# NIHR | INVOLVE

# Patients and the public
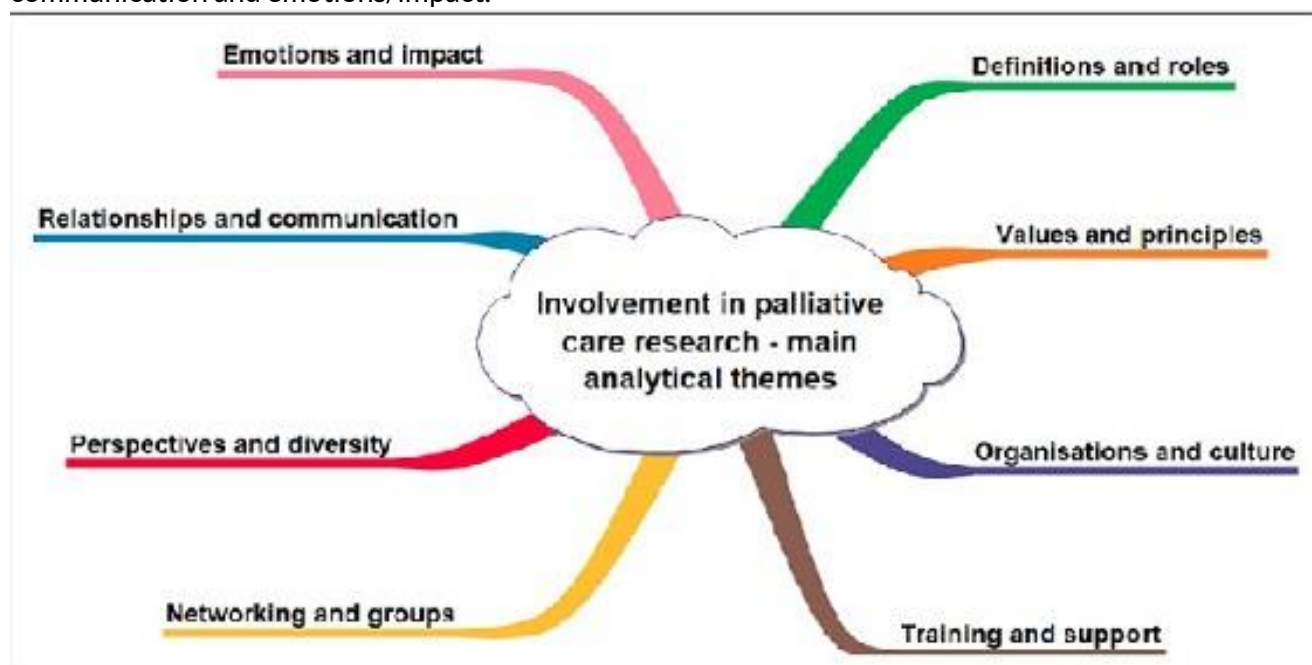
September 2019

## Palliative Care Review Now Published

The review can be downloaded  here.

**Background:** Patient/carer involvement in palliative care research has been reported as complex, difficult and less advanced compared to other areas of health and social care research. There is seemingly limited evidence on impact and effectiveness.

**Aim:** To examine the evidence regarding patient/carer involvement in palliative care research and identify the facilitators, barriers, impacts and gaps in the evidence base.

**Data sources:** Electronic databases were searched up to March 2018. Additional methods included searching websites and ongoing/ unpublished studies, author searching and contacting experts. Eligibility criteria were based on the SPICE (Setting, Perspective, Intervention, Comparison, Evaluation) framework. Two quality assessments on methodology and involvement were undertaken.

**Results**: A total of 93 records were included. Eight main themes were identified, mainly concerning facilitators and barriers to effective patient and carer involvement in palliative care research: definitions/roles, values/principles, organisations/culture, training/support, networking/groups, perspectives/diversity, relationships/ communication and emotions/impact.



Evidence on the impact of involvement was limited, but when carried out effectively, involvement brought positive benefits for all concerned, improving the relevance and quality of research. Evidence gaps were found in non-cancer populations and collaborative/user-led involvement.

**Conclusion:** Evidence identified suggests that involvement in palliative care research is challenging, but not dissimilar to that elsewhere. The facilitators and barriers identified relate mainly to the conduct of researchers at an individual level; in particular, there exists a reluctance among

professionals to undertake involvement, and myths still perpetuate that patients/carers do not want to be involved. A developed infrastructure, more involvement-friendly organisational cultures and a strengthening of the evidence
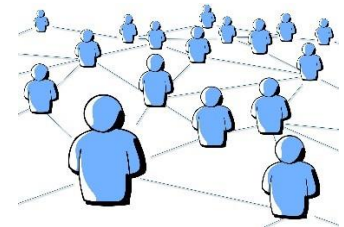base would also be beneficial.



## Supporting collaboration in learning and development for patient and public involvement (PPI)

In the autumn 2016 edition of the NIHR INVOLVE newsletter, we reported on the development of the Sharebank, a network for training, learning and development in patient and public involvement (PPI).

