

Public Involvement and Engagement (PIE) Sub-Group

NIHR Applied Research Collaboration North West Coast (ARCNWC) - Methodological Innovation, Development, Adaptation and Support (MIDAS) theme

SUMMARY

In order for the Public Involvement and Engagement Methodological Innovation, Development, Adaptation and Support (MIDAS) theme to make sure their work and focus was of meaning to researchers, clinicians and members of the public across the region a scoping exercise was conducted between September 2021 and April 2022.

A short online survey aimed to gain insight into public involvement and engagement linked to health research across the region and identify good practice and areas of challenge.

We had responses from 45 people including academics, health professionals, public involvement facilitators and members of the public.

There were many initiatives, groups and programmes of public involvement in health research identified, these were based within NHS trusts, Universities and community groups.

Those who answered the survey felt that the Public Involvement and Engagement sub-group would be most useful by sharing exemplars of PPIE as well as lessons learnt when initiatives have not worked well, by advocating for equality, inclusion and diversity and more community orientated PPIE activities and by collating key guidance over payment processes and infrastructure within institutions.

The main challenges identified in relation to public involvement were the tendency for groups and initiatives to engage with the 'usual suspects' with a need for increased effort to reach out into communities to involve those less likely to be heard and navigating institutional barriers.

The Public Involvement and Engagement in health research scoping exercise

AIM OF THE SCOPING EXERCISE

The initial meeting of the Public Involvement and Engagement Sub-Group as part of the NIHR Applied Research Collaboration North West Coast (ARCNCW) - Methodological Innovation, Development, Adaptation and Support (MIDAS) theme highlighted that we were unsure of how the sub-group could best support researchers, health professionals and members of the public across the region. We were keen not to just rush in and set up a series of online meetings and lectures or develop resources without a clear sense of what people wanted.

As leads for the sub-group Lucy, Beccy and Riz felt it was important for the work of the sub-group to be of value and meet the needs of those working in health research across the North West Coast; whether as a researcher, health professional, member of the public, charitable organisation or engagement worker.

THE ONLINE SURVEY

We developed a short online survey administered through Microsoft Forms to ask people across the region what they thought the sub-group should focus on and to identify areas of good practice and what barriers there are to meaningful Public Involvement and Engagement across the region.

The survey was distributed via a flyer (Figure 1) on professional social media accounts and through the Applied Research Collaboration distribution lists.

We were keen to reach as many people and gain as many views as possible.



Figure 1; the flyer used to promote the survey

Respondents and the reported public involvement and engagement activity across the region

THE PEOPLE WHO RESPONDED

We had responses from 45 people including academics, health professionals, public involvement facilitators and members of the public (see Figure 2)

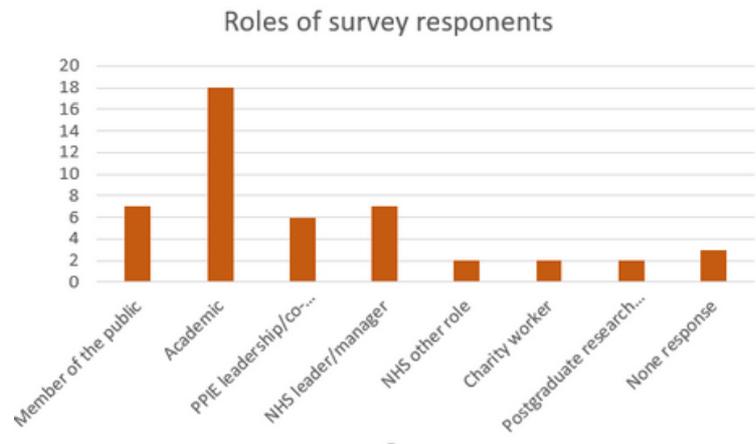


Figure 2 The survey respondents

PUBLIC ENGAGEMENT PRACTICE REPORTED ACROSS THE REGION

There were many initiatives, groups and programmes of public involvement in health research identified, these were based within NHS trusts, Universities and community groups.

There were 15 public involvement groups named housed within **NHS services** including primary and secondary care services. Some of these groups were condition orientated e.g. dementia, autism and some had a broader remit e.g. children and young people.

There were 8 public involvement groups named which were housed within **Universities** across the region.

There were 7 public involvement groups named which were **user-led organisations and/or charitable organisations**.

There were 6 public involvement groups named which were organised as part of **regional research networks** e.g. ARC, Liverpool Health Partners.

