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2023-03-09

Deposited version:

Accepted Version

Peer-review status of attached file:

Peer-reviewed

Citation for published item:

Marques, S. C. S., Doetsch, J. N., Teixeira, R., Abate, G., Brødsgaard, A., Brubakk, A.-M....Barros, H. (2022). Increased interaction and procedural flexibility favoured participation: Study across European cohorts of preterm born individuals. *Journal of Clinical Epidemiology*. 143, 169-177

Further information on publisher's website:

[10.1016/j.jclinepi.2021.12.027](https://doi.org/10.1016/j.jclinepi.2021.12.027)

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2 **participation: Study across European cohorts of preterm born**
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38 **Word count: 3979**

39

40 **ABSTRACT**

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

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

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

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

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

61 **Keywords:** European cohorts, Premature, Participation, Multi-situated qualitative study,
62 Collaborative methods.

63

641 INTRODUCTION

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

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

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

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

872 2. MATERIAL AND METHODS

882.1 Study Design

89 We used an inclusive qualitative approach of flexible multi-situated methods comprising the
90 concept of multi-sites and situated knowledge (28;29;30). The study protocol (31) provided a
91 shared flexible framework which included a collaborative visual methodology (VideoStories)
92 (32;33), focus groups (FGs) and individual semi-structured interviews. The epistemological
93 principle of flexibility in implementation also maximized inclusiveness and diversity of
94 contributors to the study.

95 **2.2. Participants and Settings**

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

99 **2.3 Data Collection**

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

105 **2.4. Data Analysis**

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

113 participation. Final interpretative analysis of relevant elements emerged by the generic application
114 of the mode of contents contingency.

115 **3 RESULTS**

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

119 **3.1. Overrepresentation of female gender**

120 **3.1.1 Cross-Contextual**

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

123 **3.1.2 Context-Specific**

124 The disproportionality of gender representation amongst the participants is attenuated in the
125 context of adult cohorts. The contribution of fathers responding on behalf of their children was of
126 1:6; the gender distribution of adult participants was 20 males to 26 female and non-binary gender
127 individuals.

128 **3.2. Motivations**

129 **3.2.1 Cross-Contextual**

130 **3.2.1.1 Altruism/solidarity**

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

135 **3.2.1.2 Gratitude/sense of duty to reciprocate**

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

141 **3.2.2 Context-Specific**

142 **3.2.2.1 Expectation of direct benefit**

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

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

150 As for the child cohorts, parents in IT (n=3) and BE (n=4) pointed out the expectation of direct
151 benefit for their children as a concurrent motivation. They were not fully aware of the
152 independence of the EPICE/SHIPS studies from the clinical follow-up of their children while also
153 voicing their frustration/distrust in the healthcare system (Quotes 9, 10). For all other parents in
154 EPICE/SHIPS, the expectation of any direct benefit was either absent or denied (n=27/34) (Quote
155 11).

156 **3.2.2.2 Being part of a researched group**

157 The positive feeling of being part of a selected researched group was pointed out as an important
158 motivation by one EPIBEL participant and nearly half of the adults from POPS (n=13/28) (Quote
159 12).

160 Additional data collected in the last POPS follow-up wave's questionnaire allowed to
161 contextualize the local representativeness of these findings for the whole cohort. Of 241
162 participants who contributed to this study via open-ended responses on motivations: 82% framed
163 their answers under altruism/solidarity; 32% also/or under the expectation of direct benefit; and
164 10% also/or under the positive feeling of being part of a selected researched group.

165 POPS is the largest and longest cohort. It stood out as the one promoting most varied interaction
166 with participants over time. Nevertheless, participation significantly declined after participants
167 reached adulthood (74% at the 19 years follow-up; 34% at the 28 years follow-up; and 39% at the
168 35 years follow-up) in line with the decrease of frequency of interaction.

169 **3.3. Motivational deterrents**

170 **3.3.1 Cross-Contextual**

171 **3.3.1.1 Perceived insufficient/irregular interaction and insufficient/inadequate information**

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

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

180 **3.3.2 Context-Specific**

181 **3.3.2.1 Perceived entanglement of clinical and research follow-ups**

182 Most parents confessed either not having retained information on participation in a research or on
183 its prospective trait at the enrolment of their newborn due to distressful, overwhelming experience

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

196 **3.4. Situational elements related to studies’ strategic procedures**

197 **3.4.1 Cross-Contextual**

198 **3.4.1.1 Combining multiple, flexible strategies**

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

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

208 **3.4.1.2 Increased frequency of interaction and face-to-face encounters**

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

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

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

227 The relevance of these findings is reinforced when looking closely into the interplay with histories
228 of interaction and participation trends across cohorts with comparable life cycle periods. The
229 NTNU LBW Life shows significantly higher retention of adult participants (76%) than the POPS
230 (39%), while resorting to apparently similar multiple retention strategies over time. They differed
231 greatly in periodicity and methods of interaction. As for the four EPICE/SHIPS studies, the PT
232 cohort showing the highest retention (83%), stood out by its divergent strategies of extending the

233 face-to-face assessment at 5 years to the whole cohort, yearly monitoring and birthday postcard
234 sent to all children (**Table 3**).

