

The space between procedural and situated ethics: Reflecting on the use of existing materials in design research on children affected by stroke

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<https://doi.org/10.21606/drs.2024.769>

Abstract: Conducting design research in hard-to-enter care environments with children affected by stroke poses important ethical questions. Research focuses on procedural ethics *or* on situated ethics, emphasizing a hard-cut between research practices before and during fieldwork. This paper explores this duality through an investigation of publicly available existing materials (i.e., biographies and YouTube videos). What was intended as a preparatory step before ‘entering the field’ becomes the primary way to better understand the role of the built environment in everyday lives of families affected by childhood stroke. In this paper we reflect on the shared space the investigation creates within a research consortium. We highlight how this exploration invites thinking differently about research practices in terms of ethics related to using existing materials as data, developing sensitivity to the research context, and opportunities for allowing differences between collaborating researchers.

Keywords: research ethics; care environments; childhood stroke; existing materials

1. Introduction

People are very diverse and all have their own specific experiences and ways of being in the world. This is the case for adults as well as for children. There is more or less broad consensus and awareness that involving children in design research and processes is important (Parnell & Patsarika, 2019) to create a better fit between design outcomes and children’s diverse lived experiences as these might differ significantly from assumptions of professional



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designers (Ramioul et al., 2020). Therefore, each child can be understood as a unique and valued ‘user/expert’ (cf. Ostroff, 1997) of our shared world. This understanding ties in with a ‘rights-based approach’, which considers children as citizens with rights, and by involving them in research and design they can participate in decision-making processes that affect their lives (Knowles-Yanez, 2005). It also aligns with recent childhood sociological and geographical approaches that understand children as active constituents of the world; as makers of space (Hackett et al., 2015).

Conducting research with children in general and children with health issues in particular, in sensitive and hard-to-enter formal and informal care environments, poses important ethical questions. A growing body of studies in design research and other disciplines discusses children as participants and the ethical issues related to conducting research with children considered vulnerable (cf. Spiel et al., 2020). Research ethics refers to applying ethical principles to the research process as a reflection of moral rules and values (Roth & Von Unger, 2018). Discussions in the domain of research ethics in design and social sciences tend to contrast procedural ethics with situated ethics in the field, highlighting how the former are considered insufficient in preparing researchers for the complexity of the field (Guillemin & Gillam, 2004). Thus, to complement formal procedures that must be followed before entering the research field, situated ethics—that is, the ethical situations encountered during fieldwork (Ellis, 2007) that demand ethical decision-making—are equally central to conducting research. Accordingly, they must be understood and addressed as they emerge during the research process (Quinones et al., 2023).

This paper explores the space between procedural and situated ethics through publicly available existing materials such as biographies and YouTube videos. This exploration forms part of an interdisciplinary European project involving researchers from architecture, cognitive neuroscience, health economics, neurology, and pediatric cardiology with the aim to investigate the role of the built environment in the everyday lives of children with stroke and their families. In this paper, we focus on how researchers in the field of architectural design, with different educational backgrounds (anthropology, (engineering) architecture, human geography, and interior design) and levels of research experience (from PhD student over postdoc to assistant professor), working in research groups in Austria, Belgium and Germany, explored existing materials as data.

The aim of this paper is threefold: 1) to show how the use of existing materials helped us (cope) with the reviews of the ethical committees as well as with gaining an understanding of the complexities of the field; 2) to point at the ethical issues we encountered related to the use of existing materials; and 3) to better understand the role these materials played in constituting a shared space for reflection within the research consortium.

After briefly situating our research in the broader field of research ethics and giving examples of how each of us engaged with existing materials, we present our analysis. We conclude by considering how the ways we have been working with existing materials can contribute to thinking differently about research practices.

2. The space between procedural and situated ethics

Research related to ethics of involving children as participants mainly focuses either on procedural ethics and the Research Ethics Committees (REC) that evaluate research (e.g., Parsons et al., 2015) *or* on situated ethics that arise between participants and researchers when in the field (e.g., Graham et al., 2012). These studies bring into view a gap between static, anticipatory procedural ethics – bent towards Beauchamp and Childress’s (2001, 1st edn, 1979) principles of bioethics: autonomy, beneficence, nonmaleficence, and justice –, and the dynamic, unpredictability and messiness of ‘immeasurable’ (Sleeboom-Faulkner et al., 2017) ethics when researchers enter the field (the real world) (cf. Pleysier et al., 2019).

