

INVOLVE at 21

Celebrate the progress of public involvement in research and consider the opportunities ahead

Introduction

INVOLVE held its 10th conference on 28th November 2017 at [Church House](#), London. 2017 marked INVOLVE's 21st year so the conference was a chance for celebration as well as reflection on some of the key developments and opportunities for advancing public involvement

368 delegates attended, including international representatives from as far afield as Canada and Australia, many of whom had been present at the launch of the International Network the previous day. Out of these delegates 160 were lay members, the rest comprising of public involvement leads, practitioners, researchers, managers/commissioners and those from the voluntary sector.



The Assembly Hall



Gary Hickey with Anne MacKenzie
and her team from Western Australia

Opening Plenary Session

[Plenary Presentations](#) available to view.

The conference was opened by Sophie Ainsworth (YPAG member and founder of RAISE *Raising Awareness of Invisible Illness in School and Education*) and Zoë Gray (Director of INVOLVE). Their session focused on the progress of public involvement over a timeline of 21 years, linked to world events (some more frivolous than others!) over that period. This was presented alongside Sophie's journey and management of her condition. Zoë urged delegates to make a public involvement [pledge](#) as INVOLVE are working with Patient Focused Medicines Development on a pledge campaign. The session concluded with Zoë encouraging delegates to go the extra mile together to form a public involvement mega colony.



Zoë Gray and Sophie Ainsworth



Plenary session speakers

Sophie and Zoë were followed by the inspiring Simon Stones who described his personal journey and how he became involved in research. Like Sophie, Simon is a YPAG member and his passion for involving children and young people in research was evident in his presentation.

#INVOLVEat21 Simon Stones says research is the best treatment ever at the INVOLVE conference

@SimonRStones presenting at the #INVOLVEat21 conference. Choose whether to be silent or stand up #FindMyVoice



Simon Stones

Laila Xu spoke about her experience of being in the Great Ormond Street Hospital YPAG and described how she had been involved. Before dashing back to collage Laila spoke about what the group wanted to see in the future which is summarised below:

- Children and young people as **partners** from the early stages of research
- Involving more children and young people as **Research Ambassadors**
- Ensuring future research is more **relevant** to children and young people and establishing an ongoing dialogue with them



Laila Xu

#INVOLVEat 21 Inspirational young public member speaker GOSH BRC #GenerationR

Anne MacKenzie's journey with INVOLVE started with a conversation at a previous INVOLVE conference and led to an ongoing relationship. Anne discussed how INVOLVE helped her establish public involvement in Western Australia and that she initially worked by herself, but now runs a team of 10 people as the Consumer & Community Health Research Network.

Some highlights of the network over the last 10 years are:

- 90 events attended by over 2103 consumers and community members
- 105 training workshops
- 557 positions filled on 68 committees



Anne MacKenzie

#INVOLVEat21 listening to how INVOLVE works with International Groups such as in Western Australia consumer and community health research network spreading PPI in health research around the globe.

*Learning about how the world involves people
#INVOLVEat21 starting with Australia*

The opening plenary session was closed by Louise Wood, Director of Science, Research and Evidence at the Department of Health (now Department of Health and Social Care). Louise discussed the findings from the Future of Health Report which drew together stakeholder views on the future of health and healthcare in England in 20 to 30 years' time to inform strategic discussions about the future priorities of the NIHR, and the health and social care research communities more broadly.

Several themes were identified:

- **Transformation** in organisation and delivery of health and social care
- **Patient expectations and voice** are growing
- Increasing **health inequalities** driven by wider determinants
- Challenge of **lifestyle and environmental drivers** for public health needs – obesity and air pollution
- Growing burden of **mental ill-health** (young and old highlighted)
- **Demographic pressures** (ageing population with multi-morbidities)
- Challenge of keeping pace with **advances in technology** and positive/negative consequences of new personal digital devices
- **Global challenges** and changing patterns of disease - infectious disease – climate change and AMR



Louise Wood

The lay review of the report also highlighted several important issues:

- The life-course approach was welcomed
-*“What does it mean to be born well, live well and die well?”*
- The report presented an over-medicalised view of the future
- Self-management, as described in the report, is not as straight-forward an issue for patients
- Discussion on inequalities did not reflect of patient experience
- There was a perceived reluctance of NIHR to grapple with implementation
- There was a danger of “ghettoising” public involvement - need new methods and approaches
- “The future is about equality not coding”

Louise concluded with her public involvement pledges which were:

- 👍 *Commitment to hear from lay member(s) in two of our all-staff meetings a year*
- 👍 *Lay member to join meeting of each Deputy Director’s team each year.*

“We need to expand and deepen public involvement, with a focus on inclusiveness and diversity”. Great to hear this from @klouisewood at #INVOLVEat21

Welcome recognition from @klouisewood about the @OfficialNIHR and beyond for those working to support the patient influence in research #INVOLVEat21.

