

newsletter

Welcome to our summer newsletter. We are delighted to share with you examples of some of the different ways children and young people are being involved in research. Please do contact us if you are carrying out work that you would like to share with others or if you would like further copies of this newsletter.

Involving young people in public health research

By Louca-Mai Brady, Senior Research Officer, National Children's Bureau; and Amrita Ghosh, Young People's Public Health Reference Group member

"As a young person I understood research to mean exploring a subject in depth, but when I got involved in the group, and had the opportunity to carry out my own research within a group of young people, I realised that research isn't just simply 'finding out' things but a series of different stages. From having had the opportunity to be involved in different parts of the research process I understand the importance of involving young people in research. I have also noticed that young people's opinions can

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**National Institute for Health Research
'Medicines for Children' Research
Network workshop**

If you would like a copy of the newsletter in an audio or large print version, or if you would like it in another format, please contact us. Printed on recycled paper.

vary a lot from adults'. This shows the importance of involving young people in research: on one hand the young people are taught a new skill that they can put into action as they grow up, and on the other our involvement helps researchers to learn from us and make sure that research about young people is also relevant to them."

These are the words of Amrita Ghosh, a member of the Young People's Public Health Reference Group (YPPHRG), who recently co-facilitated a workshop with Louca-Mai Brady and another group member at the University of Brighton Health and Social Policy Research Centre Conference 'Critical Perspectives on User Involvement.'

The Young People's Public Health Reference Group was established by the Public Health Research Consortium (PHRC) in November 2005, as a pilot project to contribute to its research work on public health issues relating to young people. The National Children's Bureau (NCB) is a main collaborator in the PHRC and facilitated the group with support from the PHRC and INVOLVE. The overall aim of the project was to establish a model for a reference group through which young people could contribute to the UK's public health agenda.

In March 2008 an award was made by the Wellcome Trust for a project (now known as PEAR, the name chosen by the group, which stands for Public health, Education, Awareness, Research) which has expanded and extended the work of this pilot. The project includes groups in London and Leeds, a website (which will be launched shortly after this article is published), and a conference planned for Autumn 2010.

Learning from the pilot project

All the young people and adults involved in the

pilot project felt that the group had had a positive impact on public health research, as well as exploring innovative methods of involving young people in research projects of varying size and complexity. Researchers thought that the group had 'brought to life' public health research for children and young people, and provided a reality check to academic views. Concrete outputs for the project, such as research summaries and posters, were really valued both by young people and adults, and the group's work has reached and generated interest among a wide audience.

There were some challenges in recruiting a diverse range of young people to something quite academic and involving a long-term commitment, and also in balancing the expectations of group members and researchers. Pilot group members also wanted to be involved in projects earlier, and for longer than was often possible. Group members said it is important to see the impact of their work and how they were 'making a difference'. We have sought to address some of these issues by recruiting a wider range of young people through a second group which has been established in Leeds, and recruiting from a broader pool than was possible for the pilot group. As well as developing plans for involvement in a wider range of research projects, at different stages of their development, the project also has a small budget for the group to commission their own project. The website and planned conference (see above) will also create opportunities for young people and researchers to share information and ideas.

NCB would welcome contact from public health researchers who would be interested in working with the group, either for input from the group on their research or in relation to the project that the group will be commissioning around

the impact of bullying on mental health. For further information, or to discuss opportunities to work with the group, please contact:

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National Children's Bureau, 8 Wakley Street,
London EC1V 7QE

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Website: www.york.ac.uk/phrc/YPPHRG.html



Promoting children's participation in research: Children should be seen *and* heard

This meeting – funded by the National Research Ethics Service – with INVOLVE, European Forum for Good Clinical Practice and the Royal College of Paediatrics and Child Health, will take place on 23rd November 2009 at the Hotel Russell in London.

Continuing research depends on the participation of public and patients, whether they are adults or children. Involving them in setting priorities, planning, designing and conducting research is one way we can develop trust to promote greater participation in relevant studies. The National Research Ethics Service (NRES) has therefore organised this meeting to promote the relevant involvement of children and young people in the design and conduct of research, to investigate the needs of children who may participate in research and to debate the issue of payment to minors in research.

For more information and booking please go to the NRES website: www.nres.npsa.nhs.uk/training-events/#ChildParticipation



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Please let your colleagues know that they can go on our website www.invo.org.uk to join our mailing list and receive a copy of our newsletter by email or in the post. **Continued →**

INVOLVE Coordinating Centre News



Conferences for better research

The NIHR has been organising a series of health research conferences with the ten Strategic Health Authorities during 2009. Entitled 'Committed to better research in the NHS' these joint events aim to promote the benefits of research, showcase local activity and engage further with local NHS staff and academics so that they can understand more fully the range of opportunities available through the National Institute for Health Research (NIHR).

