Perspectives of Adult Offspring of Participants Recruited to a Randomised Trial in Pregnancy: A Qualitative Study

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None

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Author contribution
Nike Franke: Design and conceptualisation study, data-collection, transcribing interviews, data-analysis, drafting manuscript, revision manuscript

Trecia Wouldes: Design and conceptualisation study, data-analysis, revision manuscript

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Abstract

Background: Routinely assessed outcomes in paediatric health studies may not reflect families' priorities. Increasing our understanding of childhood experiences of research participation may contribute to improving the quality of consent and better align study aims with the concerns of relevant communities.

Objective: To explore young adults' views on their participation in medical research during their childhood, specifically around the acceptability of consent and their priorities regarding health, development, and well-being as potential trial outcomes.

Methods: A qualitative descriptive 20-year follow-up study of a medical trial which aimed to improve outcomes after preterm birth. Semi-structured dialogue transcripts were analysed using inductive thematic analysis.

Setting and participants: Seventeen young adults whose parents consented to their participation in a clinical trial when they were fetuses, and in follow-up studies as pre-schoolers and school-aged children.

Results: Overall, participants expressed comfort with their parents consenting to medical research on their behalf. However, autonomous child assent may not be attainable due to children's susceptibility to suggestions. Participants generally expressed satisfaction with the outcomes investigated in the follow-up studies, although some suggested other outcomes of interest such as mental health and learning disabilities.

Conclusions: Current consent procedures were deemed acceptable as parents hold responsibility for making decisions on behalf of their children, and their commitment to their child's well-being ensures that they make appropriate choices. The outcomes assessed in this trial and health and developmental outcomes in the follow-up assessments aligned well with outcomes of interest to the young adult participants.

Background

Medical research aims to improve human health, making it a matter of public interest [1]. Limited resources require careful prioritisation of research questions. Shifting the role of research participants from passive to engaged may avoid mismatches between research that is being undertaken and research that participants believe is important [1]. In addition, understanding the research priorities of consumers may enhance future research quality and participation [2].

International guidelines for paediatric research require both parental consent and child assent [3, 4], with parental consent protecting the child and child assent acknowledging their emerging autonomy [5, 6]. It is increasingly recognised that children should have the right to participate in decisions that affect them, provided that the decision reflects children's capacity and understanding [7, 8]. However, children may not perceive themselves as autonomous decision-makers [9], due to limited experiences of real choices and influence from authority figures [9, 10].

To date, there are no reports about adults' perceptions of their childhood enrolment in longitudinal medical research or their preferences about measured outcomes. Exploring childhood experiences, consent and assent arrangements, and outcome preferences may enhance the quality of consent and assent processes in paediatric health research and better align study aims with the concerns and priorities of relevant communities.

This qualitative study engaged with adult children of participants in the Australasian Collaborative Trial of Repeat Doses of Corticosteroids for the Prevention of Neonatal Respiratory Disease (ACTORDS) Trial [11]. The ACTORDS Trial was a multi-centre randomised trial conducted in 23 hospitals across New Zealand and Australia between 1998 and 2004. Participants in this trial were at risk of preterm birth, had already received a single course of corticosteroids, and were randomised to receive either a repeat dose of antenatal corticosteroids or placebo to assess potential benefit for neonatal respiratory disease and other morbidities. Their children were assessed at birth [11], 2 years [12], and 6-8 years [13, 14], and were approximately 20 years old during the current follow-up study.

The current study aimed to understand the perspectives of young adult offspring of participants in the ACTORDS trial on their childhood participation in this longitudinal research. It explored their opinions on parental decision-making, the acceptability of consent and assent arrangements, and their priorities regarding health, development, and well-being as potential outcomes of a trial which aimed to improve outcomes after preterm birth.

Methods

Design

This qualitative study was nested within the adult follow-up of the ACTORDS trial. It used a thematic analysis approach [15] and adhered to the consolidated criteria framework (COREQ) [16] (Appendix 1).

