

RECAP preterm

Collaborative Research on Very Preterm Birth: Concepts and Methods – Working with the RECAP preterm Data Platform

Dissemination, Translation and Sustainability

Aisling Walsh, Senior Project Manager
Overcoming Barriers to Patient Involvement




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My name is Aisling Walsh and I am a Senior Project Manager for Maternal and Newborn Health at EFCNI. I come to the table with much experience in stakeholder engagement, particularly that of the patient experience within various EU and international research projects, both at pre-clinical and clinical stage.

In this presentation, I would like to give a brief overview of some common barriers to patient representatives participating in research and some suggestions to mitigate these, drawing on the wealth of experience that we have at EFCNI.




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Barriers to patient involvement

 Researcher	 Patient	 Concerns
Research/ medical expertise, know-how	Personal experience Link to community	Lack of - knowing how to contribute - clarity of roles and tasks
Dedicated time / funding	Organisational challenges, no resources	Lack of time & money

Recommendations:

- Draw up a list of specific tasks for patient input (do not make assumptions!)
- Check – in regularly
- Make it easy to contribute
- Financial support as a full partner



So, we understand the reasoning and objectives behind the involvement of patients in research – on paper. How does this work in practice and what holds patients back from becoming involved?

As a researcher, you are very familiar with your area of medical expertise and know-how whereas the patient has first-hand, personal experience of the medical condition and in many cases, a link to the community. You both need each other but often times, there is a gap in understanding on both sides what precisely the involvement of patients should look like. As is the case in many professions and partnerships, clarity on roles and responsibilities may be missing. In order to avoid this trap, take some time to reflect on a list of specific tasks for patient input → and try to avoid making assumptions about what type of tasks the patient will want to be involved in. Offer a wide range of activities both directly and indirectly linked to scientific content. Check in with your patient representatives regularly – by email or even better, have a quick call, this can often be less time-consuming than exchanging back and forth and saves time for you both. Utilise online document exchange platforms also for patient involvement where they can comment directly on documents and make suggestions.

A sometimes sensitive but very important point is quite literally “Put your money where your mouth is.” Show the value of the patient input into your research by paying them as a full partner in your research project.

Barriers to patient involvement

		
Researcher	Patient	Concerns
Academic jargon/ technical language, acronyms	Plain language	Missing what is being discussed




Recommendations:

- Use as much lay language as possible
- Open and honest dialogue with parents on understanding
- A sound knowledge of English as a basic requirement for international research



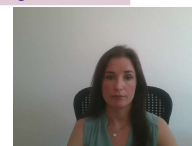
A big disconnect between researchers and patients is the type of language used. As a researcher you are familiar with and often use academic terms, technical language and many acronyms that to the average person, are not easily understood or at the most, only vaguely familiar. If we want to effectively involve patients, they have to understand the very essence of your work. This means using as much lay language as possible when speaking about your research and if unsure of the level of understanding of the patient representatives, create an open and honest space where the patients can comfortably say when they do not understand or follow. Unfortunately, for international research, the default language is English meaning that for patient involvement in such projects, a sound level of English is required. For the moment, there does not exist an easy way around this.

Barriers to patient involvement

 Researcher	 Patient	 Concerns
Interesting research questions; Good data; evidence, Publications Solution for the future	Receiving the right care and therapy at the right time Coping with daily life (worries, emotions, traumas) Direct solution for child/ family	Missing interest, awareness, „Unattractive“ research questions Fear that nothing changes




Recommendations:

- Listen and address the parents' concerns and link to the research question
- Full partner
- Finding solutions to different perspectives



Both parties are coming to the table with differing perspectives and sometimes differing ideas of what the research should achieve. Naturally, as a researcher, you are focused on the research question and finding good data and evidence with the view of finding a solution for the future. As a patient or parent, the primary objective of research is to find the right care or therapy at the right time which eases daily life and the associated worries and emotions. These sometimes different perspectives can lead to patients feeling that there is a certain level of awareness and/or interest missing from the researcher-side or that the research question is not attractive or relevant to their lived reality which in turn can lead to the fear that nothing will change for the patient or their family in their daily lives or the lives of future patients/families. So, how can we address these differing perspectives? As previously mentioned, it is important to consider the patient as a full research partner and together find solutions to differences in perspective. Always have an open ear for patients and/or parents' concerns, encourage them to raise these and link them back to the research question.

