Health Canada Santé Canada

Assisted Human Reproduction Implementation Office (AHRIO)

Infertility Counselling Workshop Report

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Canada

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Infertility Counselling Workshop Report

The following pages capture the comments noted from the workshop workbooks, flip charts, and the transcripts of the workshop. The comments and opinions expressed in this publication are those of the workshop participants and do not necessarily reflect the views of Health Canada.

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Executive Summary

Rodney Ghali welcomed the participants and thanked everyone for taking time out of their busy schedules to attend the workshop on infertility counselling. The purpose of the session was:

- to provide an overview and discuss the impacts of the *Assisted Human Reproduction (AHR) Act* on infertility counselling in Canada;
- to engage participants in a dialogue about infertility counselling services in Canada; and
- to discuss the development of a regulatory framework for infertility counselling in support of the *Assisted Human Reproduction Act.*

Most workshop participants were Canadian, but a number of international guests also attended and contributed to discussions with their different perspectives. In some instances, it was important to note their comments separately from those of the Canadians so as to distinguish between Canadian and international views on certain questions.

Mr. Ghali provided an overview of the *Assisted Human Reproduction (AHR) Act*. Subsequently, participants addressed, in their table groups, a number of questions related to their infertility counselling practice.

What is your definition of infertility counselling?

A range of responses were provided. Participants suggested that infertility counselling deals primarily with psychosocial impact, implications and also involves therapeutic work. It was agreed that the definition of infertility counselling should be kept general, so as not to narrowly define the scope of practice. There were differing opinions as to whether or not infertility counselling includes an assessment component. However, most agreed that the role of the infertility counsellor does not include "gatekeeping."

How are your counselling services provided?

Counsellors can work either on-site or off-site. However certain services, such as pre-IVF counselling, third-party reproduction counselling and implications counselling seem more appropriately offered on-site. Off-site services could include therapeutic counselling, crisis counselling, assessment and follow-up.

Ideally, counselling is provided prior to treatment, but it can also take place during or after treatment. Participants noted variations in the way services are dispensed, but most participants were familiar and agreed with the approaches used. The group concluded that the closest models that might apply to Canada are the Australian and New Zealand models, where clinics are required to provide counselling for all participants in third-party conception as a condition for accreditation by the Reproductive Technology Accreditation Committee (RTAC). Only the Australian state of Victoria has legislation that mandates counselling for all participants in AHR services.

Who are your clients?

This discussion led to general agreement regarding who receives counselling. Clients include: individuals or couples receiving treatments, (including single women and same sex couples), donors, surrogates and minors. Clients can also include: offspring (children or young adults) conceived through assisted reproduction, spouses, existing children and extended families.

What services are you providing?

Participants suggested that the following counselling services are provided, some to a larger extent than others: patient counselling; counselling to assist with decision-making regarding the choice of treatment, ending treatment or exit counselling; implications counselling; donor counselling, recipient counselling, combined donor and recipient counselling; long term follow-up counselling for donors, recipients, offspring; education counselling; ethical counselling; counselling related to stress or anxiety and coping/management, grief counselling; relaxation training, crisis intervention; therapy related to depression; marital counselling and sexual counselling; adoption and resources counselling; counselling related to selective reduction; posthumous counselling; sperm banking counselling; counselling for surrogates; counselling for minors; counselling for people who have longer term psychological issues that require more intensive psychotherapy; and finally, genetics counselling. Many participants suggested that psychosocial counselling is coming forward as a preferred approach to infertility counselling. Additionally, it was noted that some infertility counsellors also conduct research, and provide consultation about psychosocial and ethical issues to the other members of the treatment team.

What should be the objectives of infertility counselling?

There were a number of views regarding the objectives of infertility counselling. Overall, the participants indicated that infertility counselling should enhance informed consent, set out psychosocial ramifications and implications, and also facilitate decision-making. It was suggested that distinctions needs to be made between infertility counselling and assessment, and also between assessment and gatekeeping. Additionally, distinctions need to be acknowledged between patient care provided by nurses, information counselling provided by medical staff and psychosocial, therapeutic and implications counselling provided by professional counsellors.

What should the qualifications of the counsellor be?

There was general agreement that the infertility counsellor should be a member of a provincial professional regulatory body with a psychosocial focus, and that it would be preferable for the counsellor to hold a master's degree in a psychosocial or counselling related field (social work, psychology). This degree should come from an accredited institution. Participants supported the "grandfathering in" of counsellors with extensive experience. The question about counsellor qualifications led to a discussion regarding the need for an association of Canadian counsellors.

What should the training of the counsellor be?

In addition to meeting the aforementioned educational requirements, counsellors should have training specifically in the provision of infertility counselling. Education and training would result in a basic knowledge of the medical, psychosocial, legal and policy aspects of reproductive health. A three-tiered counsellor qualification and training system was proposed for advancing the skills and knowledge base of infertility counsellors. This system would consist of entry, advanced and supervisory levels. It was envisaged that specialized training in infertility counselling could potentially be completed in modules and that it would be clinically supervised.

What might be the standards of practice / models of delivery?

Participants advised that the standards of practice should be defined by discipline-specific professional regulatory bodies and provincial bodies'

codes of ethics. Standards of practice relating specifically to infertility counselling will need to be developed as part of the regulations or as a condition for licensing and accreditation. Canadian counsellors might consider adapting standards already developed internationally by organizations such as the British Infertility Counselling Association (BICA), the Australian and New Zealand Infertility Counsellors Association (ANZICA), and the European Society for Human Reproduction and Embryology (ESHRE).

Additionally, it was suggested that there should be clinical and administrative supervision of counsellors. The format and number of counselling sessions would be dependent upon the clients and treatments involved. Furthermore, some services should be offered on-site while others could be off-site. Regarding the number of sessions, participants recommended that for third-party reproduction a minimum of one counselling session should take place, if not two, for both donors and the recipients. It was also suggested that there should be a sample mandatory model which clearly separates the roles of different clinic staff, and that the counsellor exclusively should be providing the mandatary implications counselling. It was noted that the new code of practice published by the UK's Human Fertilisation and Embryology Authority (HFEA) distinguishes between implications advice and implications counselling, and states that only trained counsellors can provide implications counselling.

Implementation of the AHR Act

When discussing the implementation of the Act, a range of issues were identified by the participants, beginning with the importance of being clear about whose needs are being met and who qualifies as an infertility counsellor. Issues were raised concerning the counsellor's standards of practice, the level of counsellor autonomy, and the control of services provided by the counsellor. Issues were also raised regarding payment for training and counsellor accreditation. There was some mention of the resistance to change on the part of the medical profession. Finally, when considering the implementation of the *Assisted Human Reproduction Act*, questions were raised regarding how enforcement will be carried out.

Participants also identified opportunities that may result from the Act's implementation. These include: reducing the stigma associated with counselling and infertility, having a positive impact on the way medical and other services are provided, and becoming involved in the development of counselling regulations and training.

Framework for infertility counselling services

With regards to possible approaches that could advance the development of a regulatory framework for infertility counselling services in Canada, the group suggested that an advisory committee of experienced infertility counsellors could, amongst other things, define "counselling", help determine standards and training, contribute to drafting regulations and provide feedback on policy documents related to other aspects of the legislation.

Additionally, international representatives from various counselling groups were invited to make presentations about their associations. They provided information regarding criteria for membership, how often their associations meet, sources of funding, etc. Representatives from Australia / New Zealand, Germany, the United Kingdom and the United States presented an overview of their respective counselling organizations.

Finally, Canadian counsellors grouped together on the second day of the workshop to form the Canadian Infertility Counsellors Association (CICA).

Overview of the *Assisted Human Reproduction (AHR) Act* and Infertility Counselling

Mr. Ghali provided an overview of the *Assisted Human Reproduction (AHR) Act*. He discussed various provisions of the Act relating to: the prohibitions, controlled activities, health reporting information requirements, and the creation of the Assisted Human Reproduction Agency of Canada (AHRAC). Mr. Ghali highlighted the three basic objectives of the Act:

- to protect Canadians using AHR procedures to help them build their families without compromising their health and safety;
- to prohibit unacceptable practices such as human cloning; and
- to ensure that AHR related research which may help find treatments for infertility and serious diseases, takes place in a controlled environment.

During his presentation, Mr. Ghali pointed out relevant provisions as they relate to infertility counselling, including:

- that the Act requires that counselling services be received prior to a licensee accepting health reporting information or accepting a donation of human reproductive material or of an *in vitro* embryo; and
- that regulations may be made regarding counselling services.

Participants noted that a gamete (sperm or egg) "donor" includes anyone using their own gametes for their own reproductive purposes, as well as those providing gametes for third-party reproduction use. As a result, provisions regarding mandated counselling apply to all of these "donors."