Research on this experienced gap focuses on boundaries, hurdles, taboos, necessary evils and minefields (Richards et al., 2015; Yanar et al., 2016). Some try to bridge this gap by offering researchers guiding reflective questions to prepare and conduct research with children (Phelan & Kinsella, 2013). Others see opportunities in exploring this gap. They reflect on what can be learned from encounters between (doing) design research – situated ethics – and healthcare ethical protocols – procedural ethics (Tutenel et al., 2019). What characterizes both approaches to this gap is that there is a hard-cut between research practices before and during fieldwork.

In our research project, this gap became significant because of the time it took to gain ethical approval from the RECs in the three EU countries, ranging from three months to more than one year; alongside immense differences between how such committees work and evaluate research. Previous research has already brought into view these differences across countries (e.g., Fluss, 2004) and emotional costs like embarrassment and failure researchers experience, or tensions between researchers’ conscience and procedural requirements (e.g., Pitt, 2014; Monaghan et al., 2013). In our case, turning delayed access to participants (frustration) into productivity changed the position of existing materials in our research project. It is important to note that the use of existing materials was already integrated into the research proposal to inform the selection of methods and topics for subsequent fieldwork.

Initially, we saw these materials as a stepping stone towards the ‘real’ research. However, due to the time required to gain ethical approval for the fieldwork, these materials became more than that. As they were all we had at the time, they became the data to better understand the role of the built environment in the everyday lives of families affected by stroke. A consequence of this widened gap (in time) is that it made us understand that the hard-cut boundary between procedural and situated ethics is in fact permeable. Working with publicly available existing materials helped us reflect on ethical issues commonly related to procedural and to situated ethics.

In this context we selected three themes for the (architectural design) researchers to reflect on:

1. A few lines, up to a paragraph on how you approached your investigation of the selected materials

2. Some striking examples of how the built environment features in the materials you looked at and that your approach to ‘the data’ resulted in
3. A short reflection on why (or to what extent) this step in the research has been relevant for you, for your research, to prepare you for fieldwork with families

Reflections and examples were gathered via e-mail and integrated in this paper.

3. Access to the field through existing materials

“What really stood out from [title of book] is how throughout a (long) period of rehab all sorts of objects and devices (orthoses?) are used to adapt [the child’s] body, influencing her being and moving within her environment. Also, in terms of the formal and informal care environments: In [another girl’s] story it is described explicitly how so much of the work recommended within (formal) therapy contexts was transferred to the everyday (informal, +/-home) environment; constantly improvising to accommodate these exercises.” (Pleuntje)

Design researchers in the field of architecture (education) have already used existing materials as data to access the field of study. Some have used autobiographies (Baumers et al., 2010; Kinnaer et al., 2016; Jellema et al., 2019), while others used visual accounts such as TV documentaries (Tutenel et al., 2023) to gain insight into lives and the significance of the built environment in peoples’ experiences. Using such materials aligns with research indicating that professional and student designers prefer condensed, design-relevant raw data, coupled with narrative elements (Van der Linden et al., 2019). They are also drawn to graphically rich information (Annemans et al., 2014), enabling them to quickly pick up overarching themes and delve deeper into project-specific details (McGinley & Dong, 2009).

Building on this previous research we started searching for existing materials about childhood stroke. As this was an exploratory phase of the research, we did not search in a systematic way. In fact, because childhood stroke is a rare disease, we were enthusiastic about and thankful for anything we could find (e.g., on the internet or via tips of patient organizations) and started from the idea that if people find things relevant to share publicly in whatever form, it is worth our attention as researchers. Most of these materials can be described as recovery journeys of families learning to live with the effects of childhood stroke. In total, we included five books each about one family, two children’s books, one anthology, two accounts published in a journal, and fourteen visual accounts in the form of YouTube clips. Because of the ethical tension we do not include references for these materials in this paper. Four of us focused on written narratives and one of us on visual material. Each of us approached the materials from a different perspective/angle:

- Pleuntje formulated guiding questions that related to the built environment generally (e.g., What are the physical settings that I notice?), care environments specifically, other technical and material aspects as well as attention for the ‘voices heard’ in the narratives. While identifying relevant excerpts the (changing) condition of the child (disabilities/sensitivities related to activities) was added as an important category.

