

Models of Care Providing Fertility Preservation for Cancer Patients

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Aims



- 1. Describe the barriers to oncofertility care
- 2. Describe the essential components of oncofertility care
- 3. Describe strategies for improving oncofertility care

Why Are We Interested In Models of Care?



- Fertility preservation cited as one of the top five unmet needs for cancer patients (Klosky et al. 2015)
- Oncofertility care should be an integral part of cancer care from diagnosis through to survivorship
- Oncofertility care often under-implemented for children and adult cancer patients

Barriers To Oncofertility Care



- Availability of oncofertility referral pathways
- Availability of specialist expertise /training
- Health care professional involvement in care
- Access to age appropriate care
- Timing

- Reaching rural patients
- Reaching CALD patients
- Age of patients
- Gender of patients
- Costs
- Health Literacy

What Barriers Do Oncofertility Care Do Patients Report?

- Phase 1
 - Focus group consultation with 50 consumers 2014
 - Anazodo A. C., Gerst, B., Stern, C., McLachlan, R. I., Agresta, F., Jayasinghe, Y., Cohn, R., Wakefield, C.E., Chapman, M., Ledger, W. & Sullivan, E.A. (2016). Utilising the experience of consumers in consultation to develop the Australasian Oncofertility Consortium Charter. *Journal of Adolescent and Young Adult Oncology*. 2016 Sep;5(3):232-9. doi: 10.1089/jayao.2015.0056. Epub 2016 Mar 16
- Identified domains valuable or missing from their experience
 - 1. HCP's communication
 - 2. Oncofertility documentation
 - 3. Oncofertility decision/support
 - 4. Training
 - 5. Age appropriate care
 - 6. Psychosocial care
 - 7. Referral pathway
 - 8. Reproductive survivorship care

Systematic Reviews on Reproductive Concerns and Support Needs

Phase 2

How Can We Improve Oncofertility Care for Patients? A Systematic Scoping Review of Current International Practice and Models of Care. Accepted October HRU

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Models of Oncofertility Care – Systematic Review



Rates of Referral



- Clinician referral rates to fertility specialists varied substantially:
 - 15% 'routinely' referred (Forman, Anders et al. 2009)
 - 20% referred (Rabah et al. 2010)
 - 29% 'routinely' referred (Mahajan et al. 2016)
 - 38% 'actually' referred (Abe et al. 2016)
 - 46% 'often' referred (Overbeek et al. 2014)
 - 47% 'routinely' referred (Quinn et al. 2009)
 - 54% 'regularly/always' referred (Louwé et al. 2016)
- FP referral rates have been shown to increase over time (Dearing et al. 2014, Sigismondi et al. 2015, Ben-Aharon et al. 2016)

What Factors Influence Referral?



 Oncologists report higher referral rates to fertility specialists for adult male patients compared with female patients

(Arafa and Rabah 2011, Collins et al. 2011, Yee et al. 2012)

- Paediatric centres have higher rates for boys rather than girls (Anderson et al. 2008)
- Only 36% felt that pre-pubertal patients should be referred (Köhle et al. 2011)

Factors Affecting Referral To Fertility Clinician

Patient Characteristics

- Patient initiated discussion about FP or expressing concerns about future fertility (Adams et al. 2013, Buske, Sender et al. 2016)
- Being male (Arafa and Rabah 2011, Yee et al. 2012)
- Specific types of cancer (Goodman et al. 2012, Bastings et al. 2014)
- Aged 20-34 years referred most (Goodman, Balthazar et al. 2012, Bastings et al. 2014, Pacey et al 2013)
- Having no children (Goodman et al. 2012, Pacey et al 2013)

Clinician Characteristics

- Having a female clinician (Quinn, Vadaparampil et al. 2009, Shimizu et al. 2013, Bastings et al. 2014)
- Clinicians having favourable attitudes towards FP (Quinn et al. 2009, Shimizu et al. 2013)
- Clinicians with more knowledge (Quinn, Vadaparampil et al. 2009, Shimizu et al. 2013)
- Clinicians who had these discussions more frequently (Forman et al. 2009, Louwé et al. 2016)

