Title: Increased interaction and procedural flexibility favoured participation: Study across European cohorts of preterm born individuals

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ABSTRACT

Objective: To understand participation and attrition phenomena in-context of European cohorts of individuals born preterm through the in-depth exploration of situational elements involved.

Study Design and Setting: A multi-situated qualitative design using focus groups, individual semi-structured interviews, and a collaborative visual methodology. A purposive sample of 124 participants (37 professionals, 87 cohort participants) was recruited from Belgium, Denmark, Finland, Italy, Norway, Portugal, and The Netherlands.

Results: Main motivations to participate included altruism/solidarity and gratitude/sense of duty to reciprocate to healthcare professionals. Major deterrents were insufficient interaction and information sharing or postal questionnaires alone. Combining multiple strategies for contact and data collection, shorter periodicity and face-to-face interaction favours participation. Professionals’ main concerns were financial and human resources constraints and societal changes related to communication. Population mobility, migration, and displacement emerged as a challenge to trace participants, especially vulnerable or foreign-origin.

Conclusions: Retention would benefit from tailoring inclusive strategies and consistent promotion of altruistic research goals throughout the cohort life cycle. Parents’ points of view were determinant until children reached adulthood, whereas mothers continued to be main facilitator.

Increasing regular interaction with participants, improving flexibility in contact and assessment methods, enhancing the sharing of study’s results, and prioritizing face-to-face assessments can help to mitigate attrition.

Keywords: European cohorts, Premature, Participation, Multi-situated qualitative study, Collaborative methods.
INTRODUCTION

Population-based cohorts are commonly conducted epidemiological studies and powerful study design in public health research. The use of large population-based samples promotes representativeness and the ability to capture the impact of policies and programme interventions on health quality and equity (1; 2; 3).

Despite the unquestionable relevance of such studies (4), external and internal validity are threatened by the loss of participants, affecting representativeness and biasing the measured associations. Alongside an adequate cohort recruitment, the main faced challenge is maximizing retention. Studies may face considerable selection biases with losses of 20% participants (5; 6; 7). Understanding the elements that influence participation and retention in various settings is therefore critical for the success of longitudinal research.

Most studies providing insight into maximizing participant retention lack geographical variability, relevant details and consistent descriptions of the adopted strategies. Inferential leaps or generalization to other populations and settings, and subsequent usefulness of similar strategies may thus differ (8; 9 10; 11; 12; 13; 14; 15). Further primary research on participation is needed to expand the diversity of assessed populations, methods and settings (15). Although behavioural decision-making is complex, fluid and situational and influenced by individuals’ personal traits, experience and emotional response (24; 25; 26), a paucity of literature regarding points of view and motivations to participate in cohorts remains (17; 18; 19; 20; 21; 22; 23).

The present study provides a more in-depth understanding of the variability of motives, facilitators and disincentives for participation, considering lived experiences of participants and professionals involved in various European cohorts of individuals born very preterm (VPT:<32 weeks of gestation) and/or with very low birth weight (VLBW: <1500g).

2. MATERIAL AND METHODS

2.1 Study Design
We used an inclusive qualitative approach of flexible multi-situated methods comprising the concept of multi-sites and situated knowledge (28;29;30). The study protocol (31) provided a shared flexible framework which included a collaborative visual methodology (VideoStories) (32;33), focus groups (FGs) and individual semi-structured interviews. The epistemological principle of flexibility in implementation also maximized inclusiveness and diversity of contributors to the study.

2.2. Participants and Settings

A total of 124 participants of eight cohorts from seven European countries contributed to these findings. The sample comprised 37 professionals, 41 parents of participants and 46 participants (Table 1).

2.3 Data Collection

Data were collected between April 2018 and June 2020 by local researchers. A combined multi-site purposive sampling strategy achieved a balanced socio-geographic heterogeneous sample (31). Country’s official language was used, except for the FGs of professionals in Finland and Norway which were conducted in English. All audio recorded data, including verbal narratives from the VideoStories, were transcribed and translated to English (Table 1).

2.4. Data Analysis

Data were handed over to the coordination team in Portugal for analysis. Data were submitted to a triangulation of phenomenological thematic analysis with discourse analysis. Both visual and verbal depictions were treated as narratives (34; 35; 36). Data sub-sets were sorted and categorized by hand, looking for recurrent themes to determine emerged patterns and relevant deviances. Additional information was gathered via a questionnaire from participants (n=370) on the last follow-up of the Dutch cohort (POPS) and from cohorts’ management teams via internal survey, email and study publications on studies’ waves, management procedures and
participation. Final interpretative analysis of relevant elements emerged by the generic application of the mode of contents contingency.

