

INVOLVE@21

PenCLAHRC provided the opportunity to attend the Involve Conference in Westminster, London. The day focussed on “celebrating the progress of public involvement in research and consider the opportunities ahead”.

It promised to be a very full day, structured with presentations from a diverse community of people engaged with Involvement. After the opening plenary session, to include Zoe Gray, Director, INVOLVE and Louise Wood, Director of Science, Research and Evidence, Department of Health, you knew the day was going to be jammed packed with networking, poster presentations and getting to know more about involvement.

The day could be tailor made to your interest(s) as ‘parallel’ sessions took place in three set blocks. The first included Diversity, International, alongside Children & Young people and Public members as Co-applicants. The attendees split into their preferred session. This session was then followed by the next two parallel sessions that included; Dissemination methods and the role of the public, the ageing population/social care, co-production, learning and development and innovation. This list is not exhaustive.

Alongside my interest and current level of involvement, I chose to attend – Diversity. The ageing population/social care. Learning & development.

Diversity presented by The AudioLab to include Bella Starling Central Manchester University Hospital NHS Foundation Trust and Jemma Tanswell, Reform Radio CIC. The project looked to remove the mystic around science and worked with young unemployed adults to provide a safe flexible space, enabling the development of positive relationships with peers and Researchers. It was piloted in 2016 and they believe the next session should run at the same time as the Manchester

Festival of Science. Using the Media skills brought to the project by Reform Radio, it looked to raise interest and awareness in science.

The second presentation delivered by Delia Muir, University of Leeds, outlined the research project bringing art based approaches to improve the diversity of involvement.

After lunch, the Ageing population/social care presentations attracted my interest. Again, the University of Manchester gave an interesting account of their 5 year project involving older people with dementia. We learnt they had adopted a myriad of ways to gain effective involvement with their public/patient participants. These included bite size sessions, visual and audio aids seating arrangements and even accessible small rooms with acoustic and differing light settings. Please see attached image. The team looked to involve older people with dementia in a multi-site international research programme (SENSE-Cog) covering U.K., France, Cyprus and Greece. SENSE-Cog explored the combined impact of Dementia and looked to develop new tools and at-home support to promote quality of life.

The last session in parallel 2 covered Young researchers improving research and practice with Lesbian, Gay, Bisexual and Transgender (LGBT) young people living in public care. The University of East Anglia gave a very interactive account of their research, involving a quiz to gauge our level of LGBT terminology and ultimately how public care is ill equipped to support those individuals' questioning their sexuality and or gender. The project looked to develop concepts that could remove barriers within public care and give the message "do listen, do ask, don't be afraid and just be a friendly ear!"

The Learning and development session was presented by an INVOLVE learning and development project group member Amander Wellings, alongside Lucy Frith from NIHR Research Design Service North West. Together, the two groups had developed sub-groups to design and produce useful guides to Patient and Public Involvement (PPI) and Amander had been instrumental in developing the NIHR booklet called “Starting out” Some members of PenPIG had been involved of giving their viewpoints both as newer and more established participants and it was great to learn that this information has been used towards the publication of a new Public Information Pack (PIP). It was apparent that Amander is passionate about involvement, having some 14 years’ experience and this was infectious.

The last session of the day was hosted by the East Midlands Sharebank: A cross-institutional approach to learning and development for public involvement in research. The team outlined Sharebank was a network from participating organisations who share involvement training. Members work together to create resources and a programme of Learning and Development events. The Sharebank facilitates the giving, receiving and reciprocating of the basic building blocks to develop fruitful relationships in research, working towards a common goal. To close, a Q&A took place.

The day was jam packed with information and I came away realising that PPI is bigger than I could ever have imagined. To put it into context, according to Anne McKenzie, Network Head, Consumer and Community Health Research Network, University of Western Australia. Western Australia is 10 times the geographical size of the United Kingdom and yet, they are lagging behind the UK in size of involvement. The Department of Health continues to support involvement, confirming it has a huge value to the NIHR going forward.

It was clear to see that there is no one correct way to be involved. Music and art plays a larger part in poorer socio-economic areas but gives as much value as does the structure of PenPig within the South West Peninsular. It would be impossible to say that we should all do it the same way, as the research and affiliations influence the PPI. A positive message that came across throughout, is that there are many imaginative ways to be involved and the opportunities are out there and INVOLVE is there to support both new and more established participants alike and the however you came to being involved it continues to be seen as the way forward in Health research.

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