

Service user and carer involvement in the National Mental Health Development Unit

Contents

1. Executive summary	3
2. Background	6
3. Method	9
4. Results	12
5. Discussion	24
6. References	28
7. Appendices	29

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1. Executive summary

The National Mental Health Development Unit (NMHDU) has been working with the National Involvement Partnership (NIP) to promote service user and carer involvement in Government led (Department of Health and NHS commissioned) mental health projects and initiatives. NIP includes a number of organisations focusing on service user and/or carer involvement. The partners are NSUN, Together, Afiya Trust, Catch-a-Fiya, Attend, Equalities National Council, the Mental Health Foundation and the Social Perspectives Network.

This report highlights the findings of an evaluation of service user and carer involvement within NMHDU and prior organisations such as the Care Services Improvement Partnership (CSIP) and the National Institute for Mental Health in England (NIMHE). We evaluated how NIP has facilitated service user and carer involvement in this context. Findings were analysed and are presented in accordance with the PPPI (Purpose, Presence, Process and Impact) framework, as devised by NIP during the course of this project.

Data was collected from a variety of sources; service users, carers and professionals who had been involved in NMHDU, NIMHE and CSIP projects. We collected data through several methods; surveys, interviews, practice examples, and collecting feedback surveys from NIP activities.

NIP activities included running promotional events to develop networks of service users and carers, facilitating seminars to share information between service users, carers and professionals, organising focus groups for NMHDU projects in order to represent the voice of service users and carers, collecting case studies to inform the mental health strategy, and distributing questionnaires to members of the network.

The evaluation highlights how NIP and NMHDU have worked together to facilitate service user and carer involvement. Within this, there have been positives and negatives. Ensuring diverse representation from service users and carers was challenging. The two organisations attempted to ensure diverse representation across different demographic groups, with some degree of success. However, particular care needs to be made to ensure that carers and people with severe mental illness can be represented. Furthermore, the language and culture of involvement may be off-putting to people who have not been involved previously.

NMHDU had involvement processes in place prior to NIP input. Service users and carers contributed to key documents and were involved in steering and advising projects. However, some people wanted or needed more support to be involved. This included practical support (such as expenses and fees being paid), and emotional support. Feedback from NMHDU suggested that NIP had dealt with these matters sensitively when they arose, but NIP should explicitly focus on providing clear guidance on support, which may influence people's decision to get involved.

Feedback to service users and carers about the impact of their involvement was needed. Changing circumstances with projects and programmes made it difficult to maintain this consistently across the lifespan of NMH DU and prior organisations. Collecting and providing feedback from organisations like NMH DU (and others who may commission NIP in future) is another task that NIP should undertake.

This study should be commended for its use of various, pragmatic methods, but it should also be noted for its small sample size, which was not necessarily representative of service users and carers more widely. One notable example is that there were a large number of responses from white British females over the age of 45.

Within the PPPI framework, NIP appears to have the potential to facilitate involvement practices within organisations such as NMH DU. Both NIP and NMH DU have a wealth of information about how to involve service users and carers effectively. NIP is now in the position to collect, share and harness this information. The key challenge for the future will be how NIP orientates itself within the new external environment. The legacy of NMH DU regarding service user and carer involvement will depend upon the continued existence of service user and carer-led collaborations like NIP.

Recommendations

- What is the *purpose* of involvement? Organisations seeking to involve service users and carers should consult with service user led organisations (such as NIP) to agree the reason why involvement is needed.
- The culture and language of service user and carer involvement should be understandable within the context of everyday life, not just within the context of policy and practice. This will:
 - Facilitate the *presence* of a more diverse range of service users and carers within the network.
 - Help NIP to build links with a more diverse range of statutory, voluntary and private organisations.
- *Processes* should be in place for service users and carers to move from being interested in involvement to becoming active participants. Follow up for participants after initial engagement is essential in order to maintain interest.
- Continuity needs to be embedded into the culture of service user and carer involvement. Therefore, upon completion of projects, NIP can help signpost those involved other opportunities and projects.

- Practical and emotional support should be available to help people become involved. NIP could develop mentoring schemes; those who have been involved in the past could support others to become involved.
- Organisations that wish to involve service users and carers should provide feedback to those who have been involved NIP could collate and disseminate feedback, providing participants with information about project *impact*.

2. Background

Service user led organisations play a vital role in allowing people with mental health problems to support each other in taking control of their own lives and finding a road to recovery. *Something Inside So Strong* (2001) is a collection of accounts by individuals of their mental distress and the variety of ways they have explored to manage their mental health. Although the third sector have a belief in social inclusion, and in placing the needs of the service user first, it has been argued that they are not the voice of service users and that service user involvement needs to improve within the sector (Crepaz-Keay, 2008).

The National Institute of Mental Health in England (NIMHE), which was the national organisation supporting policy implementation from 2002–2008 prior to the establishment of NMH DU in April 2009, had conducted various pieces of work to demonstrate service user and carer involvement. The Making a Real Difference project (MaRD; NIMHE, 2007) aimed to improve service user and carer involvement in mental health development work. MaRD developed a series of 'products' that could be used to guide and improve involvement standards, for example; a set of minimum standards to support involvement with people from marginalised groups, and a set of guidelines for regional development workers regarding payment for service user and carer involvement.

Effective service user and carer involvement is needed at a national level across all Government departments. The aim is to ensure that the advice of service users and carers is taken on board when developing and implementing decisions, particularly in relation to decisions about policy and practice within the field of mental health. The work of the National Mental Health Development Unit (NMH DU), for the Department of Health and the NHS, provides an ideal platform by which to test appropriate models of service user and carer involvement, which if successful can be translated into other areas of Government and beyond.

The NMH DU was preceded by similar organisations such as the Care Services Improvement Partnership (CSIP) and the aforementioned National Institute of Mental Health in England (NIMHE). Both of these organisations strived to involve service users and carers within their work. When they were disbanded, the national support for putting policy into practice and practice moved to NMH DU and many of the national work programmes continued. Seven separate work programmes were run during the existence of NMH DU, these are listed as follows:

- Mental Health Commissioning
- Improving Access to Psychological Therapies
- Mental Health Equalities Programme
- Social Inclusion and Social Justice
- Improving Mental Health Care Pathways
- Promoting Wellbeing and Public Health
- Personalisation

In April 2009, NMHDU invited applications for the following tender, entitled:

“Delivery of Service User and Carer Involvement in the work of NMHDU to assure and improve programme outcomes and to increase active participation in all aspects of our work”.

The purpose of issuing this tender was to further develop capacity for service user and carer involvement within NMHDU. The National Survivor User Network (NSUN) was the lead organisation of a multi-agency partnership that won the bid. This became known as the National Involvement Partnership (NIP), which aimed to assist service user and carer involvement at a national and regional level. NIP includes a number of organisations specialising and focusing on service user and/or carer involvement in mental health. The partners included NSUN, Together, Afiya Trust, Catch-a-Fiya, Attend, Equalities National Council, the Mental Health Foundation and the Social Perspectives Network.

