

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**



NATIONAL STANDARDS
for PUBLIC INVOLVEMENT

Claire Kerr, Senior Lecturer

Helen Savage, NICPR Public Representative

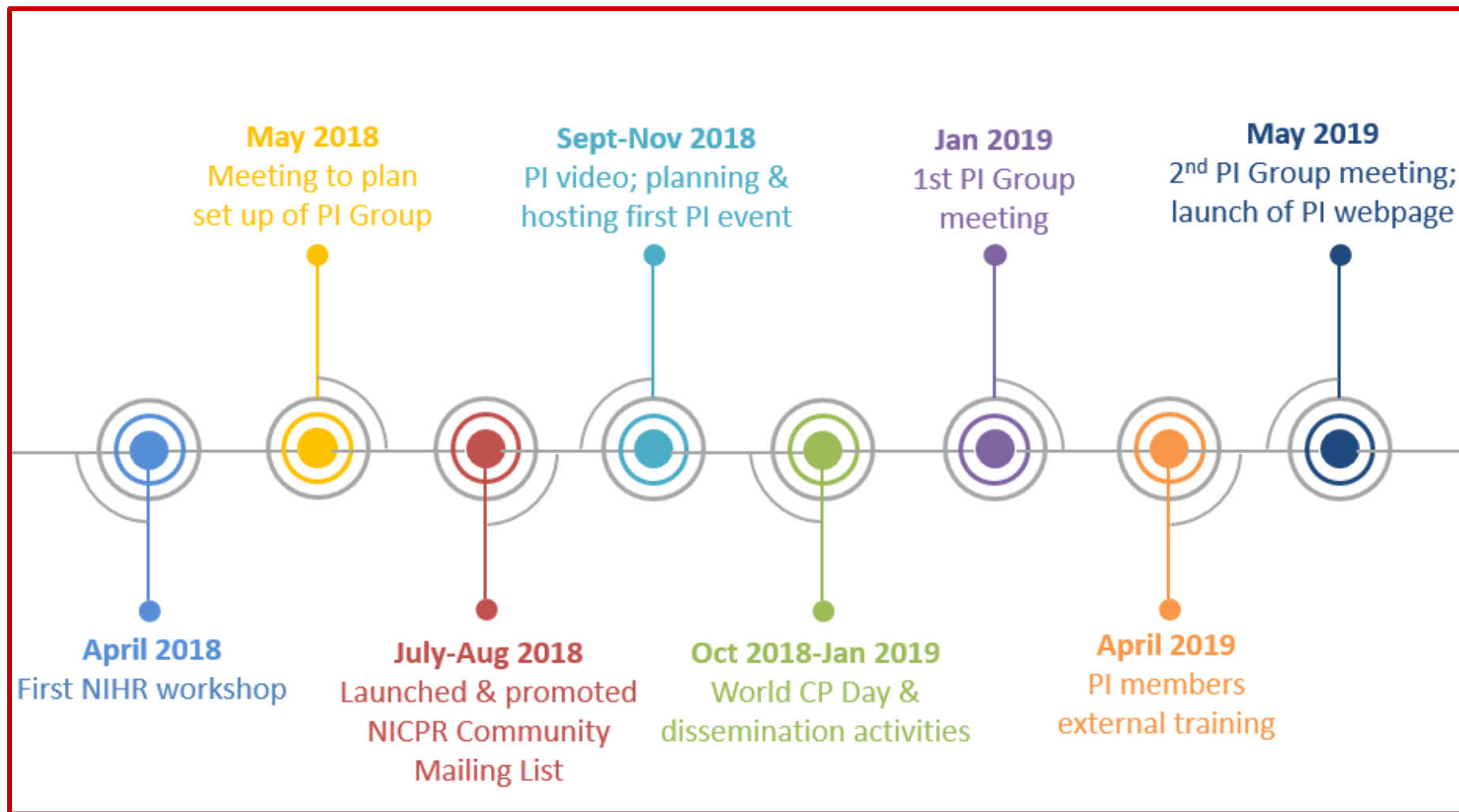
Karen McConnell, NICPR Research Fellow

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.

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

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.

NICPR

Please subscribe to the Northern Ireland Cerebral Palsy Register (NICPR) community mailing list by completing the form below. By subscribing you will receive emails about NICPR news, events, research and how you can get involved with our work. We look forward to hearing from you and working together to make sure cerebral palsy (CP) research is relevant and useful to those who need it. Thank you!

Please note personal details will be held by MailChimp and not passed on to any third parties.