- Piet's interest was firstly, to get a feel of what different environments were brought into view in the clips (e.g., the street, the hospital, the bedroom, ...); secondly, to look for instances of change and how these are expressed in the YouTube clips (e.g., "She can't do [this] anymore, so we did [this or that]"). The latter aligns with a personal interest in how people take care of one another and themselves as 'everyday designers' (Wakkary & Maestri, 2008).
- Birgit tried to comprehend the emotions conveyed within the narratives, aiming to capture emotional responses experienced by the families. Within this collection, quotes concerning the built environment were highlighted.
- Anne-Sophie looked for key areas of interest, including information about the child's hobbies, abilities, and challenges, descriptions of their daily environment (e.g., home, school, and neighborhood), references to healthcare environments (e.g., healthcare facilities and therapies), and insights into family relations.
- Maja extracted textual fragments related to healthcare environments and grouped these into themes. This 'relationship' to healthcare environments was defined as any fragments related to situations taking place in healthcare facilities but also transitions from home (or another environment) to a healthcare facility and vice versa. A differentiation was made between the fragments associated with discovering the child's diagnosis and subsequent therapy and recovery processes.

As Pleuntje's quote at the start of this section testifies, using these materials could indeed be relevant for design researchers; e.g., how the built environment is constantly shaped and reshaped through technologies used on the body; how the boundaries between formal and informal care environments become blurred. As such, what we at first considered the research field (working together with families) broadened; the existing materials were not used as stepping stone towards the field but became part of it. What we did not take into account are the ethical aspects related to considering such materials as research data.

4. The research ethics of existing materials

In considering existing materials as research data, we have increasingly become aware of and reflected on the ethical aspects of using these materials in research.

In the following section, we discuss various aspects we struggled with, or that became important to us. Some work on the ethics of existing materials and the use of published (on- and offline) written or video narratives in research has been done in other fields such as nursing, health sciences, and sociology (e.g., Burles & Bally, 2018; Morrow et al., 2014). Qualitative researchers in these fields have studied subjective experiences accessed through solicited and unsolicited narratives for many years (e.g., O'Brien & Clark, 2010, 2012; Legewie & Nassauer, 2018; Snee, 2013).

We first delve into three issues linked with procedural research ethics. These center around the implications of designating certain elements as data. Within the realm of procedural ethics, this distinction is pivotal, as it triggers the application of ethical principles and guidelines. Within the consortium, these issues made us reflect on ethics and on our own research assumptions. We rely on literature to reflect on the questions we ask ourselves. Additionally, we address two issues that align more with situated ethics, highlighting their ethical significance and exploring the impact they have within our research consortium. We present these issues relying on the researchers' e-mail reflections.

Our reflection aligns with prior research on ethics of secondary data (cf. Burles & Bally, 2018) that highlights ethical concerns commonly associated with procedural ethics, but also points at 'ethically significant moments' (Guillemin & Gillam, 2004, p. 262) that do not always manifest as moral dilemmas.

4.1 Can existing materials be valid research data?

The first topic we discussed was whether we could consider these materials as research data.

Everything has the potential to be data, but it is only through a researcher's active involvement that something becomes data. Researchers try to 'let the data speak for themselves', but the problem is that no data do so (Gould, 1981). As 'results', unanalyzed data mean very little, nor do results emerge from data by themselves. Instead, data are simply materials researchers engage with, applying their expertise and contextual knowledge to discern their importance and derive meaning from them.

So, indeed, the biographies and YouTube videos we found are not data by themselves. They became data when we decided to explore whether and how these materials might offer opportunities to gather insight into the role the material environment plays in the lives of families affected by childhood stroke.

Initially – and at times, still – we asked questions about the trustworthiness of these accounts. Do such personal and subjective accounts reveal or represent something real that can be generalized? Such discussions foreground a longstanding and ongoing debate among qualitative researchers. Roughly speaking, qualitative researchers tend to lean either towards a more positivist or causal side of the research spectrum, or towards a more interpretivist approach which attempts to legitimize research without linking it to a realist ontology and foundational epistemology (cf. Bochner, 2018).

Asking questions about the 'realness' of these narratives suggests a more positivist orientation, adhering a form of 'subtle realism' (Hammersley, 1995). Asking 'what might be learned?' hints more towards the relevance or truth-value (cf. Huttunen & Kakkori, 2020) these materials might carry within a research context, which leans more to the interpretivist side of the continuum.

By making explicit this continuum we do not intend to value one side over another. However, we believe that in qualitative research connecting the study of child health, illness and

well-being with design research, a positivist leaning is more dominant. If research aims to do justice to the subject at hand, it is important to keep an eye on the whole continuum or at least try to be more aware of one's own research assumptions and the limitations thereof.

