CountMeIn!
Action plan for 2015 - 2016

Developed in April 2015, by the participants at the Newcastle CountMeIn!
Scientific Meeting

v.1

BRIEF SUMMARY

At the CountMeIn! 2015 Scientific Meeting, the participants identified priority topics around participation research and practice that require advancing. Participants gathered as working groups around these topics, and developed action plans. From the discussion on the day and from post-event analysis it was clear that some working groups developed highly converging action plans. We have collated and synthesised these plans into eight priority topics. The priority topics, in no particular order, are:

A. **Multi-agency, multidisciplinary collaboration to think, learn and do participation & related research**, including promoting participation across disciplines, engaging with networks across disciplines and sectors, improving communication about participation outcomes and interventions between agencies and sectors, involving charity organisations in research, joint treatment plans across education and health to advance participation outcomes, using the WHO ICF across multidisciplinary teams to advance participation outcomes, interdisciplinary research methods to investigate participation interventions and outcomes.

B. **Understanding what participation is and measuring participation outcomes**, including research to define participation, research and practice related to measuring participation, participation from the perspective of the person's, participation across settings, culturally sensitive measures, research into relationship between participation and quality of life, research into participation outcome measures – especially into the issues of sensitivity and responsiveness, international perspectives to participation outcomes and their measurement, reviews of participation outcomes and related measures.

C. **Service User Involvement in the context of participation outcomes and interventions**, including involvement of parents, children and young people by service providers, use of novel approaches to service user involvement in participation research or practice, empowering children to take ownership of participation research and practice, successes and challenges in service user involvement.

D. **Engaging clinicians in doing and using participation research**, including good examples of mentoring and leadership training for clinicians on participation research, post-graduate training in participation, projects to increase focus on participation outcomes and interventions in clinical networks and groups, linking participation outcomes with priorities for services and policy, influencing service managers to focus on participation, incorporating participation outcomes and interventions in clinical supervision and/or appraisals.

E. **Role of technology in improving participation**, including goal setting and technology, use of technology in interventions, encouraging children and parents' confidence to use technology, examples of working with other disciplines (e.g. engineers) to advance and implement technology to improve participation, interactive home-based/school based adaptations to increase participation through technology and outcome measures for technology interventions aimed at participation.

F. **Encouraging large participation studies**, including working across geographical areas to pull together information/data, collaborations across countries in Europe, multi-centre studies, links with charitable organisations, sharing information, use of national databases, international work

G. **Effectiveness of participation Interventions,** including research into intervention definitions (ingredients or delivery), classifications of intervention populations (e.g. by using diagnosis, gender, activity limitations, participation restrictions), research into common language to describe interventions, research into intervention fidelity, examples of the use of the MRC Framework to advance therapy interventions, identification of specific intervention research priorities, linking participation interventions to participation outcomes (effectiveness, mechanisms of change)

A number of working groups have already started on these topics. We would be grateful if the co-ordinator(s) for each working group could identify themselves to us, so that we can sign post others who want to join your group too.

In the following, "working group" refers to the groups formed on the day and any additional participants joining them since then. These are the groups who have the power to take the specific work forward. "Facilitator group" refers to the co-ordinating sub-group of CountMeIn! Network, currently Carolyn Dunford, Katrina Bannigan and Niina Kolehmainen. The facilitator group does not have the power to advance the work, but can take supportive actions and these are highlighted in the purple boxes under each priority topic.

THE PRIORITY TOPICS

The following pages describe each of the eight priority topics in more detail, using the materials produced by the working groups at the 2015 Meeting.

A. <u>**Multi-agency, MDT collaboration to think, learn and do participation & related research**</u>
  (Co-ordinator: tbc, Key link members: tbc)

General discussion topics:
- Present situation: Not enough MDT collaboration/sharing around participation research
- Thinking outside of Health – other agencies. Social Care, Charities etc.
- Creative collaborations – involve people from very different perspectives
- Getting medics involved. Important collaboration – education opportunities
- Shared language to discuss participation, shared vision
- Using information others have already and bringing together under the 'participation' umbrella
- Use of ICF as vehicle for change and developing collaborations, to focus thinking
- Get the ICF better known, used and applied within clinical settings
- Dissemination of research (for learning about research) – including to children and families – discussing 'participation' to develop families as collaborators
- Map where you are within your own service
- Develop trust to say it's OK to not be involved, be creative about research. Within the team – Uni links
- Assessment focus on participation and outcome measure
- Have students
- 'Others' parents too – think about their understanding
- Goal focussed – define this with the child
- Asking 'so what'- Passion – 18-24 months to make change
- Supervision
- Rethink how we disseminate research – How do we engage clinicians?