Barriers to patient involvement

 Researcher	 Patient	 Concerns
Advice-Giver, Decision-maker	Advice-seeker, doing what is expected	Fear of not being taken seriously Lack of evidence for benefits of involvement Lack of self confidence

Recommendations:



- Involve parents as an equal partner from the very start with the same rights as other stakeholders
- Take time to explain the research aims and objectives clearly
- Dedicated research coordinator to help with education and/or training and build a bridge between researchers and patients

Building on differing perspectives, the perception of roles between patient and researcher also varies: the researcher is often viewed as the advice-giver and decision-maker and the patient as the advice-seeker and doing what is expected. This perception of roles can lead to the fear, from the patient-side, of not being taken seriously which in turn can lead to a lack of confidence and raise questions on the benefit of being involved in such research. Once again, involving the patient as a full and equal partner from the very beginning with the same rights as other partners can go a long way in building a strong and trusting relationship between both parties. As a researcher, being present and available for the patient to explain the research aims and objectives clearly and answer any questions creates a strong foundation for this relationship. Having a dedicated research coordinator to help with building a bridge between researchers and patients is advised wherever possible.

Position Paper: Involvement of parent representatives in neonatal research

Position Paper is built on:

- Elaboration with EFCNI Parent Advisory Board
- Experiences by EFCNI and partnering organisations:
 - Exchange with partnering parent organisations
 - Discussions with different stakeholders
- Endorsed and supported by 50 organisations

Position Paper
Involvement of
parent representatives in
neonatal research



The Position Paper is endorsed by parent organisations from around the world:

The Position Paper is endorsed by the following parent organisations from around the world:



Printed version: EFCNI booth / free download

As many of you know, we at EFCNI, are very passionate about the involvement of patients and/or their representatives in research. In 2017, we gathered together numerous years of experience and knowledge in consultation with our Parent Advisory Board, our partner parent organisations around the world and various healthcare organisations. This experience and knowledge resulted in the publication of a Position Paper on the involvement of parent representatives in neonatal research which was endorsed and supported by 50 organisations. Much of what we are speaking about in this lesson is referenced in the position paper and namely....

