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### Access to Fertility Preservation for Trans and Non-Binary People in Aotearoa New Zealand

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#### ABSTRACT:

*There is a growing need for healthcare professionals to discuss fertility preservation options with trans and non-binary people before commencing medical transition as part of informed consent-based models of care. In this article, we adapt the Five-A framework of healthcare access to examine fertility preservation information and services. To do so, we present an analysis of data from Counting Ourselves, the first comprehensive national survey in Aotearoa New Zealand of trans and non-binary people's health and the first study exploring their access to cryopreservation information and services. Among 419 participants who had received gender-affirming hormones or surgery, 33.7% received information about options for fertility preservation and 15.8% accessed fertility preservation services. Findings from the study indicate the need for greater understanding of trans and non-binary people's desire for genetically related children, and what type of information and form of delivery would be most helpful to ensure equitable outcomes in relation to decision-making around fertility and future family-building.*

**KEYWORDS:** family preservation; healthcare access; informed consent; trans and non-binary

#### Introduction

Fertility preservation, the process of storing gametes or reproductive tissue for future use, is increasing trans and non-binary<sup>1</sup> people's possibilities of having genetically related children. Although gender-affirming healthcare is medically necessary for many trans and non-binary people, some treatments such as hormone therapy or surgery can adversely affect a person's fertility (Baram et al. 2019; Mattawanon et al. 2018). The increased recognition of trans and non-binary people's reproductive rights and fertility options is disrupting the commonly held assumption that medically transitioning rules out the possibility of having genetically related children. While not all people who medically transition want to be parents, or feel the need to have genetically related children, international gender-affirming healthcare guidelines recommend that trans and non-binary people should be fully informed about fertility preservation options and have access to fertility preservation services if needed (ASRM 2015; Oliphant et al. 2018). In this article, we outline challenges affecting the reproductive decision-making of trans and non-binary people. We then examine the factors determining access to fertility preservation among trans and non-binary people in relation to findings from *Counting Ourselves* (Veale et al. 2019), the first comprehensive national survey of the

health and wellbeing of trans and non-binary people living in Aotearoa New Zealand (hereafter, Aotearoa).

Access to fertility preservation, like healthcare generally, can be measured in relation to various social determinants. Penchansky and Thomas (1981) characterise these dimensions of access to care in terms of a Five-A framework: affordability, availability, accessibility, accommodation and acceptability. More recently, the United Nations (2000) proposed the AAAQ framework for the right to health. It stipulates that health, and the underlying determinants of health must be available, accessible and acceptable to all people as well as scientifically and medically appropriate and of good quality. We draw on a modified version of these frameworks by Levesque, Harris, and Russell (2013), in conjunction with their distinction between potential and realised access, to address both demand and supply-side-factors influencing trans and non-binary people's uptake and use of fertility preservation services.

In the Five-A framework outlined by Levesque, Harris, and Russell (2013), affordability is determined by a person's ability, capacity and willingness to pay for services; availability and accommodation relate to the ease with which a person can reach a provider's location, and whether a provider has the personnel, technology and facilities to meet a person's preferences and needs in a timely manner; acceptability concerns the extent to which a person is comfortable and can communicate with the provider, depending on factors such as age, gender, sexuality, class, ethnicity and ability; approachability encompasses a person's knowledge of service availability and whether they can identify and access existing services and information; and appropriateness denotes the adequacy and quality of service provision.

In this article, we pay particular attention to affordability, approachability and access to culturally competent and non-discriminatory services as dimensions of acceptability and appropriateness. We focus on these aspects of access to fertility preservation as key barriers identified by research participants in the *Counting Ourselves* study.

#### *Desire for parenthood*

Emerging literature on trans reproduction and family formation indicates that trans<sup>2</sup> young people and adults imagine and desire diverse paths to parenthood, including adoption, fostering, step-parenting, and parenting genetically related offspring. Many trans people who report not desiring

genetic parenthood or fertility preservation express preference for alternative ways of creating families, such as adoption (Auer et al. 2018; Chiniara et al. 2019; Riggs and Bartholomaeus 2018; Von Doussa, Power, and Riggs 2015). Adoption can be a difficult pathway for trans people to navigate due to the decreasing number of children available for domestic and international adoption, including in Aotearoa (NZLS (New Zealand Law Society) 2014), and prejudice against selecting adoptive parents who are trans (Goldberg et al. 2020).