Mr. Ghali discussed the development of a regulatory framework under the Act and the upcoming consultations process. Regulations will govern the practice of AHR activities to ensure the protection of the health and safety of all those involved. Additionally, regulations will provide the flexibility needed to keep pace with scientific and medical advances. The key areas for regulatory development will be as follows:

- Section 8 (Consent)
- Controlled Activities
- Health Reporting Information Requirements
- Licensing
- Inspection and Enforcement

As the regulatory framework is developed, Health Canada will need to ensure that the very diverse stakeholder community is fully consulted. This community includes over 300 different organizations and individuals as well as provinces and territories. Stakeholder consultations will take place over the next three years and will consist of various public involvement activities such as workshops and paper-based consultations.

Discussion 1 – Your infertility counselling practice

Further to Mr. Ghali's opening remarks and presentation on the AHR Act, the following questions were raised and will need to be considered in the development of regulatory policy.

Questions proposed by the participants

1. Which treatments are included in the scope of mandatory counselling?
2. Is the freezing of embryos allowed?
3. Does the Act specify the number of offspring per donor?
4. Does the term "consent" in the Act refer to the consent between the doctor and the patient?
5. Does the Act allow for varied consent?
6. Are there any statutory considerations if consent hasn't been provided?
7. Will the Assisted Human Reproduction Agency (AHRAC) have a responsibility to consult the public?
8. Does a consultant working in a clinic require a licence to practice?
9. Does the Act set out the specific composition of the AHRAC's Board of Directors?
10. Will AHRAC's Board of Directors positions be paid positions?
11. How does the three year mandatory review fit in with the development of regulations?
12. Does the Act also mandate counselling for fertility drug recipients / users?
13. Must clinics hire their own counsellors?
14. How do we ensure that an individual receives counselling?
15. Will the Agency collect data and will that data be available to researchers?
16. Is it incumbent on the clinic to make counselling services available?
17. Do people using their own gametes require counselling?
18. Are patients who use their own gametes in AHR procedures (such as *in vitro* fertilization) considered to be making a "donation" under the Act?
19. Are minors addressed in this legislation?
20. Are there any age restrictions for gamete donors?
21. Is there a mechanism for minors to consent to the storage of their tissue?
22. Are there provisions for substitute consent (by an adult) on behalf of very young minors?
23. Is tissue (ovarian tissue with eggs) storage addressed by the Act?
24. Does the Act mention the age of the surrogate and does it mandate whether or not a woman should have had a child prior to being a surrogate?

The participants addressed the following questions related to their infertility counselling practice. The comments captured during the round table discussions and in plenary are set out below.

All table-groups addressed four questions:

1.1 What is your definition of infertility counselling?

1.2 How are your counselling services provided?

1.3 Who are your clients?

1.4 What services are you providing?

1.1 What is your definition of infertility counselling?

Many participants agreed that the definition of "infertility counselling" should be expressed in general terms, so as not to narrowly define the scope of practice.

It was suggested that infertility counselling deals primarily with the psychosocial impact of infertility, in terms of intervention, treatment and the aftermath of both successful and unsuccessful treatments. Infertility counselling deals with implications, that is, helping patients to understand and contemplate their treatment options and the short and long term implications of treatment. It also involves therapeutic work to help patients cope with the consequences of infertility and treatment.

Infertility counsellors assist with stress management, providing patients with coping strategies to deal with the psychological stress of infertility and the physical and mental stress of undergoing AHR treatments. Counsellors encourage patients to be assertive in defining and meeting their needs within a system that can sometimes be intimidating. Counsellors also promote self-care during AHR treatments and work at maximizing treatment efficacy and success by helping patients who are dealing with weight loss, smoking cessation and stress reduction.

Education is also an important element of infertility counselling. Counsellors educate patients in terms of what they can expect, what might happen, and the kinds of difficulties they may experience as they go through AHR treatments.

Education of the staff within clinics is also an important element in terms of helping the nursing staff, the lab staff, and the physicians to understand some of the psychosocial implications of treatments for the patient. Additionally, it was expressed that sometimes clinic staff need to be educated regarding the *benefits* of counselling, so that patients are not dissuaded from seeking out and accepting counselling services.

Counsellors conduct crisis intervention and provide grief counselling. Participants noted that some patients are referred to a counsellor only during a crisis, after treatment has failed.

Many, but not all participants, felt that infertility counselling has an assessment component. There were differing opinions as to the degree of assessment that should be conducted by an infertility counsellor, whether it is assessing risk factors for the individual or the couple, or assessing how patients understand the implications of treatments they plan to undertake, or whether it is in fact assessing a patient's suitability to parent.

> *"I think that our role is to assess whether they (patients) are ready and knowledgeable psychosocially and emotionally about proceeding with treatment, be it IVF with their own gametes or using third party gametes."*

Some participants expressed concern about the scope of assessments where the resulting child is also a client.

> *"We felt very uncomfortable about what it means if the resulting child is your client. Does that mean that you are assessing parenting capability or does it just mean you are instructing parents on how to handle disclosure issues to the children and kind of keeping an eye out for the child before it is conceived?"*

Many participants emphasized that assessment should be distinguished from *gatekeeping*.

> *"We do not believe that gatekeeping and screening are the roles of an infertility counsellor. Assessment is an important piece of our work, particularly for certain programs, and it is important to differentiate those two roles. If we are going to be able to provide the kind of counselling our patients need, we cannot also be the gatekeepers. This does not mean that there is not a place for gatekeeping. The physicians need to put some policies in place that make it pretty clear as to what the criteria are, the criteria that must be met, so that we are not the ones dropping the hammer and keeping the gate. Hopefully decisions will be based on good empirical data, of which there is not necessarily a lot."*

Infertility counsellors enhance informed consent by helping patients to better understand what they are consenting to and the implications of their consent, including the psychosocial impact of undertaking treatment. Participants felt that infertility counselling should address the emotional and psychosocial factors that contribute to informed consent.

> *"We have to be very explicit and careful in terms of informed consent on the clients' part, as to whether in fact our role is to support them, or to make judgments about their appropriateness for treatment. This is something that we have to be explicit about from the outset in all fairness to the clients. If this is part of our job, they have to know that is part of our job."*

Participants recognized that the scope of "infertility counselling" can be difficult to define.

> *"The term counselling is a bit problematic because there are so many different types of counselling that go on at an infertility centre, i.e. medical information orientation counselling, preparation support. Counselling is kind of a catchall and it is done by nurse clinicians, it is done by the people in the lab who are explaining to the gentleman how to do his sperm donation; it is done by so many of us. What is really the scope of our practice? How do we define counselling in terms of what we do? For instance, when we do psychosocial infertility counselling, which then differentiates from the many types of counselling that go on within the context of a medical treatment setting."*

It was suggested that a complete definition is really the first step.

> *"The first thing we really need to do is to have a very clear definition of counselling, because the concern was that, if we are opting for a two tier counselling system, that clinics will sort of speak to the minimal requirements."*

The following definition, provided by Jean M. Haase, was put forth for consideration:

> *"A process which includes clinical assessment, therapeutic intervention, education, emotional support and advocacy. The professional engages supportively and therapeutically with the recipients in an exploration of how they have been impacted by the medical, social and emotional aspects of involuntary childlessness. Coping mechanisms, decision making and support systems are assessed, as is the level of knowledge, understanding and acceptance of the implications of treatment. Where indicated, therapeutic treatment interventions are applied with the goal of improved functioning and empowerment of the patient. Concern for the well-being of the recipient, the donors (if used) and the resulting child, is an essential element in all infertility counselling. The counsellor should also be familiar with specialized resources related to fertility problems, as well as alternative options such as fostering and adoption, and be able to make appropriate referrals where needed."*

Participants noted that the Human Fertilisation and Embryology Authority (HFEA) and the European Society for Human Reproduction and Embryology (ESHRE) have published definitions for "infertility counselling." These definitions include: information and education, supportive counselling, therapeutic counselling and implications counselling.

The International Participants

The international group identified that "infertility counselling" can be defined in very different ways. The definition is dependent upon the way that it is defined by the person either providing or using the service. Counselling might be offered in order to provide information, support and the opportunity to discuss the implications of proposed treatments. Alternatively, counselling might involve relevant therapeutic work. Finally, in some services, counselling may be used to assess the suitability to enter treatment or to parent.

Situation by Country:

Victoria, Australia

The state of Victoria is unique in that counselling is mandatory for all recipients and donors (and their spouses) involved in assisted human reproduction procedures (whereas in the rest of Australia, clinics must provide counselling for all participants in third-party conception as a condition for accreditation by the Reproductive Technology Accreditation Committee (RTAC)). Counsellors attached to a clinic must be licenced (in other parts of Australia all clinics must have a counsellor who is a member of the Australian and New Zealand Infertility Counsellors Association (ANZICA)). Assessment and screening regarding the suitability to parent do not form part of infertility counselling, but patients may be assessed regarding their understanding of AHR procedures and the implications of those procedures.

Germany

Counselling is not mandatory in Germany. Patients are able to choose their counsellor. Counsellors do not conduct assessments regarding a patient's suitability to parent or regarding suitability for AHR treatments (since it is the medical team which conducts these kind of assessments).

