

INVOLVE newsletter

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

Winter 2003/2004

Welcome to the Winter edition of the INVOLVE newsletter. This edition contains information on several new publications that will soon be available on our website. There's also a variety of news and articles that we hope you will find helpful and stimulating, including articles on active involvement in a clinical trial and user involvement in research in mental health.

Do write in and let us know what you think, and, better still, consider contributing an article about your experiences of active involvement in research.



Calling for participation!

INVOLVE's 4th National Conference - 'People at the Heart of Research' - will take place on the 10th and 11th of November 2004 at the East Midlands Conference Centre in Nottingham. The theme this year is 'the research cycle.' If you think you might like to contribute to the conference - perhaps by presenting your research, running a workshop, or submitting a

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poster - now is the time to act by replying to our Call for Participation. You have until the 15th of March 2004 to submit your conference proposal.

If you are on our mailing list you should have received a copy of the Call for Participation. If you haven't, or if you have any questions about the conference, please contact the conference administrators, Professional Briefings, on Tel: 020 7233 8322 or e-mail london@profbriefings.co.uk Copies of the Call for Participation can also be downloaded from our website www.invo.org.uk or from www.profbriefings.co.uk/involve.htm

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

Training research project

The report of the findings of the TRUE (Training Research: User Evaluation) project will shortly be available as an executive summary and full report. The TRUE project was commissioned by INVOLVE to map what training for public involvement in research is available in England; to evaluate some training current at the time of the project; and to develop guidelines for good practice in training. The executive summary and the full report (which is 160 pages long) will be available to download from the INVOLVE website. We expect to have a full article about the TRUE findings in the Spring newsletter.

As a follow through to this piece of work, INVOLVE are planning a seminar on the 22nd of April for training commissioners, training providers, recent training participants, and training funders. The object of the event will be to discuss a framework for good practice in training for involvement in research, and to discuss how to overcome some of the gaps between training need and training provision nationally. This will be an invitation-only event. For further information please contact Roger Steel rsteel@invo.org.uk at the Support Unit.

Capturing the experiences of those involved in the TRUE project: Report and Video. This report by Alison Faulkner is almost complete. It looks at the experiences of those involved in the TRUE collaboration, and provides some useful lessons on issues to do with research collaborations that involve service users. When available it will be found in the publications section of our website www.invo.org.uk/pub.htm. There is a short video which compliments the report. We hope to make this available from

the Support Unit - further information will be placed on our website.

Briefing Notes for Researchers: Second edition

The second edition of this INVOLVE booklet will soon be available from the Support Unit as 'Involving the Public in NHS, Public Health and Social Care Research: Briefing Notes for Researchers'. Watch the 'Publications' page of our website www.invo.org.uk/pub.htm where you will be able to download the booklet.

Following the same successful format as the first edition, the second edition is updated and covers health and social care research rather than just research in the NHS. It includes fresh examples of research projects involving the public, as well as additional references and links. The booklet is published in a clearer format and is 74 pages long.

Membership of the INVOLVE Group

INVOLVE is changing the way that new members are recruited to join the sub-groups and we are inviting people to apply to join. If you are interested in applying to become a member of INVOLVE please see the flyer enclosed in this edition of the newsletter.

INVOLVE is a Group with about 20 members. The Group, which meets four times a year, includes a broad mix of people who use health and social care services, carers, representatives of voluntary organisations and health and social service managers and researchers. The Group has a main group and three sub-groups. Currently people are recruited to the sub-groups by invitation of the chair of the main group. All members of the main group are appointed by the Director of Research and Development. The current system of recruiting members means that whilst a wide diversity of experience

and knowledge exists within the membership, appointment to the sub-groups tends to be from amongst those already known to INVOLVE. We feel that INVOLVE would benefit from recruiting members from a wider pool of people. We also feel that it is important to ensure that a clear and more transparent process should be adopted in the recruitment of new members.

Commissioners' workshop report

The report of the commissioning workshop is now available in the publications section of the INVOLVE website: www.invo.org.uk/pub.htm

The report summarises the presentations and discussions held on the 2nd of 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 common themes across the workshop were:

- The need for definitions of terms used in commissioning e.g. commissioning and peer review.
- The need to make language more accessible.
- Payment and the financial implications of involving members of the public.
- Support for everyone involved in the process and the value of building relationships.
- The need to 'close the loop' by informing members of the public, who had been involved in research, of the outcomes of the research.

If you would like an audio or large print version of the report please e-mail admin@invo.org.uk

If you are interested in obtaining copies of our publications and are unable to download documents from our website please contact the Support Unit for a copy.