The basis for NIP involvement was reviewed in order to establish strengths, gaps and the potential for development in involvement for service users and carers across NMHDU. A scoping review gauged the level of service user and carer involvement and highlighted examples of good practice (Faulkner, 2010). A guideline of minimum standards for service user and carer involvement in were drawn up. This was based upon earlier work, such as MaRD. The guideline recommended working to the principles of Purpose, Presence, Process and Impact (PPPI), as defined below:

- Purpose: having a clear purpose for involvement enables everyone to understand their role, avoiding tokenism and involvement for its own sake.
- Presence: the number of service users and carers involved; their characteristics in relation to the project or programme
- Process: at what level in the project or programme are service users and carers involved? Are good practice guidelines (such as for expense and payment policies) being applied?
- Impact: what impact, if any, are service users or carers having on the project or programme?

Therefore, the NIP engaged in a number of activities in partnership with NMHDU. A full list of NIP activity, including the nature and scope of the work is given in Appendix 1. This includes the following:

- 1) NIP promotional events. This involved organising and facilitating two service user and carer events based upon the PPPI standard. These events aimed to build up a network of service users' and carers' contact details. They also aimed to inform potentially interested parties about development work within national policy and practice organisations, such as NMHDU.
- 2) Seminars, which involved organising and facilitating a seminar with attendees from service user and carer networks. This involved a

collaboration between NIP and the Mental Health Equalities Programme, and covered how to negotiate with GP consortia and new commissioning landscape in light of *Equity and excellence: Liberating the NHS* whitepaper (Department of Health, 2010).

- 3) Four focus groups, two with service users and two with members from the Council of Voluntary Organisations. These took the form of two in-depth half-day sessions. The work was commissioned by the NMHDU Social Inclusion and Social Justice workstream, around the themes of liaison and diversion within the criminal justice system.
- 4) Collating a series of 30 case studies of service users and carers. This was for use in the formation of the new Mental Health Strategy.
- 5) Working with the Mental Health Commissioning workstream to provide input with the commissioning framework, including a guideline for GPs, which led to a mental health commissioning panel of which NIP represents service user and carer views.
- 6) Distributing two questionnaires to service users and carers within the network. One questionnaire was commissioned by the Mental Health Strategy team, and one was for the Improving Access to Psychological Therapies workstream within NMHDU.

This report evaluates the work of NIP in relation to NMHDU. Specifically, it uses the PPPI standard as a model for service user and carer involvement in order to evaluate the following:

- service user and carer involvement within NMHDU (including work carried over from CSIP and NIMHE), and;
- the effectiveness of NIP in facilitating service user and carer involvement.

3. Method

3.1 Design

The evaluation followed the emerging PPPI model (Faulkner, 2010), which provided a background for service user and carer involvement. Data were collected to gauge the level of involvement in NMH DU (with reference to projects carried over in previous organisations such as NIMHE and CSIP), and to see how NIP had influenced service user and carer involvement work in NMH DU.

A mixed methods design was employed throughout the study, including qualitative methods (interviews, good practice examples) and quantitative methods (structured surveys).

3.2 Sample

The sample database was drawn up in collaboration with the NIP steering group. The database included service users, carers and professionals who had previous contact with national mental health organisations (either with CSIP, NIMHE or NMH DU).

In November 2009, surveys were sent to service users (n=51) and carers (n=8) on the NIP database. This garnered 14 responses, a comparatively low response rate (23%). Of those who responded, the majority were female (71%) and all but two were aged 46 or over, the remaining two respondents were aged between 31 and 46. Some 67% described their ethnicity as White British, one described themselves as White and Black Caribbean, one described themselves as White and Asian, two described themselves as Indian, one as 'Other', and one gave no answer. English was the first language for all but two of the survey respondents. In addition, ten of those service users and carers had taken part in a qualitative follow-up interview. Twenty six professionals were invited for telephone interviews, of which four responded.

In June 2010, following NIP promotional events, a second round of surveys were sent to all service users (n=123) and carers (n=62) on the NIP database. We received 26 responses, again representing a low response rate (14%). The majority (81%) were aged 45 or older, but there was an even spread of gender (54% female). The majority of the sample described themselves as White British (20/26, 76%). English was the first language for all but two of the survey respondents. In addition, 17 of those service users and carers took part in a qualitative follow-up interview. Forty three professionals were invited to complete a telephone interview with a member of the research team, of which eight responded.

Feedback data from the NHS White Paper seminar and the Liaison and Diversion focus groups facilitated by NIP are also presented, 17 people provided feedback for the seminar and 22 provided feedback on the focus groups.

3.3 Measures

Initially, the evaluation team created two surveys to gauge service user and carer involvement; a service user/carers survey and a professionals' survey. Surveys were reviewed and developed by members of the NIP steering group. The same questions were used for both service users and carers, as we were keen to establish similarities and differences in how these questions were answered amongst the two groups. The questionnaire was initially based on the draft of the scoping report (prior to the development of the PPPI framework) and the MaRD report.

The service user/carers survey was designed to investigate the following key areas; which projects service users and carers had been working on (and in which work programmes these were situated), the purpose of their involvement, the amount of support offered to become involved (including emotional and practical support), perceived level of influence, and satisfaction with involvement. The survey included a mixture of yes/no questions, open-ended questions to allow participants to explain and elaborate, and 5 point Likert scale questions (i.e., asking participants to respond to the statement or question on a scale that included the following options; 'Always, Often, Sometimes, Rarely, Never'). The survey also asked demographic questions regarding age, gender and ethnicity. Finally, survey respondents were asked whether they would like to take part in a telephone interview to explore their views in further detail. A full version of the questionnaire is shown in Appendix 2.

The professionals' survey explored similar areas. However it was more focused on the mechanisms that had been in place to ensure successful involvement, such as training and support, and the need to involve people from marginalised groups. For this reason, the professionals' survey included a higher proportion of qualitative questions, and was better suited to a telephone interview than to a questionnaire. It was then developed in order to guide the interview process. The survey nevertheless had a number of questions on a 5 point Likert scale in order to gain quantitative data about involvement. The professionals' survey is given in Appendix 3.

Following the NIP promotional events, the aforementioned surveys were developed to include questions based on the PPPI framework to investigate the purpose, presence, process, and impact of involvement. Questions were also included to investigate the effect of the NIP events that had taken place up until that time. Full versions of the revised service user and carer questionnaire are shown in Appendix 4 and the professional questionnaire is shown in Appendix 5.

3.4 Procedure

Surveys were sent out via email to service users and carers on the NIP database. An email was sent out to professionals on the database inviting them to take part in a telephone interview. For all potential participants, a

reminder email was sent out seven days later to each of the people who had not yet responded. Telephone interviews were conducted by members of the evaluation team. Notes were taken during the telephone interviews. These notes represented a written record of the interview.

3.5 Data analysis

Quantitative data was entered into SPSS Version 16 for Windows (SPSS, 2007). Descriptive statistics were used to explore the data. Qualitative data was analysed using Content Analysis. One researcher (JA) analysed all of the transcripts, searching for key themes that arose within the data. A second researcher (DR) also looked at the transcripts independently. The two researchers then met to discuss the analysis, and reached consensus about the meaning of the themes. Analysis frameworks for the data were developed and refined throughout the evaluation, in case new themes were developed.

4. Results

Data are presented in two sections. Firstly, the results are presented relating to involvement prior to the implementation of NIP. Secondly, results are presented in relation to involvement work of the NIP. The data are structured around the four tenets of the PPPI framework in both instances.

4.1. Service user and carer involvement prior to NIP and the PPPI

This section describes how service user and carer involvement was implemented in NMH DU, CSIP and NIMHE prior to the input of NIP and the development of the PPPI framework. However, the results have been appraised according to the theoretical framework for PPPI (against the standards of purpose, presence, process and impact). It assimilates data from the surveys and interview data referring to projects that existed prior to NIP.