Some respondents named advisory groups established as part of specific research projects or engaging with the public from **national advocacy or patient forums**.

What could the sub-group focus on to benefit public involvement and engagement activity across the North West Coast region?

There were many and varied responses from those who answered the survey about what the Public Involvement and Engagement sub-group should focus on.

Networking and showcasing

Responses identified the need to create opportunities to **share exemplars of PIE** as well as providing opportunities to hear about lessons learnt when initiatives have not worked well. This was seen as helpful in raising the profile of PIE occurring across the region but also for facilitators of public engagement from the region to meet and share their experiences. Opportunities to network and collaborate would aid mentorship of less experienced colleagues whilst also providing a safe space to share 'real world' cases where despite best intentions PIE initiatives have not worked as planned or as well as they should have.



"Sharing good news stories but also sharing where things have not gone so well and what improvements have been implemented"

Respondents highlighted that more could be done to showcase exemplars of inclusive PIE, highlighting engagement work which has managed to "reach out more widely" through case studies. Facilitation of an open and honest conversation about how public involvement practice can move forward alongside and top tips for others would be useful for other researchers and public involvement facilitators.

What should the sub-group focus on to benefit Public Involvement and Engagement activity across the North West Coast region?

Wider inclusion and equitable access to involvement and engagement activities

The lack of diversity and inclusion was linked to specific patient populations, geographical areas within the region as well as certain community groups. Responses indicated that PIE can be tokenistic and there remains a need to challenge some accepted practices and ways of working. Responses highlighted the important role of the sub-group in advocating for equality, inclusion and diversity and more community orientated PIE activities across the region. Many respondents discussed that many groups, networks and panels consisted of the "usual suspects" and this limited the diversity of views and experiences which are informing research across the region.

Respondents commented that research should be driven right from the beginning according to community priorities and involvement activities and research need to be designed to make sure that they are accessible, appropriate and participatory, Whilst there are some great examples of this happening across the region, more needs to be done to promote this work and show different approaches to PIE.

Some comments identified that there was an increased need for public involvement and engagement activities to be evaluated, this would help highlight where "deep PIE" rather than tokenistic opinion had been taken place and how this had impacted on all those involved.

"There needs to be more done to engage with existing established community organisations to develop networks and gain insight into communities. People need to hold meetings out in the community to involve people who would not normally be involved"

What should the sub-group focus on to benefit Public Involvement and Engagement activity across the North West Coast region?

Building capacity and skills in relation to public involvement and engagement in health research

Responses indicated that whilst the North West coast region included programmes of involvement and engagement work which is nationally recognised, there was a need for further work to equip members of the public and professionals in important skills. Respondents reported that a skills audit to identify what is missing from the workforce in terms of roles, skills and competencies would help the region identify where investment should be focussed. Respondents reported there was a need to build capacity and a "*large pool of interested and accessible people*" to facilitate the full spectrum of PIE activity.

There was seen to be areas within the region where there was strong pockets of PIE work, but some areas which needed to be developed. These were identified as linked to geographical areas e.g. South Cumbria, Blackpool and also with certain communities of people e.g. neurodiversity.

As well as focussing on the skills of researchers and health professionals who lead and are involved in public involvement work, respondents also identified the need to explore how to educate members of the public so that they feel confident to take part and ask relevant questions. This training currently is often 'ad hoc' and delivered to a variable standard.

"Explore how to educate people participating as public advisors so that they feel confident to take part and ask relevant questions"

What should the sub-group focus on to benefit Public Involvement and Engagement activity across the North West Coast region?

Tackling infrastructure and processes

Responses indicated that it would be useful to have a way to share, collate key guidance and explore processes within and across institutions for paying and rewarding public involvement. The infrastructure within some institutions was described as burdensome and it was felt that some shared learning could occur around overcoming these.



Whilst there is national guidance and resource to guide those involved in PPIE activities, respondents felt that some practical top tips and sharing of how difficult bureaucracy can be successfully navigated would be useful. There was an identified need for clear policies for organisations on how to recruit, retain, train, support, and most importantly pay people in ways that are inclusive and transparent.

Payment processes were identified as a key barrier and challenge to supporting people to become meaningfully involved and it was felt by some respondents that payment processes and involvement scheme policies have not kept pace with the changes within public involvement work.

