

# INVOLVE

Promoting public involvement  
in NHS, public health and  
social care research

(formerly Consumers in NHS  
Research)

## Report of commissioning workshop



Wednesday 2<sup>nd</sup> July 2003  
King's Fund, London

Jane Royle, along with assistance from Sarah Buckland and Helen Hayes, was responsible for writing this workshop report.

## Thanks

We would like to thank the following people who made the workshop possible:

- Jackie Downer, Brian McDonald and Shirley Nurock for their 'snapshot' presentations
- Derek Stewart for chairing the day and facilitating workshops
- Stuart Eglin and John Sitzia for facilitating workshops
- Peter Beresford, Vinod Kumar and Carol Lupton for their help in planning the event
- Barbara Dawkins for organising the seminar
- All of those who took part in the seminar and contributed to the discussions

## Note

Please note on 1 September 2003 we changed our name from Consumers in NHS Research to:

## INVOLVE

Promoting public involvement in NHS, public health and social care research

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An audio and large print version of this booklet is available from the INVOLVE Support Unit

# **INVOLVE COMMISSIONING WORKSHOP**

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## **1. INTRODUCTION**

This report gives a summary of the presentations and discussions held on 2<sup>nd</sup> July 2003, when invited members of the public, commissioners and researchers with experience of public involvement in the commissioning process attended a one day workshop. The purpose of the workshop was to explore ways of:

- improving the commissioning process and therefore have better funded research
- improving the contribution that members of the public make and
- for members of the public, commissioners and researchers to share experiences and to identify concrete ideas on how to improve public involvement in the commissioning process.

The report is a record of what went on at the workshop.

This workshop was organised by INVOLVE – further details about INVOLVE are in Appendix I.

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## **2. THE WORKSHOP**

Derek Stewart, Vice Chair of INVOLVE, chaired the day and welcomed participants to the workshop (see Appendix II for programme of the day). Derek said how pleased we were to have brought together people with different experiences of commissioning and that the day would be a learning process for everyone. He thanked people for coming. Derek explained the purpose of the day and said that a brief report would be written that would be sent to all participants.

Participants briefly introduced themselves (see Appendix III for list of workshop participants).

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## **3. SNAPSHOT PRESENTATIONS**

Three snapshots were presented providing different public involvement perspectives on the commissioning process. Presenters used their experience to illustrate what had worked well and the challenges of involvement either on a commissioning board/advisory group, or as a peer reviewer or a grant applicant.

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## **Jackie Downer, MBE**

Black woman consultant for people with learning difficulties

### **Background**

Jackie described her involvement with the Department of Health's Policy Research Programme commissioning group for the Learning Disability Research Initiative. When she was first asked to get involved in research she did not know what research was and her support worker/enabler had to explain what it was about. The research jargon was difficult and at meetings researchers spoke a different language which those with learning difficulties did not always understand. Her support worker/enabler was very important to her and explained any words she did not understand and broke down paperwork and research papers into manageable chunks.

*'We didn't know the jargon. It wasn't an easy road.'*

### **What has worked well?**

Jackie identified the following positive aspects of her involvement: getting paid, sitting around the table and being involved and seeing if research has made a difference.

*'At least now we are sitting around the table and getting money, and listening to each other.'*

### **What have been the challenges?**

Jackie felt that involving people with learning difficulties was a challenge for both those with learning difficulties and the researchers. Those with learning difficulties were not always ready to be involved or to sit around a table with researchers. Researchers were not ready to slow the speed of the research down and work at the pace of those with learning difficulties.

*'Are they ready for us and are we ready for them? We need to be ready as well. We are not used to sitting at the table.'*

Jackie also highlighted language as a key barrier to involvement. Grant applications are not accessible to local groups of people with learning difficulties. They need help in understanding how to apply, complete the forms and understand the phrases. The application process needs to be made more accessible.

