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ESTD 1845

SCHOOL OF
NURSING AND
MIDWIFERY

NORTHERN IRELAND
CEREBRAL PALSY REGISTER

Piloting UK Standards for Public Involvement in Research:

The Northern Ireland Cerebral Palsy Register 'test-bed' experience

Claire Kerr, Karen McConnell & Helen Savage

11th June, 2019

Cerebral Palsy is a wide-ranging condition

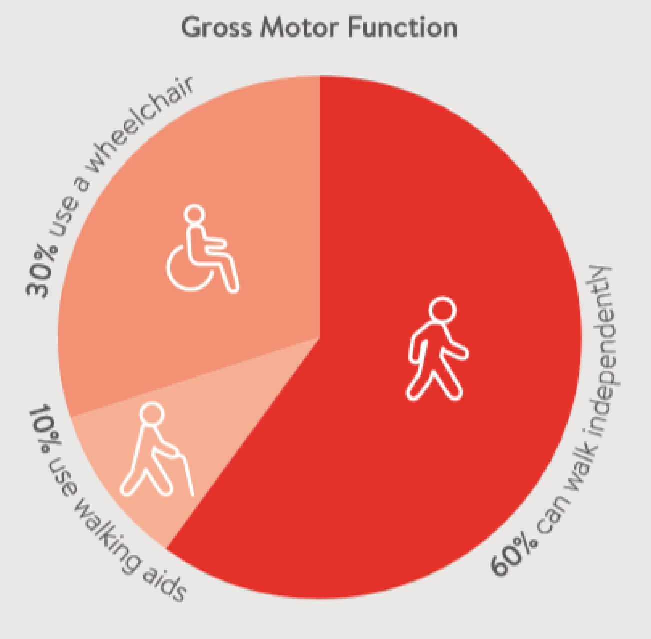
Jason Smyth

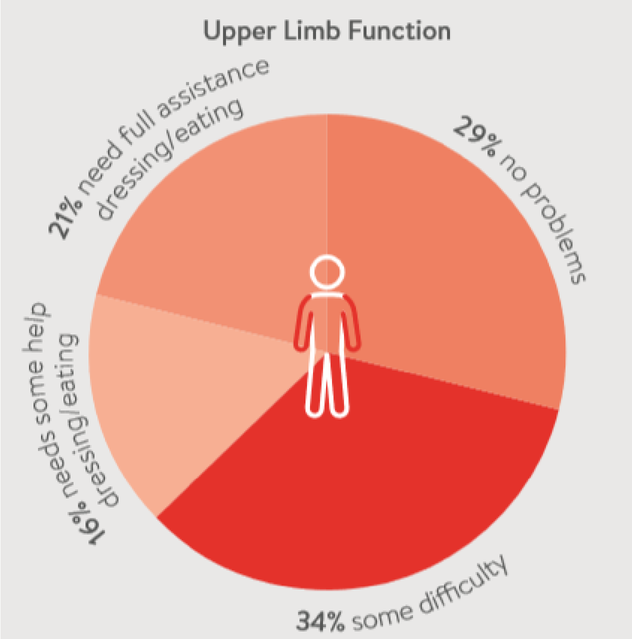
@smyth_jason

The Fastest Paralympian on the Planet. Double double gold medalist and WR holder in 100m & 200m #Goldsmyth

Cerebral Palsy in Northern Ireland

Approximately 55 children are born with CP each year in NI





Epilepsy
1 in 2 have
had seizures
at some stage

Visual impairment
1 in 3 have visual
impairment

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

Public Involvement (PI) in NICPR

- Parent and patient membership of the Northern Ireland Cerebral Palsy Register (NICPR) Advisory Committee
- Annual report
- Family conference/study days

- But how to EMBED public involvement day-to-day?