It brings together people from different organisations, including staff and patient/public partners, to share their training, knowledge and resources relating to PPI.
In 2015/16, the Sharebank was piloted amongst five organisations: two NIHR Biomedical Research Units in Nottingham (Hearing and Digestive Diseases); the NIHR East Midlands Collaboration for Leadership in Applied Health Research and Care; NIHR East Midlands Research Design Service; and the Nottingham University Hospitals NHS Trust Research and Innovation team. Since that time, the Sharebank has expanded to include 14 research-active organisations in the East Midlands and it continues to grow!

This grassroots initiative works in full partnership with staff and patient/public contributors and uses a mutually agreed terms of reference. It is built on the goodwill, hard work and mutual trust of those involved.

In 2018, INVOLVE offered the Sharebank founder, Dr Adele Horobin, the opportunity to explore the potential for establishing regional Sharebanks elsewhere in the country. Through a part-time secondment to INVOLVE, Adele has established links in various parts of the country to learn how other regions collaborate and explore which aspects of the Sharebank model can give added value.

As part of this secondment, Adele collaborated with fellow East Midlands Sharebank Co-ordinators Raksha Pandya-Wood, Njoki Pratt, Paul Radin, Deborah Wilson and Andy Wragg to coordinate a national meeting focussed on PPI. It provided the opportunity for staff and patient/public partners to share and explore collaborative ways of creating and delivering patient and public involvement (PPI) training, learning and development.
 The event was held in Nottingham on 20 June 2019. It was free to attend and INVOLVE offered to reimburse expenses for any patient/public partners who wished to attend. In all, 29 people attended, from as far north as Newcastle and as far south as Southampton, including nine patient/public partners. The day included short presentations which introduced examples of how regions are already collaborating on PPI. These included: the Wessex Public Involvement Network (Wessex PIN)2, by Heidi Surridge of the NIHR Evaluation, Trials and Studies Co-ordinating Centre; the Working Together partnership in Oxfordshire and Thames Valley3, by Lynne Maddocks of the NIHR Oxford Collaboration for Leadership in Applied Health Research and Care; and the East Midlands Sharebank4, by Dr Adele Horobin of the NIHR Nottingham Biomedical Research Centre.

The presentations sparked a debate about the different ways that organisations collaborate and how issues such as finance and workload can be shared.

Also invited was Dr Kristina Staley, who introduced her team's approach to training for involvement. This focusses less on addressing gaps that a patient or public contributor might have in their knowledge of research. Instead, the emphasis is on building awareness of the expertise that they have to offer and how to influence researchers effectively.

The event concluded with a workshop to uncover the challenges and solutions related to planning, delivering and monitoring/evaluating collaborative PPI training initiatives. Everyone really valued the discussions, and the opportunity to network with others. A number of practical tools were highlighted, such as the FutureNHS collaboration platform for invited users to collaborate online around specific projects (https://future.nhs.uk/connect.ti).  In feedback, people reported that they would follow up on connections made and report back to others in their teams. It appeared to have buoyed a number to look further into the scope for establishing a Sharebank in their area or in further encouraging colleagues to take up PPI training. One public member new to PPI reported that they felt able to contribute more to their PPI group. There was also interest in attending more events such as these.

Adele's secondment with INVOLVE is set to continue until March 2020 and new initiatives are being planned to help support regions in their collaborative working on learning and development in PPI.

**References:**

1. Horobin A. Going the extra mile – creating a co-operative model for supporting patient and public involvement in research. Research Involvement & Engagement 2016; 2:9. Available at https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0025-z

2. Wessex Public Involvement Network. Available at: https://sites.google.com/view/wessexpin [Accessed 29 July 2019].

3. Working Together Training and Development Programme. Available at: http://bit.ly/workingtogetherprogramme [Accessed 29 July 2019].

4. Sharebank. Available at: http://learningforinvolvement.org.uk/sharebank/ [Accessed 29 July 2019].

5. Staley K, Cockcroft E, Shelly A, Liabo K. 'What can I do that will most help researchers?' A different approach to training the public at the start of their involvement in research. Research Involvement & Engagement 2019; 5:10. Available at https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-019-0144-4

## How can community organisations support clinical research?



For the health of society, and the integrity of science, we expect medical research to reflect the diversity of human society. For numerous reasons, this is not always the case. But community organisations could hold the solution this. Research has shown that some groups in society are less likely to be involved in research due to issues around:

- Communication on the commitment required, and the benefits of, research
- Awareness of, and referrals to research
- Trust and reciprocity

Historically, participants have been gathered through traditional methods of GP / Consultant referrals and advertisements in GPs and hospitals. However, it is recognised that these methods

often attract 'the usual suspects', who are predominantly white and middle class. To engage a broader range of participants, we need to address the issues above, and this change needs to come from within the research community.

However, it is not easy as a researcher to address the issues above. Particularly when budget and timings are tight, as they nearly always are. It is fair to say that effectively connecting with groups of people, be that South Asian millennials or African-Caribbean grandparents, requires a different type of knowledge, experience, and skill-set.

