

RECAP preterm

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

Dissemination, Translation and Sustainability

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Towards patient partnership: Capacity building and compensation



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My name is Nicole Thiele. I am Vice Chair of the Executive Board at the European Foundation for the Care of Newborn Infants, EFCNI, – and I am proud to work now for more than 10 years with EFCNI.

My closer family experienced very preterm birth more than 50 years ago. And I can say that until today, all my work with EFCNI has been and still is every day eye-opening for me as it allows me to see and to compare how much we can actually impact the life and outcome of persons born preterm and their families. And research certainly is one important element to help increase our understanding and to find solutions or recommendations to the many open questions and uncertainties. The patient should be in the centre of our work and I think patient engagement not only in healthcare but also in research is critical. If done in the right way, it can support creating even more meaningful projects to support this vulnerable group even more.

In this presentation, I'll take up what has been said by Professor Luc Zimmermann and Aisling Walsh: We can all see the role of patient representatives in research projects is currently shifting. However, the Patient partnership we aim for requires not only “patient experts” with a broad field of competencies and skills but also fair compensation of the patient's work –both is something we need to build on - for a smoother way into successful collaboration.

„Patient engagement“ – a role change



- Provide patient/ family(direct) support

Inform, help, support, navigate



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- Shape policy frameworks
- raise awareness among the public

Collaboration at political/ regulatory levels



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- Support and shape research and education

Partnership in research and educational programmes for patients and professionals

Adapted from: EUPATI

Before I start, I'd like to mention that I will use in my presentation the term "patient" as an overarching term. With this term, I am referring to individuals with lived experience in preterm birth and also informal caregivers including family and friends but also patient representatives/ patient advocates.

As was highlighted before, we see the role and activities of patients and their associations broadening and expanding everywhere around the world.

Besides providing patient support, patient representatives and their organisations are now also collaborating at political or regulatory levels. And more and more, the patients become partners in research. Actually, in some regions and countries like Australia, Canada, UK or Ireland, or certain disease areas, e.g. HIV, cancer this approach is already much more advanced and lived than in other regions/ countries or health areas, including maternal and newborn health areas.

Patient engagement in research - What is your understanding?



Source: REFLECT_TOP 10 Don'ts & Do's_Patient Engagement in Research

Speaking about patient engagement, we notice that, although we all use the expression „patient partnership in research projects“, we do not always understand it in the same way:

Actually, the term „patient partnership“ is not always clearly understood by patients and professionals. And it means different things to different people in different countries and different contexts. Additionally, the definition tends to become sometimes a bit „muddy“ because the term is used interchangeably for the concepts of patient participation, patient engagement and patient involvement.

There still is not a clear guidance for patient partnership in research within the field of neonatology and different approaches might be good for different projects. But these different approaches then can also lead to different interpretations.