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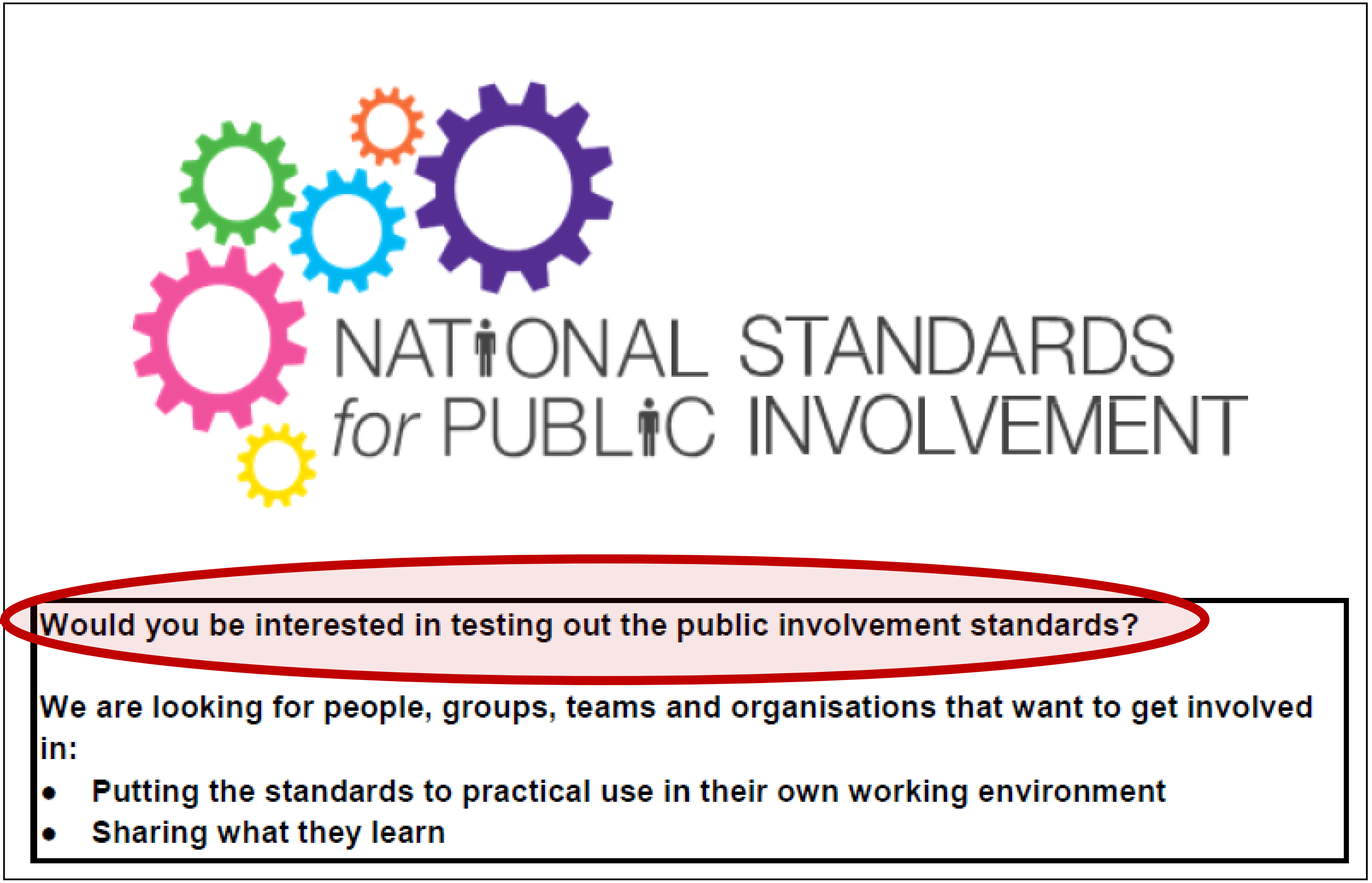
February 2018



NATIONAL STANDARDS *for* PUBLIC INVOLVEMENT

Would you be interested in testing out the public involvement standards?

We are looking for people, groups, teams and organisations that want to get involved in:

- **Putting the standards to practical use in their own working environment**
- **Sharing what they learn**

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What are the Public Involvement (PI) Standards?

NATIONAL STANDARDS
for PUBLIC INVOLVEMENT

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.