Recent studies suggest that between one-third and two-thirds of trans people desire genetically related children (Birenbaum-Carmeli, Inhorn, and Patrizio 2020; Riggs and Bartholomaeus 2018; Strang et al. 2018; Tornello and Bos 2017). Cryopreservation, the process by which gametes (oocytes/eggs and sperm) or reproductive tissues are cooled and stored at very low temperatures to maintain their viability, provides some trans people the potential to realise their family-building desires and time to consider options while medically transitioning.

Despite many trans people's desire for genetic parenthood, research undertaken in Germany and the USA indicates the uptake of fertility preservation services for trans youth (Lai et al. 2020; Nahata et al. 2017) and adults (Auer et al. 2018) remains relatively low, including among those who are offered fertility information and counselling by healthcare professionals (Bartholomaeus and Riggs 2020; Chen et al. 2017). Trans people encounter various barriers to accessing fertility preservation services, including healthcare professionals' assumptions about trans parenthood or lack of knowledge about gender-affirming healthcare (James-Abra et al. 2015; Riggs and Bartholomaeus 2020), and the cost of freezing, storing and using gametes, especially in countries where fertility preservation is not considered medically necessary or not publicly funded (Abern and Maguire 2018; Defreyne et al. 2020; James-Abra et al. 2015; Jones, Reiter, and Greenblatt 2016; Tishelman et al. 2019). In a review of literature on trans youth and fertility preservation, Lai et al. (2020) outline the unique barriers young people under the age of 25 face including pressure from parents, high cost, and delays in transitioning.

#### *Access to information and approachability*

International guidelines for gender-affirming healthcare recommend that healthcare professionals discuss fertility preservation options with patients before initiating hormones and surgery (ASRM 2015; Coleman et al. 2012; Oliphant et al. 2018). A limited body of research suggests that trans and non-binary people generally value healthcare professionals' expertise on fertility preservation and believe providers should discuss options to aid their decision-making, regardless of whether they pursue such services themselves (Bartholomaeus and Riggs 2020; Defreyne et al. 2020; Riggs and Bartholomaeus 2018). Despite these recommendations, there are differences between some studies of healthcare

professionals' and trans people's experiences of discussing fertility information in healthcare settings. For example, in a US study by Chen et al. (2019) on healthcare professionals' knowledge of fertility preservation, 91% of participants 'often' or 'always' discussed the adverse effects of gender-affirming hormones on fertility with their patients; reflecting the importance gender-affirming healthcare guidance places on ensuring patients are informed about potential side effects. Yet, in a non-clinical Australian study, only one in five (22%) trans and non-binary people reported discussing future cryopreservation options with their healthcare provider (Riggs and Bartholomaeus 2018). It is not clear what proportion of these participants were taking or considering gender-affirming hormones at the time of their healthcare interactions, or when they had accessed care.

Additionally, the extent to which various groups have access to information about fertility preservation options remains inconsistent across the health sector. As discussed below, the dissemination of trans-inclusive information regarding cryopreservation depends largely on healthcare providers' clinical knowledge and cultural competence in this area. While contemporary consumers actively seek online resources to learn more about managing their health and well-being (Lupton 2017), material about fertility preservation on clinic websites can sometimes be inconsistent, absent, or presented in ways that create barriers for potential service users. For example, while two fertility clinics in Aotearoa currently have Rainbow Tick accreditation<sup>3</sup> (Fertility Plus and Repromed), neither website has specific information for trans and non-binary people. Although trans and non-binary individuals and couples have used the fertility preservation and assisted reproduction services of Aotearoa's largest clinic, Fertility Associates, information relating to trans people's fertility has only been formally available on the clinic's website since 2020 (Ker and Shaw 2022).

#### *Cultural competence*

Lack of culturally competent and safe healthcare presents a barrier for trans and non-binary people seeking fertility preservation. Gender dysphoria – the discomfort experienced by some trans and non-binary people due to incongruence between their gender and their body (Oliphant et al. 2018) – is a perceived barrier preventing trans people from undergoing cryopreservation. A person's dysphoria can be exacerbated by misgendering (Galupo, Pulice-Farrow, and Lindley 2020) or when healthcare professionals make assumptions about a person's body based on their sex characteristics (Armuand et al. 2017; Chen et al. 2017). Implicit bias, which is a product of social norms privileging cisgender identity, experiences and bodies (James-Abra et al. 2015; Pearce 2018), impacts the acceptability of health services for trans and non-binary people. Bias is particularly evident in fertility settings where service providers lack education or understanding about LGBTQIA+ healthcare issues and language or fail to set aside their own personal values (Epstein 2018).

