women's
health
matters!

Assisted Reproductive Technology in the ACT

Experiences of trying to get pregnant or become a parent

June 2022

the voice for women's health and wellbeing in the ACT

womenshealthmatters.org.au

Acknowledgements

Thank you to all those who completed the Assisted Reproductive Technology survey and to those who participated in a focus group or interview. We are grateful that you contributed your insights, experiences, and opinions to this research. We hope that through documenting your views and experiences, we can contribute to changes that lead to better services and support for people who are trying to get pregnant or become a parent in the ACT. We also wish to acknowledge Meridian's valuable support for the research process.

About Women’s Health Matters

Women’s Health Matters is an independent, non-partisan think tank that works to improve the health and wellbeing of women in the ACT and surrounding region. Women’s Health Matters believes that the environment and life circumstances which each woman experiences affects her health outcomes. Women’s Health Matters focuses on areas of possible disadvantage and uses research, community development and health promotion to provide information and skills that empower women to enhance their own health and wellbeing. Women’s Health Matters undertakes research and advocacy to influence systems change with the aim to improve women’s health and wellbeing outcomes. Women’s Health Matters is funded by ACT Health. The findings and discussion presented in this report are those of Women’s Health Matters, and not necessarily those of the ACT Health Directorate.

Contents

Executive Summary

In March 2022, Women's Health Matters conducted survey, focus group and interview research on the experiences of people who have had difficulties getting pregnant or becoming a parent, to inform policy and legislative development on Assisted Reproductive Technologies (ART) in the ACT.

We made several findings in the following areas:

- Why some people did not use ART
- Factors considered in deciding whether to have ART
- Overall experiences of ART
- Cost
- Support
- Need for holistic, person-centred care
- Information and evidence-based treatment
- Equality and access for LGBTIQ+ people and single people
- Pregnancy loss

Why some people did not use ART

Not all people who have difficulties getting pregnant or becoming a parent use ART. We found that while people had various reasons for not using ART, the most common ones were the cost of treatment and the possibility that they might still be able to have a child without ART.

$ Cost of treatment

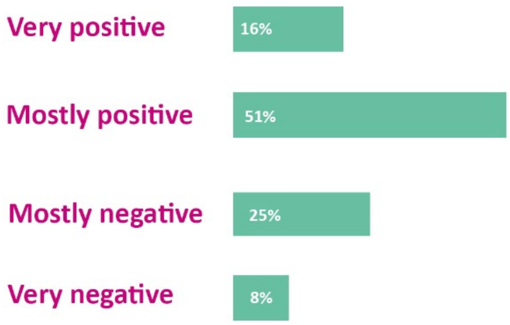
? Possibility of having a child without ART

Factors considered in deciding whether to have ART

Whether people went on to have ART or not, the cost of treatment was the factor most often cited as a top consideration in decision-making (apart from respondents' desire to have a baby or become a parent). Age, and the age of one's partner, was the next most commonly-cited factor.

Overall experiences of ART

Through our survey we found that the majority of people who used ART had generally positive experiences of treatment.



Many appreciated the opportunity to get pregnant and become a parent and understood that without ART this might not have been possible, even though the process was often difficult and costly. However, a significant portion of people had negative experiences, and our focus groups and interviews explored these experiences further.

Negative experiences were associated with factors including a lack of emotional and psychological support, problems with the treatment itself, exclusionary or discriminatory practices, and health system responses to pregnancy loss.

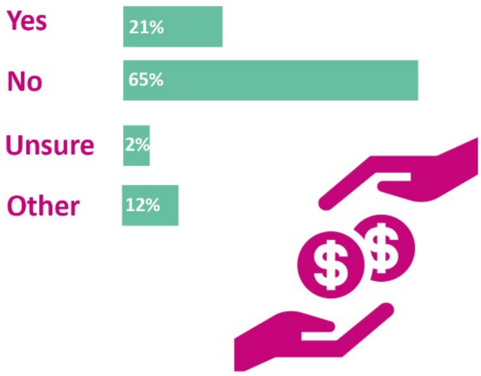
The key issues that influenced people's positive or negative experiences were: the quality of service provision, especially the quality of communication, information and care by staff; the effectiveness of the service (success in having a baby/becoming a parent); the cost/expense; and their mental/emotional wellbeing.

Cost

The lack of a bulk-billed or other low-cost public option for fertility services in the ACT was mentioned by many participants, and the financial impact of undergoing treatment was the most widely raised issue in the research. Many participants acknowledged that it was only because they were comparatively well-off that they were able to undergo treatment, and that even with fairly good incomes they were having to forego other expenses such as holidays, retirement savings or investments, or spending on their existing child or children.

A substantial proportion of participants had needed to pause treatment or stop it altogether because of the cost, while many others felt it was likely they would need to do so.

Did you have to stop ART because of the cost of treatment?

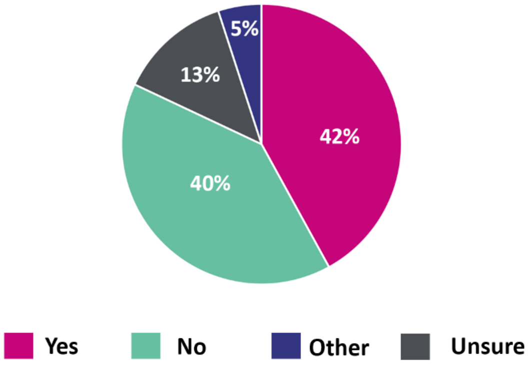


The high cost of treatment was particularly difficult for LGBTIQ+ people, single people, and people using surrogates. These people often lack access to rebates and need to pay additional costs, such as purchasing sperm internationally in response to shortages and delays in accessing sperm from Australia.

Support

Roughly equal numbers of people felt they had enough support around the time of their treatment, compared with the number who felt they did not. In many cases support was provided by peers, family members, friends and online networks, rather than through the ART clinic. For some people this was adequate, but others found their provider to be lacking in the level and type of support provided.

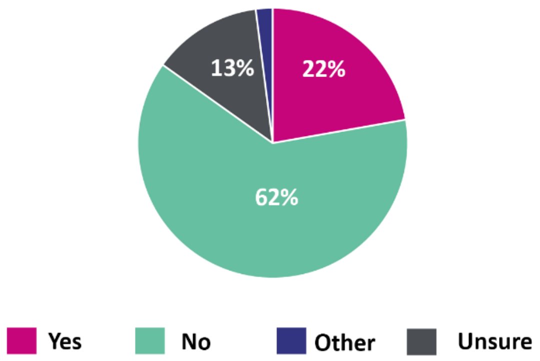
Did you have enough psychological/emotional support before, during and after ART?



We found that most people had been offered professional counselling by their ART provider, as is required by the National Health and Medical Research Council (NHMRC) guidelines, and that this counselling was usually offered at no extra cost and promoted in a non-stigmatising way. However, most people offered counselling by their ART provider did not use it, even though the majority of people undergoing treatment had no other source of professional counselling

Where counselling was used, it was generally seen as being good quality, but some noted it focused only on the ART process instead of the person as a whole. Where people were required to do compulsory counselling for donor conception, this was often not seen as supportive, and in some cases felt distressing and discriminatory.

Peer support was identified in the research as a key area of need, with many people wanting more opportunities to share their experiences, learn from each other, and feel less alone in the process. However, only a fifth of those surveyed had been given advice by their provider about support networks or other services.



Did the provider or a counsellor they provided advise you about other services and support networks?

Need for holistic, person-centred care

A number of focus group and interview participants commented on feeling like "just a number" in the treatment process or being treated as a way for the provider to make money. Similarly, several survey respondents said it was stressful to undergo treatment and this distress was compounded by staff being cold and overly clinical. However, some people noted that individual nurses were kind and caring, making calls to check in.

In the face of these issues, some participants attempted to take control and maintain some power in the situation by accepting a role as "consumers" purchasing a service from a business, for example setting limits on the amount to be spent, or the number of cycles. While these approaches might help some individual people, it is clear that people generally who are undergoing ART need compassionate care that recognises them as a whole person with rights and interests that should be protected in the process.

Several participants mentioned that Body Mass Index is being used inappropriately to deny or create barriers to treatment and said providers should not be allowed to do so.

Information and evidence-based treatment

Most people felt that their provider had given them accurate, user-friendly, accessible information to help them make decisions about their treatment. However, many people found it important to seek extra information from online and peer networks, to help them advocate for effective treatment, while many also wanted more transparent information about the success rates of different clinics. A number of people mentioned a desire for the treatment process to be more personalised and to have more testing and diagnosis earlier on, rather than follow a standard process of "trial and error" moving from intra-uterine insemination to IVF.

Equality and access for LGBTIQ+ people and single people

Some participants noted instances of GPs, specialists and ART clinics being uninformed about the fertility needs of LGBTIQ+ people, and in some cases actively discriminating against them. Many participants felt practitioners could benefit from additional guidance (e.g. training) about inclusive and client-centred practice.