NIHR | National Institute for Health Research

CHIEF SCIENTIST OFFICE

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

HSC Public Health Agency

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Standard 1

Inclusive opportunities - we provide clear, meaningful and accessible opportunities for involvement, for a wide range of people across all research.

Standard 2

Working together – we create and sustain respectful relationships, policies, practices and environments for effective working in research.

Standard 3

Support & learning - we ensure public involvement is undertaken with confidence and competence by everyone.

Standard 4

Communications - we provide clear and regular communications as part of all involvement plans and activities.

Standard 5

Impact - we assess, report and act on the impact of involving the public in research.

Standard 6

Governance - we ensure the community of interest voices are heard, valued, and included in decision making. We implement, report and are accountable for our decisions.

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(1) Create a PI group of adults and young people with cerebral palsy and their family, carers and friends.

(2) Collaboratively determine terms of reference, activities and training needs of PI group.

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Develop flexible, jargon-free communication methods to meet the needs of different audiences.

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Standard 1

Inclusive opportunities - we provide clear, meaningful and accessible opportunities for involvement, for a wide range of people across all research.

Standard 4

Communications - we provide clear and regular communications as part of all involvement plans and activities.

Standard 2

Working together – we create and sustain respectful relationships, policies, practices and environments for effective working in research.

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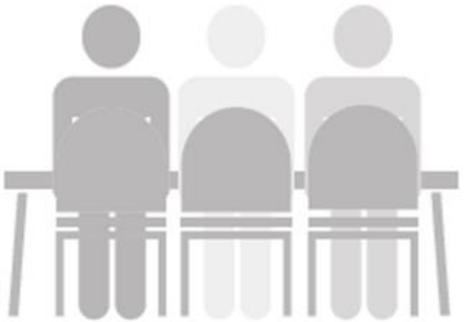
Impact - we assess, report and act on the impact of involving the public in research.

Standard 3

Support & learning - we ensure public involvement is undertaken with confidence and competence by everyone.

Record and monitor PI activity and develop standardised evaluation processes



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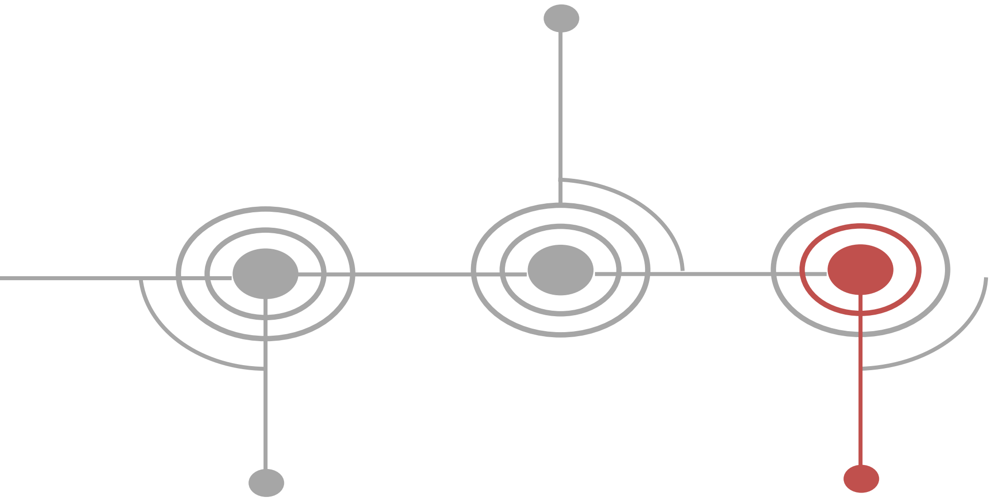
March 2018

- NICPR named as one of ten ‘test-beds’ to work with NIHR on piloting the UK PI Standards
- Variation in locations, size, conditions and affiliations
- Supported by workshops, teleconferences & shared resources

