

INVOLVE newsletter

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

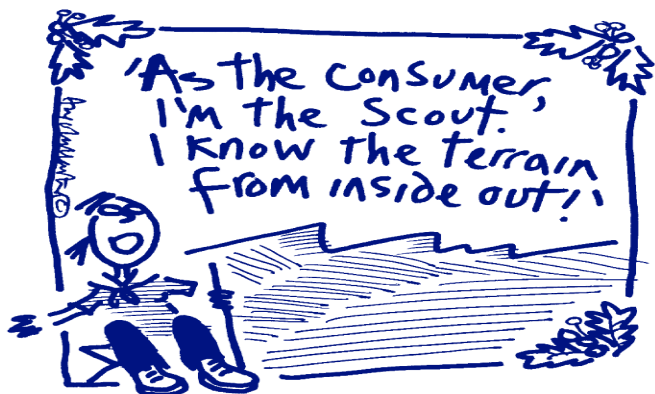
Autumn 2003

Welcome to the Autumn newsletter of INVOLVE. As usual, we have a variety of news and articles, including a piece on research ethics and how this can affect people's choices, news of a research report on principles of involvement in research, and the launch of a new publication on the state benefits system and involvement of service users. We hope you will find the newsletter informative, stimulating and useful. Keep those articles coming in, we are always interested in hearing from you!

Recent commissioning work

There has been a flurry of commissioning work undertaken by INVOLVE and the Support Unit recently:

- Many regular readers will be aware that we are commissioning an evaluation of the public involvement in eleven London primary care research projects. We will be able to let you know the outcome of this process shortly.



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- We are in the process of commissioning an evaluation of the work of Folk.us in Devon. Folk.us provide advice, training, and support researchers and people who use services who want to be involved in research in the county.
- A piece of user led work to identify definitions of user-controlled research is currently being commissioned. We hope this exciting piece of work will help establish user controlled research as a substantive option in mainstream research.
- After a tendering process, we have recently commissioned Alison Faulkner, Independent Survivor Researcher, to work with members of the TRUE project (see page 2) to produce a report and video on their experiences of being involved in this collaboration.

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.

Support Unit News

New Support Unit staff introduce themselves...

Philippa Yeeles: Over the past year I have been working as a user researcher evaluating a voluntary mental health service from the perspective of its service users. I have also recently qualified as a social worker and have completed a Masters in Applied Social Studies.

I think that participatory research has much to offer in bridging the gap between research and practice in public health, health and social care. In my role as Research Involvement Officer with the Support Unit I'm very much looking forward to supporting and promoting participatory research.

I have taken over from Paul Jones working full time with a focus on involvement in NHS and public health research. My telephone number is 02380 623234 and my e-mail is pyeeles@invo.org.uk

Maryrose Tarpey: I have recently joined the Support Unit as the Research Project Manager. This is a half time post that focuses on the commissioning and managing of research for INVOLVE. I have a background in designing and carrying out research and evaluation studies of health and social care services. My work has included training users and providers of services in the research process and working with commissioners and policy makers on how research findings are put into practice. My main work for INVOLVE will be linked to the commissioning of an evaluation of user involvement in eleven London Primary Care research projects. To contact me, call 02380 626230 or e-mail mtarpey@invo.org.uk

TRUE research project completed

This project, Training in Research for Service User Evaluation (TRUE) was commissioned by INVOLVE last year to look at what training is available nationally for public involvement in research, to make some specific studies of trainings, and identify good practice. Once peer reviewed, we hope to have an electronic version of the full report available towards the end of the year. The outcomes should be of interest to anyone involved in or contemplating issues to do with training for public involvement in research.

A seminar is also planned for early 2004 to present the results of the research and enable key stakeholders to meet and discuss issues of practice and training provision for involvement in research at a national level. For more details please contact Roger Steel at the Support Unit.

Research Governance leaflet in demand, but...

In the Summer newsletter we mentioned the leaflet 'Research governance made simple' written by Dr Katrina Wyatt of Exeter and North Devon RDSU and Rachel Purtell of Folk.us. This has proved popular and we have had a number of enquiries and requests for copies.

We should emphasise that this leaflet is aimed at people who use services and members of the public, and the leaflet's interpretation of the Research Governance Framework (RGF) 2001 has been developed accordingly.

An important point to note is that, while there will be ethics review of social care research, it will not necessarily be undertaken in the same way as in health. In particular, it may not be undertaken by the existing NHS Research Ethics Committees. Consultation is currently underway on the nature of an alternative system for ethics review of social care research.