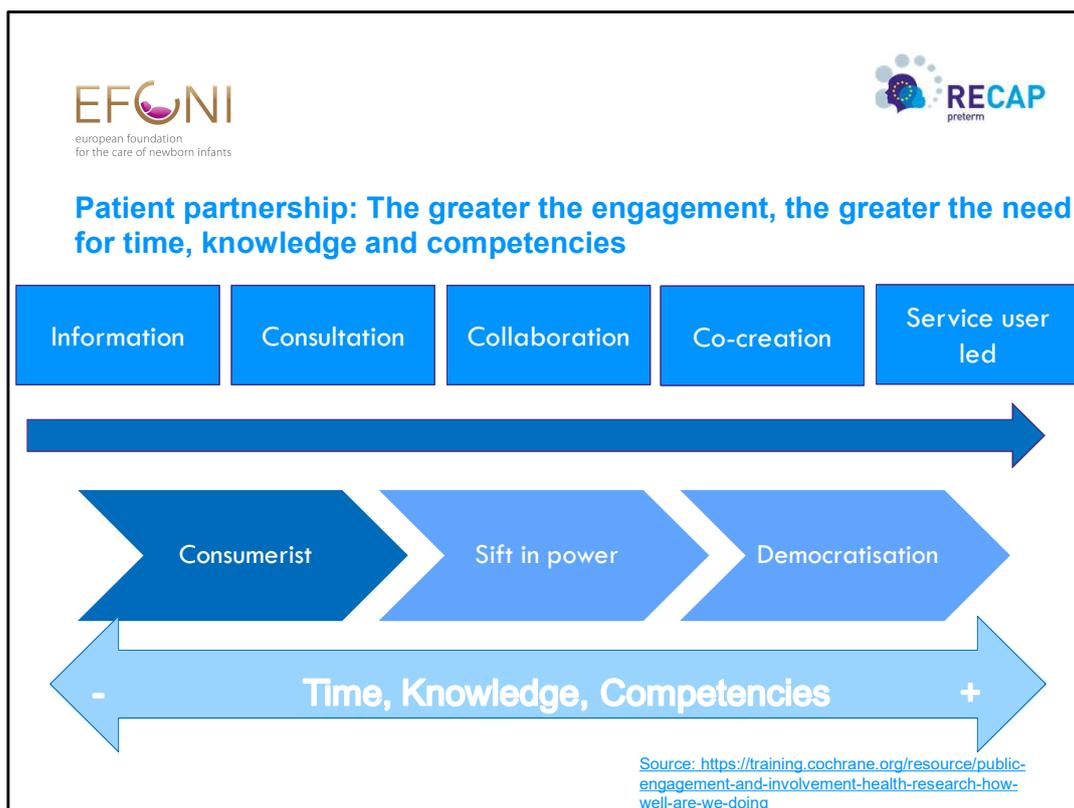
Also, as we have heard before, training on patient partnerships for researchers is currently lacking, so that knowledge levels on patient involvement and how to overcome the current barriers vary enormously.

Unfortunately, there are still today many areas, where patient involvement is not at all happening, is being used as tick box exercise – or it is done in an unsatisfactory way. The three situations that you see in these comics co-developed by the Ottawa Hospital Research Institute seem to be funny at first sight – but they are actually very typical for us and all patient representatives have experienced these situations and heard and still even hear these same sentences and not only once.

And there are further hurdles: For example: we need to find ways to be more inclusive and diverse – how can we involve those referred to as „hard to reach“ (some prefer the expression „seldom heard“)?; We need to create safe spacings within research teams so that we can establish the culture of reflection and learning about involvement. The patient should be represented in the project with the self-confidence and should be equipped with certain competencies to contribute as equal partner to the topic. Ideally, several patient representatives / patient experts should be involved, or at least a group that can combine the necessary skills: Some patients have the readiness to contribute as full members of research teams while others may bring a range of expertise such as in ethics or as „knowledge brokers“. Other patients bring the collective voice of specific, affected communities. Their knowledge and expertise offers insights about people who are unable to communicate on their own behalf.

In order to fulfill this new role, we need „patient experts“. And I mean not only patients by lived experience, but those who receive dedicated education and training – and I'll come back to this a bit later.

This shift in roles can be very challenging, not only for the patient representatives involved, but also for the project team, who might not be used to discuss with patients, who might not know how to react if patients who may not share a same opinion. This will require new approaches and structures and a common effort on both sides.



It is increasingly acknowledged that patient engagement in research can add to creating better projects and outcomes. The graphic is adapted from a Cochrane training on patient partnership and shows very nicely the process we are currently undergoing: We are moving away from mere consultation and information-giving to the patient. “Consultation” is becoming more and more important– meaning that patients and public are asked for their views. Currently, we can observe this shift also by the huge increase in questionnaires or surveys which are being released. However, both these processes do not involve patients as partners. Their contribution has no influence on the research project per se.

The first steps for real partnership with patients is the concept of collaboration: This can mean for example that the questionnaire or survey that will go out to the patients is actually developed together with patient representatives. And that these have an equal voice to that of the researcher. Still, in this concept it is the researcher who decides which areas in the research process the patient is going to be involved in.

Whereas in the co-creation process, which also is explained in more detail in the presentation by Aisling Walsh, there is joined ownership of the project and collected decision-making.

Finally – there is the service user led research where ownership, control and directing lies with patients/public. A very nice example for this is the project “European Standards of Care for Newborn Health”, where EFCNI is leading an interdisciplinary European collaboration that developed standards of care for key topics in newborn health.

