

Article

In safe hands: child health data storage, linkage and consent for use

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Abstract

While there is potential for societal benefit from linkage and integration of large datasets, there are gaps in our understanding of the implications for children and young people, and limited inclusion of their views within this discourse. We aimed to understand the views and expectations of children, young people and their parents/caregivers in Aotearoa New Zealand regarding child health data storage, linkage and consent for use. This qualitative study included 24 Māori and non-Māori children, young people and their families across five focus groups, recruited from a community-based health service. A mixed Māori and non-Māori research team facilitated participant recruitment and data collection. Child, adolescent and parent/caregiver groups were held separately. Sessions were audio-recorded and the verbatim transcripts were analysed thematically. We identified three themes: (i) I am more than a number: seeing patients as people; (ii) In safe hands: data as power; and (iii) What are your intentions with my data? Consent as an active relationship. A key challenge was the reductive and stigmatizing potential of data integration for minoritised groups. Hypothetical discussions of data sharing and linkage were contingent on trust between the participant and the health professional, with negotiated data ownership. Consent was conceived as an active relationship needing renewal and renegotiation as children reached adulthood. Current consent processes for ongoing use of child data require further deliberation. Without a strong ethical and child rights-based approach to issues of child health data management, consent and linkage, we risk exacerbating health inequities and experiences of breach of trust.

Keywords: health data, child health, qualitative research, ethics, consent

INTRODUCTION

Aotearoa New Zealand (henceforth referred to as New Zealand [NZ]) and the rest of the world are in the midst of a data revolution (Turnbull, 2014), whereby more data is collected, stored, used, reused and linked than ever before. Data sharing has increased rapidly, as has our ability to link data, and there is increased secondary use of data in predictive analytics and models. Children are particularly vulnerable in this context due

to their inability to consent to various data processes for themselves.

There is an increasing need for research focusing on child rights in the digital age (Livingstone and Bulger, 2014; Livingstone and Third, 2017). The 2021 Lancet and Financial Times Commission on Governing health futures 2030: growing up in a digital world, emphasized the need for 'trust in digital health by enfranchising patients and vulnerable groups [and] ensuring health and digital

Contribution to health promotion

- Data linkage is a relatively new possibility in health research, and little is known about the possible impacts for children. Children's own views on how their data are used are rarely considered.
- In this focus group study, children and their caregivers were concerned about their data being used to portray already stigmatized groups in a negative light.
- Children and their caregivers believed that trust and ongoing negotiations were important considerations for consenting to data use.
- To avoid breaching trust and worsening health inequities, children's rights must be recognized as central to conversations and decisions about health data.

rights' (Kickbusch *et al.*, 2021). Digital rights for children refers to child rights (outlined in the United Nations Convention on the Rights of the Child (Ministry of Social Development, 2014), the OECD Recommendation on Children in the Digital Environment (Organisation for Economic Co-operation and Development, 2012), and others), applied in the context of digital environments, technologies, and the subsequent data generated (Kickbusch *et al.*, 2021). However, it is also important to consider children's moral rights, particularly the 'right to an open future' (Feinberg, 1980), which should protect children from having important life choices shaped by others before they have the ability to choose for themselves. Without a strong ethics- and rights-based approach to child health data management in the current digital climate, there are risks of potential harm, including privacy breaches, the continued production of racialized datasets and prediction models, and failure to attain adequate consent prior to linkage.

Supporting data rights also gives a voice to minoritised and traditionally marginalized populations, such as Indigenous groups, regarding their own health, well-being and rights to self-determination (Walter, 2016). Walter (2016) refers to Indigenous data sovereignty as '...the right to determine the means of collection, access, analysis, interpretation, management, dissemination and reuse of data pertaining to the Indigenous peoples from whom they have been derived, or to whom they relate' (Walter, 2016). In NZ, this is supported by the rights articulated in the Treaty of Waitangi and the United Nations Declaration on the

Rights of Indigenous Peoples (Te Mana Rauanga, 2016). Health and other research must therefore consider how data linkage can engage with Māori data governance, whether the outcomes of data linkage will provide meaningful benefits, and what protective mechanisms are in place to minimize any anticipated harms (Cormack *et al.*, 2019). Currently, the predictive potential of linked datasets is limited by acknowledged racial bias in data collection, algorithm development and analytical decisions, which can uncritically reproduce racialized outcomes (Cormack *et al.*, 2019; Knight *et al.*, 2021).