Four of the conferences have now taken place and the fifth is in the North West of England on 16th October 2009. The INVOLVE Coordinating Centre has a stand and workshop at all of the conferences. We look forward to meeting you there. For further information, the dates of the remaining conferences and information on how to book a place please visit the NIHR website: www.nihr.ac.uk/events/Pages/Regional_conferences.aspx

Does your website link to ours?

If you would like to link to the INVOLVE website please email webmaster@invo.org for text and web page details. And if your organisation has information about public involvement in research on your website, we will consider linking to you. Please email webmaster@invo.org with details of your organisation, the relevant web page and any accompanying text.

Newsletters and events

We are very happy to write articles about INVOLVE for your newsletter or send literature for your events, but please do provide us with at least two weeks notice.

Comments

Finally, if you have any comments or suggestions regarding this newsletter or our website, please email us at webmaster@invo.org.uk



**Members of the INVOLVE team (L to R):
Sarah Bayliss and Barbara Dawkins**

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

Interesting articles and publications

• Getting ready for user involvement in a systematic review

Elizabeth Smith, Peter Beresford, Sheila Donovan, Jill Manthorpe, Sally Brearley, John Sitzia and Fiona Ross.

Health Expectations 12, pages 197–208

This paper aims to support the critical development of user involvement in systematic reviews by explaining some of the theoretical, ethical and practical issues entailed in ‘getting ready’ for user involvement.

• Health researchers’ attitudes towards public involvement in health research

Jill Thompson, Rosemary Barber, Paul Ward, Jonathan Boote, Cindy Cooper, Christopher Armitage and Georgina Jones.

Health Expectations 12, pages 209–220

The research explores the attitudes of researchers to public involvement in research, how they interpret Department of Health policy, what motivates and demotivates them and what their experiences have been to date.

• Nothing Personal – disturbing undercurrents in cancer care

Mitzi Blennerhassett

This book not only takes the reader through a patient’s cancer experience from diagnosis and treatment to the present day, but shows how speaking out led her into involvement in health services as part of an unofficial patient ‘movement’ until the NHS Cancer Plan gave

patients and carers a valid voice. Prose is structured around poems written at the time of treatment, in which feelings are laid bare. Foreword by Professor Karol Sikora. Published 2008 Radcliffe Publishing
Website: www.radcliffe-oxford.com/books/bookdetail.aspx?ISBN=184619010X

• **The research dance: university and community research collaborations at Yarrabah, North Queensland, Australia**

Kevin Mayo, Komla Tsey and the Empowerment Research Team (Janya McCalmkan, Mary Whiteside, Ruth Fagan and Leslie Baird) *Health & Social Care in the Community* (2009) 17 (2), Pages 133–140

This article has helpful implications for research conducted outside Australia. It reflects on collaborative research relationships between indigenous communities and universities in social health and empowerment programmes. This article is focused on Family Well Being programme and Indigenous Men's Support Groups. These programmes have incorporated a process whereby the community has set research agendas, local researchers have been employed, and university researchers have facilitated the development of appropriate programmes, the capacity of the community to manage these, and programme evaluation. The article recommends positive strategies for successful partnerships and outlines some challenges faced by both community and university researchers in programmes.

• **Dancing to our own tunes: Reassessing black and minority ethnic mental health service user involvement**

Jayasree Kalathil with contributions from Hanif Bobat, Michelle Bhalroo, Patricia Chambers, David Crepaz-Keay, Chandra Fowler, Matt Gregory, Paul Grey, Raza Griffiths, Andrew Hughes, Carol Jenkin, Theresa Kiyota Rahman,

Dominic Makuvachuma-Walker, Terry Simpson, Premila Trivedi, and Jan Wallcraft.

National Survivor User Network in collaboration with Catch-a-Fiya 2008

This in depth consultation is the first of its kind which has been fully funded, developed and undertaken by service users and survivors. It explored the experiences of black and minority ethnic service users of being involved, both the problems and the possibilities, and highlights barriers to involvement and what has and has not been achieved, drawing important conclusions about meaningful involvement. Available at: www.nsun.org.uk/WebPageFiles/65/NSUN_Report.pdf

Children and young people engaging in their own research

By **Mary Kellett**

Since 2000 we have seen an increase in the number of children and young people engaging in their own research. This is an important element of meaningful involvement and an active voice. Children and young people have different research agendas from adults, they ask different questions and collect data from their peers that are frequently inaccessible to adults as outsiders. The Children's Research Centre (CRC) at the Open University (<http://childrens-research-centre.open.ac.uk>) is a unique centre which exists solely to train and support children and young people to undertake their own research. No-one is excluded, research by marginalised children and those with learning disabilities is particularly welcome.