Recruitment

Participants in the current study were young adults who were the offspring of participants in the ACTORDS Trial. Recruitment to the current study occurred in two stages: 1) Participants were initially invited to participate in a 20-year follow-up of the ACTORDS trial and as part of that were asked if they were interested in receiving information about this qualitative study; 2) Those who expressed interest were approached via email and phone. Participant sampling was consecutive in the order of consent to the overarching 20-year follow-up study.

Data collection

Participation options for the semi-structured dialogue included in-person, online face-to face, or via phone, either individually or in a group setting (i.e., focus group). The discussion was guided by a list of topics (Appendix 2), developed by the authors and pilot-tested in a sample of four participants in a similar study. All participants received a fuel voucher to acknowledge their contribution. Dialogues were facilitated by NF, who was unknown to the participants and who had prior experience in conducting and analysing interview data. Discussions were audio-recorded and transcribed verbatim and checked for accuracy by NF. No notes were taken during the discussions to encourage a natural conversation. Participants were given the opportunity to review their own

transcript. Recruitment ceased when researchers were satisfied that data saturation was achieved.

Data analysis

To analyse the transcripts, an inductive thematic analysis approach was followed as described by Braun, Clarke [15] Data analysis involved reading the transcripts repeatedly, coding inductively, and revising initial coding after discussions between NF and TW to ensure an authentic reflection of participant experiences. Resulting themes and subthemes were refined and supported by quotations from interview transcripts, with the latter allowing readers to review interpretation, thereby further strengthening the robustness of the findings.

Ethics approval

Ethical approval was obtained from the Auckland Health Research Ethics Committee (Ref. AH22712).

Results

A total of 134 young adult offspring of ACTORDS participants were approached. Of these, 101 did not respond, eight were interested but could not be further contacted, three were cognitively incapable to participate, and five declined. Seventeen young adults aged 19-23 years participated in semi-structured dialogues. Most were of NZ European descent and 11 were female (Table 1). Gestation at birth ranged from 26.1-38.3 weeks, with the majority being born preterm and singletons. There were no differences in these characteristics between those who participated and those approached who did not. Further details are reported in the COREQ Checklist (Appendix 1). Eleven participants chose an individual interview, while six participated in a focus group held in a community centre to minimise travel distances. Thematic analysis yielded five themes involving 1) retrospective understanding of the trial and follow-up studies; 2) aspects of health that participants deemed important; 3) reflection on childhood research experience; 4) participants' views on parental consent, and 5) facilitators and barriers to the qualitative 20-year follow-up study (Table 2).

Theme 1: Retrospective understanding of the trial and follow-up studies

Study awareness and engagement

Nine participants of the 17 participants had forgotten about their study participation until they received an invitation to the 20-year follow-up. However, participant D had been aware of the study throughout her childhood due to a fridge magnet provided by the ACTORDS trial. This led participant D to actively engage with the research by asking her mother questions and even incorporating her study participation into a school assignment. Additionally, three other participants actively engaged with the study after the 6-8-year follow-up, seeking information from their parents.

Memories around 6-8-year follow-up assessments

All except for two participants had some recollection of assessments done during the 6-8-year follow-up, with physical tests most commonly mentioned (*n* = 9). These physical tests included blood tests, and six participants expressed negative memories associated with the blood draws. Participant A described these experiences as "definitely quite scary". Similarly, participants G and H expressed confusion regarding the purpose of the blood tests, while participant C reported feeling worried about the amount of blood that was drawn.

Theme 2: Aspects of health that participants deemed important

Outcomes of importance that were measured as part of the 6-8-year follow-up study

Upon receiving a list of outcomes assessed during the 6-8-year follow-up, three participants expressed the belief that all measured outcomes were important. Participant O captured this sentiment, stating, "because it's my body and my life." Ten participants showed a particular interest in physical outcomes, specifically body composition, lung function, heart rate, blood pressure, and motor skills. However, participant K expressed concerns that assessing body composition, particularly body weight, might evoke negative reactions from certain children and suggested excluding it from the assessment. Five participants emphasised the importance of measuring children's cognitive development, with participant L humorously remarking, "memory is obviously an issue if I can't remember any of it". Four participants highlighted the significance of assessing

children's health-related quality of life, while three participants identified behaviour as an important outcome.

