



## A retrospective study of positive and negative determinants of gamete storage in transgender and gender-diverse patients

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### ABSTRACT

**Background:** GenderGP is a novel, online telemedicine service for transgender and gender-diverse individuals. As part of the service, people are offered fertility counseling in regard to gamete storage.

**Aims:** This study aims to formally categorize the reasons that transgender and gender-diverse people do and not store gametes prior to hormonal treatments. We hope to use this data and subsequent research to inform healthcare policy, improve the healthcare experience for transgender and gender-diverse people, and inform legislation for permanent change in UK healthcare.

**Methods:** Data sets (electronic medical records) from June 2015 – April 2020 were derived from the GenderGP patient database. All patients starting treatment with GenderGP and undergoing routine fertility counseling were included in the study.

**Results:** Of 3667 patients aged 10–85, 2722 (74.2%) were aged 18–45. 151 (5.4%) patients stored gametes. 678 (18.5%) patients wanted to store: 268 (39.5%) could not afford gamete storage, 84 (12.4%) had no local services, 307 (45.3%) did not want to delay hormone treatment. 2085 patients did not want to undertake gamete storage, 480 (23.0%) hoped to adopt, 1605 (77.1%) did not want children. All ages showed similar patterns.

**Discussion:** Financial barriers mean many transgender and gender-diverse people cannot access fertility healthcare. Many participants suffered low self-esteem and struggled to envisage an accepting healthcare system, making them less likely to seek advice. Many patients favored adoption over gamete storage. Younger patients (<18) often had very definite views on gamete storage. Many older patients without children would consider gamete storage and adoption, once their transition is complete.

### KEYWORDS

Fertility preservation; gamete storage; gender-diverse; NHS; transgender

### Introduction

Cryopreservation of sperm and ova, gamete storage (GS), is a widely accepted technique for preservation of fertility in people undergoing medical treatments that may render them subfertile (Mattawanon et al., 2018). These treatments include chemotherapy or radiotherapy for cancer patients as well as gender-affirming hormone treatments or surgical reconstruction techniques for transgender and gender-diverse patients. The World Professional Association for Transgender Health (WPATH) *Standards of Care* clearly recommend that healthcare professionals routinely offer their transgender and gender-diverse patients information and access to services to “preserve reproductive function” (WPATH,

2012). Across the world, there are organizations which support the right of transgender and gender-diverse people to have options for fertility preservation, yet no Royal College in the United Kingdom has publicly declared support for this to date (Aug 2020).

We recognize that some transgender and gender-diverse people retain a degree of fertility following gender-affirming hormone treatments, however there is significant variation in levels of fertility. Those taking androgen blockers have reduced sperm quality, due to anti-androgens binding to testosterone receptors in the body, both centrally and peripherally. This inhibits the action of testosterone, removing the downstream effects of testosterone including spermatogenesis

and maintenance of the mature testicle (Schneider et al., 2017). Some research in cisgender men indicates spermatogenesis can resume following a short (14–18 week) exposure to anti-androgens, but complete reversal following anti-androgen use long term is as yet unstudied (Meriggiola et al., 1996). Conversely, some people using androgens for masculinization therapy regimes have been able to conceive after stopping their medication, or whilst actively taking testosterone (Light et al., 2014).

Gamete storage (GS) uptake in transgender and gender-diverse patients is globally under-researched but has previously been shown to be low, with a multifactorial explanation for poor uptake. Some transgender people do not wish to store gametes. They may have completed their families, not wish to have children to whom they are genetically related (some preferring adoption), not wish to delay gender-affirming treatment (Chen et al., 2018, 2019; Moravek et al., 2018) or experience gender dysphoria associated with their reproductive anatomy (Armuand et al., 2017; Nahata et al., 2017). There is a growing field of research into transgender and gender-diverse patients' experiences of their healthcare professionals when exploring fertility preservation, with many people unfortunately quoting a lack of information as a reason not to store gametes (Bartholomaeus & Riggs, 2020).

Other transgender and gender-diverse people have a desire to store gametes, but access to specialized National Health Service (NHS – the UK free public healthcare system) fertility services can be problematic. Primary care doctors (general practitioners – GPs) may have little or no knowledge of this area of medicine compared with the management of cancer patients (National Institute for Health and Care Excellence, 2013). There are regional differences in access to fertility services. NHS funding can be patchy with local Clinical Commissioning Groups (CCGs) regarding transgender medicine as being of low priority, or conversely, shifting the responsibility on to the Specialized Transgender services (Gender Identity Clinics – GICs) whose central funding does not accommodate fertility treatments. Alternate private GS options can be very costly and inaccessible for many people (Abern & Maguire, 2018;

Millar et al., 2015). There is no doubt that negative attitudes and perceptions of transgender and gender-diverse people by healthcare professionals and society also impacts on their ability to access GS (James-Abra et al., 2015; Riggs et al., 2014).

Some of these issues are not specific to transgender and gender-diverse people, with recent evidence highlighting similar problems in GS uptake for cancer patients, with low referral rates from oncology departments (Abdallah et al., 2018). Historically in the UK, NHS fertility services have only been provided for infertile couples and cancer patients having chemotherapy or radiotherapy (Human Fertilisation and Embryology Authority, n.d.; National Institute for Health and Care Excellence, 2013). Although these services have been a postcode lottery, the NHS has funded transport and accommodation for many patients to access GS facilities (NHS, 2017). National UK guidelines make separate provision for cancer patients with regards to fertility services but make no specific mention of transgender and gender-diverse patients (National Institute for Health and Care Excellence, 2013). This reflects the situation in Australia where reproductive preservation facilities are made available for oncology patients within the public healthcare system but not for transgender and gender-diverse patients (Bartholomaeus & Riggs, 2020).

