

newsletter

Winter 2014-15

Welcome to the Winter 2014-15 issue of the INVOLVE newsletter. This special bumper edition features a selection of involvement and engagement activities with children and young people.

Involving children and young people in research: not the usual suspects

By Louca-Mai Brady, Lorna Templeton, SB and BB (young advisors)

Involving young people in the Youth Social Behaviour and Network Therapy Study (YSBNT) project

YSBNT is a 30-month project which is adapting and testing an intervention (way of delivering services) originally developed for adults, so that it can be used with young people using drug and alcohol services and their families and social networks.

The study is also looking at how best to involve young people with experience of using drug and alcohol services in the research process. So far 10 young people have been involved at different points through one-to-one and group meetings, as well as by phone and email. The young advisors have been involved throughout the project in a range of ways, including contributing to the development of research and training materials and the YSBNT

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'Not the usual suspects' at INVOLVE 2014

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.

intervention currently being piloted. We are now planning how they will be involved in the next stages of the research, including analysis and writing up.

Developing flexible and young person-centred methods of involvement

The study is also looking at how best to involve a group of young people who don't often get involved in research. Our original plan was to go for a traditional model of public involvement, and have an advisory group of 10-12 young people who would be actively engaged throughout the project. We found out very quickly that this was not going to work! There were a number of reasons for this, including more problems than we anticipated with services being able to identify and support young people who could potentially be involved. The young people who did express an interest were also often at points in their lives or living in circumstances in which it was difficult for them to commit to ongoing involvement. This could be because of work or education commitments, because they were living in hostels or other temporary accommodation and/or because they had a lot of other things going on in their lives. As well as changing circumstances it was difficult to keep in contact with many of the young people involved because of changes to addresses or phone numbers and often limited internet access or phone credit. Issues of consent and safeguarding for young people under 18 are also inevitably more complicated if those young people are not living with their birth families.

Despite these challenges we have managed to work with a number of young advisors throughout the project; their input has been extremely helpful and has informed key elements of the intervention/project. Although a traditional model of an advisory group which gets together regularly in one place has not really worked, we have been able to work with the young advisors to develop a much more flexible and young people-centred way of working. We start by going to where the young people are and meet them in places they feel comfortable (e.g. fast food restaurants or coffee shops) rather than expect them to come to us. For the analysis and writing up stages we are looking at how we can get young advisors' input by phone, post and online in ways that work for them. The young people involved are helping us to develop a better model of involvement should this pilot project develop into a bigger trial study. We hope that learning from the study will contribute to the wider emerging evidence base on young people's involvement in research, and inform other studies and involvement

activity with young people whose voices are less frequently heard in traditional models.

What difference has this involvement made?

So far the young advisors' involvement has informed key elements of the YSBNT intervention and their input into recruitment materials and plans on how to approach young people has been invaluable in helping recruitment. But the final word should go to two of the young advisors who have been involved in the project:

"I think it's important to involve young people who have used [drug and alcohol] services as they can understand what it's like for others who are in the shoes that they've been in. I personally needed someone that has been through what I was going through as they understood me better and knew what I was feeling and thinking – no offence to people that have got degrees! I wanted to get involved with this project because I've always wanted to do something like this to show others that it is possible and there is light at the end of the tunnel – and that no matter what circumstances they're in they've always got a voice." (SB, 18)

"I got involved in the project because I think that it's important that young people can get the help that they need in the most helpful and supportive way so it doesn't damage them. I think I've gained an insight into research with young people and the opinions of young people held by social agencies and professional networks...I didn't realise just how useful I'd find it, hearing everyone's experiences is wonderful, everyone's unique and that's very comforting." (BB, 18)

The YSBNT project is funded by the National Institute for Health Research Health Technology Assessment (HTA) programme (project number 11/60/01) and led by Professor Alex Copello from the University of Birmingham. More information: www.nets.nihr.ac.uk/projects/hta/116001

Disclaimer: The views and opinions expressed in this article are those of the authors and do not necessarily reflect those of the HTA, National Institute for Health Research (NIHR), NHS or the Department of Health.

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INVOLVE Coordinating Centre news

Children and young people web pages

A new area on the INVOLVE website contains information and resources on involving children and young people in research: www.involve.nihr.ac.uk/find-out-more/involving-children-and-young-people/. The web pages include reasons for involving young people, quotes about involvement from young people, details of organisations and projects working in this area, and links to useful references. We will continue to develop these pages, which will be further enhanced by articles from this issue of the newsletter.

New INVOLVE animation

Earlier this month, we launched a new two-minute animation based on the true story of a young man, Tom, who was diagnosed with an illness and through this became involved in research.

Tom was a key member of the advisory group for the animation project, and he writes: "My own journey was one of great difficulty but out of it came some wonderful chances to get involved in health research and make a difference. I hope that this project can show other people just what is possible."