Hospital Factors Which Affect Referral



- Difficulties finding facilities or specialists (Goodwin et al 2007, Yee et al 2012, Dyer and Quinn 2016, Mahajan et al 2016)
- Lack of FP resources (Preaubert et al. 2016)
- Problems integrating FP into routine cancer care (Preaubert et al. 2016)
- Having access to care navigation (nurses, counsellors, psychologists or fertility navigators plays a role in coordination and referral (Gilbert et al 2010)
- The use of checklists or prompts in EMR/prescribing systems improved referral practices (Reinecke et al 2012, Sheth et al 2012, Salsman et al 2016)
- 2 studies have found distances to the fertility specialists had no impact on whether patients were referred (Lee et al 2011, Goodman et al 2012)

Referral pathways



Integration into standard practice in cancer centres



Established pathways between cancer & fertility specialists



Care navigation



Oncofertility Decision Aids



- Provide assistance to understand FP options and to weigh up the advantages and disadvantages
- A number of types
 - Decision trees (Gardino et al. 2010)
 - Web-based or electronic educational tools (Huyghe et al. 2009, Merrick et al 2012, Garvelink et al. 2013)
 - Brochures/booklets (Peate et al. 2011, Murphy et al. 2012, Peate et al. 2012, Tam et al. 2016)
- Available for children and adults

Benefits of Decision Aids



- Patients, parents, partners and HCPs have reported high levels of usefulness or satisfaction with the material (Nagel and Neal 2008, Peate et al. 2011, Tam et al. 2016)
- Use resulted in less FP decisional conflict (Huyghe et al. 2009, Peate et al. 2012)
- Trends towards having higher knowledge
- Lower regret at 12 months (Peate et al. 2012)
- More likely to discuss FP with their oncologist (Peate et al. 2012)
- More likely to be referred to a fertility specialist (62% vs 56%) (Peate et al. 2012).

Concerns About Decision Aids



- Patients, parents and healthcare providers held concerns about the content and readability(Murphy et al. 2012)
- Parents felt there was too much medical terminology and too much information in general (Murphy et al. 2012)
- Some patients found the information upsetting (Peate et al. 2011)
- An assessment of reading age of all material to be "considerable" (Merrick et al 2012)
- Quality varied (Merrick et al 2012)

Oncofertility decision aids





Provides better understanding, helps decision making, reduces regret



Types of Communication



- Clinicians generally only use verbal communication (Gilbert et al. 2010, Yee et al. 2012)
- Referral to written and online resources occurs (Reinecke et al. 2012, Besharati et al. 2016)
- Clinicians reported that patients and parents are usually given printed resources, then directed to certain websites for further information (Fuchs et al. 2016)
- One study found that 60% of clinicians rarely or never gave any FP educational materials to patients (Quinn et al. 2012)
- Clinicians are not consistent in providing comprehensive information (Buske et al. 2016)

Timing of Communication

- Significant variation
- Cancer survivors and nurses believe the clinician should initiate the conversation about FP (Gorman et al. 2012, Murray et al. 2016)
- Between 23% and 50% of discussions were initiated by the patient or a family member or friend (Rabah et al. 2010, Scanlon et al. 2012, Yee et al. 2012, Chin et al. 2016, Yee 2016)
- Low rates of fertility discussion linked to not wanting to upset patients and families (Vadaparampil et al. 2007)

Quality of Communication

- Satisfaction with quality (Wilkes, Coulson et al. 2010, Hill, Nadler et al. 2012, Garvelink et al. 2013, Kelvin et al. 2016)
- Frustration with quality (Gorman et al. 2012, Corney 2014, Wright et al. 2014, Banerjee and Tsiapali 2016, Ellis et al. 2016)

Role/Needs In Communicating About Oncofertility Care



Clinician Role

Patient Needs

- Majority of clinicians believe it was their role (Duffy et al. 2012, Overbeek et al. 2014)
- 1 study found that 40% of clinicians thought that patients should bring up the topic (Ghorbani et al. 2011)
- Should follow soon after information about diagnosis
- More information should be given by fertility expert (Garvelink et al. 2012)

- Patient preference to receive information around diagnosis (Crawshaw et al. 2009, Lee et al. 2011)
- Parents had the same views (Stein, Victorson et al. 2014, Ellis et al. 2016)
- Communication needs to be clear and objective