*'They speak a different language ... we are all learning. Even getting the money was a challenge. If you don't know how to write a grant you won't get the money.'*

### **What could be done better?**

Jackie identified a range of things that could be done better. These included paying members of the public, avoiding the use of jargon, changing grant applications, feeding back the results of research and saying goodbye at the end of the project, and ensuring that members of the public are given equal recognition and the credit for their involvement.

'Let us get paid like you lot get paid. It hasn't been easy but it has made a difference.'

'It is important to say whether research has made a difference.'

'It is important to say goodbye to us.'

'We are professionals as well but we don't realise it.'

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## **Brian McDonald**

High Secure Representative for Mindlink on the Forensic Mental Health Research and Development Committee

### **Background**

Brian spoke of his experience on the Advisory Committee and as a peer reviewer for the National Programme on Forensic Mental Health. The Forensic Mental Health programme is aiming to make research more accessible to service users and already offers support for service users to be involved.

### **What has worked well?**

Brian highlighted some of the factors that he thought were important for commissioners and researchers to address, to ensure that public involvement was effective and that members of the public felt able to fully participate in meetings. These included advice for commissioners before meetings, advice for commissioners and chairs at meetings and advice for service users.

Brian's advice to commissioners was to provide information before meetings, on what the work will involve. The Forensic Mental Health programme has produced an introductory booklet which explains forensic mental health; service user involvement; and who everyone is on the committee and what they do. A pre meeting briefing to discuss in advance issues that will be covered is also helpful. It is also helpful to check in advance that those involved are OK about the meeting and know where to go.

At the meetings, Brian suggested that it helps if people introduced themselves and that it is important to have ground rules. Commissioners and chairs need to be reminded to use plain language and it is important to make sure that people understand the scoring system for assessing proposals.

Service users need to remember that they only need to comment on what they understand. Their expertise is from a user perspective and that is not to say that they know more or less than the other members of the advisory committee.

*'It is no different from other experts who also do not understand everything.'*

The Forensic Mental Health programme provides a user involvement induction pack which provides clear information in order to make the work more accessible.

### **What have been the challenges?**

Brian's experience was that committees can be very imposing and there is a danger of forgetting what you know. You need to remember that you are being asked to provide the expertise from the user perspective.

*'When working with all these professors, doctors, chief executives and people with PhD's there is the danger that you forget what you do know, and that you are an expert in your own experience/condition.'*

Brian identified having to deal with large amounts of paper work as another challenge.

*'The first time it was so large it came in a van, not through the letter box. It can take two - three days to read.'*

Language used was also a challenge as it can often separate service users from researchers. Everything needs to be written in plain English.

*'It is not rocket science - you need simple information to make the work accessible.'*

Brian's final piece of advice was to be prepared for the meeting.

*'Have a good nights sleep and be prepared for a long day, it may be intensive.'*

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## **Shirley Nurock**

Alzheimer's Society Quality Research in Dementia (QRD) research grant programme, London Region Coordinator of the Consumer Network

### **Background**

Shirley gave a brief background to the Alzheimer's Society award winning QRD Consumer Network programme set up four years ago. Consumers are involved in reviewing and prioritising research proposals, sitting on grant award panels, helping to design and monitor all research projects being funded by the Society and have a voice in strategy setting. Shirley has been caring for her husband since he developed dementia over 16 years ago. He was in long-term care for six years and died recently.

The presentation then focused on Shirley's experience of being the first carer to be awarded a research grant by the Alzheimer's Society. Her research focus has been on exploring the roots of satisfaction and conflict, choices, expectations and quality of life, for people with dementia, their relatives and statutory carers in long term care homes.

### **What has worked well?**

Shirley identified the following advantages that being a lead applicant with personal experience brought to the research.

*'Having personal experience of the situation enabled me to incorporate questions in the interview schedule that I, and the two QRD monitors on the project, felt were very important but which the researchers had not thought mattered.'*

Another benefit was being able to read the transcripts and pick up immediately on what was important, what could be improved and why it was happening.

Although the research team are currently experiencing some difficulties publishing, Shirley is actively disseminating the findings from the research at conferences and seminars all over the UK as well as speaking to care homes. She also hopes to write guidelines for good practice so that changes can be implemented.