Potential priority: How can we move from where we are now to one vision for the future?

Actions the working group is planning to take forward:
- Promotion of what we do/education
- Having networks/using technology to access information/contacts with similar interests
- Engaging the existing MDT special interest groups to liaise with each other/share information
- Finding out what's important to different services
- Improving communication links between multi-agencies prior to research
- Involving charity organisations in research
- Increase confidence to share ↑ involvement (health, social care, education, medical)
- Keynote speaker from social care and Education, EHCP, inviting those groups
- EHCP – someone who could speak in relation to this – bridge the gap
- Making ICF more visible → feed back to MDT teams and encourage broader attendance at meetings
- "Tapping" into education – introducing ICF in schools
- Key representatives from other agencies to attend and feedback through key channels for their area of work
- Local champions to build relationships and share knowledge
- Locally use supervision

Actions that the CountMeIn! facilitator group is planning to take forward:
- Engage with British Academy of Childhood Disability for CountMeIn!2016 event to encourage wider MDT participation
- Continue to work across disciplinary boundaries on all participation research
- Support and mentor strong candidates across AHPs to apply for PhD and post-doc fellowship funding
- Encourage CountMeIn! colleagues across AHPs to apply for research internships and MSc opportunities by circulating information about available opportunities (keep an eye on twitter!)
- Continue to link up with BACD and existing MDT collaborators for research and dissemination
- Continue to seek funding for multidisciplinary participation research

- Circulate collaboration opportunities for multidisciplinary participation research via the CountMeIn! Network

Additional actions recommended to the working group:
- Identify and link up with existing national MDT networks as much as possible (e.g. BACD, EACD) to avoid duplication

B. <u>Understanding what participation is and measuring participation outcomes</u>
Co-ordinator: tbc
Key link members: Carolyn Dunford, Niina Kolehmainen, (Kristina tbc?)

General discussion topics:
- Developmental expectations
- Forum within CountMeIn! community
- Listening, Agreement, Consensus
- Therapy driven participation
- Child led/individualised construct
- Willing to compromise/sign up
- Making impact to change practice
- Theory
- What it isn't
- Domains to which participation should be directed.
- Individualised nature of participation
- Human needs/givens (8), safety, security, recreation
- Are your needs being met?
- Gap between levels of participation and what person wants to do
- Dimensions of participation
- Taking risks
- Are you participating/caring about – as a 2 year old vs 25 year old
- Participate in order to live their lives

Topics specific to measurement:
- Clearly define what we are measuring, at what level of participation,
- Objective measurement
- Subjectively from the person's perspective
- To be used in all settings, all ages, for all conditions
- Time as a commodity – how much time spent participating in desired
- Culturally sensitive measures
- Quantifiable relationship between participation and QoL
- Go through what's available
- One won't fit all
- How to make it sensitive
- Reviewed regularly
- Detect small changes
- Probably individualised
- Using outcome measures which is sensitive enough to capture change.
- With outcome measures that measure children's participation, not just parent's view of their child's participation
- Sensitive for change – the outcome measures must capture the child's

Actions the working group is planning to take forward:
- EACD pre-congress ½ day workshop (Jenny Carroll, current Treasurer of EACD)
- European dimension, COTEC meeting, Ireland next year, Roadshow
- Gain consensus
- Participation in activity / in life --- <u>not</u> participation in therapy.
- Risk of turning participation into a structure
- Literature review of what is participation and of participation outcome measures

Actions that the CountMeIn! facilitator group is planning to take forward:
- Apply for research funding to advance participation outcome measurement
- Explore options to join European collaborators in an initiative to implement PEDI-CAT – explore if this could be used as an immediate measure to capture participation outcomes while further research to more suitable measures will be conducted [where the further research is expected to take several years before resulting in a 'third generation' participation measure]

Additional actions recommended to the working group:
- See existing, published reviews on participation measures, and recent NIHR report by Morris et al.
- See existing reviews on what participation is/means to children and young people [e.g. Powrie et al]
- Connect with European, and wider international, partners as much as possible

C.   Service User Involvement
    (Co-ordinator: tbc, Key link members: tbc)

General discussion topics:
Where are we now? Service users involved in pockets. Find a way of getting parents passionate. Language used to enthuse parents more. Use of online forums. Empowering parents to help them be as informed as possible.