"Currently it can be difficult to involve people and pay them. We are having to register them as employees, which requires, passport, NI number, bank details etc. it also raises a lot of concern for people on benefits who don't know what happens to this information and where it goes and if there is a risk they could lose their benefits. We need clear guidance that combines NIHR guidance, HMRC requirements, but is written in plain English so researchers and PPI people can easily follow it."

What are the barriers to meaningful Public Involvement and Engagement in health across the North West Coast region?

Lack of wider inclusion and equitable access to involvement and engagement activities

There are a number of challenges that those responding to the survey felt can create barriers for meaningful PIE in health research across the North West Coast region.



As highlighted in the previous section, the most common response was linked to a sense that whilst there was a range of public involvement programmes and initiatives happening across the region these did not always engage with those less able or likely to join in and attend formal meetings. Respondents commented that many community members may not be aware of opportunities to engage or feel that PIE activities were "*not for people like me*", either being focussed within certain geographical areas e.g. Liverpool or certain groups of people.

This was seen to lead to the "*tokenistic involvement of few individuals that get involved and who are not representative of the population*", these comments mirror previous responses around what the PIE MIDAS sub-group could focus on to raise the agenda of inclusive PIE in health research.

"We need to re-think our academic approach to consider new ways to engage and find out what communities want! We still expect people to come to us"

Respondents wrote about the need to reconsider ways of working to move from an academic rigid approach to a more flexible collaborative community approach to PIE. These more inclusive practices were seen as having merit in breaking down barriers to meaningful PIE.

What are the barriers to meaningful Public Involvement and Engagement in health across the North West Coast region?

Lack of sustainability and institutional commitment

Many of the responses identifying barriers to meaningful PIE activity across the region were linked to the challenges of ensuring sustainable involvement and engagement practices.



Funding 'pots' were often only available for short-term initiatives with little space and time to build strong working relationships with groups of people or maintain these groups in the longer term. It was reported as difficult financially to maintain groups following the end of a project and maintaining contact and working relationships was not always prioritised by institutions. The often rigid structures within health services and especially Universities as well as a lack of true commitment to public involvement could create challenges for researchers wanting to build relations over a longer period of time with community groups. Good will and personal commitment was often required to 'prop up' under funded and under recognised public involvement activities.

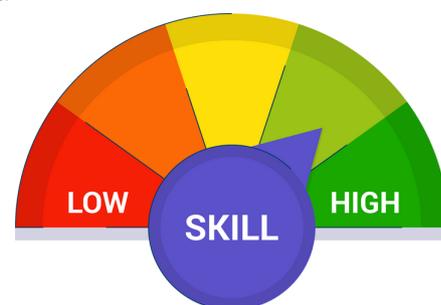
The lack of a long-term plan of ways to work with members of the public was reporting to difficulties in accessing people to gain their views at short notice and PIE activities being reactive rather than proactive and community led. This was also commented on in relation to the grant-making bodies, who were perceived as having expectations but short lead in times which did not always facilitate meaningful PIE.

"Institutions and grant awarding bodies don't allow time for proper PPI in research grant development leading to PPIE being done 'on the hoof'."

What are the barriers to meaningful Public Involvement and Engagement in health across the North West Coast region?

Lack of capacity and capability

Several of the respondents identified that there was a need to build PIE skills, experience and confidence in the workforce across the region. Some of the points relating workforce development link directly to previous sections highlighting the need to build new ways of working; equipping researchers with the skills and confidence to work in a more collaborative and community orientated way.



Respondents identified that there was a need for increased training and understanding around the use of creative methods within engagement and involvement activities as well as building capability around evaluating the practices and impact of PIE work. It was also identified that there is a need to build capability around understanding the differences between engagement, involvement and coproduction.

In relation to earlier responses around the lack of inclusive PIE practices, it was felt that there needed to be more trained PIE facilitators who had the skills and could work in a meaningful way with diverse populations. The need to build capacity "*beyond those usually leading PIE*" was identified.

"We need more skilled facilitators, but building the workforce to be more diverse."

There were different levels of training and awareness building mentioned by respondents to overcome challenges. These ranged from a need to build general awareness of the merit of PIE and different models of working to more focussed training for those more heavily involved in public involvement and engagement. There was a recognition that whilst meaningful PIE was often associated with a specific skill set, it shouldn't be seen as "*somebody else's job*".

Thank you!!

Thank you to the researchers, health professionals, academics and members of the public who completed the survey and shared their views.

**This scoping exercise and short report was written by
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