See the animation here:

www.involve.nihr.ac.uk/thisismystory



Children and young people social media examples

In the last issue of the newsletter we reported on our new Guidance on the use of social media to actively involve people in research and accompanying examples of projects. Three of these projects involve children and young people: Children of the 90s, Queer Futures and The Acne Priority Setting Partnership (PSP).

To find out more go to:

www.involve.nihr.ac.uk/posttypepublication/guidance-on-the-use-of-social-media/

invodIRECT

Do you work for an organisation or network that involves children and young people in research? Have you seen invodIRECT, our online map of groups and organisations that support public involvement in health and social care research? You can visit invodIRECT to search the map, contact others and add your own details.

To find out more go to:

www.involve.nihr.ac.uk/find-out-more/invodirect/

Benefits Advice Service for involvement

The Benefits Advice Service for involvement is a new, free, confidential service offering personal advice and support on how payment of fees and expenses for public involvement might affect people in receipt of state benefits.

The National Institute for Health Research (NIHR), in partnership with others, is offering a service that covers advice on payment of fees and expenses for public involvement in health or social care research, service design or service delivery.

The NIHR is offering this confidential service to:

- **members of the public** involved with NIHR organisations or NIHR funded research projects
- **staff within NIHR organisations** who are supporting members of the public to get involved.

The service will be provided by Bedford Citizens Advice Bureau initially as a pilot for one year.

Further information on the service and how to access it is available on the INVOLVE website www.involve.nihr.ac.uk/resource-centre/benefits-advice-service/

Interesting articles and publications

Consulting with young people to inform systematic reviews: an example from a review on the effects of schools on health

Farah Jamal, Rebecca Langford, Philip Daniels, James Thomas, Angela Harden and Chris Bonell
Health Expectations, December 2014, epublication ahead of print

This article describes the process and impact of consulting with a young people's advisory group to inform decision making in a systematic review on the effects of schools and school environment interventions on children and young people's health. Consultations were conducted with a pre-existing group of young people brought together to advise on public health research. Their views were sought at two key stages: (i) at the beginning when general views relating to the policy problem under study were elicited; and (ii) half-way through to advise on how to focus the review on key priorities. The authors conclude that the involvement of young people ensured that the scope of the review was appropriate and that issues which were important to young people were considered. The group was especially valuable in terms of prioritising in a relevant and meaningful way.

<http://onlinelibrary.wiley.com/doi/10.1111/hex.12312/abstract>

Involving disabled children and young people as partners in research: a systematic review

S Bailey, K Boddy, S Briscoe and C Morris
Child: Care, Health and Development, October 2014, epublication ahead of print

This systematic review investigated how disabled children have been involved as research partners; specifically how they have been recruited, the practicalities and challenges of involvement and how these have been overcome, and impacts of involvement for research, and disabled children and young people. The authors searched relevant bibliographic databases and websites and identified nine examples of involvement from the papers they reviewed. They highlight recommendations such as developing effective communication techniques, using flexible methods that can be adapted, and ensuring that sufficient

support and funding is available for researchers undertaking involvement. They found that positive impacts of involvement for disabled children include increased confidence, self-esteem and independence. However, they point out that the majority of these positive impacts were authors' opinions rather than data as few details were reported about disabled children and young people's involvement in studies, and the quality of evidence was low. They conclude that there is scope for methodological research to inform appropriate approaches to public and patient involvement in childhood disability research.
<http://onlinelibrary.wiley.com/doi/10.1111/cch.12197/abstract>

Evaluation of consumer involvement in the NIHR Clinical Research Network: Children 2013-14 – Overview report

Emma Wallace with Amber Eustace
National Children's Bureau, December 2014

Monitoring and evaluation of involvement activities is one of the four key aims of the National Institute for Health Research (NIHR) Clinical Research Network (CRN): Children Consumer Involvement Strategy 2013-14. To help address this aim, the National Children's Bureau (NCB) Research Centre was commissioned to monitor and assess the impact of consumer involvement activities, and to contribute to reviewing and revising the impact strategy and its implementation on an annual basis. This report presents the findings from their evaluation of the strategy and concludes that it has been successful in delivering and supporting a range of consumer involvement work with children, young people and parents during the period in question. The report includes 10 case study examples.

www.crn.nihr.ac.uk/blog/resources/evaluation-of-consumer-involvement-in-the-nihr-clinical-research-network-children-2013-2014/

See pages 10 and 11 in this newsletter for articles about the NIHR CRN: Children Specialty's Young Persons' Advisory Group.

If you have written or know of any articles or publications relevant to public involvement in research that might be of interest to readers, please contact Paula Davis at the Coordinating Centre with details: pdavis@invo.org.uk

'If you build it they will come'

By Jaffa Panel members*

The 'Jaffa' Panel is a patient and public involvement (PPI) lay research panel based at Brighton and Sussex University Hospitals Trust (BSUHT). We meet weekly to give researchers the opportunity for an early lay review of their research ideas. The group helps to ensure that the research questions and topics are relevant to patients. It also reviews written materials, including plain English research summaries and patient information sheets. The panel currently has 10 active members, with ages ranging from 16 to 83. There is a very welcoming and inclusive dynamic, where discussion flows freely between the generations.

