



VARTA

Victorian Assisted Reproductive
Treatment Authority

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VARTA Guidance on Person-Centred Care

Victorian Assisted Reproductive Treatment Authority



This Guidance was developed by the Victorian Assisted Reproductive Treatment Authority (VARTA) to help assisted reproductive treatment (ART) services provide the best possible care. The Guidance highlights what person-centred care means to people undertaking ART and provides good practice tips for clinics to consider.



VARTA Guidance on Person-Centred Care

Victorian Assisted Reproductive Treatment Authority



Foreword

Victoria has a proud history of pioneering assisted reproductive treatment. Ever since the first Australian baby was born through IVF in Melbourne 40 years ago, Victorian researchers and clinicians have conducted world leading research to improve outcomes for people requiring fertility treatment.

Every year, tens of thousands of Victorians seek help to have a family. In 2019 and 2020, the voices of people who had experienced assisted reproductive treatment (ART) were heard during the Gorton Review of Assisted Reproductive Treatment.¹ They spoke about the immeasurable pain of yearning for a child and shared valuable insight into the impact of clinic practices on patient experiences and wellbeing.

To build on that work, in 2019 the then Minister for Health asked the Victorian Assisted Reproductive Treatment Authority to produce guidance for clinics on person-centred care. After consulting more consumers of fertility treatment, the academic literature, and those working in the sector, I am delighted to present this practical guidance. It is designed to inspire clinic leaders and their staff to strive for exceptional care. Care that leaves all people, regardless of the outcomes of their treatment, feeling they were given the best chance to have a baby whilst experiencing the best possible care.

Louise Glanville



Chairperson, VARTA

1. *Helping Victorians create families with assisted reproductive treatment. Final Report of the Independent Review of Assisted Reproductive Treatment* (May 2019).

Introduction

This Guidance was developed by the Victorian Assisted Reproductive Treatment Authority (VARTA) to help assisted reproductive treatment (ART) services provide the best possible care. The Guidance highlights what person-centred care means to people undertaking ART and provides good practice tips for clinics to consider.

The Guidance recognises that ART is stressful for all those participating in treatment and that the psychological burden of treatment is one of the most commonly cited reasons for stopping treatment.² A person-centred approach can:

- increase patient satisfaction and emotional wellbeing
- enhance patient self-care
- improve patient understanding of and compliance with treatment protocols; and
- increase the likelihood of patients continuing treatment until a viable pregnancy is achieved, which in turn leads to higher cumulative live birth rates.

Decreasing the stress of treatment not only has a positive impact on patients but is also likely to improve staff wellbeing, job satisfaction, and engagement and retention.

Implementation

This Guidance is not intended to be exhaustive and implementation can be tailored to an individual clinic's circumstances. Factors that help promote a culture of person-centred care within an organisation include:

- leaders prioritising and promoting person-centred care and leading by example
- the appointment of a staff member with appropriate skills and expertise to develop strategies and manage a cohesive program of person-centred care initiatives
- ongoing training, education and support for staff so they have the skills and resources to deliver high quality person-centred care

- continual encouragement of staff to contribute to enhancing patients' experiences
- acknowledgement of successes and rewarding individuals and teams for contributions and effort to enhance person-centred care; and
- use of patient experience surveys, patient-reported outcome measures and patient feedback and complaints processes to continuously review and improve.

Background to the Guidance

In 2019, the former Minister for Health Jenny Mikakos asked VARTA to implement Recommendation 20 of the Final Report of the Gorton Review³ of Assisted Reproductive Treatment, which called for the Regulator to develop guidelines for person-centred care in ART.

Meaning and key dimensions of person-centred care in ART

Person-centred care is respectful of and responsive to the preferences, needs and values of patients and those supporting them. The widely accepted dimensions of such care are respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers, and access to care.⁴

In the context of ART, person-centred care should also account for the unique challenges people face, including the impact of infertility on relationships, financial costs of treatment, and the grief associated with failed cycles and decisions to end treatment without a child. >

2. Domar AD, Patient Retention, Nursing Retention: The Importance of Empathic Communication and Nursing Support, in Domar, Sakkas and Toth, *Patient-Centred Assisted Reproduction* (2020).
3. *Helping Victorians create families with assisted reproductive treatment*. Final Report of the Independent Review of Assisted Reproductive Treatment (May 2019).
4. Australian Commission on Safety and Quality in Health Care: National Safety and Quality Health Service Standards (second edition).