Posters and Stands

Delegates were able to network and view the 32 posters that had been accepted for the conference. The posters were being judged on design and use of plain English. There were also various stands from all areas of health and social care. The stands were:

- Charities
- International/standards
- Learning and Development
- NIHR
- Biomed Central
- The McPin Foundation and National Survivors User Network
- Generation R
- Social Care Institute of Excellence



There was also a joint INVOLVE RDS stand reflecting the partnership between the two organisations.

Standards

The Standards Partnership Development Group hosted a successful drop in session at the conference. The session featured; the revisions made to the standards and rationale based on the feedback from the public consultation, a chance to meet with members of the partnership from across the devolved nations, the story of the standards development and discussions around the next steps including pilots. The public summary from the consultation was available and more information can be found on the standards development website (<https://sites.google.com/nihr.ac.uk/pi-standards/home>).

Parallel Sessions

There were 24 parallel sessions that ran throughout the day, the majority of which were chaired by RDS Public Involvement Leads. The abstracts, and those of the posters, are available via the INVOLVE website and authors were also offered the opportunity to have their abstracts published in [Research Involvement and Engagement](#)

The parallel sessions covered a wide range of topics. The majority of presentations were jointly delivered with members of the public, and all had public members involved in their development.

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### Session 1.1: Diversity

#### **The AudioLab: Diversifying audiences and producers of public engagement with research**

Bella Starling, Central Manchester University Hospitals NHS Foundation Trust  
Jemma Tanswell, Reform Radio CIC

#### **Learning from other fields: Can arts based approaches improve the diversity of involvement?**

Delia Muir, University of Leeds

Rosie Davies, who chaired the Diversity session reflected eloquently on the first session:

“We were delighted that there was a large audience for this session which included two presentations. The first was on the AudioLab project – this project was run as a partnership between the Central Manchester NHS Trust, Bella Starling, and an online digital radio station called Reform Radio, Jemma Tanswell. We found out how the partners had engaged disadvantaged young people looking for employment with an interest in creating digital outputs, and how positively those involved had responded. Some went on to be actively involved in research projects and researchers were better equipped to work with public contributors who might not see science as ‘for them’. Questions included a discussion of how working with this group needed a great deal of flexibility and ability to respond to peoples’ interest and energy in each session, and strong relationships between public contributors and staff.



*For those at the #INVOLVEat21 conference who want to listen in full to #AudioLab, which was presented by @bellastarling and @jempot85 today, here it is: [http://www.reformradio.co.uk/projects/xHfxnvYq2EMTcEQPz ...](http://www.reformradio.co.uk/projects/xHfxnvYq2EMTcEQPz...)  
Let us know what you think.*

The second presentation was on how arts based approaches can improve the diversity of involvement. Delia Muir did this work as part of a Wellcome Trust Engagement Fellowship. Two projects were described, one based on sculpture and the other about a play on dementia. These approaches had attracted a variety of people. These arts based approaches had facilitated discussion in an accessible, safe and fun way.

While the activities were stimulating and useful, Delia described some practical challenges about planning and facilitating such work. Questions included the need to have Facilitators with appropriate skills and confidence, and the need for researchers to find partners to work with who can support this kind of work."



## Session 1.2: International

### **Your ticket to co-building in Canada: Creating a patient-oriented research course**

Malori Keller, Saskatchewan Centre for Patient-Oriented Research, Canada

Tim Bell, Canadian Institutes of Health Research, Canada

Eva Vat, NL SUPPORT, Canada

### **User-involvement in a Danish research project on empowerment of cancer patients in follow-up**

Clara Rübner Jørgensen, University of Birmingham

Nanna Bjerg Eskildsen, University of Southern Denmark

Delegates from Canada and Denmark presented at the International session. The Canadian presentation outlined how they developed and evaluated a course to teach people about conducting research together. Although public involvement isn't new in Canada working together across 13 very different provinces and territories is quite a challenge! However, this course has spread awareness and changed how people do research.