3 RESULTS

Results are organized in major cross-contextual and context-specific situational elements involved in participation and attrition phenomena that were identified at various levels and stages for the eight European cohorts under study. Quotes are displayed in Table 2.

3.1. Overrepresentation of female gender

3.1.1 Cross-Contextual

Our findings are dominated by female gender’s viewpoint in researcher (n=34/37) and participants (n=59/87) stances.

3.1.2 Context-Specific

The disproportionality of gender representation amongst the participants is attenuated in the context of adult cohorts. The contribution of fathers responding on behalf of their children was of 1:6; the gender distribution of adult participants was 20 males to 26 female and non-binary gender individuals.

3.2. Motivations

3.2.1 Cross-Contextual

3.2.1.1 Altruism/solidarity

Altruism/solidarity emerged as the leading underlying motivation factor. The positive feeling of contributing to improve medical knowledge and health care practices to the future benefit of others and society appeared as the main representational axis across narratives from parents (n=40/41) and adults born preterm (n=34/46) (Quotes 1, 2, 3).

3.2.1.2 Gratitude/sense of duty to reciprocate
The motivation of gratitude/sense of duty to reciprocate to healthcare professionals/scientific community or redirected to others seconded altruism/solidarity in most narratives by the same individuals. Its concurrent expression prevailed amongst parents across child cohorts (n=27/34); became notoriously absent amongst the young adults inquired in the context of EPIBEL cohort; and resurfaced amongst one fourth of their mothers and adults aged 30-39 (Quotes 4, 5, 6).

3.2.2 Context-Specific

3.2.2.1 Expectation of direct benefit

The expectation of direct benefit to learn about prematurity, oneself, and others, replaced the relevance of gratitude/sense of duty to reciprocate amongst many adult research participants (n=31/46). It gained expression in more than half of younger adults’ narratives (n=4/7) and in more than 70% of those aged 30-39 (Quote 7).

As adults, face-to-face physical assessments were highly appraised (n=27/37). Two thirds of them added being particularly motivated by the expectation of direct benefit and positive health behaviour changes from health assessments (Quote 8).

As for the child cohorts, parents in IT (n=3) and BE (n=4) pointed out the expectation of direct benefit for their children as a concurrent motivation. They were not fully aware of the independence of the EPICE/SHIPS studies from the clinical follow-up of their children while also voicing their frustration/distrust in the healthcare system (Quotes 9, 10). For all other parents in EPICE/SHIPS, the expectation of any direct benefit was either absent or denied (n=27/34) (Quote 11).

3.2.2.2 Being part of a researched group

The positive feeling of being part of a selected researched group was pointed out as an important motivation by one EPIBEL participant and nearly half of the adults from POPS (n=13/28) (Quote 12).
Additional data collected in the last POPS follow-up wave’s questionnaire allowed to contextuize the local representativeness of these findings for the whole cohort. Of 241 participants who contributed to this study via open-ended responses on motivations: 82% framed their answers under altruism/solidarity; 32% also/or under the expectation of direct benefit; and 10% also/or under the positive feeling of being part of a selected researched group.

POPS is the largest and longest cohort. It stood out as the one promoting most varied interaction with participants over time. Nevertheless, participation significantly declined after participants reached adulthood (74% at the 19 years follow-up; 34% at the 28 years follow-up; and 39% at the 35 years follow-up) in line with the decrease of frequency of interaction.

3.3. Motivational deterrents

3.3.1 Cross-Contextual

3.3.1.1 Perceived insufficient/irregular interaction and insufficient/inadequate information

Irregular interaction and insufficient information sharing on findings were major motivational deterrents. A large majority of parents (n=31/41) and adults aged 30-39 (n=27/37), either when addressing major deterrents or suggestions to improve participation, manifested a sense of dissatisfaction towards interaction and information sharing along with a failed expectation of increased frequency, regularity and adequacy (Quotes 13, 14, 15).

In addition, half of the youngest adults that for the first-time provided consent on their own have specifically addressed the expectation of being kept “well informed” about the study and its findings to keep participating (Quote 16).