Interesting articles and publications

•Involving users in low back pain research

Bie Nio Ong and Helen Hooper

The project aimed to determine how patient and professional perceptions of low back pain and its treatment relate to the use of healthcare and to subsequent outcomes. Conclusions are drawn as to possible approaches for user involvement in health services research design.

Health Expectations, Sept 2003, pp 332-341

•ESRC Research Findings:

21 From the Growing Older Programme

Older Women's Lives and Voices:

Participation and Policy in Sheffield

Joe Cook, Tony Maltby and Lorna Warren

This study had two main aims: 1) to raise awareness of issues affecting the quality of life of older women across different ethnic groups and their involvement in services available to them; and 2) to achieve this by taking a participatory approach to the project, wherever possible involving older women in designing and carrying out the research, and in promoting and evaluating change.

www.shef.ac.uk/uni/projects/gop/index.htm

•The multiple roles of 'patients' in healthcare research: reflections after involvement in a trial of shared decision-making

Hazel Thornton, Adrian Edwards, Glyn Elwyn

The DoH 'Health in Partnership' study that this paper reflects upon involved consumer advocates, patients' associations and patients throughout the whole study, from pre- to post-study phases. This paper was written by the involved consumer steering group member together with the two lead researchers.

Health Expectations Sept 2003, 6, p189-197
www.healthinpartnership.org/studies/edwards.html

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Interesting articles and publications (continued)

The following two reports are now available on the Service Delivery and Organisation website <http://www.sdo.lshtm.ac.uk/> under the change management section of commissioned projects:

- **Review of the literature: Service user involvement in change management in a mental health context** (Rose et al)

www.sdo.lshtm.ac.uk/changemanagement.htm

- **Review of the literature: Service user involvement in change management: Current practice and research needs in the context of NHS modernisation** (Crawford et al)

www.sdo.lshtm.ac.uk/changemanagement.htm

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

Strategies for Living: Research findings and report now available

The findings of the user-led research projects investigating differing aspects of coping with mental distress, which were supported by the Strategies for Living project within the Mental Health Foundation, are now available. Among the important topics investigated were:

- impact of the loss and regaining of occupation
- benefits advice
- issues for black women in Bradford
- coping in psychiatric hospital settings
- self-help groups for people who self-harm
- the effect of dance on women's mental well being
- the experiences of the carers of people

diagnosed with bi-polar disorder

- mental health advocacy in Wales
- coping with 'unusual beliefs'
- leave from hospital for detained patients.

The recent Strategies for Living newsletter (Issue 20) focuses on the key findings from these projects and can be accessed at www.mentalhealth.org.uk/page.cfm?pagecode=PISLUN The project summary reports can be downloaded free from: www.mentalhealth.org.uk/page.cfm?pagecode=PISLUNUK Strategies for Living are hoping to have the full reports available online soon. For paper copies, please e-mail strategies@mhf.org.uk or call 020 7802 0300.

Strategies for Living have also produced a report entitled 'Surviving user-led research: Reflections on supporting user-led research projects.' This describes the realities of supporting user-led research as experienced by the Strategies for Living II team. It includes the achievements and challenges of this process in relation to issues of power, roles and relationships, ethics, resources, and training. It also outlines the lessons learned from these experiences. The report can be ordered from www.mentalhealth.org.uk or by telephone on 020 7802 0300. Price £30 (£15 for service users) ISBN 1 903645 50 6 Y



User involvement in research in mental health

Diana Rose, SURE Co-ordinator

The Service User Research Enterprise (SURE) at the Institute of Psychiatry in London was established two and a half years ago. The unit conducts research from the perspective of service users and does this in collaboration with clinical academics. We believe that people who have experienced certain services and treatments bring a unique perspective to the study of these very services and treatments. For example, people who have experienced acute in-patient care know about this from a different perspective to those who have worked in such facilities and those who study them from an academic point of view. This user perspective can be worked up into or incorporated in a research design which allows the gathering of new information and a different perspective on analysing this information. To do this, SURE employs service users to both gather and analyse data in the belief that service user researchers can be the lynchpin of innovative research practice and novel results.

SURE often conducts participatory research. In this model, the participants are not 'subjects' in the traditional sense of research subjects but full participants in the research process. Everything is done to see that the participants are able to follow a project through to its conclusions so that they 'own' the results of the research.

