

RESEARCH IMPACT AND ENGAGEMENT SEMINAR



Enabling the participation of children and young people with cerebral palsy in adapted cycling research 2009-2012

21st May 2015

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How to incorporate patient and public involvement in the research process



Ethics of research with disabled children

- United Nations Convention on the Rights of the Child (United Nations, 1989)

Articles:

12 'rights of children to participate'

23 'children with a disability should have special care and support so they can lead full and independent lives'

24 'right to best quality health and healthcare'

31 'children have a right to relax, play and join in a wide range of activities'

Children and Young people's Participation Standards for Wales(2007)



We will:

listen to your ideas, views and experiences

take you seriously and treat you fairly

work with you to do something about the things you tell us are important

work with you to help change things for the better

Roger Hart's Ladder of Young People's Participation



Created by The Freechild Project - <http://freechild.org>

Rung 8: Young people & adults share decision-making

Rung 7: Young people lead & initiate action

Rung 6: Adult-initiated, shared decisions with young people

Rung 5: Young people consulted and informed

Rung 4: Young people assigned and informed

Rung 3: Young people tokenized*

Rung 2: Young people are decoration*

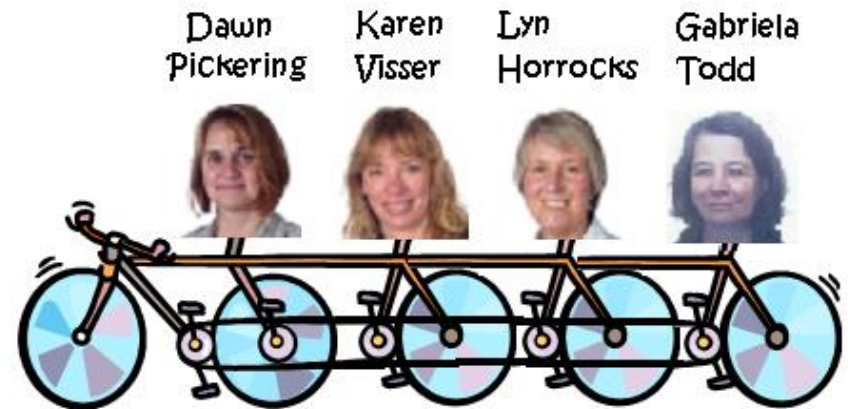
Rung 1: Young people are manipulated*

Note: Hart explains that the last three rungs are *non-participation*

Adapted from Hart, R. (1992). *Children's Participation from Tokenism to Citizenship*. Florence: UNICEF Innocenti Research Centre.

Reflections from experience

- Assist in reviewing the patient information and consent forms.
- INVOLVE
- Further consultation





Involving People – Scoping exercise

The screenshot shows the 'Involving People' website. On the left is a green navigation menu with links: News, Events, About Us, Public Involvement Case Studies, Get Involved in Research, Involving People in Your Research, Network Members' Area, Newsletters, Useful Documents & Links, Contact Us, Feedback, Cymraeg, and Site Map. Below the menu are logos for NISCHR (National Institute for Social Care and Health Research Clinical Research Centre) and GIG CYMRU NHS WALES, along with funding information from the Welsh Government.

The main content area features a 'Welcome to the Involving People website' heading. Below this are three call-to-action cards, each with a circular profile picture:

- Are you a patient, carer, service user or member of the public living in Wales?**
Find out how you can [become actively involved](#) in the design and development of health and social care research.
- Are you a researcher based in Wales?**
Find out how Involving People can help you [involve members of the public in your research](#).
- Already an Involving People network member?**
Access the [network members' area](#).

Below the cards are two news sections:

- Current Features**
 - [Opportunity for member of the public to chair the NISCHR Public Delivery Board](#)
Member of the public to Chair the NISCHR Public Delivery Board, overseeing and providing direction for public involvement and engagement in Wales.
 - [Changes from April 2015](#)
Read more about changes coming into effect from 1 April 2015.
 - [Involving People Annual Meeting 2015](#)
Read all about our Involving People Annual Meeting
 - [Involving People Action Plan Update](#)
Find out how we've been meeting our objectives
 - [News from NISCHR CRC](#)
Read the latest news from the National Institute for Social Care and Health Research Clinical Research Centre (external link)
- Latest Involving People News**
 - [Opportunity for member of the public to chair the NISCHR Public Delivery Board](#)
20 March 2015
Member of the public to Chair the NISCHR Public Delivery Board, overseeing and providing direction for public involvement and engagement in Wales.
 - [Presentations from the Involving People Annual Meeting 2015](#)
13 February 2015
Thank you to everyone who attended the Involving People Annual Meeting 2015.
 - [Benefits Advice Service for involvement](#)
4 February 2015
A new confidential service has been launched to offer personal advice and support on how payment for time and expenses for public involvement might affect people in receipt of state benefits.

At the bottom, there is an accessibility and terms of use footer, and a taskbar with system icons and the date/time (13:50 20/05/2015).

Parent contributions

- Feedback and suggestions provided greater clarification for parents and children regarding what we were trying to find out
- Greater accessibility to researchers e.g. *“you can see more about us on our web site: provision of web address”*
- Increased conciseness and relevance of information presented e.g. *“Reduce information on measuring as you will guide them through this on your visits”*; How can my child take part – *“just leave it at 1 point”*
- Simpler language – *“we will observe the data protection act”*; *“any worries you can contact...”*
- Simplification of flow diagrams regarding participation - *if you say “no”*; *if you say “yes”*

Co-production Result!



- Information - more comprehensive
- Yet simplified
- Greater relevance
- Greater conciseness
- Increased lay terminology in presentation
- Greater accessibility for parents and children
- Greater accessibility for researchers
- Increased collaboration and confidence

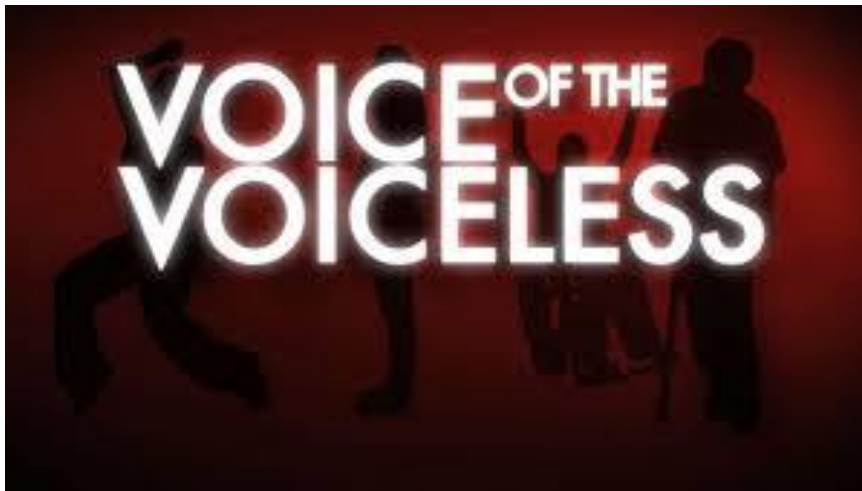
Co-production increased co-production

- The snowball effect!
- Collaboration and networking
- Translated into Urdu
- Translated into Welsh





cutcaster.com - 901435009



Children's story book



Co-production presentation, 2014

Imogen
8 years old
Cardiff

“ I can do it by myself ”



Race Running



International Athletics stadium,
Fridays 5-7pm





'VOCAL' study

- Consultation
- Participant Information Sheets
- Consent form
- Pilot methods

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