Outcomes participants thought should have been measured

Five participants identified outcomes they considered significant, whether in their own lives, regarding future children, or in general. They mentioned several physical outcomes that were not included in any of the follow-up studies, such as liver function, kidney function, diabetes, and sleep apnoea. Additionally, they expressed interest in neurodevelopmental outcomes, including mental health, depression, emotional intelligence, and learning disabilities.

Theme 3: Reflection on research experience

Positive experience

Fifteen participants shared positive reflections on their trial and follow-up participation. Seven participants expressed gratitude, highlighting the perceived benefits of prenatal corticosteroids exposure. Two participants credited the study for their normal, healthy lives. Participant F speculated that the corticosteroids positively influenced his intelligence. Two participants mentioned the reassurance of additional support received by their families during the study. Overall, seven participants had positive experiences during the 6-8-year follow-up, finding it enjoyable and "cool to be part of a medical trial". Three participants appreciated the attention and the gift, and five participants expressed excitement and curiosity about the latest follow-up at age 20. Four participants made positive comments about the trial's long-term study design, well-trained assessors, and outcome monitoring.

Negative experience

Ten participants shared negative experiences related to the trial and the 6-8-year follow-up study. Three participants attributed negative consequences to prenatal corticosteroid exposure, such as loud breathing, elevated heart rate during pregnancy, and excessive body hair. Six participants found the 6-8-year follow-up to be a long day, with participant N specifically recalling doing "a whole bunch of walking that day". Participant H found the report of the 6-8-year follow-up

findings confusing. Regarding the 20-year follow-up, three focus group participants expressed vulnerability and apprehension about the study' potential impact and the nature of the assessments, as described by participant F: "because if it's measured that means there's a possibility for something to happen, right?".

Theme 4: Participants' views on parental consent

Parental consent is appropriate

Each participant expressed satisfaction with their parents consenting on their behalf, citing diverse reasons. The prevailing rationale (*n* = 12) was the belief that children aged 6-8 years are incapable of informed decisions due to their limited cognitive abilities and their susceptibility to suggestions. Eight participants reported their parents were committed to serving their children's best interests, although participant C also acknowledged his parents' potential altruistic motivation: "So they'd wanna take you there in the best interests of the study and getting the results too". Participants G and L pointed out that the original trial did not require child consent as they were still part of their mother's body and therefore it was their mother's decision to make.

Need to listen to the child

Eleven participants emphasised that although they were content with their parents' decision to participate in the research, children should also be consulted. Three participants said they would have been able to consent on their own behalf. Seven participants reported that they felt confident their parents would have respected their refusal to take part in the research. However, participant H said she was too shy to express her opinion at age 6-8 years, and participant D reported her parents would not have listened to her.

Theme 5: Facilitators and barriers to the current qualitative 20-year follow-up

Reasons for participating

Participants showed strong commitment to the trial and follow-ups. The main rationale for participating in the current discussions included curiosity about long-term outcomes (*n* = 11), group allocation (i.e., placebo vs intervention; *n* = 2), and seeking additional information about the study (*n*

= 3). Nine participants stated altruistic reasons, wanting to help others (*n* = 8), while participant L emphasised the importance of research. Two participants mentioned parental encouragement to participate and three participants expressed pride in participating in the study.

Current and potential facilitators

Participant H found the various discussion options in the current qualitative follow-up helpful. Six participants offered suggestions to encourage potential participants, with the most common suggestion being to provide more information. Participants recommended using simple language, providing detailed information, and explaining how the findings might contribute. Email and brief video formats were suggested, as well as the option to complete a survey instead of participating in a discussion.

Discussion

The objective of this qualitative study was to collect young adults' viewpoints on their childhood participation in research. All participants expressed comfort with their parents providing consent on their behalf. Participants recognised that their mothers made decisions about their participation in the original trial, considering that it involved their mothers' bodies. Participants believed their involvement in the follow-up studies should also be determined by their parents, given that parents typically make important decisions throughout childhood and prioritise their child's wellbeing. Thus, participants in this study hold views that align with international guidelines for paediatric research, wherein parental consent serves as a safeguard to ensure the child's wellbeing and enables decision-making in the child's best interest [6].