As part of these consultations, INVOLVE facilitated a second workshop with social care service users on ethical review in July 2003. The report on this is now publicly available. Contact Roger Steel at the Support Unit for a copy.

INVOLVE Conference 2004

Our next national conference will take place on Wednesday 10th and Thursday 11th November 2004 at the East Midlands Conference Centre in Nottingham, so please make sure you put these very important dates in your diary!

Involving young people

The second workshop with young people and researchers to develop a guide on involving young people in research, took place in London on 11th October. Perpetua Kirby is currently producing the final draft, and we hope the guide, which is aimed at researchers, will be available from us at the end of the year.

Briefing Notes for Researchers

The design work for the second edition of the Briefing Notes for Researchers is now being completed, and we hope the new booklet will be available in December. Building on the success of the first edition, this revised second edition takes into account the broadened remit of INVOLVE to include social care and public health research.

Revised Guide to Paying the Public

Following feedback since this guide was first published on our website and further discussion on the issue of state benefits and payments, a revised and updated guide to paying the public for involvement in research will shortly be available on our website. This includes some additional examples of payments, and some changes in layout to make it easier to use.

Interesting articles and publications

- **Social service users' own definitions of quality outcomes**

The Shaping our Lives project, working in partnership with Black User Group (London), Service User Action Group (Wakefield), Ethnic Disabled Group Emerged (Manchester) and an alliance of user groups in Waltham Forest (London), looked at the application in practice of ongoing work about what service users meant by 'user-defined outcomes.'

Joseph Rowntree Foundation Findings
June 2003

<http://www.jrf.org.uk/knowledge/findings/socialcare/673.asp>

- **Doing it for real: a guide to setting up and running a User Focused Monitoring project**

User-focused monitoring (UFM) is a dynamic approach for evaluating mental health services that places the subjective experience of the service user at the heart of the process. The Sainsbury Centre for Mental Health now supports UFM projects in the form of a network of service user led monitoring projects. For further information and a guide to setting up and running a User Focused Monitoring project visit the Sainsbury Centre for Mental Health website:

<http://www.scmh.org.uk/wbm23.ns4/WebLaunch/LaunchMe>

- **On our own terms - Users and survivors of mental health service working together for support and change.**

Jan Wallcraft with Jim Read and Angela Sweeney

Published on behalf of the User Survey Steering Group

Sainsbury Centre for Mental Health 2003

Interesting articles and publications (continued)

- **It's Our Lives**

- A short theory of knowledge, distance and experience**

Peter Beresford.

There is now a greater interest in user involvement in research and evaluation and in user-controlled and participatory research. There is also a new emphasis from government on 'evidence-based' policy and practice and the importance of basing public services on a strong knowledge base. This new publication addresses the questions these developments raise. It explores a new practical and theoretical approach to including experiential knowledge in the development of policy and provision and suggests new ways of relating research to lived experience.

Citizen Press in association with Shaping Our Lives

Available from: Citizen Press, Tempo House, 15 Falcon Road, London SW11 2JP

ISBN 0 95117554 2 0

Price £8.75 including postage

- **An evaluation of a young disabled people's peer mentoring/support project**

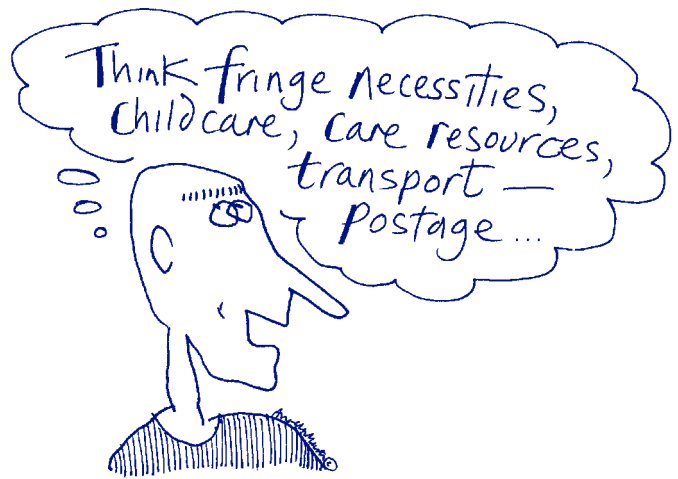
The project developed a range of activities to address the needs of young disabled people over a two year period, building on previous work. The project was evaluated with the help of both adults and younger disabled people.