4.2 Is it ethical to repurpose existing materials for research?

The existing materials we selected and used were not written or recorded with the intent to say something about the built environment. Is it ethical to use these materials for our research?

To help us with this question we started looking at studies that focus on the ethics of secondary analysis. Research funding bodies strongly promote the practice of conducting secondary analysis (Morrow et al., 2014). Secondary analysis and the promotion thereof are at the same time critiqued for being examples of neoliberal ideas dominant in the current Western world (Slavnic, 2017), for fitting with quantitative research but not with qualitative research – ignoring the co-constructive and situated nature of qualitative research materials (Irwin et al., 2013) –, and for assuming to pose only few ethical challenges (Weller, 2023).

Researchers point at two ethical considerations on secondary analysis that stand out: responsibilities towards participants in the original research, and the need to achieve a contextual understanding of the data by identifying and countering risks of misinterpretation (Morrow et al., 2014).

Related to the former, an important concern is that we use these materials for a different purpose than intended by their makers; even more so, they were not made in any research context. In our research, we use existing materials to learn about the everyday lives of families affected by childhood stroke. Since people's practices are always carried out in and by material and built arrangements one can argue they will be able to teach us something about these arrangements. Hence, our research is perhaps not so much about using materials for a different purpose but rather viewing or reading them from a specific perspective.

Regarding the risk of misinterpretation, interpretation can be understood differently (Kerdegan, 2015, p. 18-19): in terms of epistemology or ontology. In the epistemological view, the researcher can observe and analyze reality –as something 'out there' from a distance. In the ontological view, this distance is impossible. This ontological view points at the fact that writing or recording materials are on the one hand already ways people make explicitly conscious their learning, understanding, and experiences. On the other hand this view points at the impossibility of a researcher being a neutral and objective observer. Researchers must be conscious of their embeddedness in a specific cultural and historical setting, and their understanding of themselves and the entities they encounter as grounded in their practical activity in this setting (Packer, 2011, p. 184).

Both stances towards interpretation (and research) are present amongst the architectural design researchers within the consortium. To leave room for different perspectives the distinction between substantial and ethical validation is helpful (Angen, 2000). Substantive vali-

dation is how the research accounts for prior research, theory and self-reflexivity (e.g., publishing in peer-reviewed journals). Ethical validation – whether research informs or has the potential to transform practices – is ensured in our use of existing materials by presenting our intermediate analyses and what we learn from them within our research groups and the whole consortium as well as towards an advisory board of people with relevant expertise or user/experts. Also, writing this paper exemplifies ethical validation. That is to say; we did not plan to do so; it was not a ‘work package’ as such in the project proposal, rather, working with these existing materials became important (to us) and of relevance to the subject matter.

4.3 How to use this material?

Due to the enhanced role these materials began to play in our research, we started to wonder if and how we could use these materials in for example, possible publications.

A critical aspect of evaluating research ethics pertains to the extent to which data provide distinctive opportunities for examining a specific phenomenon (Legewie & Nassauer, 2018).

“Consistent with the principle of beneficence, if certain data holds the potential to offer the most valuable insights into a particular issue, conducting the research even in the absence of consent may be the ethically sound decision, provided that the anticipated benefits outweigh potential risks.” (Legewie & Nassauer, 2018, p. 8)

Discussions about this issue relate to the concepts of confidentiality and privacy (anonymity), regarded as essential ethical principles of research (O’Brain & Clarck, 2010). In relation to the publicly available existing materials, this becomes somewhat blurry and confusing. Also because these materials are in most cases persistently available and easily traceable (Roberts, 2015). Following O’Brain & Clarck (2010), the primary concern pertains to using techniques such as pseudonymized quotations, blurring persons depicted or not mentioning URLs, seemingly employed to safeguard the identities of narrators. However, applying (procedural) ethical guidelines surrounding confidentiality and anonymity appears unsuitable. In the case of public materials it disregards the intellectual property of the authors and neglects to acknowledge them as the originators of their creative contributions.

Researchers working with publicly available materials must navigate the public-private spectrum, the intended audience, topic sensitivity, and practical challenges when seeking consent (Burlles & Bally, 2018). If authors grant consent, researchers can discuss aspects related to privacy. However, when no attempt is made to obtain consent, researchers must assess the potential for harm and work to minimize it.

