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

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How to incorporate patient and public involvement in the research process

IDENTIFYING & PRIORITISING
- Patients and the public can
  - Engage early user groups and organisations to help inform research priorities
  - Be consulted about research topics and priorities, important to them and their carers
  - Collaborate with researchers to identify topics for research
  - Identify topics for research themselves

MONITORING & EVALUATION
- Patients and the public can
  - Have continued involvement with the study to maintain focus and address issues as they arise
  - Collaborate with researchers to evaluate the research process
  - Reflect on their role and what they have learned

IMPLEMENTATION
- Patients and the public can
  - Increase the likelihood that results of research are implemented by adding validity to the findings
  - Develop patient information for new therapies/interventions within networks, GP surgeries etc

DISSEMINATION
- Patients and the public can
  - Advocate on different avenues for disseminating results
  - Jointly present the findings with researchers
  - Write information for local patient groups
  - Inform clinics
  - Assist in getting results/findings published in specialist/nursing organisation websites
  - Help distribute results within their informal networks
  - Produce summaries of findings

ANALYSING & INTERPRETING
- Patients and the public can
  - Assist in developing themes from data
  - Be consulted to see if they understand and interpret data in the same way as the research team

DESIGN
- Patients and the public can
  - Inform the design of the research study
  - Clarify the research question and affirm its importance
  - Ensure the methods selected are appropriate for patients
  - Assist in creating a recruitment strategy
  - Review and comment on proposed questionnaires and data collection methods

DEVELOPMENT OF THE GRANT PROPOSAL
- Patients and the public can
  - Help to ensure that the research proposed and chosen methods are ethical
  - Inform areas where patients and the public could be involved
  - Provide ongoing advice on where patients and the public could be involved
  - Define outcome measures
  - Advise on the comprehensiveness of the Top Summary
  - Raise awareness about costs of involvement, exonerate and prevent researchers to cost for involvement
  - Be named as co-applicants

UNDERTAKING / MANAGING
- Setting up a steering group to manage the research
- Patients and the public can
  - Share the project throughout the research process
  - Assist in writing the patient information and consent forms
  - Assist in designing the detailed protocol
  - Participate in conducting interviews and surveys
Ethics of research with disabled children


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

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

Reflections from experience

- Assist in reviewing the patient information and consent forms.
- INVOLVE
- Further consultation
Involving People – Scoping exercise
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
Children’s story book

Where can I ride my trike?
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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