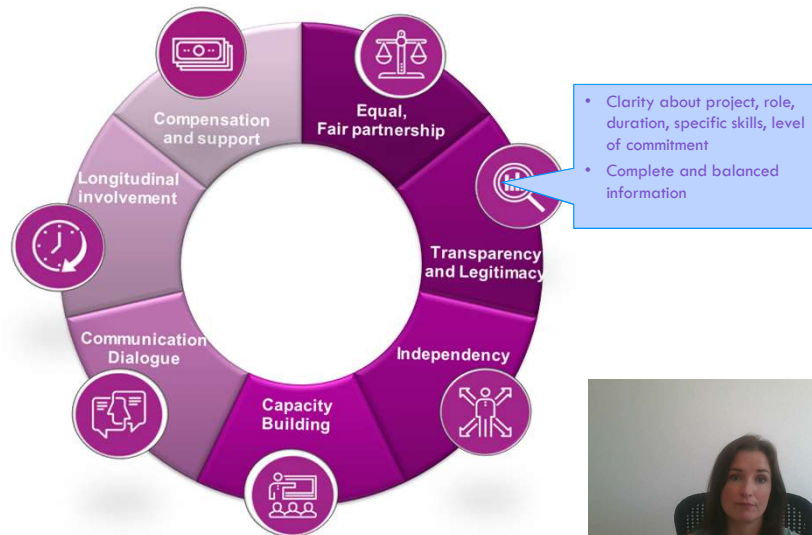
Guiding principles defining interaction

- Same rights throughout all project phases



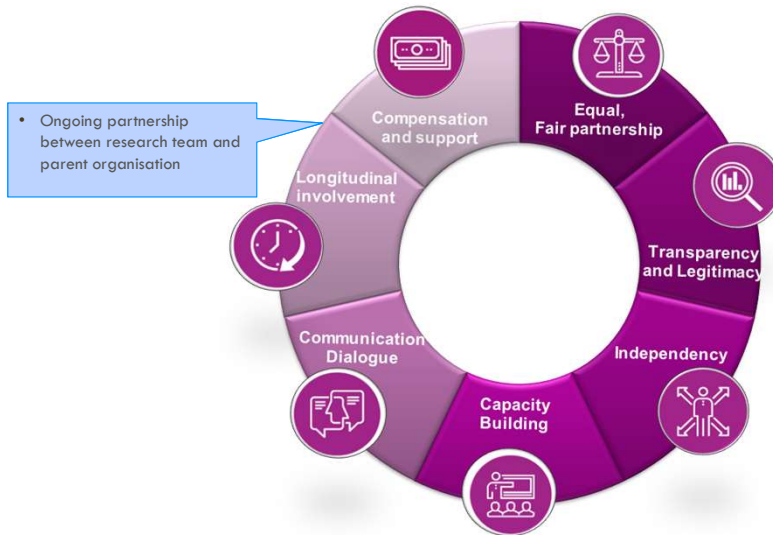
..the 7 guiding principles guiding and defining the interaction between researcher and patient. In this presentation, I have touched on several of these principles. The importance of having an equal and fair partnership throughout all stages of the research, including the issue of payment, which merits a bit more discussion in the next presentation.

Guiding principles defining interaction



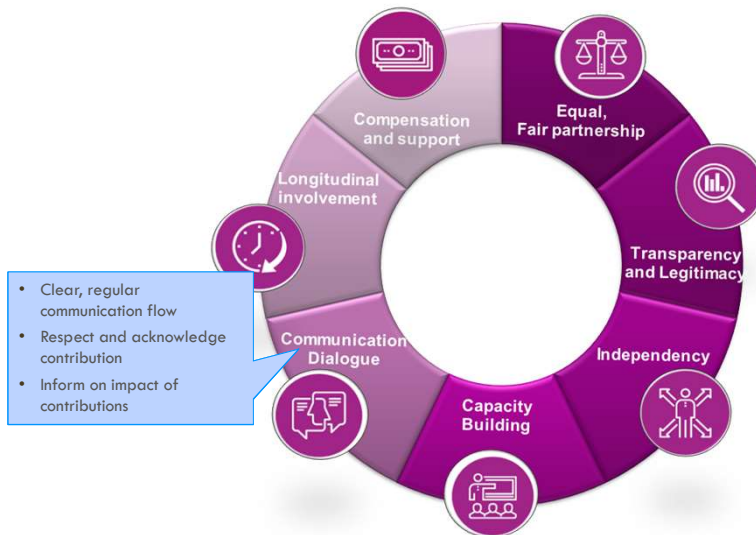
We also touched on the importance of transparency and legitimacy on the role of and expectations of patient representatives so those involved can make a decision on their commitment, the time investment needed, specific skills and so on. This also covers the necessity to be open and share all information related to the research.

Guiding principles defining interaction



Engaging and involving patients right from the development of the research idea or question and throughout as an equal and full partner can ensure not only a complete contribution but also foster a certain level of commitment based on shared values and principles.