3.3.2 Context-Specific

3.3.2.1 Perceived entanglement of clinical and research follow-ups

Most parents confessed either not having retained information on participation in a research or on its prospective trait at the enrolment of their newborn due to distressful, overwhelming experience
at the time (n=29/34). As recruitment occurred at the hospital unit before discharge, clinical and research follow-ups have been perceived by parents as intertwined, as part of the care package for their children. All parents, interviewed face-to-face (n=28), shared emotional accounts on trying to cope with mandatory extensive clinical appointments, therapies, and treatments along with the study solicitations. Targeted parents that did not respond to one or more follow-up waves (n=9) added descriptions of being mother of twins or more children, severe child impairments, single parenthood and/or frustration/distrust in the healthcare system for not having responded adequately to their needs. When reasoning about the motives for their decision, except for one mother that claimed failure in contact, non-response was explained by “no surplus of energy” or “inattention” due to their demanding lived experience as a mother. While some did not even remember not having responded, the majority expressed that researchers should have insisted on obtaining their positive response (n=7/9) (Quotes 17, 18).

3.4. Situational elements related to studies’ strategic procedures

3.4.1 Cross-Contextual

3.4.1.1 Combining multiple, flexible strategies

All cohort participants expressed appreciation for flexibility and multiple alternatives offered by studies to facilitate participation. It is a question both of preference and of some not being at all approachable via particular methods. The use of email (75%) combined with phone (67%) and/or postal mail (39%) with reminders, emerged as the most favoured combinations. Sixty-three percent of all participants particularly recommended not to use postal mail alone and 17% of participants in adult cohorts, including the youngest, explicitly repudiated the use of social platforms such as WhatsApp and Facebook (Quotes 19, 20 and 21).

Most adults (n=36/46) endorsed the combined use of multiple flexible/tailored methods to minimize non-response and attrition bias (Quotes 22, 23).

3.4.1.2 Increased frequency of interaction and face-to-face encounters
Parents of EPICE/SHIPS and POPS participants, after those participants reached adulthood, mainly responded via questionnaires at a distance. The Finnish Sibling study and NTNU LBW Life heavily relied on face-to-face assessments combining physical/medical examination with onsite administration of questionnaires. In EPIBEL, participants experienced both kinds of assessment twice.

More than half of participants aged 30-39 reported to expect further face-to-face assessments/interaction. That included all participants of The Sibling study who indicated having experienced long physical and emotionally demanding exams, including painful muscle biopsies for research purposes (n=9/9). In POPS, 61% of inquired participants also stated the failed expectation of shorter periodicity of interaction, including face-to-face events like the last one at the 19 years study wave (n=17/28) (Quote 24).

In all child cohorts, parents expressed their disappointment for the lack of initiatives to engage more with them and/or facilitate interaction between participants. All parents who had participated in face-to-face assessments and gatherings reported these experiences as motivating (n=34/41) (Quote 25). Significantly, in EPICE/SHIPS-PT, all those who made improvement suggestions for study bonding also emphasized face-to-face interaction. According to them, it is the strategy *par excellence* to enable “closeness” and “familiarity” with “the faces behind the study” (Quote 26).

The relevance of these findings is reinforced when looking closely into the interplay with histories of interaction and participation trends across cohorts with comparable life cycle periods. The NTNU LBW Life shows significantly higher retention of adult participants (76%) than the POPS (39%), while resorting to apparently similar multiple retention strategies over time. They differed greatly in periodicity and methods of interaction. As for the four EPICE/SHIPS studies, the PT cohort showing the highest retention (83%), stood out by its divergent strategies of extending the
face-to-face assessment at 5 years to the whole cohort, yearly monitoring and birthday postcard sent to all children (Table 3).

3.4.1.3 Postal questionnaires alone act as deterrent

Most participants manifested their endorsement of being contacted through multiple ways as commonly took place in all cohorts under study, while 39% stated their expectation of also keeping postal interaction. However, that was not extended to postal questionnaires.

When looking closely to common study waves across the child cohorts, we found that postal questionnaires were associated to poorer response in all four settings while even poorer in Belgium and Denmark. In Denmark no alternative methods were offered. Suggestively, some of the mothers in Denmark that had not responded to both follow-up waves via postal questionnaire, had participated in other research studies with their children (n=3/7). As they explained, the chosen procedure was the closing factor in the weighing process for their decision of non-response (Quote 27).