The institutional barriers created by the Medicare system continue to create problems for LGBTIQ+ people and single people wishing to become parents. Individual doctors and specialists were reported as having widely varying approaches to Medicare rebates for LGBTIQ+ people and single people, with some actively enabling access while others block it. Several people reported having to pay full cost for multiple intra-uterine insemination cycles (including the cost of sperm) in order to demonstrate “medical infertility” and thereby access Medicare rebates for IVF.

Pregnancy loss

Many respondents told us about having miscarriages, in some cases repeatedly, and some had still births. Participants pointed out that support for pregnancy loss is still not adequate.

Many felt that ART providers could do better in supporting people with experiences of miscarriage, giving support more proactively and separately from the question of whether or when to undertake another cycle.

Some participants spoke of the great pain caused by having to go through stillbirth in a maternity ward alongside happily expectant and new parents. It is clear that pregnancy loss needs to be addressed both within the context of ART, and in reproductive health and maternity services more generally.

Recommendations

1. That the ACT Government consider the findings of this report in developing legislative, policy and program responses to infertility and fertility service needs in the ACT
2. That the ACT Government consider establishing or supporting the establishment of a public fertility service or other low-cost option for ART in the ACT, with a focus on inclusiveness and access for LGBTIQ+ people and single people
3. That the ACT Government work with other stakeholders and service providers to improve understanding of and support for the rights of LGBTIQ+ people and single people to become parents and to access fertility services on an equitable basis, for example through training
4. That the ACT Government work with the Commonwealth Government, other stakeholders and service providers to promote equity in access to Medicare rebates for fertility services, including for LGBTIQ+ people and single people
5. That the ACT Government continue working towards providing dedicated, sensitive care for pregnancy loss
6. That the ACT Government, together with stakeholders, investigate ways to help create and promote options for peer support for people undergoing ART
7. That the ACT Government share the findings of this report with stakeholders and service providers as appropriate.

Background

In April 2021, the Legislative Assembly passed a motion calling on the ACT Government to:

a. review the availability of support services for individuals and couples choosing to access ART to ensure that appropriate information and care are readily available—pre, during and post treatment;
b. investigate and review comparable ART regulatory arrangements in other states and territories;
c. consider establishing a regulatory framework for ART in the ACT, including consideration of the position of sexuality and gender diverse couples;
d. consider the establishment of a register that will contain mandatory information in relation to all births resulting from ART treatment where donor gametes are used;
e. support the welfare of donor conceived people by providing regulated access to identifying information about their donor and links to siblings from the central register looking to connect;
f. consider the potential impact of the Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021 currently being considered by the Commonwealth Parliament and related issues on the ACT's current legislative arrangements;
g. consider the accessibility of ART for individuals coming from low socio-economic backgrounds;
h. report back to the Legislative Assembly no later than August 2022 on findings.

The Health Policy and Strategy Branch of the ACT Health Directorate, which has responsibility for preparing a response to the motion, invited Women’s Health Matters to engage with consumers to inform the response. WHM agreed to conduct consultations focusing on a), c) and g) above.

A key consideration in this policy area is whether the ACT should adopt legislation to directly regulate the provision of ART services, as exists in Victoria, New South Wales, South Australia and Western Australia. Currently, guidance for services in the ACT is provided by the National Health and Medical Council’s *National Ethical Guidelines on the use of assisted reproductive technology in clinical practice and research (2017)*[1], which provides an overarching framework for services across Australia. There is also self-regulation by the Reproductive Technology Accreditation Committee (RTAC) of the Fertility Society of Australia.

If legislation is introduced, there are questions about what principles should underpin it and what specific provisions it should contain. It is beyond the scope of this report to evaluate current regulatory approaches and guidance for service provision. However, in considering potential legislation, it is vital that people’s experiences of infertility and help-seeking are understood and addressed. The purpose of this report is to contribute to policy-makers’, service providers’ and other stakeholders’ understandings of these experiences.

Even if stand-alone legislation is not pursued, there are opportunities for governments, providers and stakeholders to improve access to ART treatments and experiences of people undergoing them. For example, the Commonwealth Government has responsibility for Medicare rebates and eligibility rules, while the ACT Government is responsible for managing health services such as hospitals,

---

[1] National Health and Medical Research Council (NHMRC) (2017). Ethical guidelines on the use of assisted reproductive technology in clinical practice and research. Canberra: National Health and Medical Research Council, https://www.nhmrc.gov.au/art#block-views-block-file-attachments-content-block-1

mental health services and maternity services. Through their direct interactions with patients, ART providers and their individual staff members shape people's experiences in ways that are impactful and often deeply personal.

As the findings of this report indicate, there are opportunities in all of these domains to improve the health and wellbeing of people who are struggling to get pregnant or become a parent, and to assist them better to meet their goals for parenting. For example, Women's Health Matters has previously advocated for greater efforts to make Medicare and other systems more accessible for people such as women in same sex relationships who are considered "socially infertile."[2]

The topic of ART is relevant to WHM's ongoing work on access to health services, the suitability of those services and their responsiveness to the needs of marginalised women, sexual and reproductive health, and maternity services. As well as informing the ACT Government's response to the Assembly motion, the research will also help inform WHM's ongoing advocacy and health promotion work.

Issues in Assisted Reproductive Technology

It is beyond the scope of this report to conduct a full literature review but there are several key issues that have been documented and which have been addressed through the research.

Inclusive approaches to ART

It is important that research and policy development on issues of infertility and ART are inclusive of the full range of sexualities and genders. Historically, Assisted Reproductive Technology (ART) has mostly been used by women in heterosexual relationships, but increasingly people of a diverse range of genders, sexualities and family structures are using, or are interested in using, ART. LGBTIQ+ people and couples sometimes face barriers to accessing ART relating to their gender and/or sexuality, and our research has aimed to explore these barriers, among others. Finding out about how gender and sexuality impact on experiences of infertility and ART helps policy makers to understand the different experiences across ACT communities.

Infertility

Infertility is common, and ART is increasingly so. Around 1 in 6 couples in Australia experience some form of infertility.[3] This is leading to an increase in ART usage, whereby more than 1 in 25 people who give birth do so using some form of ART.[4] For many single people and people in same-sex or gender diverse couples, ART is among the few avenues for becoming parents.

Infertility affects 18.6% of women by their early- to mid-30s and is associated with endometriosis and polycystic ovarian syndrome (PCOS).[5] As with reproduction generally, the focus of services and policy-making on fertility is often on cis-gendered women as mothers in heterosexual relationships.

---

[2] Women's Health Matters (2019), "This is what the real experience is like…" The views of same sex attracted women in the ACT about their health; their health needs; their access to services, supports, and information; and the barriers to maintaining their health. https://www.womenshealthmatters.org.au/wp-content/uploads/2020/10/SAME-SEX-ATTRACTED-WOMENS-HEALTH-AND-WELLBEING-REPORT-FINAL.pdf

[3] NHMRC Guidelines, p13

[4] Ibid

[5] Australian Longitudinal Study on Women's Health (2019), Reproductive Health Policy Brief, https://alswh.org.au/wp-content/uploads/2020/02/2019_Major-Report_Reproductive-Health-Policy-Brief.pdf p2

Even in these relationships, however, it is estimated that 20% of cases of infertility are due to male factors, and another 30% arise from both male and female factors.[6]

Same sex couples and single people face additional challenges in trying to become parents, in many cases relying on ART, surrogacy or other informal methods to overcome the lack of gametes and potentially of gestational carriers, in addition to the kinds of fertility problems faced by heterosexual couples.

It is important to note that not everyone who has trouble getting pregnant or becoming a parent will identify themselves as experiencing infertility, not everyone will seek medical help with their difficulties, and not all of those who do seek help will go on to obtain it. This is in part due to issues of cost (discussed below), but it is also related to health system and social barriers that align with inequalities based on class, race, disability and other factors. More fundamentally, for some people who do not conceive easily or do not have an easy path to becoming a parent, they will not necessarily perceive this as a medical issue, or as an issue they are comfortable taking into a medicalised space.[7]

Emotional and psychological impact of infertility and ART

Experiences of struggling to get pregnant or become a parent are often painful and are recognised as leading to a burden of psychological distress. However, as the NHMRC guidelines acknowledge, “ART involves complex decision-making and individuals and couples may find it an emotional and stressful experience.”[8] The complex and compounding nature of distress arising from infertility, combined with distress arising from ART treatment (particularly where it is unsuccessful), is explored in more detail in this report.

