CATEGORY: CLINICAL GOVERNANCE ADVICE

# Reproductive health for women with an intellectual disability

This statement has been developed and reviewed by the Women's Health Committee and approved by the RANZCOG Board and Council.

A list of Women's Health Committee Members can be found in Appendix A.

Disclosure statements have been received from all members of this committee.

Disclaimer This information is intended to provide general advice to practitioners. This information should not be relied on as a substitute for proper assessment with respect to the particular circumstances of each case and the needs of any patient. This document reflects emerging clinical and scientific advances as of the date issued and is subject to change. The document has been prepared having regard to general circumstances.

First endorsed by RANZCOG: February 1997
Current: July 2021
Review due: July 2026

Objectives: To provide advice on fertility management to women with intellectual disabilities.

Target audience: Health professionals providing gynaecological care.

Values: The evidence was reviewed by the Women's Health Committee (RANZCOG) and applied to local factors relating to Australia and New Zealand.

Background: This statement was first developed by Women's Health Committee in February 1997 and last reviewed in November 2020 and July 2021

Funding: The development and review of this statement was funded by RANZCOG.

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## 1. Plain language summary

This statement provides guidance for practitioners providing fertility and/or menstrual management advice to women with intellectual disability who lack full decision-making capacity. These women face the same issues of fertility and menstrual management as other women, however the issues in relation to providing informed consent are more complex. It is very important that practitioners proving care to women with disability ensure that information is presented in a way that enables these women to participate in decision making to the degree that they are able. The legal framework relevant to care of women with intellectual disability differs between jurisdictions. Practitioners must be aware of their local legal framework and regulations. In addition, practitioners are strongly encouraged to engage with experts in the care of women with disabilities, particularly when considering offering a termination of pregnancy or permanent sterilisation.

## 2. Summary of recommendations

| Recommendation 1 | Grade |
|---|---|
| All women, including those with a disability, have the right to make decisions about whether they will use contraception and which method of contraception they use. | Consensus-based recommendation |
| **Recommendation 2** | **Grade** |
| Reversible methods, including long acting reversible contraceptive (LARC) implants (e.g. Implanon or levonorgestrel intrauterine system) should be considered first and in preference to irreversible surgical options. | Consensus-based recommendation |
| **Recommendation 3** | **Grade** |
| As in all clinical situations, treatment offered to women with intellectual disabilities must be in accordance with the legal and guardianship provisions of the relevant jurisdiction. | Consensus-based recommendation |
| **Recommendation 4** | **Grade** |
| Consultation with others experienced in the care of young women with disabilities is strongly recommended prior to considering irreversible approaches or where there is a lack of consensus as to what is in the best interest of the woman. | Good practice point |

## 3. Discussion and recommendations

All women, including those with a disability, have the right to participate in decision making about whether they will use contraception and which method of contraception they use. It is a fundamental legal and ethical principle that a patient's informed consent must be obtained before an examination or treatment may be conducted [1].

Women with an intellectual disability face the same issues of fertility and menstrual management as other women, however the issues in relation to providing informed consent are more complex and differ between jurisdictions [2].

Although women with an intellectual disability may have difficulty fully comprehending the nature, extent, consequences, and risks associated with a specific medical treatment, every effort should be made to help them understand the proposed treatment. To enable this to occur women should be provided with accessible and accurate information and any additional supports required to enable them to make their own decisions.

| Recommendation 1 | Grade |
|---|---|
| All women, including those with a disability, have the right to make decisions about whether they will use contraception and which method of contraception they use. | Consensus-based recommendation |

The focus of care must be the woman's quality of life and her reproductive rights. Women with an intellectual disability should be assessed and provided with choices that offer the most benefit for them with the least risks and side effects as would be considered for women of the same age and reproductive circumstances but without an intellectual disability. Reversible methods, including long acting reversible contraceptive (LARC) implants (e.g. Implanon or levonorgestrel intrauterine system) should be considered first and in preference to irreversible surgical options.

| Recommendation 2 | Grade |
|---|---|
| Reversible methods, including long acting reversible contraceptive (LARC) implants (e.g. Implanon or levonorgestrel intrauterine system) should be considered first and in preference to irreversible surgical options. | Consensus-based recommendation |

Some women with an intellectual disability may lack the capacity to provide legally valid consent even with appropriate support. The laws regarding this situation are different in Australia and New Zealand and subtly different in each Australian state and territory.

Where the treatment proposed is minor and reversible and a woman has been previously assessed as lacking capacity to consent, a practitioner should obtain written legal consent from a substitute decision maker as defined by the relevant local laws. Further advice should be sought if a woman has communicated that she does not agree to a proposed treatment or if there is no substitute decision maker available.

Where it is felt by the practitioner the woman may lack capacity to provide informed consent, advice should be sought from a medical professional qualified to make a capacity assessment (for example, a neuropsychologist or psychiatrist). Persons with serious impairment in some areas of mental function may still be able to participate in decisions affecting their reproduction.