New Zealand

No legislation currently exists to make any counselling mandatory in New Zealand (although the passage of AHR legislation which may deal with counselling is anticipated in the near future). However all clinics offer counselling to anyone experiencing infertility and seeking treatment. All clinics insist that anyone involving a third party (donor/surrogate) and all donors have a minimum of one session with a counsellor.

Counsellors do not assess the suitability to parent though they may be involved in a team process to delay or deny a service to anyone at risk of harm. Counsellors help to ensure the patient makes informed decisions regarding treatment and its consequences. Counsellors help prepare patients and provide support by giving them coping strategies to deal with infertility, treatment and outcomes, that includes becoming parents or living without children.

The National Ethics Committee on Human Assisted Reproduction (NECHAR) insists on counselling and the filing of counsellor reports for participants in assisted reproduction treatments that require case-by-case ethical approval (surrogacy, inter-generational gamete donation, unusual or new application of technology).

The Reproductive Technology Accrediting Committee (RTAC) of the Fertility Society of Australia (FSA) licenses New Zealand clinics that voluntarily apply for a licence and also insists on the provision of information/support/and preparation counselling for participants of assisted reproduction. All clinics choose to abide by this recommendation.

United Kingdom

In the UK, the offer of counselling is mandatory, but patients are not obliged to accept counselling services. It is unusual for sperm donors to take up the offer of counselling, however egg and embryo donors are almost always seen. This may reflect the way that counselling is presented to these different groups; for example, in many centres, treatment will not proceed for egg and embryo donors and recipients unless they accept the offer of counselling. Screening and assessment for parenting are not considered part of the counselling service *per se*, and there has to be a clear distinction between the counselling role and any part that counsellors play in the screening and assessment of those seeking treatment. This is a highly contentious area in the UK; the British Infertility Counselling Association (BICA) is of the view that it is not appropriate for counsellors to play any part in screening and assessment other than supporting prospective parents through the process; however some counsellors are prepared to undertake it. The Human Fertilisation and Embryology Authority (HFEA) requires that the two functions are separated so that prospective parents know when counsellors are undertaking screening and assessment work, but the HFEA does not prohibit counsellors from becoming involved in that work.

United States of America

Counselling is not mandatory in the USA and there is no government regulatory agency. However, counselling is recommended by the American Society for Reproductive Medicine (ASRM) in conjunction with medical treatment for infertility, assisted reproduction technologies, specific medical conditions, and/or special circumstances.

Mental health professionals in the USA have at least one graduate degree (master's or doctoral degree or an MD for psychiatrists) and clinical training in one of the following fields: psychologist, psychiatrist, social worker, marriage & family therapist, and psychiatric nurse. All mental health professionals in the USA must have a licence to practice. The American Society for Reproductive Medicine Mental Health Professional Group defined the qualifications guidelines for mental health professionals in reproductive medicine in 1995: "A qualified infertility counselor should be able to provide the following services: Psychological assessment and screening; diagnosis and treatment of mental disorders, psychometric testing (psychologist); decision-making counseling; couple and family therapy; grief counseling; supportive counseling; education/information counseling; support group counseling; referral/resource counseling; staff consultation, crisis intervention; sexual counseling; psychotherapy; and psychopharmacological treatment (psychiatrists and qualified psychologists and nurses)." Additionally, qualified counsellors

should have: "1) a graduate degree in a mental health profession; 2) a licence to practice; 3) training in the medical and psychological aspects of infertility; 4) clinical experience, and 5) continuing education."

The issue of whether or not the infertility counsellor should provide assessment and screening is less relevant in the USA than in other countries. Infertility counsellors are mental health professionals trained to provide assessment and screening. Counselling topics and issues to be addressed and assessed are further defined by ASRM guidelines, e.g., recommended guidelines for screening and counselling of oocyte donors (1994); psychological guidelines on embryo donation (1996); guidelines for gamete and embryo donation. (2002); guidelines for gestational carriers (2004 pending); and revised minimum standards offering assisted reproductive technology. (2003).

A more significant debate in the USA is the role of the infertility counsellor as a "gatekeeper," i.e., whether or not the infertility counsellor should determine which patients should be denied treatment for psychosocial reasons, (e.g., patients with diminished mental capacity; chemical addiction, relationship coercion or violence). Some infertility counsellors (regardless of professional training) feel that the counsellor's role should be to support and educate patients about the medical treatment being undertaken whereas others feel that the counsellor's role is determining suitability and capability to participate in treatment. However, this long-standing debate is now influenced by the recent ASRM Ethics Committee Opinion that fertility programs may withhold services if there are reasonable grounds to believe the patients will be unable to provide adequate child-rearing (2004). These decisions must have a substantial, non-arbitrary basis and take into consideration the federal *Americans with Disabilities Act* which prohibits discrimination or denial of infertility treatment to disabled people if the denial is based on ill-formed doubts or stereotypes. The ASRM Ethics Committee further recommended that fertility programs have explicit policies and procedures and that decisions involve evaluation by a mental health professional and a review by the treatment team before a final decision is made to deny treatment.

1.2 How are your counselling services provided?

A number of models are used to provide infertility counselling services that are dispensed in hospital and clinical settings. One model is to have the counsellor work in the clinic as his/her sole place of employment. In that case, the counselling is integrated into the multidisciplinary services offered by the team, and counselling supports the total care. Alternatively, counselling services can be offered off-site. Off-site counselling services are largely provided as a result of self-referrals. Additionally, participants indicated that counselling is sometimes provided over the telephone. Finally, in addition to being counselled, many patients receive written material regarding the treatments they are about to undergo. There now exists an abundance of information regarding infertility counselling, including handouts for tips on coping (with treatments, relationships), and reading materials and Web sites about infertility. Patients are also made aware that counselling is available in follow-up to treatment.

For some, infertility counselling services start at the clinic with third-party mandated counselling and with anyone else who seeks out a counsellor. One to two hour on-site counselling sessions are provided for couples and individuals. Also, one hour health focus sessions are offered by nurses, embryologists and counsellors for *in vitro fertilization* (IVF) treatments. For donor insemination (DI) patients using known donors, infertility counselling can be initially offered to the known donor (and partner if applicable), followed up by a session with both the patient/partner and the donor/donor's partner.

"Mandated clients are very different from the self-referred clients. For some of them, the doctor will say, 'You cannot proceed any further until you see the counsellor.' That is a different experience for us than somebody who has sought out our services."

Where timing for the provision of counselling services is concerned, participants expressed that ideally a patient is counselled *before* entering into a treatment process. However, counselling can also be provided during or after a cycle. Participants suggested that not enough post-treatment counselling is being done.

"What are the patient's expectations of counselling, especially when it is required? A lot depends on how the counselling is presented to the patient in the first place… This is kind of a key issue."

Participants also discussed which services should take place on-site versus what could be offered off-site.

"Three different ways of providing counselling are suggested: on-site independent, on-site collaborative or off-site independent."

It was suggested that on-site services should include: mandatory pre-IVF counselling, third-party counselling and implications counselling. The counsellor in third-party counselling should be involved with all parties, that is, the recipients, the donors, and whoever else is involved. Where third-party reproduction is concerned, some participants felt that a minimum of one hour of counselling should be offered to each party (one hour for the donor, one hour for the recipient) while others recommended that a number of infertility counselling sessions take place, including two sessions each for both donors and recipients.

Several workshop participants indicated that they are in private practice and they see patients off-site. The following was suggested as perhaps suitable for off-site counselling: therapeutic c-ounselling, crisis counselling, assessment, follow-up, couple and sexual counselling. An advantage of off-site counselling is that one person could serve many clinics and, therefore, be more cost-effective. Some participants indicated that they valued the positive aspects of being off-site, of not having such a tight affiliation with the facility, thus giving clients a little more autonomy or at least perceived autonomy. However, one disadvantage of working off-site is that patients often arrive at the counsellor's office at the end stage or when they are in crises, or when they are contemplating decisions made regarding treatment. Counsellors that are working on-site have the opportunity to participate as members of the multidisciplinary team, and contribute to decisions about patient care or clinic policies. They may also more easily provide ad hoc consultations about patient care.

It was noted that mandated counselling needs to be clearly defined in order to better assess what services are offered on or off-site.

"One of the things that we really need to define is what is going to be considered to be mandated counselling. What falls under that role? Is it talking about psychosocial or implications counselling, genetics counselling, etc.? Does it include self-care, stress management, relaxation, etc. I think that we have to clear that up. When we do that, it might help determine what really needs to be on-site versus off-site."

Participants noted that in Australian and New Zealand, clinics are required to provide counselling for all participants in third-party conception as a condition for accreditation by the Reproductive Technology Accreditation Committee (RTAC). Only the Australian state of Victoria has legislation that mandates counselling for all participants in AHR services.

> *"The closest models that might apply to Canada are the Australian and New Zealand situations, where mandatory counselling does apply."*

Counsellors suggested that mandated counselling would in fact triple their workload. One approach to deal with volume, an approach which is in place in several clinics, is to conduct group information sessions.

