Guideline

« Key Considerations for Successfully **Involving** Affected **Parents** in **Neonatal Research** »

Background

This guideline is based on findings from Care PartIES, a participatory research project that included parents of preterm babies, researchers from the University of Zurich, and the organization Frühchen & Neokinder Schweiz (preemies and hospitalized newborns in Switzerland). Care PartIES identified which research questions parents find especially important and in which ways they wish to actively participate in neonatal research in their role as parents.

Aim

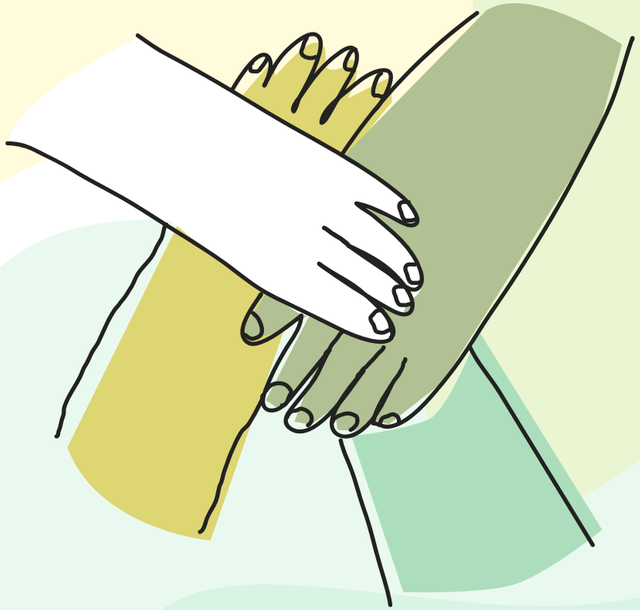
This guideline contains recommendations for successfully involving parents in neonatal research. It is intended for neonatology professionals and researchers, patient organizations, and others interested in neonatology.

Parents' perspectives on neonatal research

Care PartIES findings show that neonatal research does not usually focus on the specific topics parents find most interesting. These topics include communication between the parents and healthcare professionals and the effectiveness of certain support services (e.g. psychosocial support) for families while children are hospitalized in the neonatal unit. In addition, these findings show that parents often focus on a different time horizon compared to neonatal professionals: instead of considering only the period of time when their child is in the neonatal unit and focusing on the child's immediate clinical outcomes, they concentrate above all on their child's long-term development. Another issue parents find important is the impact this situation can have on their own mental and physical health as well as on the health of the entire family. Enabling parents to contribute such perspectives to research projects can greatly increase the practical relevance of the research for families.

Ways to involve parents in research

Care PartIES also found that parents are open to participating in research projects at different levels. One common method of involving parents is asking them to complete surveys. Some, however, are interested in participating to a greater extent, for example by providing feedback on research proposals and/or being involved in designing research questions. This would enable them to include their perspective earlier in the research process. Parents can also assist later on during a research project's implementation by recruiting other parents to participate. In addition, some parents are interested in becoming involved in the publication process and being listed as coauthors.



Degree of participation

The degree to which parents participate in a research project depends on their immediate circumstances. Some parents prefer to participate to a lesser degree, while others are willing to become more deeply involved and, for example, also participate in project meetings. In general, parents' willingness to participate in a research project is lower while their child remains in the neonatal unit and is greater after the hospital stay is over.

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The right time to request participation

It is essential to choose the right time to ask parents to participate in a research project. If a project focuses mainly on the time spent in the neonatal unit, it is appropriate to approach parents directly in the unit. In such cases, it is important to consider whether the family's child is stable and if they are already familiar with the unit's procedures. According to many parents, this is not the case until two weeks after a child's birth at the earliest. When choosing the right time to approach parents, it can be helpful to consult the neonatal unit's nursing staff; they are usually able to judge best whether a family might be interested and ready. Furthermore, it makes sense to have a healthcare professional who already knows and has a relationship with the parents ask them to share their experience with researchers.

On the other hand, for projects with research questions that extend beyond a child's stay in the neonatal unit, the child's discharge could be the right time to ask a family to participate in such a project at a later time. Some parents need more time to process the experience of their baby's premature birth and may not be emotionally ready to participate when they are first asked. Other parents may not be interested in being actively involved in research due to a lack of time or a previous negative experience with a research project. In such cases, healthcare professionals should make sure the same families are not approached too often. In general, this guideline recommends always having informational material about research and its relevance readily available in the neonatal unit.

General recommendations

- Parents' **emotional security** is a relevant factor in deciding whether to participate in a research project. Due to the emotional stress associated with a premature birth and/or a child's stay in the neonatal unit, an empathetic approach towards the parents is vital.
- Parents appreciate it when they can plan their involvement in advance, when the extent of their participation is clear, and when they receive compensation for their involvement – all of which signal **appreciation**. In addition, offering childcare, for example during a workshop, shows parents that their everyday lives have been considered.
- To make the process more **straightforward** for parents, it is helpful to clearly define different project steps from the start and/or regularly inform participants about upcoming project steps and the publication of research results.
- Parents like receiving **project information** in writing and in plain language so that they can take time to read it and mentally prepare themselves for the study.
- A study's aims and benefits should be clearly stated. It is important for them to be personally **relevant** to the involved parents and for the parents to understand the significance of their participation.
- It is beneficial to include **different perspectives**, for example from both mothers and fathers. And using an interpreter can help remove language and cultural barriers.
- Ensuring data – especially health-related and personal information – is **anonymized** and **clearly stating how data will be used** are key criteria for increasing parents' willingness to participate in a research project.

Contacts for parent recruitment

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info@fruehchenschweiz.ch

Né Trop Tôt (French-speaking Switzerland)

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info@netroptot.ch

Global Foundation for the Care of Newborn Infants

gfcni.org
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Recommended reading

Global Foundation for the Care of Newborn Infants (GFCNI, 2021)

Position paper: Involvement of parent representatives in neonatal research

Available at:

gfcni.org/research/collaborate-with-us

Scan the QR code below for more information on the project's website:

Scan the QR code below for more information about Frühchen & Neokinder Schweiz:

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Note: A participatory process was used to create this guideline. Parents who were involved in the Care PartIES project helped revise this guideline, and experts in the field were asked to provide feedback.

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