There is potential for societal and health gains when utilizing large data sets (Statistics New Zealand, 2018a), including integrated data from a range of sectors in addition to the health system (Statistics New Zealand, 2014). In NZ, for example, the Integrated Data Infrastructure (IDI) enables the production of additional statistics and research without additional respondent burden through data linkage from the education, welfare, immigration, justice, and health sectors (Statistics New Zealand, 2014). The integration, or linkage, of datasets has occurred relatively rapidly, however, posing challenges for data privacy and protection (Turnbull, 2014; Kickbusch *et al.*, 2021), and the extent of linkage does not appear to be widely understood by the public (Gulliver *et al.*, 2018). Previous research with adults has identified there is potentially social licence for the integration of such data, with important caveats such as data quality, context, researcher responsibility, privacy and consent (Thabrew *et al.*, 2022). However, a review suggests there are key tensions inherent in debates around data sharing involving Indigenous communities, including the lack of consideration of implications for participants and the importance of Indigenous perspectives, especially in relation to data sovereignty in NZ (Reeves *et al.*, 2022).

There is also limited child and family voice present in these debates. It is important that children's and young people's views are included, given their lack of voice in decision-making and their inability to consent for themselves. Research involving digital health and data challenges must capture diverse perspectives, including age, ethnicity and regional location (Kickbusch *et al.*, 2021). The aim of this study was to understand the views and expectations of children, young people and their parents/caregivers with regards to child health data storage, linkage and consent for data use in NZ.

METHODS

Study design

We undertook focus groups with children, young people and their parents/caregivers, informed by a

critical approach to research that was cognisant of our researcher positionalities, especially as a team made up of Indigenous and non-Indigenous researchers. We were informed by Kaupapa Māori methodological principles (Malpas *et al.*, 2017; Reid *et al.*, 2017), as a response to systemic racism, and the continuous effects that this has on, for example, health research and health outcomes in NZ. Focus group conduct was guided by Community-Up research values (Smith, 1999; Cram, 2001) as a way of recognizing our accountabilities and responsibilities to the communities we were researching with (Cram, 2009), and as guiding principles for undertaking research in a multicultural and transdisciplinary research team (Cram and Phillips, 2012). The principles centre on the importance of respectful relationships, being seen and known in the community, listening before speaking, sharing and hosting, reflexivity, being careful and being humble (Smith, 1999; Cram, 2001).

Recruitment

Potential participants were selected from a convenience sample of families (children, young people and their parents/caregivers) involved in a community-based health service. The study was publicized by the programme coordinator during one of the regular weekly sessions. The coordinating researcher also attended the sessions to talk about the study (with emphasis that participation or non-participation would not impact on care within the service). Families who had indicated their interest were then contacted by the coordinating researcher by telephone, text message and email.

Data collection

We held five focus groups in total across the region with parents/caregivers (two groups), children aged 5–12 years (two groups), and young people aged 13–16 years (one group), either after school or during school holidays. The focus groups were conducted by CW, NR, KT and another facilitator. The facilitators had undertaken similar previous research and had experience working in community health settings (Appendix 1). The parent and child focus groups took place in community centres and were held simultaneously but in separate groups, with one to two facilitators taking each group. The focus group with young people were held separately. All sessions began with a welcome and whakawhanaungatanga (process of establishing relationships, kinship, relating well to others) to establish connections, kai (food) and working through the participant information sheets and consent forms together. Participants asked questions about the study process and the researchers' reasons for undertaking the study. Written informed consent was obtained

from all adults, parental proxy consent was obtained on behalf of the children, and the children also gave assent to participate themselves. We collected participant demographic data (gender, ethnicity, age) on a separate questionnaire.