When recommending procedures that are intended or are reasonably likely to render a woman permanently infertile or involve a termination of pregnancy, consultation with others, who are experts in the care of women with disabilities, is strongly recommended.

Permanent sterilisation of women who lack capacity to give consent and of all children, in all states and territories of Australia mandates an application to an independent tribunal or statutory body. The common law position in Australia is determined by the Marion case [3]. Regulations vary by state and territory [4] Practitioners must be aware of local regulations regarding the provision of these types of procedures to women with intellectual disability who lack decision making capacity.

In New Zealand, provided the patient is not a minor, the legal guardian can consent to sterilisation. When there is not unanimity between the views of the doctor, the patient, their families and the legal guardian despite providing the time, information and supportive resources needed to reach a unanimous decision, advice from other experts or an ethics committee should be sought before proceeding. In rare cases where unanimity cannot be reached clinicians may need to obtain a legal opinion on whether to seek authority from the High Court. Welfare guardians are specifically prohibited from consenting to sterilisation in minors. A court order must be sought to determine if sterilisation is in the best interests of the child [5].

The legal consent process for a termination of pregnancy also differs between Australia and New Zealand. In Australia, as for sterilisation, an application to an independent tribunal or statutory body is required. In New Zealand in any case where the patient lacks the capacity to consent, by reason of mental incapacity, to an abortion, an abortion can

be performed provided this is supported by two Ministry of Justice appointed certifying consultants and they have sought advice from an expert experienced in the assessment of the patient's condition and the likely effect on it of the continuance of the pregnancy or an abortion [6].

| Recommendation 3 | Grade |
|---|---|
| As in all clinical situations, treatment offered to women with intellectual disabilities must be in accordance with the legal and guardianship provisions of the relevant jurisdiction. | Consensus-based recommendation |
| **Recommendation 4** | **Grade** |
| Consultation with others experienced in the care of young women with disabilities is strongly recommended prior to considering irreversible approaches or where there is a lack of consensus as to what is in the best interest of the woman. | Good practice point |

## 4. References and endnotes

[1] In New Zealand patient rights to informed consent are specified under the Code of Health and Disability Services Consumers' Rights 1996 ("Code of Rights")

[2] In New Zealand, the adult guardianship law, the Protection of Personal and Property Rights Act 1988 and the right to informed consent under the Code of Health and Disability Services Consumers' Rights 1996 ("Code of Rights") are the main legislation that applies to adults with impaired capacity.

[3] *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 175 CLR 218 *(Marion's Case).*

[4] People with disability in Australia 2020. https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/summary

[5] Consent for sterilisation in mentally incompetent adults is governed by the "Protection of Personal and Property Rights, 1977. This act outlines the powers and duties of welfare guardians.

[6] Contraception, Sterilisation, and Abortion Act 1977, section 34

## Other suggested reading

Family Court of Australia: http://www.familycourt.gov.au/

Family Court of New Zealand: http://www.courts.govt.nz/family/

The relevant Guardianship authority in States and Territories in Australia can be located in the Office of the Public Advocate's Interstate Offices and Tribunals.
http://www.opa.sa.gov.au/resources/links/interstate_juridisctions

New Zealand Protect of Personal and Property Rights 1988.
http://www.legislation.govt.nz/act/public/1988/0004/latest/whole.html#DLM126587

New Zealand Contraception, Sterilisation, and Abortion Act 1977.
http://www.legislation.govt.nz/act/public/1977/0112/latest/whole.html#DLM18513

Coles Medical Practice in New Zealand. https://www.mcnz.org.nz/assets/News-and-Publications/V6-Coles-Medical-Book-2017.pdf

The Sterilisation of Girls and Young Women in Australia. Australian Human Rights Commission. https://humanrights.gov.au/our-work/sterilisation-girls-and-young-women-australia-issues-and-progress

Consent and contraception. A Comparative Analysis of the Legal Frameworks for Accessing Contraception. Women With Disabilities ACT. https://www.wwdact.org.au/wp-content/uploads/2018/04/WWDACT-Contraception-and-Consent-Final-Report.pdf

## Links to other College statements

Consent and provision of information to patients in Australia regarding proposed treatment. (C-Gen 02a)
https://ranzcog.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical%20-%20General/Consent-and-provision-of-information-to-patients-in-Australia-(C-Gen-2a).pdf?ext=.pdf

Consent and provision of information to patients in New Zealand regarding proposed treatment (C-Gen 02b)
https://ranzcog.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical%20-%20General/Consent-and-provision-of-information-NZ-(C-Gen-2b).pdf?ext=.pdf

Emergency Contraception (C-Gyn 11)
https://ranzcog.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical%20-%20Gynaecology/Emergency-contraception-(C-Gyn-11).pdf?ext=.pdf

Long Acting Reversible Contraception (LARC) (C-Gyn 34
https://ranzcog.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical%20-

%20Gynaecology/Long-acting-reversible-contraception-(C-Gyn-34)-Review-July-2017.pdf?ext=.pdf