Joseph Rowntree Foundation Findings

August 2003

<http://www.jrf.org.uk/knowledge/findings/socialcare/813.asp>

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



'A Fair Day's Pay'

The issue of paying people to take part in research whilst they are on state benefits is a tricky one. Without due care, people who use services can lose the very benefits they rely on if they are considered by their benefits office to be 'working.' This potentially includes time spent on active involvement in research or service development. This issue is often a barrier for people who might otherwise be keen to be involved in research.

For example, the Incapacity Benefit system allows for some part-time paid work if this complies with the hours and earnings limit set out in the permitted work rules. What is not always appreciated is that work can none the less lead to these benefits being reviewed and possibly disallowed.

The Mental Health Foundation has published a guide to payments to service users for involvement. Based on the experience of a number of NHS Trusts in developing good practice policy, 'A Fair Day's Pay' explains the benefit rules and systems, advises on procedures, and makes recommendations for good practice arising from development work with Jobcentre Plus at local and regional levels.

This publication refers to mental health service user involvement in services, not specifically

research, but there is plenty of information that will apply to the involvement in research of other people who rely on the benefits system. 'A Fair Day's Pay' details some of the issues flagged up in INVOLVE's 'A guide to paying members of the public who are actively involved in research' and could be used alongside it. The issue of public involvement in health and social care research (as well as services in general) and the Benefits system is currently a controversial one, and we are aware of other work being carried out to try to address the problem. We hope to be able to report on this in future newsletters.

'A Fair Day's Pay' was written by Judy Scott, and is available from The Mental Health Foundation Cost: £8, or free for people who are unwaged. Please call 020 7802 0304 or visit www.mentalhealth.org.uk

'A guide to paying members of the public who are actively involved in research' is available free from INVOLVE and can be downloaded from our website: www.invo.org.uk

Moving towards a new model of involvement for older people

An innovative and exciting new research study is currently being developed to explore ways in which Older People's Forums may be supported while participating in their own research projects. It is hoped that the 'Older People's Project Support' (OPPS) study will develop an approach that may enable Older People's Forums to play more empowered roles. This, in turn, may improve the extent to which their voices are heard.

Funding was awarded after the Project Leader, Sam Taylor, carried out a UK-wide evaluation

of the research training and information needs of Older People's Forums and Groups. The overall aim was to identify barriers, if any, that were preventing Forums from participating in their own research studies. The study revealed that some Forums are keen to carry out their own small-scale projects to influence local and national policy development. At present, they confront barriers due to a lack of research experience, basic skills, and access to relevant and user-friendly information.

Although the OPPS Project is in its early stages of development, Sam and the OPPS Project Team aim to create a workable and user-friendly approach to participatory research that may be used by Older People's Forums in the future.

The OPPS study is jointly funded by the University of Teesside and Help the Aged. A publication focusing on the evaluative study will be published in the future. Dr Sam Taylor can be contacted about the OPPS feasibility project at: Postgraduate Institute, School of Health & Social Care, University of Teesside, Middlesbrough, TS1 3BA
Tel: 01642 384125
E-mail: Sam.Taylor@tees.ac.uk



Principles of successful consumer involvement in NHS research: Results of a consensus study and national survey

Rosemary Telford, Jonathan Boote (Sheffield Care Trust, ScHARR, University of Sheffield) and Cindy Cooper (ScHARR, University of Sheffield) (2003).

This study was designed to find answers to the following three questions:

1. What are successful ways of involving consumers?
2. Can researchers and consumers agree on successful ways of involving consumers?
3. How many NHS research projects are involving consumers successfully?

The research project used two research methods, an expert workshop and a Delphi process. It aimed to find out if it was possible to develop and agree principles of successful consumer involvement in NHS research and measurable indicators of each principle. For the expert workshop six researchers and seven consumers with knowledge and experience of consumer involvement in research were invited to try to agree a number of principles and indicators. The Delphi process involved a wider group of 96 researchers and consumers with knowledge and experience of consumer involvement being asked, through two postal rounds, for their opinions on the principles and indicators developed at the expert workshop. The following eight principles were agreed with each principle having one, two or three indicators:

1. The roles of consumers are agreed between the researchers and consumers involved in the research.

2. Researchers budget appropriately for the costs of consumer involvement in research.
3. Researchers respect the differing skills, knowledge and experience of consumers.
4. Consumers are offered training and personal support, to enable them to be involved in research.
5. Researchers ensure that they have the necessary skills to involve consumers in the research process.
6. Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research.
7. Consumer involvement is described in research reports.
8. Research findings are available to consumers in formats and in language they can easily understand.