*"My physician has changed my care in Canada based on research I've found on Facebook in U.K. I realised if I'd been involved in the research I could have shaped it in the first place" BOOM  
@NIHRINVOLVE #INVOLVEat21 @SDenegri*

In Denmark public involvement is a relatively new concept and team presented how they incorporated user-involvement into the research process from the beginning. They reflected that experiences and expectations of service users may vary depending on the local context and that researchers need to be sensitive to these differences when drawing on expertise from another country.

### **Session 1.3: Children and young people**

#### **Involving children and young people successfully and effectively: Using IAP2 Spectrum Framework and Hart's Ladder**

Charity Gondwe, Parent/Carer

#### **How to prepare researchers to interact with children and young people in PPIE: Sharing YPAG North England's experience**

Neil Davidson, Great North Children's Hospital

Tracy Scott, The Newcastle upon Tyne Hospitals NHS Foundation Trust

The Chair of the Children and Young People's session, Helen Hancock, provided feedback on these though provoking sessions, the first of which was presented by Charity a parent and carer:

"Charity provided compelling information about why it is important to involve children and young people; the audience were invited to think about their own practice and behaviours and to consider ways in which they could more proactively engage with and involve these groups. Charity spoke of her experiences of recognising the important contributions to research, and the risks of not doing so on the development of an evidence base.

The session highlighted the different needs of children and young people, compared to adults. The session identified ways to include children and young people with additional needs by making reasonable adjustments; these are often not expensive or difficult to put in place.

The session offered an important opportunity for those attending to reflect on and share their experiences of involving children and young people in research; many were keen to do more. One of the young people attending highlighted the need for more information about how to become involved; she was provided with details of how to engage and to become involved. One of the reflections from the audience was that the need to be more inclusive of children and young people with additional needs.

Neil and Tracy provided important insights into the challenges and opportunities of developing and running the Young Person's Advisory Group North England (YPAGne). YPAGne is a dynamic forum for young people to interact with researchers at various stages in their research projects.



Neil, Tracy and the members of YPAGne (via recorded videos) covered practical issues of time, resource, facilities, food (!), as well as more nuanced insights into enabling meaningful interactions and impact. They shared insights into the importance of preparing researchers adequately for interacting with groups such as YPAGne, in order that maximum impact is achieved by all. The benefits of giving careful consideration to the differing needs, individually and collectively, of YPAGne members, supporting staff and researchers, to optimise contributions were clear. Rapid reflective cycles after each meeting have enabled YPAGne to constantly innovate in its approach and foster the best possible environment for engagement. Other key insights included the importance of space for open, focussed, conversation. Innovative approaches to ways of working included the use of technology within and following sessions, including provision of feedback; those attending the conference were provided with an opportunity to engage with this technology. Questions focused on the substantial work achieved, on sustainability and on the need to further develop groups like this.”

*Researchers often skip the science or talk in too much detail about the research’ - voice of a YP. Reduce the amount of time talking TO them and increase the time interacting WITH them. @YPAGne #INVOLVEat21*

## **Session 1.4: Public members as co-applicants**

### **The benefit of a partnership approach enabling the patient voice to be heard loud and clear and the added value this brings to the research**

Nicola Heron and David Coyle, NIHR Devices for Dignity

### **Being a lay co-applicant on national peer reviewed research funding grants**

Raksha Pandya-Wood, Steven Blackburn, Ruth Day and Carol Ingram, NIHR Research Design Service Public Involvement Community (PIC) Group

Lizzie Thomas from the INVOLVE Advisory Group chaired the well attended, interactive co-applicants session. Lizzie was particularly pleased that the first talk was co-presented with a public applicant, David Coyle. The talk focused on the impact patients as co-applicants can have on research through describing the breadth and depth of the involvement.

