

INVOLVE newsletter

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

Summer 2005

Welcome to our summer newsletter. As usual, we have a wide variety of articles and lots of news and information about public involvement in research. Have a good read, and a good summer!

The PC11 Project

The PC11 Project's aims were to evaluate the effects of consumer involvement and training in 11 Primary Care Studies that took place in the London area (funded by Research and Development, Department of Health). Based in Exeter, we are a group of researchers, academics, lecturers, service users and representatives from Folk.us (an organisation that promotes and supports consumer involvement in research).

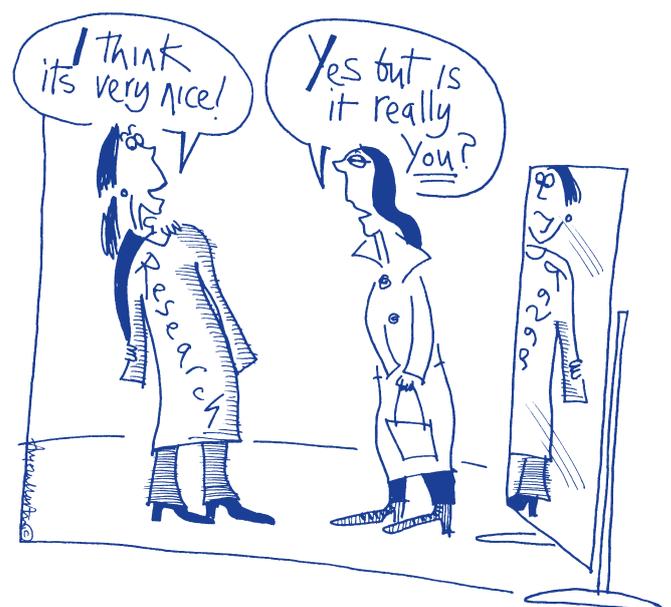
The 11 projects involved different groups, eg older people and those with chronic illness, and covered a broad range of subjects, such as mental health, communication difficulties, testicular cancer, orthodontic needs, child health surveillance and tuberculosis. The funders also commissioned a programme of training for all participants.

As well as analysing documents from the 11 projects, we sent out questionnaires and held interviews and focus groups. When we had collected all our data, we held a feedback event so that researchers and consumers **Cont →**

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This newsletter is also available on tape and in large print. If you would like a taped or large print version, please let us know.

from the 11 projects could tell us whether our initial findings were accurate.

Many people told us about their experience of valuing different sorts of knowledge and background, learning with others and making a real difference. They also spoke about one-to-one support and sensitivity to differing needs. They said it was important to be clear about different roles and responsibilities, and to use language that can be understood by everyone taking part. Many people mentioned the need for sufficient time, money and skills, and the importance of feeling motivated towards a common goal.

Consumers made a difference to the projects in many ways - in several they changed the questions included in interview schedules and suggested different ways of finding people to interview. They took part in interpreting answers to interview questions, and also made sure that findings were presented in a straightforward, easy-to-understand manner.

On our questionnaire, we asked people to identify themselves as a 'service user', 'carer', 'researcher' or 'other'. Many people ticked more than one of these alternatives, not wanting to put themselves in only one category.

We concluded that consumers have a positive impact on research and that individuals benefit from being involved in collaborative research. Some had enjoyed aspects of the programme wide training, but more people said that they had benefited from learning together on their own particular project.

We also found that it is better to evaluate the impact of consumers using criteria developed and agreed by individual projects.

We have many recommendations from our

evaluation, including some changes to policy in research funding, commissioning and approval systems. Other recommendations represent best practice, and are aimed at everyone involved in collaborative research. They reflect the issues raised by the project participants, such as the importance of respecting different types of knowledge and the need to encourage shared learning within project teams.

For further information please contact:

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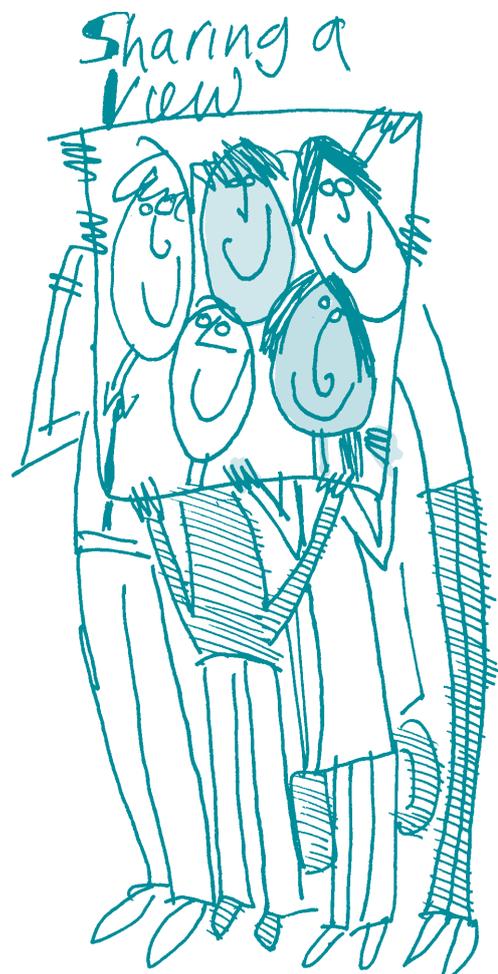
or

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A copy of the report summary will be on the INVOLVE website as soon as it is available.



Support Unit News

Thank you!

If you are one of the many people who responded to our questionnaire about what you would like to see in a new INVOLVE information pack for the public, to replace the 'old' consumer guide, this is a big **'thank you'**. The questionnaire was included in our last newsletter, and we will be looking carefully at the ideas and information people have sent us over the summer before we begin work on the information pack itself. At a later stage we hope to get back in contact with people who gave us their names and addresses and invite them to get involved again.

INVOLVE Conference 2006

Autumn 2006 may seem like a long way away for our next conference, but our new conference planning group will meet for the first time in early September 2005, when we will be brainstorming for ideas, exploring possible themes and key issues as well as suggesting formats for different sessions. Your contributions to this process will be welcome! You can contribute now - complete the form on the conference pages of our website <http://www.invo.org.uk/Conference.asp> or contact Philippa Yeeles at the Support Unit.

Large print Briefing Notes for Researchers

There is a large print version of our publication 'Involving the public in NHS, public health, and social care research: Briefing notes for researchers'. Written in 20 point text, it is available on our website and we can supply ring bound copies for people who need large print. Contact the Support Unit for a hard copy.

Training networking event

We are planning a training networking event in the Autumn. This will principally be for people involved in training in, or related to, public involvement in health and social care research as well as people and organisations who are considering using training. This will be a loosely structured follow up to the seminar we held in April 2004 and will be an opportunity for people to meet and discuss the practicalities, approaches, principles, and ethics of training in this area. The event will also highlight the potential of the INVOLVE training web pages and database as a one stop hub for training activity in the public involvement in research area. The event will be held in London on 1st November 2005. If you are interested, put the date in your diary and let us know! We will send you a registration form and further details when they are ready.

Consultation responses

INVOLVE has responded to two National Institute for Health and Clinical Excellence (NICE) consultations relating to its merging with the Health Development Agency.

- Operating model for the Centre for Public Health Excellence (CPHE)
- Consultation on the role of regional teams in the new organisation.

To view our responses please visit our website <http://www.org.uk/Documents.asp>

Research glossaries

We would like to hear from you if you know of, or have developed a glossary of research terms as part of training or for a network specifically aimed for public involvement in research. If you have any glossaries that you would be happy to share with us, please contact Helen Hayes at the Support Unit hhayes@invo.org.uk Tel: 02380 626235.

Interesting articles and publications

- **Report of the Ad Hoc Advisory Group on the Operation of NHS Research Ethics Committees**

Considers the work of NHS Research Ethics Committees and how they meet their primary purpose of protecting the rights, safety, dignity and well-being of actual or potential participants in NHS research. Available free of charge from the DH Publications Order Line: 0870 1555 455 or by email at dh@prolog.uk.com quoting order number 268110. Can also be downloaded from the Department of Health website <http://www.dh.gov.uk>

- **'Take small steps to go a long way' consumer involvement in research into complementary and alternative therapies.**

By Charlotte Paterson

Complementary Therapies in Nursing and Midwifery (2004) volume 10 page 150 -161
This investigation sets out to learn about consumer involvement in complementary medicine research from those who have experience of practice in this area.

- **The experiential knowledge of patients: a new resource for biomedical research?**

By J. Francisca Caron-Flinterman, Jacqueline E.W. Broerse, Joske F.G. Buncers
Social Science and Medicine 60 (2005) pages 2575-2584

Governments and patients' movements are increasingly in favour of active participation of patients in biomedical research processes. One of the arguments concerns the contribution patients could make to the relevance and quality of biomedical research based on their 'experiential knowledge'. This article reflects on the validity of patients' experiential knowledge in the context of biomedical research.