NHS funded GICs are extremely slow, with patients entering waiting lists expecting a minimum 3-year wait (Gender Identity Clinic, 2020) before being assessed by a doctor. The first appointment does not usually result in direct, often life-saving, interventions such as puberty blockers or hormones (Gender Identity Clinic, n.d.). Faced with this delay, some transgender people turn to self-medicating (GenderGP, 2020). Self-medication with any substance is dangerous and often expensive, and this practice is one of the driving forces behind GenderGP working to remove barriers in gender-affirming healthcare.

This article draws on independent research undertaken by GenderGP to further understand the reproductive choices of their patient population. This study was partly inspired by research illustrating low uptake of gamete storage in transgender and gender-diverse patients undergoing

therapies that may render them infertile (Armuaud et al., 2017, Chen et al., 2018, 2019; Moravek et al., 2018, Nahata et al., 2017). This is in addition to anecdotal evidence from GenderGP staff and patients, highlighting low uptake of GS across transgender and gender-diverse people of all ages. Here, we aim to formally categorize the reasons transgender and gender-diverse people choose not to store their gametes prior to undergoing hormonal treatments. Currently, little research has been done on this topic within the UK, where the majority of GenderGP service users reside. By identifying reasons people choose not to store gametes, GenderGP hopes to build and improve organisation-level structures to aid service users in accessing options for reproductive healthcare. Furthermore, we look to improve reproductive and family access for transgender and gender-diverse people across the UK by formally proposing systemic changes to the NHS, UK fertility services and social care systems to make them more understanding, inclusive, and accessible to the transgender and gender-diverse population.

### **GenderGP: A history and pathways through care**

Founded in 2015, GenderGP is a private digital service for transgender people wishing to access gender-affirming treatments and legal documentation. Dr Helen Webberley, the founder of GenderGP, experienced the UK healthcare system failing its transgender and gender-diverse patients. When trying to help these patients access the resources they needed for their transition, Dr Webberley found that long waiting lists, unnecessary psychiatric evaluations (Ashley, 2019) and lengthy assessment processes incumbent to traditional NHS services presented infinite hurdles. GenderGP runs in parallel with NHS services, providing gender affirming pathways that minimize barriers. Since its inception, GenderGP has treated over 6,000 patients aged 8 to 89, and although prepubescent children are not directly managed by GenderGP, many parents of younger children make contact early, ensuring a smooth pathway of care for their children when puberty starts.

GenderGP does not provide GS services but is able to help service users navigate local healthcare guidance to aid their decision making. As part of the GenderGP service, users are offered routine fertility counseling. There are GS-specific questions in the initial medical and psychological information-gathering questionnaires, which are then discussed in session with counselors or therapists. Information leaflets on GS and fertility services are also offered. In terms of GS, from the Help Center, patients are directed to a separate page devoted to fertility (GenderGP, n.d). Here there is specific advice, FAQs, and signposting to other services including *Fertility Network UK* and the *Human Fertilisation and Embryology Authority* for more general information on fertility.

Most patients have searched organically on Google for transgender care or have been recommended by friends. Social media, forums, referrals from charities and from other health care providers, also contribute to our patient group.

The pathway is being constantly refined and improved to provide an up to date, robust and safe service that is well received by the transgender and gender-diverse community. A customized electronic platform ‘The GenderGP Portal’ has been developed as a tool for electronic health record-keeping and communication, as well as an extremely valuable database. Patients can access their specific records as well as communicate directly with the GenderGP team. Encrypted data protection safeguards comply with national and international standards.

While many individuals use the website to educate themselves around issues affecting the transgender and gender-diverse community, others use it to access medical care. Using the principles of informed consent, the Help Center guides the user through the Pathway whether they are looking for advice, prescriptions, a blood testing kit, counseling or one of the many other services offered. Robust safeguarding measures ensure that even the most vulnerable patients are supported. If any concerns are highlighted by the Pathway Team, or the patient feels they would benefit from more information on how the service can support them in their transition, an Early Intervention Session (EIS) with a counselor

or gender therapist (equivalent to ‘social workers’ in the US) is offered either in person or online.

Core information about medical, psychological and gender histories, as well as specific attitudes toward GS, is obtained through questionnaires reviewed by the multidisciplinary team (MDT). The MDT is made up of a team of specialist gender counselors, therapists and psychologists, and doctors.

An online Information Gathering Session (IGS) is then arranged by the counseling team where issues raised in the questionnaires are explored in more detail. At this stage, other issues such as fertility and gamete storage are also discussed.

Further counseling is available and can be accessed as little or as often as the patient requires. The IGS is reviewed by the MDT and if no further exploration or counseling is required, the patient moves forward on the pathway.

In a small minority of cases it may be felt that more detailed consultations would be appropriate (e.g. young people, severe psychological distress). In this instance, additional consultations are offered with the counseling team or doctor. With all direct interactions with the GenderGP clinicians, fertility and GS are discussed according to proformas. With the patient’s (or parent’s, if patient is under 18) consent, their general practitioner (GP – family doctor) is written to and informed of the process. It is not unusual for patients not to want to involve their doctor and for them to use GenderGP independently of other care. In those that wish to involve their GP, collaborative care is sought, enabling the patient to access blood tests and prescriptions through the NHS. They can also obtain information regarding local NHS and private services for gamete storage, significantly reducing the overall costs. The final step is for all of the notes to be reviewed by the medical team and for consent for treatment to be obtained.