The child groups were play-based, with games, drawing and breaks. The focus group topic guide was developed by the researchers focusing on six key domains: health information, data sovereignty/ownership, storage, sharing, linkage and consent (Appendix 1). Sessions typically lasted from 40–90 min, although the children's sessions were interspersed with games. The sessions were audio-recorded and independently transcribed, and photographs of the art sheets were taken.

Data analysis

We undertook reflexive thematic analysis of the focus group data, in alignment with the methods outlined by Braun and Clarke (2019, 2022). The coding was inductive, semantic and (critically) realist. This reflected the original accounts and observations of participants. However, the analysis was informed deductively by a set of predetermined aims, objectives, and topic domains that guided data collection and could produce applied findings.

CW led the thematic analysis and began by familiarizing themselves with the dataset through listening to the recorded focus groups, rereading the data and transcript checking. The coding stage involved tagging or labelling the data in the manner described above using nVivo version 1.2. The codes and data extracts were then collated for initial generation of themes. CW identified candidate themes from the data and reviewed the themes against the dataset. At this stage, YA joined the analytic process to collaboratively sense-check the themes against the data and provide potential alternative interpretations of the data from their perspective as a clinician researcher. The themes then underwent further refinement in conjunction with the wider research team, including Indigenous and non-Indigenous team members, during the writing process.

FINDINGS

Twenty-four children, young people and parents/caregivers participated in the study (Table 1). We identified three cross-cutting themes: 'I am more than a number: Seeing patients as people'; 'In safe hands: data as power'; and 'What are your intentions with my data? Consent as an active relationship'. Illustrative data excerpts are presented below, and participant quotations have been attributed by ethnicity and participant type (child, young person and parent/caregiver). Square brackets enclose words intended to clarify meaning or provide a brief explanation.

Table 1: Participant demographics

Participants, <i>n</i> (%)		24
Parents/caregivers <i>n</i>		10 (42)
Female		9 (90)
Ethnicity ^a	Māori	6 (60)
	NZ European	8 (80)
	Pacific Peoples	–
	Asian	1 (10)
Teenagers <i>n</i>		4 (17)
Female		1 (25)
Ethnicity ^a	Māori	2 (50)
	NZ European	3 (75)
	Pacific Peoples	1 (25)
	Asian	–
Children <i>n</i>		10 (42)
Female		4 (40)
Ethnicity ^a	Māori	7 (70)
	NZ European	9 (90)
	Pacific Peoples	–
	Asian	1 (10)

All figures are presented as *n* (%).
^aTotal ethnicity output used; percentages add to >100% as participants could identify with more than one ethnicity.

Theme 1: I am more than a number: Seeing patients as people

Children and young people were clear in their desire to be seen as more than a number. They described their health information and data in relation to stories about their health, both with respect to their current illnesses and conditions, health indicators and health behaviours (e.g. currently have asthma) and what has happened in the past (e.g. previous injuries, trips to hospital).

“Health data is about knowing information about your health story and problem.” – Young person B, male, Māori

“Information that is linked to you and that is about you, like maybe like what your health, your status, what your blood type is, all about that.” – Child D, male, Māori

These examples of health data make up each child’s ‘story’, which would change over time, indicating that their health story was ongoing, evolving and still being written.

“Like, um, do you watch YouTube, you’ve got your birth number, like, I have one and I know mine, I’m not going to say it. Um, your weight, what you’ve done in the past and what has happened over the

years, like, to your body. Like, you could have had asthma, or you could have things, like mental changes too.” – Child E, male, NZ European

Participants in all groups emphasized that their health story was about being more than a number. Adult participants discussed how their data represented a real person behind the numbers, that data did not tell the ‘full picture’ about an individual, and that this might pose challenges for data linkage in the future. This was especially important if the data was perceived to be racialized, which might lead to further stigma.

One parent described how they believed that pooled data did not fully represent them as a person in the same way that information learned in a one-on-one conversation might.

“You’re not talking about a Māori [person] that you got from your data – you’re talking about me as an individual, but if you want me to engage then how about we have a conversation as a real person. You’re not going to get that if I was immunised or not immunised at five years [...] you’re not going to get that information from where I grew up or where I went to school. You’re going to get that from me, you’re physically going to get it from me, but you can’t get that from data or pooling data, and not all Māori tick the box that they’re Māori.” – Parent C, female, Māori

This excerpt highlights two important points about the limited predictive potential of linked datasets: firstly, it echoes the idea that data points do not ‘represent’ a whole person; secondly, it points to challenges with accurate data collection (and therefore data linkage and use in prediction models) in the health system where Māori are often undercounted (Harris et al., 2022).