VARTA Guidance on Person-Centred Care

This Guidance is designed to highlight the importance of person-centred care for all people involved in ART, including:

- individuals or couples contemplating or undergoing treatment, including fertility preservation
- donors and surrogates
- people with diverse sexualities and genders
- people from a diversity of cultural, religious, ethnic and linguistic backgrounds; and
- support partners or family members.

In this Guidance, **person-centred care** is intended to signal the importance of “person first” treatment and catering for the individual needs of all people involved in ART. The term “patient” in this Guidance should be understood to include all these people.

Framework for considering person-centred care

Research in the field of ART has identified 10 dimensions of care which are specifically relevant to ART as follows: information, competence of clinic and staff, coordination and integration, accessibility, continuity and transition, physical comfort, attitude of and relationship with staff, communication, patient involvement and privacy, and emotional support.⁵ This Guidance builds on these dimensions, with some modifications to suit the Victorian context.

“Face to face initial consultations from specialists, nurses, counsellors and finance are all very useful, however I also found them to be extremely overwhelming. Just getting your head around the fact that you require ART can be difficult enough, without being lumped with all the information in one go and trying to process it. Brochures to accompany these chats would be extremely helpful – they could then be referred to later.”

VARTA person-centred care survey participant

Patient decision making and access to information

Patients report feeling overwhelmed with information when they first attend clinics and appreciate information being broken down and communicated in a range of ways. To help make decisions, patients want accessible and accurate information about treatment options, the risks and benefits of those treatments (including add-ons), and their personal chance of success (based on their age, health, cause of infertility and lifestyle factors). It is also important to give patients the opportunity to clarify information following their consultation without incurring additional costs, for example, by a staff member making a follow up call to resolve any questions which may arise.

Patients prefer a stepped approach to treatment with the least invasive options explored first. They want a clear roadmap of the planned treatment, so that they are aware of the overall plan, potential deviations that may be required, and options which may be available if the treatment is unsuccessful.⁶ Patients also want detailed information about administration of medication, possible side-effects, and who to contact if they have questions. Financial stress can play a significant role in the emotional strain which can be experienced by patients. Accordingly, clarity around the expected costs of treatment is also important to help manage patient financial planning. Patient involvement in decision making is central to person-centred care to ensure treatment reflects patient's values and preferences.

5. Dancet et al. (2011) “Patient-centred infertility care: a qualitative study to listen to the patient's voice”, Human reproduction (Oxford, England), 26(4), 827-833.

6. For an example of a tailored experience map, see further VARTA's webpage on person-centred care.



Good Practice Tips



- When patients are considering treatment, provide written information as well as verbal information so they can absorb the complexities of ART and think about their options. Printed information should cover:
 - the available treatment options
 - the likely prospects of success, considering the patient's circumstances
 - the high chance that multiple cycles may be needed to achieve a pregnancy
 - comprehensive information about the full cost of treatment (clearly stating likely out-of-pocket costs)
 - the evidence base for novel treatments or add-ons, if offered
 - possible risks associated with treatment procedures (including side-effects)
 - who patients can contact with questions during treatment
 - how to provide feedback or make a complaint; and
 - how to access support.
- Allow enough time for consultations so patients can thoroughly discuss their needs, priorities and preferences. Patients should not feel rushed. Encourage patients to ask questions to confirm they understand their options, including potential risks and benefits. Ensure there is a mechanism for clinic staff to follow up with patients after their consultation with the treating specialist to resolve questions which may arise.
- Make education materials readily available in a range of formats such as brochures, illustrated guides, diagrams, flowcharts, and audio and video tools, so that patients can understand and follow treatment steps or confidently administer required medication.
- Contact patients after treatment so that:
 - if a pregnancy has been achieved, patients are offered pregnancy related health information and referrals, or
 - if treatment has been unsuccessful, patients are sent written correspondence which sets out options to discuss next steps, with an offer of at least one free counselling session.

Attitude and competence of clinic staff

Patients highly value staff who are knowledgeable and respectful and provide individually tailored advice and care. This pertains to all staff who interact with patients, including scientists and administrative staff, as well as those working in fertility specialists' treating rooms. Patients appreciate clinic staff taking the time to listen to them, especially when it demonstrates an acknowledgement of the patient's unique circumstances and needs. Patients also value swift recognition and resolution of errors when they occur. For example, incorrect information on patient forms or pathology documents are not only inconvenient and stressful for the individual concerned but can also undermine trust in the clinic's overall competency and commitment to safe care. Continuous professional development and regular evaluation of staff practices can help staff

discuss their interaction with patients, including challenges they face and ways to improve.