A final ‘capacity’ statement is then requested from the patient, to demonstrate their understanding of the effects of gender affirming hormones, blockers and risks to fertility and the importance of exploring GS options prior to this if they wish to consider having children to whom they are genetically related in the future. This

statement is signed by the parent or guardian if the patient is under 18. Prescriptions are then issued and either signed by the patient’s doctor (if collaboration has been agreed), or via the GenderGP medical team. If the latter is the chosen route, the medication is dispensed through a regulated retail pharmacy. A subscription payment model enables the patients to be retained as part of the GenderGP community for as long as they wish, with monitoring blood tests and repeat prescriptions being issued as regularly as needed, and ongoing guidance being provided to their doctors.

This model has many advantages to the patient; they receive unlimited access to specialist advice and support, easily accessible from any location. This is appealing to more isolated communities (e.g. the elderly, those with physical disabilities, those who cannot drive or travel easily). There are no age restrictions, yet all procedures are robust and safe with serious concerns being addressed and actioned quickly. Minors are assessed with their legal guardians and given specialized support with respect to their age. Patients are free from gatekeeping and waiting lists in a system that demedicalises transitioning. The model is proactive and reactive, backed by fierce advocacy, actively campaigning for change.

Although services have only been active for five years, valuable data have been collated during that period. The database has been extremely useful in developing an effective healthcare screening programme for the GenderGP community, in particular breast, cervical and prostate, which are often neglected by NHS services when it comes to transgender and gender-diverse individuals. It has also been invaluable for accessing data on attitudes toward fertility. It is this qualitative data on attitudes toward GS that we have explored in this article.

## Methods

### *Study design*

We present data on 3667 transgender and gender-diverse patients who have contacted GenderGP, seeking medical treatment. Inclusion criteria: 1) any patient starting treatment with



GenderGP; 2) any GenderGP patient undergoing routine fertility counseling. Subjects were recruited retrospectively via anonymised data sets. The full results encompass transgender and gender-diverse patients from across the globe. As the majority of our patients are UK based, we will be focusing on these patients in our extended analysis. We note that our data are skewed toward those able to access GenderGP services and is not necessarily representative of the entire UK transgender population.

### **Ethical considerations**

All procedures were in accordance with the ethical standards of the 1964 Helsinki declaration and its later amendments. For this type of study formal consent is not required.

All patients seeking hormonal treatments have undergone counseling specifically targeted at GS and all patients have consented to the use of their anonymised data. GenderGP receives an 'Informed consent and capacity statement' from each patient, indicating their understanding of GS and their reasons for declining if applicable. Where the patient is under-18, their parent or legal guardian signs the 'Informed consent and capacity statement' on their behalf.

At all stages of the GenderGP assessment process and if appropriate, patients were offered further opportunities to discuss GS with the gender therapists or medical team.

### **Data collection**

Data sets (electronic medical records) from June 2015 (the inception of GenderGP) through to May 2020 were accessed from the GenderGP patient communication platform. Anonymised data were extracted from these records and coded for analysis.

As explained above, patients were counseled on GS at several different stages through the assessment process. Their ultimate decision as to whether they wished to proceed with GS was documented, along with any reasons given for their decision. Patients were not specifically asked to qualify their choice but many volunteered this information, which was also recorded.

Service users were asked whether they have accessed fertility treatments or if they wish to access gamete storage services. If the person was comfortable, staff explored the reasons they may have chosen to store or not, these qualitative data are recorded in the patient record. Where the patient is under 18, these conversations happened in the presence of their legal guardian.

### **Analytic approach**

This study aims to identify the most common reasons transgender people choose not to store their gametes. We intend to follow up on specific variations within and across age groups in subsequent papers.

Each patient had their electronic medical records examined by one person, who extracted the data into a spreadsheet. Their decision on whether or not to store gametes was recorded. Any reasons regarding their decision were also recorded and coded by a second person. The codes were developed by the second person identifying common themes within the data sets, which were then agreed by the person who had extracted the data and applied accordingly. Where a patient gave multiple reasons for their decision, they were coded by the one they placed more emphasis on. This was at the discretion of the coders and was agreed by both.

Qualitative data was also gathered by the first person, who recorded and summarized common themes in the discussion notes recorded in support of a person's coded decision.

## **Results**

### **Sample**

A total of 3667 patients were included in the study with an age range of 10 – 85 years. Of these 3667 patients, 349 (9.5%) were self-medicating or already taking prescribed medication and 22 (0.6%) had undergone gender-affirming surgery, leaving a total of 3296 (89.9%) patients who were commencing medical treatment (including GnRH agonists) for the first time.