1. Purpose

The role of purpose in service user and carer involvement cannot be overstated. This relates strongly to the idea of managing expectations. Identifying the purpose of involvement from the beginning and communicating it to those who are involved is essential. This relates to clarity of role in projects. A clear sense of purpose, it was felt, would immeasurably improve the mechanism for service user and carer involvement:

“Purpose is very important, otherwise it never works”. (NMH DU Professional)

“As advisors we are there to advise and influence not to make policy or manage. I have seen service users resign from national committees because their role was not made clear from start; they assumed they were there to make policy”. (Carer)

“It would be valuable to involve service users who are already heavily involved in the third sector developing new services. We have expertise and experience which could be utilised at the planning and development stage. This would be far more valuable than occasionally asking someone to talk generally about service user involvement at the odd conference”. (Service user)

According to the survey data, all but one service user felt that the policy and practice organisation had shown a clear purpose in their involvement, and 86% felt that their role had been clearly explained.

2. Presence

Survey data revealed that all of the 14 respondents to the service user/carers questionnaire had previously been involved in helping to change policy for mental health. All had heard of NIMHE and CSIP, and all but one (a service user) had heard of NMH DU. The service users and carers who responded to the questionnaire had been involved in a variety of projects. On average, the

respondents had been involved in three work programmes each. The exact breakdown across each of the work programmes is shown below in Table 1:

Table 1: Number of service users / carers involved in NMH DU programmes

Work Programme	No. involved (n=14)
Mental Health Commissioning	6
Improving Access to Psychological Therapies	6
Mental Health Equalities	8
Social Inclusion and Social Justice	6
Improving Mental Care Pathways	9
Promoting Wellbeing and Public Health	5
Personalisation	6

All but one service user had attended national meetings for the projects they had been working on. When asked whether they considered service users or carers to be more involved in mental health policy; 42% said they thought service users were more involved, 14% said they thought carers were more involved. The remainder said that there was a similar level of involvement for each.

According to data from the interviews, there was some scepticism about the representativeness of service users and carers involved in previous NMH DU (and NIMHE/CSIP) projects. Furthermore, it seems that there was an established, traditional culture of service user and carer involvement, bound up with an established 'language'.

“From a BME perspective it is not the way we envisaged involvement. There is still a long way to go to make service users and carers feel valued and respected. There is little or no key involvement nationally, and none at a strategic level.” (NMH DU Professional)

“You have to fit in, it’s not for everybody...you have to learn the jargon...” (Carer)

“NMH DU language is a barrier” (Carer)

Service user representativeness in the projects could have been biased towards people who had certain types of mental health problems, and/or had 'recovered' from their mental health problem.

“Just the same faces and the same voices spouting their own views”. (Service user)

“People with severe mental health problems are rarely represented. Individuals with conditions such as long term and enduring psychotic conditions are poorly represented simply because the vast majority of “service user advisors” are mostly individuals with depressive conditions not, for example schizophrenia.” (Carer)

*“There is a danger that one group is expressing the needs of others without having any real understanding what those needs truly are”.
(Carer)*

Again, regarding representativeness, there was some discrepancy between service user involvement and carer involvement. Carers sometimes felt that their own identity had not been developed as fully as those of service users.

“in New Horizons: carers only have one sentence.” (Carer)

*“Lumping service users and carers together is no good for carers because they will always put the service users’ needs before their own”.
(Carer)*

However, this view was not universal:

“I feel very blessed to have been working in a time where I was listened to as a carer”. (NMH DU Professional/carer)

Communication between NMH DU and voluntary sector organisations was seen as essential. A lack of communication was acknowledged. This appeared to be being addressed:

“NMH DU need to link in with voluntary organisations, who may have databases of service users and carers”. (Carer)

“We want to work with NSUN to review the policies we have about involving service users and carers and would like them to recommend others...hopefully we will be able to learn from a range of approaches... we would like to see observations that come out the evaluation as they happen so that we can start to make ongoing changes” (NMH DU Professional)

Some projects attempted to achieve diversity of representation. The Shift initiative within the Social Inclusion and Social Justice programme aimed to tackle stigma and discrimination surrounding mental health issues in England. The early intervention for psychosis programme worked alongside other workstreams in attempting to achieve diversity:

*“The board attempted to be representative of service users and carers across the gender, age, ethnicity, faith, sexual orientation and region.”
(Practice example, Shift)*

“There was regular participation with some members from the Promoting Equalities in Mental Health work programme to try to ensure diversity in representation, for example, the programme evaluated outcomes relating to further education opportunities for people from black and minority ethnic backgrounds.” (Practice example, early intervention in psychosis)

3. Process

This relates first to ensuring that service users and carers are involved at an adequate level within programmes and projects. Views of the process of involvement were often positive. From the survey, 71% of the respondents felt that their involvement was always or often valued; only one respondent felt that their involvement had never been valued. 86% said their involvement had been positively received by other members of the project board.

Two examples show how managing the involvement process requires facilitating clear, structured, tangible activities. The early intervention for psychosis programme included a declaration and practice manual co-written by service users and carers.

“All 14 members of the advisory board were informed of all activities by email and invited to participate in clearly defined events such as conferences, presentations and consultations. Members of the advisory board discussed and contributed to plans, proposals and projects. They acted as advisors as opposed to decision makers; board members were free to offer a wide range of responses and ideas.” (Practice example, Shift)

“Several chapters of the practice manual for early intervention were co-authored with service users and carers. The programme included regular ‘hothouse’ events. These were facilitated as interactive sessions that mixed service users and families alongside service professionals and other partners (such as local authority workers and youth agencies).” (Practice example, early intervention in psychosis)

Involvement processes also need to support service users and carers to be involved. From the survey, 71% also said that they felt they had been adequately supported always or often during the period of their involvement, the remaining 29% felt that they had sometimes been adequately supported. Some service users and carers who had been involved in projects wanted clarification on some aspects of the payment process.

“Advisors received a daily rate based on MaRD guidelines. Board members received one day training on negotiating and marketing skills using role play with a senior civil servant, and one day training on voice production and public speaking with a coach from the National Theatre. There was also the option for up to £1000 worth of Continuing Professional Development training, including the opportunity to train as a Mental Health First Aid instructor.” (Practice example, Shift)

“I have to ask for travel expenses and there’s no payment for attendance”. (Carer)

“The MaRD payment stuff isn’t clear, does time include travel time?” (Service user)

Regarding specific emotional support, half said they received emotional support when needed, however 29% said that they rarely or never received this. 76% said they always or often received prompt payment of fees and expenses, however, 14% said that this rarely happened. Interview data presented above suggested that some participants had difficulty claiming expenses, which acted as a barrier to people becoming involved.

4. *Impact*

Having a demonstrable impact on projects and programmes is vital to service user and carer involvement. Survey data revealed that 71% felt as though they were able to have an influence in the projects that they were working on, 14% gave a neutral answer, and 14% felt that they had limited influence. Half said they felt their voice was always or often heard, 21% said that it was sometimes heard, 14% said that their voice was rarely heard. Data from practice examples suggest some ways in which service users and carers could see the impact of the project directly.