Guiding principles defining interaction



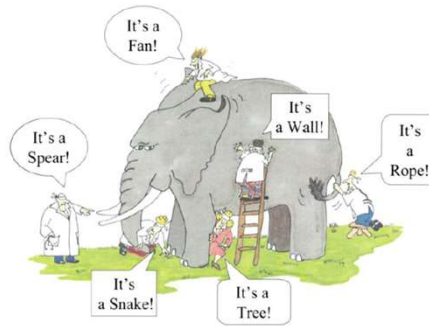
Clear, open and regular communication throughout the entire duration of the research ensures a good communication flow and demonstrates respect and acknowledgement of the patient contribution. So, how can we apply these guiding principles in practice? What are some tools that we can use?

Co-creation



Co-creation is one such tool - a process that has been widely used in product development is now also entering the scientific research arena. Co-creation refers to the process whereby all consumers or users of an end product play a central role throughout the entire development process. The aim is to ensure that the end product is usable for all stakeholders. Here on this slide you can see an overview of stakeholders in the neonatal ecosystem and ideally, these should all be represented in a co-creation process within neonatal research. Why?

Why co-creation is important?



As this slide illustrates well, we all see things from our own perspective which can sometimes make it difficult to see the whole picture. In this particular picture, each of the characters is focusing on a specific part of the body and their own interpretation of that, not being able to see that all of these parts make up the entire body of the elephant. As already mentioned, in research the researcher and patient may have very different views on the end objectives and what the perceived value of these are. The purpose of a co-creation process is to identify these differences of opinion and/or challenges and work on solutions together to these.

Co-creation in practice

RECAP preterm
in a nutshell

Start date:
01.01.2017

Duration:
51 months

Participants:
20 transdisciplinary
institutions from 12
different countries

EC funding:
€ 9,713,230

Full project title:
**Research on European
Children and Adults born
Preterm**

Contact:

Project Coordination
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Please feel free to contact the Project Management Office if you have a child or adult VLBW cohort anywhere in the world and would like to join the Network.

Find more information online

Have a look at the project website for more information about the background, methods, topics, and people involved. Visit us at: www.recap-preterm.eu

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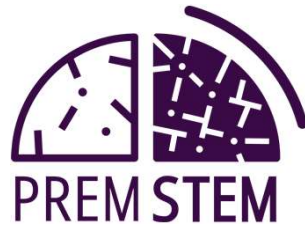
**Research on European
Children and Adults
born Preterm -
RECAP preterm**



- EFCNI involved in grant writing
- EFCNI as full partner (SC, GA, WP leader)
- Delphi process
- RECAP partners present at annual EFCNI Parent Summit



Co-creation in practice



<https://www.premstem.eu/>

- Role of patients - EFCNI, CPA, PCAB
- Identifying challenges, developing solutions
- In-depth interviews, dedicated workshops
- Several ways to involve patient representatives (umbrella and/or PABs or national groups, focus groups etc)



EFCNI is a work package leader within PREMSTEM. PREMSTEM is an EU H2020 project developing a stem cell therapy to repair brain damage in preterm born babies. Within our work package, we are coordinating and developing a co-creation process to ensure the smooth transition from pre-clinical study to clinical trial. We also work with other patient organisations within the project including the CPA in Australia and we have set up a Patient/Consumer Advisory Board to ensure the patient contribution from the start. In the co-creation process so far we have gathered all stakeholders around the table to identify and map current and potential challenges and as we move along the process, we will start trying to address these challenges through in-depth interviews and various workshops.

This is one example of strong patient engagement in research but there are several ways to do this depending on the type and scope of research - through PABs as in the project above, or through umbrella patient organisations, national organisations or then through specific and often smaller focus groups. This will depend on the specific disease and/or medical condition, number and type of countries involved.

With that, I hope that you have gained some insights and perspective into barriers to patient involvement and some real life examples of overcoming these. The following lesson will detail more on these guiding principles to patient involvement – namely capacity building and compensation.

Thank you

In case of questions, please feel free to contact:

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