2463 (67.2%) of all patients were assigned male at birth (AMAB), 1054 (28.7%) were assigned female at birth (AFAB) and in 150 patients

**Table 1.** Dataset coding for all UK participants (n = 3286).

Gamete storage decision	Under 18 (n = 344)					18-45 (n = 2424)					Over 45 (n = 518)				
	Patients n (%)					Patients n (%)					Patients n (%)				
	England (n = 308)	Northern Ireland (n = 3)	Scotland (n = 12)	Wales (n = 21)	England (n = 2122)	Northern Ireland (n = 64)	Scotland (n = 98)	Wales (n = 140)	England (n = 490)	Northern Ireland (n = 3)	Scotland (n = 9)	Wales (n = 16)			
Gametes stored	15 (4.9)	0 (0.0)	1 (8.3)	0 (0.0)	120 (5.7)	1 (1.6)	1 (1.0)	5 (3.6)	2 (0.4)	0 (0.0)	0 (0.0)	1 (6.3)			
<b>Patients who wanted to store gametes but were unable to</b>															
Delay in treatment <sup>a</sup>	40 (13)	0 (0.0)	0 (0.0)	4 (19)	198 (9.3)	6 (9.4)	4 (4.1)	14 (10.0)	15 (3.1)	0 (0.0)	0 (0.0)	0 (0.0)			
Expense	11 (3.6)	0 (0.0)	0 (0.0)	0 (0.0)	211 (9.9)	4 (6.3)	6 (6.1)	9 (6.4)	1 (0.2)	0 (0.0)	0 (0.0)	0 (0.0)			
Invasive	6 (2.0)	0 (0.0)	0 (0.0)	0 (0.0)	11 (0.5)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.2)	0 (0.0)	0 (0.0)	0 (0.0)			
Locally unavailable	2 (0.7)	0 (0.0)	0 (0.0)	0 (0.0)	45 (2.1)	0 (0.0)	2 (2.0)	1 (0.7)	20 (4.1)	0 (0.0)	0 (0.0)	0 (0.0)			
<b>Patients who did not want to store gametes</b>															
Does not want children	110 (35.7)	1 (33.3)	3 (25.0)	13 (61.9)	933 (44.0)	29 (45.3)	45 (45.9)	70 (50.0)	178 (36.3)	3 (100.0)	3 (33.3)	7 (43.8)			
Genetics <sup>b</sup>	3 (1.0)	0 (0.0)	0 (0.0)	0 (0.0)	37 (1.7)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.4)	0 (0.0)	0 (0.0)	0 (0.0)			
Adoption	53 (17.2)	2 (66.7)	4 (33.3)	2 (9.5)	316 (14.9)	13 (20.3)	25 (25.5)	28 (20)	1 (0.2)	0 (0.0)	0 (0.0)	0 (0.0)			
Family complete	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	104 (4.9)	1 (4.7)	1 (6.1)	5 (2.1)	126 (25.7)	0 (0.0)	0 (0.0)	3 (18.8)			
Gender dysphoria	30 (9.7)	0 (0.0)	1 (8.3)	0 (0.0)	93 (4.4)	8 (12.5)	8 (8.2)	4 (2.9)	8 (1.6)	0 (0.0)	0 (0.0)	0 (0.0)			
Infertile	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	30 (1.4)	0 (0.0)	0 (0.0)	5 (3.6)	41 (8.4)	0 (0.0)	1 (11.1)	2 (12.5)			
Older <sup>c</sup>	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	93 (19.0)	0 (0.0)	0 (0.0)	3 (18.8)			
<b>Outcome unknown</b>															
Wanted storage, outcome unknown	25 (8.1)	0 (0.0)	3 (25.0)	1 (4.8)	18 (0.9)	0 (0.0)	1 (1.0)	1 (0.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)			
Unknown	13 (4.2)	0 (0.0)	0 (0.0)	1 (4.8)	6 (0.3)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.4)	0 (0.0)	0 (0.0)	0 (0.0)			

Note. Complete results from all UK based patients showing all recorded gamete storage decisions across 3 age groups.

<sup>a</sup>Treatment refers to hormone treatment – either testosterone or estrogen and progesterone. These patients wanted to store gametes but did not wish to delay starting their hormone treatment to achieve this.

<sup>b</sup>This refers to those patients who did not wish to pass their genetics on to any future children.

<sup>c</sup>These patients considered themselves either too old to start a family or were too old to be able to store viable gametes.

**Table 2.** Dataset coding for all participants (n = 3667).

	Under 18 (n = 360)	18-45 (n = 2722)	Over 45 (n = 585)
Gamete storage decision	Patients n (%)	Patients n (%)	Patients n (%)
Gametes stored	17 (4.7)	147 (5.4)	4 (0.7)
<b>Patients who wanted to store gametes but were unable to</b>			
Delay in treatment <sup>a</sup>	46 (12.8)	245 (9.0)	16 (2.7)
Expense	11 (3.1)	255 (9.4)	2 (0.3)
Invasive	6 (1.7)	12 (0.4)	1 (0.2)
Locally unavailable	2 (0.6)	62 (2.3)	20 (3.4)
<b>Patients who did not want to store gametes</b>			
Does not want children	131 (36.4)	1209 (44.4)	218 (37.3)
Genetics <sup>b</sup>	4 (1.1)	43 (1.6)	2 (0.3)
Adoption	64 (17.8)	414 (15.2)	1 (0.2)
Family complete	0 (0.0)	133 (4.9)	149 (25.5)
Gender dysphoria	33 (9.2)	139 (5.1)	8 (1.4)
Infertile	0 (0.0)	37 (1.4)	49 (8.4)
Older <sup>c</sup>	0 (0.0)	0 (0.0)	113 (19.3)
<b>Outcome unknown</b>			
Wanted storage, outcome unknown	32 (8.9)	20 (0.7)	0 (0.0)
Unknown	14 (3.9)	6 (0.2)	2 (0.3)

Note. Complete results from all patients showing all recorded gamete storage decisions across 3 age groups.

<sup>a</sup>Treatment refers to hormone treatment – either testosterone or estrogen and progesterone. These patients wanted to store gametes but did not wish to delay starting their hormone treatment to achieve this.