These can be found in abundance in community and grass root organisations across the UK, who work daily to build relationships and trust, and inspire action to improve people's lives. Unfortunately, many of these organisations are struggling to survive in an environment where government funding is being cut.

Is there a way to foster working between community / grass roots organisations and clinical researchers to make our research system more inclusive, and provide some sustainability and security for these organisations?

Social Action for Health is a charity based in North East London who empower communities to live healthier lives. As an example of their work involving communities in research - the team are currently conducting outreach amongst Pakistani and Bangladeshi populations across East London, raising awareness and collecting DNA samples to support research that aims to fight heart disease, diabetes, and other conditions which are predominant in the South Asian population in London.

The organisation also delivers smaller projects, like their Maternity Voices Partnership, which brings together women across communities who have recently given birth to understand how the maternity services in the area could be improved, which then informs local commissioning and service design.

Across the UK there are many organisations like Social Action for Health, examples include Community Links in London, the BAME cancer communities in Nottingham, and the Basil Skyers Myleoma Foundation. In the US, diversity in clinical research has become a more prominent issue over the last few years, and groups like the MS Minority Research Engagement Partnership Network are driving forward inclusive research, along with platforms like Savvy Cooperative and Antidote who are using technology to reach a broader range of participants.

What sets organisations like these apart is their acute awareness of cultural nuances, and their ability to connect with different groups of people, engage them in their health and research, and build lasting trust and relationships.

It is likely that the pressure on UK researchers to diversify their participant pool will only mount in the coming years. Today, more than 40 million patients are needed in around 300,000 clinical trials worldwide every year, but 85% of trials are discontinued because of patient retention. Community organisations could provide vital support here, but they are massively under-utilised in this space.

So how can researchers work with community organisations to strengthen and broaden participation in research, and in turn provide more opportunity for these organisations to utilise and deliver their skills? These organisations could provide support including:

- Communicating the benefits of being involved in research, through co-creating specifications and materials with different groups

- Raising awareness of clinical research projects, reaching a broad range of participants through community networks, and small focus groups in appropriate settings

- Building trust by engaging with different groups in a way that is respectful and reciprocal

But what are the practical steps that researchers and community organisations can take to start working together? Is this something both sides would value?

We are interested in exploring this further and would really value your time, either through an email with your thoughts, at jackannette0@gmail.com. If you would like to speak in more detail about your experience, or what you would find useful, please don't hesitate to contact me. @NIHRINVOLVE are planning to host a Twitter poll on this topic in the near future.

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## Diversity and inclusion in dementia research

*Lucy Whitman is a writer whose books include Telling Tales About Dementia:*
*Experiences of Caring, and People with Dementia Speak Out.*

Care interventions to support people with dementia from ethnic minorities must be evidence-based to receive funding, but what if research is lacking? Lucy Whitman investigates whether minority ethnic groups are being overlooked by the research community. Read her paper here.

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## 90% of research participants have a good experience

In the 2018/19 Research Participant Experience Survey, 90% of respondents agreed or strongly agreed that they had had a good experience of taking part in research. Five key areas of importance to participants have been identified which will be used to inform study design and delivery in the future. Read the full report here.

## New NHS trust tops clinical research league table for first time in 8 years

The league table is published by the NIHR Clinical Research Network and provides a picture of research activity across all NHS trusts and CCG regions in England. The table data includes how much clinical research is happening, where, in what types of trusts and involving how many patients. Read about it here.

## Over 20,000 research participants recruited through Join Dementia Research

We're pleased to announce that over 20,000 study participants have been involved in vital research thanks to Join Dementia Research, the innovative service delivered by the NIHR. We would like to sincerely thank everyone who has given their time so far. If you haven't already, please sign up, and if you have, please help us spread the word so we can bring more volunteers and researchers together. Read about it here

## Patient, public involvement and engagement (PPIE) Small Grants Scheme: Awards announcement

This round of the Scheme set a focus on applications supporting diversity, inclusion and co-production in public involvement in research. With over 50 applications received from across the network 10 awards were made in August. For further details and to keep in touch with news please visit the site here.

## Lay Research Review Panel

Integrating Patient and Public Involvement into the beginning of sexual health research.

The British Association for Sexual Health and HIV/ Terence Higgins Trust (BASHH/THT ) Lay Research Panel is an important resource for researchers applying for or setting up sexual health research. Most organisations now require patient and public involvement (PPI) to be part of the projects they choose to fund. This is because we know that PPI results in more robust and acceptable research.
Finding people to be involved in sexual health research can be challenging which is why BASHH/THT set up a joint Lay Research Panel. Comprising a diverse range of lay reviewers who have received training in peer review, the panel offers an opportunity for researchers to have their proposal and/or research materials (e.g. participant information sheets) reviewed by the lay panel. The panel can also help recruit lay members for steering groups.
To submit a project for lay review, please go to the panel's website where you can find more information and download an application form.