ? Only some of the time |
| I did not feel supported by CSIP staff during my involvement | √ True | X False | ? Only some of the time |
| I did not have access to CSIP facilities such as the library, computers, photocopying machines and admin support | √ True | X False | ? Only some of the facilities |
| I was able to use my life experiences and tell people about these during my involvement | √ True | X False | ? Only some of the time |

Please add any comments below about how you felt valued (or not) during your involvement:

5. Please circle the box beside each statement that best describes your belief about each one.

Participation

| | | | |
|---|-----------|------------|----------------------------|
| I did not understand what was happening most of the time | √ True | X False | ? No opinion |
| I was able to use my initiative | √ True | X False | ? Only some of the time |
| If I disagreed with members of CSIP staff these differences of opinion were dealt with well | √ True | X False | ? Only some of the time |
| I did not feel part of the whole team | √ True | X False | ? Only some of the time |

| | | | |
|--|-----------|------------|----------------------------|
| I felt myself and other members of the public with experiences of using services or as carers were in the minority | √ True | X False | ? No opinion |
| Meetings took place in comfortable surroundings and drinks were offered to us all | √ True | X False | ? No opinion |
| The meetings did not have regular breaks | √ True | X False | ? Only some of the time |
| The meetings were not of the right length for me | √ True | X False | ? Only some of the time |
| I was involved in the whole process from the beginning to the end | √ True | X False | ? No opinion |

Please add any comments below about what was helpful or not in enabling you to participate:

6. Please circle the box beside each statement that best describes your belief about each one.

CSIP staff

| | | | |
|--|-----------|------------|----------------------------|
| CSIP staff enjoyed working with me | √ True | X False | ? No opinion |
| CSIP staff did not listen well to me | √ True | X False | ? Only some of the time |
| CSIP staff were prepared to learn from me | √ True | X False | ? Only some of the time |
| CSIP staff did not seem adequately prepared to properly involve me in their work | √ True | X False | ? No opinion |

Please add any comments below about what was helpful or not in the way that CSIP staff behaved towards you:

7. Please circle the box beside each statement that best describes your belief about each one.

Gains and benefits of being involved

| | | | |
|---|-------------------------------|---|--|
| I found the experience of being involved to be rewarding | <input type="checkbox"/> True | <input checked="" type="checkbox"/> False | <input type="checkbox"/> Only some of the time |
| The method of how to get paid is unclear | <input type="checkbox"/> True | <input checked="" type="checkbox"/> False | <input type="checkbox"/> No opinion |
| The amount of money I was/will be paid is fair | <input type="checkbox"/> True | <input checked="" type="checkbox"/> False | <input type="checkbox"/> No opinion |
| I understand that payment will be paid promptly | <input type="checkbox"/> True | <input checked="" type="checkbox"/> False | <input type="checkbox"/> No opinion |
| I feel that I have contributed positively to the work of CSIP | <input type="checkbox"/> True | <input checked="" type="checkbox"/> False | <input type="checkbox"/> No opinion |

Please indicate below about the gains and benefits that you have experienced from being involved:

8. Please circle the box beside each statement that best describes your belief about each one.

After being involved

| | | | |
|--|--|---|-------------------------------------|
| I do not know how I will receive feedback about my involvement | <input type="checkbox"/> True | <input checked="" type="checkbox"/> False | <input type="checkbox"/> No opinion |
| I know that support for me after my involvement is available | <input checked="" type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> No opinion |

Please tell us in the box below about what was or will be helpful or not to you, after your involvement:

9. If you were starting again what would you like to be different to make sure that your experience of being involved was positive and enjoyable for you and for others?

Thank you very much for completing this questionnaire.

Your time is appreciated and the results will influence the way that service users and carers work with CSIP staff in the future.