"Being treated as an individual and really listened to [is one of the most important features of person-centred care]. My specialist had amazing staff that made you feel welcome and remembered."

VARTA person-centred care survey participant



Good Practice Tips



- Make person-centred care an integral component of all staff KPIs. Set clear expectations that all staff establish and maintain respectful, supportive and positive relationships with patients. Provide staff with feedback and opportunities to undertake relevant training aimed at continuous improvement, at least annually.
- Listen to patients' questions and concerns and act on them within reasonable timeframes. Staff ratios should allow for the time needed to cater for individual patient's needs.
- Ensure clinicians stay up to date with the latest evidence for gold standard practice, including an awareness of the evidence base for treatments and add-ons offered.
- Demonstrate a high level of attention to detail to minimise the risk of errors occurring and ensure staff are trained to act promptly and transparently to resolve errors when they occur.
- Include training in person-centred care in induction programs for new staff which is appropriate to that staff member's skills, work history and experience level. Before new staff interact with patients independently, ask them to perform several patient sessions with their trainer present to ensure they have reached an appropriate level of competency.
- Ensure all staff hold membership of their relevant professional organisation and participate in at least 4 hours of continuing professional development each year on topics relevant to enhancing their understanding and delivery of person-centred care.
- Survey patients at least annually to measure their experience and changes in staff and clinic performance over time.⁷ Use patient feedback to improve processes and practices, and build staff capability.

Coordination and continuity of care

Patients value continuity of care and building relationships with staff who know them and understand their circumstances. They like to know the roles and responsibilities of staff, including scientists in the lab who might call them with updates about their gametes or embryos. Patients highlight the importance of having access to health professionals and clinic staff within a reasonable timeframe to discuss aspects of their care and want to receive consistent information and advice. Where possible, patients prefer a central point of contact who has a holistic view of their care and treatment needs, such as a case manager, patient liaison officer or dedicated nurse. Such coordination and continuity of care requires good documentation and information

systems which are accessible to all staff who interact with the patient. This applies to billing and accounts, too. Some patients have reported receiving phone calls regarding bills at sensitive times.

Patients say that transition of care between health professionals can be stressful and that they prefer to know about this in advance. For example, if a patient's usual doctor is not available to perform their egg collection or embryo transfer, patients want to be notified of this ahead of time. Patients also appreciate follow-up to find out how their pregnancy is tracking or scheduling appointments to discuss options or next steps where treatment has not been successful.

7. For examples of relevant surveys which could be used or adapted to an ART setting, see further VARTA's webpage on person-centred care.

“After one of my egg picks ups, I was called by a nurse to check how I was. She told me two eggs had fertilised. I then received the official call from the lab about an hour later who told me only one egg had fertilised. When I questioned the discrepancy, the doctor in the lab became audibly frustrated and angry. I should not have been having to manage his emotions in that situation.”

VARTA person-centred care survey participant

Good Practice Tips



- Appoint at least one senior member of staff with appropriate skills and expertise (e.g. a senior health professional or manager) to:
 - manage a cohesive approach to person-centred care
 - provide leadership on person-centred care within the clinic
 - review patient management practices and identify areas of strengths, challenges and opportunities⁸
 - oversee clinic systems to ensure they are coordinated and responsive to patient needs; and
 - discuss and resolve complaints from patients and take steps to address system or staff issues.
- Create a system where all patients are assigned one or two key points of contact, such as a case manager, patient liaison officer or dedicated nurse, who can oversee their treatment and is available in person, by phone or email to respond to questions or concerns within reasonable timeframes. Ensure that patients are provided with clear process for contacting this person (for example by direct email and through an online booking system which allows a patient to schedule a call ahead of time). If a key contact person is not available within a reasonable timeframe to respond to a query, systems and processes allow for other staff to review patient records and appropriately respond to urgent queries.
- Advise patients of the key health professionals who are likely to be involved in their care at the start of treatment, including their names and roles. Tell patients ahead of time if someone other than their treating specialist will be performing procedures such as egg collections or embryo transfers.
- Ensure systems and processes allow patients to access information about their treatment plan, appointments, medication and test results in a timely and streamlined manner.

8. Two self-assessment tools are available on VARTA's webpage on person-centred care to assist clinics in reviewing current practices and identifying strengths, opportunities for improvement, necessary steps and actions, and responsibility and timeframes for change.