Teenage participants echoed the concern about the predictive potential of data linkage while they were more ambivalent towards data linkage in general, with one participant stating that, ‘if it’s anonymous, I probably wouldn’t mind’ (Young person D, male, NZ European), and another referring to prediction modelling:

“I don’t think that’s right – I reckon the future can’t tell itself.” – Young person C, male, NZ European

Their discussion highlighted that aggregated and linked data could diminish the health story and context of the individual, especially if data from a person with similar demographic characteristics was being used to represent a collective health story.

“The information could like change, like, if one person is the same they might, “oh, let’s just shorten this down, it’s basically this” and they do it for the next person, and then they get to another person and it’s like “oh, it’s only this”, and when it first started it was all of this.” – Young person C, male, NZ European

They likened it to someone profiling them before they met them:

“They assume things you, like, without even knowing you.” – Young person A, female, Māori
“Judging a book by its cover.” – Young person B, male, Māori

Theme 2: In safe hands: data as power

Data sovereignty was discussed among participants with regards to the relationships between power, ownership, access, and control of data. When asked directly, ‘who does your child’s data belong to?’, parents and caregivers felt strongly that they and their child had ownership of their child’s health data, that it was part of them and that they and their child should determine who should be able to access it and use it.

Children and young people tended to attribute multiple ownership(s) of their health data according to who would take care of them—to themselves, their parents (*‘Because they’re your, they are in charge of you, really’* – Child A, female, Māori), their wider whānau, and, occasionally, health professionals. When asked who should own Hemi’s (fictional child character) health information, one child offered ‘whānau’ (family, extended family):

Because they say “it’s his mum”. Or, yeah. She has to know really, because she’s halfly in charge of him because she looks after him, she does stuff with him and she looks out for him, like parents look out for you. – Child A, female, Māori

Later in the discussion, another child centred the role of Hemi himself.

Child B (male, Māori): It should mostly be him [Hemi].
Interviewer: Yeah, why is that?
Child B: Because it’s his, not his mum’s or anyone else’s.

There was more uncertainty around the role of health professionals, with a contrast between concepts of ‘permission’ to use data versus assumed good intentions, as demonstrated in the following exchange between two teenage participants:

Young person B (male, Māori): You own your data....

Young person D (male, NZ European): In a way...

Young person B: The doctors... only you have permission.

Young person D: Well, they have permission anyway.

Young person B: Well, you still own it, nobody else apart from the doctor, who owns at least half of it, probably mostly to help us all, so yeah

Despite this uncertainty, child and teenage participants agreed that health professionals should ‘ask you to use it’ (Child A, female, Māori).

‘It’s like lending it’. – Young person A, female, Māori

The perceived safety of the data was an important consideration for whānau when considering data sharing and potential data linkage. This did not refer to data security, but rather data caretaking—who was responsible for looking after their data and ensuring it was used in a respectful manner. For example, young people cited a lack of trust in the institutions linking the data as a potential barrier for some people being willing to share their data.

“...you can’t confirm the future until it’s happened – some of those things might not happen. I probably wouldn’t mind [data linkage] too much, but maybe someone who didn’t trust the government that much because of– I don’t know why somebody wouldn’t trust the government, but people don’t, so yeah.” – Young person D, male, NZ European

This was echoed in discussions around specific clinical encounters, where patient-clinician trust was paramount for active participation; participants acknowledged it would determine whether they freely shared their own health information or not. For example, one parent likened their willingness to consent for data sharing and linkage to their willingness (or not) to engage actively in clinical encounters:

“I know we’re all human at the end of the day, but that really sort of triggers in your brain, like, “okay well, we’re just going to get the Pamol [paracetamol] and leave” or “we’re actually going to stay and ask more questions and get more [information].” – Parent D, female, Māori

Another parent commented that a lack of trust and care would impede their willingness and ability to

consent for data sharing, stating they would ‘*Not just withhold information, not even bother. I literally don’t engage*’ (Parent C, female, Māori).