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The physical processes and emotional invasiveness of some gamete retrieval processes can heighten dysphoria if health professionals treat a trans person based on their sex assigned at birth, and do not respect their gender (Armuand et al. 2017; Chiniara et al. 2019; Nahata et al. 2017; Tasker and Gato 2020). In their ethnographic study of a Swedish fertility clinic, Erbenius and Payne (2018) note that healthcare professionals had to actively challenge the ‘mundane transphobia’ and gendered assumptions embedded in images, questions and language around reproduction in the clinic. In a qualitative study of US trans young people’s attitudes towards future reproduction, participants spoke about the importance of using gender-neutral language, and how distinguishing between gender and bodily diversity or physical sex characteristics could improve trans people’s access to fertility care (Kyweluk, Sajwani, and Chen 2018). Given the increasing visibility of non-binary people (Clark et al. 2018), clinic practices should also respect non-binary people’s language preferences and meet their specific gender-affirming healthcare needs.

## *The context of Aotearoa*

The determinants of trans and non-binary people’s access to cryopreservation are largely affected by a country’s healthcare system (Mattawanon et al. 2018). Though some Aotearoa service providers are better informed and responsive regarding professional advice and counselling around gender-affirming healthcare (Ker et al. 2020), a recent report stated, ‘[C]ontrary to the right to health, there remain major gaps in the availability and accessibility of [gender-affirming healthcare] services; while some services fail to meet an acceptable standard’ (NZHRC 2020, 44). This extends to adjacent services such as cryopreservation for trans and non-binary people. Access to publicly funded gamete cryopreservation is available for medical reasons, but there are significant gaps in provision. As of 2019, for example, half of the 20 District Health Boards (DHBs)<sup>4</sup> in Aotearoa publicly fund sperm cryopreservation (PATHA 2019), but egg cryopreservation is not publicly funded in any of the country’s regions (Oliphant et al. 2018). Because the accepted criteria to access public funding is based on medical infertility and only covers procedures or treatments that irreversibly harm a person’s reproductive capabilities, oocyte cryopreservation is not available in any of the country’s regions unless prior to an oophorectomy (including for trans and non-binary people).

Without public funding – currently only available for people assigned male at birth in Aotearoa – the average fertility clinic treatment cost per cycle for egg collection and freezing is approximately \$7000, with an additional \$7000 for future egg thawing, insemination, and embryo transfer. This excludes consultation fees and medication, between \$3000 to \$4500, and gamete and embryo storage costs.<sup>5</sup> An indirect cost relates to differential access based on fertility clinic location. As Aotearoa’s three main fertility providers are located in major cities, lack of transport or proximity to clinics may delay

and/or prevent treatment among people living in provincial or rural areas.

The existing literature on gender-affirming healthcare defines and discusses healthcare access in general terms (Corneil, Eisfeld, and Botzer 2010). However, few studies have explored in-depth aspects of access such as timeliness of care, or the relationship between access and informed consent. To explore these dimensions, we utilise Levesque, Harris, and Russell (2013) distinction between potential and realised access, as noted above. This distinction is important, as previous fertility preservation literature demonstrates the variability in desire for, and available information about, fertility preservation services. The aim of the article is thus threefold: to contribute empirical data from Aotearoa to the literature, to examine potential and realised access to cryopreservation, and to promote better fertility information and services for trans and non-binary people in relation to decision-making about their reproductive futures.

## **Methods**

### *Survey design and participant recruitment*

*Counting Ourselves* was a national community-based survey hosted on Qualtrics and open for participation between June–September 2018. Survey advertisements were shared through social media (e.g. Facebook), word-of-mouth, and through trans and non-binary community organisations’ and healthcare professionals’ networks. People were eligible to participate if they were trans and non-binary, aged 14 years or older, and currently living in Aotearoa. The final total sample consisted of 1178 respondents ( $M_{age} = 29.5$ ). As Table 1 shows, slightly under half of participants were non-binary (44.4%) and the remaining participants were evenly split between trans men and trans women. A high percentage of participants were younger, with 46% under the age of 25, or ticked Pākehā (NZ European) as their ethnicity, either on its own or alongside other ethnicities. The study received ethical approval from the New Zealand Human and Disability Ethics Committee (18/NTB/66/AM01).