PPI – to raise issues and influence research carried out

Actions the working group is planning to take forward:
- Ask parents 'What do they view as participation?' 'What are barriers?' 'What do they think their child likes doing?'
- Use current chat rooms/Facebook groups eg. Matthew's friends' Hemi-help; Blended diet, Cystic Fibrosis etc.
- Tweet on Facebook groups/Twitter pages targeting parents/service users re upcoming events/meetings on Participation
- Using the cooperation with children to take ownership of their own feeling of level of participation
- Service user led research

Actions that the CountMeIn! facilitator group is planning to take forward:
- Invite a young person key note speaker to the CountMeIn!2016
- Apply funding to carry out PPI on participation interventions (see also 'Participation interventions' working group)
- Partner with others to review the intervention research priorities from the JLA priority-setting partnership, identify priorities for participation research, and submit these to NIHR as topics

Additional actions recommended to the working group:
- Use INVOLVE guidance to advance PPI
- Seek to engage with existing service user involvement groups where possible

D.   Engaging therapists in doing and using research
   (Co-ordinator: tbc, Key link members: tbc)

- Includes, e.g. to read more, more fun, seminars, allocated time, doing clinically led research
- For research to be included in job descriptions and aligned with appraisal
- Someone from the study explaining exactly what is needed so that it isn't so daunting to be involved
- Greater knowledge of research at point of qualification

Actions the working group is planning to take forward:
- Make links with higher education and therapy teams
- Mentoring and leadership training for therapists re research
- Offer postgrad training in participation
- Enhancement of CYPF networks and groups – involvement of students to build capacity
- Link with priorities for services and policy. Templates/examples of how research can link with practice which emphasises participation
- Influencing managers of services to focus on participation
- Identify communication channels for therapists and research
- Articles, e.g. OT News article, CYPF article, strengthen CYPF groups for CPD and supervision
- Motivate OT to participate in research studies

Actions that the CountMeIn! facilitator group is planning to take forward:
- Support and mentor strong candidates to apply for PhD and post-doc fellowship funding
- Encourage CountMeIn! colleagues to apply for research internships and MSc opportunities by circulating information about available opportunities (keep an eye on twitter!)
- Continue to seek funding for participation research
- Circulate collaboration opportunities for participation research via the CountMeIn! Network

Additional actions recommended to the working group:
- Identify and link up to existing research and networks as much as possible – these are most likely to provide support for learning. See e.g. BACD Strategic Research Group web site for information.
- Think outside a single discipline, seek to be multidisciplinary

E.   Role of technology in improving participation
    (Co-ordinator: tbc, Key link members: tbc)

Priorities for 12 months
- Identifying a small number of outcome measures
- Develop a forum to network
- Re-evaluate participation within current services
- Reach out to other professionals who can help us to promote participation eg IT experts, engineers for adaptations

Where we are now
- Awareness of technology eg social media to enable increased social participation
- Use of technology as clinicians/researchers and also children's use of technology
- Scared of technology!! Online safety. Cost, How to use, Keeping up with changes
- Organisations falling behind eg NHS
- Children's participation has changed to favour technology – text, Skype X-Box online, Google, Social media email etc

Where will we be in 5 years?

- Acceptance of technology and its value in participation

Actions the working group is planning to take forward:
- Goal setting to reflect importance of technology
- Its use in intervention – use technology eg fit bits to measure activity and motivate
- Educating children and parents about online safety in order to encourage participants and confidence in technology
- Could we have a database of IT experts, tutors, engineers that we can call on to assist us?
- Interactive home-based/school based adaptations to increase participation with technology
- Use of forums online

Actions that the CountMeIn! facilitator group is planning to take forward:
- Provide mentoring and research support for research funding applications stemming from the plans of the working group, if this was considered helpful by the working group