Evidence-based Medicine, Obstetrics and Gynaecology (C-Gen 15) *https://ranzcog.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical%20-%20General/Evidence-based_Medicine_Obstetrics_and_Gynaecology_(C-Gen-15)-March-2021.pdf?ext=.pdf*

Investigation of intermenstrual and postcoital bleeding. https://ranzcog.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical%20-%20Gynaecology/Investigation-of-intermenstrual-and-postcoital-bleeding(C-Gyn-6)-March-2018.pdf?ext=.pdf

Heavy menstrual bleeing. Patient information. https://ranzcog.edu.au/womens-health/patient-information-resources/heavy-menstrual-bleeding

# Appendices

## Appendix A Women's Health Committee Membership

| Name | Position on Committee |
|---|---|
| Professor Yee Leung | Chair and Board Member |
| Dr Gillian Gibson | Deputy Chair, Gynaecology |
| Dr Scott White | Deputy Chair, Obstetrics and Subspecialties Representative |
| Dr Jared Watts | Member and EAC Representative |
| Dr Kristy Milward | Member and Councillor |
| Dr Will Milford | Member and Councillor |
| Dr Frank O'Keeffe | Member and Councillor |
| Prof Steve Robson | Member |
| Professor Sue Walker | Member |
| Dr Roy Watson | Member and Councillor |
| Dr Susan Fleming | Member and Councillor |
| Dr Sue Belgrave | Member and Councillor |
| Dr Marilyn Clarke | ATSI Representative |
| Associate Professor Kirsten Black | Member |
| Dr Thangeswaran Rudra | Member |
| Dr Nisha Khot | Member and SIMG Representative |
| Dr Judith Gardiner | Diplomate Representative |
| Dr Angela Brown | Midwifery Representative Australia |
| Adrienne Priday | Midwifery Representative New Zealand |
| Ms Ann Jorgensen | Community Representative |
| Dr Ashleigh Seiler | Trainee Representative |
| Prof Caroline De Costa | Co-opted member (ANZJOG member) |
| Dr Christine Sammartino | Observer |

## Appendix B Overview of the development and review process for this statement

*i. Steps in developing and updating this statement*

This statement was originally developed in February 1997 and was most recently reviewed in February 2021. The Women's Health Committee carried out the following steps in reviewing this statement:

- Declarations of interest were sought from all members prior to reviewing this statement.
- Structured clinical questions were developed and agreed upon.
- An updated literature search to answer the clinical questions was undertaken.
- At the February 2021 teleconference meeting, the existing consensus-based recommendations were reviewed and updated (where appropriate) based on the available body of evidence and clinical expertise. Recommendations were graded as set out below in Appendix B part iii)

*ii. Declaration of interest process and management*

Declaring interests is essential in order to prevent any potential conflict between the private interests of members, and their duties as part of the Women's Health Committee.

A declaration of interest form specific to guidelines and statements was developed by RANZCOG and approved by the RANZCOG Board in September 2012. The Women's Health Committee members were required to declare their relevant interests in writing on this form prior to participating in the review of this statement.

Members were required to update their information as soon as they become aware of any changes to their interests and there was also a standing agenda item at each meeting where declarations of interest were called for and recorded as part of the meeting minutes.

There were no significant real or perceived conflicts of interest that required management during the process of updating this statement.

*iii. Grading of recommendations*

Each recommendation in this College statement is given an overall grade as per the table below, based on the National Health and Medical Research Council (NHMRC) Levels of Evidence and Grades of Recommendations for Developers of Guidelines. Where no robust evidence was available but there was sufficient consensus within the Women's Health Committee, consensus-based recommendations were developed or existing ones updated and are identifiable as such. Consensus-based recommendations were agreed to by the entire committee. Good Practice Notes are highlighted throughout and provide practical guidance to facilitate implementation. These were also developed through consensus of the entire committee.

| | | Description |
|---|---|---|
| Evidence-based | | Body of evidence can be trusted to guide practice |
| | | Body of evidence can be trusted to guide practice in most situations |
| | | Body of evidence provides some support for recommendation(s) but care should be taken in its application |
| | | The body of evidence is weak and the recommendation must be applied with caution |
| | | Recommendation based on clinical opinion and expertise as insufficient evidence available |
| | | Practical advice and information based on clinical opinion and expertise |

## Appendix C Full Disclaimer

Purpose
This Statement has been developed to provide general advice to practitioners about women's health issues concerning Reproductive health for women with intellectual disability and should not be relied on as a substitute for proper assessment with respect to the particular circumstances of each case and the needs of any person with an intellectual disability. It is the responsibility of each practitioner to have regard to the particular circumstances of each case. Clinical management should be responsive to the needs of the individual person with an intellectual disability and the particular circumstances of each case.

Quality of information
The information available in Reproductive Health in Women with an intellectual disability is intended as a guide and provided for information purposes only. The information is based on the Australian/New Zealand context using the best available evidence and information at the time of preparation. While the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) had endeavoured to ensure that information is accurate and current at the time of preparation, it takes no responsibilityfor matters arising from changed circumstances or information or material that may have become subsequently available. The use of this informationis entirely at your own risk and responsibility.
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