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## Parent perspectives on the secondary use of birth cohort data

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### SUMMARY

Parents who have given permission to enroll their children in longitudinal birth cohorts and research repositories have agreed to provide researchers with access to a vast amount of data on themselves and on their children's growth and development. These parents' perspectives on data sharing are critical: they are gatekeepers to this data and they are the guardians of child research participants. Their opinions and preferences have not been captured to this point in the literature. Consultation with research participant stakeholder groups is essential for establishing and maintaining respectful and mutually-beneficial research relationships.

### INTRODUCTION

"The value of data lies in their use"<sup>1</sup>. Worldwide, funders and custodians of public research encourage, if not mandate, the sharing of data<sup>2-4</sup>. The recognised benefits of secondary use of research data, typically held in Research Data Repositories (RDRs), include (a) increased diversity, novelty and complexity of research opportunities; (b) cost savings through economies of scale to benefit the public, funders, researchers and trainees; (c) lessened risk of "failure to discover"; (d) promotion of intra- and inter- disciplinary research; (e) maximisation of research participants' contributions; and (f) lessened future research and respondent burdens<sup>2-5</sup>. As RDRs are relatively new, processes that facilitate re-use while honouring participant preferences have not yet been fully developed. Issues that must be addressed include consideration of privacy, risk and consent over time, especially for child participants; access and ownership; and, regulatory governance<sup>6-7</sup>.

RDRs can contain extensive information such as parental and child data, collected across the lifespan including biological, epidemiologic and longitudinal data on health, lifestyle, development and service utilisation. RDRs must address concerns relating to the operational and practice standards for maintaining and using these data. Some commentators believe the standards for biological vs. non-biological data to be quite divergent, given their manner of collection, potential for de-identification and storage requirements [8]. In applying standards of biobanks to non-biological research repositories, the latter may be subjected to overly restrictive or inappropriate requirements; conversely, important considerations may be overlooked. Those providing the data, the research participants, have a vested interest in determining standards of practice for research repositories including those relating to privacy, consent, access and communication. Current research on parent perspectives has focused primarily on biobanking; little has been undertaken in the area of non-biological RDRs. In this research, we have undertaken qualitative research to understand parent opinions about data repositories; these findings are critical to build and sustain trust in RDRs.

### DESCRIPTION

We used qualitative methods to describe the perspectives of parent who participate in a longitudinal pregnancy cohort on the secondary use of their, and their child's, non-biological data<sup>9</sup>. The study sample of parent participants was drawn from two Alberta pregnancy cohort research studies. Purposive sampling was used to identify parent participants who were fathers, maternal ages both older and younger than 30 years, visible minorities, and new immigrants. Thirty-seven people consented to take part in this study, 19 in individual interviews and 18 in focus groups (4 groups of 3-6 participants). Semi-structured interview guides were used to elicit parental perceptions regarding (1) the nature of research; (2) motivations to participate in research; (3) the benefits and risks to sharing research data and RDRs; (4) the strengths and weaknesses of RDR governance strategies; (5) 5 alternatives for RDR consent; and (6) the role, if any, of the burgeoning maturity of child research participants. Interviews and focus groups were audio-recorded and confidentially transcribed. A coding framework was developed using methods described by Patton and informed by focus group methodology<sup>10</sup>. Institutional ethics approval was obtained prior to the start of this study.

Both positive and negative opinions towards non-biological research data sharing and RDRs were revealed. There are several points of contention for parents, which will directly impact RDR implementation. Under positive perceptions, parents recognised (a) the overwhelming value and benefits to society, researchers,



participants and funders for data to be retained and shared, and (b) the rigour, trustworthiness and protectiveness of RDR governance strategies that control data access using applications, access criteria, committee oversight, and external regulation. Under negative perceptions, parents expressed concerns that (a) parent and child privacy is at risk and identity protection is a paramount concern; (b) 2 consent alternatives were inappropriate and inefficient: traditional, opt-in consent and opt-out consent; and, (c) governance strategies are weak around ensuring accountability of secondary researchers once access is granted. Under contentious issues, parents disagreed on (a) how child data varies from adult data; (b) how to recognise the burgeoning maturity of child research participants; (c) the most appropriate consent option (i.e. no clear preference between broad, broad-periodic, and tiered consent); and, (d) how to involve the public in RDR governance (see Table 1 for sample transcript quotes).

THEME	SAMPLE QUOTE
Positive Perceptions	"I think in general if [data's] used properly and ... for a noble cause then I [sic] totally agree with [data sharing], because we can save a lot of time and there is ... a lot of things that are already collected to certain questions that you can reuse on [sic] certain parameters, that you can use for different research, so [sic] they can have a base and I'm sure every researcher is going to continue to dig further but why go back to square one when you have already some grass roots there." [mum, visible minority, new immigrant]
Negative Perceptions	"... if you [the RDR] don't know exactly who's using [the data in the future] then I wouldn't want certain things associated with my data, I know that makes the data maybe less useful but, yeah for me it would be more like name and, and things like that, age I see how that's beneficial." [mum, < 30 years]
Contentious Issues	"Well I think that whenever it's children [sic], you want sort of higher safeguards right and, and more checks and more security, particularly around the personal identification type of stuff because it's not [sic] them deciding, it's their guardians or whatever." [mum, ≥ 30 years] "I just don't think that [sic] children's data versus adult's data should be something differently. I think they should all be. If someone's participating in the study, you're going to protect that information. It should be protected whether its child or an adult." [mum, ≥ 30 years] "If you started doing that, if you contacted [children] when they became an adult or whatever that would be another logistical [issue]. I think as a parent you just trust that, you just trust the consent of the parent when the child was a child, from my opinion anyways." [mum, < 30 years] "I don't really think [the child] should be involved in decision making, you know I think that she should have the option that [at] whatever 18 or whatever it is in the province to have her data opted out, or taken out if she's really that you know passionate about [it]." [mum, ≥ 30 years]

TABLE 1. Sample participant quotes representing major themes recognised in transcripts

## CONCLUSION

Our findings suggest that research participants in a community-based, descriptive, non-intervention longitudinal cohort are supportive of non-biological data retention and sharing. Parent participants expressed trust in the original research team, which seems to extend to the research enterprise and RDRs when accompanied by altruistic motivations and detailed governance strategies. Parent participants dislike extreme consent options that are too active or too passive for parents. RDRs must prioritise protections of participant privacy and mechanisms to ensure secondary researcher accountability. Our findings suggest that parents are not universal on their preferred approach to handling the uniqueness of child data and the burgeoning autonomy of child research participants. We must understand the nuances of this divergence so that we can develop strategies to effectively and appropriately address it. Future research is necessary on child and adolescent perspectives on data sharing and consent to RDR participation, and on clarifying the preferred consent model for parent research participation. The implementation of leading edge data repository governance and data sharing strategies that protect privacy and address consent will enhance the development of new knowledge. This new information can be applied to policies and programs to improve outcomes for children and families.

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