NATIONAL STANDARDS
for PUBLIC INVOLVEMENT
Official Test Bed Site 2018 - 19

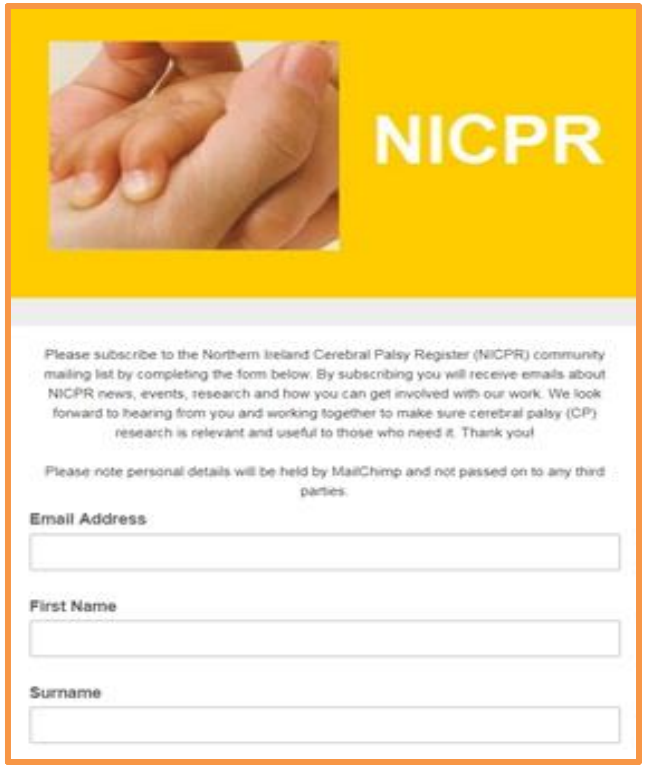
April 2018
First NIHR
workshop
(London)

May 2018
Local meeting to
plan set up of
dedicated
PI group



July-Aug 2018

Launched & promoted
Community Mailing List



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

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/NI-CPR

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)

Hearing impairment
1 in 10 have hearing impairment

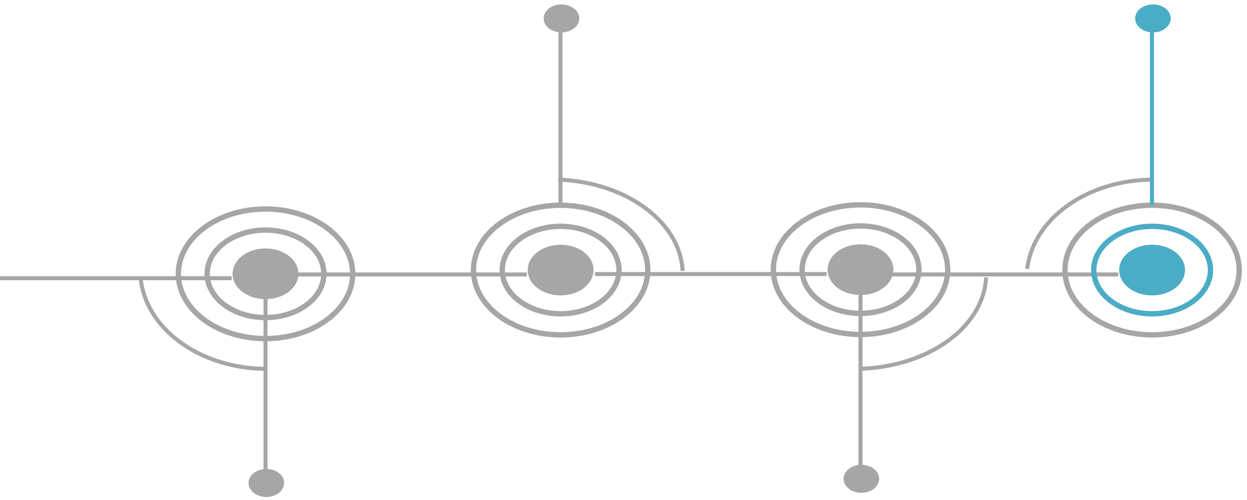
Communication impairment
1 in 2 have problems with communication

Feeding problems
1 in 4 have feeding problems

Aims of the NICPR:

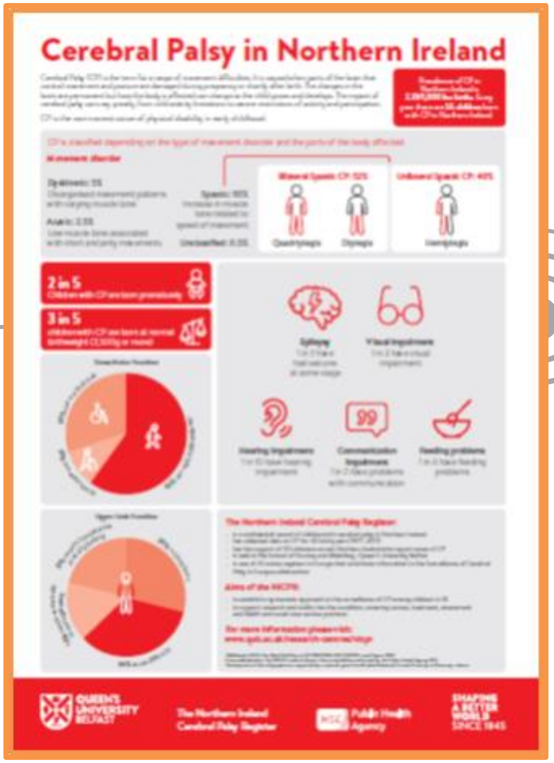
- to establish a systematic approach to the surveillance of CP among children in NI
- to support research and audits into the condition; covering causes, treatment, assessment and health and social care service provision

Sept-Nov 2018
PI video;
planning &
hosting first PI
event



Considerations
Location and Access
Dietary requirements
Communication requirements
Childcare

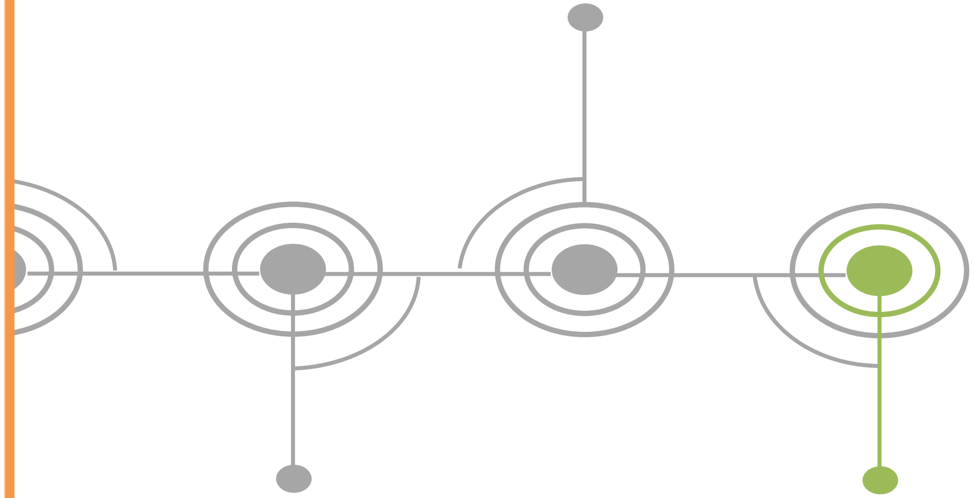
Attendance numbers (32/16/6)