Email Address

First Name

Surname

NICPR community mailing list sign-up form

go.qub.ac.uk/NICPR' and contact information: 'If you have any questions or would like more information please contact us by email at nicpr@qub.ac.uk or telephone 028 9097 1616.' The flyer also features statistics: '2 in 5 Children with CP are born prematurely', '3 in 5 children with CP are born at normal birthweight (2,500g or more)', 'Gross Motor Function', 'Hearing impairment 1 in 10 have hearing impairment', 'Communication impairment 1 in 2 have problems with communication', and 'Feeding problems 1 in 4 have feeding problems'. It also includes a pie chart showing '88% have intellectual disability', '12% have no intellectual disability', and '88% have no intellectual disability'. The flyer ends with the 'Aims of the NICPR:' and logos for Queen's University Belfast, Northern Ireland Cerebral Palsy Register, HSC Public Health Agency, and Shaping a Better World Since 1845."/>

Cerebral Palsy Community Mailing List

The Northern Ireland Cerebral Palsy Register (NICPR) invites you to join a community mailing list for persons with cerebral palsy, their families, friends and carers. We will use this mailing list to email NICPR news, events, research and ways to become involved with our work.

If you would like to subscribe please visit following link: <http://eepurl.com/ds--Hj> or scan the QR code.

If you change your mind you can unsubscribe at any time.

The NICPR is managed by researchers at Queen's University Belfast in collaboration with the Public Health Agency. For more information on the NICPR please visit our website: go.qub.ac.uk/NICPR

If you have any questions or would like more information please contact us by email at nicpr@qub.ac.uk or telephone 028 9097 1616.

2 in 5 Children with CP are born prematurely.

3 in 5 children with CP are born at normal birthweight (2,500g or more).

Gross Motor Function

Hearing impairment 1 in 10 have hearing impairment.

Communication impairment 1 in 2 have problems with communication.

Feeding problems 1 in 4 have feeding problems.

Aims of the NICPR:

- to establish a systematic approach to the surveillance of CP among children in NI
- to support research and audits into the condition, covering causes, treatment, assessment and health and social care service provision

QUEEN'S UNIVERSITY BELFAST | NORTHERN IRELAND CEREBRAL PALSY REGISTER | HSC Public Health Agency | SHAPING A BETTER WORLD SINCE 1845

NICPR community mailing list promotional flyer

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.

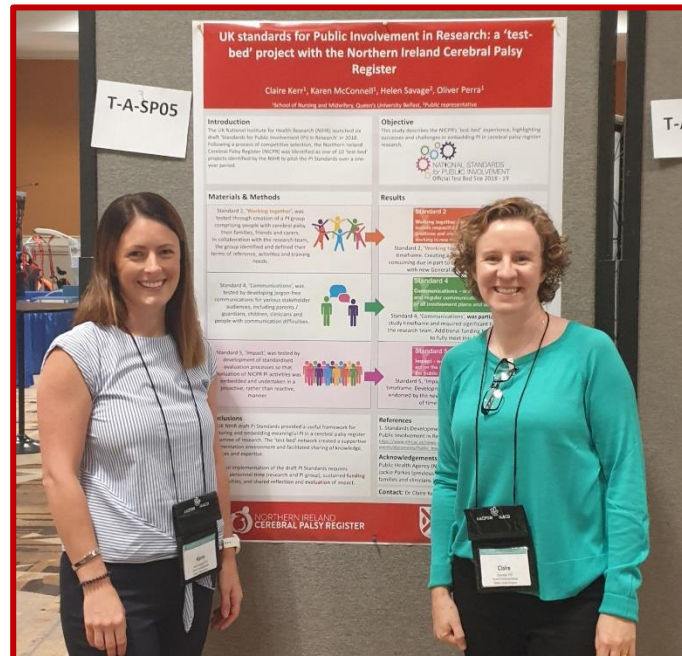


Helen Savage, NICPR Public Representative



Nursing students at the NICPR poster display

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.



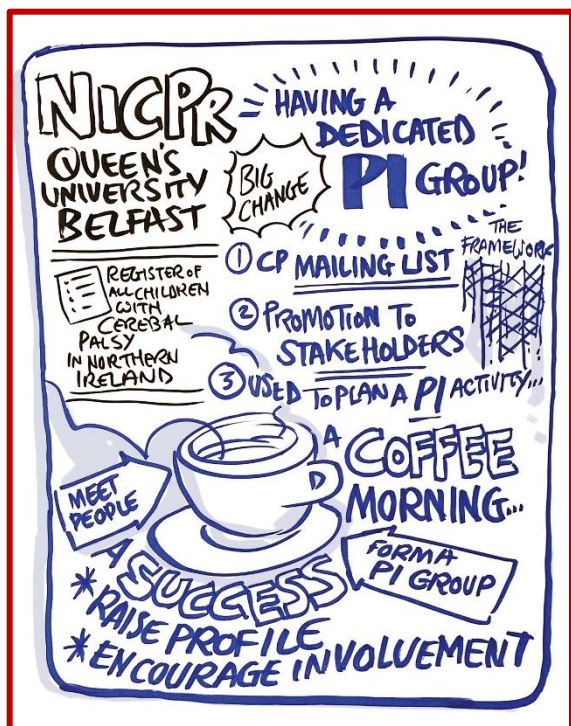
Karen McConnell and Claire Kerr presenting a poster at the American Academy conference

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.