The Jaffa Panel presented at the INVOLVE Conference in November 2014 (see <http://tinyurl.com/q8shshq>). With two presenters aged 16 and another two aged under 25, many questions were asked about how to get busy young people involved with research. Aidan, aged 16, succinctly replied: "If you build it they will come!"

However, if you're going to build it, you have to build it right. The Jaffa Panel has evolved some good working practices. Here are some reflections from younger members about their experiences:

- We don't encourage acronyms; they are confusing. We request simple language that everyone can understand. 'Jaffa' doesn't stand for anything - we are the Jaffa Panel because our lovely coordinator provides us with Jaffa cakes at our weekly meetings (which encourages us to come!)
- Different forms of communication work better for different people. Friendly text reminder messages work well for some of us, emails work better for others. However, we don't do stamps!
- We need meetings to be at a regular time and day, at a venue we can get to easily from college or university.
- We have a really encouraging and supportive coordinator which helps us feel at ease and able to participate. We have been encouraged that there are never any 'wrong' questions: "At first I felt very nervous, but as the meeting progressed I realised that the people in the meeting were asking the same sorts of

questions that I was thinking and this gave me the confidence to participate myself."
(Archie, aged 16)

- There is a lot of shared learning between the generations. We all have different skills. Younger panel members set up a Google drive account and taught older members to use it. This has made sharing files and documents easier for us all.
- With the helpful Trust administrative staff we have streamlined an effective reimbursement system which is paid in cash weekly in arrears. This includes an hourly rate plus travel. We now also have an efficient in-house taxi booking system for members who have special requirements and cannot use public transport.
- We have collectively produced and agreed some 'Ground Rules' for how the panel operates and the types of behaviours and attitudes we want to encourage. Mutual respect for each other is high up on the list which has helped foster good intergenerational respect and working. Garry, an older member of the panel, said: "I am appreciative of the benefits young people can bring to the panel as so often panels consist predominantly of only one generation."

One younger Jaffa Panel member challenged us to write a 'Slam Poem' for the INVOLVE conference (for information on Slam Poems see: http://en.wikipedia.org/wiki/Poetry_slam). This neatly encapsulates how we like to operate and is reproduced in the online version of this article.

What difference has the Jaffa Panel made to researchers and their research?

We have made a video in which five researchers highlight the changes they made to their research having received Jaffa Panel advice:

www.youtube.com/watch?v=zbLY2fzXtws



Jaffa Panel film on YouTube

[Continued>>](#)

ALPHA – a young people’s research advisory group

By Hayley Reed and Oliver Sanders

Development and Evaluation of Complex Interventions for Public Health Improvement (DECIPHer) is a Public Health Research Centre of Excellence, that conducts research on interventions to promote children and young people’s health and wellbeing. The centre is a collaborative partnership between the Universities of Bristol, Cardiff and Swansea. Public involvement is a central part of the centre’s work and we have developed a research advisory group of young people aged 14-21 called ALPHA (Advice Leading to Public Health Advancement). The group of up to 20 young people live in South Wales, and were recruited through youth centres and projects. Their role is to advise researchers by discussing and debating their views on public health topics and the research the centre plans to carry out.

The group has been developed for the centre and works across a range of projects. The advantages of this are that:

- centre funding allows employment of staff, specifically to support public involvement, with experience and skills of youth work and research
- the group works on projects during bid development, the stage of the research process at which it is most difficult to resource public involvement but also arguably the most important as many research decisions are made during this stage
- young people can develop long term relationships with centre staff which is key to maintaining their involvement
- young people can provide feedback for researchers after involvement sessions which the centre uses to improve future interactions with young people.



Jaffa Panel film on YouTube

What difference has being involved with the Jaffa Panel made to the young people?

Aidan, aged 16, said: “I both enjoy and feel grateful for these opportunities as they are not generally given to people as young as I am.”

Other reflections from the younger people about things they have appreciated include:

- Helping to prepare for the INVOLVE conference gave us a sense of responsibility. Having a challenge to aim for, and being part of a team was rewarding.
- Helping us to understand more about research
- Working with a range of people (including clinicians, researchers, academics and other panel members). Our views and opinions are always listened to and are equally valid and valued as other panel members.

Aspirations for the Jaffa Panel:

- To recruit more members (including young people inviting other young people to come and see how the panel works) to reflect a range of ages and mix of our local community
- To identify our own research question
- To explore how the panel might become co-led by a lay person or even self-led.

*Written by Jaffa Panel members: Shana Pezaro, Victoria Hamer, Archie Bell, Aidan Bishop, Garry Bisshop, Teddy Carlin, Elliott Cotterell and Duncan Barron

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ALPHA film on YouTube

We have learnt that recruiting young people into an advisory group based in a university should be done through a stepped approach. Firstly visiting young people in places they are comfortable (e.g. youth clubs and schools) and giving them clear information on what the group's role is. The second step is to invite the young people to come into the university, with support from a trusted adult if they wish (e.g. a youth worker), for a trial meeting for them to decide if this is a group they want to be part of.