Much of the work we do is qualitative in nature although we do not eschew quantitative analyses. Qualitative work is important for exploratory analysis when we do not know in advance what respondents will tell us about their experiences. We use qualitative software

to analyse large amounts of qualitative data. Sometimes qualitative work precedes the construction of a quantitative measure. For example, focus groups may be used to generate questionnaire items as well as producing information in their own right.

SURE has pioneered descriptive systematic reviews from the service user's perspective. An example is our work on Consumers' Perspectives on Electroconvulsive Therapy (ECT). The method developed in this Review is now being applied to the field of consumers' views on new anti-depressant medications. In these systematic reviews we consider papers written by clinical academics, reports by user organisations or in collaboration with them and first-hand accounts or 'testimonies' about the receipt of certain treatments. We have pioneered web-based research concerning testimonies.

SURE also has a presence on the local Trust's Research and Development Steering Group via the Consumer Research Advisory Group (CRAG). This is a group of 12 local service users, two of whom attend the Steering Group as representatives. SURE's co-ordinator is also a member of the Steering Group. This structure is meant to ensure that user involvement in the Steering Group is democratic and avoids tokenism.

Lastly, SURE aims to assist clinical academics to involve service users in their research. To this end we run a 'SURE clinic' (for distressed academics!) once a week to discuss with professional researchers how they might meaningfully achieve this.

This article is adapted from SURE's website:
<http://web1.iop.kcl.ac.uk/iop/Departments/HSR/index2.shtml>

Getting involved in clinical trials - our experience!

Anne Langston, PRISM (Padget's disease: a randomised trial of intensive versus symptomatic management) Trial Co-ordinator and Marilyn McCallum, NARPD (National Association for the Relief of Padget's Disease) Director

The drive for consumer involvement in clinical trials has increased over recent years but there is often little if any guidance about how to actually DO this. We didn't set out with a specific plan about involving consumers in the PRISM trial, but by recognising the benefits of working together and through a naturally evolving relationship, we have developed an integrated approach to consumer involvement in clinical trials, and would very much like to share our experience with you!

Padget's disease of bone (PDB) is a chronic bone disease that is often painful and can have very disabling long-term complications such as bone deformity, fracture and even deafness. 125 years after it was first described by Sir James Paget, there are still a lot of unanswered questions about the management of this condition and the PRISM trial is a UK based, non-commercial, multicentre, randomised controlled trial, studying its treatment.

Within the UK there is only one formal support group for sufferers of PDB; the National Association for the Relief of Paget's Disease (NARPD). The NARPD was founded in 1973 and aims to offer support and information to Paget's disease sufferers, to sponsor research into the causes and treatment of the disease, and to raise awareness of the disease among the medical profession and the public. NARPD members include patients, carers, and health professionals.

From the outset, the PRISM trial management group and the NARPD have worked in partnership to aid the design, conduct and delivery of the PRISM trial. The NARPD has been involved with the PRISM trial from the conceptual stages and helped to 'set the question'. Since then, the NARPD has become involved in almost every aspect of the development and execution of PRISM, and almost without being aware of it has ensured that the research is relevant, and is targeted to answer specific and important questions. It's impossible to describe every aspect of the NARPD-PRISM trial relationship in a short article. However, from the trial's point of view the primary advantage has been the harnessing of a well-informed and interested population, who have developed a sense of ownership of the trial. Also, NARPD members have become familiar with trial methodology, and this had fed through to very high response rates for follow-up quality of life questionnaires - an important component of the trial. Another consequence of making trial information freely available to NARPD patient members is that the PRISM trial has received a sizeable number of requests from patients asking to take part. Furthermore this active partnership has led to unsolicited patient advocacy of the trial.

But this isn't all one sided! There have been benefits to the NARPD and its membership as well! The trial has promoted awareness of the NARPD and Paget's disease to sufferers, the general public AND health professionals. But the best things in life are never easy! It has been exceedingly hard work for both parties, but we do wholeheartedly feel that this relationship has been very rewarding, on both professional and personal levels.

For further information on the research please contact Anne Langston Tel: 01224 551126 or Email: a.langston@abdn.ac.uk

Getting involved: the next steps for NHS users interested in research

The North West Users Research Advisory Group (NWURAG) has been recruiting new members. We decided we wanted to increase the proportion of lay members to 50% and advertised widely for service users interested in health research to contact us. We had a terrific response, with 35 people expressing an interest in joining. Unfortunately, we only needed 8-10 new members.

We decided that rather than waste all that enthusiasm, we would hold a special event to inform these interested people about ways of getting involved, and to ask them to think about what would suit them best. In all, 36 people attended the event and the feedback was good. After the day we asked people to state where they would most like to become involved, and subsequently invited 10 of them to join NWURAG. We hold our first meeting of the new Group in January 2004 and hope to expand our work in exciting new directions.

