RECAP preterm

Establishing research priorities

Original research

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Priorities for collaborative research using very preterm birth cohorts

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ARCHIVES OF DISEASE IN CHILDHOOD

Hypothesis-driven research agenda for child very preterm cohorts

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From science to health

Hello, as I said in my introduction, I am going to present to you how we established the research priorities for this work package ''hypothesis-driven The results that I am going to present have been published in an open access article in the Journal Archives of disease in childhood.

RECAP preterm

How should the platform select its priorities ?

Build on the knowledge within the cohorts

23 cohorts followed up over multiple years

Large network of researchers

>500 publications

External stakeholders
- Clinicians involved in care (obstetrics, neonatolgy, pediatrics, psychology)
- Researchers
- Policy-makers
- Educators
- Parents
- Adults born very preterm

So how should the platform set it priorities? Clearly, it should build on the knowledge within the cohorts. We have 23 cohorts which have followed up children born very preterm with a large network of researchers and over 500 publications. But, we also wished to consult with external stakeholders who have an interest and concern with very preterm birth, clinicians, researchers, policy makers, educators and people with lived-experiences of preterm birth.

To consult with these stakeholders, we used a Delphi formalised consensus method. This involves establishing and expert panel, people with knowledge on the subject and who have diverse perspectives. Participants respond to successive questionnaires to identify common principles or proposals. So, a first questionnaire is sent in the first round to all of the participants and their results are synthesized and then fed back to them. A second questionnaire them asks more questions which involve commenting on the results and providing new responses and these can be synthesized and fed back in a third round to finalize the results. Responses can be qualitative, this means free text comments, or quantitative, that means rankings or scores. The benefits of this procedure are that it gives everyone an equal voice, ensures anonymity in the panel and allows iteration and interaction. In the end, it generates summary measures of agreement and a consensus on highly rated items.

To establish the first questionnaire, we sought to brainstorm about research priorities within the cohorts. So first we compiled literature from cohort publications on studies that looked at outcomes in childhood. We read through these papers and in particular the discussions to look for the themes that were identified as needing further research. We then carried out a survey with the cohorts to add to this list. At the end of this process, we had a list of 28 research themes.

External panel for the DELPHI consensus

- People with knowledge and familiarity with care and needs of children born very preterm

- Clinicians, researchers, educators, policy makers, parent representatives, adults born preterm

- 2-4 people suggested by each cohort (71 in all)