*“We are more than our clinical conditions”  
says David Coyle #involveat21*



The Research Design Service (RDS) Public Involvement Public Involvement Community explored the role, responsibilities and support of lay co-applicants on national peer reviewed research funding grants. Lizzie reflected that it had “an interesting ‘conversation’ section with Carol and Ruth, two public co-applicants followed by audience discussion sections in facilitated groups”



## Session 2.1: Dissemination methods and the role of the public

### **"Don't smile – A love story with a dental theme": National award winning theatre and debate disseminating dental research to at-risk adolescents**

Sue Pavitt, School of Dentistry, University of Leeds

Richard Boards, Janet Briggs, Ellen Loughhead and Jenny Boards, SMILE AIDERS Patient Public Involvement Forum, School of Dentistry, University of Leeds

### **Who cares about ambulance performance measures?! The role of PPI in developing an animation for dissemination of the PhOEBE programme**

Andy Irving and Daniel Fall, University of Sheffield

"Don't smile – A love story with a dental theme" is an intriguing title for a session. This is the name of a play that disseminated dental research and debated the wider implications of poor oral health, social isolation/psychological wellbeing and NHS dental access. This is hugely important as the presenters state that "45% of Yorkshire's 12-year-olds have rotten teeth, second-worst UK prevalence, correlated with social/health inequality. Whilst largely preventable, reaching those most vulnerable/deprived is challenging. Disadvantaged teenagers intrinsically don't like to be told what to do. Don't Smile was inspired to test if using theatre might impart knowledge nonjudgmentally, allow debate and improve oral health awareness." One of the amazing results of this play was that one young person who watched it now intends to apply to study Dentistry at University.

The session shared tips/guidance/contacts and their web-based documentary to inform others how to undertake a similar dissemination approach.

*Interesting presentation about the way that Sue Pavitt disseminated and evaluated their dental research #INVOLVEat21*

Andy Irving and Daniel Fall from the PhOEBE programme felt that "Everyone is a potential recipient of ambulance service care and expects a good quality service, but measurement of care and performance are difficult and complex concepts to describe. The PhOEBE programme's patient and public advisors felt important messages from the study could be better presented to the general public using an animation to describe the findings and the changing nature of ambulance services in England." The result of their input can be seen in this short animation



[https://www.youtube.com/watch?v=Qu7T90\\_DwV4](https://www.youtube.com/watch?v=Qu7T90_DwV4)

## Session 2.2: User led research

### Raising awareness of invisible illnesses in schools and education (RAiISE)

Sophie Ainsworth, RAiISE

### Unreliable and incapable? Exploding myths about employing people with lived experience of addictions to lead research

Sarah Wadd and Maureen Dutton, University of Bedfordshire

Sophie Ainsworth continued the theme of invisible illnesses when she described Raising



Awareness of Invisible Illnesses in Schools and Education (RAiISE), a user-led research project inspired by the negative experiences that young people face while studying and living with invisible illnesses <https://raiise.co.uk/> Sophie also made delegates aware of the future aspirations of RAiISE which are to:

“develop information packs for staff in schools and colleges, in order for them to be better equipped for supporting students with invisible illnesses. The packs will include communication strategies, a health passport, consensus top tips and various materials to help improve the support available for young people at school, enabling them to achieve their full potential in a happy and safe environment.”

*@Sophie\_ains is a very inspiring patient who is making important changes raising awareness of invisible illnesses in school - hats off to you!  
#INVOLVEat21*

Perceptions of involving people with lived experience of addictions were exploded by Sarah Wadd and Maureen Dutton. Their model is breaking down barriers and stereotypes such as those who have experienced addiction being unreliable, incapable, untrustworthy, emotionally unstable and incompetent.

*Interesting talk being given by staff from @uniofbeds on debunking the myths of employing people with lived experiences of addictions to lead research. People with these experiences must be heard to help prioritise research in this area! #INVOLVEat21*

## Session 2.3: Regional networks

### **Regional working in East of England: Co-designing a patient and public involvement (PPI) feedback tool**

Elspeth Mathie, Graham Rhodes and Anna Ellis, University of Hertfordshire and NIHR CLAHRC East of England

### **Working together to advance public involvement: Co-production and partnership working within a regional public involvement network**

Tina Coldham and Claire Ballinger, NIHR Wessex Public Involvement Network

The two presentations on regional networking focused on the development of a co-designed generic PPI Feedback process which is now being trialed in PPI groups, and the vision and development of the Wessex Public Involvement Network (PIN).