<sup>b</sup>This refers to those patients who did not wish to pass their genetics on to any future children.

<sup>c</sup>These patients considered themselves either too old to start a family or were too old to be able to store viable gametes.

(4.1%) their birth assignment was not electronically recorded. The average age at presentation was 33.5 years for AMAB and 23.4 years for AFAB.

A total of 3286 (89.6%) patients were UK-based as follows: 2920 England, 70 Northern Ireland, 119 Scotland, 177 Wales; 963 were AFAB and 2299 AMAB, 24 did not have their assigned sex at birth recorded. The following results refer to this UK-based population.

### Key findings

The majority of transgender and gender-diverse people in this study do not want children. Amongst this majority, a large number of people would consider adoption or have adopted children. Many older transgender and gender-diverse people starting hormone treatments have already had children and completed their families, and thus did not see a need to access GS. A small group of older participants saw themselves as too old to have their own children but a few would consider adoption. The younger participants often had very definite views on their fertility. Some had firmly decided to explore or undergo GS despite the delay to treatment and expiry date

on using gametes. Others were equally as firm in their conviction to never have children to whom they were genetically related, and so have opted not to store gametes.

### Decisions on gamete storage

Table 1 gives a full breakdown of the number of UK-based patients in each age group, how many stored gametes, and the number in each coded qualifying reason behind the decisions not to store. Table 2 shows the same, for the total study population.

146 (4.4%) UK based patients stored their gametes, of which 130 were aged 18 or over at the time of questioning; 126 were AMAB and 4 were AFAB. There were 71 (2.2%) UK-based patients where their decision on gamete storage was unknown.

### Patients who wanted to store

A total of 661 (20.1%) patients wanted to store their gametes but were unable to do so. Four main reasons were coded for this: not wanting to delay starting hormone treatment, expense, invasive procedures, and service unavailable locally. Not wanting to delay hormone treatment was the most popular answer across all age groups, and the most common answer in the under 18 group (n = 344). In the 92 (26.7%) young people who would have considered GS, 47.8% stated that they did not wish to delay hormone treatment by the lengthy processes associated with GS (especially egg harvesting in people AFAB).

In the 18–45 age group (n = 2424), financial inaccessibility (39.7%) and not wanting to delay hormone treatment (37.3%) were the top two most common reasons for those wanting to store gametes (n = 531) eventually deciding not to. Based on qualitative data from the electronic medical records, 678 people (28%) of those aged 18–45 who wanted to store their gametes did not do so due to lack of NHS resources.

Half (50.0%) of over 45s who wished to store gametes stated that they were unable to do so due to lack of local service provision. Though a quarter (24.3%) of the over 45 age group had already completed their family, 7.3% had not had any children and still expressed an interest in GS.

***Did not want to store***

2457 (74.8%) patients did not wish to store their gametes. The most common reason given for not wanting to store gametes in all age groups was not wanting children. 1077 (44.4%) of all patients aged 18–45 stated that they do not want children. In both the under 18 and 18–45 age group, adoption was the second most popular choice. Second in the over 45s group was the reason that their families were already complete. 424 (12.9%) patients regarded themselves as either too old to have children, had already completed their families or were infertile.

The majority of patients (93.4%) in this study did not store gametes, although a quarter of them did want to be parents (based on qualitative data from electronic records) and regarded adoption as a potential alternative to having children to whom they were genetically related. 444 (13.5%) of patients gave adoption as their primary reason for not wanting to store gametes. 152 (4.6%) patients highlighted gender dysphoria as the main negative determinant for GS. Qualitative data showed that this often centered around sexual reproductive anatomy (including ejaculation), sexual intercourse, or dysphoria around carrying a baby and parturition.

In the remaining patients who did not wish to store, many complex reasons were given. Low esteem and a jaded view of an accepting societal framework were dominant features. A common fear was the pressure on any future children to have to navigate a transphobic society as the child of a transgender or gender-diverse person. Service users were anxious that their own bad experiences would follow their children. They did not want them to experience a “difficult path in society”. This was often linked to a feeling of generally poor self-worth, with several people stating they were not good enough to be a parent. The feeling of not being enough was linked to several other attitudes. Firstly, that they personally were not enough – that they did not know how to be a good parent and would therefore automatically be bad and their children would be unhappy. Another common theme was that, being transgender or gender-diverse, they would not be able to find a loving partner willing to have children with them and as a single,

parent they would be a poor parent. This anxiety was heightened in a several patients who could not see a happy future as a gay, transgender or gender-diverse person with a family. A small number of people also expressed attitudes of internalized transphobia to the extent they believed being transgender or gender-diverse was “bad”, they did not want to pass on “bad genes”.

All of these attitudes are rooted in the transphobia endemic in UK and global society. The negative influence of the right-wing media was explicitly outlined by a few service users. The constant physical, verbal and digital attacks on transgender and gender-diverse people today is a driving force behind the decision made by many to hide away from those areas of society that have harmed them. Many see the world as an “anti-transgender” place. Public and social media bullying, anti-transgender lobbyists and forums, bad experiences at school or work, poor academic outcomes are endemic in the life stories of transgender and gender-diverse people. This clearly feeds into the feelings of poor self-worth explored above and also into the common theme expressed by service users that the world is too dangerous a place to bring children into.