The impact of infertility and of ART is compounded by the length of time over which many people struggle to get pregnant or become parents. This is illustrated by research from the Australian Longitudinal Study on Women’s Health, which found that on average, women who underwent ART completed 4.6 cycles (during the reference period 1996-2020), with the number of cycles per woman ranging from 1 to 36, and the median number of cycles being 3. The average time on ART treatment was two years, ranging from less than 1 year to 18 years.[9]

The hope offered by ART needs to be seen in the context of patients’ often intense desire and willingness to make sacrifices for the goal of parenthood. In recognising the difficult position of people seeking help with infertility, the NHMRC guidelines state that:

> *“Clinics must provide accessible counselling services from professionals with appropriate training, skills, experience and competency to support individuals and couples in making decisions about their treatment, before, during and after the procedures.”*

---

[6] https://www.healthymale.org.au/causes-of-infertility-in-men

[7] Arthur L. Greil and Julia McQuillan (2010), “Trying” Times: Medicalization, Intent, and Ambiguity in the Definition of Infertility, *Medical Anthropology Quarterly*, 24(2), pp. 137-156 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3383801/; Emily Gilbert, Ruth Walker and David Simon et al (2021), “We are only looking at the tip of the iceberg in infertility”: perspectives of health providers about fertility issues and management among Aboriginal and Torres Strait Islander people, *BMC Health Services Research*, 21 https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-021-06714-8

[8] NHMRC Guidelines, p34.

[9] ALSWH, Reproductive Health Policy Brief

In addition, the NHMRC guidelines require clinics to provide advice about additional services and support networks. Issues of support, information and referral were explored through the survey and focus group/interview research for this report and findings are presented below.

Cost of ART treatment

While Medicare subsidises two-thirds of the cost for all ART treatments deemed clinically necessary[10], it is still common for people undertaking treatment to spend thousands of dollars for each cycle, while some spend tens of thousands or even hundreds of thousands of dollars across a number of cycles and treatments.

A major report by the Australian Longitudinal Study on Women's Health found that between 1996 and 2020, the average out-of-pocket expense for women using ART was $7,535 per woman, ranging from $0 to $59,378.[11]

For those considered "socially infertile" (same sex couples and single people), access to Medicare is often not possible, and costs are accordingly higher. The cost of treatment also often varies by location, with those living in more remote regional and rural areas, and in under-serviced areas, being more likely to face higher costs, often including a requirement to travel.

The inequalities and barriers created by the current cost structures are prompting other jurisdictions to work towards establishing public fertility services which would be able to provide free treatment cycles and other services.[12]

Method

In March 2022, WHM conducted an online survey. The survey was promoted through email, newsletters and social media, including by stakeholder organisations such as Meridian. People of all genders, including people from the LGBTIQ+ community, were eligible to complete the survey, provided they were over 16 years old, lived in the ACT, and had experienced difficulties trying to get pregnant or become a parent. The survey was open for just under two weeks, and we received 175 complete responses.

We used the survey to recruit for a focus group, which we ran with six participants at the end of March. We also conducted interviews with three people who were not able to participate in planned focus groups.

---

[10] Ester Lazzari, Edith Gray and Georgina M. Chambers (2021), The contribution of assisted reproductive technology to fertility rates and parity transition: An analysis of Australian data, *Demographic Research*, 45(35), pp. 1081-1096, https://www.demographic-research.org/volumes/vol45/35/45-35.pdf

[11] ALSWH (2021), Reproductive health: Contraception, conception and change of life - Findings from the Australian Longitudinal Study on Women's Health, https://alswh.org.au/wp-content/uploads/2022/02/ALSWH-Major-Report-Reproductive-Health-2021.pdf

[12] For example, the Victorian Government has committed $70 million to establish public fertility care services in Victoria https://www.premier.vic.gov.au/public-ivf-make-starting-family-easier-victorians#:~:text=The%20Victorian%20Budget%202021%2F22,it%27s%20financially%20out%20of%20reach.

Survey results

Demographics

Of the 175 people who completed the survey, 170 described themselves as women or female, while 3 described themselves as men/male and 2 as non-binary. Around 15% of respondents (28 out of 175) indicated they were LGBTIQ+. The majority of these were bisexual cis-gender women (12) and gay or lesbian cis-gender women (6). Most respondents (160) reported being in a couple relationship, while 11 were single.

Only three of the respondents were Aboriginal or Torres Strait Islander people. Eleven respondents reported speaking another language at home, and 16 reported being from a migrant background.

Seventeen respondents were people with disabilities.

The majority (63%) of respondents found it "not bad" (n=60) or "very easy" (n=47) to manage on their income, compared with those who found it "difficult sometimes" (n=57) or "difficult always/impossible" (n=7).[13]

The large majority (84%) of respondents were in the 25-34 year (n=72) or 35-44 year (72) age groups, with only 6 aged 16-24 years and 11 aged 45-54 years.

Full data tables are presented in the Appendix.

Experiences of trying to get pregnant or become a parent

We asked respondents to describe (in free text) the difficulties they have had with getting pregnant and/or becoming a parent. The answers to this question show that many people have spent a number of years, and multiple cycles of ART treatments, trying to become parents. This involves multiple failed treatments, and in many cases, still no child resulting from treatment. Many respondents told us about having miscarriages, in some cases repeatedly, and some had still births. Some respondents had become pregnant and had a child through ART, but this was usually after repeated attempts and often miscarriages.

> *"We had several failed transfers, miscarriages after so It took 2 years of IVF to have our son."*
>
> *"10 years of infertility with husband. Successful IVF in 2017 and 6 failed cycles in 2021."*
>
> *"We've done IVF for five years. My partner has been the primary egg maker and intended to carry the pregnancy. Last year we had a still birth. Recently I have made the eggs and this year she will try with our eggs for the last few rounds with her and then we will try for me to carry the pregnancy."*

Unsurprisingly, undertaking ART over many years and cycles is very costly, and this is particularly so for people such as single women and LGBTIQ+ couples who may lack equitable access to the Medicare rebate (which is reserved for those deemed "medically infertile"):

> *"I am a single woman attempting IVF with donor sperm. There is a 10 month waiting list for local sperm so I got overseas. It is extremely expensive and cost me $1600 per vial. The most frustrating is not being able to access Medicare straight away as a single woman. I had to do 2 rounds of IUI to be deemed "infertile" to be able to access Medicare. The whole process has*

---

[13] See the Appendix for details.

> *cost $28,000 and that's only 2 rounds of IUI and 1 round of IVF. The system is definitely hard for single women."*

Others mentioned the lack of bulk billing options in Canberra, in comparison with other jurisdictions such as NSW and Queensland:

> *"Tried natural for 12 months with no success, can't find a bulk billing gyno in Canberra. Had a great one in Brisbane but can't afford it here. I have ovarian cysts that need to be removed but the doctor quoted several thousand, whereas it was going to be free in Brisbane."*

We did not require people to explain the reasons why they were having difficulty getting pregnant or becoming parents, but many told us that they had polycystic ovarian syndrome (PCOS) and/or endometriosis. Some were cis women in relationships with other cis women or non-binary people who did not have sperm to conceive (and some of these told us about using insemination with donor sperm at home to try for pregnancy), and one was a cis man in a relationship with another cis man.

A large number of respondents who were cis women in relationships with cis men told us that their infertility resulted at least in part from issues with their male partner's fertility. The disparity between this fact, and the fact that the survey responses were overwhelmingly from cis women, with only one heterosexual cis man completing the survey, confirms that reproduction and infertility are still seen as primarily "women's business", and there remains a lack of engagement from and with men as participants, patients and parents in research and policy-making on ART.

A number of respondents mentioned that their weight was an issue for receiving treatment, in some cases citing discrimination by professionals who refused treatment or made treatment conditional on weight loss.

Respondents who had not undertaken ART

In designing the survey, we wanted to represent people's experiences of being *unable* or *not wanting* to access ART in the ACT, as well as the experiences of those who *have* used ART. The majority of those who completed the survey (n=137 or 78%) had used ART, while much smaller numbers (between 4 and 14) had sought medical help but not gone on to have treatment, had considered but not decided to use ART, had not considered ART, or had considered or undertaken ART elsewhere (not in the ACT).

The bulk of the findings reported below relate to those who *have* used ART. Detailed results about the other groups are provided in Appendix A. It is important to note that the most common factors our survey respondents reported as reasons why they did *not* use ART were the cost of treatment (n=16), and the possibility that they might still be able to become pregnant without treatment (n=17).

For those who had sought medical help but had not gone on to have treatment, the cost of treatment was the most commonly-cited consideration in deciding whether to seek help (after their desire to have a baby or become a parent).

> *"As a single person, the cost of accessing reproductive technology is extraordinary, especially as my barrier is due to my single status rather than a health related barrier."*

When asked what changes would make it more likely for them to access treatment, almost all responses across the four groups mentioned increasing the amount of the Medicare rebate and widening eligibility, establishing a bulk-billing service, or otherwise introducing low-cost options.

Due to the small numbers of respondents in different categories, it is not possible to draw conclusions from the data about the impact of demographic characteristics (such as difficulty managing on current income) on the likelihood of having used ART. However, given the overwhelming finding from our research overall, as well as other research, that respondents found the cost of ART to be high and burdensome, it is almost certain that the cost is prohibitive to a large number of people who could otherwise benefit from ART.