### **What have been the challenges?**

Shirley highlighted several challenges she had faced as the grant applicant. First, funding for the project had to go through an academic institution and it took a long time to find a willing co-applicant; a lengthy application form then had to be completed and an interview attended with the Grants Award Panel.

'Filling in the application form took months! It was always a mystery how you figure out the amount of funding required down to the last penny. I didn't exactly enjoy the interview and was horrified to find that my knees were knocking!'

Second, Shirley found the interviews more tiring than the younger research doctors. Third, the research was stressful.

'Carers of people with dementia are notoriously stressed and some aspects of the research process were surprisingly stressful. I could have done without that - I've been exhausted for 16 years!'

Fourth, Shirley's computer skills were not always adequate and she felt out of her depth learning how to use the special software package for analysing qualitative data. Fifth, the research was slow and ran over its projected completion date. Sixth, on writing up one of the papers for publication there were fundamental differences between Shirley's conclusions and those of the researchers.

'Is this what happens when a carer and researchers look at an emotive question from very different perspectives? But why is my perspective any less valid than theirs?'

Overall Shirley felt that her experience of being the first carer to be awarded a grant by the Alzheimer's Society had been very positive and recognised that the dissemination of findings, by an involved consumer, seems to have more impact on audiences than when spoken by a researcher or clinician.

'I have tried very, very hard because I am aware it is the first time a carer has been awarded a grant by the Alzheimer's Society and I feel a certain responsibility to make it work well so that others may have similar opportunities in the future.'

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## 4. WORKSHOPS

There were three workshop themes. These were:

- Members of the public on commissioning boards/advisory groups
- Members of the public as peer reviewers
- Members of the public and grant applications

The workshops were repeated so that there was an opportunity for participants to attend two of the three topics. The workshops explored

people's experiences of public involvement from members of the public, commissioners and researchers perspectives and focused on what has worked well, what have been the challenges and suggestions on how things could be made better.

The report summarises the key points that were discussed at both the morning and afternoon sessions of each workshop.

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## **Workshop A**

### **Members of the public on commissioning boards/advisory groups**

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#### **Facilitator: Derek Stewart**

#### Participants at workshop

Morning: Gill Gyte, Alex O'Neil, Brian McDonald, Siobhan Peattie, Derek Podesta, Robert Johnstone, Gwyneth Raymond, Lisa Bostock, Marcia Kelson  
Afternoon: Pamela Baker, Vinod Kumar, Marianne Miles, Mary Nettle, Andrew Nocon, Ayesha Wise.

Participants at the workshops brought with them different experiences of commissioning boards/advisory groups. Some had experience of being a public member, others of finding and supporting members of the public to be members.

#### **What have been the challenges?**

For the commissioners:

- finding members of the public who are used to large committees
- wanting to involve members of the public but needing to know how to involve them more effectively

'How to make consumer involvement meaningful and not just tick boxes.'

For the members of the public:

- the language and jargon used

'What is meant by commissioning?'

- not being listened to

'Not being heard or being heard and not listened to.'

- being in a minority on a group

'Being in a minority on a commissioning group - often there is only one consumer'

'There is professional gate keeping in research which is often scientifically driven with researchers not understanding that consumers should have a say in the research agenda. Researchers are used to informing the public rather than engaging with them.'

- getting commissioners to value different ways of research.

'The quality of methodology was often a decision factor on commissioning boards as opposed to the quality of the research question.'

'For researchers, publication is a priority rather than dissemination of research to users.'

### **What has been helpful and how could things be done better?**

Suggestions were made on how things could be made better. These included: providing support such as payment and training, and cultural changes such as improving information and communicating.

#### Providing support

- Having an induction pack for all members which includes a set of ground rules to ensure respect.
- Ensure public involvement is being properly budgeted for to include their expenses and time for attending meetings and reading papers.
- Interpreters to support those with learning difficulties.