While parental consent is required and appropriate, participants stressed the importance of involving children in the decision-making process, and assent of the child is a requirement for ethical research [17]. However, limited experiences of real choices and influence from authority figures may impede children from perceiving themselves as autonomous decision makers [9, 10]. In this study, some participants acknowledged that their decision to participate could have been influenced by parental suggestions, such as promises of rewards. Additionally, not all participants were confident

that their parents would have respected their refusal to participate, underscoring the potential influence parents have on children's choices and the need to ensure that children's decisions are not unduly influenced.

In clinical trials, the primary objective is usually to improve health. In trials of interventions around the time of birth, follow-up studies likewise commonly focus on later health impacts, but the outcomes assessed are usually chosen by the researchers rather than the participants. Understanding consumer research priorities can enhance future research quality and relevance [2]. Thus, one of the objectives of this study was to explore whether the outcomes assessed after this clinical trial were those considered important by the participants themselves. We found that participants expressed satisfaction with the outcomes investigated in the ACTORDS childhood follow-up studies. This is consistent with the findings of an earlier study on long-term follow-up after neonatal studies, where parents of participating children considered that the outcomes chosen by the researchers were largely appropriate [18].

Furthermore, participants in the study expressed gratitude for their involvement in the original trial and believed that prenatal corticosteroid exposure positively impacted their quality of life. However, some participants had misconceptions about the effects of prenatal corticosteroid exposure, attributing certain health conditions to it. This highlights the importance of ongoing follow-up communication to provide participants with accurate information and address any misconceptions that may arise.

While data saturation was likely reached, non-response from potential participants and an over-representation of participants of NZ European descent indicate the possibility of important perspectives remaining undetected. Purposive sampling could have ensured a more ethnically diverse sample, and incorporating a survey or alternative data collection method might have appealed to participants with limited availability for face-to-face interactions. A strength of this study was piloting the interview schedule, enabling adjustments to topics and wording to minimise misinterpretation of the questions.

Conclusion

The current study explored young adults' perspectives on their childhood participation in medical research. Current consent procedures were deemed acceptable as parents hold the responsibility of making decisions on behalf of their children, and their commitment to their child's well-being ensures that they make appropriate choices. However, concerns were raised regarding children's assent, which may be influenced by the parent-child relationship. To promote children's agency, researchers should provide children with opportunities to express their preferences, opinions, and concerns, and take their voices into account when making decisions that may affect them. The trial's outcomes and the health-related follow-up outcomes aligned with participants' interests. Ongoing communication with research participants may help address any misunderstandings about the effects of medical interventions.

“What is already known on this topic”

- Medical research, which aims to improve human health and is of public interest, necessitates prioritization of research questions due to limited resources.
- There are no reports on adults' perceptions of childhood enrolment in longitudinal medical research or their preferences on measured outcomes.
- Exploring childhood experiences, consent and assent arrangements, and outcome preferences can improve the quality of consent and assent processes in paediatric health research.

“What this study adds”

- The finding that current consent procedures were deemed acceptable reinforces parents' role as primary decision-makers in paediatric research.
- The concerns regarding children's assent emphasize the importance of giving children a voice and involving them in the research process to express their preferences.
- The discovery that some participants had misconceptions about the effects of prenatal corticosteroid exposure, underscores the importance of providing accurate information to research participants.

“How this study might affect research, practice or policy”

- Ongoing communication with research participants may help address any misunderstandings about the effects of medical interventions.
- Researchers should give children opportunities to express their preferences and concerns, considering their views when making decisions that may impact them.
- By involving children in the research process, researchers can enhance their engagement, promote autonomy, and foster agency.