People who had or are having ART

Factors considered when deciding whether to pursue treatment

There were 137 survey respondents who indicated they had undergone or were undergoing ART treatment in the ACT. When asked to nominate the top three factors they considered when deciding whether to pursue treatment, the most commonly-cited factor (apart from their desire to have a baby or become a parent) was the cost/expense of treatment (n=81 or 59%). The respondent's age and if applicable their partner's age was also widely cited as a key factor (n=52 or 38%). Significant numbers of people also nominated "Knowing about others' good/successful experiences with ART" and "How the treatment might impact on your mental/emotional wellbeing" as among the top factors for them.

When invited to expand on their answers in an optional free text question, many spoke about the high costs and difficulty affording ART, the lack of options for bulk-billing in the ACT, and in some cases people told us about using superannuation or home deposit savings for ART. Some people had sought treatment elsewhere because of the bulk billing options available in other jurisdictions.

> *"We could get a rebate but honestly it was just too expensive to contemplate IVF for us. If we hadn't found the Sydney clinic that bulk bills, we wouldn't have been able to do IVF."*

People in couple relationships where neither body produces sperm (including cis women and some non-binary people), as well as single women, told us about not having access to Medicare rebates because they were considered "socially infertile" rather than "medically infertile". For some, this was reported as discriminatory treatment. This experience is inconsistent across providers, however, with a number of people reporting that changing providers led to a completely different approach, with full support for a definition of fertility that would give them access to Medicare.

> *"[A]fter lots of trouble with the first doctor we changed to a new doctor, [who]… signed on for us to have the Medicare rebate. And with their clinic we were able to access a huge online database of donors. Which then moved us forward in the process much faster."*

Several people in these situations reported a requirement to pay full cost for failed cycles of Intra-Uterine Insemination (IUI) treatment in order to qualify for the rebate (being deemed medically fertile until proven infertile by failed treatments).

Other issues raised included the difficult mental, emotional and psychological impacts of treatment, the difficulty and cost of access to donor sperm, and difficulty getting appointments and finding the right medical care.

Experiences of ART – how many and when

To investigate people's experiences of ART in more detail, we asked respondents to consider answering questions about all of their significant ART experiences (acknowledging that some people would have more than one). The survey thereby elicited data about a total of 171 experiences (from 137 respondents). For more detail see Appendix A.

The majority of experiences were current or recent (within the last year) (n=91 or 53%), while a significant proportion had been longer ago (during the last 2-10 years) (n=69 or 40%) and a few (n=10 or 6%) occurred over 10 years ago.

Positive or negative experiences of ART

Most experiences of ART were considered positive by survey respondents. Of these 171 experiences, two thirds were seen as mostly or very positive (n=114), while one third (n=57) were seen as mostly or very negative.

We also asked participants to indicate the top three reasons for their negative or positive experiences. These answers highlight key issues that are important to people using ART: the quality of service provision, especially communication, information and trustworthy, expert staff, the effectiveness of the service (success in having a baby/becoming a parent), the expense, and their mental/emotional wellbeing.

For experiences that were considered positive, the main reasons given were "Professional, expert, trustworthy service" (n=63 or 55% of respondents), "Have had a baby/become a parent through ART" (n= 55 or 48%), "Good experiences with staff" (n= 47 or 41%) and "Good communication/information" (n=35 or 31%).

For experiences that were considered negative, the main reasons given were "No success in conceiving/completing a pregnancy so far" (n=34 or of respondents) "Expensive/cost" (n=27 or 47%), "Negative impact on mental/emotional wellbeing" (n=25 or 44%), and "Poor communication/information" (n=16 or 28%).

Support

To explore further the issues of support for people undergoing ART, we asked a series of more detailed questions.

We asked whether people felt they had enough psychological and emotional support before, during and after ART. The number of people who felt they had enough support was roughly equal to the number who felt they did not. Some indicated that the adequacy of support differed between the time periods, with enough support during the treatment, but not enough before or after.

The majority of people said that their ART provider gave them an option to access professional counselling (n=107 or 63%). Of these, most (n=66 or 62%) confirmed that the counselling was offered by the provider at no extra cost (i.e. as part of the treatment cost and not as an additional fee). Similarly, most reported that the counselling was promoted as part of regular service provision, in a non-stigmatising way (n=71 or 66%).

This does not mean, however, that counselling offered by the ART provider met the needs of all people undergoing treatment. Indeed, only a minority (n=34 or 32%) of those offered counselling ended up using it. This is particularly significant as the large majority (n=104 or 61%) of those ART experiences occurred at a time when participants did not have other sources of professional counselling.

The comparatively small number who did access counselling through their ART provider generally found it to be of high quality, with the vast majority reporting it as excellent or good (n=28 or 82%). Counselling offered by the provider was most commonly accessed during (n=21 or 62%) or before (n=18 or 53%) treatment (rather than after).[14]

Only around one in five people were advised by their ART provider about other services and support networks to help with their mental and emotional wellbeing or their treatment. This is notable as peer networks (both in-person and online) were identified through our focus group as a key area of need.

We invited respondents to expand on issues of support more generally (not just counselling) in an optional free text question. While some people said they had excellent care and support from their ART provider, many people felt they lacked support. In some cases this was because counselling was not offered, or was only available for an additional fee. In other cases one or more sessions of free counselling were offered, but respondents were not able to benefit from this because of limited appointment availability, or because the counselling was not supportive or appropriate. A number of people said that they were aware of support being available but chose not to access it.

> *"At [our clinic] we were invited to get free ongoing counselling with their in clinic counsellor. She was empathetic and inclusive and supported us through years of treatment and our stillbirth."*
>
> *"There was limited counselling available through the clinic. Usually only in very limited hours which was difficult to co-ordinate with work, given it already stuffs up your schedule. Also, we were offered one session per cycle. It is absolutely not enough."*

Some answers indicated that counselling was provided in a way that was focused on the ART process, rather than being of therapeutic benefit in a holistic way, addressing other issues relevant for patients such as previous sexual abuse.

> *"I am a sexual abuse survivor and found the process of treatment very triggering at times, and also the idea of my body not being 'good enough' was also very triggering - there was never the space given to even think about bringing up these issues during my treatment."*

Nurse calls to check in were appreciated, and in some cases this was the main emotional and psychological support. Inclusive practices were also important in helping people feel supported. Some people had good support from family and friends even though the treatment was difficult and the provider was focused only on the clinical side of the process.

> *"The nurses would regularly ask about how I was finding things over the phone and all knew my history with a previous unsuccessful IVF round."*
>
> *"[Our current clinic] has been really queer friendly - including having visibly queer staff who for instance actively accepted my queer identity and ask about my pronouns etc."*
>
> *"A lot of my support was from family and friends. While I felt well supported at my appointments etc. I am not sure a lot of psychological or emotional support was offered specifically from the clinic."*

---

[14] Percentages do not sum to 100% because the question asked respondents to select all that apply (before, during and after).

Several respondents said that the process of receiving treatment was stressful and distressing, but the professionals involved did not demonstrate empathy, understanding or warmth.

> *"[When our cycle failed] it seemed that staff did not know what to do. No warm or empathy was shown even though I was visibly distraught. Lots of awkward silence during follow up blood tests, you could tell they couldn't wait to get me out of the room. What I needed was for someone to acknowledge how hard this all was, to validate how I was feeling and connect me with supports. I felt so alone."*

Particularly bad experiences were reported by people who had to attend mandatory counselling because of needing gamete donation; in many of these cases the counselling was experienced as discriminatory and distressing, rather than supportive.

> *"At [one clinic] they made us do mandatory counselling with a counsellor who was heteronormative, and clearly not experienced with queer couples and she grilled us about 'how will this baby go with no father?' She really made us feel like we were being tested if we were worthy parents. She set herself up as the gate keeper for parenting. Even though straight couples do not have to do counselling to be parents."*

Information

In a large majority of ART experiences (n=124 or 73%), respondents felt they had been provided with accurate, user-friendly, accessible information to help them make decisions about their treatment.

As discussed below, however, a strong theme in the focus group was participants' experiences of seeking extra information from other sources, such as research publications and peer networks, to help them advocate for effective treatment. Also notable was a desire for more transparent information about the success rates of different clinics.

Stopping ART due to cost

When we asked survey respondents whether they had needed to stop ART treatment because of its cost, a significant minority (over one fifth) told us that they had. Many others told us that it was likely they would need to do so in the near future, that they had taken breaks from treatment in order to save money for further cycles, that they had to use sub-optimal treatments, or that they had needed to seek financial support from other sources to continue treatment.

> *"We have had to delay treatment each time we have done a cycle, in order to be able to afford it."*
>
> *"Without family support we wouldn't have the funds to continue at this point."*
>
> *"IVF would be far more successful for my situation than Ovulation Induction, but IVF is too expensive, so I have to keep going with OI."*

Views on rules that should apply to ART providers in the ACT

In an optional free text question, we asked respondents about the kinds of rules and regulations they thought should apply to ART providers in the ACT. The largest number of comments in response were about the need for better access to low-cost, subsidised treatment in the ACT, especially for people who are less able to afford treatment.