'By having an equal number of consumers on the board/group or the consumer score having a higher rating would address the imbalance on committees.'

- Training for those with no experience of large committees.

#### Cultural changes

- Ensuring that there is transparency in the decision making process.
- Demonstrate to researchers the difference members of the public will make to research – the value of user involvement through examples.

'It is a culture change for users and researchers. User involvement is a challenge for researchers and professionals. Users require confidence building and training.'

'There could be flexible working methods to allow users to participate as an equal.'

- When a person's time on a commissioning group is complete, have an interview and evaluation process of what being involved was like.

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## **Workshop B**

### **Consumers as peer reviewers**

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#### **Facilitator: John Sitzia**

Participants at workshops:

Morning: Pamela Baker, Marianne Miles, Sue Spiers, Vicki Raymond, Sarah Carr, Marry Nettle, Bill Perbedy

Afternoon: Gill Gyte, Alex O'Neil, Brian McDonald, Derek Podesta, Joy Stokes, Gwyneth Raymond, Marcia Kelson, Joe McNamara

Participants at the workshops brought with them different experiences of peer review. Some had personal experience of carrying out peer review, others had experience of identifying members of the public to peer review and explaining to them what was required.

Members of the public had been involved in peer review at a range of stages in the research process. These included peer reviewing position papers at the prioritisation stage and research proposals at the commissioning stage, monitoring research in progress and peer reviewing final reports.

'The main activity for consumer input in the peer reviewing process is commenting on research applications. We want to know how relevant the research will be to a person with MS and how it is going to benefit people with MS.'

#### **What have been the challenges?**

For the commissioners:

- ensuring the quality of the review is carried out by independent external experts

- using the same term for all reviewers so that members of the public get integrated into what is normally happening
- deciding what they want members of the public to do

*'We ask consumers to look at multidisciplinary proposals. Some consumers are not sure why they have been asked - there is still confusion. Also how do you reconcile different comments?'*

- the costing of peer review carried out by members of the public – how are they going to fund payment
- helping the researchers that commissioners fund to understand user involvement

*'This is new for users to be involved for some researchers and academics. They don't understand user involvement.'*

For the members of the public:

- defining peer review. Different terms are being used to describe the peer review process including: independent review, quality assurance and expert review

*'Who are peer reviewers and what are they reviewing?'*

- the format of the application form can be a real barrier

*'Being asked to peer review felt like a weight on my shoulders. Why ask me? Are there any other consumers doing this?'*

*'It's a daunting task and I was given a very short time to do it.'*

### **What has been helpful and what could be done better?**

#### Providing support

- Having a plain English summary of the research.
- Giving members of the public the option to comment on all aspects of the research proposal to be peer reviewed.

'The consumer first looks at 'what is the ultimate benefit going to be to the consumer' and then looks at the amount the research will cost.'

- Providing training for members of the public on 'what does research mean'.
- Being able to pay members of the public for peer reviewing.
- Making it clear to members of the public that what we are asking them to do is review the 'user perspective' but that they should feel free to comment on anything else.

I'm happy to comment on 'real life' but not on methodology and budgets.'

- Having guidelines produced by consumers for Cochrane (and adapted for the Health Technology Assessment programme) which clarify what is required from peer review.

'Remembering that all peer reviewers are experts in 'their own bit' and that they are all equal and providing different aspects.'

- Having clear guidelines on payment. Discussion on payment in the workshop highlighted that there is disparity in whether or not members of the public get paid and, if they do, in the amount currently being paid to members of the public who carry out peer review.
- Providing more support for members of the public in the peer review process.

'How do you arrive at the expert user input? Is it through guidance or training?'

'There is a danger with guidance that we may 'strait jacket' or constrain consumers.'

### Cultural changes

- Putting proposals in a form that people with learning disabilities can understand e.g. using pictures in the proposal and/or using a video to explain it.
- Providing options for feedback e.g. via email or over the phone. Linked to this it was noted that members of the public may not be able to afford to print out lots of documents sent by email.