Parents and participants manifested their expectation for data collection alternatives other than questionnaires to be returned by mail. The procedure should be flexible in administration and return of forms, such as by phone, in electronic form/online or face-to-face. Researchers should also ensure that questionnaires are short and straightforward (n=18/34 parents; n=23/46 participants in adult cohorts) (Quotes 28, 29, 30). Those participants more adept of “more personal approaches”, more favourable to “clarify doubts” and to “deepen contributions” (interviews, FGs), further advised to replace postal questionnaires by alternative methods of enquiry (Quote 31).

Of those adults of the POPS cohort who responded to the open-ended question on most dissatisfactory aspects: 71% framed their answers under insufficient/inadequate interaction and information sharing on the study and its findings (n=66/93), while 31% singled out the
insufficiency of face-to-face procedures and/or the inadequacy of questionnaires to include participants with varied attributes and/or to “deepen contributions” (n=29/93).

3.5. Situational challenges faced by the researcher stance

3.5.1 Cross-Contextual

3.5.1.1 Financial and human resources constraints

Losing study participants through failure to locate/contact or to respond due to burdensome or potentially unsuitable follow-up procedures emerged as the major concern of inquired professionals in all settings (n=37/37). There was also a considerable level of convergence between researchers and cohort participants’ standpoints regarding some desirable traits in procedures. In all settings, professionals advocated the usefulness of: a) flexibility to reconcile study and participants’ agendas; b) flexibility in proximity: alternative methods, locations and language mediators, monetary assistance (e.g., cash/ voucher incentives/ specific rewards); c) bonding enhancement: adequate study information, goals and prospective trait (research characteristics), continuity of familiar faces in the researcher stance (familiarity), sharing results with participants. However, all discussions raised situational challenges to implement such strategies due to constraints in available human and financial resources.

Denmark, Finland and Norway have nationwide registries with personal identity numbers covering virtually all individuals residing in those countries and enabling data linkage. Due to insufficient financial and human resources, selecting and implementing the most appropriate and inclusive strategies for interacting with cohort participants proved to be a challenge (Quotes 32, 33). Research teams in non-Nordic countries added to those challenges the extra effort and resources required just to keep track of participants (Quote 34).

As revealed in the discussions with professionals involved with the EPICE/SHIPS and the EPIBEL cohorts, the dependency on short-term research funding limited the possibilities to provide participants with information on research continuity. Consent to participate in research
must be restricted to the protocol framed by the funded project and as such cannot anticipate long-term future interactions for which funding is not yet assured. Professionals felt constrained to ensure regular contact in-between study waves and continuity in research staff.

EPIBEL is exemplary on how the effect of these cumulative constraints severely impacts the ability to trace, interact and retain cohort participants. Over its 20 years of existence, research teams were able to perform three follow-up waves, the last two with a periodicity of 8-9 years while each time most efforts and resources were absorbed just to trace, re-invite and provide incentives to the particular event. Not only had the cohort follow-up been restricted from a national follow-up to the Flanders region, it had also been limited to Dutch-speakers, though the country recognises three officially spoken languages and internal mobility and migration is common (Quote 35).

3.5.1.2 Societal changes related with communication systems

It was further apparent that the fast rhythm of changes regarding communication in the last fifteen years has hampered the efficiency of available tracing systems. Though the impact seemed less evident for the adult cohorts in Nordic countries, EPICE/SHIPS-DK has faced similar challenges. Most influential elements reported were: a) the impact of progressive dismissal of home phone landlines and reliance on changeable mobile/electronic contacts detached from physical addresses; b) the increased informatization of databases and work processes with replacement of systems at times asynchronous and discordant; and c) legislations and regulations increasingly constraining access to personal data and record linkage (Quotes 36, 37, 38).

3.5.1.3 European Union geopolitical environment

This shared scenario related with population mobility, immigration and displacement challenges increases the cohorts’ vulnerability to other logistical constraints and emerged as another relevant situational challenge for all research teams. Though stressed in all FGs, these challenges were more emphasized in Italy and Belgium and in the context of child cohorts recruited in 2011-12.
After being discharged and/or stopping clinical follow-up, particularly foreign immigrants and vulnerable families that moved frequently became difficult to trace and to be provided with context-sensitive alternatives to participate (Quote 39).