“A sub group of the advisory board have co-produced a series of four DVDs that can be used as a resource for employers’ education and awareness raising programme.” (Practice example, Shift)

“The programme was viewed by professionals at the NHS Institute of Innovation and Improvement as an example of social movement. The project lead was invited to work with the World Health Organisation Europe & European Commission to establish user and carer involvement. Service users and carers were involved in conference presentations and workshops with professionals.” (Practice example, early intervention in psychosis)

Data from the interviews highlighted the importance of demonstrating that involvement had had an impact. It was important for those involved to feel a sense of achievement and closure. Participants highlighted a lack of continuity in projects and programmes, and may have felt disappointed that they had put time and energy into projects that were only funded for a short period. There was recognition by at least one professional that this area needed improvement in future:

“There has been a lot of upheaval...don’t know what will happen when the project finishes... I hope the work can be continued in another project”. (Service user)

“The programme came to nothing, I felt let down, left in limbo”. (Service user)

“Money has been spent by NIMHE and CSIP to train me as a facilitator and but I’ve never been used”. (Carer)

“The project was fantastic. There was a lot of work put into it by service users but the products have not been made widely available for some reason. I don’t know why this decision was made.” (Service user)

“There are ups and downs. We haven’t got everything right, but there is goodwill. We will continue to work with service users and carers to get it right”. (NMHDU Professional)

To some extent it may not be that programmes ‘came to nothing’, but that there was a lack of sufficient feedback mechanisms to ensure that service users and carers were informed about the impact of their involvement.

4.2. Service user and carer involvement following NIP and the PPPI

This section describes how service user and carer involvement was implemented in NMHDU during and after input from NIP. The PPPI framework had been developed fully by the time that these data were collected.

1. Purpose

To some, the initial work by NIP in scoping involvement work in NMHDU was a good way of beginning to look at the purpose of involvement.

“It’s important to identify roles early on. The initial NSUN report was very useful in kicking things off. This was a good guide for getting going with service user and carer involvement.” (NMHDU Professional)

“Overall, service user and carer involvement has gone well within NMHDU. However, this has not been in a traditional sense, such as having service users on councils. Our model throughout has been different, we wanted to have involvement permeating through all the work that we’ve done.” (NMHDU Professional)

NIP promotional events aimed to provide opportunities for involvement amongst people with experience of mental health problems, and the friends and family who support them. They aimed to expand the pool of service users and carers who were involved. There was considerable positive feedback from NIP promotional events. For one event, 87% felt ‘good’ or ‘very good’ about understanding of the purpose of their involvement, and 96% felt ‘good’ or ‘very good’ about being listened to and having their opinion valued. Many of whom appreciated the opportunity to meet with others, share their views, experience and ideas.

“I am new to the work of NMHDU and hope to get more involved. I have found staff to be very approachable and interested in my experiences so far. This is a refreshing change from local services.” (Service user)

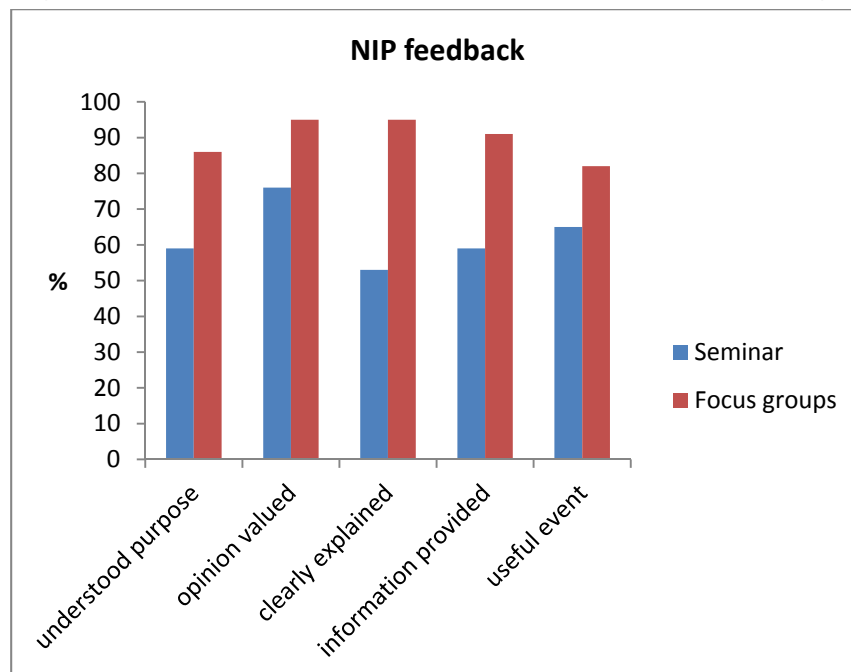
However, participants at these events said they had unclear purpose. The language of involvement may have been confusing or discouraging for some people. Perhaps more importantly, some commented that there was little opportunity to follow up with involvement activity after the event.

“It was difficult and confusing. Feeling frustrated...didn’t have a feeling of what aims of the day were, what they were hoping to achieve.” (Carer)

“There is a need to follow up people after the events to encourage them to participate.” (Service user)

The NIP seminar in collaboration with the Mental Health Equalities Programme, and the focus group in collaboration with Social Justice workstream were better received. This was because they appeared to have greater sense of purpose. Figure 1 shows the percentage of people who rated the seminar and focus group as ‘good’ or ‘very good’, relating to the purpose of the event and the quality of information provided. The focus group was particularly well received.

Figure 1: Feedback from NIP events; seminar and focus group



Participants appreciated in the fact that they helped facilitate information flow between professionals and service users/carers. Many who attended felt that they provided a learning opportunity. Participants reported sharing experience and identifying common barriers to involvement.

“I’ve discovered a wealth of knowledge to take back to service users/commissioners” (Focus group feedback)

“I picked up a good idea from a fellow participant on an easy way to reach out to GPs and inform them about existing involvement networks” (Seminar feedback)

“I found out about Department of Health policy on how it might be influencing ‘service users’ and carers. Hearing from delegates on their frustration with services was enlightening.” (Seminar feedback)

The relationship between the commissioning body (NMHDU) and the consultant (NIP) was pivotal in agreeing the purpose of involvement. Both organisations were involved in co-ordinating the seminar.

“Service user and carer involvement worked well during my time at NMHDU. Initially we met with NIP to identify issues that we could work on together. The Whitepaper Seminar had been identified as a priority for us to work together on. The purpose was to get people thinking in their localities about what they could get involved in.” (NMHDU Professional)

However, there was also a need to clarify the meaning of involvement and to manage expectations, both within NIP and within NMHDU:

“Some attendees used the day as a platform to air their own grievances, but it was very well managed by the chairs for the seminar and NIP facilitators” (NMHDU Professional)

“There is a need to manage expectations, I think NIP had a lot of experience in this area and had obviously thought a lot about it, this showed on the day of the White Paper seminar” (NMHDU Professional)

2. Presence

Of the 26 people who responded to the second survey, 19 (73%) identified themselves as 'having experienced past or present mental distress' and 15 (57%) identified themselves as being carers. Twenty two (85%) had heard of NSUN, 23 (86%) of NMHDU, 19 (73%) of NIMHE and CSIP. However, only 12 (46%) had been involved in NMHDU projects. The number of people involved in NMHDU programmes is shown in table 2.