'At the Joseph Rowntree Foundation the peer review process happens around a table and not remotely.'

- Having clear structures on how to score research proposals.
- Knowing what the balance is between user comments and other peer reviewers comments.

'We [the Joseph Rowntree Foundation] would not fund a piece of work that was not valued by users.'

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## **Workshop C**

### **Consumers and grant applications**

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#### **Facilitator: Stuart Eglin**

Participants at workshop:

Morning: Jackie Downer, Vinod Kumar, Joy Stokes, Andrew Nocon, Ayesha Wise

Afternoon: Sue Spiers, Robert Johnstone, Vicki Raymond, Sarah Carr, Lisa Bostock, Bill Peberdy

Participants at the workshop brought with them experiences of writing grant applications and funding applications.

#### **What have been the challenges?**

For the members of the public:

- the time needed to put bids together

'The deadlines for grant applications are often too tight; they need to be more flexible.'

- the words and language are a barrier to understanding the process
- the format of the application forms

'The format for grant applications needs to be more user friendly; the criteria for applying is not easy.'

- getting funding for research

'Researchers know how to get funding - it is harder for service users. Commissioners tend to fund those that they know/feel safe with and this makes it hard for others to break into this.'

- dissemination of research findings

'Researchers lose interest at the end of projects and move onto new projects - so research findings don't get widely disseminated.'

- ways in which members of the public were involved

'Researchers are good at making it sound that they have been inclusive - but in reality, often tokenistic'.

'There needs to be more involvement in research than just involvement on a steering group without making a difference to how research is conducted.'

- the control that researchers have

'At the moment researchers are in control. Often they make the decisions about whether to involve consumers, who to involve and how to involve them.'

## **What has been helpful and how could things be done better?**

### Providing support

- The Forensic Mental Health programme has identified some academic links who are willing to work with and support service users for a particular call for proposals.
- The Social Care Institute for Excellence (SCIE) provides funding to assist public involvement in writing applications for their own commissioning.
- Material needs to be more accessible and there needs to be more flexibility in the way that people could apply for funding.
- Guidelines for researchers when involving members of the public – they often want to do it genuinely but don't know how to approach the subject.
- User empowerment training to assist users to link with others to write proposals.

- Guidelines needed for the commissioning process – to assist funders in discerning what is real public involvement in a project.

### Cultural changes

- Change the 'grant culture' so that service users can find out how to get funding and how to find academics to link with to make applications.
- Going back to the members of the public and explaining how the research went.

'It is important to thank participants who have been involved in research and let them know when the research will be published.'

'We need to ensure that applications have built into their plans (and carry it out) ways in which information is disseminated and fed back to participants.'

- Ensuring applications address dissemination.

'Applicants should be expected to look at other ways of disseminating research.'

- Helping researchers and service users to get together in making applications.
- Providing some money (pump priming) to help applicants put together full proposals (those successful at outline application stage).

'Commissioners need to be encouraging and provide support and training for researchers and consumers.'

- Asking applicants about involvement and ensuring that research will truly involve consumers.

'Providing feedback to those applying for funding as to how they could have done things better.'

- Changing the system to encourage people to get together; but this needs to be built up gradually and convince others of the value.
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## 5. COMMON THEMES ACROSS THE WORKSHOPS

The following are the common themes that went across the workshops.

1. The need for definitions of terms used in commissioning e.g. commissioning and peer review.  
  
*'Commissioning is what commissioning does.'*
2. The need to make language more accessible.  
  
*'We didn't know the jargon ... they speak a different language.'*
3. Payment and the financial implications of involving members of the public.  
  
*'Commissioners need to check that adequate budgeting is in the proposals for consumer involvement.'*
4. Support for everyone involved in the process and the value of building relationships.  
  
*'Support users and researchers to involve people. Health professionals can feel disempowered and need to talk to each other about their experiences.'*
5. The need to 'close the loop' by informing members of the public, who had been involved in research, of the outcomes of the research.  
  