Cerebral Palsy in Northern Ireland

2 in 5

3 in 5



Oct 2018-Jan 2019

World CP Day & dissemination activities

2019 Knowledge Without Borders

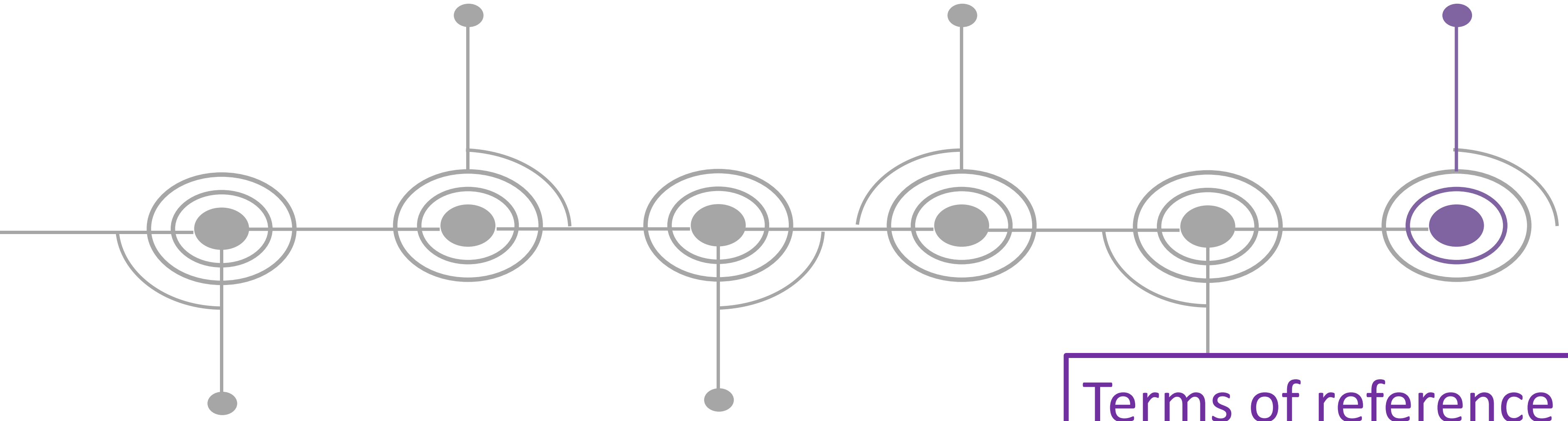
Combined AACPDM 73rd Annual and IACD 2nd Triannual Meeting

SEPTEMBER 18–21, 2019
ANAHEIM, CALIFORNIA USA

31st EACD CONFERENCE
MAY 23-25 2019 PARIS, FRANCE
Under the High Patronage of
Mr Emmanuel MACRON
President of the French Republic