The International Participants

At the international level, there are a multitude of models in place. In some jurisdictions, counselling is mandatory whereas in others it is optional. In some areas, counselling is offered at arm's length or it is provided in-house. Counselling can be treatment related or provided based on the needs of the client. It can be fee paying or free. Counselling can be offered for a brief or extended period of time, and offered to individuals, couples or groups.

Victoria, Australia
Counsellors who are licenced have appointments to clinics and some also offer outside private appointments. All counsellors hired by clinics must be members of the Australian and New Zealand Infertility Counsellors Association (ANZICA).

Germany
Patients are self-referred or referred by doctors. Patients are seen in private practice or within a counselling institution before, during or after treatment. Clients include couples and increasingly, families with children. There are few links between counselling services and the daily life in the clinic.

New Zealand
All counsellors employed in Fertility Society of Australia (FSA) licenced clinics offering assisted reproduction must be eligible for membership in the Australian and New Zealand Infertility Counsellors Association (ANZICA). They belong to other professional organizations (representing the fields of social work, psychology or counselling). All patients at clinics have access to counselling services on either a self-referral basis or as part of IVF or third party reproduction. The fee for counselling is included in the cost of the treatment in some cases. When the treatment is being government funded, the fee for counselling is also paid for by government allocation. Additional counselling sessions may be paid for by the patient. People may access counselling even if they are not patients of the clinic. Counsellors in clinics are guided by ANZICA and RTAC and NECHAR minimum standard guidelines for counselling. Some counsellors, social workers and psychologists in general private practice accept referrals from clinics or patients are self-referred.

United Kingdom
All the above models (cited in the introductory paragraph above) operate in the UK. Additionally, some counsellors see themselves, and are seen, as an integral part of the multi-disciplinary team and engage in team discussions, clinic policy making, etc., while others are wholly separate and play no direct role in the team.

United States of America

There is no regulatory body in place in the United States. While mental health professionals are guided by the professional and ethical standards of their specific field, infertility counselling is further defined by American Society for Reproductive Medicine (ASRM) and the professional interest group of ASRM: the Mental Health Professional Group (MHPG). This organization has set the standard of patient care regarding both medical treatment and counselling in the field of reproductive medicine. Each clinic/physician decides whether or not to adopt professional guidelines and recommendations of ASRM/MHPG. However, failure to follow the professional standards of care as defined by ASRM/MHPG leaves the clinic vulnerable to lawsuits and consumer dissatisfaction.

Infertility counsellors may be integrated into clinical practice in three ways: 1) Referral to an independent, private practitioner who is outside the medical practice: 2) As an independent contract consultant affiliated with the medical practice; 3) As an employee of the medical clinic. Counselling services may be covered by the patient's insurance coverage or may be on a fee-for-service basis in which the patient pays out-of-pocket.

The insurance/Medicare industry is recognizing the importance of infertility counselling services. As a result, there is increased insurance payment and support from both medical caregivers and consumers for these services.

Counselling of identified gamete donors and surrogates/gestational carriers is paid for by the intended parents while counselling of anonymous gamete donors is covered by the clinic or contracting agency. In states with legal regulations on gamete donation and gestational/carrier arrangements, counselling is required for all participants.

1.3 Who are the clients?

Participants agreed that clients include the following: individuals or couples receiving treatments (including patients who are not necessarily "infertile", such as single women and same sex couples), donors, surrogates, and minors who potentially face infertility as a result of a life threatening disease. The offspring (children or young adults) conceived through assisted reproduction are also potential clients.

> *"The more we can be clear about who our clients are, the more we avoid getting those roles blurred if the decision is to allow counsellors to be involved in the assessment role, which is a controversial area."*

Additionally, counselling is often provided to patients' spouses and the existing children in a family, whether they are part of the surrogate's family, the donor's family or that of the couple seeking treatment.

> *"Some clients are extended families, including the existing children, maybe step-children, blended families. A couple of us have done interventions with the couples' families: sisters, brothers, parents."*

Participants also stressed that clients not only include the couples or individuals you are working with, but also by extension, the *child* that is being created as a consequence of the intervention.

Counselling services may also be provided to support clinic staff.

"For those who work within medical settings, clients are the nurses that come in to see you, the lab staff that come in to see you, the physicians that come in to see you. They come in to see you to deal with patients, deal with others, deal with their spouses. Within those settings, counsellors are providing services to the staff in a limited way, but certainly support services to the staff."

Finally, participants mentioned that counselling occasionally extends beyond the bounds of infertility counselling, that is where patients present an issue related to infertility but have psychological needs that go beyond infertility.

The International Participants

Clients can be persons experiencing fertility difficulties and also the non-infertile, which includes patients, donors, spouses, families, offspring, and service providers (clinic staff or otherwise).

Victoria, Australia

Counsellors are available to see patients at any stage of treatment. All people having IVF or donor treatments must see a counsellor and this includes all recipients, donors and spouses. Counsellors are available for support and follow-up counselling in-house.

Germany

Counselling is not specifically for donor insemination (DI) patients. Counselling can be provided to any type of patient. Most counselling services are fee-based, therefore not everyone can afford the treatment. Counselling services are less expensive when offered through an institution.

New Zealand

Counselling is not legally mandated. However, counselling is provided at all clinics. All patients are offered counselling at any stage: before, during or after treatment. At most clinics, the cost of one session is built into the cost of treatment. Not all patients choose to take up this offer. All gamete donors and recipients of gametes and all parties involved in surrogate arrangements see a counsellor in preparation for treatment. All family members also have access to counselling. Embryo donation has not yet received ethical approval in New Zealand. It is anticipated that counselling will be insisted on for those who will be involved in embryo donation and that this will likely be legislated.

United Kingdom

Counsellors in the UK mostly provide counselling to recipients of donated gametes (as couples or individuals) and to egg and embryo donors. Relatively few patients who use their own gametes, (i.e., for *in vitro* fertilization (IVF) or intrauterine insemination (IUI)), seek counselling (although at some clinics their numbers appear to be increasing). The UK needs improved counselling services for minors using fertility preservation services, given that they currently access services in very small numbers and are much younger than the usual client group.

United States of America

Although there are no legal requirements for infertility counselling in the USA, increasingly the standard of care is to provide counselling for all participants in third-party reproduction and assisted reproduction. In addition, individuals and couples may be referred for counselling by medical caregivers (i.e., a physician or nurse) or patients may self-refer for counselling.

1.4 What services are you providing?

Counsellors provide services using a multidisciplinary approach, which includes the provision of guidelines to clients, and information on context and impact. The counsellor also makes clients aware of impacts on health and relationships. It was noted that psychosocial counselling is coming forward as a preferred approach to infertility counselling.

Participants detailed the wide range of services they can be called to provide; this includes: patient counselling before, during and after treatment; counselling to assist with decision-making regarding the choice of treatment, ending treatment or exit counselling; implications counselling; donor counselling, recipient counselling, combined donor and recipient counselling; long term follow-up counselling for donors, recipients, and offspring; education counselling (providing information, counselling for parenthood preparation); ethical counselling (i.e., the education and discussion about ethical issues related to the treatment that patients will undergo); counselling related to stress or anxiety and coping/management, grief counselling; relaxation training, crisis intervention; therapy related to depression; marital counselling and sexual counselling; adoption and resources counselling in terms of alternative family building methods; counselling related to selective reduction in cases of multiple pregnancy; posthumous counselling; sperm banking counselling; counselling for surrogates and patients accessing the services of a surrogate; counselling for minors; counselling for people who have longer term psychological issues that require more intensive psychotherapy; and in some cases, genetics counselling.

> *"Some counsellors are involved in educational preparation for parenthood sessions. This is not counselling but it is part of the process of getting ready to be a parent, particularly where donated gametes are being used."*

It was also noted that some infertility counsellors conduct research, and provide consultation about psychosocial and ethical issues to other members of the treatment team.

The International Participants

In addition to providing infertility counselling services, information sessions are given to individuals (donors and recipients), couples, groups and families. Counsellors may also provide education, including information regarding cross-cultural and religious issues, and parenthood preparation. Counselling is provided to minors using fertility preservation services. Genetics counselling is provided for patients undergoing pre-implantation genetic diagnosis (PGD). Additionally, counsellors can be involved in the training of new counsellors, nurses and doctors. Counsellors can also help patients and donors to better understand the laws and regulations that deal with AHR procedures and services.

Victoria, Australia

Counselling usually takes place one-on-one and rarely in groups. It is provided for all people having IVF or donor treatments, including all recipients, donors and spouses.

Genetics counselling is provided for pre-implantation genetic diagnosis (PGD). Counselling is a free service.

Germany

Individual and couples counselling is provided, along with information on therapies and implications. Counsellors provide training for young counsellors and nurses, with experienced counsellors acting as consultants on psychosocial issues.

New Zealand

Education and information regarding the emotional impact of infertility is provided to individuals, couples and groups, as well as to self help groups, the general community and other professional groups. Counselling (support, information, preparation, implications, therapeutic and genetic) is provided to anyone experiencing involuntary childlessness and pregnancy loss, and it is accessible to any other family member. Support groups are also organized. Liaison with other relevant agencies also takes place.