(The full list of indicators can be seen on the ScHARR website).

Amongst other findings the research found that few current NHS research projects appear to be involving consumers, and when they do, only a small number meet the developed principles of successful consumer involvement in NHS research. In addition some researchers remain unsure about the meaning of 'consumer involvement.'

The researchers advise that the usefulness of the principles and indicators have yet to be tested and further developments can be expected. For further information about this study, please visit the ScHARR website:

<http://www.shef.ac.uk/~scharr/public/research/coninv.html> or contact: Rosemary Telford, University of Sheffield, Public Health, ScHARR, Regent Court, 30 Regent Street, Sheffield S1 4DA
E-mail: r.telford@sheffield.ac.uk

Ethical regulation of research - getting the balance right

By Alastair Kent, Director, Genetic Interest Group

In order to protect the interests of all those who wish to get involved in research there needs to be a framework for regulation. The present system of NHS research ethics committees covering local (LRECs) and multi-centre (MRECs) work reflects this framework. The way of working seems to have been derived from the experience of regulating large scale projects, often involving hundreds or even thousands of individuals in projects that span many centres - such as clinical trials for new drugs, for example. Whilst this is appropriate for large projects, governance of research is not a 'one size fits all' situation.

For example, increasingly, patient groups for those with rare genetic disorders involved with the Genetic Interest Group (GIG) have come to feel that the system discriminates unfairly against them - making it more difficult than it needs to be to get research under way - even when those with the disorder want it to happen. We suspect that GIG's issues are not unique, and that many of the other groups wishing to participate in research have similar experiences.

People in this situation are not suggesting that the regulatory framework be abandoned and a free-for-all be allowed to emerge instead. Proper regulation is important, but the framework should be sufficiently flexible to allow those who hope to participate in and benefit from the research to play a proper role in its governance and to participate in ways appropriate to the project and its intended

outcomes. We should not be dependant on others deciding on our behalf in a paternalistic fashion the projects that get the green light.

Following two recent stakeholder workshops convened by patient group representatives for GIG to raise the issues with academics, regulators and funders (reports available on our web-site: www.gig.org.uk), we want to open out the discussion to a much wider range of people who use health and social care services affected by research. If possible, we would like to identify common issues and themes so that we can work to propose a flexible framework for research governance in which our views about what should or should not be done are given proper weight.

If you share all or some of our concerns about ethical review and wish to influence for change in the present framework so that it is more appropriate to people who use services, we would like to hear from you. Contact Melissa Winter (melissa@gig.org.uk) to register your interest.



NOTICE BOARD

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

Practising Partnerships and Inclusion: A participative enquiry with older gay men and lesbians in Dorset

Help and Care is a voluntary organisation working on the side of older people and carers of all ages throughout Dorset. We have recently secured funding from the community fund to examine the experiences, aspirations and concerns of older gay men and lesbians in Dorset. Older gay men and lesbians will lead the project with support from a range of staff at Help and Care, including a research worker. If anyone is interested in taking part in the research or would like to find out more, please contact Nichola, in confidence, on 01202 432288 or 0771 7702122, or by e-mail at olgmp@helpandcare.org.uk

Deadline for contributions for our next newsletter:

9th January 2004

We welcome contributions about any aspect of consumer involvement in health and social care research (any length between 50 and 400 words). If you have any questions about submitting an article, please contact the Support Unit for a copy of our 'Guide for Contributors.'

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.

ARVAC

The Association for Research in the Voluntary and Community Sector (ARVAC) was founded in 1978. Members come from community and voluntary groups, universities and research institutes. They hold conferences and workshops and produce a quarterly bulletin. They also have outreach workers who provide training and facilitation in basic research methods for small community groups and offer information on community sector research. For more details: ARVAC 2d Aberdeen Studios, 22-24 Highbury Grove, London N5 2EA. Tel: 020 7704 2315 E-mail: arvac@arvac.freeserve.co.uk

'The Impact of Involving Users and Carers in Research'

The NHS R&D Forum is holding this workshop on the 21st of January 2004 at the Kings Fund, London. Details of the event will be made available on the NHS R&D Forum website at www.rdforum.nhs.uk or you can get in touch with us at the Support Unit.

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