Celebrating

years of knowledge on CP



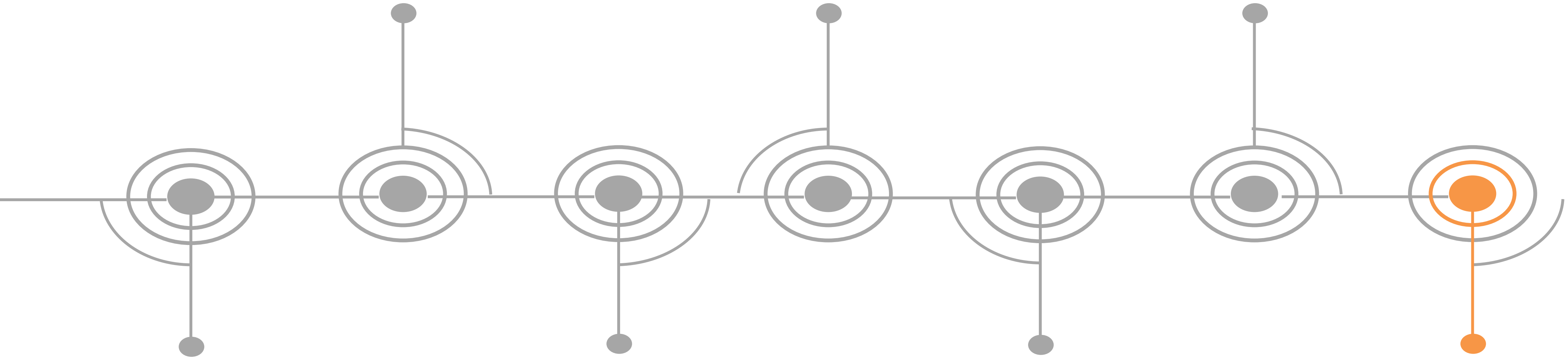
Jan 2019

1st PI group meeting

Terms of reference of group
Scope of activities
Training needs

HSC Public Health Agency
Research and Development

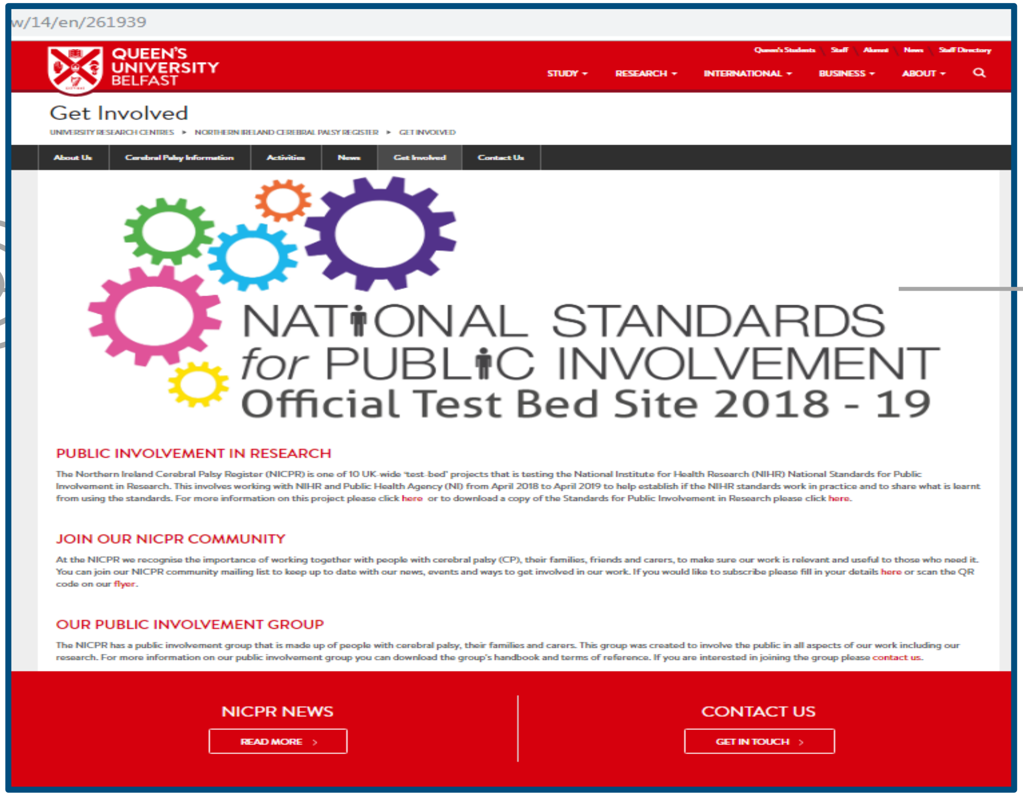
NICTN
CANCER TRIALS NETWORK



April 2019
PI group training

May 2019

2nd PI group meeting;
PI webpage;
Final NIHR workshop



Get Involved

PUBLIC INVOLVEMENT IN RESEARCH

The Northern Ireland Cerebral Palsy Register (NICPR) is one of 10 UK-wide 'test-bed' projects that is testing the National Institute for Health Research (NIHR) National Standards for Public Involvement in Research. This involves working with NIHR and Public Health Agency (NI) from April 2018 to April 2019 to help establish if the NIHR standards work in practice and to share what is learnt from using the standards. For more information on this project please click here or to download a copy of the Standards for Public Involvement in Research please click here.

JOIN OUR NICPR COMMUNITY

At the NICPR we recognise the importance of working together with people with cerebral palsy (CP), their families, friends and carers, to make sure our work is relevant and useful to those who need it. You can join our NICPR community mailing list to keep up to date with our news, events and ways to get involved in our work. If you would like to subscribe please fill in your details here or scan the QR code on our flyer.

OUR PUBLIC INVOLVEMENT GROUP

The NICPR has a public involvement group that is made up of people with cerebral palsy, their families and carers. This group was created to involve the public in all aspects of our work including our research. For more information on our public involvement group you can download the group's handbook and terms of reference. If you are interested in joining the group please contact us.