Effective and inclusive communication

A culture of effective communication across the organisation is critical for person-centred care and safety. Managing patient expectations, ensuring access to health professionals and clinic staff within reasonable timeframes, and regular communication about the progress of treatment or updates about test results can reduce distress, anxiety or confusion, and improve satisfaction with treatment. Patients value technology including secure online portals or smartphone applications which facilitate access to their treatment plan, appointments, health records, medication schedule, treatment instructions, and resources for further information relating to their treatment. Effective communication also requires that staff recognise the real or perceived power imbalance between patients and care providers (in particular treating specialists). For example, patients note that it can be an intimidating experience to page a specialist even if the paperwork advises that all after hours enquiries should be made this way. Providing an after-hours hotline where a nurse may assist with more basic enquiries or can triage the issue and contact the fertility specialist on behalf of the patient can reduce some of the stress which may be experienced by patients wishing to clarify aspects of their treatment. Making a complaint can also be stressful for patients, and some have reported that their concerns were not acknowledged and resolved in a timely fashion.

It is important for staff interaction and clinic processes to be sensitive to the diverse pathways to ART and fertility preservation. The decision to undertake fertility preservation or ART as a single person can be difficult and emotionally challenging, and these patients can feel out of place in a couple-oriented environment. People with diverse sexualities and genders can also feel marginalised in a heteronormative, cis gendered setting. For these people, it can be confronting to be presented with information and forms designed for heterosexual couples, or to be asked repeatedly to explain their circumstances. Similarly, partners can feel overlooked, and appreciate having access to all relevant information about what is expected of them during the treatment process and being included in key discussions and correspondence relating to treatment.

“There is significant trauma leading to my decision to seek fertility services as a single woman. I am not ‘socially infertile’ or any of the other vile terms used by the fertility clinic and my health insurance provider to describe my situation. I wasn’t treated ‘badly’ in a medical sense, but as a result of being treated as if I was part of the major patient group, and not according to my circumstances in any way, I will never NEVER go back for additional rounds of treatment.”

VARTA person-centred care survey participant

Good Practice Tips



- Demonstrate effective communication and inclusiveness in policies and processes.
- Train staff to communicate in a way that conveys high levels of knowledge and empathy and can respond sensitively to patients' emotions when they receive bad news.
- Ensure that clinic processes and practices recognise and mitigate the real or perceived power imbalance between patients and care providers.
- Make sure there are comprehensive clinic guidelines around handling complaints from patients with clear timelines for acknowledging complaints, updating patients on the status of internal reviews and resolving complaints.
- Appoint staff champions to liaise with key patient groups (single people, LGBTQIA+ patients,⁹ people from a diversity of cultural, ethnic and linguistic backgrounds). Wherever possible, staff who are members of the LGBTQIA+ community or have culturally or linguistically diverse backgrounds are appointed to relevant staff champion roles, in order to allow such staff members to bring their lived experience to interactions with patients, and to improve clinic engagement with diverse communities. The role of staff champions is to:
 - provide support to individual patients when needed
 - coordinate patient support groups
 - advise and assist other members of staff in complex cases; and
 - review and tailor clinic processes and practices to meet the needs of diverse patient groups.
- Ensure information for single people, members of the LGBTQIA+ community and patients from a diversity of cultural and linguistic backgrounds is appropriate to their circumstances. This includes tailoring forms and correspondence to the needs of specific user groups, as well as the partners of those seeking treatment.
- Provide regular gender and sexual diversity training to ensure staff competence in LGBTQIA+ identities and care.
- Consult community experts and organisations to enhance cultural understanding and competence, and provide cultural awareness training for staff.
- Offer interpreter services to linguistically diverse patient groups during consultations. Provide patient information in relevant languages.

9. For resources to support LGBTQIA+ patient inclusion, see further VARTA's webpage on person-centre care.

Providing a comfortable physical environment and protecting patient privacy

Patients can arrive at a clinic feeling apprehensive and stressed, so clinics that are welcoming and provide a comfortable physical environment can make a big difference to their overall experience. The clinic environment should be considerate of all those who attend. While fertility clinics facilitate the creation of much wanted babies for many patients, a significant number are unsuccessful. Patients who have experienced many failed cycles report that pictures of babies displayed in clinics can be distressing. LGBTQIA+ patients appreciate diverse patient groups being visually represented and included in images displayed in a clinic environment or on clinic websites.

“At some ... clinics, there is a lack of privacy at the reception area. It can be awkward having to give all of your personal details including your birth date when people are sitting nearby.”