United Kingdom
Counselling is normally for individuals or couples and group work is relatively unusual. Some counsellors are qualified to offer genetics counselling, but relatively few. Genetics counselling is therefore usually provided from a separate genetics counselling service.

Some counsellors have a formal role in providing supervision to nursing staff and others. Counsellors may also run support groups for staff members and for patients, and counsellors are sometimes called to chair group discussions regarding social and ethical issues. Counsellors in the UK may also be involved in the training and education of colleagues and other medical/scientific staff. They have a role in developing links, educating and liaising with outside agencies (e.g., adoption services, relationship counselling services, patient support organizations).

United States of America
Counselling is provided to individuals and couples (regardless of sexual orientation). Counselling may be for issues related to infertility, treatment for infertility, third-party reproduction, family-building issues (e.g., adoption); offspring; and/or issues related to reproductive health (e.g., medical illnesses impacting fertility; smoking cessation to improve fertility or participate in AHR treatments). Infertility counsellors may provide therapeutic counselling or conduct support groups, marriage or sex therapy, or family therapy. Most agencies providing third-party reproduction arrangements (oocyte donation, surrogacy/gestational carriers, embryo donation, and/or sperm donation) either employ an infertility counsellor on staff or have a consultative arrangement with an infertility counsellor. The incidence of infertility counsellors as an on-site employee versus an independent off-site consultant is fairly evenly divided – with advantages and disadvantages to both arrangements. The advantages of an on-site employee are: the counsellor's familiarity with the clinic's protocols and procedures; ease of communication with other caregivers; and ready, less stigmatizing access to mental health care. Advantages of an off-site infertility counsellor are: professional autonomy and clear boundaries between caregivers; increased client comfort in expressing negative feelings about staff or clinic procedures; and greater emotional as well as physical distance from the clinic.

Discussion 2 – Elements of a proposed regulatory regime

The participants addressed four questions related to the elements of a proposed regulatory regime. The following pages reflect the comments captured during the table-group discussion and in plenary.

All table-groups addressed four questions:

2.1 What should be the objectives of infertility counselling?

2.2 What should the qualifications of the counsellor be?

2.3 What should the training of the counsellor be?

2.4 What might be the standards of practice / models of delivery?

A number of questions were raised by the participants prior to the table group discussion commencing. They are captured below with responses by Rodney Ghali

1. Question: Who will pay for the counselling?

   Response: The *Assisted Human Reproduction Act* does not address access to or payment for services. Payment for health care falls under provincial jurisdiction.

2. Question: Can we assume that Health Canada could have some role in training and making funding available for training?

   Response: Within the context of the Act that would not be something that Health Canada would engage in.

3. Question: Would the new Agency Board of Directors have the funding to meet the needs of infertility counsellors?

   Response: The Agency will have a separate budget and will make its own decisions regarding spending. Where Health Canada is concerned, it is suggested that the department would not provide this kind of funding.

4. Question: Who will have the authority to do inspection and enforcement in order to ensure compliance? To issue licences?

   Response: The Agency will be responsible for issuing licences, inspecting licensee premises and enforcement. Licensees will have to ensure that they meet all counselling requirements set out under the Act and under eventual regulations.

5. Question: Who might set and ensure adequate standards for counselling?

   Response: Perhaps this is best addressed amongst professionals in infertility counselling.

2.1 What should be the objectives of infertility counselling?

There were a number of views regarding the objective of infertility counselling. Overall, participants agreed that infertility counselling should enhance informed consent.

> *"Enhanced and informed consent is one of the main objectives of infertility counselling. It allows clients to be fully informed about the procedure and the psychosocial issues."*

It was also agreed that infertility counselling should set out psychosocial ramifications.

> *"The psychosocial aspects of treatment should be an integral part of all infertility treatment programs."*

Participants listed very specific objectives of infertility counselling: to help the patient navigate their way through the process, to discuss implications and ensure that clients make informed and good decisions with regard to treatment in order to avoid regret (particularly in the case of third-party reproduction), to allow patients to share painful emotions related to infertility itself and its medical treatment, and finally to help them cope with the aftermath of treatment whether it is positive or negative.

> *"The objective of infertility counselling is to help the couple, offer coping strategies, offer preparation for procedures, facilitate decision-making, explore options and implications of family building and to explore the impact of infertility on people's lives as well as on the lives of significant others."*

Facilitating decision-making includes providing information and making patients aware of options, assessing high-risk patients and where required, intervening with high-risk patients and making recommendations.

Many participants agreed that distinctions need to be made between infertility counselling and assessment, and also between assessment and gatekeeping. Some participants felt that, *to a degree*, the infertility counsellor can play a gatekeeping role (by identifying concerns), but that infertility counsellors clearly are not the sole gatekeepers.

Additionally, distinctions need to be recognized between patient care provided by nurses, information counselling provided by medical staff and psychosocial, therapeutic and implications counselling provided by professional counsellors.

Finally, participants also recognized the involvement of counsellors in policy development.

> *"Counsellors should have the opportunity to be involved in service delivery and policy development and also should take responsibility to be involved in those areas as well."*

2.2 What should the counsellor's qualifications be?

There was general agreement that the infertility counsellor should be a member of a provincial professional regulatory body with a psychosocial focus. It was also suggested that it would be preferable for the counsellor to hold a master's degree in a psychosocial or counselling related field (social work, psychology), and that this degree should come from an accredited institution.

Participants recognized that there are highly skilled individuals who do not meet the aforementioned qualifications but who are currently offering valuable infertility counselling services. There was general support for the idea that individuals with extensive experience could be "grandfathered in" as meeting the requirements. Along the same lines, infertility counselling courses which may eventually be offered by universities or professional bodies, could also serve to standardize and grandfather certain individuals.

> *"We did not want to set the bar too low, so that we were basically taking anybody who can do anything. And we did not want to set it too high, so that we were exclusionary or elitist. So we sort of tried to stay in the middle."*

The question about counsellor qualifications led to a discussion regarding the need for an association of Canadian counsellors. The following day, counsellors grouped together to form CICA, the Canadian Infertility Counsellors Association.

2.3 What should the counsellor's training be?

As previously outlined, now and in the short term, qualified counsellors would hold a degree in a psychosocial discipline in combination with a membership in a college with a psychosocial focus. In addition to meeting educational requirements, counsellors should have training specifically in the provision of infertility counselling. Participants advised that counselling skills are common, but there are distinctive features to infertility counselling given that it deals specifically with infertility issues, AHR procedures and third-party family formation.

Participants recommended that, in the longer term, adequate training might include postgraduate courses offered by universities and postgraduate workshops given at conferences. Eventually it is hoped that counsellors can enroll in graduate internships in reproductive health.

Education and training would result in a basic knowledge of the medical, psychosocial, legal and policy aspects of reproductive health. This includes knowledge of: medical procedures involved in AHR treatments; psychosocial counselling skills as they relate to individual, couple and group counselling; third-party reproduction issues; same sex and single women's issues; ethical and legal issues; adoption issues; blended family issues; multicultural and religious issues; community resources; and grief counselling and stress management.

A three-tiered counsellor qualification and training system was proposed for advancing the skills and knowledge base of infertility counsellors. The first tier would require basic entry-level experience and knowledge to begin to practice as a counsellor. Those seeking a more advanced infertility counselling placement would have to meet the requirements of the second tier, which could include in addition to the basic knowledge requirements, some involvement in infertility counselling research (and perhaps the completion of a mind-body program).The third tier would be comprised of mentors and supervisors, including those holding academic positions in the field of infertility counselling, i.e., those involved in conducting research and publishing articles. Basically, the third tier would train the first to become the second, etc.

It was envisaged that specialized training in infertility counselling could potentially be completed in modules. This would involve a certain number of hours of supervision by an experienced infertility counsellor. Additional mentoring could be supplied through telephone and/or internet consultations, also with an experienced infertility counsellor.

Additionally, continuing education should potentially be supported by a Canadian counselling organization. Finally, training would be complemented by continuing education credits and conferences.

> *"An association of Canadian counsellors would be more than a monitoring body, it would be a support and educational body for counsellors to advance their skills."*

Some participants commented that infertility counselling training should not be provided by physicians, nurses or care givers who are involved in medical care. They recognized though that it will be the clinic's responsibility to ensure that their infertility counsellors receive training.

> *"If it is going to be part of the regulation that counselling must be provided, the responsibility for ensuring that you have a trained counsellor surely comes back to the licensee or the clinic. It would be in their very best interest, to ensure that the counsellors have the funding to get adequately trained."*

2.4 What should be the standards of practice / models of delivery?

Participants advised that discipline-specific standards of practice should be defined by the professional regulatory bodies and provincial bodies' codes of ethics. There should be clinical and administrative supervision of counsellors. Standards of practice relating specifically to infertility counselling will need to be developed as part of the regulations or as a condition for licensing and accreditation. Canadian counsellors might consider adapting standards already developed internationally by organizations such as the British Infertility Counselling Association (BICA), the Australian and New Zealand Infertility Counsellors Association (ANZICA), and the European Society for Human Reproduction and Embryology (ESHRE).