Progress on our original aims

WORKING TOGETHER

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. ✓

COMMUNICATIONS

Develop flexible, jargon-free communication methods to meet needs of different audiences.

WORK IN PROGRESS

IMPACT

Record and monitor PI activity ✓

…and develop standardised evaluation processes. ??

Reflections on piloting the PI Standards and lessons learned...

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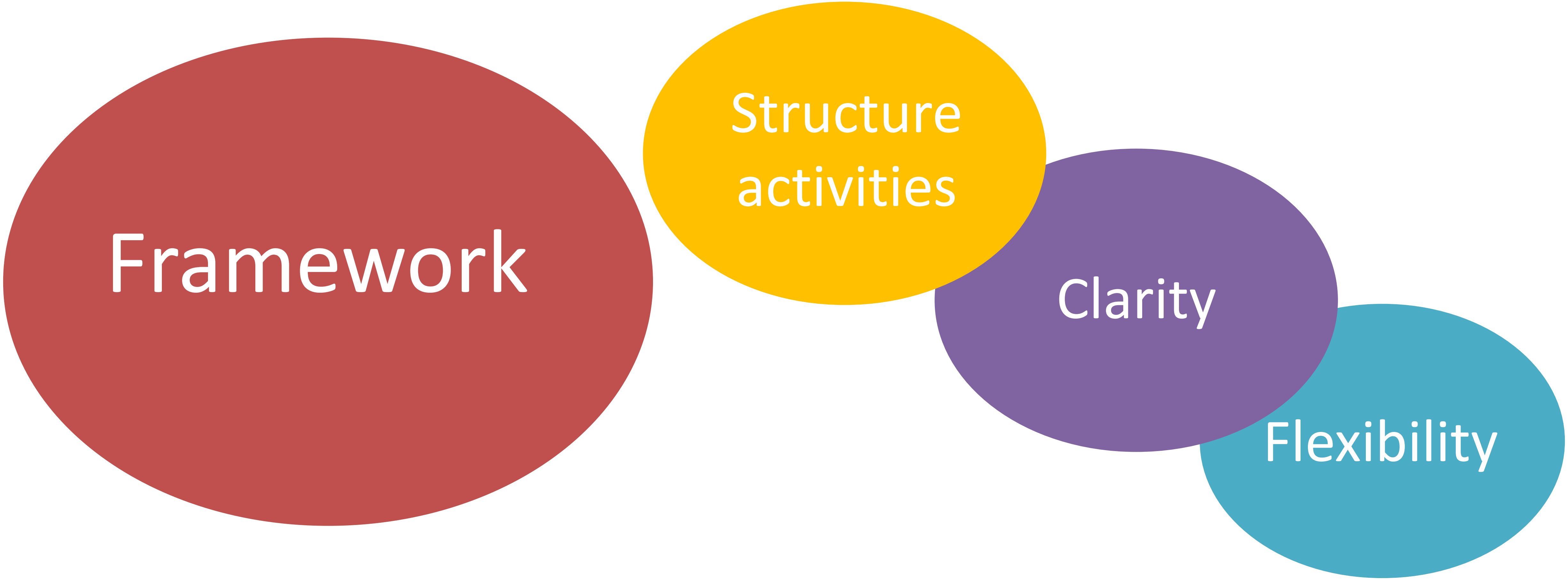
What was been the **greatest benefit** of implementing the Standards in your project/organisation/network?



Framework

Structure activities

Clarity

Flexibility

What was the **greatest challenge**?

Resources

Overwhelming

Over-complicated

How to measure impact?

Some last thoughts from Helen on her PPI experiences to date…

“Shared my personal journey”

“benefitted me personally as I have gained confidence with public speaking, meeting new people and getting involved with new projects that will make a difference to people’s lives now and in the future”

“Encouraged others with CP, and their families, to engage with public involvement that will result in high quality research to improve the lives of people with CP”

“Advocated for others with CP”

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Thank you

c.kerr@qub.ac.uk

nicpr@qub.ac.uk

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

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