The first presentation highlighted that despite significant investment of their time debating complex issues public contributors rarely got acknowledged or thanked for their involvement. Consequently a feedback tool has been developed which is being trialed by six regional groups. The team are aiming to encourage other groups to work together to promote feedback whilst at the concurrently managing expectations.

*#INVOLVEat21 great 2 share regional collaborations  
session - Wessex & East of England @ClaireBallinge1  
@TinaColdham*

Claire Ballinger and Tina Coldham (Co-Chairs of the Wessex PIN) outlined their motivation for establishing the group; shared the achievements so far; discussed the principles and practicalities involved in setting up a regional group and debated what could help or hinder the creation of such a group.



*Really impressive potential of this regional partnership  
in Wessex @ClaireBallinge1 @TinaColdham  
@wessex\_clahrc #INVOLVEat21*

## Session 2.4: The ageing population / social care

### Overcoming the challenges of involving older people with dementia, hearing and vision problems in research: Sharing learning and future progress

Jahanara Miah, Suzanne Parsons and Steven Edwards, University of Manchester

### Young researchers improving research and practice with lesbian, gay, bisexual and transgender (LGBT) young people living in public care

Jeanette Cossar, Fey Dougan, Candice Luke, Mo Cherkouai and Brett Service, University of East Anglia

There was a thought provoking session focusing on the difficulties of involving older people with dementia, hearing and vision problems in research. It was asserted that it was challenging, but possible and the project was praised for meaningful involvement.

*Great example of good practice involvement for people with dementia, hearing and vision problems @researchdialog - really achieving meaningful involvement. Well done 🙌🙌 #INVOLVEat21*

The Chair of this session, Gill Green, reflected on the second presentation in the Aging population/social care session which was about LGBT young people living in care and mainly presented by four young people who had experienced this and recently left care. Gill observed that “They spoke about this aspect being overlooked and the need for it to be considered as a key part of care provision. They showed how they had been involved at each stage of the research and were an integral part of the project. The audience response was fantastically positive and emotional. One woman said she was “blown away” by the presentation.”

*I loved the presentation by the young researchers involved in this...all taking a turn to speak, very engaging...and funny! #INVOLVEat21*



## Session 3.1: Co-production

### **Moving from patient and public involvement towards co-production in a large mental health trial in primary care: PARTNERS2 experience**

Vanessa Pinfold and John Gibson, McPin Foundation

### **Sharing ideas and principles of co-production in health and social care research and developing guidance for researchers and public stakeholders**

Kati Turner, Population Health Research Institute, St George's, University of London

Tracey Johns, NIHR Research Design Service East of England, University of Essex

Jonathan Paylor, NIHR Research Design Service London, Kings College London

Gary Hickey, INVOLVE

The Co-production parallel session was extremely popular, and INVOLVE's new Chair, Tina Coldham, provided the following thoughts on the content:

"This session heard from Vanessa Pinfold and John Gibson, at the McPin Foundation on their experiences and musing of co-production in their work on "Moving from patient and public involvement towards co-production in a large mental health trial in primary care: PARTNERS2 experience". McPin, whilst not a user led organisation has survivor researchers working for them in various roles, and in actively doing research thus they are grappling with the concept of co-production and what it means in practice. They gave us their angst ridden thoughts and it seems a work in progress, and helpful at that.

This compared nicely with the session led by Gary Hickey of INVOLVE on "Sharing ideas and principles of co-production in health and social care research and developing guidance for researchers and public stakeholders". This work is some research itself to try to understand what co-production in research looks like, and what resources would be helpful to researchers for Involve to provide. Kati Turner, survivor researcher, St George's, University of London, Tracey Johns, RDS EoE, & Jonathan Paylor, RDS London gave us their input and thoughts so far which mirrored thoughts from McPIN.

There is a lot to do on co-production in research, we are on a journey, and this up to the minute discussion showed some light on the subject and that there is a way to go and do research in this way to prove what works and what doesn't. A question from the floor challenged the notion that co-production is a useful concept itself because it has soon become corrupted to mean little more than tick box exercises by some. Gary pointed out what is important is that the principles emerging with regard to co-production in research will help steer a path forward, and that anyone can use these to challenge bad practice."



