Putting research on everyone's agenda

By members of the National Institute for Health Research (NIHR) Diabetes Research Network Patient and Public Involvement (PPI) Working Group*

Engaging people in clinical research is high on the National Institute for Health Research (NIHR) Clinical Research Network's agenda and has been since its formation in 2005. In the NIHR Diabetes Research Network (DRN), raising public awareness of diabetes research is a key activity within our patient and public involvement programme.

The public has a right to participate in research and, thankfully, traditional barriers that have previously prevented people accessing research information are coming down. Initiatives like the UK Clinical Trials Gateway (www.ukctg.nihr.ac.uk/default.aspx), the NIHR-hosted website that will soon be the best way to search for information about clinical trials in the UK, are leading the way in making this information available.

Within the DRN, we coordinate a variety of community events and initiatives, aimed at making research more accessible and highlighting opportunities for people affected by diabetes to become actively involved. One example of the involvement on offer is to work with the local DRN lay reference panels, through which people affected by diabetes offer their perspectives to the design and delivery of studies that we support.

In 2012 we published examples of our engagement activities in a report 'Improving Public Awareness of Clinical Research' (www.ukdrn.org/ppi/articles.aspx). In this, we examined each activity and reflected on what worked well, and

the benefits and difficulties that we faced in delivering these initiatives.

DRN public engagement Our regional centres organise a variety of events, including Open Days that allow people to come and meet the team, and hear some of what is happening in their area. Regional Introductory Days have a more structured format that includes presentations on how research works, as well as ways of becoming actively involved.

We also coordinate Information Stands at a range of healthcare and community events, often marking awareness days, such as:

- International Clinical Trials Day (20 May)
- Diabetes Week (second week in June)
- World Diabetes Day (14 November).

Other activities aim to raise awareness among minority ethnic communities. We have been fortunate to be invited to religious festivals and cultural celebrations to discuss how research benefits individuals and communities.

Another innovative method was the use of small DRN cards, which were added to all prescription bags containing diabetes medications. To pilot this initiative, we worked with the local DRN lay panel to design the cards, and collaborated with cooperating pharmacies in one London borough to disseminate them.

A local DRN centre also worked closely with its host NHS Trust to produce a mural in the reception that highlighted the benefits and successes of diabetes research in the area.

DRN engagement workshop at INVOLVE 2012 Conference

The ‘Improving Public Awareness of Clinical Research’ report also supported the delivery of an engagement workshop at the 2012 INVOLVE Conference in Nottingham. This included presentations about local DRN activities and talks

from Natalie Ellis and Peter Donnelly, patient advocates who work with two of the local DRN lay reference panels.

Delegates were encouraged to share their experiences of engaging the public, and a number of initiatives and examples of good practice were raised:

- the Stem Ambassador Programme (http://tinyurl.com/ajd3oe8) at the NIHR Birmingham Liver Research Unit reaching young people and their parents to address the misconception that liver disease is self-inflicted
- research nurses hosting local 'Living with Diabetes' days
- overcoming the difficulties in reaching some minority ethnic communities by meeting with them, rather than posting leaflets or literature
- making available audio versions of research information for those with visual impairment
- working with religious leaders or respected members of communities who have influence over some minority ethnic populations
- working with health educators in prisons to reach this seldom-heard community
- developing 'common threads' among seldom-heard communities to avoid the dilution of activities aimed at single communities
- using 90-second clips on YouTube with researchers talking about their study
- using 'new media' reaches a wider audience than is often anticipated.

Other issues discussed included why people in certain age groups do not engage with healthcare professionals, and the difficulties in reaching people in some rural communities.

Improvement ahead

Clinical research needs to increase its visibility and improve the way that it engages members of the public. The NIHR is looking at methods of developing better information in more accessible formats. But there is still much to do. Members of the public still find it difficult to access clear information about studies in which they might like to participate, and struggle to find opportunities to become actively engaged in topics that are of interest to them.

For any research organisation to successfully engage the public, it is vital to have resources, a flexible approach, and enthusiastic staff with the will to include the public in all its activities, creating a partnership that satisfies everyone involved.

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