Table 2: Number involved in NMHDU programmes

Work Programme	No. involved (n=12)
Mental Health Commissioning	4
Improving Access to Psychological Therapies	3
Mental Health Equalities	6
Social Inclusion and Social Justice	4
Improving Mental Care Pathways	6
Promoting Wellbeing and Public Health	7
Personalisation	4

Participants indicated that they felt diversity issues in involvement were well covered. Gender, age, sexual orientation, disability, social class and race were felt to be well represented in the projects. Over 60% said yes in all cases. However, ensuring diverse representation of different groups of people presented challenges

“Race and gender were well represented throughout; in fact the gender reference group had a good ethnic mix within it. Regarding age, we tried to involve people in specific projects that older people could relate to, for example a project that involved looking at care homes. Areas such as religion, disability and sexuality were more challenging, largely because they were new areas to our portfolio as of April last year.” (NMHDU Professional)

NIP worked with the NMHDU strands to try to help NMHDU involve service users and carers from a range of backgrounds. One example of this arose when inviting service users and carers to NMHDU seminars and focus groups. Another involved the collection of case studies of service users for the mental health strategy:

“NIP ensured that we involved and invited a good mix of service users and carers. They had a targeted audience of service user and carer networks, which we reviewed together with NIP. We had a fairly good representation across gender, race, age and disability.” (NMHDU Professional)

“We have secured a greater number of case studies by engaging people in localities via a service user run organisation facilitating the collection. I know that people will have been engaged sensitively and their needs responded to within the process.” (NMHDU Professional)

Those professionals involved in organising the focus groups along with NIP echoed positive sentiments around the how service users and carers were reached. In one case, service users were given the deciding vote on an interview panel for a NMHDU tender.

“It ensured that service users and carers were involved in the process from beginning to the end.” (Focus group feedback)

“The fact that we have had an opportunity to have our views heard changed other peoples’ perspective. I am more inspired to continue campaigning for change.” (Focus group feedback)

“The involvement of NSUN in engaging the right group of service users for this piece of work was invaluable” (Focus group feedback)

“In one case I was on the interview panel with two service users, so they had the deciding vote over who was chosen.” (NMHDU Professional)

This view was not always shared across all NIP activity, particularly; the initial promotional events may have been more aimed at people who had been involved before. The culture of service user and carer involvement may have been off-putting for some who attended these events who had been less involved in the past:

*“Many people already knew each other and what it was all about.”
(Service user)*

“I was very disappointed to see the event being chaired by white middle class men who were leading on a number of national projects. This is not a reflection people who work in and deliver services or the diversity of people who receive services”. (Service user)

In particular, carers with full-time employment and people with severe mental health problems may find barriers in attending. In this case promotional events may not always represent the best way to involve people representing these groups:

“As a working carer I am excluded from these events... I know several others who are carers and do not know about how to get involved. You don't seem to know how to find us! How was the event advertised? ...I only saw it by chance as an email was forwarded to me”. (Carer)

“The event wasn't aimed at people living and going through severe mental illness.” (Carer)

3. Process

Most respondents to the survey (8 out of 11) said they always or often received documents and information on time. However, some participants did not feel as though they received sufficient support in their role; three out of the 10 respondents said they rarely or never received sufficient supervision, administrative support, or emotional support throughout the project.

“The fact that we have had an opportunity to have our views heard changed other peoples' perspective. I am more inspired to continue campaigning for change.” (Focus group feedback)

Regarding payment of expenses and fees, half (5/10) said they 'sometimes' received them on time. Difficulties were expressed around the rates of payment for travel expenses and the time taken for reimbursement. This needs to be addressed in future meetings and events.

“It took me some time to find out what the payment rates were and which policy they came from...whether they would pay for travelling time or overnight accommodation...on balance I decided that the approach was not thought-through and therefore potentially dangerous to my mental health and I decided not to participate.” (Service user)

“The cost of attending the meeting was not met until some six weeks after the event and then only after several emails.” (Service user)

There were some suggestions for future improvement, for example, not everyone thought that service user and carers should be together in such events.

'I'm not sure if carers and service users should be lumped together as they have different agenda.' (Seminar feedback)

Optimum involvement processes were also somewhat hampered by the external financial environment. For example, NMHDU funding was finite, and staff members were often limited to spending up to £4,000 per project. Commissions between NMHDU and NIP needed to fit within this budget framework:

"It was difficult to work within the £4,000 constriction. Time boundaries were of concern. It was sometimes difficult to balance with NMHDU watching budget and NIP watching the quality of involvement." (Service user)

"Some projects were hampered by short tenure; from September 2010 we knew that the funding would no longer be available from March 2011 onwards." (NMHDU Professional)

4. Impact

Twenty of the 26 survey respondents (77%) had been to a NIP promotional event. The majority (15 out of 20 - 75%) said that these events were good or very good. However, the majority (15 out of 20) also said that they had not been involved in national mental health projects since attending the event, and half said they had not significantly influenced to be more involved in NMHDU projects (9 out of 18, 50%), although some (6 out of 18, 33%) said that it had influenced them significantly. All but one (20 out of 21 - 95%) intended to be involved in NMHDU projects in the future.

Service users and carers valued the opportunity to contribute to discussions at seminars and focus groups. This is an example of a tangible impact which can be felt immediately by those who had been involved, particularly for professionals who could learn directly from service users and carers about pertinent issues.

"I thought my involvement was needed to ensure that the service user view is incorporated into designing and shaping services" (Focus group feedback)

"The fact that we have had an opportunity to have our views heard changed other people's perspectives. I am more inspired to continue campaigning for change." (Focus group feedback)

"the perspective of carers as expert partners, we live in communities and need support networks and that carers are integral to mental health services." (Seminar feedback)

The importance of feedback to service users and carers to show impact cannot be underestimated.

“This experience will be more meaningful if we get feedback about what difference our ideas have made which hopefully will happen as part of this process.” (Seminar feedback)

“At the White Paper event, service users and carers were invited to give feedback. This worked well, and would definitely do this more extensively if doing something similar in the future. Feedback is good practice because otherwise service users and carers’ involvement can feel a bit tokenistic.” (NMHDU Professional)

Professionals viewed NIP as a positive step for service user and carer involvement, and professionals expressed interest in using the Partnership in their work. There were some positive views towards the Purpose, Presence, Process, Impact (PPPI) framework for involvement, although it may need some more testing in practice before it is wholly applicable:

“The workshops were very dynamic and useful. We want NIP to get up a source of service user and carer reference groups across the work stream. I think all the issues of the PPPI model are relevant and it’s a good idea...but I have found it a bit problematic... would need to be working full time to get all the information needed...didn’t have time to start filling it all out.” (NMHDU Professional)

“There is a future for this kind of work and involvement...a powerful dyad of professional and carer can change practice.” (NMHDU Professional)

“It has added a whole new dimension to involvement...allows service users and carers to be much more integrated...they are integral to the work, and are the staff rather than just being on the periphery.” (NMHDU Professional)

One of the aims of NMHDU and NIP was to leave a legacy of service user and carer involvement work within mental health. The co-operation of the two organisations was seen as essential for this to happen, possibly for logistical and continuity reasons such as staffing.