To constitute the external panel for the Delphi consensus, we sought people who had knowledge and familiarity with the care and needs of children born very preterm. We sought people with different backgrounds, as I said previously, clinicians, researchers, educators, policy makers, parent representatives and adults born very preterm. To constitute the panel we asked each cohorts to suggest 2 to 4 people from diverse backgrounds. In all, 71 people were nominated to the panel.
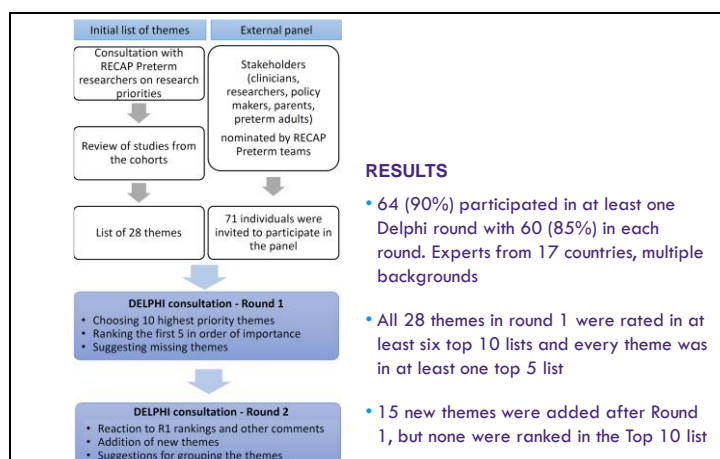
This schema gives a synthesis of the way that we constituted the initial list of themes and constituted our external panel. Once this had been done, we did the first round of the Delphi and we asked the participants to choose the 10 highest priority themes, in their opinions, and to rank the first five in order of importance. We also asked them to suggest missing themes. In the second round, the participants reacted to the Round 1 rankings and provide comments about it and they also gave us their opinions about the new themes that had been suggested. 64 of the people invited to participate, or 90%, participated in at least one round and we had experts from 17 countries with multiple backgrounds. All 28 themes were ranked as a priorities by at least some of the panel which showed that we didn't want to create a short list of themes but that we wanted to use this process to identify the whole range of research that needed to be done on this topic. found the 15 themes were added in Round 1, but none of these themes were ranked in the top 10 list.
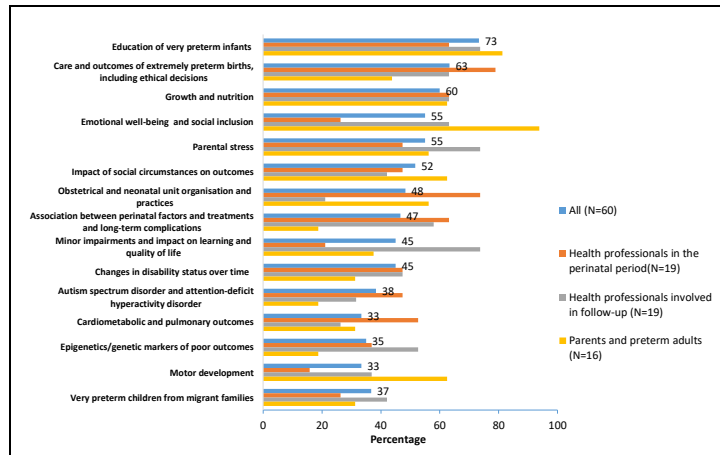
Here are the results from this Delphi and here we see that the most highly ranked theme was on education, with 73 percent of experts putting that theme in their top 10 list of priorities. The different colours show the different backgrounds, with health professionals in the perinatal period, health professionals involved in follow-up and parents and preterm adults. As we can see for instance for the first theme, all there three group ranked this theme highly. There were some differences in the rankings by background, with, for example, parents and adults putting more emphasis on emotional well being and social inclusion whereas health professionals in the perinatal period were more concerned with obstetrical unit organization and practices.
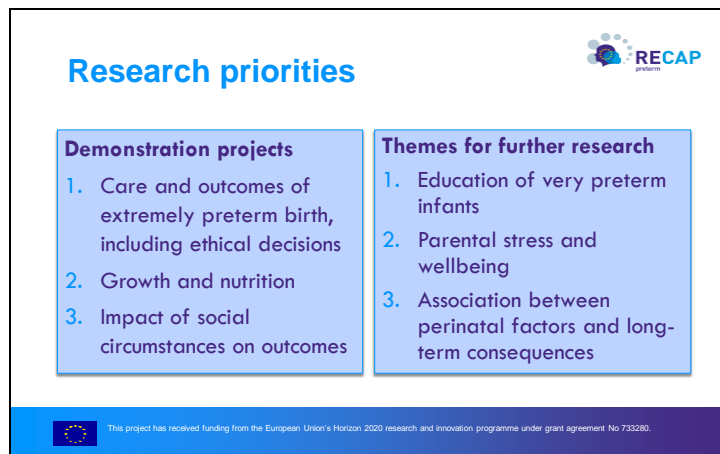
Based on this list, we were able to select three themes for our demonstration projects: care and outcomes of extremely preterm birth, including ethical decisions, Growth and nutrition and Impact of social circumstances on outcome. In the modules that follow, there will be presentations on two of these projects. We also established three themes for further research, that means we are developing proposals with different institutions to implement studies in these areas: on is education of very preterm infants, Parental stress and wellbeing, Association between perinatal factors and long-term consequences

So for more information on the Delphi technique, here are some reference. I have also put the reference for the study that we published in Archives in Disease of Childhood.

Also as part of the study, in the supplement, you can find the initial list of the 28 themes in plain language descriptions.

Learning goals

- Why should we involve stakeholders in developing research priorities
- What is a Delphi consensus process
- What did key stakeholders say about research priorities on the consequences of VPT birth in childhood

Here are our learning goals and thank you for listening.