The survey questions were developed in consultation with a community advisory group and peer reviewed by other researchers and government agencies. They were drawn from existing population surveys in Aotearoa, so comparisons could be made with the overall population. Given the lack of official data about trans and non-binary people’s experiences nationally, the survey team developed questions about gender-affirming care or about specific challenges trans and non-binary people faced trying to access general healthcare. In this article, we focus on survey demographics and questions about reception and satisfaction of fertility preservation information or services. Specifically, participants who accessed gender-affirming hormones were asked if they had received information and/or services about cryopreservation, either before or after starting hormones. Participants were then asked: ‘Is there anything else you wish to share about options

**Table 1***Demographic Characteristics of Participants*

Demographic characteristic	<i>n</i>	%
Gender (total <i>n</i> = 1,175)		
Non-binary assigned female at birth	397	33.7
Trans woman	328	27.8
Trans man	324	27.5
Non-binary assigned male at birth	126	10.7
Ethnicity (total <i>n</i> = 1,117) <sup>1</sup>		
New Zealand European/Pākehā	1009	90.3
Māori	161	14.4
Pacific Islander	52	4.7
Asian	49	4.4
Other	25	2.3
Parent (total <i>n</i> = 882)	142	16.1

Note. Total *n* values differ due to different numbers of participants responding to each question.

<sup>1</sup> Multiple responses were allowed.

for trans or non-binary people who want to use their own eggs or sperm to have children?' to which they could write a free-text response.

## Data analysis

Quantitative data were analysed using IBM SPSS Statistics version 26. We conducted chi-square tests to compare differences within demographic variables including age groups, ethnicity, gender, and sex assigned at birth (trans men, trans women, non-binary people assigned male at birth (AMAB), and non-binary people assigned female at birth (AFAB)). We explored how the information received, and/or services used differed between participant groups based on these variables.

Our analysis of free-text responses used a directed approach to content analysis, outlined by Hsieh and Shannon (2005). This approach sought to identify the key aspects of accessing fertility preservation services among participants, and how these aspects of access aligned with or differed from the Five-A framework of patient-centred access. We used the framework to generate categories with which to code and organise the free-text responses. The data that could not be categorised into the existing codes were grouped into new categories, such as 'transition decisions' and 'alternative family-building options'. These new categories helped us identify aspects of access which could not be addressed by the Five-A framework in depth, and to consider the relevance of existing theories of access in the context of gender-affirming healthcare and fertility preservation.

## Quantitative findings

### *Receiving information (potential access)*

Of participants who accessed gender-affirming hormones and/or genital surgery<sup>a</sup> (*n* = 419), one-third (33.7%, *n* = 141) indicated they had received information about options to

**Table 2***Proportion of Participants who had Received Information About or Accessed Fertility Preservation Services Across Age Groups*

Age group	Received information about fertility preservation services		Received fertility preservation services	
	<i>n</i>	%	<i>n</i>	%
14-18	10	52.6	4	21.1
19-24	64	52.9	28	23.1
25-39	54	35.8	30	19.9
40-54	10	13.5	4	5.4
55 and older	3	5.6	0	0.0
Full sample	141	33.7	66	15.8

Note. *n* = 419.

preserve their eggs or sperm 'to have children later'. Younger participants were more likely to have received this information, with over half of 14-24 year olds receiving reporting having received this (Table 2). There was a linear decreasing trend across older age groups to only a few participants aged 55 or older having received this information. There were no significant differences in who had received this information based on ethnicity, gender and/or sex assigned at birth.

Over half of the participants (57.3%, *n* = 81) who received information reported they were 'extremely' or 'somewhat' satisfied with the information they received; 27.6% (*n* = 39) reported neither satisfaction nor dissatisfaction, and 15.1% (*n* = 21) reported dissatisfaction with the information. Trans women (*n* = 49) were more likely to be extremely or somewhat satisfied with the information received (68.1%) than trans men (*n* = 21; 42.9%),  $\chi^2(3, n = 140) = 8.45, p = .038$ . There were no statistically significant differences for age or ethnicity on level of satisfaction with this information.