Notably, data sovereignty and ownership was innately tied to parents/caregivers feeling able to access their own and their child’s data when required, and that this was part of families being able to be active and safe participants in their health journeys.

“We don’t know about that medical side of it unless they actually start sharing the information with us.”
– Parent F, male, NZ European

Self- or whānau-access to data (or lack of) was raised as a challenge to ideas of data sharing and linkage for the benefit of wider society. How could participants feel comfortable with data sharing and linkage when they felt they could not access their own data themselves? In this way, data sovereignty—including ownership, access and control—was equated with power, and trust in health professionals, institutions and the State, was key to whānau feeling comfortable with sharing access to their data.

Theme three: what are your intentions with my data? Consent as an active relationship

Participant discussions highlighted the importance families placed on ongoing consent discussions between themselves and their clinicians. They emphasized the benefits of data sharing to help other children and families with similar conditions, with the caveat that consent for sharing remained a central aspect of the clinical relationship.

Parent H (female, NZ European): [Our daughter’s data] is being shared in Australia and everything, with [daughter].

Parent F (male, NZ European): And England.
Parent H: And England.

Parent F: We’ve always had consent forms.

Parent H: [Paediatrician] has always asked us for consent.

In this way, consent discussions could be empowering experiences for families, allowing them to be active participants in their own health journeys, while also helping others.

Yeah it’s a big thing, like, it is quite important research that we have to think about who we are giving it to, yeah, but they are using it for good things for him, so that’s all that matters. – Parent A, female, Māori

However, the ‘intention’ behind data sharing or linkage and being fully informed of any changes was

also important for children and families. One child remarked:

Child G (female, Māori): [Data sharing] can be kind of good and be kind of bad sometimes.

Interviewer: How do you reckon it’s kind of good?

Child G: Because you are sharing it to the right people, but sometimes can be shared to the wrong people and then you can get in trouble.

Similarly, the parent below emphasizes the importance of discriminate sharing—knowing *who* the data was being shared with, for what *purpose*—and understanding how it would *benefit* their child.

“So, in regards to being, you know, going to the doctor and them offering to give [the data] to other people – for me personally I’ve always been asked. I like to give out consent and I like to know who it’s to, so, “who are you going to send it to?”, “are you going to send it to Tom, Dick and Harry?”, “are you going to send it to a Professional, and what do they do?” “And how is this going to benefit [child]?” – Parent D, female, Māori

Participants perceived consent as an active relationship that needed renewal over time—for example, as children grew older. Discussions among child participants suggested a conceptualization of age-related consent processes, with participants acknowledging changes in ‘responsibility’ for data as children got older,

Interviewer: What if Hemi is 7 years old?

Child A (female, Māori): His parents.

Interviewer: What if Hemi is 13 years old?

Child A: Him and his parents.

Child B (male, Māori): Him, it’s him!

Interviewer: What if Hemi is 16 years old?

Child A: His, ‘cause he can move out.

Likewise, parents/caregivers queried the need for renewed consent if the original intention for the data sharing had changed, rather than treating consent for data sharing or linkage as a one-time transaction. One parent stated:

“I think if a new research company is coming in and wanting the same information that I have previously given consent for, I would want to know who and what again, because I want to know where your security lies. Just because I gave it twenty years ago or five years ago, doesn’t mean I am okay with it now because it could have been misused before so it would continuously be requested each time you

go to pull it because I want to know what you're using it for, I want to know how it's going to be presented." – Parent C, female, Māori

All hypothetical discussions of data sharing and linkage were contingent on trust between the participant and the health professional, highlighting that a trusting relationship within the framework of informed consent can facilitate open data sharing. This was evident even in the child focus groups, where child-like, ingenuous consideration of the concepts at hand was predicated on a trusting environment where the range of characters in the child's life ("*Your mum or dad or your family members. People that you trust.*" – Child I, female, Māori) were helpful and had their best interests at heart. The active consent relationship—if done well—may be an empowering, healing (and mana-enhancing) relationship within the health system and provide safe opportunities for data sharing and linkage.