*This is the closest I have come to understanding the difference between coproduction and PPI. #INVOLVEat21  
WELL DONE @McPinFoundation*



## Session 3.2: Learning and development

### Developing resources for a learner-centred approach to learning and development for public involvement in research

Lucy Frith, NIHR Research Design Service North West

Amander Wellings, INVOLVE Learning and Development Project Group

### The East Midlands Sharebank: A cross-institutional model for sustainable learning and development for public involvement in research

Adele Horobin, NIHR Nottingham Biomedical Research Centre

Colleen Ewart, Patient and Public Involvement Contributor

Jane Stewart, NIHR Research Design Service East Midlands

The Learning and Development session was opened by the INVOLVE Learning and Development project group who explained what new resources were available; where they can be found and how they might be used to support their own (and others) development.

*Look out for a new online database of PPI training resources & materials being developed by @NIHRINVOLVE, coming in late 2018! #INVOLVEat21*

Adele Horobin described the Sharebank model and how it was developed. Essentially The Sharebank has brought NIHR and NHS organisations together, aligning strategic objectives for public involvement support and helping public and researchers to share their experiences. It provides the means for organisations to share training and resources for public involvement at minimal cost.



The audience was also given an opportunity to give their views on the Sharebank model, and the team offered to provide advice to anyone who was interested in establishing their own.

*#involveat21 Adele Horobin talks about a PPI Sharebank creating resources and workshops for everyone: alone we can do so little, together we can do so much*

## Session 3.3: Innovation

### Taking involvement online: Development and evaluation of an online forum for patient and public involvement in palliative care research

Lisa Brighton and Sylvia Bailey, King's College London

### Children and young people's involvement in evidence synthesis on mental health in children and young people with long-term conditions

Erin Walker, Katie Hughes and Summer Teale, Great Ormond Street Hospital NHS Foundation Trust

The Innovation session commenced with a session on taking involvement online. The aim of this session was to share learning from the development and evaluation of an online forum for patient and public involvement (PPI) in palliative care research: [www.csipublicinvolvement.co.uk](http://www.csipublicinvolvement.co.uk) The presenters felt that developing and evaluating the online forum has led to three key differences: increased coproduction skills, improved research quality, and a new knowledge base for developing online PPI platforms.



*The wonderful Sylvia Bailey waving the flag for 'silver surfers' and using online fora for involvement in research - important that online efforts aren't the only approach #INVOLVEat21*

This was followed by a presentation by Erin Walker and two young people – Katie Hughes and Summer Teale. This session focused on the involvement of children and young people (CYP) with relevant experience, in a large NIHR funded evidence synthesis project of mental health interventions for CYP with long-term conditions. They described how this involvement had a powerful and meaningful impact not only on the research but also on the review team and the CYP themselves.



*"Systematic reviews can be quite a boring form of research" the best quote today - said in jest - but seriously listening to how in to involve children & young people in the process - inspiring! Erin Walker #INVOLVEat21*

## Session 3.4: Public involvement in the charity and voluntary sector

### Partnering to improve BME access, inclusion and involvement in research: Exchange visits with third-sector organisations for shared learning and improvement

Susan Hrisos, Julie Marshall and Lyndsay Yarde, Institute of Health and Society, Newcastle University

### How collaboration with the voluntary sector led to strong public involvement in product development for self-management of diabetes

Hildegard Dumper and Sandra Tweddell, West of England Academic Health Science Network

Public Involvement in the Charity and Voluntary Sector started with a presentation called “Partnering to improve BME access, inclusion and involvement in research: Exchange visits with third-sector organisations for shared learning and improvement”. This described an exchange visit programme during which a period of time was spent within each other’s organisations to observe what others do, including how they go about priority setting and how they gather, evaluate and report data. The aim was for everyone involved to reflect on and improve what they do respectively, and to find a **common-** ground methodology for improving access, inclusion and evaluation of more meaningful research. It described the shared learning and participatory approach used during successive projects which improved inclusivity.

*Enabling Inclusion’ collaborative study: “Hard to reach” group also “easy to ignore”. Outcomes from Shared Learning Events inform development of a Community Research Toolkit for inclusive research. #BMEinresearch #INVOLVEat21*



The second session focused on the Diabetes Digital coach project as a case study in the value of working with the voluntary sector to achieve good co-production. A PPI toolkit was available for delegates, and it was hoped that delegates would gain a greater understanding of the range of partners available to them.