There are important factors that help to support young people to be involved which may be different to involving adults. Providing pre-paid transport is key as young people cannot always afford to pay for transport in advance and get reimbursed. Accrediting their time is valuable to young people, as they are in the stage of life where they need for the first time to prove to potential employers or educational establishments that they have skills and experience. In ALPHA this accreditation has been through Millennium Volunteering, the Duke of Edinburgh's Award and individual references for jobs, and is additional to giving young people vouchers for attending meetings.

To give young people a real voice we have found it is important to allow space in the meetings for them to raise their own issues or ideas. Therefore we developed a system where the young people can write what they want from the research centre and we update at the meetings on what we have been able to do with their ideas. In the past the young people have asked to shadow researchers to see what doing research is like in the 'real world'.

We were able to make this happen in schools in South Wales and Bristol, and young people really valued the experience (see their blog at <http://decipher.uk.net/the-reality-of-research-in-schools-young-peoples-perspectives/>).

At the individual project level, an example of how young people's input has helped shape research is with a project about the role of social media after a youth suicide. The group made a distinction about how social media would be used after a suicide, to after an accidental death; therefore the researcher decided to use a comparison of these different types of death. Another project enabled the young people to design the mascot and create the study name as well as help write all of the information which will go to participants in the study.

ALPHA website: <http://bit.ly/1yJiQ24>

Twitter: @ALPHA_DECIPHer

ALPHA film is available at:

www.youtube.com/watch?v=SRf1jSDwig8

DECIPHer website: <http://decipher.uk.net/>

Twitter: @DECIPHerCentre

The work was undertaken with the support of DECIPHer, a UK Clinical Research Collaboration (CRC) Public Health Research Centre of Excellence. Joint funding (MR/KO232331/1) from the British Heart Foundation, Cancer Research UK, Economic and Social Research Council, Medical Research Council, the Welsh Government and the Wellcome Trust, under the auspices of the UK Clinical Research Collaboration, is gratefully acknowledged.

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ALPHA film on YouTube

INVOLVE conference 2014

Facts and figures

Our **9th** biennial INVOLVE conference took place on **26** and **27** November **2014** at the National Exhibition Centre (NEC), Birmingham. It was our largest conference so far with:

- more than **530** delegates over **2** days
- **92** presentations and workshops offered within **5** parallel sessions
- **85** posters
- well over **1,700** tweets using the conference hashtag over the **2** days.

Thanks to all of the presenters, poster exhibitors, delegates and conference organisers for making INVOLVE 2014 such a success.

Conference web pages

Resources from the conference, including abstracts, posters and photographs are now available in the conference area of our website: www.involve.nihr.ac.uk/involve2014/conference/

Keynote speeches and plenary sessions

Keynote speakers were Russell Hamilton (Director of Research and Development at the Department of Health) on public involvement in the changing landscape of the NHS, Simon Denegri (Chair of INVOLVE and National Institute for Health Research (NIHR) National Director for Public Participation and Engagement) on the Breaking Boundaries review and Tracey Brown (Managing Director of Sense About Science), who spoke about the work of her organisation.



Sally Crowe

Interactive sessions in the main auditorium were popular. On day one, Sally Crowe facilitated a 'Sharing experiences and impact of public involvement on



Voting during Sally's session

research' discussion and voting session, which captured delegates' experiences of public involvement and offered the chance to vote on whether those experiences and their impacts were largely positive (indicated by yellow cards) or negative (blue cards). On day two, Tina Coldham chaired a lively 'Question Time' debate with panel members Ade Adebajo, Peter Beresford, Ann-Louise Caress and Maggie Wilcox discussing topics such as how to safeguard the funding of public involvement in the current political climate, whether there has been progress with inclusion and diversity, and how the public involvement 'movement' could be more influential.



Sharon Nolan and Nicola Williams

Conference posters

All conference poster presentations were entered into a plain English poster competition. Our team of judges were looking for posters that were jargon free, clear and easy to understand. Marks were awarded for language and design and the winners collected their prizes at the conference dinner. Congratulations to:

- Sharon Nolan, Communication and Patient and Public Involvement Manager, North Bristol NHS Trust for Research mystery shop (overall winner for design and plain English)



Russell Hamilton, Simon Denegri and Tracey Brown

- Liam Ennis, Institute of Psychiatry, King's College, London for Service user involvement in mental health research: pathways to study success (highly commended for plain English)
- Rhianna Broadway, Norfolk and Suffolk NHS Foundation Trust for Developing a service user engagement strategy in a mental health NHS Trust: inspire (highly commended for design).

Several posters at the conference had a children and young people theme:

- Developing a vitamin D paediatric clinical study: pilot consultation involving young people and parents (Hannah Batchelor)
- Introducing Blue ICE: a self-harm prevention app (Samantha Warren)
- Young People's Mental Health Advisory Group (Megan Rees)
- Developing mobile applications for and with young people with long-term conditions (Veronica Swallow)
- Stronger together: collective endeavours of a cleft and research organisation to promote the role of young people affected by a cleft in research (Stephanie Tierney).