Communications Between HCP's

- Three papers described difficulties experienced by HCPs in communication with professionals of the same speciality (Shimizu et al. 2015)
- Difficulties in communicating with different specialities (Shimizu, Kato et al. 2015, Abe et al. 2016)
- This was echoed by the patient perspective that clinicians should communicate more effectively with each other (Garvelink, et al. 2013)



Age Appropriate Care



- AYA patients showed high ratings of importance for information on treatment effects on fertility risk, FP and other parenting options (Gupta et al. 2013)
- Wanting detailed, verbal and written information on options, risks, benefits, side effects and success rates of FP (Wilkes et al. 2010, Hershberger et al. 2013, Bastings et al. 2014, Richter et al. 2016)
- Health care professionals should have expertise in caring for patients of all ages and good support systems.

Patient Preferences Concerning Provision Of Care



- Tailored to the patient's age (Corney and Swinglehurst 2014)
- Tailored to life stage, relationships and fears (Wilkes et al. 2010)
- Tailored to personal story (Murphy et al. 2014)
- Patients wanted to be respected and listened to (Kirkman et al. 2013)
- Adult patients wanted information about parenthood options and ART (Murphy et al. 2012, Fuchs et al. 2016)
- Young patients wanted more age appropriate content and lower reading level or felt they have been given too much information (Murphy et al. 2012, Fuchs et al. 2016)

Who Should Be Involved In Consultations?



Clinicians Perspectives

- Clinicians have reported conflicting information about the levels of comfort with FP discussions;
 - low levels of discomfort with discussions about infertility and FP for paediatric and adolescent patients are reported (Vadaparampil et al. 2008, Fuchs et al. 2016)
 - Clinicians find these consultations difficult (Vadaparampil et al. 2008)
 - Clinicians being embarrassed (Quinn et al. 2009)
 - Awkward because of parent presence (Quinn et al. 2009)
- Two studies reported a preference amongst clinicians treating AYA patients to discuss provision of care without the parents being present (Bashore 2007, de Vries et al. 2009)

Patient Preferences with Care



- 56% would have liked their parent to be present with the remaining (Ginsberg et al. 2008)
- 44% preferring their parent not to be present during the initial conversation about FP (Ginsberg et al. 2008)
- Patients with partners reported that they would like their partner to be present for FP discussions (Richter et al. 2016)
- A study examining views on written information found that females would rather read it with a parent (Murphy et al. 2014)

Provisions of Care

- The majority of centres do not have a policy on provision of FP information.
- In a US study, 4/30 centres (13%) had referral pathway (Clayman et al. 2013)
- Another US study of 5/28 centres, only 18% had a referral pathway (Warner et al. 2016)
- 75% of clinicians felt guidelines were needed for their institution (Vadaparampil et al. 2008)
- Of 306 clinicians in one study, 62% were aware of an established referral pathway to a local fertility unit (King et al. 2012)
- Referrals are most often from academic centres (64%), followed by oncologists (28%), (Lee et al. 2011).

Age appropriate care •--



Verbal & written consultation

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Choice of family or friends present for consultation



Information relevant to stage of life/healthy lifestyle



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Clinician Knowledge and Training

- Almost half of oncologist in one study not aware of FP options for female patients
- Oncologists had little or no training in FP (Quinn et al 2009)
- US paediatric oncology study 93% no training on FP (Fuchs et al. 2016)
- National study in Canada of 25 fertility clinics found only 13 (52%) had training

Clinicians Comfort Level

- Patients perceived that clinicians were uncomfortable or dismissive (Gorman et al 2012)
- Some studies have reported high comfort level (Gilbert et al 2010, Kashanian et al 2016)
- Comfort level improves with more regular discussions (Besharati et al 2016)

Level of Training in Nurses and Allied Health Professionals

• Knowledge gaps are also reported in nurses and allied health professionals (Ussher, Cummings et al. 2016)

What Type of Training is Required?