If you have written or know of any publications or articles relevant to public involvement in research that might be of interest to readers, please contact Helen Hayes at the Support Unit with details: hhayes@invo.org.uk

New book about user involvement in research

By Lesley Lowes

It was at the Consumers in NHS Research (now INVOLVE) Third National Conference in 2002 in Harrogate that the idea for an edited book on service user involvement in research really took off. There were some excellent presentations of experiences of service user involvement in research from the perspectives of both service user and professional researchers. These were just what Ian and I, as editors, wanted to capture in our book, and everyone we asked was keen to contribute. Thus, our book 'Involving Service Users in health and social care research' became a reality.

People who had agreed to contribute were asked to send us a brief outline of their chapter and some details about themselves. When we had enough contributors, we put together a proposal for the publisher describing the content of the chapters, why the book should be published, and who would want to buy it. The publishers liked it! We signed contracts and then the real work began.

We believe that service user involvement in research should be considered in the context of a continuum, with poles of the continuum reflecting the diversity of approaches. The chapters in this book are written by service user and professional researchers. Some are written collaboratively and some by individual

authors, but each places different emphases on issues identified as important and which have shaped their own approach to service user research.

The importance of service user involvement in research is increasingly being recognised. However, service user research methodology is in its infancy and, as the chapters in this book testify, many practical, ethical, methodological and philosophical issues need careful consideration on whatever level of the continuum research is placed. Contributors to this edited volume offer recommendations, based on their own experiences, that address many of the questions and problems that can arise when undertaking service user research. We hope that this book contributes significantly to the advancement of service user involvement in health and social care research. The full reference is: Lowes L & Hulatt I (Eds) (2005) Involving service users in health and social care research. London: Routledge. (Expected date of publication 5th July 2005)

For more information, please contact Leslie Lowes by email at lowes@Cardiff.ac.uk

Guidance for good practice involving users in mental health research

The Service User Research Group in England (SURGE) who are part of the UK Mental Health Research Network (MHRN) have just published guidance for good practice for user involvement in mental health research.

SURGE is set up to support mental health service users and people from universities and NHS Trusts as they work together on mental

health research. They support people through the UK Mental Health Research Network to involve service users in research and to connect with each other where similar goals or needs can be identified.

The guidance is for researchers and service users who wish to develop collaborative research projects and programmes involving service users within the UK Mental Health Research Network. The aim is to assist in the development of user involvement in research and user-controlled research throughout the UK MHRN. The guidelines are based on an extensive review of the literature, contributions from SURGE partners and visits to case sites. The document has two sections:

1. Literature Review

The literature review provides much of the evidence for the guidelines, covering a range of issues from the benefits of involving service users in research through accessible language, training and support of payments and resources.

2. Guidance for Good Practice

The guidelines broadly follow the research cycle from underlying principles through capacity building and undertaking research to dissemination and implementation, with the addition of a section on user-controlled research.

The guidelines can be downloaded from the Mental Health Research Network website www.mhrn.info/surge.html

For further information or if you do not have access to the internet please contact Sarah Gibson, SURGE Co-ordinator at the Mental Health Foundation.

Email: sgibson@mhf.org.uk

Tel: 020 7803 1116

Involving Service Users, Carers and Public as Equal Partners

A Learning and Development Resource for NHS Staff

Between 2000 and 2001 the West Midlands Partnership for Developing Quality (WMPDQ) carried out a survey and workshop of User Involvement and Public Participation in the NHS West Midlands. They identified statutory functions (e.g. Patient Forums), but there was very little evidence of a 'whole systems' approach to user/carer involvement. It also highlighted the need for specific training and support for health and social care staff to enable them to work effectively and confidently in user involvement work.

The Birmingham and Black Country Strategic Health Authority and Birmingham Heartlands and Solihull NHS Trust commissioned a project to develop, try out and evaluate a 'learning and development' resource. The resource would assist NHS staff to engage effectively and respectfully with service users, carers and the public in three main areas of activity, including research and development. The resource was developed to help NHS staff gain knowledge, skills and confidence in how to involve service users, carers and the public and to provide them with an opportunity to get involved in training and supporting others.

About the training and development resource:

- It uses many examples of user involvement work so staff can learn by other people's experiences.
- It gives information to trainers about top-tips for training, things to prepare and consider in training and background information.
- It builds on general information about user

involvement and then focuses on research and development (or other NHS activities).