To view these posters and more search the conference database on our website at www.involve.nihr.ac.uk/involve2014/conference/

Feedback and reflections

We were delighted to see so many people tweet about INVOLVE 2014 using #INVOLVE2014 (<https://twitter.com/hashtag/involve2014>). Several delegates also blogged their personal views and

reflections on the conference, including:

- Louca-Mai Brady: Public involvement with children and young people – some reflections from INVOLVE 2014 (3 December 2014) <http://tinyurl.com/pt2t53p>
- Alison Cameron: NIHR INVOLVE – changing landscapes (8 December 2014) <http://tinyurl.com/nsc8gla>
- NIHR Clinical Research Network: INVOLVE Conference 2014 (10 December 2014) <http://tinyurl.com/n8at7kl>
- Paul Radin: Involvement, Fast & Slow. Should I stay or should I go? (25 December 2014) <http://tinyurl.com/max8v87>
- Julie Bounford and Elspeth Mathie, Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England PPI Theme: The PPI Toolbox (9 January 2015) <http://tinyurl.com/otwddgn>

People are already beginning to think about and plan for INVOLVE 2016...



INVOLVE conference delegates

Involving young people in the design and delivery of health research

By Jenny Preston and Sarah Money Penny (member of the NIHR Young Persons' Advisory Group)

Thanks to the support of the National Institute for Health Research (NIHR) Clinical Research Network (CRN): Children (originally known as the NIHR, Medicines for Children Research Network) set up in 2005, more than 56,000 children have taken part in almost 300 trials, many concerning novel drugs and treatments. This has had an impact on the care that all children receive. This is driving more researchers to seek the input of patients and families in the development of their work, which is leading to a transformation of the cultural and regulatory environment for children's research. The Network has been at the forefront of patient and public involvement in research for some time. In 2006, it started its first Young Persons' Advisory Group based at the Network's coordinating centre in Liverpool. Since then, four more groups have been established in London (see article on page 11 of this newsletter), Nottingham, Birmingham and Bristol. Each group has approximately 15-20 members aged between 8 and 19 years old.

The remit of the group is to engage young people with research and to work in partnership with, and offer support to, researchers. The group provides a forum for young people to learn about, and comment on, various aspects of the research cycle from the identification of research questions to the dissemination of research findings. The group also works alongside national and European governing bodies, such as the National Research Ethics Service (NRES) and the European Medicines Agency (EMA) as well as organisations such as the Royal College of Paediatrics and Child Health (RCPCH), helping to remodel guidance they provide to researchers to help them design and deliver ethically robust research for children, as well as support researchers in the design and deliverability of their studies.

With the paediatric research community increasingly focusing on the real-world relevance of research, the influence and impact of the Young

Persons' Advisory Group is growing dramatically. This shift in culture is further evidenced by the number of researchers approaching the group for support and this includes life sciences organisations. In 2013-14 an evaluation carried out by the National Children's Bureau (NCB) Research Centre of the group's activities (www.crn.nihr.ac.uk/children/resources) highlighted their involvement in over 60 activities to support individual research projects. The majority of projects were medical studies (81%). Among these the most common study types were randomised control trials (28% of all recorded studies) and observation studies (27% of all recorded studies).

Also important is the need to engage researchers at the earliest stage possible in protocol development to ensure the outcomes and acceptability of the study suit the needs of patients and families. Several examples of this can be found in the highlighted evaluation report, but one particular example is of a company that approached the group to help develop informed consent documentation. The study involved investigating a therapy to help spasticity due to cerebral palsy in 8 to 18-year olds and, at a later date, 0 to 8-year olds. The company approached the group for advice and attended a group meeting not knowing what to expect. The company was pleased to leave the meeting with several different versions of informed consent/ assent forms and other ideas, including the use of different technologies such as Apps. One concern of the company was discussing the delicate topic of cannabis, which is a component of the drug in the study, and was referred to as 'plant based' in the assent forms. The level of understanding of the group was much higher than the company expected, which encouraged much more open and frank discussions. This led to some really good outcomes, including a clear definition of the drug being tested, a revised structure for the informed consent/assent forms for different age groups, a review of diaries to be used by patients and families, and some good ideas about keeping children motivated throughout the trial with stars and certificates. The ethics committee highlighted that the assent/ consent form was very good and the study rapidly received ethical approval. Shortly after the study was approved it recruited its first patient worldwide from the Evelina Children's Hospital in London. The study is now on the way to achieving its recruitment targets.

Sarah Money Penny, a member of the Liverpool Young Persons' Advisory Group, highlights the importance of working alongside researchers:

"To be able to work alongside researchers and be taken seriously is really motivating... it is great to see that industry is open to involving young people in their research to develop a more patient friendly end product."

We need to promote and develop similar collaborations and encourage as much involvement in the early stages of research development as possible.

