IN Bulletin 8 – Young peoples' involvement in paediatric dentistry

Welcome to the eighth issue of our IN: Bulletin.

This bulletin focuses on Young peoples' involvement in paediatric dentistry. YPAGne (Young Person's Advisory Group North England) member Ollie Waterhouse and Greig Taylor NIHR Academic Clinical Fellowship, Specialty training Registrar in Paediatric Dentistry explain.

IN Bulletin 7 – Shared Research

Welcome to the seventh issue of our IN: Bulletin.

This bulletin focuses on shared research where those who have been supported by a social care scheme interview others. Shared Lives Peer Researchers Rachel Turner and Paul Vickery and Principal Investigator Nadia Brookes explain.

Sophie Ainsworth



I stumbled into the world of research and healthcare, following a diagnosis of Lupus in 2014, when I was 14 years old. Since then I have become a passionate advocate for patient voice in healthcare, particularly for children and young people, who are often overlooked. Following my diagnosis, I became a participant in research studies, both as a patient and being on advisory groups. I have sat on the advisory group for the TRECA Study, which develops multimedia interventions for patient information sheets. I have also worked closely with the Alder Hey Clinical Research Facility and Lupus UK on a variety of projects and have been an NIHR Patient Research Ambassador for two years.

Most of my work nowadays focuses on RAiISE, a charity I founded two years ago which stands for Raising Awareness of invisible Illnesses in Schools and Education. It is dedicated to supporting students who are living with 'invisible' illnesses to ensure they are given the support they need in school by equipping teachers with resources and information to do so.

IN Bulletin 6 – Involving young people in research

Welcome to the sixth issue of our IN: Bulletin.

This bulletin focuses on young people in research. Sam Goold, INVOLVE's Public Involvement Officer, meets a researcher and young person from a healthy eating research project.

Jane Taylor



I have spent most of my working life in higher education and now work part time for the Open University. My interest in patient and user involvement comes from my own experience as both patient and carer. I was diagnosed with rheumatoid arthritis aged 26 and antiphospholipid syndrome and osteoporosis in my 30s. Over the intervening years I developed a couple of other long term conditions for good measure! As well as my own experience I support a sibling with schizophrenia and diabetes and a daughter with a number of health conditions.

I am currently Chair of Arthritis Research UK's Patient Insight Partner group and have worked with the charity in a voluntary capacity for 8 years bringing patient insight to various research activities including review and evaluation of funding applications and training of researchers in using PPI.

I also chair the European Patient Insight Group for APPROACH, a 5 year IMI-funded project on osteoarthritis involving 25 European partners and one USA partner – advising on clinical trial design, ethical issues and patient communication.

I am a member of a Maternal and Foetal Health Advisory group at St. Mary's Hospital, Manchester and a Member of an Expert Advisory Group for the Taskforce on Multiple Conditions.

I am passionate about ensuring that all patient and carer voices are represented and are part of the whole research cycle from shaping research questions to ensuring findings get widely disseminated.

INVOLVE Advisory Group Minutes May 2018

Cheryl Gowar



I am particularly concerned with people being able to take an active role in the management of their long-term conditions, and with the appropriate treatment and support infrastructure being in place to allow for that.

My main concern is to challenge inequality in health and care provision. My career started in academic research but I moved into the health and social care sector in 2011 when I started working for RADAR (the Royal Association for Disability Rights), now Disability Rights UK.

Currently, I am the Policy and Campaigns Manager at NAT (National AIDS Trust). There I have led on projects involving access to good healthcare for people from Black, Asian, and minority ethnic (BAME) communities, trans people, and people being held in immigration detention.

Public Information Pack (PIP) Booklet 2: Getting started

2018. How to get actively involved in NHS, public health and social care research – Getting started.

The Public Information pack (PIP) is made up of four booklets and is for members of the public who are interested in getting involved in NHS, public health and social care research. The booklets have been produced by INVOLVE with support and advice from members of the public to help us ensure we cover the kind of information people need when first getting involved in research.

The other three booklets in the series are:
PIP 1: A quick guide
PIP 3: Finding out more
PIP 4: Jargon buster

No. of pages: 31