> *"It should be cheaper. Everyone who needs ART should be able to access it."*

Many people commented on the lack of bulk billing and public health options in the ACT, pointing out that these are greatly needed. Some argued that there should be equity in costs and low-cost options between states and territories, observing that bulk-billing and other low-cost options exist in other jurisdictions. Several noted that they had travelled interstate or were even planning to move interstate to access more affordable treatment.

> *"Should be the same cost in every state; government should help a lot more."*

> *"[F]or lower income families [the lack of bulk billed options in Canberra] potentially means giving up on their journey before it begins, or going up to Sydney for the opportunity to conceive within their budget."*

Some people suggested that increased levels of support (such as fully or partly subsidised cycles) could be provided for people with medical conditions or who had already done several unsuccessful cycles.

Many people said that Medicare rebates should be increased, and that Medicare should be available to all on an equal basis, including same sex couples and single women. Some recommended a cap on fees to help keep expenses down for patients.

> *"All people should be eligible for Medicare rebates, regardless of their sexuality."*

More generally, several people commented that there should be universal and equal access to treatment. The need for equal access for people of all genders and sexualities was highlighted, and some respondents added that providers should be required to do mandatory LGBTIQ+ training.

Addressing another access issue, some people asked for providers to no longer be allowed to impose Body Mass Index (BMI) limits on prospective patients.

> *"NO BMI LIMITS. Treatment should be accessible to everyone, everywhere!"*

> *"[C]linics should not be able to set weight limits for ART if patients are willing to sign that they understand risks involved. This is happening purely to keep clinics statistics looking better."*

Many respondents asked for changes to ensure that providers become more caring, supportive and focused on mental and emotional well-being of patients.

> *"I would like there to be more care given to mental health and emotional support during the period of undergoing ART."*

> *"All staff should have basic mental health training and accidental counsellor skillsets."*

> *"[M]ore mental health support that specifically targets ART, including grief."*

Some told us that there should be more counselling sessions provided for free, more options when choosing a counsellor, and that counsellor support should be embedded in the process if treatment was not successful.

> *"Active follow up if cycles don't work out. I think the clinic should contact you to book a follow up appointment; I think patients should be offered an appointment with a counsellor (embedded in process)."*

Respondents indicated that they felt providers should make available more open, rigorous and usable information about success rates, the likely number of cycles needed, costs, treatment options and procedures.

> *"Should be required to provide a minimum set of information about your treatment options…They should have to publish success rates every year with clear notation of the types of population groups the data refers to."*

In terms of changes to treatment practices themselves, some respondents told us that clinics were overbooked, with long wait times, and that limiting patient numbers might lead to better treatment. Access to donor material (particularly sperm) was raised as an issue, with respondents asking for systems that would provide quicker, more affordable access to sperm, while noting the need to consider impacts on donor-conceived children.

> *"I'd like it to be easier for people to access donor sperm/eggs etc. It's incredibly time consuming (8 months!) and wastes precious time."*
>
> *"Please don't make access to donor services including international donors more difficult as it is in other States."*
>
> *"The impact of anonymous donation on donor conceived children is not to be underestimated – reading the experiences of donor-conceived children completely changed how my wife and I planned to expand our family."*

In terms of overall regulatory principles, many respondents told us that they would support greater accountability for providers, requiring honesty, transparency, ethics, attention to patient feedback, and professional standards based on qualifications and training. They noted that doctors should be required to act in people's interests and that providers' profit should not be the goal.

> *"Those undergoing fertility assistance should not have to advocate so strongly, their doctors should be acting in their interests. There is a large range of approaches in the ACT but a direct and honest approach would help people better than approaches designed for doctor profit."*

Focus group and interview data

Data gathered from the focus group and interviews were consistent with the key themes identified through the survey. These themes are summarised below.

Cost of ART

The high cost of ART is a major consideration and has impacts on people's wellbeing even if they are able to afford treatment. People reported using their superannuation or other savings to pay for treatment, because it was too expensive to cover within their regular income. In other cases, people spoke of putting other parts of life on hold or foregoing spending on other things in order to do ART. The cost of ART also impacts on the way that people access the treatment and potentially also its effectiveness, as people reported having to take breaks to save money to continue treatment (which is an issue when the passage of time is likely to reduce the chances of getting pregnant).

> *"[W]e're very, very lucky, third or fourth round to get our son. But if we'd been in Sydney or Melbourne or any of the other cities that have the low cost bulk billing clinics, we wouldn't have had that financial stress and pressure and it has definitely, the financial side has taken, that's the hardest, it's been the hardest stress on the relationship, and it's been the hardest part of the IVF journey. I think…I would have probably just spent whatever it took. But for [my husband] he was like, I don't know if we can do this. And then tension, the tension between us of like what? What are you going to spend? When are you going to set the limits? Is this ever going to work?"*

Medicare eligibility and coverage

Closely related to the issue of cost are issues relating to the Medicare rebate and eligibility for this support. Single women and people in same sex couples reported having to pay full cost for cycles of intra-uterine insemination and ovulation induction in order to establish "medical" infertility – often applied as a precondition for eligibility to the Medicare rebate. There were considerable differences reported between different providers, with some willing to support single women and same sex couples to access the rebate while others were unwilling to do so (reportedly due to practitioners' concerns about potential repercussions under the current regulatory regime of Medicare).

One couple reported being told by a specialist, "I wouldn't be comfortable recommending a same-sex couple for the Medicare rebate," and the specialist then stopped providing services to them, which delayed treatment for a year while working through options for new providers. More generally, many participants who are LGBTIQ+ or single parents were negatively impacted by the sense that society generally does not support them becoming parents (as expressed through the Medicare restrictions).

Access to sperm

The availability and choice of sperm, as well as its high cost, was also identified as a problem for single women and LGBTIQ+ people. A number of people were concerned that new regulations for ART might lead to further restrictions on the availability of sperm (while recognising the importance of donor conceived people to have access to information about their family members).

Discrimination against LGBTIQ+ people and others who do not "fit"

Some issues were reported with providers being either uninformed about the needs of LGBTIQ+ people, or in some cases actively exclusionary, and many participants felt practitioners could benefit from additional training, information and guidance about inclusive and client-centred practice. Many noticed that ART procedures are often based on a “standard” model of a heterosexual couple who progress in an orderly way through intrauterine insemination to IVF, without needing surrogates or donated gametes.

> *“[T]he system doesn't really know how to deal with people who don't fit into the sort of preconceived ideas of prospective parents”*

> *“[W]hen things aren't, you know that cookie cutter…relationship that turns up and gets pregnant very quickly and easily…every single time I turn up to that clinic, I have to advocate for myself or for others in the process. And yeah, it's very, very draining.”*

It is important to note that it is not only specialists and doctors who create barriers for LGBTIQ+ people and single people: in some cases the nurses, reception staff and counsellors as well as pamphlets, forms and advertising combine to make it clear that those who are not in standard heterosexual couples are not welcome, or not included.

> *“[A]ll the terminology is male/female couples, like on the…website it was talking about coming in with your partner and doing this.”*

By contrast, participants told us of warm and inclusive practices in some clinics, which made gender-diverse people feel welcome by, for example, asking about pronouns and not insisting on using legal names.

> *“[The] first thing [the receptionist] did was actually ask what my pronouns were, asked what my preferred name was. She noticed that there wasn't the same name on all my medical records, like just this sort of stuff that inclusive queer people do as part of delivering inclusive services, all the small things, whereas at [the other clinic] they had insisted on calling me by my legal name and things like that. I mean, that always puts me on edge.”*

The importance of counsellors being competent and trained to work inclusively with LGBTIQ+ people was also raised, particularly as the mandatory counselling rules for donor conception are more likely to apply to LGBTIQ+ people than others.

Need for respectful, person-centred care

Together with the inadequacy of a “cookie cutter” approach, participants raised the need for practitioners to be supportive of people’s whole selves as individuals and couples going through a difficult experience. Many felt diminished and treated as units or numbers (rather than people) through the process.

> *“You do feel like a number. Like where's that personal empathy and care?”*

Some participants felt that providers treated them primarily as money-making opportunities. Others, while appreciative of ART providers’ medical expertise, felt that they took an overly clinical and cold approach to treatment, where human consideration and compassion would be more appropriate. Some participants noted the positive impact that individual practitioners (in many cases individual nurses) had, through following up about patient welfare and experiences in a caring way. Warm and caring approaches to treatment were highly valued and appreciated, where these occurred.