Adding complexity to our research is the fact that the majority of the materials involve adults (e.g., parents, care professionals) writing about or depicting (very young) children. Information regarding whether the children provided their consent is missing for most of the material we found. The same concern applies to the individuals (accidentally) featured in the YouTube videos. Although we simultaneously know that “not acknowledging them, pixelating faces or pseudonymizing quotes can also be unjust, disempowering, and unnecessary, and can reduce ‘pride’” (Yanar et al., 2016, p. 122). Questions we are reflecting on are: How

do we decide to seek explicit consent from the authors or not? In the case of written works, will authors be acknowledged for their creative contributions? When it comes to YouTube videos, will we only use and make reference to materials from public channels, such as those associated with hospitals or patient organizations, rather than from individual channels? What about the recognizability of buildings or spaces we might want to show? And, do we blur or pixelate people's faces in publications, even if acknowledged? In sum, how do we decide on our criteria or good practices to assess whether using specific materials in a research context might potentially cause harm?

4.4 How to hold intimate knowledge in a collaborative space?

The materials studied allow, in various ways, an intimate knowledge of – or at least a glimpse into – the lives of families affected by childhood stroke. Intentionally looking into families' lives in this way would also seem to have an ethical dimension. Furthermore, the individual researchers look for ways to share their insights within the consortium. The collection our findings form together highlights the (situated) ethics in the relation between researchers and makers of the secondary materials who are not aware of their personal narratives becoming part of such a collection. We illustrate this with examples of intimate aspects of people's lives that we gain access to.

- **The (child's) body.** Through a phase of rehabilitation and physical therapy Pleuntje tracks a child's changing interactions with her environment using a wheelchair but over time transitioning to walking with a 4-pronged cane, then a regular cane, and switching to a foldable cane. Maja comments on the noticeable differences between adult stroke and childhood stroke:

“The stories in the existing material have shown that impairments and challenges after a stroke can greatly differ between children and adults; stroke in children is much more unpredictable, and the condition can deteriorate or improve in different life phases. Their recovery path is also very individual compared to the structured rehabilitation system for adult stroke survivors.”

- **Family life and emotions.** Birgit learns that families may face social exclusion when it comes to, e.g., accessing facilities like swimming classes or playgroups due to a child's impairments. Maja notes parents expressing their feelings about sharing spaces with other patients; one mother did not like her child to share a bathroom with another patient, while another felt that by staying in a double room, she was supported by having another parent there to share what they were going through.
- **Sensitive contexts**
 - *Healthcare facilities.* Maja pays particular attention to the way families experience healthcare facilities and comes across different descriptions of how parents interact with space in inpatient healthcare facilities: modifying the room environment to create a positive environment for the child, constantly observing the child and carving out a space for

themselves even when there is no adequate space in the room, and trying to get them out of the room and promote activity. Anne-Sophie recognizes that every family's journey through the medical and rehabilitation system is unique but also identifies a recurring theme in the narratives that accommodations for family members during inpatient stays are frequently insufficient.

- *Home environments*. Birgit identifies the strong preferences one particular child has for tidiness, routine, and rituals, mirroring behavior observed in kindergarten. Piet highlights how new objects and ways of doing things at home because of the stroke, affect the everyday of all family members. He also looks beyond the person being interviewed in a video to what else is in the picture; things or actions that might have become so mundane to them that families did not even bother to bring them into focus (e.g., using a wall or a chair as assistive technology; turning the kitchen into a therapy room).

By conducting the research in this way we learn about differences between the architectural design researchers within the consortium. While these differences may pose a challenge or be problematic in relation to procedural ethics (i.e., formulating/ agreeing on a research plan) and aligning the way fieldwork is conducted simultaneously by different researchers, they are experienced as productive and enriching in the context of this project. Research using existing materials was considered helpful for various reasons: to gain insight into what families want to report and what they find challenging; to formulate topics and questions for the next research phase that might have been overlooked without this exploration; to inform our thinking about how children may participate in the research; it helped to develop empathy and sensitivity; it prepared us emotionally and intellectually; and even made it possible to identify potential collaborations that could enrich the project's research.

One of the tangible outcomes of this 'shared space' was a research protocol to be used by the various partners to do fieldwork (in three countries). Unlike the analysis of existing materials, this was not part of the initial research plan. However, we had a chance to do this in the time it took to answer to the demands of the most challenging ethics committee, which required submitting a research protocol.