*'It's important to say goodbye to us.'*

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## 6. SUMMING UP

There was no formal feedback from each of the three workshop groups. Participants were asked for their views on what other outputs from the day they thought would be helpful. Also they were given the opportunity to share any important issues or lessons from the day.

The following issues were raised.

- How do we access people who don't want to know?
- How do we let consumers know that they can be involved?

- How do we ensure that people [researchers and commissioners] come back and tell you [members of the public] what has happened.
- How can members of the public get involved with private providers e.g. drug companies?
- How do we influence Primary Care Trusts (PCTs) and smaller scale research?
- We should not keep accepting the benefit system – we need to do something about it.
- Are we going to come back together? Are we going to have an advisory group? Reports can take a long time and may not be accessible.

*'Is this the beginning or the end?'*

- We need to draw together implications from the three workshops.
- It is important to get the draft report circulated as soon as possible for comment so that comments can still be fresh in peoples' minds.
- It would be helpful to have a clear and concise way of saying what research is.

*'It's OK not to know because sometimes we don't know.'*

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## **7. NEXT STEPS**

This is the first step in seeing how we can support those involved in the commissioning process. We are hoping to use this information to help with producing guidance.

Please let us have any suggestions on what you would like and think would be helpful.

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## **Appendix I**

### **Background to INVOLVE**

#### **Promoting public involvement in NHS, public health and social care research (formerly Consumers in NHS Research)**

INVOLVE is an advisory group on public involvement in research and development (R&D) in the Department of Health. We met for the first time in 1996, as 'Consumers in NHS Research.' For the next five years we offered advice to the Director of R&D for the NHS on involving members of the public in NHS Research.

In 2001 we also began to cover R&D commissioned in other areas of the Department of Health through its 'Policy Research Programme'. This includes R&D in the areas of public health and social care. In 2003 we changed our name to INVOLVE to reflect this wider remit.

The group meets four times a year. We have about 20 members, a broad mix of people including: users of health and social care services, carers, representatives of voluntary organisations, health and social services managers, and researchers. They are appointed by the Director of R&D at the Department of Health. We believe that involving members of the public leads to research that is:

- more relevant to people's needs and concerns
- more reliable
- more likely to be used.

#### **What do we mean by 'the public'?**

When talking about the public we mean people who are:

- patients and potential patients
- informal (unpaid) carers
- people who use health and social services

As well as:

- members of the public who may be targeted by health promotion programmes
- organisations that represent the interests of people who use health and social care services
- groups asking for research because they believe they have been exposed to potentially harmful substances or products e.g. asbestos or pesticides.

#### **What do we mean by 'involvement'?**

By public involvement in research we mean active involvement, where the people are not the 'subjects' of research but are active participants e.g. on a research steering committee.

Active involvement is where research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

### **What are our aims?**

We aim to ensure that public involvement improves the way that:

- decisions are made about what should be a priority for research
- research is commissioned (chosen and funded)
- research is carried out
- research findings are communicated

### **What are our objectives?**

- To develop key alliances and partnerships which can promote greater public involvement in research
- To support members of the public to play an active role in research
- To monitor and assess the effects of public involvement in NHS, public health and social care research.

### **The INVOLVE Support Unit**

INVOLVE has a Support Unit to carry out its work. The Support Unit is based in Eastleigh, Hampshire. There are 9 members of staff (6 of whom work part-time) to carry out and support the work of INVOLVE. The Support Unit:

- builds links with and provides information, advice and support to members of the public and researchers
- gives talks and workshops and organises conferences on public involvement in research
- has its own website, and keeps a database of research projects that have actively involved the public

### **INVOLVE publications**

We have produced a range of publications, including:

- Involving the public in NHS, public health and social care research: Briefing notes for researchers (2004) (second edition)
- Getting involved in research: A guide for consumers (2001)
- A guide to paying members of the public actively involved in research (2003)
- Various conference and workshop reports

We also produce a free quarterly newsletter. If you would like to receive this, and other information about INVOLVE, please contact us by telephone or email and we will add your details to our mailing list.