VARTA person-centred care survey participant

Patients also highlight the importance of ensuring privacy and minimising the discomfort which may be experienced before and during treatment processes. Patients report that it can be physically and emotionally uncomfortable to be asked to remove clothing only to then wait for extended periods for treatment to commence, particularly if there are inadequate measures in place to protect their privacy. Given the sensitivities involved in treatment, privacy should also be ensured in all conversations between patients and clinic staff, particularly when conveying bad news. Discussions about the outcome of egg collections should be handled sensitively and with regard to the privacy of patients, noting that it can be confronting for patients to overhear details of the outcome of other women's egg collections. The same applies to conversations regarding the number or quality of embryos available for transfer. Patients report that privacy can also be an issue when they are called without warning at work or other public places where they are not able to comfortably talk about their treatment or process news relating to adverse outcomes.

Good Practice Tips



- Review the clinic environment to ensure it is comfortable for all patient groups, including those returning after failed cycles, single people, and LGBTQIA+ patients.
- Protect patients' privacy in clinic processes. Ask staff to ensure that:
 - the comfort and privacy of patients is protected before and during treatment;
 - conversations about treatment and the outcomes of an egg collection or treatment cycle are discussed with patients in private spaces where others cannot hear the discussion; and
 - all calls with patients about treatment or test results are scheduled ahead of time (e.g. by text message or email) to allow discussions to occur in private.

Emotional support for patients

Patients report that ART can be an emotionally draining experience and appreciate being offered appropriate support before, during and after treatment from their health professionals and others they engage with during their treatment. The sensitive and compassionate handling of bad news conversations is particularly important. The use of a clear protocol for communicating bad news,¹⁰ along with appropriate staff training in handling difficult conversations, can help reduce the stress associated with these conversations and be beneficial for both patients and staff involved.

Effective support through counselling and other means can help patients identify coping mechanisms and tools for mental health and wellbeing, make decisions about treatment, deal with and normalise the feelings they may experience during treatment, or accept feelings of grief and loss if treatment is not successful. Patients note that accessing support when needed, including on weekends or after hours, can have a significant impact on their emotional wellbeing. Ending treatment is a particularly difficult time for patients and support at this stage is critical. Emotional support during fertility treatment and at times of loss is also important for partners.

Given that the support needs of patients vary, it is beneficial to involve them in developing a support plan, ideally before treatment commences. Patients want a range of support options, including individual therapeutic counselling and group support. Some patients find it helpful to hear about and share experiences with others in similar circumstances and value facilitated discussions, peer support groups or mentoring programs. Online tools and resources to support patients with practical tips and strategies can also help manage expectations and emotional needs.

“Follow up after failure [is important], we found the trauma / shock / grief that we needed help with was up to a year later. We tried contacting our doctor and clinic and they would have nothing to do with us unless we continued with IVF. That was very hard on us and we felt alone.”

VARTA person-centred care survey participant

“I would absolutely love to see the implementation of a mentor type program where past ART patients volunteer to support new patients on their journey. Living in a small rural area ... meant we had very few people we were able to talk to about what was going on and how we were coping.”

VARTA person-centred care survey participant

“A ‘quick screen, dispense medications, off you go’ approach is not conducive to engaging and supporting men who may have fertility concerns or be struggling with early parenthood.”

Men’s Lived-experience survey participant
(Plus Paternal: A focus on fathers case for change)

10. For an example of a bad news protocol in a health care setting, see further VARTA’s webpage on person-centred care.

Good Practice Tips



- Offer patients emotional support at key stages of the treatment cycle and proactively check-in after adverse outcomes or when ending treatment. Ensure information is available about internal and external resources and support options to help them feel empowered. Provide appropriate referral pathways in complex cases, including advice about obtaining a mental health plan from a patient's GP if required.
- Give patients the option of working with a counsellor to develop an individual written plan of support before the start of treatment which can be recorded and updated as required to reflect their changing support needs.
- Create a "duty counsellor system" where a counsellor is available quickly if a patient needs to speak with a counsellor urgently. Patients who wish to access support can make an appointment to speak with a counsellor within 24 hours of contacting the clinic or be referred to an appropriate external support service out of hours.
- Ensure access to support is provided as needed and is not limited to a single session of counselling within treatment cycles, and counselling remains available to patients for up to 12 months after treatment is completed.
- Provide staff with appropriate training to keep up to date with best practice. Give staff access to in-house or external experts to discuss strategies to manage complex cases.