- It encourages 'stepping on' and 'stepping off' of the training so staff can build on previous learning at their own pace.
- It encourages staff to agree what activity they will look at within their own organisation through the development of action plans, thus making sure that staff get organisational commitment for their work.
- The resource can be used to support existing training programmes.

The training is for any member of NHS staff who would like training and support in user involvement. Two trainers are needed for the training. At least one (if not both) of the trainers must be a service user/carer. Experience of training would be helpful to use this resource but trainers can support each other to help develop this role.

If you would like to know more about how the project was set up and evaluated please contact Sandy Herron-Marx on 0121 414 3571 or by email at: s.herronmarx@bham.ac.uk
For information about accessing the training please contact Linda Dunn on 0121 695 2488 or by email at: Linda.dunn@bbcha.nhs.uk
NB: See the training pages on the INVOLVE website www.invo.org.uk/Training.asp



The impact of involuntary job loss on those disabled by society: a pilot study to encourage effective participation

By Joan Monkman

Hello, my name is Joan Monkman and I am a 68 year old widow. In November 1999 I faced involuntary ill-health retirement from my job in local government. At that time my future seemed to yawn like a gaping chasm and despite having a very active brain I felt rejected and unwanted by society. As a result I suffered a period of acute depression.

Eventually, as the saying goes – ‘I picked myself up, dusted myself down, and started all over again’. I got involved with charity work and joined Age Concern in my area as a volunteer. I was assigned to various committees concerned with issues relating to the older citizen. As a result of this work I was invited by Staffordshire University to take part in a project to promote participation in local research. I joined this group and was trained in a variety of research and consultation methods. I was paid appropriately for my involvement in this research project which pleased me greatly as I felt valued as a person for my contribution to this research.

We divided into groups and identified our own topics for research, in my group this proved to be the impact of involuntary job loss on those disabled by society, as there seemed to have been a limited amount of research done in this area. I worked with my fellow researchers in participation with the University facilitators to highlight the problem for investigation.

A qualitative method of research was considered appropriate and a semi-structured interview process was designed by our group of potential researchers.

We advertised for people to interview via local press, radio, word of mouth, etc. The interviews were tape recorded (with permission from participants) and later transcribed fully to facilitate analysis. We travelled extensively throughout Staffordshire conducting these interviews which took place mostly in people's own homes.

At the end of the year long course there was an exhibition (combined with the other groups) of our work at the University and we gave a presentation which was open to the general public as well as University personnel. Also, a paper was published, entitled ‘The impact of involuntary job loss on those disabled by society: a pilot study to encourage effective participation.’ This appeared in volume 19, number 3 (May 2004) of *Disability and Society*.

I enjoyed participating in this course immensely. I particularly liked working along with like minded people and got a lot of satisfaction through participating with professionals and members of the public. Throughout the course I felt valued for my input and contribution and, as a result, have gained in self-confidence.

I would encourage anyone who has been in my position to participate in voluntary work and research which I find is a very rewarding occupation.

For further information on the project and the work at Staffordshire University, please contact Ruth Chambers:

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Tel: 01782 294025

NOTICE BOARD

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in R&D. If you would like to put an article on our notice board please contact the Support Unit.

Part of the solution: involving service users in research

The Trent RDSU, Shaping our Lives, and the Centre for Social Action have formed a partnership to offer training and consultancy for researchers, practitioners and service users who wish to develop collaborative research projects.

The first stage of this partnership is workshops as an introduction to service user involvement in research. These will be held in Leicester in September and November 2005.

Fees will be £60 for researchers and practitioners and £30 for service users. For further information and to find out about the varied services offered please contact:

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Friendly disclaimer: The views expressed in this newsletter and in any enclosures are those of the authors and not necessarily those of INVOLVE, the Support Unit or the Department of Health. Articles are selected for the sole purpose of stimulating ideas and debate on public involvement in research.

NICE 2005: Health and Clinical Excellence conference

The National Institute for Health and Clinical Excellence (NICE) Annual Conference will take place in Birmingham from 7th-8th December 2005. Poster submissions are being requested on NICE guidance implementation, public health, audit, clinical governance, clinical risk management, R&D and public involvement. The deadline for submissions is 9th September 2005. For more information, please visit the NICE website <http://www.nice.org.uk>

Deadline for contributions for our next newsletter: 26th of September 2005

We welcome contributions about any aspect of public involvement in NHS, public health and social care research. Please ask the Support Unit for information about submitting an article.

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