It is possible that some participants may not have received information because they expressed that they did not want or need it. Satisfaction rates could also have been affected by the person's desire for fertility preservation services, or the way in which information was delivered. However, this finding in conjunction with the free-text responses regarding the lack of information received, suggests that a significant number of healthcare providers were not offering trans and non-binary people information or advice about fertility options consistent with best practice guidelines (Coleman et al. 2012; Oliphant et al. 2018).

The timing of receiving information is important for trans and non-binary people to make informed decisions about gender-affirming healthcare that may impact their fertility. Of the participants who had accessed gender-affirming hormones and received fertility preservation information, 92.3% (*n* = 169) reported receiving this information before starting hormones. There were no statistically significant differences between the experiences of trans men, trans women, or non-binary people AMAB or AFAB  $\chi^2(3, n = 183) = 0.48, p = .923$ .

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## Accessing services (realised access)

Here, accessing services refers to undergoing the process of cryopreservation and obtaining and storing gametes or reproductive tissue. Of participants who accessed gender-affirming hormone therapy and/or genital surgery ( $n = 419$ ), 15.8% ( $n = 66$ ) had accessed fertility services to preserve their eggs or sperm 'to have children later'. Trans women were almost twice as likely (21.6%,  $n = 43$ ) as non-binary participants AFAB (11.1%,  $n = 4$ ), non-binary participants AMAB (11.1%,  $n = 2$ ), and trans men (9.7%,  $n = 16$ ) to have accessed cryopreservation services  $\chi^2(3, n = 418) = 10.68, p = .014$ . Although the uptake rates for participants in the present study are higher than previous studies have indicated (e.g. Bartholomaeus and Riggs 2020), these findings are consistent with studies indicating uptake is generally higher among people AMAB than those AFAB. Table 2 shows that one in five participants aged between 14-24 who had undergone hormone therapy had accessed cryopreservation services. This is in contrast to the lower uptake rates among younger participants compared with other age groups found in two studies (Chen et al. 2017; Nahata et al. 2017). There were no significant ethnicity differences in who had received these services.

Of the participants who accessed fertility preservation services ( $n = 90$ ), 90% ( $n = 81$ ) underwent fertility preservation before starting hormone therapy. Most participants (62.4%,  $n = 58$ ) reported being extremely or somewhat satisfied with the fertility preservation services they accessed; 23.7% ( $n = 22$ ) reported neither satisfaction nor dissatisfaction; and 14.0% ( $n = 13$ ) reported dissatisfaction. There were no significant differences in the level of satisfaction trans women, trans men, or non-binary people AMAB or AFAB had with fertility preservation services,  $\chi^2(3, n = 92) = 5.90, p = .117$ . However, when we looked only at sex assigned at birth, participants AMAB were more likely to be extremely or somewhat satisfied with their fertility preservation services (71.9%,  $n = 41$ ) than participants AFAB (48.6%,  $n = 13$ ),  $\chi^2(1, n = 92) = 5.08, p = .024$ . There were no statistically significant differences for age or ethnicity on satisfaction levels. Dissatisfaction could be due to a range of factors such as the quality of services or participants' treatment within the services.

## Free-text response findings

In total, 134 participants responded to the free-text question about available options for trans and non-binary people seeking to cryopreserve their own gametes; eight responded with a written 'no' (to sharing qualitative information in this section) and were removed from the analysis, leaving 126 responses included. 73.8% ( $n = 93$ ) of respondents identified as a trans man (35.7%) or trans woman (38.1%), and 26.2% ( $n = 33$ ) identified as non-binary. Three themes were identified from the findings, relating to information dissemination, cost and cisnormativity.

## Receiving and seeking information

For Levesque, Harris and Russell, the availability of health information is a key determinant of accessing care as it enables people to 'actually identify that some form of services exists' (2013, 5) and therefore helps them to make informed choices about their health. A small number of participants ( $n = 9$ ; 7.1%) commented that they were offered information or were aware of their options but were not interested in using it because they were certain they did not want children. However, a greater number of participants ( $n = 36$ ; 28.6%) who commented on receiving or seeking information mentioned that they were given limited or insufficient information and options about fertility preservation. Just over one quarter (27.2%,  $n = 9$ ) of non-binary participants mentioned a lack of receiving sufficient information, compared to 10.7%, ( $n = 10$ ) of binary participants.