DISCUSSION

Our study identified three cross-cutting themes that underpin how children, young people and their parents/caregivers view child health data use. First, health data was embodied as a health story that represented a child's unique journey and being more than 'just a number'. Second, there was a sense of data ownership and that any data linkage depended on it being in safe hands. Finally, informed consent for child data use was conceived as an active relationship. This dynamic relationship must be revisited if intentions for data use change and when children reach an age where they can consent for themselves. Notably, while the focus groups were not framed in terms of child rights, discussion of fairness based on moral rights to an open future arose in relation to several topics, including protecting against continued production of racialized datasets, failure to attain adequate consent prior to linkage, building and retaining trust, and reducing misuses of health data that can inadvertently exacerbate health inequities.

In the context of large datasets ('Big Data'), it appears that informed consent no longer matches the way that child health data is used in the face of network growth and fresh opportunities for data linkage (Turnbull, 2014; Adams *et al.*, 2022). Indeed in large linked datasets, people can be included with no direct contact required, with informed consent being impracticable. Often individuals have limited choice as to whether they provide information that ends up in integrated data sets, such as the IDI, as it is routinely collected in essential services. In NZ, data cannot currently be withdrawn from the IDI (Statistics New Zealand, 2018b). As a result, a child cannot retrospectively withdraw

their parents/caregivers' proxy consent (given by virtue of attending the service) when they reach an age where they can consent for themselves. This means that parental consent on behalf of the child essentially commits children to a lifetime of potentially unconsented data retention and linkage. Additionally, linkage of de-identified data as in the IDI currently sits outside of standard ethical procedures as 'low risk observational studies', removing a usual layer of ethical scrutiny.

The dynamic process between children, their parents/caregivers, and their 'burgeoning autonomy' (Beauvais and Knoppers, 2021) highlights the need for an active relationship between the data holder and the data subject (Turnbull, 2014; Taylor *et al.*, 2018). At a basic level, when obtaining consent there should be a clearly identified specific purpose for the use of data, and this should include disclosure of possible future intentions (Toi Aria, 2017). It may still be possible to reap the benefits of data storage and linkage while also respecting the child's moral 'right to an open future' (Feinberg, 1980) by providing children with the ability 'opt-out' and withdraw consent for use of their data (Beauvais and Knoppers, 2021). While this may be suitable for large biobanking projects and other longitudinal studies, it may be more difficult for studies on shorter timeframes and tighter budgets (Beauvais and Knoppers, 2021). This will pose logistical challenges regarding re-identification of de-identified data and retaining sufficient contact information for families, especially among more transient populations, and over time when young people grow up and become autonomous adults.

Previous and ongoing research has been particularly concerned with questions of data governance when data is repurposed in future contexts. A 2018 study of a public-private partnership between a National Health Service trust in the UK and an artificial intelligence venture explored how the 'contextual integrity' of data collected for use in one context can be violated when it is used in another context that is not bound by the same norms of appropriateness (Winter and Davidson, 2019). The DATAGov study offers a co-produced, people-centred model for involving patients and the public in decision-making processes about health data usage and sharing in the context of rare diseases (de Freitas *et al.*, 2021). Micheli and colleagues suggest that, as well as discussion of principles guiding data sharing and use, and who can access and participate in data governance, it is critical that questions of *value production* and how value is *redistributed* are also considered (Micheli *et al.*, 2020). This is central to the consideration of both child and Māori health data and the re-production of outcomes as a result of data linkage to ensure that children retain their 'right to an open future' (Feinberg, 1980).

