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Community Research Engagement Network (CREN): helping communities understand the benefits of engagement and participation in research. A participatory community perspective of engagement in research. By Lily Keck, Claudia Sykes and Dr. Nagina Khan

Posted on May 2, 2024 by mthompson

Why is it important to work together to involve and engage communities in research?

It is very important to understand what public involvement means. It has been defined by INVOLVE, the national advisory group that supports public involvement, as "Research being carried out **'with'** or **'by'** members of the public rather than 'to', 'about' or 'for' them.

The public can contribute to research in a few distinct ways:

- **Engagement** – where information and knowledge about research is shared with the public and
- They are involved in **all stages of the research process**.
- Most importantly, it is a **two-way process**.
- **Participation** – is then a process where people take part in a research study.

In the past we have excluded groups that have been deemed 'hard to reach'. Due to certain communities being labelled in this way, they are infrequently approached, excluded by the system, and consequently are less likely to engage with health and care research. This has been to the detriment of many groups who were and are in need of appropriate and timely health and social care services as they may have been impacted by the wider social determinants of health. Therefore, being able to engage with those who are facing health inequalities is crucial for achieving health equity, tailoring interventions, informing policies, and having better representation in health and care research for impacting better and positive health outcomes for the whole of society and individuals that make up those diverse communities. For example, as part of the NIHR's Be Part of Research, Alka Pandey took part in the LOLIPOP 100K study at Wycombe Hospital in Buckinghamshire. The study invited people of South Asian heritage to undergo tests to help researchers understand why conditions such as heart disease and diabetes are more common in this group. Alka has a family history of type 2 diabetes, and felt the study gave her a route of getting her risks checked and helped her feel reassured about her own health. She has now also shared it with family and friends to encourage them to take part in it for better health in the future.

Furthermore, community engagement in research is important for researchers and the wider research community at large, as it can generate new research questions or fresh insights into research challenges, improve the relevance and quality of research, as well as increase visibility for both the research and the researcher's profile. The main aim of researchers is to help their communities and the individuals who reside in them; therefore, meeting the original aspirations of the researcher and research teams undertaking such collaborative approaches to their work.

Involvement and participation of communities is important, as a broad range of participants means results are generalisable to a broader population. So, if an intervention has not been tested with different groups, it's possible it will not be effective for a cross section of the population and everyone that needs it.

The principle of "no decision about me, without me" means that under-served groups should be included in research, so that decisions reflect their needs too.

Using an asset-based approach to help with public can be incredibly powerful, as provisions are being built on existing resources and strengths within the community. Being able to tackle low levels of participation in research and support communities in gaining better health outcomes starts with understanding the differing needs of each of those communities, empowering individuals, and co-producing solutions.

How we are doing it?

The Research Engagement Network Development programme is a multi-partner project with the University of Kent, the National Institute of Health and Care Research (NIHR), Kent and Medway ICB and Kent County Council. The aim of the programme is to increase engagement and participation in research by local people in Kent and Medway, and to develop a Community Research Engagement Network.

They key element of this programme is that is led by the Voluntary, Community, Social Enterprise (VCSE) sector. Building on the knowledge and skills in community engagement within the VCSE sector, each organisation that is leading in their geographic area are working with key voices from their local communities, to be trained and supported in research skills.

These engagement events explore the benefits of engagement and participation in research with different communities and hearing from diverse voices. From this, we hope to enlist the trusted advocates from the local community that attend, to be trained and supported in research skills. The idea is advocates can take their learnings back to their communities to spread the awareness and importance of engaging with research, hopefully creating a more sustainable impact.

Community research advocates also commit to attending Community Research Engagement Network (CREN) meetings. The aim for the CREN meetings is a "community of practice" model – bringing together academics, research teams and advocates to share ideas, discuss issues and barriers in participating in research, as well as a space to promote existing and upcoming research projects.

Why and what was good, any the downfalls to look out or prepare for?

We found that some simple steps that work as well as any great strategies is that researchers need to be updating the communities they are working with throughout the entire research process. Especially after they have been involved in a project, and that includes reporting of the results, publications and feeding back and giving back to the individuals so that they do not feel like external helpers.