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Table 1. Demographic Characteristics of the Sample and Interview Details (N = 17)

ID	Gender	Gestational age (weeks)	Age (years)	Plurality	Ethnicity	Discussion		
						Format	Mode	Duration (minutes)
A	Female	30.7	23	singleton	NZ European	Group	In-person	47
B	Male	29.0	22	singleton	NZ European	Group	In-person	47
C	Male	31.7	22	singleton	NZ European	Group	In-person	47
D	Female	31.0	19	singleton	Indian	Group	In-person	47
E	Female	31.0	20	twin	NZ European	Group	In-person	47
F	Male	28.3	20	singleton	NZ European/ Other	Group	In-person	47
G	Female	38.3	22	singleton	NZ European/ Other	Individual	Videocall	24
H	Female	33.1	23	singleton	NZ European	Individual	Videocall	20
I	Female	28.0	22	singleton	Chinese	Individual	Videocall	14
J	Female	31.4	22	singleton	NZ European	Individual	Phone	13
K	Female	31.6	23	twin	NZ European	Individual	Videocall	18
L	Female	31.0	20	twin	NZ European	Individual	Videocall	15
M	Male	31.6	23	twin	NZ European	Individual	Videocall	25
N	Male	26.1	20	triplet	NZ European	Individual	Videocall	16
O	Male	34.4	19	singleton	NZ European	Individual	Phone	15
P	Female	37.0	23	singleton	NZ European/ Māori	Individual	Phone	21
Q	Female	31.3	23	singleton	NZ European	Individual	Phone	15

Table 2. Illustrative Quotations from Participants

Themes and subthemes	Topic	Quotation	*n*
Theme 1: Retrospective understanding of the trial and follow-up studies			
Study awareness and engagement	Some knowledge on the purpose of the trial	… she said to me that she was given steroids when she was pregnant with us, with me and my twin sister, to help us grow or develop or something. (L)	17
	First heard about the study in adulthood	For me, I had no idea. My whole life I had no idea we were part of this study. And then me and my twin sister got a letter in the mail and it was from the University of Auckland. (E)	9
	Aware since childhood	… I kind of knew about the study my whole life because there was a fridge magnet on my fridge that said ACTORDS. (D)	8
	Actively seeking information	Yeah and I think since then [6-8-year follow-up] I've always been asking questions about it. Because some of it's a bit vague and confusing in my memory so I'm always asking my mom about it, yeah. (H)	4
Memories around 6-8-year follow-up assessments	Physical	I just remember lying on that thing. Oh my goodness. It seemed like, I feel like there was a couple of trays [of blood] they'd taken. (C)	9
	Cognitive	And then I remember like the cognitive stuff like trying to put puzzles together. Trying to draw things and memory kind of stuff. (K)	8
Theme 2: Aspects of health that participants deemed important			
Outcomes of importance that were measured as part of the 6-8-year follow-up study	Physical	… and then I guess the blood one would be quite interesting as well, because my mom's got high blood pressure, so be interesting to see if I get that as well later in life. (H)	10
	Cognitive development	… the brain activity I think would probably be my main concern. If they [own hypothetical children] were mentally disabled, I think, would probably be my biggest fear. (G)	5
	Health-related quality of life	health related quality of life, I thought that was like a more subjective well-being type of thing. I think and subjective well-being is an important thing to mention. (I)	4
	Behaviour	behaviour is the one that stands out to me out of all those. (N)	3
Outcomes participants thought should have been measured	Physical	I had severe apnoea when I was a baby as well. I have had that most of my life. But I didn't recognise that when I was like, starting to grow up a bit. (P)	2

Themes and subthemes	Topic	Quotation	*n*
	Neurodevelopmental	So, I don't know whether premature kids are more likely to have learning disabilities and stuff. (H)	3
Theme 3: Reflection on childhood research experience			
Positive experience	Positive perceived effects of corticosteroids	… it was going to help with lung development. To help increase the chances of surviving if born early. So, I'm pretty happy they did that. (Q)	7
	Reassurance of trial participation	… they just felt really lucky to have had that extra kind of support and kind of knowledge and people trying to help when we were born. (M)	2
	Positive 6-8-year follow-up	… like it is curiosity and excitement about you know, realising "Oh, this was actually a huge part of my life. (G)	7
	Excited for 20-year follow-up	When I got the letter it was actually like, it's quite interesting when you get a letter like that and see, you're quite intrigued into what it was all about, so yeah. (F)	5
	Good quality research	… obviously, the blood testing is never fun, but like you know, the people who did the testing were really good at making sure that it was, it wasn't seen as a scary thing. (M)	4
Negative experience	Negative perceived effects of corticosteroids	I know my mom would always say that the reason, because I, when I was born, I had quite a lot of body hair. And she said, the reason that was caused by whatever was put into her. (G)	3
	Long day at 6-8-year follow-up	I do feel, like even though I was eight years old I felt like it was quite a long process. I don't know, that may or may not be true but I do remember feeling that way afterwards. (C)	6
	Unclear 6-8-year follow-up results	Yeah some of it was a bit confusing, all the graphs and everything. (H)	1
	Feeling vulnerable looking back	If it's measured that means there's a possibility for something to happen, right? Like what sort of impact does that have on my life now? (F)	3
Theme 4: Participants' views on parental consent			
Parental consent is appropriate	Children aged 6-8 unable to understand	The alternative to my parents consenting for it would be my consenting for it. And I don't think I would have quite understood what the study was about if you had asked me to consent. (I)	8
	Children too susceptible to suggestions	You could've [asked], you want a Cookie Time cookie and do some tests?, I'd be like yes, fantastic idea. [..] if I was told that you've just got	4