Additional actions recommended to the working group:
- Please feel free to approach the working group for input and linkage to others (e.g. researchers in technology, or outcome measurement) if you thought this helpful

F. Encourage larger studies
(Co-ordinator: tbc, key link members: tbc)

General discussion topics:
- Joint funding between LA and Health.
- Building networks of people to collaborate with, better links with other geographical areas to pull together information/data
- Collaborate with countries in Europe in studies to get bigger groups of participants, multi-centre studies.
- Greater links with charitable organisations
- A specific place/website to go to- NHS Bright ideas – to look for information on studies that we can contribute to
- Sharing information – National database, using SEND data
- Scholarships – international work, funding for larger studies and scholarships/bursaries
- Financial support to attend conferences/courses where you hear about research and can engage
- Multi-agency working – not always discipline specific

Actions the working group is planning to take forward:
- To have one central point to look for research studies that are being undertaken and we can contribute to.

Actions that the CountMeIn! facilitator group is planning to take forward:
- Support implementation of consistent outcome measurement of participation (see point B above)
- Continue to collaborate with national and international partners (see above)
- Continue to apply funding for large, national and international research studies of participation

Additional actions recommended to the working group:
- For existing centralised places, please see e.g. major national funders' data bases (NIHR, NIH, EU), BACD Strategic Research Group web site, and CanChild web pages.

G. Effectiveness of Intervention

Co-ordinator: niina.kolehmainen@newcastle.ac.uk
Key link members: Jennifer McAnuff, Rob Brooks, Maria Quinn, Cat Duff

General discussion topics:
1. What are the outcomes we are looking for?
2. Agreement on the definition of intervention
3. Agreement on the outcomes of intervention
4. More collaboration nationally to achieve this
5. Undergraduate training to reflect this
6. Who is the intervention effective for ie groups, diagnosis, individuals?
7. What basis do we set boundaries ie diagnosis, gender, motor ability etc?
8. Use of common, understandable language to describe intervention
9. How do you ensure that intervention is done in a consistent way?
10. As a network, begin to establish and agree common terms, interventions and promote the usage
11. Where do interventions come from - research or clinical work? Needs to be both
12. Look at MRC Framework
13. Engagement in looking at the issues around intervention. Making time engaging managers
14. Network agree to make intervention a priority → attractive to get funding nationally. Hard core expertise connected locally. Admin support
15. How do you allow time to look at the bigger picture? Have individual clinicians who can take a lead and feed into the network
16. Parallel work around participation outcomes
17. What are the barriers to participation?

How to measure participation? How can we measure change in participation?
- Develop outcomes that can measure change
- Individual assessments/outcomes
- Outcomes – or is it possible to have a standardised assessment?
- Implement interventions into clinical practice
- We have some knowledge about effective interventions but larger studies are probably needed
- Goal setting – interventions from a learning perspective, that build on the child's strengths

Actions the working group is planning to take forward:
- Formulate proposal to seek interest from the CountMeIn! Network to take forward work on effectiveness of intervention.
- Form working group who will set a specific action plan.

Actions that the CountMeIn! facilitator group is planning to take forward:
- Support implementation of consistent outcome measurement of participation (see point B above)
- Continue to collaborate with national and international partners on intervention research (see above)
- Continue to apply funding for large, national participation intervention research studies
- Apply funding to carry out PPI on participation interventions (see also 'Participation interventions' working group)
- Partner with others to review the intervention research priorities from the JLA priority-setting partnership, identify priorities for participation research, and submit these to NIHR as topics

Additional actions recommended to the working group:
- Link up with working group B (above) on outcome measurement and with working group, with working group C on PPI, and with working group F on technology interventions

In addition to the eight priorities described above, a ninth priority was also identified and a working group formed. However, the materials produced by the group did not outline further action plans, it is therefore not included in the priorities for moving forward.

Review Local Provision
(Co-ordinator: tbc, Key link members: tbc)

General discussion topics:

- Developmental model of participation
- Functional age matched
- What to engage? What age?

Techniques for engaging children

- Books
- Literature
- Networking
  - Locally
  - COT
- Good practice in team

[School-based
accessible
family delivered]

Actions the working group is planning to take forward:
- None stated

Actions that the CountMeIn! facilitator group is planning to take forward:
- No plans to review local provision at the moment

Additional actions recommended to the working group:
- None at the moment