There have been some exciting research projects in recent months which have **Continued →**

contributed much to our understanding of children's issues and concerns. One example of a project that changed practice is WeCan2, funded by Mencap and supported by CRC. This was a project undertaken by a group of six young people with learning disabilities who were researching meaningful participation in youth decision-making forums. Their slogan was 'Have a say, take part and be heard!' The young people, Allan Aoslin, Ross Baines, Alice Clancy, Ryan Singh, Lizzie Jewiss-Hayden, and Josh Strudwick, spent 12 months collecting and analysing data from meetings they attended such as youth council, anti-bullying meetings and youth opportunity fund meetings. Josh and Allan listened, watched and recorded what happened at the meetings they attended. Lizzie collected evidence of all the big words used at meetings that she could not understand. Ross did some interviews about what changes needed to be made to include young people with a learning disability, Alice helped as Ross's deputy and Ryan watched and made notes about the kind of things that shut him out in meetings. Altogether they collected 300 pages of evidence from 70 hours of meetings.



Ross Baines, member of the WeCan2 project group

Findings showed that difficulties occur when:

- People speak too fast.
- Minutes of meetings are not sent out in advance and have to be read during the meeting.
- Minutes and agenda papers with small print and no pictures are hard to read.
- People use too many big words: e.g. in just one youth council meeting Lizzie checked 66 big words such as 'ethnically diverse.'
- Timings of meetings are often fixed for straight from school when they were hungry and tired which affects how well they could participate.
- Places of meetings frequently do not have good disabled access.

The young people used their findings to build a toolkit for those who work with young people to help them to include those with learning disabilities more effectively. They asked for big writing, pictures on the papers and time to read them before the meeting. They asked that people speak more slowly and don't use big words. They also asked for frequent breaks and refreshments to help them to concentrate. The young people made a set of traffic light cards to use in meetings to let people know when there was a problem. If people were going too fast or if a young person did not understand something they could hold up a red card. If a young person needed to ask a question they could hold up a card with a question mark on it. The red, green and yellow cards could also be used as voting cards for no, yes and unsure.

Then they collected data to find out how these changes were being used in community youth forums and if they were making a difference.

They found differences in three areas:

improving their ability to understand the business of meetings, enabling them to participate more meaningfully and being actively listened to.

Those working with young people also learned a lot from using the toolkit, as can be seen in this quote from a youth professional:

“We have learned not to be afraid about involving people with a learning disability. We have learned that we work with all young people as individuals and so we needed just to think slightly further outside the box. And we have learned that often the things useful for young people with a learning disability are also useful for everyone.”

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Involving children and young people in health care settings

By Jane Coad

Involving children and young people – an example from the field

The project outlined below used a collaborative framework with children and young people in a health care setting. It is hoped that the project values and methods can be adapted for wider use with other projects.

Coad et al. (2007) undertook a project to ascertain children’s views across a broad range of ages and abilities about a purpose-built Children’s Unit in a new hospital build. The novelty of the approach was that it was driven by the opinions of children and young people through the use of child-friendly multi-methods, based on a combination of interviews; drawing;

artwork and questionnaires in order to explore preferences about décor, colour and environmental textures. Twelve older children and young people (aged 10-18) volunteered to act as an ‘advisory expert group’ to the project. The group were given supportive ongoing training, and with carefully planned adult support, developed all data collection tools and validated data analysis. The aim of the group was to collaborate with the team on the project in order to develop appropriate methods in the planning and design of the Children’s Unit.

From the outset, ground rules were agreed for this advisory expert group. All the stages of the research process were delivered in a convenient location, at hours that fitted around school (or in one case college) and at a pace appropriate to the needs and abilities of the children involved. At each meeting the need for the project, the different roles of the children/ adult researchers, time commitment and positive personal benefits of their involvement, such as projects being used for school/GCSE work was discussed. Payment for children and young people’s contributions in research projects have been debated in the literature, and is contentious, due to parental attitudes and potential negative effects on welfare benefits by adding cash to the household income (Jones, 2004). In this project, the advisory expert group were asked preferences and it was agreed that vouchers of their choice should be given once the project was complete.