Some participants who said that their healthcare provider had not told them about fertility preservation options stated they wanted to be informed of their options or 'know more' about fertility, even if they did not want children at that point. As mentioned earlier, the desire to preserve fertility does not necessarily coincide with the desire for genetically related children, as the following quotations illustrate:

*[Healthcare providers] may not ask you if you want to [undergo fertility preservation]. I was not told or given that option pre-hysto[rectomy], even if I wanted kids, they did not tell me. (Non-binary AFAB, age 25–39)*

*The possibility of freezing or donating my eggs before hormone and/or hysterectomy treatments was not discussed with me. It did not occur to me to consider this until after these procedures. It would have been helpful to have talked this through before starting treatments, as I may have decided to donate or freeze my eggs. (Trans man, age 40–54)*

As these comments suggest, the timeliness of receiving information, especially in relation to both reproductive options and medical transition, may affect whether a person can realise their access to fertility preservation services.

Of the participants who commented that they sought cryopreservation information themselves, almost all expressed difficulty finding relevant information about their options. One non-binary 25-39-year-old participant AFAB stated, '[I]t's hard to know where to start, where to go and how it all works.' The following comment is one of a number that indicated a lack of clear information about the availability of options for participants AFAB:

*I've briefly looked into options for freezing eggs, which was particularly relevant when I wanted to start hormone therapy (testosterone), but found it was very expensive and was unsure of the availability in Aotearoa NZ. Because of cost and not really being interested in having children I didn't research further, but I wish the*

*options and info about them were more accessible.* (Non-binary AFAB, age 19–24)

While some participants were clear that they did not want to pursue cryopreservation, others expressed that trans and non-binary people nevertheless have the right to know about their options.

#### *Cost as a key barrier*

The most common issue participants raised in response to accessing cryopreservation was being unable to afford services and gamete storage costs. Several participants noted that, even when adequate information or options were offered to them, high cost was the most significant barrier to accessing services. Many participants ( $n = 39$ ; 30.9%) described available services as too expensive for either themselves or others due to some services, notably egg freezing, not being publicly funded. The initial and ongoing costs of gamete storage inform whether a person may choose to utilise services. As one participant commented, 'I was only told it costs a LOT and is a constant cost to keep the fertile things alive. I chose not to do this' (non-binary AFAB, age 19–24).

Several comments on affordability further indicate how participants weighed up whether the costs are 'worth' utilising cryopreservation services. Some AFAB participants conveyed the compounding disincentives linked to high costs, the invasive nature of gamete storage processes, and, as one non-binary AFAB 25–39-year-old put it, the 'not super great probability of success'. This view was reinforced by other participants:

*I might have stored sperm against a future change of mind [on wanting genetically related children], but I felt that the process was too expensive to bother ensuring against such a remote possibility.* (Trans woman, age 25–39)

*My mum wants me to freeze my eggs because she wants biological grandchildren, but it's so expensive and intrusive and I don't even know if I will use it so it's not worth it.* (Trans man, age 14–18)

A few participants emphasised that because these were important services for some people, they should be publicly funded. As one participant commented, '[storing gametes is] expensive for young people (specifically students) but essential so you don't ruin your future. I wish there was a subsidy for sperm/egg storing' (trans woman, age 19–24). Some responses further indicated that people may decide to prioritise more urgent gender-affirming healthcare such as hormones or paying for chest reconstruction surgery, than expensive fertility preservation that is a longer-term concern.

#### *Cisnormativity in fertility services*

Another aspect of accessibility in line with the Five-A framework concerns the sociocultural factors informing the

extent to which a person finds services culturally responsive and safe. For trans and non-binary people, healthcare providers' knowledge and affirmation of gender diversity is crucial in accessing services safely. Participants who commented on the acceptability of services ( $n = 15$ ; 11.9%) generally explained that lack of knowledge or competence can prevent trans and non-binary people from being comfortable discussing fertility options with them. Reasons for this reticence included the potential stigma attached to being a parent who is trans (Chen et al. 2019), or that trans and non-binary people might consider the prospect or actual experience of storing gametes 'weird', 'traumatising', or 'dysphoria-inducing' because of healthcare professionals' assumptions about a presumed link between gender and reproductive capacities.