Themes and subthemes	Topic	Quotation	*n*
		to do these tests for these people, I'd be like, I don't want to do some tests, that's weird. (B)	
	Parents committed to children's best interests	… my parents made the decisions for me. They're going to feed me, they're going to take care of me as a child, so I know they're doing it in the best interests. And everyone being premature babies, our parents wanted us to have the best possible outcome, to have a high percent chance for that. And I don't have a problem with it at all (C)	6
	Mothers' right to decide	… it's her choice because at the time it was her body, you know. I wasn't even, I guess, in this world yet, so I don't hold any envy or anger towards her for consenting on my behalf, because it wasn't really my choice in the first place. (G)	2
Need to listen to the child	Participants felt they were capable of consent at age 6-8 years	I think if my mom was like to explain it to me when I was seven I would have been like able to make the decision that you know "yeah, I'll do it", like if it's for the better of, you know, medical research, like I'm "yeah I'll do it". (L)	3
	Parents would have respected children's wishes	I'm sure if I kicked up a fuss my mom wouldn't have forced me to do it. (H)	7
	Child reluctant to express their opinion	I don't think I would've said no to them, 'cause even if I did say "no", I don't think they'd listen to me. (D)	2
Theme 5: Facilitators and barriers to the qualitative 20-year follow-up study			
Reasons for taking part	Curiosity	Because I am wanting to know what's going on with my health and if that steroid is good for people to, you know, if they are going to go into early stages of labour. (P)	11
	Altruism	I'm happy to be part of something that hopefully helps people (H)	9
	Encouraged by parents	my mom's always just told me that it's really important to be a part of the research. Um, and that I should definitely do it because it's 20 years in the running or something like that. (L)	2
	Proud to be part of such an important study	It's really interesting to be a part of it. I mean, not every child is part of something as big as that. (N)	3
Current and potential facilitators	Flexibility of data-collection	I feel like I found it fairly easy, especially because you gave different options of how people could take part in it, as well, so I was quite flexible. (H)	1

Themes and subthemes	Topic	Quotation	*n*
	More information on the study	Maybe emphasize like how important this will be or how the findings for this may be used or something. So that people feel they're actually contributing to something. (I)	4
	Questionnaire format	Maybe they could like, instead of doing face to face talking, they could just like answer the questions like typing it out or something, I don't know. Because, you know, at least you get, even though you can't see them, at least you'll get like some sort of answer. Maybe. Like, yeah, like a survey that they can fill out. (H)	2

Appendix 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist
This checklist is intended to supplement the manuscript by providing further detail on methodology.

Domain 1: Research team and reflexivity

Personal Characteristics (page 5)

1. Interviewers: Nike Franke (NF)
2. Credentials and 3. Occupation: PhD – Research fellow, Liggins Institute, University of Auckland
4. Gender and ethnicity: Female, New Zealand European
5. Experience and training: NF has conducted semi-structured interviews prior to current research.

Relationship with participants (page 5)

6. Relationship established: No established relationship with any of the participants
7. Participant knowledge of the interviewer: Participants were aware of the reasons for conducting the study, which were detailed in the participant information sheet and consent form. NF introduced herself and her role in study prior to starting the interview
8. Interviewer characteristics: European ethnicity; belief in the need for consumer voices in health research. Analysis from a Eurocentric world view.