Similar comments were also expressed in the much younger patients who already seemed to have strong perceptions of the acceptance of transgender and gender-diverse people in society, many of them forming their opinions from regular use of the internet, chat rooms, forums and from social media. Parental influence and prejudices were also likely to have had some impact on the decisions made by the younger people about GS. However, the pattern of decision making, and reasoning was very similar to the patient cohort overall. This was most apparent in the group that did not want GS, where reasons given, were often identical to those mentioned above.

Across the entire global patient population, there were other patients who had previous gender affirmation surgery, or were deemed by themselves or by their parents as too young to make an informed decision (65 patients in under 18 age group). An additional 32 younger people expressed an interest in GS. Many of these were younger adolescents starting puberty blockers and



were therefore not likely to immediately threaten their fertility.

## Discussion

Poor uptake of fertility preservation in transgender and gender-diverse people is well recognized (Chen et al., 2017; James-Abra et al., 2015; Moravek et al., 2018). What is less well understood are the reasons for this, whether it is due to a lack of desire to have genetically related children, a preference for adoption, gender dysphoria in relation to reproductive and sexual anatomy, or lack of funding or access to fertility services.

Where patients did not wish to store gametes, the clear majority reason was that they did not want children. Our coding method does not allow for a more detailed breakdown of the specific reasons behind this, but clearly shows this is a majority in each age group.

This research showed that 678 people (18.5%) in the 18–45 age group did not store their gametes due to lack of NHS resources. Related to this is the 268 (7.3%) people across all age groups who gave ‘expense’ as the main factor preventing them from accessing GS. In the UK, local NHS fertility services are commissioned and funded through local Clinical Commissioning Groups (CCGs, usually run by GPs), who allocate funds based on need. Although fertility treatments for cancer patients and infertile couples had previously been widely available through the NHS, more recently many fertility services have been reduced and even discontinued due to local funding issues. Transgender and gender-diverse people were not regarded as being of significantly high priority and therefore fertility treatments were not routinely offered. However more recently, the Equality and Human Rights Commission (EHRC) stated that this blanket refusal by the NHS to offer fertility treatments to transgender and gender-diverse people violated the Equality Act (UK Government, 2010). EHRC called for the NHS to offer a consistent standard of fertility treatments for transgender and gender-diverse people. In response, the NHS issued strict guidance to CCGs saying that ‘strong justification’ needed to be demonstrated by CCGs in refusing to offer fertility services to transgender

and gender-diverse people and that these decisions could be challenged in court (Everett, Everett, Everett, 2018). Despite these assurances, our study demonstrates that NHS provision of fertility treatment for transgender and gender-diverse people does not meet patient demand.

Interestingly, in a high proportion of young people who would have considered GS, 47.4% stated that they did not wish to delay hormone treatment by the lengthy processes associated with GS (especially egg harvesting in AFABs). In the 18–45 age group, not wanting to delay treatment and expense were the two most common reasons for not storing gametes, reflecting data from Australian studies (Riggs & Bartholomaeus, 2020). Arguably, these go together – if patients could afford private gamete storage, they may not have to sit on long waiting lists and thus would be able to store gametes and start hormone treatment sooner. Time is a crucial in this patient group because of the rapid physical changes seen in puberty. It is also important to appreciate that fertility preservation, using egg harvesting and implantation in this age group has a poor track record in terms of success rate. Even in the best centers, success rates (measured in terms of successful pregnancies) are only 27% in those under 35 years of age (Human Fertilisation and Embryology Authority, 2019). It is therefore not surprising that young people prioritize their pubertal changes over GS, particularly when parenting is not top of the list for most adolescents.

Across age groups, adoption was perceived as an attractive alternative to GS and this may be a realistic option. From the legal and public opinion aspect, adoption by LGBTQ+ individuals (in particular same gender couples) has met with widespread approval with one or two notable exceptions (Wikipedia, 2020). Several jurisdictions in the US have discriminated against the community by attempting to introduce legislation to prevent adoption by LGBTQ+ people, but fortunately these efforts have been largely defeated. Though traditional adoption processes have been drawn out and overly interrogative of the potential adoptive parents, several successive UK politicians from differing political philosophies have promoted adoption and have actively

tried to improve adoption rates, against a background of falling adoption rates and an increasing number of children in care.

In the over 45 age group, 7.3% had not had any children and still expressed an interest in GS. Unfortunately, there are no data specific to this older age group with which to compare our findings and therefore any conclusions that we might draw from this are purely supposition. However, it is quite conceivable that with transition imminent, the potential for becoming a parent was finally being realized, whereas prior to considering active transition it had not. In a more tolerant society and with transgender and gender-diverse people transitioning at a younger age, it seems likely that many more would consider GS or adoption as an option and would actively seek it out, particularly as GS and adoption is much more likely to be successful at a younger age. Reflecting the figures for the 18–45 and over 45 age groups, the majority of under 18s do not wish to have children, though many have considered adoption. Often, those under 18 are chastised for making decisions about their fertility as others think they are unable to grasp the enormity of such a choice. Our preliminary results do not seem to support this, but further research is required to fully understand the thoughts and choices of our younger patient population.

We recognize the work of Bartholomaeus and Riggs (2020), who explore the role of the healthcare professional as a negative and positive factor influencing a person's decision to access fertility preservation services. Key to this was the amount of information the healthcare professional was able to give, which weighed into their patient's ability to make an informed decision. We believe this article sits alongside this research as it eliminates the uninformed patient, but highlights other factors raised by Riggs and Bartholomaeus (2018) such as financial cost and delaying gender transition. Although difficult to compare across continents and different public healthcare settings, together our research hits upon several common themes. This raises the possibility that The WPATH may be able to provide more direct clinical guidelines for healthcare professionals to use when discussing gamete storage that may be easily adapted by healthcare systems globally.