- Oncofertility communication skills training
 - Greatly improve clinician knowledge and confidence with FP discussions (Vadaparampil et al. 2016)
- Online oncofertility training programs for nurses have been developed covering fertility risks, FP options and sexual function (Vadaparampil, Kelvin et al. 2016)
 - Lead to improved knowledge and change in practice locally (Vadaparampil et al. 2013, Vadaparampil et al. 2016).
 - A small pilot study has demonstrated the benefits in allied health professionals undertaking the same training

(Quinn et al. 2016)

Oncofertility training

All health care professionals need oncofertility training and communication skills training





WCOFER HUNTY MODELS

Fertility Status in Survivorship



- Lack of understanding about their fertility status (Eiser et al 2014, Wright et al. 2014
- lack of importance placed on follow-up (Eiser et al 2011)
- Limited fertility follow up (Kim et al. 2016, Pacey et al 2012)
- Limited fertility-related support in survivorship (Perz et al. 2014)
- Very low numbers of clinicians (28%) always/often checking patients' fertility parameters in survivorship. 72% rarely or never check, or inform their patients (Preaubert et al. 2016)

Survivorship Information Needs

Overlapped with the themes on communication and provisions of care

- Patients want to have individual information about their fertility after cancer treatment (Perz et al. 2014, Armuand et al. 2015)
- Many survivors had incorrect beliefs about the extent of their fertility problems, which did not reflect the information received (Crawshaw and Sloper 2010)
- Frustration with the quality of care and lack of reproductive continuity of care (Gorman et al. 2012)
- Frustration with lack of pregnancy planning and support (Gorman et al. 2011)
- Increased anxiety

Reproductive •··· survivorship care

Survivors continue to need oncofertility care following cancer treatment Opportunity to reassess fertility status



WCOFER

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KIT MODELS

Oncofertility medical care •-during fertility preservation

Assessment of medical suitability





Consider infection risk & need for antibiotic cover

02 Consideration of anesthesia risk 03 Consideration of need for blood product support during procedure



Consideration of risk due to site of tumour





Extent of Documentation



- 58% had a documented discussion (Wang, Chen et al 2016)
- Low levels in oncologists (26%) and hematologists (38%) (Gilbert et al 2010)
- Better in early stage cancers (Kumar et al 2012)
- Better in patients receiving radiation treatment (Salsman et al 2016)
- Better in some tumour groups (Srikanthan et al 2016)

Factors Which Improve Documentation



- Centres with oncofertility program (Reinechke et al 2012, Shethet al 2012)
- 1 study showed oncofertility program increased discussion and referral but not documentation (Srikanthan et al 2016)
- Care coordination (Gilbert et al 2010)

Documentation

Communication between patient, family members & colleagues needs to be well documented







What Are The Psychosocial Effects Of Infertility?

- Impact on patients identity, well-being and life plans (Crawshaw et al. 2009)
- The threat of temporary or permanent infertility associated with psychological distress (Lawson et al. 2015, Ellis et al. 2016)
- Has an effect on patients' self-esteem, confidence, quality of life and relationships (Goossens et al. 2015)
- Loneliness was reported by both male and female patients facing fertility loss, even those with good support (Goossens et al. 2015)
- 50% of young cancer patients (18-45 years), who wished to have children in the future, required some psychological care with regard to fertility and parenthood (Geue et al. 2014)

What Changes Psychological Distress?



Worse

- Lack of time to make decisions is associated with negative experiences of FP or increased stress (Yee et al. 2012, Bastings et al. 2014)
- Having unanswered questions (Corney and Swinglehurst 2014)
- Females tend to experience more distress than males due to the lack of services for FP (Crawshaw, et al. 2009)

Better

 Appropriate support, patients experience less distress, fear and decision regret, and felt more positive about the future

(Hohmann et al. 2011, Letourneau et al. 2012, Peate et al. 2012, Bastings et al. 2014, Benedict et al. 2015, Lawson et al. 2015)

What Supports Do Patients/Families Want?

- In a qualitative study participants felt that emotional support was important at all stages of treatment and recovery (Corney and Swinglehurst 2014)
- Counselling was found to be useful at many time points due to the complexity of FP decision-making (Gardino et al. 2010)

Who Can Provide Support?