CRN: Children has had a substantial amount of success in engaging with children and young people. The formation of the Young Persons' Advisory Group, topic specific focus groups, and engaging with young people in schools, has enabled young people to become more involved in the research process by giving them the confidence, information and opportunities to be able to contribute at all levels. An exciting initiative to expand our work with young people is working with Sir Iain Chalmers, Coordinator of the James Lind Initiative, in the development of a young persons' website that will sit within Testing Treatments interactive (www.testingtreatments.org). The purpose is to improve young people's understanding of the reasons for doing fair tests of treatments, what fair tests look like, and how they and everyone else has some role to play in promoting better research for better health care. Members of the Young Persons' Advisory Group have been integral in developing and having editorial responsibility for one or more modules within the website, which will be launched in April 2015.

For further information about the group or to find out how to access the group to support your study please contact

Jennifer.preston@liverpool.ac.uk

or follow the links via

www.crn.nihr.ac.uk/children/pcpie/young-persons-advisory-group/

YPAG: The Young Persons' Advisory Group

By Dr Erin Walker and members of the London Young Persons' Advisory Group

The London Young Persons' Advisory Group (YPAG) is one of five YPAG groups (see article on page 10 of this newsletter). It has been funded by the National Institute for Health Research (NIHR) Biomedical Research Centre (BRC) at Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) and University College London, and the Clinical Research Facility (CRF) which is funded by this BRC.

We meet every 6-8 weeks. Membership is open to those aged 8-21 – we have recently increased the upper age limit – and children and young people joining the group must have an interest in improving health research. Some members are patients from GOSH, some are related to GOSH staff, and several have participated in clinical trials. This YPAG meets in the CRF at GOSH. YPAGs are interested in advising on, and providing input to all stages of research, although most frequently they are asked to review participant information sheets for readability, language, acceptability to young people, and overall comprehension.

Now that YPAG has existed for a number of years, several lessons have been learned. Members of YPAG say that:

- They like to hear about different health conditions
- They like to feel useful and that their involvement made a difference
- Remuneration is important. To this end, YPAG were involved in helping the Royal College of Paediatrics and Child Health prepare guidance on payments for involvement in research.
- Meeting at the weekend is best, and scheduled appropriately to accommodate members who live outside of London
- Certificates and acknowledgement of participation and contribution is important.

As the facilitator of the London YPAG, I have noticed that:

- There is a variable level of interest and commitment from the members. Your group should include more members than you plan to have at meetings.

Continued>>

- Young people work and communicate differently than adults, and are not always good with email. Ask each young person what method of communication they like best; some prefer texting. Don't assume they all have easy access to a computer, or regular internet at home.
- It is a good idea to include parents in all communications. They rarely reply, but they do like to be informed, and can remind young people to reply to your emails.
- It is advisable to be democratic about meeting times – offer young people the opportunity to pick the meeting date by setting up a Doodle poll with days that also work well for you.

General lessons learned are:

- Target information sheets for different age categories. Have people from the group who fit in to those age categories review the sheets.
- Fun is important! Mix up ice-breaker activities, some social, some active.
- Revisit often how the group works. The facilitators from all of the YPAGs around the country get together regularly and have planning meetings.
- Do not overload meetings in an effort to accommodate high demand. Children and young people don't like it, it's difficult for the researchers, and it's not quality involvement.
- Give them time to do the activities properly.
- Avoid overreliance on PowerPoint, and if you use it, keep it simple.
- Information sheets should include pictures and colour.
- Do not condescend, be thoughtful about how you talk with the group.
- Always do a feedback activity with children and young people at the end of each meeting, and incorporate feedback into subsequent meetings.
- Seek feedback from researchers about the impact of the YPAG's input, and pass this feedback on to the YPAG members.

Having children and young people from YPAG involved in shaping research has yielded many benefits, to the research, the researchers, and the children and young people involved. Researchers have reported that consulting with

YPAG improved the quality of information sheets, by making them more child friendly and improving the comprehensibility overall. Researchers have been impressed by the observations and quality of feedback given by YPAG, and on how insightful children and young people can be about research. YPAG has also helped researchers improve study design by pointing out what would be acceptable to them, as young people, in several research studies.

Members of YPAG have gained skills in presentation (several have presented at high-profile events including the Otto Wolff lecture at the Institute of Child Health in December 2014, and at the Generation R event in September 2013), communication, and team working. They have worked collaboratively with peers of different ages. With some members, this has led to increased confidence and improved self-esteem. Furthermore, children and young people involved in YPAG have gained knowledge they wouldn't otherwise have gained in school, including what health research is, and about many different health conditions that affect children and young people.

The London YPAG has been a great success story, for researchers and YPAG members alike. In designing and delivering child health research, it is crucial to access and include the voices of those affected by the research, namely children and young people. They are loud, clear, and very insightful.