Domain 2: study design

Theoretical framework (page 5)

9. Methodological orientation and theory: Thematic analysis

Participant selection (pages 4-5)

10. Sampling: Consecutive - Participants of the overarching ACTORDS follow-up study indicated their consent to being contacted for current study. As a participant consented, NF invited them to current study.
11. Method of approach: All participants were sent an email containing the participant information sheet and consent form. This was followed up by a phone call.
12. Sample size: N = 17
13. Non-participation: NF approached 134 participants of the ACTORDS follow-up study. A total of 101 did not respond to any form of contact. Eight were interested, but could not be further contacted. For three a parent replied saying their child was cognitively unable to participate. Two declined due to having relocated and another three declined without giving a reason.

Setting (page 5 and Table 1)

14. Setting of data collection: All individual interviews took place at participants' home via phone or internet and the focus group took place in-person at a community centre.
15. Presence of non-participants: Potentially family members of the participant were present at the individual interviews, but the researcher was alone.
16. Description of sample: There were 11 females. In total, there were 12 singletons, four twins, and one triplet. Gestational age ranged from 26.1 to 38.3 weeks. At the time of the current study participants were aged between 19 and 23 years. Ethnicities included: NZ European (n = 12), Māori (n = 1), Chinese (n = 1), other (n = 2), Indian (n = 1). Families of eight urban and eight rural locations were included.

Data collection (pages 4-5, Table 1, and Appendix 2)

17. Interview guide: All interviews were guided by a set of questions and prompts. Participants were given a copy of the questions and prompts during in-person interviews. The questions were pilot-tested with a similar study sample.
18. Repeat interviews: No repeat interviews were carried out.
19. Audio/visual recording: Interviews were audio recorded and transcribed ad verbum.
20. Field notes: No notes were made during the interviews.
21. Duration: Interviews were between 13 and 25 minutes. The focus group was 47 minutes.

22. Data saturation: Saturation was reached.
23. Transcripts returned: Yes, if requested.

Domain 3: analysis and findings

Data analysis (page 5 and Table 2)

24. Number of data coders: Two coders (NF and TW; both NZ European). After the coding matrix was constructed and consensus was reached, all transcripts were coded again by NF.
25. Description of the coding tree: Yes.
26. Derivation of themes: All themes were derived directly from the data.
27. Software: QRS NVivo was used to manage the data.
28. Participant checking: Participants did not provide feedback on the findings.

Reporting (pages 5-9 and Table 2)

29. Quotations presented: Participant quotations are presented to illustrate the findings, identified by a pseudonym.
30. Data and findings consistent: There was consistency between the data presented and the findings.
31. and 32. Clarity of major and minor themes: A distinction was made between major and minor themes. Sub-themes were presented to illustrate differences between participants' experiences within each major theme.

Appendix 2

Interview schedule

Main question	**Related prompts**
What do you know about this study?	What was the purpose of the study that you were part of? What do you understand about what was done to you through the study? What outcomes were being investigated at the different assessments?
How was it to be part of this study?	When did you first learn about your participation in this study? What was that like? Did you know you were in a medical study from before birth? How do you feel about that? What do you remember about the earlier assessments (childhood, 6-8 year)? How did you feel about being approached for the most recent assessment?
What do you know about the outcomes/ findings? (Move on to next question if participants cannot remember)	How important do you think it is to investigate these outcomes? Which outcomes did you find interesting?
Show a list of outcomes measured	These are some of the things we measured, what do you think about those? Which outcomes are most important to you? Why? What else would you have liked to have known or do you think should have been assessed? Are there any outcomes you think we should not be assessing?
How do you feel about your parents consenting on your behalf?	How do you feel about your parents giving (repeated) consent -Before you were born? -When you were a child (2-8 years)? Did your parents ask you if you wanted to be part of the study (at or after age 6-8 years)?
Why did you agree to take part in the most recent follow-up?	Not everybody we approached said yes. Why might this have been? What do you think might have encouraged them to say yes?