### **Limitations and considerations for further research**

We recognize that this study is limited to those transgender and gender-diverse people able to access the paid GenderGP services. This does exclude those transgender people who are not able to afford the subscription – those with low incomes, from poorer socioeconomic backgrounds may not be as well represented in this sample. We also recognize that transgender people able to privately fund their own GS may not be well represented in this sample as it is possible those able to fund GS are also able to fund private gender-affirmative healthcare from other sources.

We have not included data on race in this study – this limits the extent to which we can propose specific interventions for those from Black and Minority Ethnic backgrounds that will specifically target issue they face with regards to GS as a transgender or gender-diverse person. We will make a determined effort to examine the effects of race in future research. It is well known and documented that Black transgender people of color face higher levels of social injustice, compounded with systemic racism in the NHS, which the effects on access to gender-affirming healthcare need proper quantification.

With regards to statistics, we appreciate that we have not conducted inferential statistics on this data. We hope to encompass this in future research that further breaks down the demographic variables of our sample (for example race, socioeconomic background, disability, geographic location) to fully assess the differences between groups in uptake of GS and how we might propose inclusive practice guidelines to serve every patient's individual needs.

Any proposed practice guidelines derived from this study are heavily reliant on data from England as that is where the majority of UK-based patients were based. Within the UK, the experience of transgender and gender-diverse people with regards to GS can vary significantly dependent on their postcode. For this reason, we need to look at Welsh, Northern Irish and Scottish patients and conduct more in-depth qualitative research about their experiences of GS

to propose targeted practice guidelines applicable to the NHS across the whole of the UK.

## Conclusion

In conclusion, this article forms a useful basis on which to further investigate and dismantle the barriers transgender and gender-diverse people face when accessing UK fertility preservation services. Our results clearly indicate a need to address the financial and geographical costs of fertility preservation facilities. The data also highlight the importance of recognizing and supporting those transgender and gender-diverse people who do not want children, allowing them to exercise bodily autonomy on decisions about their fertility without judgment. The NHS must work to be actively accepting of the needs of transgender and gender-diverse people with regards to the reproductive healthcare and all other health needs. This can only occur through recognition of the diversity of the gender-diverse population and a pledge to support every gender-diverse individual. Ultimately, the UK should strive for openly supportive and well-funded health policies accessible by all transgender and gender-diverse people.

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## Disclosure statement

The authors declare that there are no conflicts of interest.

## References

- Abdallah, Y., Briggs, J., Jones, J., Horne, G., & Fitzgerald, C. (2018). A nationwide UK survey of female fertility preservation prior to cancer treatment. *Human Fertility (Cambridge, England)*, 21(1), 27–34. <https://doi.org/10.1080/14647273.2017.1321787>
- Abern, L., & Maguire, K. (2018). Fertility preservation among transgender individuals. *Fertility and Sterility*, 110(4), e281.10.1016/j.fertnstert.2018.07.794
- Armund, G., Dhejne, C., Olofsson, J. I., & Rodriguez-Wallberg, K. A. (2017). Transgender men's experiences of fertility preservation: A qualitative study. *Human Reproduction (Oxford, England)*, 32(2), 383–390. <https://doi.org/10.1093/humrep/dew323>
- Ashley, F. (2019). Gatekeeping hormone replacement therapy for transgender patients is dehumanising. *Journal of Medical Ethics*, 45(7), 480–482. <https://doi.org/10.1136/medethics-2018-105293>
- Bartholomaeus, C., & Riggs, D. W. (2020). Transgender and non-binary Australians' experiences with healthcare professionals in relation to fertility preservation. *Culture, Health & Sexuality*, 22(2), 129–145. <https://doi.org/10.1080/13691058.2019.1580388>
- Chen, D., Kyweluk, M. A., Sajwani, A., Gordon, E. J., Johnson, E. K., Finlayson, C. A., & Woodruff, T. K. (2019). Factors affecting fertility decision-making among transgender adolescents and young adults. *LGBT Health*, 6(3), 107–115. <https://doi.org/10.1089/lgbt.2018.0250>
- Chen, D., Matson, M., Macapagal, K., Johnson, E. K., Rosoklija, I., Finlayson, C., Fisher, C. B., & Mustanski, B. (2018). Attitudes toward fertility and reproductive health among transgender and gender-nonconforming adolescents. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, 63(1), 62–68. <https://doi.org/10.1016/j.jadohealth.2017.11.306>
- Chen, D., Simons, L., Johnson, E. K., Lockart, B. A., & Finlayson, C. (2017). Fertility preservation for transgender adolescents. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, 61(1), 120–123. <https://doi.org/10.1016/j.jadohealth.2017.01.022>
- Everett, G. (2018, October 1). NHS to be sued over failing to offer transgender patients egg and sperm freezing. *BioNews*. [https://www.bionews.org.uk/page\\_138771](https://www.bionews.org.uk/page_138771)
- Fertility Network UK. (n.d.). *Fertility Network UK*. <https://fertilitynetworkuk.org/>
- GenderGP. (n.d.). *Fertility. I need some help and advice around preserving my fertility*. <https://www.gendergp.com/GenderGP-help/enquirers/fertility/#>
- GenderGP. (2020, February 18). The waiting list for NHS gender identity clinics: Patients' experiences. *GenderGP Blog*. <https://www.gendergp.com/the-waiting-list-for-nhs-gender-identity-clinic-gic-patients-experiences/>
- Gender Identity Clinic. (n.d.). *First appointment: What will happen*. <https://gic.nhs.uk/appointments/first-appointment/>
- Gender Identity Clinic. (2020, June). *Waiting times*. <https://gic.nhs.uk/appointments/waiting-times/>
- Human Fertilisation and Embryology Authority. (2019). *Fertility treatment 2017: Trends and figures*. Retrieved June 28 2020 from <https://www.hfea.gov.uk/media/2894/fertility-treatment-2017-trends-and-figures-may-2019.pdf>