The website for YPAG is: www.crn.nihr.ac.uk/children/pcpie/young-persons-advisory-group/

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To read more articles about involving and engaging children and young people in research visit our website:

www.involve.nihr.ac.uk/find-out-more/involving-children-and-young-people/

Contributors include Valerie Dunn, who talks about her experiences of involving young people through film and animation, and Tony Ghaye who shares lessons learnt from involving children as young as seven in the development of a touch-screen healthcare technology system.

BRIGHTLIGHT study

By Lorna Fern, Anita Solanki and JJ Wheeler

BRIGHTLIGHT is a national study looking at cancer care received by young people aged 13-24. This research study will follow over 1,000 young people with cancer for three years to find out if they have different outcomes depending on where they are treated and the professionals involved in their care. Young people will take part in a series of surveys over the three years which asks a variety of questions about their life since diagnosis.

How and why?

We believe if our research is designed by young people with cancer, for young people with cancer, then not only will the research be more meaningful and relevant to things that really matter to young people with cancer but also more young people will want to take part in, and then stay in, our studies.

We try to involve young people in all of our research studies and have worked with young people since the beginning of BRIGHTLIGHT. Before BRIGHTLIGHT we carried out two years of what was essentially planning work where we worked with five young people as co-researchers. They carried out interviews with other young people, helped with data analysis and delivering the results back to young people and are authors on a number of publications.

The BRIGHTLIGHT YAPPERS

With BRIGHTLIGHT, we have approached involvement slightly differently and engaged a wider group of young people – our YAPPERS. The first official BRIGHTLIGHT activity was a naming and branding workshop with nine young people which is where the name ‘BRIGHTLIGHT’ came from. Since then we have had another three workshops which have looked at design of the website (<http://tinyurl.com/lcvr6w5>), promotional materials, ways to improve recruitment, strategies to improve retention and redesign of the website (www.brightlightstudy.com) now that we are three years into the study.

Workshops

The format of the workshop begins with role play from us, the researchers. We have found that role play is an effective way to get the message across and is more interesting to the young people; it also



JJ Wheeler pictured with his mother

JJ Wheeler

(Young Advisory Panel (YAP) member):

“When I was diagnosed with cancer in 2012 it was a bolt out of the blue. Suddenly I had teams of people running around arranging treatment, looking after me or just generally being there; I was the focus of a lot of attention. I wouldn’t be sat here today if it wasn’t for the fantastic support and treatment provided by NHS doctors and support staff, my family and friends, alongside charities and other organisations.

So when I was offered the chance to give something back it was a no-brainer. One of my nurses explained that the BRIGHTLIGHT study would help the government understand how cancer and treatment affect teenagers’ and young adults’ lives, the ultimate goal being to use the data to provide more effective support. Well, that’s got to be positive, right?

I’m nearly at the end of my involvement with BRIGHTLIGHT. I’ve had the chance to meet with like-minded people of a similar age group at a BRIGHTLIGHT workshop in London. Here we discussed ways to improve the service and the type of content we think is relevant with some of the key staff leading the survey.

Personally, I was given a lot of support for free from many sources. Taking part in this study has been a great way to give something back. I also feel I am being listened to and have the opportunity to create a better experience for people in the future who find themselves in the awful situation I was in three years ago.”

Continued>>

conveys that while we are there to work we also want to have some fun in the process.

We then go through our activities, such as how to improve recruitment, or how we can ensure that young people continue to take part in the study over time; we normally do two but sometimes three activities. We try and ensure that the researchers and the young people know the purpose of the workshop and we always feed back the results to the young people. At the end of the day we allow the participants some 'free creative space' to interpret the day as they choose. In September 2013 we held a recruitment workshop and two videos were particularly powerful for recruitment (<http://tinyurl.com/o9kxft5>), and for user involvement (<http://tinyurl.com/n7u576o>).

We have found the environment of the workshop influences the creativity of the group. The venue we have used for the last two workshops is bright and airy and there is complete flexibility on meal and break times as costs are all-inclusive and food and drinks are available all day. It can be difficult to tell in a group when the energy might dip and a break is needed and with this arrangement we don't have to worry about activities running over, running short or the young people (or researchers!) needing some time out.

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NIHR/Wellcome Trust Clinical Research Facility Cambridge Children's Non- Executive Research Board

By The Children's Board Strategy Group¹

The National Institute for Health Research (NIHR)/ Wellcome Trust Cambridge Clinical Research Facility (CRF) for Experimental Medicine is part of Addenbrooke's Clinical Research Centre (ACRC)² at Cambridge University Hospitals NHS Foundation Trust. In 2013, a Children's Non-Executive Research Board was established at the CRF.

The Children's Non-Executive Board has enabled children to have a voice in the service development of the facility. It includes children who have participated in studies on the CRF (originally recruited from a peanut allergy study and an artificial pancreas study), children who have never participated in research, parents and members of staff. The Children's Board meets twice a year and welcomes new members. Thirty-five children have signed up to join the Board and there are six main members who sit as active participants. The children are aged from 5 to 16 years old, with the most active members aged from 5 to 9 years old. At the first meeting they were asked to try out the equipment in the CRF. They were also asked for their opinions about research and all their comments were fed through to the agenda for the next meeting. This has created an ongoing process, enabling their voice to be heard.