The study comprised two phases; Phase 1 consisted of 70 semi-structured interviews including art based activities and display boards to facilitate choice across a range of ages and abilities whilst Phase 2 consisted of questionnaires. The children’s advisory expert group helped to inform the project in terms of designing and piloting the

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interview tool and some of the art based data collection for Phase 1 (Christensen and James, 2000; NE-CF, 2005; Coad, 2007). Following completion of the interview phase, the advisory expert group supported the analysis of data in order to help to develop the questionnaire at Phase 2 (Coad and Evans, 2007). Full ethical approval was given by the Local Research Ethics Committee (LREC).

Evaluating the impact factor of the case study

There are lots of challenges which have been highlighted in many other articles about engaging with children and young people, but some specific ones to this project are shared.

One contention is how children and young people are influenced in their decision-making. Therefore much support is crucial in involving children of all ages and abilities. Following the completion of the project the advisory expert group and some participants became increasingly empowered about what they wanted for their Children's Unit. This appeared to have impact on the outcome of the project but some issues were difficult for the adults to respond to. For example, one was that some of the children and young people's desires for the unit were not possible within the available funding. This was debated within the advisory expert group who suggested that it was vital to tell the participants, staff and service users of this problem. Following this, it was agreed that careful planning was required about what was essential and what was desirable. Some readers may feel this was not ideal but a resolution only came about through fully communicating with the children and young people.

The other concern in projects like this is that

the most articulate children volunteer to be part of the advisory expert group. This was difficult as it was a self-selected group and in a time limited project the 12 volunteers were warmly welcomed. In any project this could mean that the most articulate and most accessible are often over-represented (Coad and Shaw, 2008). This was worrying in planning and implementing this project but in terms of measuring the impact the group did have considerable impact.

An evaluation of the advisory group was undertaken and can be accessed in full (see Coad et al. 2008) but overall the children and young people enjoyed the experience and felt valued to be not only asked their views but supported in a collaborative framework to be part of the research team. This is best said in the words of two young people in the group:

“The involvement has created a bond of trust and a sense of equality between me as a young person and the hospital Trust.”

“I think that the only way to promote young people is to get them involved in everything, let them decide if it's too boring or not. The media always portray the negative side of young people; this is partly because people only report bad things and never the good. If you get involved in more 'adult' jobs I think you feel more part of the environment that you live in, I think this in return gives you a greater sense of belonging and decreases negativity.”

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**Working together:
children and young
people can help in the
design of 'Medicines
for Children' research**

By Jenny Newman

**NIHR Medicines for Children Research
Network (MCRN) – Children and Young
People's Advisory Groups**

The NIHR MCRN was set up in 2005 to support research into the development of safe and effective medicines for children.

The MCRN recognises the importance of giving children and young people the choice to be involved in all decisions that affect their lives, and there is no reason why research involving children should be an exception. Children and young people should have a say in research that may impact on their health, as involving young people ensures that the issues researched are the issues that are important to them, and helps ensure that the research is carried out in a way they understand and are comfortable with.

In 2006 the MCRN, with support from the National Children's Bureau (NCB), set up a pilot children and young person's advisory group to explore how children and young people could be involved and have their say in the design of clinical research. The group is based in Liverpool and currently has 15 members aged between 8-19 years old. The group has been a great success and one particular accolade of the group is that it has provided invaluable advice to researchers, including the pharmaceutical industry, on various stages of their research design. It has, for example: offered views on Patient Information Leaflets for children; developed guidance for researchers designing Patient Information Leaflets; worked with researchers on the design of interview schedules; offered opinions about various study websites; and helped with the design of leaflets to promote the work of the MCRN.

The pilot group was such a success that the group in Liverpool will be re-launched in September 09 to involve more children and young people. Furthermore, two other children and young people's groups – [Continued →](#)

one based in the MCRN Trent Local Research Network (LRN) in Nottingham, and one in the MCRN West Midlands LRN based at Birmingham Children's hospital – are currently being set up. Each group will comprise approximately 10-15 young members, aged between 8-19 years, who have experience of living with a childhood condition or illness. The groups will meet between four and six times a year either at weekends, in evenings, or during school holidays, with an annual residential event where all three groups will get together.

What will the groups be doing?

The groups will receive training in research methods and clinical research. They will then be involved in a range of activities – including helping researchers with their projects, informing other children and young people about what researchers are finding out (through summaries and websites), presenting at MCRN and related conferences to promote the work of the groups, becoming lay reviewers for NIHR funding bodies, and doing their own mini research project.