“NIP has a vital role in making sure NMHDU leaves a legacy. This is because lots of NIP people have worked with NMHDU. NMHDU provides a springboard for NIP work, not only in funding but also through human resources and skills.” (Service user)

“I’d say that our legacy was in being brave about exposing what we do; making involvement demonstrable. It wasn’t perfect, and we haven’t achieved everything we wanted to achieve, but some things did change as a consequence of the work.” (Professional)

Part of this legacy lies in developing capacity for service user and carer involvement work outside of NMHDU, in the wider sense. If this happens in

the long term, then it will be a significant impact of NMHDU service user and carer involvement:

“One of the reasons we did the event jointly with NIP was to assist NIP in developing a platform with service user networks on issues around the whitepaper and equalities. I hope that NIP can use this when planning future actions.” (NMHDU Professional)

5. Discussion

Summary of findings

The findings of this report serve to highlight the practicalities, benefits and difficulties of involving service users and carers in national policy and practice work, whether it was for NMHDU, CSIP or NIMHE. The PPPI model was used to provide a framework for assessing the success of service user and carer involvement. Results indicate that the four domains of purpose, presence, process and impact were being implemented across the lifespan of the NIP to varying degrees.

Clarity of *purpose* is needed in order to ensure meaningful involvement. This evaluation indicates that people were well briefed about purpose in NMHDU (including NIMHE and CSIP) work. NIP and some of the NMHDU projects appeared to meet to discuss purpose at the outset. Projects and commissions such as the focus groups and seminars appeared to have a clear purpose, but initial NIP promotional events fared less well, which made it difficult to capitalise on contacts gained. A common purpose of involvement was information sharing, particularly in cases when service users and carers could interact directly with professionals, such as in seminars or events. Purpose needs to be set at a reasonable level as to be achievable within the circumstances. Within this, NMHDU and NIP aimed to manage expectations about the purpose of involvement.

Ensuring a diverse, representational *presence* within projects and programmes was challenging to both NMHDU and NIP. Prior to NIP, representation was limited to a minority of service users and carers. Others may have been discouraged or alienated by use of jargon terminology, service users with more severe and present mental ill health found it difficult to be involved, as did some carers. NIP itself had difficulty addressing diversity, and their initial promotional events were criticised on these grounds. Ensuring diversity for involvement across the different strands within NMHDU proved challenging, but there was positive feedback about how NIP had worked to ensure representation from a diverse spread of people. NIP also succeeded in engaging a greater number of service users and carers that had not before been involved.

It appeared that there were some examples of appropriate *process* in NMHDU prior to NIP, such as service users and carers co-authoring documents and acting as valued advisors. However, there was room for improvement in

supporting people to be involved, such as payment of fees and expenses and in providing emotional support where necessary. There also appeared to be some discrepancy between NMHDU and NIP about the level of service user and carer involvement that was expected. This was no doubt hindered by pressure from the external financial environment.

Showing *impact* of involvement work is important. One way in which this can be improved is in receiving feedback, and it is here in which it links with the process of involvement. Before NIP, there was evidence that feedback was happening in some projects, but that changing circumstances with projects and programmes led to upheaval which made it difficult. Similarly, people who attended NIP events wanted some direction on how they could follow up their interest. When service users and carers were shown the impact of their work, then the results were positive, as shown in joint information sharing events for professionals, service users and carers. In the longer term, the lasting impact of service user and carer involvement in NMHDU remains to be seen. Much will depend upon the capacity of NIP to capitalise on the legacy of NMHDU. The work with NMHDU provides a platform from which NIP can develop and expand its remit.

Strengths and limitations of the evaluation

This is evaluation used a mixture of methods to collect data and corroborate findings. This was deemed particularly important to triangulate information and check for inconsistencies. For example, participants may be positive about involvement when asked in a survey but revealed more negative views in interviews.

There are a number of weaknesses with the study design however, such as the small sample size. It should be noted that the study sample included a majority of white British females who were over the age of 45. The lack of people responding to surveys who were from BME communities is also a concern and could be said to represent the lack of diversity in service user involvement projects per se. Data collected from feedback forms and case studies also lack the transparency of that which is collected through questionnaire and interview methods.

Implications for the future

There have been positive and negative practices in the service user and carer involvement work of NMHDU (and NIMHE/CSIP). NMHDU and NIP have worked together to attempt to improve this. The two organisations have worked on several specific projects and commissions. The NIP work has been successful in developing a framework by which to appraise involvement, and has succeeded in running a number of service user and carer events which have embodied elements of good practice. However, there are some hurdles yet to be overcome, for example, ensuring that people from all groups (including carers and people with severe mental illnesses) can be represented.

NIP itself needs to orientate within the new external political environment. It needs to identify strengths and to be able to communicate them to others who may not be immediately familiar with the concept of service user and carer

involvement. Both NIP and NMHDU have a wealth of information about how to involve service users and carers, including key learning points from projects they have worked on in the past. It remains to be seen how the work of NIP will be valued within the new health commissioning framework. The new HealthWatch projects may be ideal places for NIP to promote service user and carer involvement. Local HealthWatch will be interlinked with GP Consortia, who will decide whether to commission services from organisations such as NIP.

NIP has an established track record of working with NMHDU. Many of the staff involved in NIP have also been involved in NMHDU projects prior to this. NIP therefore has the expertise to develop, and to establish its identity and unique selling points. NMHDU can be credited if NIP manages to become a self-sufficient organisation representing service user and carer involvement. Time will tell whether this will happen.

Recommendations

- What is the *purpose* of involvement? Organisations seeking to involve service users and carers should consult with service user led organisations (such as NIP) to agree the reason why involvement is needed.
- The culture and language of service user and carer involvement should be understandable within the context of everyday life, not just within the context of policy and practice. This will:
 - Facilitate the *presence* of a more diverse range of service users and carers within the network.
 - Help NIP to build links with a more diverse range of statutory, voluntary and private organisations.
- *Processes* should be in place for service users and carers to move from being interested in involvement to becoming active participants. Follow up for participants after initial engagement is essential in order to maintain interest.
- Continuity needs to be embedded into the culture of service user and carer involvement. Therefore, upon completion of projects, NIP can help signpost those involved other opportunities and projects.
- Practical and emotional support should be available to help people become involved. NIP could develop mentoring schemes; those who have been involved in the past could support others to become involved.
- Organisations that wish to involve service users and carers should provide feedback to those who have been involved NIP could collate

and disseminate feedback, providing participants with information about project *impact*.

6. References

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Appendix 1: Selection of NIP work activity within NMHDU until December 2010

Activity	Quality/Evidence of Impact	Timescale
Collation of 30 case studies <ul style="list-style-type: none"> • Advertising • Responding to enquiries • Collating case studies • Selecting & formatting case studies 	<ul style="list-style-type: none"> • Diverse response • Detailed information • Support offered and provided • Feedback 	Phase 1 Sep – Oct Phase 2 Nov - Dec 2010 20 days
Recruitment and support of Liaison and Diversion focus groups <ul style="list-style-type: none"> • Advertising • Responding to enquiries 	<ul style="list-style-type: none"> • Diverse response • Detailed information • Support offered and provided • Feedback 	16/17 Sep 2010 12 days
Initial comments on extracts of new commissioning guide <ul style="list-style-type: none"> • Good practice examples for accessible commissioning guide. 	<ul style="list-style-type: none"> • Focused response • Fast access to feedback 	13 - 24 Sept 2010 1 day
1 day seminar for 40 delegates from the NIP network: <ul style="list-style-type: none"> • 'Understanding and planning for the new policy environment' • Proposed regional events (see below) 	<ul style="list-style-type: none"> • Diverse response • Detailed information • Support offered and provided • Feedback • Dissemination model 	Sep 10 – Mar 2011 5 days
Collation of 20 Yes/No/Yes But responses into a Venn Diagram <ul style="list-style-type: none"> • Collated comments from NIP network about proposed guiding principles of new draft mental health strategy 	<ul style="list-style-type: none"> • Diverse response • Detailed information • Focused response • Fast access to feedback Dissemination model 	Oct – Nov 2010 4 days

Appendix 2: Service user and carer survey

Part A – Service user and carer involvement in mental health policy

Please mark answers with an 'X' inside the appropriate boxes unless otherwise stated

1. Do you consider yourself to be a user of mental health services, past or present?

Yes

No

2. Do you consider yourself to be a carer of someone with mental health problems, past or present?

Yes

No

3. Have you heard of the following organisations:

National Mental Health Development Unit (NMH DU)

Yes

No

National Institute of Mental Health in England (NIMHE)

Yes

No

Care Services in Partnership (CSIP)?