**DISCUSSION**

Motivations to participate were mainly related to altruism/solidarity and gratitude/sense of duty to reciprocate. Major deterrents were the perception of poor interaction and insufficient sharing of study findings. Combining multiple strategies to promote contact and collect data favoured participation while postal questionnaires as the only data gathering process acted as deterrent. For professionals, financial and human resources constraints and societal changes related to communication and challenges related to population mobility, immigration and displacement within the geopolitical environment of the European Union were the main concerns. Mobility emerged as a main challenge to trace participants, especially if foreign-born or belonging to vulnerable families.

Our findings were dominated by females’ points of view which reflected the gender profile of the represented population, particularly when involving parents of child participants. Though consideration of the child’s willingness has a rights-based dimension, their parents’ points of view and motivations are determinant to understand participation until consent and accountability is passed on (37; 38; 20). Adult males were more likely to participate when research concerned themselves, and less when it targeted their children. This gender unbalance, which is traditionally found in family and child development research, suggests women's point of view should be carefully considered when developing participatory strategies (39). Further effort in identifying men’s needs on participation and their favoured approaches is also important. Though women influence is attenuated after the cohort reaches adulthood, for participants who are not fully autonomous, mothers continue to be the ones that more likely will facilitate participation.
Altruism/solidarity was the main underlying motivation expressed by participants, which concurred with gratitude, to the exception of young adults in EPBEL. Amongst the adult cohorts, the majority added the expectation of direct benefit by personally learning more about prematurity, themselves, and others. In POPS, a significant number of individuals also pointed out being part of a selective researched group as an important motivation. Insufficient interaction and information sharing emerged as main motivational deterrent in all settings. Thus, irrespectively of the underlying motivation to endure participating, the researcher stance has been perceived as failing in reciprocity.

Motivations of altruism/solidarity have been pointed out as underlying factors to enrol in and to endure participating in longitudinal studies (18; 40; 41; 8). Our findings are similar to previous observations in what appears to be the paradoxical concurrence of this motivation, while some authors interpret it with combined concepts such as ‘conditional altruism’, ‘weak altruism’ or ‘perhaps less truthful’ to be more socially acceptable (42; 42). The child cohort studies did not presuppose any kind of incentives. It is therefore reasonable to interpret participation as an act of gift-giving, of generous transfer of socially valued objects without any guarantee of reciprocation. Amongst adults, though financial incentives for assessment completion have been used at times, the overwhelming majority did not refer to them as a suggestion to improve participation and all refuted their role in retention.

The complete absence of gratitude/sense of duty to reciprocate as a concurrent motivation with altruism occurred as a deviance particular to the youngest adults aged 19-21 years. Verbal expression of connective gratitude tends to increase with age (44; 45), which our findings reflected. Gratitude emerges from understanding others’ minds in conjunction with one’s own needs. Individuals more prone to feel it seem to have more neural hallmarks of altruism and other brain areas associated with feelings of reward when contributing to the benefit of others (46; 47). Gratitude is associated with acknowledgement and the most significant form of acknowledgement is return (bond-building strategies) (54; 54; 56; 57). Reciprocity in gift exchange is the expression
of the social bond that contributes to create and maintain balanced relationships in society which
researchers should invest in. As gratitude relates to personal well-being and social relationships
development, maintenance, and satisfaction (48; 49; 50; 51; 52), its promotion may be also
especially useful for planning research with adolescents born preterm with special needs, physical
disabilities, or social adjustment difficulties (53).

In the context of our European child cohorts, the phenomena of participation and attrition were
linked to parents’ lived experiences on having a preterm birth and on the support provided by the
healthcare system. As voiced by parents, their vulnerability and distressing experience at the time
of enrolment favoured receptivity to being researched while finding comfort in contributing to
the benefit of others (58; 59; 60). In the long-term however, the continued exposure to distressful
experiences of parenthood when combined with perceived lack of healthcare support or effort-
reward imbalance may lead to increased carelessness or non-response to research solicitations.
We also found that even parents who maintain their participation shared the perception of
inadequate psychological healthcare provision to mothers of VPT children. These results suggest
that aspects of prematurity such as psychological distress and general parental stress and coping,
either have not yet received enough research attention (62; 63; 64) or findings are not being
adequately translated into healthcare policies and practices in Europe.