All our publications can be downloaded from our website [www.invo.org.uk](http://www.invo.org.uk) or you can order a free copy from us.

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## **Appendix II Commissioning Workshop Programme**

*Chair: Derek Stewart, Vice Chair of Consumers in NHS Research*

### **10.00 Registration and coffee/tea**

### **10.30 Welcome and introductions**

Derek Stewart, Vice Chair of Consumers in NHS Research

### **11.00 Snapshots and discussion**

There will be brief presentations from:

- Jackie Downer, Black woman consultant for people with learning difficulties, MBE
- Brian McDonald, High Secure Representative for Mindlink on the Forensic Research and Development Committee
- Shirley Nurock, Alzheimer's Society QRD London Region Coordinator of Consumer Network

These will give different perspectives of consumer involvement in the commissioning process. Presenters will use their experience to illustrate what has worked well and the challenges of involvement either on a commissioning board/advisory group or as a peer reviewer or a grant applicant.

### **11.45 Coffee/tea break**

### **12.00 Workshops**

The three workshop themes are:

#### **Workshop A Consumers as members of commissioning board/advisory group**

Facilitator: Derek Stewart, Vice Chair of Consumers in NHS Research

#### **Workshop B Consumers as peer reviewers**

Facilitator: John Sitzia, Member of Consumers in NHS Research

#### **Workshop C Consumers and grant applications**

Facilitator: Stuart Eglin, Member of Consumers in NHS Research

The workshops will be repeated so there will be an opportunity to attend two of the three workshops. The workshops will explore people's experiences of consumer involvement from consumers, researchers and funders perspectives – what has worked well, what have been the challenges and suggestions on how to do things better.

### **13.00 Lunch will be served in the 1<sup>st</sup> floor restaurant**

### **14.00 Workshops**

Repeat of morning workshop sessions with opportunity to attend a different theme.

### **15.00 Break**

### **15.15 Feedback and summing up / where to go from here**

### **16.00 Tea and close**

## Appendix III

### List of delegates

| <b>Delegate</b>   | <b>Organisation</b>  |
|-------------------|--|
| Pamela Baker      | National Coordinating Centre for Service Delivery and Organisation (NCCSDO)    |
| Lisa Bostock      | Social Care Institute for Excellence (SCIE)                                    |
| Sarah Buckland    | INVOLVE Support Unit   |
| Sarah Carr        | Social Care Institute for Excellence (SCIE)                                    |
| Barbara Dawkins   | INVOLVE Support Unit   |
| Jackie Downer MBE | Black woman consultant for people with learning difficulties                   |
| Stuart Eglin      | Member of INVOLVE  |
| Gill Gyte         | Cochrane Pregnancy and Childbirth Group  |
| Helen Hayes       | INVOLVE Support Unit   |
| Robert Johnstone  | Member of INVOLVE  |
| Marcia Kelson     | Patient Involvement Unit for National Institute for Clinical Excellence (NICE) |
| Vinod Kumar       | Member of INVOLVE  |
| Brian McDonald    | Mindlink   |
| Joe McNamara      | Medical Research Council (MRC)   |
| Marianne Miles    | Multiple Sclerosis Society (MS Society)  |
| Mary Nettle       | Member of INVOLVE  |
| Andrew Nocon      | Disability Rights Commission   |
| Shirley Nurock    | Member of the Alzheimer's Society Quality Research in Dementia (QRD) programme |
| Alex O'Neil       | Joseph Rowntree Foundation   |
| Siobhan Peattie   | User Involvement Co-ordinator - Macmillan                                      |
| William Peberdy   | Member of the Alzheimer's Society QRD programme                                |
| Derek Podesta     | Member of the Alzheimer's QRD programme  |
| Gwyneth Raymond   | Older People Researching Social Issues   |
| Vicki Raymond     | User/Researcher  |
| Jane Royle        | INVOLVE Support Unit   |
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| Joy Stokes        | National Co-ordinating Centre for Health Technology Assessment (NCCHTA)        |
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