Participants expressed that the format and number of counselling sessions was dependent upon the clients and treatments involved. In the case of patients undergoing IVF procedures, starting off with a group orientation session would be appropriate, and this could possibly be offered by a nurse. This would include education and the dissemination of information. It should be followed up by a private session with an infertility counsellor. Where third-party reproduction is concerned, participants suggested that there should be a minimum of one counselling session, if not two, for both donors and the recipients.

> *"The infertility counsellors who provide the care, whatever site they are at, must have some certain standards of counselling credentials, so that there is confidence between providers and consumers alike, and that there are the same qualifications across the board."*

As previously discussed, some services should be offered on-site (e.g., mandatory pre-IVF counselling, third-party counselling and implications counselling) and other services could be offered off-site (e.g., therapeutic counselling, crisis counselling, assessment and follow-up). Whatever the site, there should be a standard for counselling credentials.

Participants suggested that there should be a sample mandatory model which clearly defines the roles of different clinic staff, and that the counsellor exclusively should provide the mandatory implications counselling.

> *"Whatever the mandatory counselling is, it needs to be provided by a mental health professional and not by someone else on staff."*

It was also noted that the new code of practice published by the UK's Human Fertilisation and Embryology Authority (HFEA) distinguishes between implications advice and implications counselling, and states that only trained counsellors can provide implications counselling.

Discussion 3 – Implementation of the *Assisted Human Reproduction Act*

The group was asked to provide their immediate reactions to the idea of implementation of the *Assisted Human Reproduction Act*. Their responses, gathered in plenary format appear below.

3.1 When you think about the implementation of the *Assisted Human Reproduction Act*, what *words* come to mind?

- **about time**
- **accreditation**
- **accountability**
- **acknowledgement**
- **Canadian**
- **challenging**
- **change**
- **children**
- **collaboration**
- **complexity**
- **coercion**
- **conflict**
- **confusion**
- **controversy**
- **cross-border**
- **definition of donor**
- **dignity**
- **effort**
- **encompassing**
- **ethics**
- **respect**
- **sensitivity**
- **standards**
- **families**
- **force**
- **future**
- **guidelines**
- **Health Canada**
- **interpretations**
- **jobs**
- **legitimacy**
- **loopholes**
- **money**
- **opportunity**
- **optimism**
- **paternalism**
- **positive**
- **potential**
- **power**
- **privacy**
- **prof. development**
- **protection**
- **resistance**
- **standardization**
- **training**

3.2 When you think about the implementation of the *Assisted Human Reproduction Act*, what *issues* come to mind?

A range of issues were identified, beginning with the importance of being clear on whose needs are being met and who qualifies as an infertility counsellor. It was noted that the word "counsellor" translates into «consultant» in French which is ambiguous. It was suggested that the French expression «consultant en fertilité» might be more appropriate. Additionally, issues were raised about the counsellor's standards of practice, the level of autonomy and control of the services provided by the counsellor.

Questions were raised relating to payment for training and counsellor accreditation. Furthermore, there was some mention of the resistance to change on the part of the medical profession. Participants also had questions regarding the recruitment of gamete donors. It was suggested that the altruistic system of gamete donation combined with mandated counselling for gamete donors may further reduce the gamete supply for DI patients. Finally, when considering the implementation of the *Assisted Human Reproduction Act*, questions were raised surrounding enforcement.

3.3 When you think about the implementation of the *Assisted Human Reproduction Act*, what *opportunities* come to mind?

Participants cited opportunities to reduce the stigma associated with counselling and infertility, to influence the way medical and other services are provided, and to become involved in the development of counselling regulations and training. Also identified was the opportunity to expand the role of counsellors and their visibility, to provide additional opportunities to conduct research, and to eventually increase the number of counsellors. Participants recognized that there will be more choices and opportunities for self-help groups and increased educational and networking opportunities. It was suggested that Canada could demonstrate leadership and potentially set world standards in infertility counselling.

Discussion 4 – Establishing a regulatory framework for infertility counselling services

A discussion on the regulatory framework for infertility counselling services elicited the comments indicated below.

4.1 What approaches could advance the development of a regulatory framework for infertility counselling services in Canada as required by the AHR Act?

Participants suggested that an advisory committee of experienced infertility counsellors could define "counselling," help determine standards and training, contribute to drafting regulations and provide feedback on policy documents related to other aspects of the legislation. The committee could also develop documents for further debate and discussion. It could work in collaboration with Health Canada on the development of regulations and on furthering the development of the Canadian Infertility Counsellors Association (CICA). It was suggested that CICA could eventually provide patients with a list of accredited infertility counsellors.

Presentations by International Participants on National and International Counselling Organizations

International participants were invited to address the group regarding various aspects of national and international counselling organizations, including their criteria for membership, how often they meet, their sources of funding etc. It was suggested that this information could be very useful when considering the mandate of a Canadian counselling group.

Australian and New Zealand Infertility Counsellors Association (ANZICA) – **Ms. Joi Ellis**

ANZICA began as a group of ten infertility counsellors that formed an independent group with links to the Fertility Society of Australia (FSA). There is liaison with the FSA but ANZICA is not funded by the FSA.

The criteria for membership were developed and a two-tiered membership system is now in place:

(1) Full membership requires that counsellors have a minimum of four years tertiary education in fields such as social work, psychology or counselling, and they must have two years of supervised general work experience in addition to significant ongoing work in the field of infertility.

(2) Associate members must occupy relevant positions such as academics or conduct research in the field of infertility.

ANZICA Membership is $55 (Australian dollars) per person. The group meets formally once a year, mostly at one of the international conferences on assisted human reproduction. Regional workshops are organized and a quarterly newsletter is produced. The group writes submissions on policy, and provides a representative to the accrediting / licensing body. They provide a representative to the Fertility Society of Australia, advising people on matters pertaining to psychosocial issues dealing with infertility. The accreditation body will only license those clinics that have an ANZICA member on their staff.

The American Society for Reproductive Medicine (ASRM) – **Dr. Linda Hammer-Burns**

The European Society for Human Reproduction and Embryology (ESHRE)

The International Infertility Counselors Organisation (IICO)

The Mental Health Professional Group (MHPG), originally the Psychological Special Interest Group of the ASRM (formerly the American Fertility Society) was formed in 1987 by a core group of about 10 mental health professionals and physicians interested in the psychological aspects of infertility. In order to become an MHPG member, one must first join and continue to pay dues to the ASRM. Dues to the MHPG are a small sum. The MHPG has

between 200 and 250 members with by-laws similar to those of the ASRM. The ASRM meets once a year during which the MHPG presents at least one two-day postgraduate course, various symposia, roundtables, and professional papers. The ASRM/MHPG has a variety of committees and MHPG members are represented on various ASRM committees such as the ASRM Ethics Committee, Patient Education, Practice Guidelines, and the Society of Assisted Reproductive Technologies, and reviewers for *Fertility and Sterility*. In addition, ASRM/MHPG members conduct research (e.g., on the characteristics of oocyte donors). MHPG and ASRM practice guidelines can be obtained through the ASRM Web site.

The European Society for Human Reproduction and Embryology (ESHRE) was founded in 1985 and ESHRE's Psychological Special Interest Group (PSIG) was formed in 1993. ESHRE/PSIG is the largest infertility counselling organization worldwide with 287 members. In order to belong to ESHRE/PSIG, one must be an ESHRE member. In 1999, ESHRE published guidelines on infertility counselling which can be downloaded from the ESHRE Web site. A summarized version of the guidelines was published in *Human Reproduction*. These guidelines relate to counselling in general, third-party reproduction and counselling for single women, among other topics.

The International Federation of Fertility Societies (IFFS) started its activities in 1950. The International Infertility Counselors Organization (IICO), a special interest group of IFFS, officially launched in Madrid at the ESHRE 2003 annual conference. In conjunction with IFFS, IICO held its first all-day post-graduate course (Global Perspectives in Infertility Counseling) at the pre-congress of the IFFS 18th World Congress in Montreal. IICO is an organization of worldwide infertility counselling organizations and individual members. A few of IICO's goals are: to promote the formation of new infertility counselling organizations, to provide professional education in the field of reproductive health counselling and to establish professional standards in the field. In the last year and a half, three new infertility counselling organizations have been established. They are in: Switzerland (which started with only 7 infertility counsellors), Japan (which started with just 10 infertility counsellors although there are 190 other members who are medical doctors and nurses), and the Latin American group that just began in Montréal during the IFFS World Congress.

The ESHRE Web site is www.eshre.com and the ASRM Web site is www.asrm.org.

The German Network of Infertility Counsellors – Dr. Petra Thorn

The Network first met in 2000, and the organization was officially formed in 2002 when it became a charitable organization. Currently we have 60 members and over 100 accredited counsellors. Some Network members are medical doctors.