It is our firm believe that, if we want to find an effective and meaningful way of working together, we have to shift more and more towards the right part of this continuum: Democratised decision making in the development, design and delivery of research – and with this, we also move forward, towards a shift in power and decision making more to the patient.

But the more we shift from the left to the right side and more shared decision making and power, the more resources - time, knowledge and competencies are needed from the patients’ side.

Source: <https://training.cochrane.org/resource/public-engagement-and-involvement-health-research-how-well-are-we-doing>

Position Paper: Involvement of parent representatives in neonatal research

Developed in 2017 with EFCNI Parent Advisory Board

- Experiences by EFCNI and partnering organisations
- Discussions with different stakeholders
- Endorsed and supported by 50 parent/ patient organisations

Position Paper
 Involvement of parent representatives in neonatal research



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

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Developed by EFCNI

As you may remember from the presentations by Professor Luc Zimmermann and Aisling Walsh EFCNI, and the EFCNI Parent Advisory Board developed in 2017 a Position Paper on the involvement of parent representatives in neonatal research with recommendations from the patient perspective. The Paper is endorsed and supported by 50 parent and patient organisations. Much of what we are speaking about in this module, and particularly the recommendations we give, is referenced in the position paper.

Guiding principles defining interaction



EFCNI Position Paper:
Involvement of parent representatives
in neonatal research

In the Position Paper, we present the so called “7 guiding principles”. These were developed to support defining the interaction between researcher and patient. In this presentation, I touch mainly the principles of “Capacity building” and “Compensation and support”.



Capacity building: Becoming a patient „expert“

- Apart from the personal experience of „living with the condition“, the new way of patient engagement requires various competencies from the patient’s side

Disease / health area	System	Methods
Disease specific knowledge Illness, treatment, living with the condition/ disease	Public health knowledge Functioning of and access to health system	Communication Solution oriented, target appropriate
Basic medical + research knowledge Methods, physiology, treatments, development of medicines	Regulatory knowledge Processes for authorisation and evaluation of medicinal products	Negotiation management and political interaction Processes for authorisation and evaluation of medicinal products

Patients engaged in collaboration or co-creation processes in research projects require certain competencies , skills and time resources to fulfill this new role.

Some people see a risk that patients increasing their competencies and skills become so familiar with the clinical or research area that they lose sight of fresh perspective. However, it is difficult for patients to understand, question and challenge researchers, or to speak up in a group of high-level experts when the language, processes and culture are unfamiliar.

Apart from being experts „by experience“ and bringing in their lived experience, the patient representative therefore needs to have a basic medical knowledge, and an understanding for research processes and methods. But also insights into the functioning of the health system and regulatory processes and training in communication, and negotiation are important.

Such trainings for patient representatives in research are offered in different ways, for example by EFCNI, or, with more focus on the understanding of the development of medicine, the European Patients’ Academy on Therapeutic Innovation (EUPATI). EUPATI runs free classes on European and national levels. Sometimes, also universities or research funders provide such opportunities for learning and support.

With the role shift, another, still thorny topic, needs to be more openly discussed: The payment of patient representatives. This is very critical issue: there are still many – also - systemic barriers, making it extremely difficult for patient representatives being engaged in research and to be paid in a clear and simple way, allowing them to cover their resources. We still see these barriers for company research as well as for institutional research at international/ European or national levels.

Link: <https://www.efcni.org/>; <https://eupati.eu/?lang=de>



Compensation and support

- Removes barriers for patient engagement
- Recognising challenge of NGOs: limited funding for pre-defined projects; no side- or pre-financing possible
- Payment does not mean „covering expenses“
- Payment means: paying for time, skills and expertise brought to research project or related activity **IN ADDITION** to covering expenses
- Compensation reflects level of time, effort, skill level; should be comparable to rates of pay of other professionals in similar roles)
- How fair is payment “based on fair market value” really?



Source: REFLECT_TOP10 Don'ts & Do's_Patient Engagement in Research

Historically, patients have always contributed to healthcare and research in a volunteer effort. The background for this may be that patient engagement was always and till today still often is regarded as a charitable or altruistic action. Patients need to be grateful or happy to be involved, as the research in the end is done for their best – they don't wish or need to be paid.