While participants indicated notions of data ownership (including multiple owners, and lending data), this was a nuanced concept that aligned more closely with ideas of ‘stewardship’ or ‘caretaking’ on the part of health professionals or researchers than transfers of proprietary rights (Adams *et al.*, 2022). Our data, and previous studies (Horn and Kerasidou, 2020), suggest that trust—at multiple levels within the health and other government-delivered systems—may facilitate data sharing. Past research has demonstrated that negative experiences in the health system may affect future engagement in other areas (Wild *et al.*, 2020). Our data suggests that data sharing depends on a trusted data steward or caretaker. The 2021 NZ Medical Council statement on informed consent asserts that this should be an ‘interactive process, not a one-off event’. Institutional trust will also be essential if NZ wants to benefit from integrated datasets. Previous key concerns for Māori regarding offshoring NZ data was the Crown’s capability to act as good stewards of Māori data, due to several reasons including lack of transparency, unilateral decision-making that excludes Māori interests, and a ‘poor track record’ (Bell Gully, 2021). Poor data stewardship, including regarding storage, usage and linkage, has the potential to damage Māori–Crown relationships and erode trust. NZ’s current health and disability system reform includes a focus on developing digital infrastructure to improve health service delivery; this provides an opportunity to also further develop a code of ethics governing child health data use requiring fair and informed consent for data retention for further purposes such as linkage (Jansen, 2016).

A key strength of this study was the high proportion of Māori participants (63%) and the prioritization of child voice. Limitations included the smaller numbers of teenage participants due to scheduling constraints around school term time, which may have limited our ability to draw firm conclusions from this group. Future research should prioritize inclusion of young people’s views, especially as the digital landscape rapidly changes. Similarly, only one parent/caregiver was male, with a high number of female participants overall (90%) which may limit transferability to other settings with a greater proportion of male primary caregivers. One parent focus group included comparatively fewer participants than the other, though there were no considerable differences in views held by the two groups. Additionally, all participants were already engaged in the same community-based outpatient service and might have held different views from their peers who were less engaged in the health system. This study specifically focuses on the views of participants of the health system, noting that these may not align with jurisdictional ethical and legislative requirements or practice.

One of the central principles of Kaupapa Māori research is *whānau-centredness*. A *whānau-centred* approach focuses on improving the wellbeing of *whānau* and addressing individual needs within a *whānau* context, rather than focusing on individual family members and single-issue problems. Issues relating to child health data therefore need to be considered in this context of interconnectedness. Additionally, while the main focus group concepts (health information, data sovereignty, storage, sharing, linkage and consent) were discussed in the context of child health data, many of the findings have applicability to health data relating to people of all ages. While views across age groups did not substantially differ, the conceptual understanding and interpretation of potential consequences of data linkage was indeed different, according to age group. This has implications in terms of how decision-making processes concerning data sharing and linkage (including requests for assent and consent) should be undertaken. While children and teenagers should indeed be involved in decision-making, this information should be tailored to support this process at different levels of understanding.

CONCLUSION

Managing data integration on a large scale requires an equivalent level of responsibility. Our study suggests that children and their families want to be seen as more than a number (their data) and that data ownership is a complex issue that warrants further discussion. Current consent processes require further deliberation, especially regarding consent for children when they become adults and the potential need for re-identification of data in the case of withdrawal of consent. Genuine and meaningful informed consent is key, but how this works in practice with large integrated datasets is questionable. Future research could include how we align participant views with practice, how dynamic or active consent could work in clinical practice, and how this relates to legislative requirements. Digital health applications provide an opportunity to ask for consent with each interaction and document this, as well as ensure continued support for explicit data collection and potential linkage. The importance of addressing these issues should not be underestimated, given the imperative for trust within the health relationship, and the data revolution that is occurring. Without a strong ethical and child rights approach to issues of child health data management and data-extractive process such as data linkage, and subsequent reporting of data, we risk exacerbating health inequities and failing

those in society who do not always have the ability to advocate for themselves.

Supplementary Material

Supplementary material is available at *Health Promotion International* online.

AUTHOR CONTRIBUTIONS

CEKW contributed to study design, data collection, analysis, interpretation, and writing of the manuscript. NR contributed to data collection and critical appraisal of the manuscript. KT contributed to data collection, data analysis, interpretation and critical appraisal of the manuscript. YCA contributed to study design, data collection, analysis, interpretation, and critical appraisal of the manuscript.

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ETHICAL APPROVAL

The study was granted ethical approval by the NZ Central Health and Disability Ethics Committee (20/CEN/156).

DATA AVAILABILITY

The study data cannot be made available in a public repository due to the strict conditions of the ethics approval.

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