- Professional and parental support assisted with receiving fertility information at diagnosis (Crawshaw, Glaser et al. 2009)
- Families helpful in providing emotional support and assistance with decisionmaking (Kim et al. 2013)
- Female patients felt that of the range of oncofertility HCPs, the most useful were oncologists and gynaecologists/fertility (Tschudin et al. 2010)
- Psychologist was beneficial and helped to improve communication between doctor and patient, and reduce anxiety when used (Razzano et al. 2014)
- Nurses are helpful with discussing options and making decisions (Kelvin, et al. 2016)
- Review did not find any literature discussing the benefits of support groups or peer support

Fertility related •····· psychosocial support





Provides support & management of psychological symptoms, reduces distress, improves patients & partners quality of life



Ethical practice of • oncofertility care





A number of ethical & legal issues Clear guidelines & recommendations

Access to ethical framework & review of cases when required



Established models and their key components

Model	Patient		Pt	Dr/nurse	Referral form/	Pt	Collaboration/	Electronic	Psychological
	Sex	Age	educational materials ^a	education ^b	established process ^c	navigator ^d	partnerships ^e	notification of eligible pts ^f	counselling ^g
Colarado Oncofertility Program (Blough et al 2014)	M/F	All	 Image: A second s	•	 Image: A set of the set of the	×	 Image: A second s	 Image: A second s	 Image: A second s
Dana-Farber Cancer Institute (Campos et al 2012)	M/F	Adult	 Image: A second s	×	~	 Image: A second s	 Image: A start of the start of	 Image: A start of the start of	 Image: A start of the start of
Seattle Children's Hospital (Johnson & Kroon 2013/Shnorhavorian et al 2012)	М	AYA	 Image: A second s	 Image: A start of the start of	 	 Image: A second s	 Image: A start of the start of	×	•
McMaster Children's Hospital (Nagel et al 2009)	М	AYA	 Image: A second s	 Image: A second s	~	×	 Image: A second s	×	•
Children's Hospital of Philadelphia (Ogle et al 2008)	Μ	AYA	 Image: A second s	 Image: A start of the start of	~	some	*/	×	×
H. Lee Moffit Cancer Center (Quinn et al 2011)	M/F	Adult	 Image: A second s	 Image: A second s	~	×	 Image: A start of the start of	 Image: A second s	•
Fertile Hope Centers of Excellence Program (Reinecke et al 2012) ^h	M/F	All	 Image: A second s	 Image: A second s	 Image: A second s	some	 Image: A start of the start of	 Image: A set of the set of the	•
Northwestern University (Oncofertility Consortium) (Sheth et al 2012/Vu et al 2017)	M/F	All	~	~	~	~	~	~	•

Program has characteristic

XProgram does not have characteristic

Not clear whether program has characteristic



What Is a Competency?



- **Competency frameworks** 'health care professionals need to have the skills to turn the available knowledge into service development and reliable outcomes'
- The availability of oncofertility competencies
 - Would allow health care staff to define how oncofertility care should be developed in line with international guidelines
 - Outline clearly the specific competency for each deliverable component of care
 - Would be instrumental in developing and maintaining HCP skills

Next Step - Global Oncofertility Competency Framework



- Phase 3 Global Competency Study
 - Using a modified Delphi Framework
 - Using evidence from phase 3 systematic review
 - Involving clinician experts and patient advocates

• Aims

- To define key competency for oncofertility care
- To define the role of HCP's
- To prioritise care into three tier service framework

G-FOrCe: Global Framework for Oncofertility Care

- A 2 round Delphi methodology was used
 - Translated into 9 Languages, participants from 16 countries
- HCP questionnaire included 106 statements
- The PFA questionnaire consisted of 93 questions
- The agreement level was set at 80%
- Throughout the survey's nine definitions were given to help the participants understand the questions and make a decision

G-FOrCe: Global Framework for Oncofertility Care

- Questionnaire 1 457 questionnaires were completed by 332 HCPs and 125 PFAs.
- 75 % of the questionnaires were totally completed
- 9 questions which did not meet a consensus so Questionnaire 2 was developed
- Questionnaire 2 138/166 participants from phase 1 agreed to participate.