- Human Fertilisation and Embryology Authority. (n.d.). *Human fertilisation and embryology authority*. <https://www.hfea.gov.uk/>
- Human Fertilisation and Embryology Authority. (n.d.). *Information for transgender and non-binary people seeking fertility treatment*. <https://www.hfea.gov.uk/treatments/fertility-preservation/information-for-transgender-and-non-binary-people-seeking-fertility-treatment/>
- James-Abra, S., Tarasoff, L. A., Green, D., Epstein, R., Anderson, S., Marvel, S., Steele, L. S., & Ross, L. E. (2015). Trans people's experiences with assisted reproduction services: a qualitative study. *Human Reproduction (Oxford, England)*, 30(6), 1365–1374. <https://doi.org/10.1093/humrep/dev087>
- Light, A. D., Obedin-Maliver, J., Sevelius, J. M., & Kerns, J. L. (2014). Transgender men who experienced pregnancy after female-to-male gender transitioning. *Obstetrics and Gynecology*, 124 (6), 1120–1127. <https://doi.org/10.1097/AOG.0000000000000540>
- Mattawanon, N., Spencer, J. B., Schirmer, D. A., & Tangpricha, V. (2018). Fertility preservation options in transgender people: A review. *Reviews in Endocrine & Metabolic Disorders*, 19(3), 231–242. <https://doi.org/10.1007/s11154-018-9462-3>
- Meriggiola, M. C., Bremner, W. J., Paulsen, C. A., Valdiserri, A., Incorvaia, L., Motta, R., Pavani, A., Capelli, M., & Flamigni, C. (1996). A combined regimen of cyproterone acetate and testosterone enanthate as a potentially highly effective male contraceptive. *The Journal of Clinical Endocrinology and Metabolism*, 81(8), 3018–3023. <https://doi.org/10.1210/jcem.81.8.8768868>
- Millar, A., Kim, B., Livne-Segev, D., Fung, R., Jarvi, K., & Millar, A. (2015). Attitudes, knowledge and beliefs regarding fertility preservation among people of transgendered experience: Preliminary results. *Canadian Journal of Diabetes*, 39(6), 536. <https://doi.org/10.1016/j.cjcd.2015.09.040>
- Moravek, M. B., Lawson, A. K., Crissman, H. P., Mahany, E. B., Randolph, J. F., & Berger, M. B. (2018). Barriers to fertility preservation in transgender (TG) patients: A survey study. *Fertility and Sterility*, 110(4), e282. <https://doi.org/10.1016/j.fertnstert.2018.07.795>
- Nahata, L., Tishelman, A. C., Caltabellotta, N. M., & Quinn, G. P. (2017). Low fertility preservation utilization among transgender youth. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, 61(1), 40–44. <https://doi.org/10.1016/j.jadohealth.2016.12.012>
- National Health Service. (2017). *Can I choose where to receive treatment?* National Health Service UK. Retrieved May 27, 2020, from <https://www.nhs.uk/common-health-questions/nhs-services-and-treatments/can-i-choose-where-to-receive-treatment/>
- National Institute for Health and Care Excellence. (2013). *Clinical Guideline [CG156]: Recommendations - Fertility problems: Assessment and treatment*. <https://www.nice.org.uk/guidance/cg156/chapter/Recommendations#people-with-cancer-who-wish-to-preserve-fertility>
- Riggs, D. W., & Bartholomaeus, C. (2018). Fertility preservation decision making amongst Australian transgender and non-binary adults. *Reproductive Health*, 15(1), 181. <https://doi.org/10.1186/s12978-018-0627-z>
- Riggs, D. W., & Bartholomaeus, C. (2020). Toward transgender reproductive justice: A qualitative analysis of views on fertility preservation for Australian transgender and non-binary people. *Journal of Social Issues*, 76(2), 314–337. <https://doi.org/10.1111/josi.12364>
- Riggs, D. W., Coleman, K., & Due, C. (2014). Healthcare experiences of gender diverse Australians: A mixed-methods, self-report survey. *BMC Public Health*, 14, 230. <https://doi.org/10.1186/1471-2458-14-230>
- Schneider, F., Kliesch, S., Schlatt, S., & Neuhaus, N. (2017). Andrology of male-to-female transsexuals: Influence of cross-sex hormone therapy on testicular function. *Andrology*, 5(5), 873–880. <https://doi.org/10.1111/andr.12405>
- UK Government. Equality Act 2010. (2010). UK Public General Acts, 2010 c.15, Part 2, Chapter 1, Section 4.
- Wikipedia. (n.d.). *LGBT adoption*. [https://en.wikipedia.org/wiki/LGBT\\_adoption#Public\\_opinion](https://en.wikipedia.org/wiki/LGBT_adoption#Public_opinion)
- World Professional Association for Transgender Health. (2012). Standards of care: For the health of transsexual, transgender, and gender-nonconforming People, 7th Version. *International Journal of Transgenderism*, 13, 4.