But in all this, we should not forget that for the patients or patient representatives, participating in a project means taking time off of either their work and caregiver duties or taking time away from their regular daily activities in their role as patient representatives.

All other project members are paid for their work. Even if professionals are not explicitly paid to be part of a project, it is still part of their job that provides them with the necessary resources and social security.

Like all other partners, patient partners bring experience, expertise and skills to the team. They may not have studied the topic and gained university expertise, but living with the condition and bringing in their personal experience, also their experience with the health care system, or that of a caregiver offers invaluable insights

In the context of patient partnership in research, patient partners should be offered payment / compensation for their time and expertise brought to a research project or related activity *in addition* to covering any expenses related to them participating in those activities. It is important for researchers to recognize that patient partners may have expenses that fall outside the typical expenses that faculty, staff, or students might have.

We also think a lot about the “fair market value” that is often applied but with a difference between the status of a researcher and that of a patient. Is it really “fair” to pay the patients so much less than the researcher? Even if the patient doesn't hold a university diploma for this special case –What does all this tell us about the way of partnership and of valuing the patients' contributions? Are the insights a patient / patient representative brings to the table so much less worthy?

Researchers should also work with their institutions to ensure that their policies encourage fair and reasonable expense reimbursement for patient partners who incur costs when participating in research. And we all need to demand that structures and policies are in place that allow the compensation of all contributing patient partners, for example also a “Patient Advisory Board” in institutional grants.

Paying all team members but the patient partner – or paying the patient partner “pocket money” for bringing his or her experiences and networks creates an imbalance in power. There definitely are costs for patient partners to participate in research projects. No or less payment allows only those patients who can afford to volunteer to bring in their perspectives. Or to commit to a project but in exchange leave other equally important tasks undone. Patient partnership and collaboration needs to be a paid engagement, as only this will allow the patient partners to commit at more full level.

There is only limited guidance and access to advice or training of researchers on how to realize this partnership is often lacking. This leads to the challenge that still today, research partners struggle when it comes to the topic “payment” or “compensation” and prefer sticking to the “old” way of doing things. The “status quo” seems to be easier than to find new ways to offer compensation.



Compensation and support

- Be aware on the resources required for patient engagement throughout the entire project
- Include costs for patient partnership in the project proposal
- Ask patient partners if they have their own rate expectations
- Think about foreseeing the position of a coordinator for patient engagement
- Reimburse individual patients for their time and give recognition for this work
- Ensure that patient partners are aware on possible tax implications and/or reporting requirements.

I'd like to highlight some tips that may help dealing with this thorny topic of „patient compensation“ a bit easier:

At the beginning of a project: Be aware on the resources required for patient engagement throughout the project

Include costs for patient partnership in the project proposal

Ask patient partners if they have their own rate expectations – particularly when they have or plan to have paid staff to facilitate the work for your project, they indeed have own rates.

Think about foreseeing the position of a coordinator for patient engagement

Reimburse individual patients for their time and give recognition for this work

Ensure that patient partners are aware on possible tax implications and/or reporting requirements. Particularly when they are still fresh in their new role, patients may lack this important information.

In conclusion:

- We have achieved a lot in advancing working in partnership with patients, but still much work needs to be done
- Cultural and systematic changes are required
- Broader commitment and buy-in to working in partnership with patients requires also giving up and development of new ways of sharing power and decision making
- Training on both sides, researcher and patients on working in partnership is required
- Compensation of the patient partner is crucial to recognise time, competencies, skills and allow for optimal contribution to a project

In conclusion, I can say: we have achieved already a lot in advancing working in partnership, but still much work needs to be done.

We need to seek for cultural and systematic changes that allow to involve patients as partners easier

Increasing the partnership collaboration means also giving up power and developing new ways of shared power and decision making.

We need more training and awareness on both sides, researcher and patients how we can make this partnership work and increase competencies and skills.

Overall, the patient as new partner in research projects also requires compensation for his or her work and fair recognition of his or her contributions.

Particularly in these currently difficult times, we need to make sure that the lived experienced voice becomes even stronger. My vision is that in our health area, we continue seeking the contributions of those directly affected by preterm birth and also, in the near future, include children as partners. In the end, they are in the centre of what we all do.

Thank you

In case of questions, please feel free to contact:

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