Their views and opinions will help to influence the MCRN Consumer Involvement Steering Group (CISG) and MCRN Board. We are interested in working with researchers involved in clinical research on the effectiveness of medicines for children.

How could the groups help researchers?

If you're doing clinical research into medicines for children, it may be possible for you to work with one or all our groups of young people. We encourage young people's involvement from the early stages of research design (before funding) right the way through to providing child friendly summaries of preliminary research findings and disseminating research findings to larger audiences.

We're currently planning the meetings for 2009 and beyond. So if you think you may be interested in working with the groups, please get in touch. Contact: Jenny Newman, Consumer Liaison Officer, Medicines for Children Research Network, Institute of Child Health, Liverpool L12 2AP. Tel: 0151 282 4534

Email: jennifer.newman@liv.ac.uk

Or: Claire Callens, West Midlands Local Research Network Email: claire.callens@bch.nhs.uk

Or: Tina Simpson, Trent Local Research Network Email: tina.simpson@nuh.nhs.uk

Some comments from the children about their involvement:

"I would like to make a change."
(8 year-old)

"I feel that my participation can help with the treatment of children with illnesses."
(14 year-old)

"I think it will be good to see and know what happens in research."
(13 year-old)

"I always had a passion for medicine since I was young and have a strong desire to be a paediatric consultant."
(17 year-old)



Members of the NIHR 'Medicines for Children' Research Network Advisory Group receiving an Ask about Medicines Award

NIHR Research Design Services

The National Institute for Health Research (NIHR) has set-up a new network of Research Design Services. There are 10 of these services in England. Each one covers a Strategic Health Authority area.

Research Design Services (RDS) will support researchers to develop high quality research proposals. The team in each RDS will be able to offer advice on statistics, health economics, qualitative research methods, quantitative research methods, systematic reviews and a range of research areas across clinical research, public health and social sciences. This will mainly be to researchers who want to apply for funding from the national, peer-reviewed funding competitions for applied health or social care research.

Public involvement and Research Design Services

Within each RDS team at least one person will take the lead for public involvement in research.

• Support to researchers

The RDS will provide advice to researchers on how to involve members of the public in their research and may also be able to help researchers make contact with members of the public who are interested in getting involved in research projects.

• Opportunities for members of the public to get involved

Each RDS will have different opportunities to get involved. These might include:

- reviewing funding applications (or research proposals)

- being part of the Research Design Service management team
- being linked with a research team to work with them on developing their research proposal.

To find your local Research Design Service (RDS) please visit the NIHR website: www.nihr-ccf.org.uk/site/programmes/rds/default.cfm

Could you contribute to the INVOLVE newsletter?

Do you have a practical example of public involvement in research or an experience that can be shared? News or details of an upcoming event? We're looking for articles from 50-700 words in length (and if we do need to edit your article to fit, we will do so sensitively). Our next newsletter will focus on the **impact** of public involvement in research, ie. how it has made a difference. We'd welcome your contribution!

Some tips about writing style

- Keep it 'friendly'
- Make it easy to read and jargon-free
- Remember to include your contact details
- See The Plain English Campaign website www.plainenglish.co.uk for more about writing.

Deadline for contributions for our next newsletter: **30th September 2009**

If you have any questions about contributing to the newsletter, please contact Helen Hayes Tel: 023 8065 1088
Email: hhayes@invo.org.uk

noticeboard

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 Coordinating Centre.

Macmillan user-led research grant competition

The fourth user-led research grant competition, funded by Macmillan Cancer Support, will be launched at the NCRI Conference in October 2009. Research should address an issue related to the impact of cancer on everyday life or investigate the involvement of people affected by cancer in research. Applications must be developed with the involvement of people affected by cancer, and be supported by a patient or carer delegate attending the conference. Awards will be made on the basis of the potential for the project to produce results that will make a difference to the lives of people affected by cancer; or the effectiveness of involving people affected by cancer in the design and conduct of the research. Details of the competition will be available on Macmillan's website shortly – www.macmillan.org.uk – which also gives information about previous awards.

Turning the Tide: Research by, for and with service users

4th Folk.us Conference

Tuesday 6th April 2010

9.30am – 4.30pm

The Peter Chalk Centre, University of Exeter

'Turning the Tide' seeks to bring together service users, carers and patients involved in

changing research culture in Devon. Please join us to chart the progress on our journey to meaningfully influence research. Fully accessible venue. Parking available. Lunch will be provided. All expenses will be reimbursed for service users, carers and patients. Free to everybody.

For more information, contributions and registration, please visit our website:

www.folkus.org.uk or telephone: 01392 403049.

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