Oncofertility Model of Care



- There was agreement that equitable services should be delivered to all patients irrespective of age, gender, religion, culture
- Oncofertility services needed to be standard practice 91%
- The need for interdisciplinary collaboration (95.9%)
- Identifiable services with a clear referral pathway (93.7%)
- HCPs knowledgeable about oncofertility guidelines (91.9%) were supported by both HCP and PFA participants

Referral Pathways



- Cancer services need to have a clearly defined referral pathway (96.1%)
- Process for referral (96%) and priorities for urgent cancer cases (93.7%) was agreed by both PFA and HCPs.
- 85.4% of PFA felt that fertility referral should be within 2 working days but only 71.8% of HCPs agreed with this in questionnaire 1

Referral Pathways



- In addition to having a referral pathway there was agreement that the referral process should be clear, providing information on:
- 1. Past medical history and fertility status (95%),
- Proposed cancer treatment and gonadotoxic risk (91.6%)
- Whether the treatment could change and become more intensive before completion (93.7%)

Consultation

- PFA and HCPs agreed that cancer centres need to have a system to identify cancer patients at risk (88.3%)
- Cancer patients not at risk should also be told they had 'no risk of infertility' (86%)
- Cancer patients should be given an opportunity to discuss oncofertility care with a fertility provider (92.9%)
- Cancer clinicians need to discuss patients gonadotoxic risk based on a patient's medical history and intended treatment (88.5%)
- Patients should also be given information about contraception during cancer treatment (95.1%)

Communication



- We did not reach agreement about whether cancer specialists should separate the discussion about diagnosis and treatment and discussion about oncofertility care (72%)
- The oncofertility consultation should be sensitive to the individual religious or cultural needs of patients (87.5%)
- HCPs should check patients reproductive understanding before having oncofertility consultations (88.2%)
- HCPs should change content to meet the reproductive health literacy needs of patients (91.5%)
- HCPs should identify appropriate resources (93.5%) and use interpreters as required (90.3%)

Decision Aids



- There was strong agreement from both HCP and PFA that decision aids should be used to support patients with oncofertility understanding and decision making (90.3%)
- Decision aids should be integrated into cancer and fertility services as standard practice (90.4%)
- Age appropriate decision aids should be available for paediatric and AYA patients (92.6%)
- HCPs (nursing staff, counsellors and psychologists) should all be familiar with using decision aids (87.6%)

Roles of HCP's

Nurses

- Have oncofertility specialist knowledge
- 2. Knowledgeable about oncofertility referral pathways
- Provide patients with information about fertility risk and options at diagnosis
- 4. Provide patients with written resources
- 5. Support patients with oncofertility decision making
- Coordinate FP before and after cancer treatment
- Be able to identify reproductive symptoms and complications
- 8. Provide practical reproductive support
- 9. Be able to identify reproductive concerns and distress
- Make appropriate referral for reproductive psycho-oncology care or psychiatric care as required

General Practitioner's Role

- Have general oncofertility knowledge
- 2. Knowledgeable about local oncofertility referral pathways
- Support patients with oncofertility referral
- Be able to identify medical reproductive symptoms and complications
- 5. Coordinate oncofertility care in the survivorship period
- 6. Provide practical reproductive support
- 7. Be able to identify reproductive concerns and distress
- Make appropriate referral for reproductive psycho-oncology care or psychiatric care as required

Social Worker and Psychologist's Role

- 1. Have oncofertility specialist knowledge
- 2. Knowledgeable about oncofertility referral pathways
- 3. Support patients with oncofertility decision making
- 4. Provide patients with resources
- 5. Be able to identify reproductive concerns and distress
- 6. Provide practical reproductive support
- 7. Provide reproductive counselling
- Make appropriate referral for specialist psycho-oncology care or psychiatric care as required

Three Tiered Oncofertility Service Development Model

Expert Service



Oncofertility care for paediatric patients High volume of oncofertility work Provide oncofertility care to complex cases Patients have access to decisional support Access to full range of pyscho-oncology oncofertility services

Access to survivorship services to manage sexual dysfunction, hormone deficiency, menstrual irregularity, FP post cancer treatment and ART

All staff are experts in providing oncofertility care and provides education/mentorship to other centres

Access to oncofertility frameworks and ethics review

Provide Clinical and Research Oncofertility Services

Conclusion



- Been able to define the barriers and challenges to oncofertility care
- Develop competency framework that will all for the development and implementation of oncofertility services
- All HCP's have a role to play which has been defined
- The components of care can be prioritised into a three tier framework helping to clear show how services should be developed.

Thank You



- Kids Cancer Alliance Translational Funding and Churchill Fellowship 2015
- Australasian Oncofertility Consumer Consortium
- International Consumers Who Reviewed Study and Provided Guidance
- G-Force Investigators
- Patients, parents and colleagues who participated