A small number of participants ( $n = 8$ ; 6.4%) described experiencing fertility services as strongly gendered settings. Some of the gendered practices which participants described included fertility clinics not using inclusive language in their information and forms, or not providing a safe space in which to obtain their gamete sample. As one participant shared: Fertility clinics are extremely gendered. I was assumed male in all paperwork and interactions with staff simply for being there to freeze sperm. It was an extremely uncomfortable experience. (Trans woman, age 19–24)

The experience of discomfort when accessing fertility preservation information and services is consistent with previous studies indicating that trans people perceive cisnormativity within fertility settings as a barrier to access (Armuand et al. 2017; Chen et al. 2017). The comments around negative affects in the present study further suggest that decoupling gender from reproductive capacities relating to fertility preservation conversations and practices will minimise barriers to accessing quality care and thereby improve reproductive health outcomes.

## **Discussion**

Realising access to cryopreservation services – which depends on factors such as the desire for children and receiving information – can only occur if information about potential access is available. Over 90% of participants who accessed gender-affirming hormones and were given fertility preservation information, received this before commencing hormone therapy (rather than after); this suggests that most people may have received this information in discussions with their healthcare professional about starting gender-affirming hormones. While the timing of receiving information was, in many cases, appropriate (i.e. before starting hormones), the overall number of participants who had accessed gender-affirming hormones or surgery who received fertility preservation information (33.7%) was unacceptably low. These rates suggest that some healthcare providers may not be adhering to best practice guidelines (Coleman et al. 2012; Oliphant et al. 2018) or may lack the training or competence to have these conversations. To corroborate this, however,

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further research is warranted on whether healthcare professionals discuss fertility preservation options with patients.

It is promising to see that there seemed to be greater information and realised access among younger participants. Although the survey did not ask when participants accessed gender-affirming care, this finding suggests that those accessing gender-affirming care more recently were more likely to have been given this information and accessed services. This is in contrast with some studies suggesting lower uptake rates among young people (Chen et al. 2017; Nahata et al. 2017). Consistent with most studies, a larger proportion of participants accessing services were trans women or non-binary people AMAB. This finding may point to the comparative technical ease of sperm versus egg retrieval, without discounting the emotional or psychological discomfort many trans and non-binary people experience through either procedure. An additional barrier to realised access for trans men and non-binary AFAB in Aotearoa is the lack of public funding for egg freezing. The greater demand for, and economic accessibility of, cryopreservation services among trans women and non-binary participants AMAB may therefore be the reason for the higher satisfaction rates among this group, as health professionals may have more experience and competence providing information about these services.

The two main reported barriers in this study to potential access to fertility preservation services were the lack of approachability and affordability. These findings support findings in Riggs and Bartholomaeus (2018) study indicating the infrequency of discussions between trans and non-binary people and healthcare providers about cryopreservation options and are largely consistent with international research highlighting unaffordability as a major barrier to access (Abern and Maguire 2018; Defreyne et al. 2020; James-Abra et al. 2015; Jones, Reiter, and Greenblatt 2016; Tishelman et al. 2019). Interestingly, few participants in our study mentioned discriminatory or culturally unsafe fertility care. This may be due to the small sample of participants who had realised access to cryopreservation, the acceptance that some healthcare professionals lack trans-related knowledge, or because the survey did not ask explicitly about the gendered elements of fertility preservation, unlike some previous qualitative studies (Armuaud et al. 2017; Tasker and Gato 2020).

To date, few studies have explored how lack of potential access affects other aspects of people's decision-making around transitioning, or their capacity to give informed consent. Despite many participants indicating they wanted to be presented with options by their healthcare provider in principle, a significant number reported that did not happen in practice, and they were not offered adequate or timely information to make an informed choice. Consistent with existing research (Bartholomaeus and Riggs 2020; Defreyne et al. 2020; Riggs and Bartholomaeus 2018), participants' comments on wanting to receive information on

cryopreservation, regardless of whether they decided to pursue these services, suggest that having this information aids decision-making. While some participants were forced to choose between more urgent gender-affirming care and fertility preservation due to pressure of cost, the data indicate provision of timely information can increase trans and non-binary people's potential access to decision-making around fertility preservation.