If certain communities aren't kept informed of how their opinions and input is being used within the research project, it runs the risk of being tokenistic. This will certainly result in further instances of negative experiences which will lead to communities disengaging in research all together, as the incentive and motivation will likely be reduced or entirely removed. Hence as we started this blog by saying 'true engagement is a two-way process' that needs consistent communication and checking in to see that the fundamental steps of engagement and involvement are being adhered to (Rosen, 1979).

There also runs a risk of over engaging and the process becoming prescriptive with certain groups that are engaged and re-engaged with, and as a result losing their interest. This prevents access to individuals that do not ordinarily wish to engage with research and that we never likely hear from.

Throughout this programme, we have recognised the value each individual brings when they give up their time to participate in the training sessions and network events held through offering participation payments. This can be through paying for their time in taking part, gift vouchers, covering travel expenses, childcare costs, translation costs etc. This is something that more researchers should implement as best practice, as it incentivises participation in addition to showing a better understanding that the communities they are trying to engage with will be valued and appreciated for their time in taking part.

What did we learn?

To summarise, the importance of working collaboratively to involve and engage communities in health and care research cannot be overstated. By following the principles of public involvement and participation, researchers can ensure that their work is not only inclusive but also reflective of the diverse needs and perspectives of the communities they serve.

Programmes like the Research Engagement Network Development programme demonstrate the need for partnership working and community-led efforts in promoting a culture of research engagement. Although, it is important to recognise issues around tokenism and over-engagement, and instead aim for more genuine, two-way communication that sustains meaningful involvement throughout the research process. By prioritising inclusivity and collaboration, this will lead researchers to have more impactful work, improving the relevance and quality of their research outcomes.

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Authors

Lily Keck

Lily Keck is the Health Equalities Lead at Social Enterprise Kent. She oversees projects looking to reduce health inequalities for people in east Kent as well as improve relationships between the Voluntary, Community, Social Enterprise Sector and Public Sector. She graduated from the University of Kent in 2022 with a BA (Hons) in Criminology with Quantitative Research & enjoys data analysis in a social research capacity.

Claudia Sykes, OBE

Claudia spent ten years as chief executive of a Kent social enterprise, where she led many programmes helping vulnerable people in the community. Claudia was awarded an OBE in 2021 for her services to social enterprise and social care. Prior to this, Claudia, a qualified accountant, worked in senior management roles in the private sector, including Shell and BT.

Dr. Nagina Khan, BHSc, PGCert, Ph.D.

Nagina is a Senior Clinical Research Fellow in Primary Care, Centre for Health Services Studies (CHSS), Division of Law, Society and Social Justice, School of Social Policy, Sociology & Social Research, University of Kent. She is the CHSS PGR Lead (interim) and Director of the MSc Applied Health Research Programme, University of Kent.

Nagina's current research supports the Integrated Care Systems (ICS) to capitalise on emerging existing networks in its research duty and mitigate the current risk of future research being conducted in silos and without focus on priorities and underserved populations. This work will diversify the public voice listened to and strengthen ICS strategic links within local research infrastructure to support evidence-based practice, apply solutions, and spread innovation.

Nagina was a senior postdoctoral researcher and Visiting Researcher, Department of Psychiatry, University of Oxford. She has worked as a Scientist at Centre for Addiction and Mental Health (CAMH). Nagina also worked with Touro University Nevada, Las Vegas, US, and with the Royal College of Psychiatrists. Nagina was a Medical Research Council (MRC) Research Training Fellow, her research was centred on complex interventions for people with depression, University of Manchester. Her post-doctoral studies were undertaken at the NIHR School for Primary Care Research, UK focusing on First episode Psychosis in young people using Early Intervention Services. Nagina's research interests include Medical Education, Professionalism, Social Justice in Healthcare, Complex Interventions for Depression, First episode Psychosis in Young People, Culturally Appropriate Mental Health Care, Women's Mental Health, Incentivisation Schemes (P4P) in Healthcare for HICs and LMICs and Global Health. Nagina is the Associate Editor at BMJ Mental Health, she is also the BMJ Leader Editorial Fellow and was an Editorial Board Member of the BioMed Central Medical Education Journal.

Declaration of interests

We have read and understood the BMJ Group policy on declaration of interests and declare the following interests: none.

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