Yes

No

4. Have you ever been involved in helping to change government policy for mental health?

Yes

No

5. In what way have you been involved? (Please describe)

6. To what extent do you feel that your involvement in mental health policy has been valued?

Always

Often

Sometimes

Rarely

Never

7. Was the purpose of your involvement in mental health policy made clear by the policy making organisation?

Yes

No

8. Have you been involved in any of the following work programmes? (Please mark any that apply)

Mental Health Commissioning

IAPT

Mental Health Equalities

Promoting Social Inclusion and Social Justice

Improving Mental Health Care Pathways

Promoting Wellbeing and Public Mental Health

Personalisation in Mental Health

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

9. Which mental health policy projects have you been involved in? (Please describe)

To what extent do you agree with the following two statements:

10. 'I am able to influence mental health policy'

Strongly agree Agree Neutral Disagree Strongly disagree

11. 'I have been accurately informed of how much influence I may have on mental health policy'

Strongly agree Agree Neutral Disagree Strongly disagree

12. Was your role in mental health policy clearly explained by the project lead?

Yes No

13. Have you attended national meetings for mental health policy projects?

Yes No

14. Have you felt adequately supported in your involvement with mental health policy? (Please mark one)

Always Often Sometimes Rarely Never

15. Between service users and carers, who do you feel is most involved in mental health policy?

Service users are more involved Carers are more involved No differences

16. Has your involvement been positively received by others working on the project?

Always Often Sometimes Rarely Never

17. Did you feel that your voice is being heard by mental health policy makers?

Always Often Sometimes Rarely Never

18. If you needed emotional support at any time during your involvement, was this provided?

Always Often Sometimes Rarely Never

19. Are you provided with clear information in order to support your involvement?

Always Often Sometimes Rarely Never

20. Did you receive prompt payment of expenses/fees for your involvement?

Always Often Sometimes Rarely Never

21. Did you receive feedback about the impact your involvement has had on mental health policy?

Always Often Sometimes Rarely Never

22. How are you made aware of how new government mental health policies might affect you? (please describe)

23. What do you feel that you have gained from becoming involved in mental health policy making? (please describe)

Part B – Demographic information

24. Age:

Under 18 46 – 60
18 – 30 61+
31 – 45

25. Gender:

Male Female

26. Ethnicity:

<i>White</i>	<i>Mixed</i>	<i>Asian / Asian British</i>	<i>Black / Black British</i>	<i>Chinese / other ethnic group</i>
<input type="checkbox"/> British <input type="checkbox"/> Irish	<input type="checkbox"/> White and Black Caribbean <input type="checkbox"/> White and Black African <input type="checkbox"/> White and Asian	<input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Bangladeshi	<input type="checkbox"/> Caribbean <input type="checkbox"/> African Other	<input type="checkbox"/> Chinese

27. Is English your first language?

Yes

No

Part C – Permission for further consultation

We would very much like to hear more about your thoughts on service user/carer involvement in mental health policy. Please complete this section of the form if you would be happy for us to contact you in the future.

28. Would you be willing to share your opinions further in a telephone interview?

Yes

No

29. What is your preferred method of contact?

Telephone

Email

30. Please fill in your contact details as appropriate:

Name

Telephone

Email

Appendix 3: Professionals' survey

1. What job do you do? Are you employed by NMH DU?

1a. What is your experience of involving service users/ carers in the work that you do?

1b. Are you aware of any policies that your organisation has about this?

1c. Which work stream(s) are you involved with?

1d. How many service users /carers are involved in the work stream(s)?

Mental Health Commissioning
 IAPT
 Mental Health Equalities
 Promoting Social Inclusion and Social Justice
 Improving Mental Health Care Pathways
 Promoting Wellbeing and Public Mental Health
 Personalisation in Mental Health

S/U	C

1e. How do you ensure that service users and carers feel that their involvement is valued?

2. How do you enable service users and carers to oversee the work of NMH DU?

2a. How would you aim to increase the number of service users and carers involved?

2b. Do you enable service users and carers to give their perspective at national programme boards?

2c. Is service user and carer involvement part of the induction package for new staff?

2d. To what extent are service users and carers made aware of the limitations of their influence?

2e. Do you offer training for existing staff to facilitate service user and carer involvement?

3. How do you monitor and evaluate service user and carer involvement?

4. Do you provide emotional support for service users and carers when needed?

Always Often Sometimes Rarely Never

4a. What kind of emotional support do you provide?

5. Do you provide a role description for service users and carers at the beginning of their involvement?

Always Often Sometimes Rarely Never

6. Do service users and carers have access to clear information in a variety of formats?

Always Often Sometimes Rarely Never

7. Do service users and carers receive prompt payment of expenses/fees?

Always Often Sometimes Rarely Never

8. Do you involve service users and carers from marginalised groups?

Always Often Sometimes Rarely Never

9. Do you give service users and carers feedback about the effect their involvement has had?

10. How are service users and carers made aware of how new policies might affect them?

11. What benefits do you think involving service users has to offer?

12. What benefits do you think involving carers has to offer?

13. Are there any other comments you would like to make?

14. Can I just ask you a few demographic questions please?

15. Age: ____ years

16. Gender:

Male

Female

17. Ethnicity

White	British	<input type="checkbox"/>
	Irish	<input type="checkbox"/>
	European	<input type="checkbox"/>
Mixed	White & Black Caribbean	<input type="checkbox"/>
	White & Black African	<input type="checkbox"/>
	White & Asian	<input type="checkbox"/>
Asian / Asian British	Indian	<input type="checkbox"/>
	Pakistani	<input type="checkbox"/>
	Bangladeshi	<input type="checkbox"/>
	Chinese	<input type="checkbox"/>
Black / Black British	African	<input type="checkbox"/>
	Caribbean	<input type="checkbox"/>
Other	Please state	<input type="text"/>

18. Is English your first language?

Yes

No

Appendix 4: Service user and carer survey

Part A – Service user and carer involvement in mental health policy

Please mark answers with an 'X' inside the appropriate boxes unless otherwise stated

1. Do you consider yourself to have experienced mental distress past or present?

Yes

No

2. Do you consider yourself to be family/carer of someone with mental health problems, past or present?

Yes

No

3. Have you heard of the following organisations?

National Survivor User Network (NSUN)

Yes

No

National Mental Health Development Unit (NMH DU)

Yes

No

National Institute of Mental Health in England (NIMHE)

Yes

No

Care Services Improvement Partnership (CSIP)