For more details, please contact Sara Morris, R&D Manager for User Involvement, Health R&D North West on telephone: 01524 592656
Email: s.m.morris@lancaster.ac.uk
www.lancs.ac.uk/depts/ihr/hrdn/index.htm

New module: user/carer Involvement in Health and Social Care Research

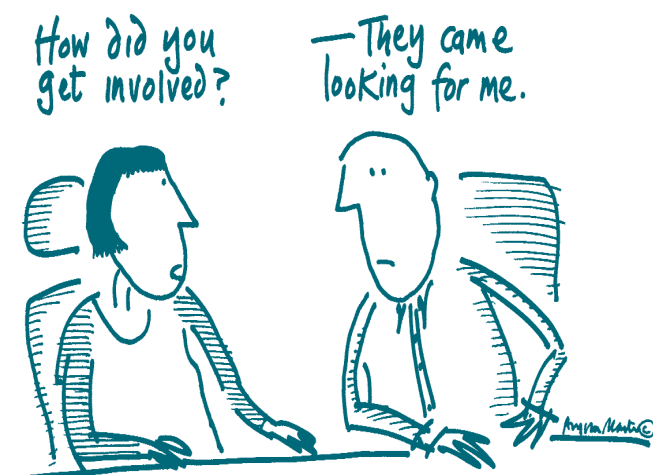
St. Bartholomew School of Nursing and Midwifery, Institute of Health Sciences, City University in collaboration with Barts and the London NHS Trust are planning to offer the above course in January 2005. Kathleen Banks, of Barts and the London Trust's Patient Public Involvement Forum, is leading this development with academic and service user colleagues. This new educational venture will take forward user/carer involvement in all stages of the research process. The course is open to healthcare professionals, healthcare researchers and users and carers.

The planning and development of this user/carer led initiative also involves academics and professionals from Primary Care Trusts, NHS Trusts and the voluntary sector. It is designed for use in multidisciplinary health care contexts, including mental health, child, maternity, acute and primary care. The module can be taken in a freestanding form or as part of an MSc interprofessional degree.

For enquiries and further information please contact: Emily Harris, Administrative Secretary Research, Health Care Research Unit, St Bartholomew School of Nursing and Midwifery, Institute of Health Sciences, City University, 20 Bartholomew Close, London EC1A 7QN, Tel: 02070405783 e-mail: e.c.harris@city.ac.uk

Deadline for contributions for our next newsletter: 15 March 2004

We welcome contributions about any aspect of public involvement in NHS, public health and social care research (50-400 words). For further information about submitting an article, please contact the Support Unit.



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.

User-led research in Bristol

Patsy Staddon, once a patient in Bristol's specialist alcohol addiction unit, the Robert Smith Clinic, has recently completed her first year of PhD research, 'Women's Alcohol Dependency:some sociological factors.' Patsy is Lead Researcher on the project, which has a Research Advisory Group of other women who have had problems with alcohol use, and who have recovered using a variety of methods. All are involved on a voluntary basis. The purpose of the research is to identify the particular needs of women who experience such problems, from a service-user perspective. Contact Patsy Staddon: tel. 0117 942 3634 or e-mail patsy.staddon@email.com

6th ENMESH Conference: Call for Abstracts

ENMESH (European Network for Mental Health Service Evaluation) is holding its 6th conference, 'Inclusion and Mental Health in the New Europe' on 3-5 September 2004 in Franklin-Wilkins Building, Waterloo Campus, King's College London. The conference has four main themes: User/Consumer Involvement, Mental Health Policy in the New Europe, the Mental Health of Vulnerable Groups and Interventions that Work. The deadline for

receipt of abstracts is 29 February 2004. For more information, see www.enmesh2004.org

The Warwick Diabetes Care Research User Group

The User Group has just published its 3rd Newsletter. To receive a copy or to go on the mailing list for the newsletter contact Geoff Aitchison at geoffaitchison@onetel.net.uk For information on the user group please visit www2.warwick.ac.uk/fac/med/diabetes/research/user/

'Working Together' Conference

This conference takes place in Birmingham on the 25th of March. It concerns ways to enable the public, users, and health and social care staff to work together to improve services within their local communities. Two training resources will be shared and there will be a short presentation by INVOLVE. Contact Ellie Boland: tel. 0121 695 2264 or e-mail ellie.boland@bbchs.nhs.uk

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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.