NICPR Public Involvement Group L-R: Claire Kerr, Sharon Campbell, Monica Acheson, Karen McConnell

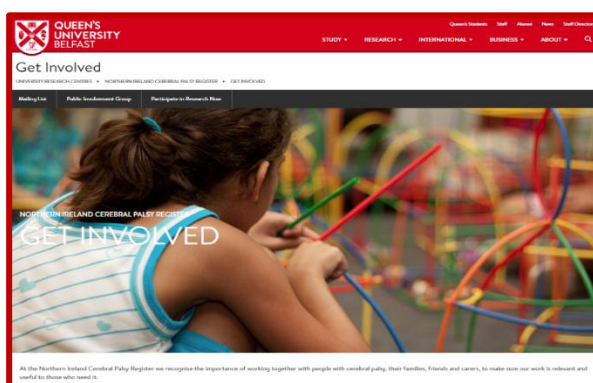
In May 2019, the NICPR launched a new '[Get Involved](#)' section on their website, and the NIHR held the final workshop to allow 'test-beds' to share their experiences of using the Standards. During discussions and presentations a live illustrator summarised the activities that had been completed.



Summary of NICPR experiences and activities



Simon Denegri presenting a certificate of participation to the NICPR team



New 'Get Involved' section on NICPR website

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.*"



Claire Kerr, Helen Savage and Martin Quinn (PHA)

Did we meet our aims?

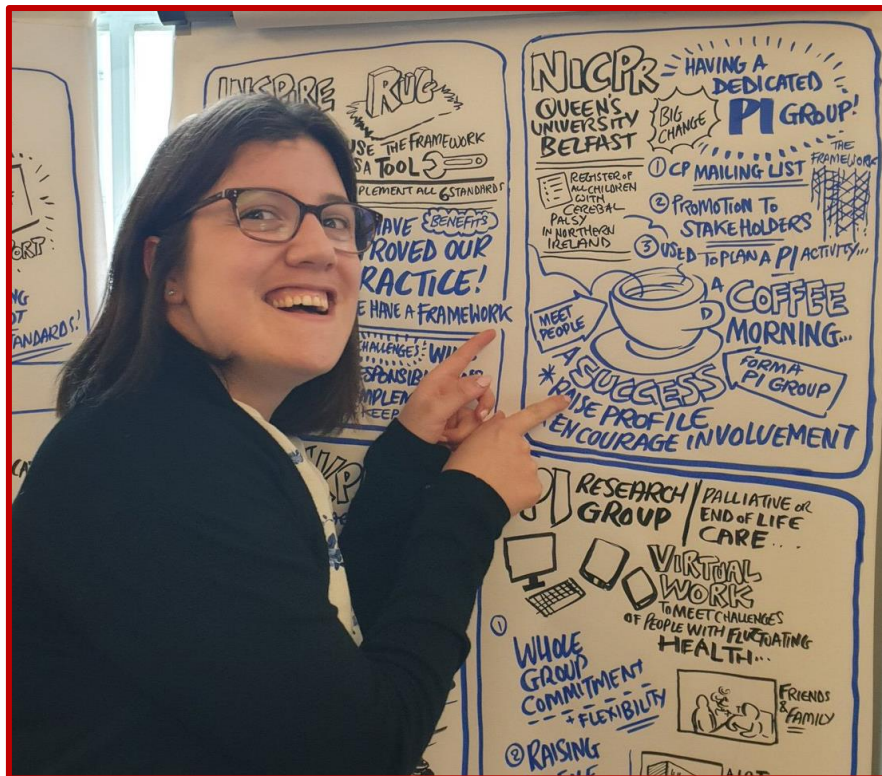
Standard 2, 'working together' was achieved during the 'test-bed' period and resulted in the creation of a dedicated Public Involvement Group. This Group currently comprises two researchers, one adult with CP and one parent of a young child with the condition. The Public Involvement Group had two formal 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:

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Email: nicpr@qub.ac.uk

Website: <https://www.qub.ac.uk/research-centres/NorthernIrelandCerebralPalsyRegister/>

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