Particularly jarring were instances in which a woman had miscarried or had a failed cycle and received a call from the clinic soon after encouraging her to book in a new cycle, without recognition of her grief and distress:

> *"[E]ven when they give you a call and say the results, I've had people ask me: So unfortunately it hasn't worked, so when do you want to start the next cycle? You're on day one already, you're on day three already... and that's where I thought, it was like, I'm a person, you know? Give me that respect. Show that respect."*

> *"I just kind of would have really appreciated just a bit more of that personal contact, to be like, I've heard this has happened to you. This is what to expect. And I just felt that was really lacking. And I felt super disappointed in that because I don't know, I've never had a miscarriage before, I've never done an egg collection before."*

Another instance of non-person-centred care was recounted by a participant, about the experience of a gender-diverse couple who they knew. The couple had a preference for one partner to carry the pregnancy and had planned for years to proceed in that way. However, the couple were then denied that choice on the basis of the provider's assessment that the person in question was overweight. They were effectively forced into accepting that the other partner, who did not want to be pregnant, would be the one to carry the pregnancy.

Pregnancy loss

The miscarriages and stillbirths reported in the survey results were also discussed in the focus groups, with participants pointing out that support for these losses is still not adequate, leaving grieving parents and would-be parents with few avenues to work through the impact of these experiences. In particular, some participants spoke of the great pain and distress caused by having to go through stillbirth in a maternity ward alongside happily expectant and new parents.

Participants also felt ART providers could do better in supporting people with experiences of miscarriage, given how widespread this experience is for people undergoing ART. In many cases, people felt that support could be provided more proactively, and that contact after a miscarriage should be about support and care, rather than being focused on starting the "next cycle".

Peer support

Participants valued the support provided by other people going through ART, both in real-life social circles and online.

> *"[The clinic staff] were very good when it started, but when it comes to the rear end and it's not successful I feel like I wasn't confident going for the support [the clinic] had because it was all very clinical. So I would have preferred if I … had been in touch with other people who are going through the same thing, shared experiences."*

> *"I feel very lucky I had quite a few friends going through IVF journeys at similar times. So we would catch up fairly regularly and just knowing a person and seeing them in person was really nice to be able to debrief."*

> *"In terms of support, I've found probably Facebook the best... all the groups that I can just ask a question to with everyone else that's going through the same crap that I'm going through. I just feel more comfortable asking them."*

Some emphasised that, in addition to bolstering their morale, these networks were very helpful in informing their self-advocacy for appropriate treatment and support, in some cases providing capacity for a holistic and tailored approach that the ART service was not providing.

Participants valued the opportunity to speak to us about their experiences and felt that it was beneficial for them. Peer support and opportunities to speak about experiences helped in the context of ongoing stigma and the taboo nature of infertility in some social circles and workplaces. The need for queer-specific peer support was also raised, noting that in some jurisdictions such groups exist but not (to participants' or the researcher's knowledge) in the ACT.

> *"[T]he other element that we still haven't really found is the LGBTQ specific support group… I think in Sydney they do have that sort of forum… [T]here's something about being in a group of people at the same time while you're all doing [IVF] together…[Meeting] once a quarter or something, once a month, I don't know. Once a cycle to just have space where you could actually talk to other queer people living in Canberra doing IVF would have been helpful."*

Treatment quality and process

Some participants said they were happy with the quality of treatment they received, but several said they would have liked the opportunity to do more testing and diagnosis earlier in the process, so that treatment could be tailored to them individually, rather than being put on a standard series of treatments (described as "trial and error"). Some noted that there is now several decades of clinical experience with ART, and felt that treatment should have evolved to be more evidence-based and responsive to individual conditions.

> *"[There should be] far more analysis …when you first meet with a fertility specialist [instead of this approach of] trialling all different things. I think there'd be enough evidence around now to probably not need to put your body through multiple different options."*
>
> *"I know I don't have a lot of sperm vials to play with and a lot of money. So I went into my nurses and I was like, why don't we just…do baseline tests at the start so that you know if there's anything wrong with me that we can fix it early on and …they're all like, no, no, no. We'll just do the next round…I'm asking you to just do everything at the start. So in a year's time, I haven't had multiple miscarriages…"*

One specific issue raised was the ability to move material between clinics, which would benefit patients but is currently not allowed by some clinics.

Another issue mentioned was the need for clinics to involve male partners more in communication and support, noting that the default is often to focus exclusively on the woman (in a heterosexual relationship).

Some participants observed that currently there is no way to get to know specialists before committing to at least a session with them and the understanding of an ongoing relationship, and one participant suggested creating opportunities to know more about the range of specialists before making a choice.

Self-empowerment and self-advocacy

Several participants spoke about setting limits on the amount of money they would spend on ART treatments, or the number of cycles they would do, and found that to be useful, since they knew they would be tempted to continue trying even beyond the point at which it would become financially, physically or emotionally damaging. Some explained that seeing themselves as "consumers" of a contracted service helped to maintain a sense of power and control in a process that could otherwise be destabilising and overwhelming. For these participants, accepting that providers are businesses looking to make a profit was helpful in preventing disappointment, while reinforcing that they had a reasonable expectation of good service as paying customers.

> *"I set myself a limit to how many treatments I was going to do. Primarily driven by finances, but I think also just because I could see that you could do this forever. And that I would get the emotional toll as well as the financial toll."*

> *"[W]e're still not getting the outcome [so] it's that consumer [choice]: no, we're not, I'm not putting any more money towards this."*

Many participants spoke about researching, finding alternative sources of information and support (especially online), and using these to support their self-advocacy for effective services.

> *"[In online forums] I found a couple of things, like…different medications that could potentially work for me that this IVF clinic didn't want to do…I took some journal papers in there and I said…why can't we do it here?"*

Several told anecdotes about instances where their self-informed self-advocacy led to breakthroughs or adjustments in treatment.

> *"So I actually went and got a second opinion. And they found endometriosis."*

Appendix – Survey questions and results

Demographics

How do you describe your sexual orientation?

149	Straight (heterosexual)	85%
12	Bisexual	7%
7	Gay or lesbian	4%
6	I use a different term (please specify)	3%
(2 – pansexual; 4 – queer)		
1	Don’t know	1%
0	Prefer not to answer	

Total = 175

How do you describe your gender?

170	Woman or female	97%
3	Man or male	2%
2	Non-binary	1%
0	Prefer not to answer	
0	I use a different term (please specify)	

Total = 175

Were you born with a variation of sex characteristics (sometimes called 'intersex')?

0	Yes	
173	No	99%
0	Don't know	
2	Prefer not to say	1%

Total = 175

At birth were you recorded as:

171	Female	98%
3	Male	2%
1	Prefer not to answer	1%[15]
0	Another term (please specify)	

Total = 175

Which of the following best describes your relationship situation?

11	Single	6%
160	In a couple relationship	91%
1	Prefer not to answer	1%
3	Other (please describe)	2%

- Married
- Was in a couple while trying to conceive, but currently single
- In a non cohabiting relationship

Total = 175

Are you an Aboriginal and/or Torres Strait Islander person?

167	Neither	98%
2	Aboriginal	1%
1	Torres Strait Islander	1%
0	Aboriginal and Torres Strait Islander	
1	Prefer not to say	1%[16]

Total = 171[17]

---

[15] Percentages do not sum to 100% due to rounding.

[16] Percentages do not sum to 100% due to rounding.

[17] Four respondents did not use or consider ART in the ACT and so were redirected to the end of the survey without being asked to answer the remaining demographic question, which is why the total for these questions differs from the previous questions.

Are you a person with disabilities?

150	No	88%
17	Yes	10%
4	Prefer not to say	2%

Total = 171

Do you speak a language other than English at home?

157	No	92%
11	Yes	6%
3	Prefer not to answer	2%

Total = 171

Those who answered yes were asked to give further details. Answers were:

- I also speak Cantonese with my family
- Cantonese
- Mandarin
- Punjabi and Hindi
- Tamil, Hindi
- Dual language household. English and Hindi
- Filipino
- Filipino
- Bengali
- Spanish
- Italian

Do you identify as being from one or more of these backgrounds? (select all that apply)

162	No/not applicable	95%
16	Migrant background	9%[18]
2	Temporary visa holder	1%
2	Prefer not to answer	1%e
1	Refugee/asylum seeker background	1%
3	Other	2%

- American turned Australian, mixed race background

---

[18] The ‘No/not applicable’ and ‘Migrant background’ categories should be mutually exclusive. The fact that the summed percentages for these two categories exceeds 100% indicates that the question may not have been clear to all respondents.

- British citizen who has just gained permanent residency
- Second generation migrant

How difficult is it to manage on your income?

7	Difficult always / impossible	4%
57	Difficult sometimes	33%
60	Not bad	35%
47	Very easy	27%[19]

Total = 171

What is your age?

6	16-24	4%
72	25-34	42%
83	35-44	49%
11	45-54	6

Total = 171

Whether respondents have had, considered or not considered ART

Have you undertaken or considered undertaking ART in the ACT, either by yourself and/or with a partner/donor/surrogate? (Select the option that best describes your situation)

137	Have had or are having ART	96%
14	Have sought medical help but not gone on to have treatment	1%
10	Considered but not decided to use ART	1%
10	Have not considered	1%
4	Considered or undertaken elsewhere (not in ACT)	<1%

Total = 175

---

[19] Percentages do not sum to 100% due to rounding.