All cohorts implemented multiple strategies specifically aiming to maximize retention but the
number and diversity of procedures differed. Diversity and frequency of applied retention
strategies did not allow to identify a straightforward trend or to make considerations on their
effectiveness. To understand variability in participation required to look further into study
designs, strategic procedures of contact and data collection, their modification along follow-ups
and what was the interplay of lived experiences.

We identified major situational facilitators and deterrents related to strategic procedures. On the
one hand, combining multiple alternatives and flexible/tailored strategies, particularly regarding
contact and data collection favoured participation. On the other hand, merely adding more
retention strategies or monetary incentives such as cash and vouchers did not seem to result in higher retention, as earlier shown (65). However, our study indicates the clear benefit of more interaction and reminders. European cohorts should reinforce resources and efforts in increasing interaction and sharing information more frequently and regularity, while including face-to-face encounters.

All eight cohorts shared the impact and challenges of influx and mobility of populations within the last decade within their geopolitical and economic contexts, whereas Italy and Belgium stand out for the much higher increase of foreign vulnerable population density (66; 67; 68; 69). Professionals in all settings shared long reported concerns that people from minority and vulnerable groups are at higher risk of loss to follow-up in cohort studies (70; 71; 72; 73; 74; 75).

**Limitations**

Limited information could be retrieved from male informants and those that had previously withdrawn their consent to participate.

**CONCLUSION**

This in-depth exploration provided valuable insights to guide the development of tailored strategies to improve participation, which would benefit from the consistent promotion of the altruistic goals of research throughout the cohort life cycle. Poor interaction and information sharing was a major deterrent factor reported by participants, alongside using only postal questionnaires as a data collection method. For child cohorts, the parents’ point of view was determinant to understand participation until preterm children reach adulthood, and mothers continued to be the main facilitator for adults with impairments.

**Practical implications**

Increasing regular interaction with participants, improving flexibility in contact and assessment methods, enhancing the sharing of study's results, and prioritizing face-to-face assessments can help to mitigate attrition. Over-representation of women in the participating cohorts suggested
that their point of view should be carefully taken into account when developing participatory strategies. It is also strongly recommended to put efforts on identifying men’s needs when it comes to participation, as well as if different approaches would favour their participation.

Abbreviations in alphabetical order

BE = Belgium
DK = Denmark
EPIBEL = Extremely Preterm Infants in Belgium
EPICE/SHIPS = Effective Perinatal Intensive Care in Europe/Screening to improve Health In very Preterm infants in Europe
IT= Italy
NL = Netherlands
NTNU LBW = NTNU Low Birth Weight in a Lifetime Perspective (Norway)
POPS = Project On Preterm and Small for gestational age infants (Netherlands)
PT = Portugal
The Sibling study = Adults Born Preterm Sibling (Finland)

DECLARATIONS

Declarations of Interest

None.

Authors’ Contributions

SCSM contribution to the conceptualization and implementation of the study, data collection, analysis and first draft of this manuscript. JD contributed to the implementation of the study, data collection, data analysis, draft of this manuscript, review and editing of this manuscript. RT
contributed to the data analysis, draft, review and editing of this manuscript. GA, AB, AMB, GC, MC, KAIE, VH, MSI, EK, JL, SP, PP, IS and EV contributed to implementation and data collection. HB contributed to the conceptualization, implementation, draft, review and editing of this manuscript. All authors contributed to the manuscript revision and approved submitted version.

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Data Availability Statement

Multi-site interview transcripts datasets generated for this study cannot be shared for legal, ethical and privacy restrictions. In accordance with multi-site ethical clearances and signed informed consent provided by participants which guarantees their anonymity and confidentiality, generated data for this study may only be accessed and handled within RECAP Preterm research team and under the framework of internal governance of the Horizon 2020 project RECAP Preterm funded by the European Union under grant agreement Nº 733280.
Ethical approval

Approval by Ethics Committees, Data Protection Authorities and signed written informed consents by all responders in their spoken languages were obtained according to national rules. As required, ethical clearance was obtained from the Ethics Committee of Antwerp University Hospital in Belgium; the Danish Ethical Committee System and Danish Data Protection Agency in Denmark; the Ethics Committee of Hospital District of Helsinki and Uusimaa in Finland; the Ethics Committee of Paediatric Hospital Bambino Gesù in Italy; the Ethics Committee of the Institute of Public Health of the University of Porto and Portuguese Data Protection Authority in Portugal; and, the TNO Institutional Review Board in The Netherlands.

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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