235 **3.4.1.3 Postal questionnaires alone act as deterrent**

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

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

246 Parents and participants manifested their expectation for data collection alternatives other than
247 questionnaires to be returned by mail. The procedure should be flexible in administration and
248 return of forms, such as by phone, in electronic form/online or face-to-face. Researchers should
249 also ensure that questionnaires are short and straightforward (n=18/34 parents; n=23/46
250 participants in adult cohorts) (Quotes 28, 29, 30). Those participants more adept of “more personal
251 approaches”, more favourable to “clarify doubts” and to “deepen contributions” (interviews,
252 FGs), further advised to replace postal questionnaires by alternative methods of enquiry (Quote
253 31).

254 Of those adults of the POPS cohort who responded to the open-ended question on most
255 dissatisfactory aspects: 71% framed their answers under insufficient/inadequate interaction and
256 information sharing on the study and its findings (n=66/93), while 31% singled out the

257 insufficiency of face-to-face procedures and/or the inadequacy of questionnaires to include
258 participants with varied attributes and/or to “deepen contributions” (n=29/93).

259 **3.5. Situational challenges faced by the researcher stance**

260 **3.5.1 Cross-Contextual**

261 **3.5.1.1 Financial and human resources constraints**

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

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

279 As revealed in the discussions with professionals involved with the EPICE/SHIPS and the
280 EPIBEL cohorts, the dependency on short-term research funding limited the possibilities to
281 provide participants with information on research continuity. Consent to participate in research

282 must be restricted to the protocol framed by the funded project and as such cannot anticipate long-
283 term future interactions for which funding is not yet assured. Professionals felt constrained to
284 ensure regular contact in-between study waves and continuity in research staff.

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

293 **3.5.1.2 Societal changes related with communication systems**

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

302 **3.5.1.3 European Union geopolitical environment**

303 This shared scenario related with population mobility, immigration and displacement challenges
304 increases the cohorts' vulnerability to other logistical constraints and emerged as another relevant
305 situational challenge for all research teams. Though stressed in all FGs, these challenges were
306 more emphasized in Italy and Belgium and in the context of child cohorts recruited in 2011-12.

307 After being discharged and/or stopping clinical follow-up, particularly foreign immigrants and
308 vulnerable families that moved frequently became difficult to trace and to be provided with
309 context-sensitive alternatives to participate (Quote 39).

3104 **DISCUSSION**

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

320 Our findings were dominated by females' points of view which reflected the gender profile of the
321 represented population, particularly when involving parents of child participants. Though
322 consideration of the child's willingness has a rights-based dimension, their parents' points of view
323 and motivations are determinant to understand participation until consent and accountability is
324 passed on (37; 38; 20). Adult males were more likely to participate when research concerned
325 themselves, and less when it targeted their children. This gender unbalance, which is traditionally
326 found in family and child development research, suggests women's point of view should be
327 carefully considered when developing participatory strategies (39). Further effort in identifying
328 men's needs on participation and their favoured approaches is also important. Though women
329 influence is attenuated after the cohort reaches adulthood, for participants who are not fully
330 autonomous, mothers continue to be the ones that more likely will facilitate participation.

331 Altruism/solidarity was the main underlying motivation expressed by participants, which
332 concurred with gratitude, to the exception of young adults in EPIBEL. Amongst the adult cohorts,
333 the majority added the expectation of direct benefit by personally learning more about
334 prematurity, themselves, and others. In POPS, a significant number of individuals also pointed
335 out being part of a selective researched group as an important motivation. Insufficient interaction
336 and information sharing emerged as main motivational deterrent in all settings. Thus,
337 irrespectively of the underlying motivation to endure participating, the researcher stance has been
338 perceived as failing in reciprocity.

