Testing the Standards for Public Involvement in Research

Lay Report from the Northern Ireland Cerebral Palsy Register, December 2019

Test bed project for the public involvement standards:

Northern Ireland Cerebral Palsy Register (NICPR), Queen’s University Belfast

Claire Kerr, Senior Lecturer
Helen Savage, NICPR Public Representative
Karen McConnell, NICPR Research Fellow
The **Northern Ireland Cerebral Palsy Register** (NICPR) has been running for over 25 years and has always had input from people with the condition and their families. In 2018 the NICPR was one of ten ‘test-bed’ projects across the UK that was selected by the National Institute of Health Research to pilot new draft Standards for Public Involvement in Research. The standards are a set of statements that describe what good public involvement in research looks like. Together they provide a framework for improving the quality and consistency of public involvement in research. During the pilot phase (April 2018-May 2019), the NICPR tested three of the six Standards. The table below summarises NICPR aims and activities for each of the Standards.

<table>
<thead>
<tr>
<th>NIHR Standards</th>
<th>NICPR Aim/Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. INCLUSIVE OPPORTUNITIES</strong>&lt;br&gt; We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.</td>
<td>Create a PI group of adults and young people with cerebral palsy and their family, carers and friends. Collaboratively determine terms of reference, activities and training needs of PI group.</td>
</tr>
<tr>
<td><strong>2. WORKING TOGETHER</strong>&lt;br&gt; We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.</td>
<td></td>
</tr>
<tr>
<td><strong>3. SUPPORT &amp; LEARNING</strong>&lt;br&gt; We offer and promote support and learning that builds confidence and skills for public involvement in research.</td>
<td></td>
</tr>
<tr>
<td><strong>4. COMMUNICATIONS</strong>&lt;br&gt; We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.</td>
<td>Develop flexible, jargon-free communication methods to meet the needs of different audiences.</td>
</tr>
<tr>
<td><strong>5. IMPACT</strong>&lt;br&gt; To drive improvement, we capture and share the difference that public involvement makes to research.</td>
<td>Record and monitor PI activity and develop standardised evaluation processes</td>
</tr>
<tr>
<td><strong>6. GOVERNANCE</strong>&lt;br&gt; We involve the public in our governance and leadership so that our decisions promote and protect the public interest.</td>
<td></td>
</tr>
</tbody>
</table>
**Timeline of ‘Test-Bed’ Activities**

The diagram below summarises the activities carried out by the NICPR during the ‘test-bed’ project.
‘Test-bed’ Journey in Pictures

During April 2018-May 2019, the NICPR team piloted the National Institute for Health Research (NIHR) draft UK Standards for Public Involvement in Research.

On 23rd April 2018, the NIHR hosted a workshop in London for the 10 ‘test-bed’ projects that were selected to pilot the Standards. Following this workshop, the NICPR launched and promoted a new NICPR community mailing list for people with CP, their family, friends and carers.
The mailing list was used to plan and host the first public event, a family coffee morning, to tell people about the NICPR and find out if anyone was interested in joining a new Public Involvement Group.

Following a successful family coffee morning, Helen Savage (NICPR Public Representative) filmed a promotional video about the importance of public involvement and the NICPR organised a poster display to engage with nursing students about cerebral palsy.
The NICPR team shared their experiences of using the Standards to (i) the Surveillance of Cerebral Palsy in Europe Network, (ii) colleagues at Queen’s University Belfast, (iii) the Public Health Agency’s Shared Learning Group of voluntary sector organisations, (iv) the 31st European Academy of Childhood Disability conference, and (v) the 73rd Annual American Academy of Cerebral Palsy and Developmental Medicine in Anaheim conference.

In January 2019, the NICPR Public Involvement Group held their inaugural meeting to discuss meeting etiquette, develop terms of reference for the group and identify training needs for public members.

Karen McConnell and Claire Kerr presenting a poster at the American Academy conference

NICPR Public Involvement Group L-R: Claire Kerr, Sharon Campbell, Monica Acheson, Karen McConnell
In May 2019, the NICPR launched a new ‘Get Involved’ section on their website, and the NIHR held the final workshop to allow ‘test-beds’ to share their experiences of using the Standards. During discussions and presentations a live illustrator summarised the activities that had been completed.

Final UK Standards for Public Involvement were launched on 18th November 2019 by the NICPR team and Public Health Agency. At this launch Helen Savage highlighted that public involvement “can contribute to high quality research to improve the lives of people with cerebral palsy, now, and in the future.”
Did we meet our aims?

Standard 2, ‘working together’ was achieved during the ‘test-bed’ period and resulted in the creation of a dedicated Public Involvement Group. This Group currently comprises two researchers, one adult with CP and one parent of a young child with the condition. The Public Involvement Group had two formal meetings during the ‘test-bed’ phase to: (i) develop their terms of reference and (ii) identify training needs for public members.

Standard 4, ‘communications’, was only partially achieved during the ‘test-bed’ period, due to governance regulations and legal requirements related to data protection, which delayed creation of the Public Involvement group. Within the ‘test-bed’ project, the Public Involvement Group revised the NICPR’s Privacy Notice to reduce the amount of legalese, and agreed content for a new ‘Get Involved’ section on the NICPR’s website. The NICPR team is working with a public member to further develop information resources for families and children with CP.

Standard 5, ‘impact’, was not achieved during the ‘test-bed’ period. Development of standardised evaluation processes was delayed due to the length of time required on Standard 2, and will be addressed by the Public Involvement Group.

Next Steps...

The NICPR is planning to use the new Standards for Public Involvement as a framework for all future research and public involvement activities. The NICPR Public Involvement Group will continue to (i) advise on engagement and public involvement of persons living with CP, their families and friends, and (ii) help guide the direction of NICPR research. For more information on the Group’s objectives for 2019/20 please click here.
The NICPR would like to thank Helen Savage for her invaluable contribution to this project.

Contact us:

Telephone: 028 9097 1616

Email: nicpr@qub.ac.uk

Website: https://www.qub.ac.uk/research-centres/northernirelandcerebralpalsyrегистerv

Postal Address:

Northern Ireland Cerebral Palsy Register
School of Nursing and Midwifery
Room 1.36 Mulhouse Building
Queen's University Belfast
Grosvenor Road
Belfast BT12 6DP