Yes

No

4. Have you been involved in any NMH DU projects?

Yes

No

If you answered 'yes' to Question 4 please go to Question 5. If you answered 'no' please go to Question 21

5. Have you been involved in any of the following work programmes? (Please mark any that apply)

Mental Health Commissioning

IAPT

Mental Health Equalities

Promoting Social Inclusion and Social Justice

Improving Mental Health Care Pathways

Promoting Wellbeing and Public Mental Health

Personalisation in Mental Health

If you ticked any of the above please describe your role:

6. Was your role in the project/s made clear?

Always

Often

Sometimes

Rarely

Never

7. Have you been involved in the direction of the project/s? (For example, member of steering group?)

Always

Often

Sometimes

Rarely

Never

8. Have you been involved in reviewing the project/s? (For example, consultations/proof reading?)

Always

Often

Sometimes

Rarely

Never

9. Are you involved in staffing decisions for the project/s? (For example, sitting on a recruitment panel?)

Always

Often

Sometimes

Rarely

Never

10. Do you feel the project/s reflects a diversity of:

a. Gender

Yes

No

Don't know

b. Race

Yes

No

Don't know

c. Sexual orientation

Yes

No

Don't know

d. Age

Yes

No

Don't know

e. Faith

Yes

No

Don't know

f. Disability

Yes

No

Don't know

g. Social class

Yes

No

Don't know

11. Do you receive meeting documents on time?

Always

Often

Sometimes

Rarely

Never

12. Do you receive sufficient information about the aims of the project/s?

Always

Often

Sometimes

Rarely

Never

13. Do you receive sufficient supervision in your role/s?

Always

Often

Sometimes

Rarely

Never

14. Do you receive sufficient administrative support in your role/s?

Always

Often

Sometimes

Rarely

Never

15. Do you receive sufficient emotional support in your role/s?

Always

Often

Sometimes

Rarely

Never

16. Do you receive sufficient training for your role/s?

Always

Often

Sometimes

Rarely

Never

17. Do you receive prompt payment of expenses/fees?

Always

Often

Sometimes

Rarely

Never

18. Do you receive feedback about your involvement in the project/s?

Always

Often

Sometimes

Rarely

Never

19. Have you been given the opportunity to present the project/s to a wider audience?

Always

Often

Sometimes

Rarely

Never

20. Please use the box below for further comments

21. Have you attended any NMH DU Involvement Partnership events?

Yes

No

If you answered 'yes' to Question 21 please go to Question 22. If you answered 'no' please go to Question 28.

22. How have you found the NMH DU Involvement Partnership events?

Very good

Good

Neutral

Poor

Very poor

23. Have you been involved in any national mental health projects since attending a NMH DU Involvement Partnership event?

Yes

No

24. To what extent has a NMH DU Involvement Partnership event influenced your involvement in national mental health project/s?

A lot

Quite a lot

Neutral

A little

Not at all

25. What do you consider to be the main challenges of service user and carer involvement in NMH DU?

26. To what extent has a NMH DU Involvement Partnership event identified some of these challenges?

Totally

Mostly

Neutral

A bit

Not at all

27. Do you intend to be involved in any national mental health projects in the future (e.g, for NMH DU)?

Yes

No

Part B – Demographic information

28. Age:

Under 18	<input type="checkbox"/>	46 – 60	<input type="checkbox"/>
18 – 30	<input type="checkbox"/>	61 – 75	<input type="checkbox"/>
31 – 45	<input type="checkbox"/>	Over 75	<input type="checkbox"/>

29. Gender:

Male

Female

30. Ethnicity:

White

Mixed

Asian /

*Black / Black
British*

*Chinese / other
ethnic group*

British
 Irish

White and Black Caribbean
 White and Black African
 White and Asian

Asian British
 Indian
 Pakistani
 Bangladeshi

Caribbean
 African
Other

Chinese

31. Is English your first language?

Yes

No

32. If you answered 'no', what is your first language?.....

Appendix 5: Professionals' survey

1. What is your job title? Are you employed by NMHDU/NSUN?

2. Which work stream(s) are you involved with?

3. How many service users /carers are involved in the work stream(s)?

Mental Health Commissioning
 IAPT
 Mental Health Equalities
 Promoting Social Inclusion and Social Justice
 Improving Mental Health Care Pathways
 Promoting Wellbeing and Public Mental Health
 Personalisation in Mental Health

S/U	C

4. How do you involve SU/C in your work?

5. Are you aware of any policies your organisation has about SU/C involvement?

6. Have you attended any NMHDU Partnership Involvement events?

Yes

No

7. If yes, how helpful have you found their meetings?

Very

Quite

Indifferent

Not very

Not at all

8. Are they relevant to your work?

Yes

No

9. How much potential do you believe the NMHDU Involvement Partnership has to recruit service users and carers?

A lot	<input type="checkbox"/>	Quite a lot	<input type="checkbox"/>	Not much	<input type="checkbox"/>	None	<input type="checkbox"/>
-------	--------------------------	-------------	--------------------------	----------	--------------------------	------	--------------------------

Please comment: _____

10. How would you use the NMHDU Involvement Partnership in your work? (Would you consider using their knowledge/expertise/database?)

11. Have you heard of the PPPI (Purpose, Presence, Process, Impact) framework for SU/C involvement?

12. How useful do you think this framework is?

Very

Quite

Indifferent

Not very

Not at all

13. Is the role of SU/C in the programme made clear?

Always

Often

Sometimes

Rarely

Never

14. Are SU/C involved in the direction of the programme? (For example, member of steering group?)

Always

Often

Sometimes

Rarely

Never

15. Are SU/C involved in the reviewing of the project/prog? (For example, consultations/proof reading?)

Always

Often

Sometimes

Rarely

Never

16. Are SU/C involved in staffing decisions for the project/prog? (For example, sitting on a recruitment panel?)

Always Often Sometimes Rarely Never

17. Do you feel the project reflects a diversity of:

a. Gender		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>
b. Race		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>
c. Sexual orientation		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>
d. Age		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>
e. Faith		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>
f. Disability		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>
g. Social class		Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>

18. Do SU/C receive meeting documents on time?

Always Often Sometimes Rarely Never

19. Do SU/C receive sufficient information about the aims of the programme?

Always Often Sometimes Rarely Never

20. Do SU/C receive sufficient supervision in their role?

Always Often Sometimes Rarely Never

21. Do SU/C receive sufficient administrative support in their role?

Always Often Sometimes Rarely Never

22. Do SU/C receive sufficient emotional support in their role?

Always Often Sometimes Rarely Never

23. Do SU/C receive sufficient training for their role?

Always Often Sometimes Rarely Never

24. Do SU/C receive prompt payment of expenses/fees?

Always Often Sometimes Rarely Never

25. Do SU/C receive feedback about their involvement in the programme?

Always Often Sometimes Rarely Never

26. Are SU/C given the opportunity to present the project to a wider audience?

Always Often Sometimes Rarely Never

Part B – Demographic information

27. Age:

Under 18
18 – 30
31 – 45

46 – 60
61+

28. Gender:

Male

Female

29. Ethnicity:

White

Mixed

Asian /

*Black / Black
British*

*Chinese / other
ethnic group*

British
 Irish

White and Black Caribbean
 White and Black African
 White and Asian

Asian British

Indian
 Pakistani
 Bangladeshi

Caribbean
 African
Other

Chinese

30. Is English your first language?

Yes

No