People who have had or are having ART

For the 137 people who indicated they have had or are having ART, we asked the following questions:

Factors considered in deciding whether to do ART

Which of the following were factors you weighed up when you were first deciding whether to do ART?

126	Your desire to have a baby/become a parent and/or your partner's desire (if relevant)	92%
81	Expensive/cost	59%
52	Your age and/or your partner's age (if relevant)	38%
26	Knowing about others' good/successful experiences with ART	19%
25	How the treatment might impact on your mental/emotional wellbeing	18%
12	How the treatment might impact on you physically	9%
11	Might still be able to get pregnant/become a parent without ART	8%
9	Knowing about other people's bad/unsuccessful experiences with ART	7%
9	Medicare rebate not available to me/us	7%
8	Difficulty accessing donated egg/sperm	6%
6	Feeling uneasy about invasive treatments	4%
6	Concern about lack of support while undertaking ART	4%
4	Not wanting to be labelled "infertile" because of needing treatment	3%
4	How the treatment might impact on your relationship(s)	3%
4	Reasons to do with my/our employment	3%
2	Concern about being discriminated against or disrespected by ART provider	1%
1	Previous experiences of trauma, violence or disrespect (not by ART provider)	1%
1	Difficulty finding a surrogate	1%
0	Religious reasons	

Other (please specify)

- We sort of got passed along to an expert as soon as I raised concerns about my fertility to a gp. Once the wheels were in motion we kind of just went with what the drs told us
- Single
- Genetic testing
- Endometriosis

Experiences of ART

Of the 137 who had ART:

75 had more than one main experience with ART	55%
62 had one main experience	45%

Of the 75 who had more than one main experience with ART:

39 chose to answer questions only for the most significant experience

36 chose to answer a separate set of questions for each main experience

Of the 36 who had more than one main experience and chose to answer separate set of questions:

5 ended up answering only one set of questions

28 answered two sets of questions = 56 experiences

3 answered three sets of questions = 9 experiences

In total, responses were collected about 171 experiences of ART (from 137 respondents). The following findings aggregate and report on the 171 experiences recorded.

When was your experience of ART?

48	Currently undergoing treatment	28%
43	Recent – in the last year	25%
46	During the last 5 years	27%
23	More than 5 years but less than 10 years ago	13%
11	More than 10 years but less than 20 years ago	6%[6]

Total =171

For these 171 experiences recorded, respondents were asked which describes their experience best: very negative, mostly negative, mostly positive, or very positive

14	very negative	8%
43	mostly negative	25%
87	mostly positive	51%
27	very positive	16%

Total = 171

Of those 57 who answered very negative or mostly negative, the reasons given for this (from a list of which respondents could select up to 3) were:

34	No success in conceiving/completing a pregnancy so far	60%
27	Expensive/cost	47%
25	Negative impact on mental/emotional wellbeing	44%
16	Poor communication/information	28%
12	Concerns about professionalism/expertise/trustworthiness of service	21%
11	Process is overly clinical and not person-centred	19%
8	Lack of adequate psychological/emotional support from provider	14%
8	Negative impact on physical health	14%
7	Other (please specify)	12%
4	Discrimination/disrespect	7%
3	Not accessible/inclusive	5%

Other:

- Didn’t connect with the doctor, felt like she thought I wasn’t really trying to lose weight, didn’t feel supported Impact on my time and the effects on trying to work and manage childcare at the same time
- Miscarriage
- My IVF experience in the ACT was unprofessional and didn't diagnose issues correctly.
- No Medicare support for ovulation induction
- Took many transfers and losses before we were successful.
- Work flexibility around covid

Of those 114 who answered very positive or mostly positive, the reasons given for this (from a list of which respondents could select up to 3) were:

63	Professional, expert, trustworthy service	54%
55	Have had a baby/become a parent through ART	48%
47	Good experiences with staff	41%
45	Good communication/information	39%
25	Service is person-centred and not too clinical	22%
25	Respectful and non-discriminatory service	22%
19	Have conceived/become pregnant through ART	17%
17	Good psychological/emotional support from provider	15%
9	Other (please specify)	8%
6	Accessible/inclusive	5%

Other

- Cost is much more accessible
- Have only just started the process
- I ended up in icu but the clinic was very supportive
- It always affordable
- My doctor is absolutely amazing. The rest of the service is ok.
- Our medical team refuses to give up!
- We chose to DIY the ART with a trusted family friend.
- We had to change clinics because our first clinic would not do double donor cycles. The second clinic had no issue with it and we're able to provide donor sperm in a short time at a much lower cost than international banks.
- We learned a lot about our infertility factors through IUI rounds

Support and information

For the 171 experiences of ART recorded, the following answers were given about support.

Do you feel that you had/have enough psychological/emotional support before, during and after ART?

72	Yes	42%
68	No	40%
23	Unsure	13%
8	Other	5%

- Yes but not from the ART clinic

- Yes, from family. But wasn’t warned about possible physical and emotional side effects by specialist.
- I feel this is three questions. Support before - not good, support during from clinic - ok, support after (when unsuccessful) - ok
- Before - no, during - yes, after - no
- Sometimes
- There’s certainly been enough opportunity for support, but the counsellor took a very cookie cutter approach to my counselling, which caused some friction. She also only seems to have experience as an IVF counsellor so is not great at helping with regards to other elements of life that impact the process
- I dont think it would have been possible to have enough support. I have a very supportive family and my doctor was wonderful... but I don't know if it was enough
- No fault of professionals, journey is tough

For each of the 171 experiences of ART:

Did the ART provider give you an option to access professional counselling?

107	Yes	63%
31	No	18%
22	Unsure	13%
11	Other	6%

- Initial session with a counsellor, but was more processed focus (orientation to IVF) not therapeutic, not actively offered at any other time.
- They forced their chosen unqualified counsellor onto us. Even though we actually already has a couple's family counsellor we had been seeing for a while
- Yes but during specific hours I couldn't access without losing work
- Technically yes, an offer was made, but when trying to follow up found the process difficult and unhelpful
- yes, however it was made clear it was for one session and my issues, as a sexual abuse survivor, are a lot more complicated than that.
- Again, it was mandated, but we have the option to continue professional counselling.
- Yes, one session
- It wasn't an option, it was mandated.
- I never needed it
- N/A, this provider was DIY
- One session

For those 107 experiences where counselling was offered by the ART provider:

If you were offered counselling, was it offered for free or for a fee?

66	No extra cost	62%
17	Extra service for a fee	16%
17	Unsure	16%
7	Other	7%[20]

- The compulsory sessions relating to using donor gametes were expensive and not rentable by Medicare or PHI. The counselling after conception and birth is free.
- It was only offered initially in the treatment plan, but no further information was provided
- One free session per round. But we've sought extra sessions.
- Two sessions per treatment cycle were no cost. Anything additional was at cost to me
- One free session. Other sessions we have paid for
- One of as free but had to pay for the rest
- I know counseling was available but was not given details and I didn't need it

Total =107

For those 107 experiences where counselling was offered by the ART provider:

If counselling was offered, did the ART provider actively promote it as part of their regular service provision, in a non-stigmatising way?

71	Yes	66%
22	No	21%
12	Unsure	11%
2	Other	2%

- Yes, but not local and had to wait a few weeks for an appointment
- They told us about it. It wasn't actively promoted but also wasn't stigmatised

Total = 107

---

[20] Percentages do not sum to 100% due to rounding.

For those 107 experiences where counselling was offered by the ART provider:

Did you receive counselling through your ART provider?

34	Yes	32%
70	No	65%
1	Unsure	1%
2	Other	2%

- We were required to attend one session. Nothing followed unless specifically sought out.
- Not yet, but I may access it as we progress

Total = 107

For those 34 experiences where participants received counselling through the ART provider:

Was the counselling you received from/through your ART provider before, during or after your treatment? (select all that apply)

18	Before	53%
21	During	62%
12	After	35%
1	Other	

- Entering second cycle

For those 34 experiences where participants received counselling through the ART provider:

How would you describe the quality of the counselling you received from your ART provider?

14	Excellent	41%
14	Good	41%
2	Poor	6%
4	Unsure	12%

Total = 34

For each of the 171 experiences:

Did you have or do you have other sources of professional counselling around the time you were/are doing ART?

104	No	61%
60	Yes	35%
2	Unsure	1%
5	Other	3%

- My employer offers an employee assistance program but the councellors aren't very good, or specialists in fertility issues
- Not at the start but following a cycle or two and ongoing
- Other sources were available but I didn't use them
- Making people have councillong that heterosexual couples don’t need to have is vile and made me feel vile. It wasn’t about support or choice.
- No, but I was having acupuncture alongside ART, he would check in with me and I felt like I didn't need any other supports

Total = 171

For each of the 171 experiences:

Did the ART provider (or a counsellor they provided) advise you about other services and support networks to help with your mental and emotional wellbeing, or your treatment?