4.5 Whose voices do we account for?

The existing materials allow us to develop a sensitivity towards the research context as we (start to) gain insight into the lives of children affected by stroke and their families. One of the aims was to get a sense of the breadth of the 'landscape of care' (cf. Milligan & Wiles, 2010) families deal with. Simultaneously, an underlying intention was to seek out a diversity of experiences.

If we consider the makers and authors of existing materials as participants in our research, it is necessary to reflect on our 'sampling strategy' or 'recruitment approach' and wonder,

whose voices are raised loud in the texts and videos and whose are hardly heard? Due to the exploratory intention of this part of the research, combined with the rare topic of interest, any and varied secondary materials were identified as relevant without formulating specific inclusion criteria upfront. It is important to point out that the researchers together master various languages, which also allowed including materials originating in different countries. This resulted in a breadth of materials with not all researchers analyzing the same, although some overlap existed.

As we shared preliminary findings within the whole consortium, we became aware of a possible bias regarding the children and families publishing their stories. While children who have undergone a stroke may live with any or multiple of a variety of impairments, a concern was raised that there is an overrepresentation of certain conditions in published accounts. Where accounts are published by or with a healthcare organization, recovery and positive outcomes are emphasized. This raises our awareness of biases that will likely be present among the families willing to participate as our fieldwork participants. Also, it emphasizes the need to consider those families who are 'always' mis- or underrepresented in research, lack access to internet resources, etc.

5. Concluding remarks: Lessons from exploring existing materials

In the space that existed for us to consider the **ethics related to using existing materials as data**, our thinking about procedural and situated ethics has changed. When it comes to 'getting ethics' or 'being ethical' (Lyle et al., 2023), we perhaps made the mistake of assuming our chosen exploratory approach would pose few ethical challenges (cf. Weller, 2023) and are now under the impression to have developed a more thorough and thoughtful practice. While the situated task of 'being ethical' in our handling of existing materials raises important questions related to the authors/makers of the materials we investigated; the reflections and discussion we had that were aimed at 'getting ethics' ensured that ethics became an intrinsic part of what we are doing.

From an ethical standpoint the materials included in our study offer some unique opportunities **to develop sensitivity to the research context** and, through narrative accounts, an intimacy or closeness to the topic that helps prepare for fieldwork. With the intent to minimally burden 'real world participants' and maximize learning from what is publicly available, there is a beneficence to using existing materials. This relates to both the scarcity of research resources and the topic of research, namely the interest in families affected by the rare incidence of childhood stroke. Assessing who is given voice in future analyses of existing materials could potentially shift strategies commonly used in the field, to decision-making around and (a more) critical appraisal of existing materials.

The space explored in this paper between procedural and situated ethics became a shared and productive space in the context of a research consortium, where **opportunities were created that allowed differences between collaborating researchers**. Making explicit and

integrating differences between novice and experienced researchers, but also between research practices, habits, and viewpoints of the research groups may be a way to care for future research participants and the project as a whole.

Authorship contribution statement: Jellema P. & Tutenel P. (joint first author): Writing: original draft, research examples, review & editing; Investigation | Moser B. & Schoss A.-S.: Research examples, review & editing; Investigation | Kevdzija M.: Research examples, review & editing; Investigation; Project coordination | Jelić A. & Heylighen A.: Review & editing; Supervision

Acknowledgements: This work has received funding from the European Union's Horizon 2020 research and innovation programme under the EJP RD COFUND-EJP N° 825575. The research was funded in part by the Austrian Science Fund (FWF) in Austria [I 5886], the Research Foundation Flanders (FWO) in Belgium [G0G5221N], the Federal Ministry of Education and Research (BMBF) in Germany [01GM2109], and by the Francqui Foundation (Fondation Francqui – Stichting) in the form of Ann's Research Professorship. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or national/regional funding agencies. Neither the European Union nor the granting authorities can be held responsible for them. The research was approved by the Ethical Committee of MedUni Wien [2263/2021], TU Dresden [SR-EK-355082022], and UZ Leuven [S67320]. We thank SCHAKI e.V. – Support group for families of children with stroke – for providing us with information and sources about families affected by childhood stroke. We thank the members of the advisory board and our partners of the Build Care collective for the inspiring collaboration and discussions: Anna Franziska Kalhorn, Magdalena Muszynska-Spielauer, Anna-Theresa Renner, Gesine Marquardt, Lisa Bartha-Doering, and Sophie Mandl. Our thanks also goes out to our (workplace) colleagues at KU Leuven (Research[x]Design and Els Ortbuis & Ruth Heying at UZ Leuven), TU Dresden, and TU Wien.

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