Our findings support previous research which highlights the diversity of perspectives on family-building and parenting desires among trans people (Auer et al. 2018; Birenbaum-Carmeli, Inhorn, and Patrizio 2020; Chiniara et al. 2019; Riggs and Bartholomaeus 2018; Tornello and Bos 2017; Von Doussa, Power, and Riggs 2015); who may have no interest accessing cryopreservation services, envisage these services as challenging or confronting, or not use the information presented to them. Economic and informational barriers may also hinder realised access to cryopreservation. As such, the timing and format of discussions around fertility preservation in healthcare settings are both key to ensuring that trans and non-binary people can exercise their right to accessing reproductive and gender-affirming healthcare.

## Limitations

*Counting Ourselves* is the first questionnaire-based study in Aotearoa to explore trans and non-binary people's access to cryopreservation information and services. The survey design of the study and broad questions about fertility preservation asked limited our ability to discern when or where people had received information or services unless they mentioned these details in their responses. Considering that both cryopreservation technologies and healthcare providers' knowledge on gender-affirming healthcare are developing rapidly, participants may have had more positive experiences in recent years. Realised access could remain compromised, nonetheless, due to the lack of affordability of non-publicly funded cryopreservation for some individuals. Future research would benefit from a comparative approach investigating disparities and similarities between trans and non-binary and cisgender people's experiences of medical infertility and access to fertility preservation. With few exceptions (Kyweluk, Sajwani, and Chen 2018; Riggs and Bartholomaeus 2018; Riggs and Bartholomaeus 2020; Strang et al. 2018), most fertility preservation studies do not include non-binary participants nor do they discuss their experiences of accessing healthcare. Though limited, our findings also suggest the importance of exploring how the unique healthcare experiences of non-binary people (Clark et al. 2018) point to additional potential challenges navigating conventional binary spaces such as fertility clinics.

## Conclusion

Despite the above limitations, this study offers timely insight into trans and non-binary people's access to fertility preservation. By considering specific elements of access,

findings identify the lack of affordability and information as key barriers to both realised and potential access. There is a need for greater understanding of trans and non-binary people's desire for genetically related children in Aotearoa, and what type of information – and form of delivery – would be most helpful for trans and non-binary people to make informed choices about their fertility. Conversations about using donor gametes or options for trans men and non-binary people AFAB to carry a pregnancy are important parts of these discussions. As one participant in the present study said, trans and non-binary people 'should have access to every service they want [...] kids are a huge deal for people and ensuring that trans/enby [non-binary] people have as much access to what cis people do is an accessibility and equal rights conversation.' For trans and non-binary people, having access to fertility preservation services is ultimately about upholding their rights to accessing safe, informed and affirming healthcare.

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### Notes

<sup>1</sup> Trans and non-binary people identify with a gender that is different to that which they were assigned at birth. We use the umbrella term 'trans and non-binary' here to include trans people with binary genders (trans women and trans men) and those with non-binary genders. Where relevant to the analysis, we also differentiate between non-binary trans people assigned male at birth (AMAB) and those assigned female at birth (AFAB). We acknowledge that not all trans and non-binary people use nor relate to these terms.

<sup>2</sup> The term 'trans' is used here because, with the exception of few studies (e.g. Kyweluk, Sajwani, and Chen 2018; Riggs and Bartholomaeus 2018; Riggs and Bartholomaeus 2020; Strang et al. 2018), the studies cited focus on binary trans people's experiences; that is, trans boys/men and trans girls/women.

<sup>3</sup> Rainbow Tick is a certification process that awards a 'tick' to businesses and organisations as inclusive of LGBTQIA+ employees and consumers.

<sup>4</sup> Each of Aotearoa's 20 geographic regions is governed by a DHB, responsible for funding and provision of health and disability services. Consequently, the provision of and funding

for gender-affirming healthcare differs across DHBs. In April 2021, major reforms to replace DHBs with one national agency were announced in the media. The proposed changes aim to ensure a consistent level of health delivery across Aotearoa and noted equity challenges faced by underserved communities, including LGBTQIA+ people.

<sup>5</sup> Costs are based on information from fertility clinic websites.

<sup>6</sup> Gender-affirming hormones and genital reassignment surgeries are separate aspects of gender-affirming healthcare that may potentially impair fertility. Not all trans and non-binary people need or want either hormones or surgery, and not all gender-affirming healthcare results in permanent infertility.

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