German couples can easily obtain a list of infertility counsellors by accessing the Network Web site. Accreditation guidelines have been developed for counsellors however, they will likely differ from infertility counselling guidelines that may be developed in Canada. This is because the academic system in Germany is very different from the Anglo-Saxon academic model. There are more similarities between the British and Canadian or the American and Canadian education systems, than between the German and Canadian systems. These differences should be kept in mind when reviewing the Network's infertility counselling guidelines. The Network has also developed an up-to-date list of books and papers on research in the field of counselling.

The Network requires that counsellors hold a graduate degree in a psychosocial profession. In addition, they must have completed training in counselling or therapy (a two or three year program in Germany). Counsellors must also have two years experience in general counselling and one year experience in infertility counselling. The Network does allow grandfathering. However, counsellors are expected to partake in continuous education and supervision and they must also be aware of the psychosocial implications of infertility.

The Network develops infertility counselling guidelines and accredits the counsellors. Counsellors become accredited only once they have submitted all necessary documents and signed forms pertaining to continuous education and supervision. The list of counsellors found on the Network Web site clearly indicates whether or not counsellors are accredited.

A little more than 50 per cent of Network membership is composed of social workers, and the other 50 per cent is a mix of psychologists, sociologists, individuals with a background in education, as well as a theologist. In order to show representation of these different groups, the Network's Board of Directors is composed of individuals with varied professional backgrounds. Accordingly, when members of the Board were elected, it was ensured that a social worker, a psychologist and two other professionals were selected. It is important that the Network's main professions be represented at the Board of Directors level.

The Network organizes two meetings per year. Initially, these meetings dealt with organizational issues. After its first two years, workshop and training components were incorporated into Network meetings. This was done in order to attract new members and to allow workshop participants to benefit from the experience of other infertility counsellors.

The annual membership fee is relatively low (approximately $80 Cdn). Funding is received from pharmaceutical companies to help organize the Network's two annual meetings. No fee is charged to attend the meetings.

In Germany, counselling is not mandated by legislation (in fact, the word "counselling" does not appear in the legislation). There are medical guidelines which stipulate that "counselling" should be provided however, the term is not clearly defined.

Network guidelines distinguish between psychosocial care and psychosocial counselling. This distinction was made because in many cases, doctors, nurses and other health professionals communicate with patients and provide psychosocial care, without necessarily providing psychosocial counselling.

The German Network of Infertility Counsellors Web site can be found at www.bkid.de. The Web site is mainly in German with an English language section.

British Infertility Counselling Association (BICA) – Ms. Marilyn Crawshaw (Ms. Crawshaw did not attend as a BICA representative but did offer information regarding the organization)

BICA was established in 1988 and has approximately 175 members. BICA offers full membership, corporate membership and overseas membership. Full and overseas membership is open to anyone who has an active interest or is working in infertility counselling, allied research or education. Organizational membership is open to any organization with an interest in infertility or in the provision of infertility counselling. Organizational members have no voting rights.

The Association accredits infertility counsellors through its joint BICA and British Fertility Society (BFS) Infertility Counselling Award (ICA) which also carries academic credits, but it is not a requirement to hold the ICA or to be a BICA member in order to practice as an infertility counsellor in the UK. BICA and BFS developed the Infertility Counselling Award to acknowledge the specialist nature of infertility counselling. The candidate must present a portfolio of work demonstrating their competence across a range of counselling standards. On-going funding problems have proved problematic for this initiative as well as the lack of national standards and regulation of counsellors in general. There are proposals to develop a two tier accreditation system in the near future, retaining the ICA but introducing an initial level demonstrating basic competence in infertility counselling.

BICA has links to but is not affiliated with the British Fertility Society (BFS). There are no plans to affiliate with the BFS. Counsellors can and some do belong to BFS in addition to their membership in BICA, but the numbers are small.

BICA members will in most cases also be paying membership fees to their own discipline's professional association (counselling, psychology or social work). It can therefore prove financially onerous to meet so many membership fees, as many infertility counsellors in the UK work part-time and receive relatively low rates of pay. Professional body subscriptions are tax deductible.

BICA produces the Journal of Fertility Counselling three times a year. The journal is free with BICA membership and includes articles and information written by members and others. BICA also produces a Practice Guides series on a range of topics, and has produced Guidelines for the Inspection of Counselling in Licensed Clinics. For a fee, BICA offers members study days about twice each year. Members typically find it difficult to obtain funding to attend. This creates concern with regards to professional development as opportunities are limited for this kind of continuing education.

BICA representatives meet three or four times each year with officials from the Human Fertilisation and Embryology Authority (HFEA), the UK's regulatory body, and Progar (Project Group on Assisted Reproduction – a multi-agency pressure group that was originally set up by the British Association of Social Workers) in order to discuss issues of common concern.

The Association publishes a list of infertility counsellors willing to take private referrals. Counsellors must meet certain qualification requirements in order to make the referral list.

Recently, the Association started to provide workshops on the emotional impact of infertility for clinic staff who are not counsellors. A workshop combining the above with training in telephone counselling skills has been offered to the HFEA. In the near future, BICA will be running introductory courses for counsellors new to the field of infertility counselling. However, funding is an on-going problem. The BICA Committee has some funding applications to outside bodies in process and is currently writing a business plan.

The BICA Web site is www.bica.net. The Web site provides information about the Association for both BICA members and members of the general public, and provides a means for the latter to access infertility counselling services.

Other Issues of Interest

As groups addressed the questions of interest, a number of related issues were identified for consideration. They are captured below.

1.1 What is your definition of infertility counselling?

- Assessment is a critical issue, but there are differing points of view on it.
- There may be a role for counsellors to provide regulatory interpretation.
- Do we need to define "counselling" under the Act (or under eventual regulations)?
- Should the definition of infertility counselling include assessment? Is this included in information gathering?
- Is there an assessment of couples?
- Is it separate from counselling?
- How many times are patients counselled?
- Is counselling gatekeeping?
- What are the measures to become parents? Does that come into the definition of "counselling"?

1.2 How are your counselling services provided?

- There was general agreement that counsellors can use clinical judgement, but that psychological assessments have no place in infertility counselling.

1.3 Who are your clients?

- For off-site counsellors, is the clinic a client?
- What about offspring? If offspring are clients, how does this affect the kind of counselling provided? We need to talk about the implications that may impact the child. There is a need for openness.
- Is counselling different when using one's own gametes versus using third party gametes?

1.4 What services are you providing?

- Who will pay for the counselling? (Average cost is between $90 and $120/hr). Some counselling services would be covered by private health insurance.
- What does "counselling" mean? It is suggested that the definition of "counselling" has broadened. Some "counselling" is offered by nurses, etc. Will the mandated counselling refer strictly to psychosocial counselling?
- What don't we do? Long term counselling is referred elsewhere.
- Free psychologist support is provided in one area.
- When do we consider the financial burden? Who pays for the service?
- Counselling as information giving – how does it relate to credentials?
- What is the difference between therapy and supportive counselling, and which do we do?

2.1 What should be the objectives of infertility counselling?

- Involve the counsellors in the definition of the psychosocial aspects of policy regarding treatment, and ensure that the counsellor's perspective is included in the policy.
- Some other professions believe they offer counselling (i.e., nurses and physicians), but it doesn't meet the definition discussed at the workshop, therefore we need to distinguish this kind of counselling from that offered under mandatory counselling provisions.
- What do we do with genetics counsellors who work in a very specialized area (association of genetics counsellors)? In the UK, the HFEA has not established a regime to regulate this area.
- How do we eliminate the pejorative aspect of counselling?
- There is an issue of clinicians trying to pass the buck.
- There is an issue of educating the clinicians.
- There is a question of how the assessment is conducted – the patient is your client.

2.2 What should the qualifications of the counsellor be?

- We need to differentiate between qualifications and accreditation.
- Should qualifications refer only to regulated professions?
- There is the issue of a dual role that needs to be considered. Patient assessment and patient counselling must be done by two different people (Note: this was one perspective and not agreed to unanimously by the group)
- The regulated professions offer an advantage regarding public protection through codes of ethics, standards of practice and complaints/ discipline procedures.
- A physician (but not psychiatrist) or nurse should not be permitted to qualify as an infertility counsellor.
- We shouldn't set the bar too low, but we don't want the counsellor to be too elitist either.
- Is Health Canada planning an accreditation system? Whoever is doing accrediting has the power to "grandfather" as part of the issuance of a licence.
- Set up postgraduate training.
- Canadian professions such as social workers and psychologists are licenced by their colleges.
- Consider the difference between the qualifications for nursing and those for mental health professionals.
- There are no courses currently offered in Canada on infertility counselling.
- Ensure people keep up with guidelines.

2.3 What should the training of the counsellor be?

- Won't Health Canada provide training? It is suggested that the government has a responsibility to ensure that the training is available in order to give content to infertility counsellors.
- We need a model for infertility training.
- There is a consumer protection issue (which is addressed by being a member of a regulated profession).
- How does one find the training?
- Is there a need to link to mental health areas of study?
- We need to have defined roles for counselling (no dual roles i.e., counsellor and nurse).
- There are requirements for continuing education credits every two years.
- Psychologists are the only M.A.s in Québec, so patients can go to any psychologist for infertility counselling.