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

349 The complete absence of gratitude/sense of duty to reciprocate as a concurrent motivation with
350 altruism occurred as a deviance particular to the youngest adults aged 19-21 years. Verbal
351 expression of connective gratitude tends to increase with age (44; 45), which our findings
352 reflected. Gratitude emerges from understanding others' minds in conjunction with one's own
353 needs. Individuals more prone to feel it seem to have more neural hallmarks of altruism and other
354 brain areas associated with feelings of reward when contributing to the benefit of others (46; 47).
355 Gratitude is associated with acknowledgement and the most significant form of acknowledgement
356 is return (bond-building strategies) (54; 54; 56; 57). Reciprocity in gift exchange is the expression

357 of the social bond that contributes to create and maintain balanced relationships in society which
358 researchers should invest in. As gratitude relates to personal well-being and social relationships
359 development, maintenance, and satisfaction (48; 49; 50; 51; 52), its promotion may be also
360 especially useful for planning research with adolescents born preterm with special needs, physical
361 disabilities, or social adjustment difficulties (53).

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

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

380 We identified major situational facilitators and deterrents related to strategic procedures. On the
381 one hand, combining multiple alternatives and flexible/tailored strategies, particularly regarding
382 contact and data collection favoured participation. On the other hand, merely adding more

383 retention strategies or monetary incentives such as cash and vouchers did not seem to result in
384 higher retention, as earlier shown (65). However, our study indicates the clear benefit of more
385 interaction and reminders. European cohorts should reinforce resources and efforts in increasing
386 interaction and sharing information more frequently and regularly, while including face-to-face
387 encounters.

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

393 **Limitations**

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

396 **5 CONCLUSION**

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

404 **Practical implications**

405 Increasing regular interaction with participants, improving flexibility in contact and assessment
406 methods, enhancing the sharing of study's results, and prioritizing face-to-face assessments can
407 help to mitigate attrition. Over-representation of women in the participating cohorts suggested

408 that their point of view should be carefully taken into account when developing participatory
409 strategies. It is also strongly recommended to put efforts on identifying men's needs when it
410 comes to participation, as well as if different approaches would favour their participation.

411 **Abbreviations in alphabetical order**

412 BE = Belgium

413 DK = Denmark

414 EPIBEL = Extremely Preterm Infants in Belgium

415 EPICE/SHIPS = Effective Perinatal Intensive Care in Europe/Screening to improve Health In
416 very Preterm infants in Europe

417 IT= Italy

418 NL = Netherlands

419 NTNU LBW = NTNU Low Birth Weight in a Lifetime Perspective (Norway)

420 POPS = Project On Preterm and Small for gestational age infants (Netherlands)

421 PT = Portugal

422 The Sibling study = Adults Born Preterm Sibling (Finland)

423 **DECLARATIONS**

424 **Declarations of Interest**

425 None.

426 **Authors` Contributions**

427 SCSM contribution to the conceptualization and implementation of the study, data collection,
428 analysis and first draft of this manuscript. JD contributed to the implementation of the study, data
429 collection, data analysis, draft of this manuscript, review and editing of this manuscript. RT

430 contributed to the data analysis, draft, review and editing of this manuscript. GA, AB, AMB, GC,
431 MC, KAIE, VH, MSI, EK, JL, SP, PP, IS and EV contributed to implementation and data
432 collection. HB contributed to the conceptualization, implementation, draft, review and editing of
433 this manuscript. All authors contributed to the manuscript revision and approved submitted
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460 named researchers contributed to the development of the study protocol and/or its local
461 implementation.

462 **Acknowledgments**

463 This study would have not been possible without the generous disposition from all participants
464 who shared their time, thoughts, and experiences – we warmly thank all of them. We further thank
465 cohorts' managers and research teams in all sites for the support provided as well as the many
466 researchers/collaborators who assisted with implementation of this study.

467 **Funding information**

468 This study is part of the RECAP preterm project funded by the European Union's Horizon 2020
469 research and innovation programme under grant agreement No 733280. This study is funded by
470 FEDER funds through the Operational Program for Competitiveness and Internationalization, and
471 by national funds of FCT – Fundação para a Ciência e Tecnologia, the Unidade de Investigação
472 em Epidemiologia (EPIUnit) - Instituto de Saúde Pública da Universidade do Porto (ISPUP)
473 (UIDB/04750/2020).

474 **Data Availability Statement**

475 Multi-site interview transcripts datasets generated for this study cannot be shared for legal, ethical
476 and privacy restrictions. In accordance with multi-site ethical clearances and signed informed
477 consent provided by participants which guarantees their anonymity and confidentiality, generated
478 data for this study may only be accessed and handled within RECAP Preterm research team and
479 under the framework of internal governance of the Horizon 2020 project RECAP Preterm funded
480 by the European Union under grant agreement N° 733280.

481 **Ethical approval**

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

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

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