*Sandra Tweddell sharing her experience as a public contributor on the Digital Diabetes Coach test bed project - a case study for PPI in the voluntary sector. @WEAHSN @DiabetesDC #IoT #INVOLVEat21*

Krysia Dziedzic, as Chair provided the following feedback:

“We heard two excellent presentations of work undertaken to enhance the roles of the voluntary sector and supporting innovations tackling diversity. The presentations were delivered by both professional and lay members in an engaging manner which stimulated open and honest discussion and debate with the audience.”

## Final Plenary Session

Simon Denegri (the outgoing Chair of INVOLVE) opened this session. His message was very simple: researchers “can’t afford to not do public involvement”. Simon urged people to tell others what they are doing so that knowledge and experience can be shared. He also emphasised that sometimes public involvement can evolve from just getting people into a room to talk. It doesn't need to be complicated. Before Simon handed over to the new Chair, Tina Coldham, he read out a poem that he had written about public involvement. Please click [here](#) to read it and the accompanying blog.



Simon Denegri



Simon Denegri, Zoë Gray and Tina Coldham

*Do it, tell it, share it! @SDenegri  
reflections on #publicinvolvement.  
#INVOLVEat21*

*Simon Denegri reflecting that we need to be better at  
communicating research outcomes to the people actually  
involved - well said. #INVOLVEat21 @cftrust*

## Winning Posters

### *Overall winner*

#### **Walking the talk - developing and modelling co-productive learning: The case for the Exchange Network**

Rachel Matthews<sup>1\*</sup>, Constantina Papoulias<sup>2</sup>, Cherelle Augustine<sup>1</sup>, Maurice Hoffman<sup>1</sup>, Mark Doughty<sup>3</sup>

1. NIHR CLAHRC Northwest London, Imperial College London/Chelsea and Westminster NHS Foundation Trust, London, UK
2. NIHR CLAHRC South London, King's College,
3. The Kings Fund



### *Plain English*

#### **Working together to better represent the unheard voices of 16-24 year olds in health research**

Caroline R Barker<sup>1\*</sup>, Megan Barlow-Pay<sup>2</sup>, Aisha Kekere-Ekun<sup>3</sup>, Anika Mazumder<sup>3</sup>, Anika Nishat<sup>3</sup>, Rebecca Petley<sup>3</sup>

1. National Institute for Health Research Southampton Clinical Research Facility and Biomedical Research Centre, University Hospital Southampton NHS Foundation Trust, Southampton, Hampshire, UK
2. National Institute for Health Research Design Service South Central, University of Southampton, Southampton, Hampshire, UK
3. Young Adult Patient and Public Involvement Group member, Southampton, Hampshire, UK



### *Overall Design*

#### **Developing good practice guidelines for the involvement of public members in project oversight groups (Trial Steering Committees, Study Steering Groups)**

Heidi Surridge<sup>1</sup>, Doreen Tembo<sup>1</sup>, Amanda Roberts<sup>2</sup>, Eleni Chambers<sup>3</sup>

1. NIHR Evaluation Trials and Studies Coordinating Centre (NETSCC), Southampton, UK
2. Public member, NETSCC Public Involvement Virtual Network and Public member of a Trial Steering Committee, Southampton, UK
3. Public member, NETSCC PPI Reference Group, Southampton, UK





## Conference Blogs

<https://evidsynthteam.wordpress.com/2017/12/05/evidence-synthesis-can-be-a-slog-we-need-to-involve-children-and-young-people/>

<http://mcpin.org/involve-at-21/>

<https://medium.com/support-letters/lessons-learned-from-the-involve-conference-274983728bd1>

<http://patientfocusedmedicine.org/pledge-waiting-kettle-boil-train-late/>

Thank you to the Conference Planning Group whose commitment and enthusiasm ensured the success of this conference! We would also like to thank our RDS colleagues who helped greatly on the day by Chairing and Co-Chairing parallel sessions, as well as being on the INVOLVE RDS stand.

### Conference Planning Group members:

Zoë Gray

Kate Sonpal

Paula Wray

Gary Hickey

Martin Lodemore

Sam Goold

Wendy Baird

Gill Green

Rosie Davies

Christine Vial

Amander Wellings

<http://www.invo.org.uk/news-events/involve-conference/>