- Therapeutic counselling is different from other types of counselling.
- Who provides the funding?

2.4 What might be the standards of practice / models of delivery?

- Issues to address include documentation, confidentiality, professional continuing education.
- An audit process needs to be put in place.
- When the counsellor is off-site, what kind of message does that send to the patient about the clinic and the place of counselling in treatment service as a whole?
- We need to define mandated counselling. Is it psychosocial counselling? Implications counselling? Does it include self-care, habit control, stress management?
- Can enhanced informed consent be reasonably done in a group setting?
- There is a need for the Act and regulations to inform counsellors as to what constitutes "counselling."

4.1 What approaches could advance the development of a regulatory framework for infertility counselling services in Canada as required by the AHR Act?

- This conversation would not happen if AHR was provincially funded.
- Regulation is suitable if it provides a standard.
- Infertility is not just a women's health problem.
- This type of workshop is helpful.
- A national association is needed with training components, an accreditation component and a continuing education component.
- Look to the clinics for funding.

Next Steps

During closing remarks, Mr. Rodney Ghali thanked all of the participants for having taken the time to participate at this critical junction in the implementation of the AHR Act. He indicated that Health Canada looks forward to the continued participation and collaboration during the regulatory development stage.

As part of their next steps, Health Canada must define the following:

- What constitutes "infertility counselling"?
- What kind of counselling should be offered to and received by:
  - Individuals using their own gametes in AHR procedures?
  - Those using third party gametes?
- How should infertility counselling be delivered?
  - Individually? In group sessions?
- What other streams of infertility counselling need to be considered?
  - i.e., genetics counselling
- What should be the minimum qualifications and/or educational requirements for counsellors?
- Is it preferable for counselling services to be integral to or independent of the clinic?
- What approaches could advance the development of a regulatory framework for infertility counselling services in Canada?
- How would the infertility counselling community like to be involved in order to further advance this initiative?

Health Canada will use the information gathered from the workshop to assist in the development of policy proposals regarding s. 14 (counselling) of the *Assisted Human Reproduction Act*. The Department will provide additional public involvement opportunities for stakeholders and other interested parties towards the development of these proposals. These activities may include: the publication of consultation documents, workshops, and information gathering sessions. Information concerning the public involvement activities associated with the development of the components of the Act's regulatory framework will be posted on Health Canada's Web site at: http://hc-sc.gc.ca/english/lifestyles/reproduction/index.htm

Annex 1

List of Participants

Name	Organization	Country
1. Ms. Susan Bermingham	Procréa Inc – Montréal	Canada
2. Dr. Eric Blyth	University of Huddersfield	England
3. M^{me} Claire Brasletien	Nustar Fertility Centre	Canada
4. Ms. Lisa Brookman	Montreal Fertility Centre	Canada
5. Ms. Heather Coburn	Social Worker (home office)	Canada
6. Ms. Marilyn Crawshaw	University of York	England
7. Mr. Ken Daniels	University of Canterbury	New Zealand
8. Dr. Judith Daniluk	Genesis Fertility Centre / UBC	Canada
9. Ms. Joi Ellis	Fertility Associates	New Zealand
10. Ms. Valerie Fines	Social Worker (McMaster University)	Canada
11. Ms. Sherry Franz	Success through reproductive technologies	Canada
12. Dr. Patricia Gervaize	The Fertility Centre / U of Ottawa	Canada
13. Ms. Jean Haase	London Health Sciences Centre	Canada
14. M^{me} Ginette Hamel	Complexe hospitalier de la Sagami	Canada
15. Dr. Linda Hammer Burns	U. of Minnesota Medical School	U.S.A.
16. Ms. Donna Jacobs	Yonge Lawrence Centre	Canada
17. Ms. Nancy Newman	Douglas College (BC)	Canada
18. Dr. Christopher Newton	London Health Sciences Centre	Canada
19. Dr. J. W. O'Riordan	Credit Valley Hospital	Canada
20. Ms. Kay Oke	Melbourne IVF	Australia
21. Ms. Lori Parker	Fenwick Psychological Services	Canada
22. M. Jean Pereira	Hôpital régional Dr. Georges-L.-Dumont	Canada
23. Ms. Margaret Russ	Total Health & Family Care Centre	Canada
24. Ms. Wendy Sherrard	London Health Sciences Centre	Canada
25. Dr. Janet Takefman	McGill Reproductive Centre	Canada
26. Ms. Petra Thorn	Network of Infertility Counsellors	Germany
27. Ms. Lynn Wolff	Lynn Wolff Supervision Consultation	Canada
28. Ms. Samantha Yee	Mount Sinai Hospital	Canada
29. M^{me} Hélène Zylberszac	Montreal Fertility Centre	Canada

Health Canada Representatives – Assisted Human Reproduction Implementation Office (AHRIO)

1.	Ms. Francine Manseau	Manager, Policy Development Group
2.	Mr. Rodney Ghali	Senior Policy Analyst
3.	Dr. Michael O'Neill	Team Leader – Consultation
4.	Ms. Bonnie Lidstone	Regulatory Affairs Policy Analyst
5.	Mr. Peter Biasone	Policy Analyst

Facilitator:

Ms. Raymonde D'Amour	Consultant Praxis

Workshop Evaluation Results

All participants were given a one-page evaluation form at the end of the workshop and completed forms were received upon adjournment.

Twenty-seven responses were received and overwhelmingly, the responses were very positive. Participants rated the facilitator as being highly skilled, the overall organization of the workshop as being excellent and they valued the opportunity to interact and discuss infertility counselling issues with Canadian and international experts. Some did note that they would have preferred more time to interact with other participants.

Here are some of the comments received:

> *"Very wonderful conference, very informative, good opportunity to meet and interact with others and become involved."*

> *"This was excellent. The informal interactions were also very beneficial and there was an opportunity for everyone to be heard."*

> *"A wonderful initiative – I was delighted to be a part of it. The inclusion of international participants was very helpful. The facilitator was highly skilled."*

> *"This has been a tremendous educational networking opportunity for me as a new individual to the field."*

Overall, the evaluations were very positive. Participants found the workshop very useful and they appreciated Health Canada's initiative to seek their input during the process of developing regulations.

Agenda

Health Canada
Policy, Planning and Priorities Directorate
Assisted Human Reproduction Implementation Office (AHRIO)

Infertility Counselling Workshop Agenda

Hôtel Château Laurier, Wilfrid Laurier Room
1220 Place George V ouest, Québec City

May 28-29, 2004

Purpose

- To provide an overview and discuss the impacts of the *Assisted Human Reproduction (AHR) Act* on infertility counselling in Canada
- To engage participants in a dialogue about infertility counselling services in Canada
- To discuss the development of regulatory framework for infertility counselling in support of the *Assisted Human Reproduction Act*

Day 1 – Friday May 28, 2004

08:00	Registration and continental breakfast	Wilfrid Laurier meeting room
09:00	Welcome and opening remarks	Rodney Ghali – Health Canada
	Introductions and review of the agenda	R. D'Amour – Consultant Praxis
	WORKSHOP	
09:15	The AHR Act and infertility counselling	Rodney Ghali – Health Canada

Day 1 – Friday May 28, 2004 *(cont'd)*

09:45 **Discussion 1: Your infertility counselling practice**

Suggested questions:

1.1. What is your definition of infertility counselling?

1.2 How are your counselling services provided?

1.3 Who are your clients?

1.4 What services are you providing?

10:45 Break

11:00 **Discussion 1: Your infertility counselling practice** *(continued)*

12:30 Lunch (served on site)

13:30 **Discussion 2: Elements of a proposed regulatory regime**

2.1 Policy intent behind the Act — Rodney Ghali – Health Canada

2.2 Explore areas where guidance could be provided to the Health Canada

Suggested Questions:

2.2.1 What should be the objective of infertility counselling?

2.2.2 What should the counsellor's qualifications be?

2.2.3 What should the counsellor's training be?

2.2.4 Standards of practice [models of delivery]

15:15 Break

15:30 **Discussion 3: Discuss issues and opportunities regarding the implementation of the *Assisted Human Reproduction Act***

16:30 Wrap-up

16:45 Information on travel reimbursements and related administrative procedures — Peter Biasone – Health Canada

17:00 **ADJOURN**

Day 2 – Saturday May 29, 2004

08:00	Continental breakfast	Wilfrid Laurier meeting room
09:00	Review the agenda for Day 2	R. D'Amour – Consultant Praxis
09:15	**Debrief Discussion 2 (continuation of "Elements of a proposed regulatory regime.")**	
10:15	Break	
10:30	**Discussion 4: The framework for infertility counselling services**	

Suggested questions:

4.1 What approaches could advance the development of a regulatory framework for infertility counselling services in Canada as required by the AHR Act?

4.2 How would you like to be involved to further advance this initiative?

CLOSING

11:30	Next steps, evaluation and closing remarks	Rodney Ghali – Health Canada R. D'Amour – Consultant Praxis

ADJOURN

12:00 Lunch (served on site)