The Board enables children to input into the design of generic and research study specific patient information. This includes input into patient information sheets, using language that other children can relate to so they understand the research.

The Children's Board has also had input into service re-design. They have provided input into the way we prepare children and young people before they come to the CRF in terms of the information we give, and also into the way we prepare rooms for children and young people on the day of their visit. They have made suggestions that have helped researchers provide an environment where children would like to

spend time and participate in research. The ideas the children brought to the sessions have helped create brighter, more colourful child-friendly rooms, including the design and decoration of a new paediatric phlebotomy room (where blood samples are taken). The children have also had a say in what toys, DVDs, games, books and other resources (e.g. iPads and a children's activity menu) are available.

The Children's Board input has helped create age-specific photo story books about taking part in research for age groups under 6 years, 6-10 and 11 plus. At the first meeting there were ideas on how to redesign the website (www.cambridge.crf.nihr.ac.uk) making it better for children and young people. Through the Children's Board the CRF has been able to develop its understanding of the patient experience. It shares research-related stories more widely with visitors, staff, patients and members of the public, using case studies and a news bulletin board featuring 'good news stories'.

The Children's Board work has fed into the wider context of the CRF. This has influenced the NHS Allergy and Diabetes clinics which have gone on to use the photo story books to develop their own for local use. This work has also influenced the development of the Children's Patient and Public Involvement (PPI) group in Southampton.

We are carrying out a small study, Children's Experience of Engaging in Research (CHEER), designed to discover what children, mums, dads, brothers, sisters and CRF staff think about the Children's Board. A focus group is being planned for April 2015 to explore experiences of older children and young people to inform our service.

The CRF believes that excellence in research is best achieved by involving and engaging patients in its work, to inform the way services are delivered and developed. This improves the patient experience directing effort into where it can add most value. The priority is to put people first, involving patients and the public in the work of the CRF. The ongoing work with the Children's Board is enabling the CRF to deliver excellence in research in a meaningful way, to those that matter the most, the patients.

¹The Children's Board Strategy Group are Caroline Saunders, Dr Carlo Acerini, Anne Elmer, Stewart Fuller, Laura Watson, Faye Forsyth, Jo Piper and Pippa Bayfield, Lindsay Carr and Shirleen Badger.

²Led by Professor Krish Chatterjee and Caroline Saunders (Head of Clinical Operations), the ACRC comprises a modern Clinical Research Facility and the NIHR Clinical investigation ward as well as the new CRF Satellite Unit. The facility offers round-the-clock care for research participants.

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Children helped create brighter rooms

We are always interested to hear about your experiences of active public involvement in research, whether you are a member of the public, a researcher or from a research organisation.

If you would like to contribute an article, news item or event notice please contact Paula Davis.

Tel: **023 8065 1088**
Email: pdavis@invo.org.uk

noticeboard

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in research and development. If you would like to put an item on our noticeboard please contact the Coordinating Centre.

BMJ blog post on involving children and young people

Louca-Mai Brady, freelance researcher and INVOLVE Group member, has written a blog post for the BMJ's Archive of Disease in Childhood about the importance and challenges of involving children and young people in health and social care research. To read the post visit: <http://tinyurl.com/myxtavp>

New journal: Research engagement and involvement now accepting submissions

BioMed Central have announced the publication of Research Involvement and Engagement (www.researchinvolvement.com/), an innovative, health and social care journal that focuses on patient and the wider public involvement in research processes and systems.

It is led by two Editors-in-Chief: Sophie Staniszewska, Patient and Public Involvement lead at the Royal College of Nursing (RCN) Research Institute, University of Warwick, and Richard Stephens, a patient advocate in research, who has overcome a number of health challenges.

The journal will have a novel structure, co-produced by all key stakeholders, including patients, academics, policy makers and service users. All articles within the journal will be reviewed by academics and patients, with both reports carrying equal weight in the editorial decision (<http://tinyurl.com/lpjc6s7>).

The journal is now accepting submissions; to submit a manuscript use the online submission system: www.researchinvolvement.com/manuscript

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

NIHR new media competition

Round 5 of the National Institute for Health Research (NIHR) new media competition is now open. If you are involved in NIHR Research (as a researcher, a patient or a member of the public) and are interested in communicating your research, then enter the competition. To enter you need to: be a member of the NIHR Faculty; have recently completed your NIHR funded research; or be a patient/member of the public involved in NIHR research.

In this round, there are two categories of the competition (raising awareness of your research and recruitment to NIHR clinical trials/encouraging participation in a research study). There is also a special prize for the film in either category that shows how public involvement has been embedded into a research project and how it made a difference.

Further information on how to enter, assessment criteria and special prizes is available at www.nihr.ac.uk/our-faculty/new-media-competition.htm

Closing date: Tuesday 31 March 2015

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INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

If you would like to receive a copy of the newsletter or find out more about INVOLVE please do contact us.