38	Yes	22%
106	No	62%
23	Unsure	13%
4	Other	2%[21]

- Only once asked
- Acupuncture
- Sort of - actually the Facebook groups for the community of people using the clinic really helped and was recommended by the consellor
- We did our own research

Total = 171

---

[21] Percentages do not sum to 100% due to rounding.

Do you feel that you were provided with accurate, user-friendly, accessible information to help you make decisions about your treatment?

124	Yes	73%
33	No	19%
9	Unsure	5%
5	Other	3%

- Yes, at the start this was done well, but after our first cycle failed, there were not clear follow up pathways
- We did our own research
- Mostly, yes. But in retrospect I would not have proceeded with my egg retrieval procedure given the small number of eggs retrieved. It's possible my doctor should have advised against proceeding.
- Most of the time
- Information provided was very risk focused

Total = 171

Did you have to stop ART because of the cost of treatment?

36	Yes	21%
111	No	65%
3	Unsure	2%
21	Other	12%

- The final round of IVF had to be our final round because of the cost. Luckily, it was successful.
- The last cycle was going to be our last whether it was successful or not, because of the cost. Luckily it was successful.
- It was clear my specialist's medical opinion wasn't based on medical research.
- We did minimal cost, as it was DIY. Formal ART was too expensive.
- Not yet. But I have set an upper limit for the number of cycles I'm prepared to finance.
- Not yet but it is ridiculously expensive
- We could afford the initial treatment, which has produced 4 ‘healthy’ embryos for later transfer. However, I worry that after the next transfer/cycle (at a cost of around $4000), we won’t have funds to complete further cycles.
- Took a break for a year due to emotional and financial toll
- not yet
- The only reason I was able to do it again flr my second child was because we did it in Sydney. It was significantly cheaper. 6k out of pocket vrs $750 for a full IVF cycle with multiple transfers
- Not yet. But it’s a consideration
- Will need to stop after this cycle regardless of outcome

- No but we have had to obtain financial support from family to be able to continue when we ran out of money.
- We are seeking financial support from our family now
- I travelled to sydney for my first 5 cycles to attend a bulk billing clinic
- Cost is a factor, but also I conceived naturally (ended in a miscarriage). Wasn't sure ART would actually work for me
- Looking to do one more cycle before the cost becomes prohibitive.
- Almost
- We have money set aside for a few rounds but will need to stop if unsuccessful even if we wish to continue.
- We may have to if we don’t conceive in the next few rounds
- We have paused a couple of times

Total = 171

People who had sought medical help but not gone on to have ART

For the 14 respondents who indicated they had sought medical help but not gone on to have ART treatment, we asked the following questions:

Factors considered in deciding whether to seek medical help

Which of the following were factors you weighed up when you were deciding whether to seek medical help? (select top 3)

Your desire to have a baby/become a parent and/or your partner’s desire (if relevant)	11
Expensive/cost	6
Your age and/or your partner’s age (if relevant)	5
Might still be able to get pregnant/become a parent without ART	5
Knowing about others’ good/successful experiences with ART	3
Medicare rebate not available to me/us	2
Feeling uneasy about invasive treatments	2
Concern about being discriminated against or disrespected by ART provider	1
How the treatment might impact on your mental/emotional wellbeing	1
How the treatment might impact on you physically	1

Knowing about other people's bad/unsuccessful experiences with ART	0
Previous experiences of trauma, violence or disrespect (not by ART provider)	0
Not wanting to be labelled 'infertile' because of needing treatment	0
Difficulty accessing donated egg/sperm	0
Difficulty finding a surrogate	0
Concern about lack of support while undertaking ART	0
Religious reasons	0
Reasons to do with my/our employment	0
Other	0

Reasons for not proceeding to have treatment

Why did you not go on to have treatment, after seeking medical help?

2 I/we were not able to receive treatment

Reasons:

- ART provider declined to provide service
- My weight was cited as a reason to deny service due to lower success rates and potentially higher costs
- Wasn't necessary in the end. Fertility specialist explored other methods first including treating other potential medical barriers to becoming pregnant and medical ovulation tracking.

12 I/we decided not to proceed with treatment

If you decided not to proceed with treatment, which of the following were the main reasons? (Select up to 3)

8	Might still be able to become pregnant/become a parent without ART
3	Expensive/cost
3	Medicare rebate not available to me/us
1	Discriminated against or disrespected by ART provider
1	Feeling uneasy about invasive treatments
1	How the treatment might impact on your mental/emotional wellbeing
1	Reasons to do with my/our employment

0	Previous experiences of trauma, violence or disrespect (not by ART provider)
0	Not wanting to be labelled “infertile” because of needing treatment
0	Difficulty accessing donated egg/sperm
0	Difficulty finding a surrogate
0	How the treatment might impact on you physically
0	How the treatment might impact on your relationship(s)
0	Knowing about other people’s bad or unsuccessful experiences with ART
0	Concern about lack of support while undertaking ART
0	Religious reasons

Other (please specify)

- We were not able to get an appointment with a fertility specialist for 3 months - have booked and are currently waiting for appointment date to arrive
- We got pregnant
- Fell pregnant naturally
- Long wait times

Changes that would make it more likely to use ART

(Optional) Are there any change (such as cost, Medicare rebate, medical practices or levels of support) that would make it more likely for you to use ART in the future?

- Cost
- Access to medicare rebates for single people, along with payment plants
- Yes if it becomes cheaper I’ll use it instead of waiting to fall pregnant naturally
- Medicare rebate would be appreciated as we don’t have private health cover
- I don’t think it is acknowledged how much of a traumatic experience IVF is and the support required.
- Medicare rebate

People who have considered but not decided to have ART

For the 10 respondents who indicated they have considered but not decided to have ART, we asked the following questions:

Are you still considering ART?

5	Yes - have not decided, still considering
5	No - have decided not to use ART

Factors considered

Which of the following were or are factors you have considered when deciding whether to do ART? (Select the top 3)

7	Expensive/cost
5	Your desire to have a baby/become a parent and/or your partner’s desire (if relevant)
4	Might still be able to get pregnant/become a parent without ART
2	Your age and/or your partner’s age (if relevant)
2	Feeling uneasy about invasive treatments
2	How the treatment might impact on your mental/emotional wellbeing
2	How the treatment might impact on you physically
1	Knowing about others’ good/successful experiences with ART
1	Medicare rebate not available to me/us
1	Difficulty accessing donated egg/sperm
1	Difficulty finding a surrogate
1	Concern about lack of support while undertaking ART
1	Religious reasons
0	Knowing about other people’s bad/unsuccessful experiences with ART
0	Concern about being discriminated against or disrespected by ART provider
0	Previous experiences of trauma, violence or disrespect (not by ART provider)
0	Not wanting to be labelled “infertile” because of needing treatment
0	How the treatment might impact on your relationship(s)
0	Reasons to do with my/our employment
0	Other (please specify)

Changes that would make it more likely to use ART

(Optional) Is there any change (such as cost, Medicare rebate, medical practices or levels of support) that would make it more likely for you to decide to do ART in the future?

- Access to bulk billed, quality gyno to sort out existing issues before trying ART
- Yes, ability to access the service as a single, access to rebates and a stream lined and faster process for know sufferers of fertility problems that didnt increase unnecessary treatments.

People who have not considered ART

For those 10 respondents who indicated they have not considered ART, we asked the following questions:

Reasons for not considering

Are there any reasons you can think of for why you have not considered ART? (Select the top 3 reasons)

6	Expensive / cost
4	Might still be able to become pregnant/become a parent without ART
3	Never thought of it as an option
2	Probably not suitable for my/our situation
2	Feeling uneasy about invasive treatments
2	How the treatment might impact on your mental/emotional wellbeing
1	Medicare rebate not available to me/us
1	Concern about being discriminated against or disrespected by ART provider
1	Not wanting to be labelled “infertile” because of needing treatment
1	Difficulty finding a surrogate
1	How the treatment might impact on you physically
0	Just not for me, or not for us
0	Previous experiences of trauma, violence or disrespect (not by ART provider)
0	Difficulty accessing donated egg/sperm
0	How the treatment might impact on your relationship(s)
0	Knowing about other people’s bad or unsuccessful experiences with ART
0	Concern about lack of support while undertaking ART
0	Reasons to do with my/our employment
0	Religious reasons
0	Other (please specify)

Changes that would make it more likely to use ART

(Optional) Are there any change (such as cost, Medicare rebate, medical practices or levels of support) that would make it more likely for you to decide to do ART in the future?

- Access to bulk billed, quality gyno to sort out existing issues before trying ART
- Yes, ability to access the service as a single, access to rebates and a stream lined amd faster process for know sufferers of fertility problems that didnt increase unnecessary treatments.