On a personal level, what attracted you to bioethics?

VR: Bioethics sits at the intersection of the two fields that fascinate me most: normative ethics and biotechnology. In particular, scientific developments in the areas of genetics and reproductive technologies raise enormous ethical challenges. In vitro fertilisation (IVF), egg and sperm donation, surrogate motherhood, genetic diagnosis of embryos and foetuses and leftover frozen embryos from IVF revolutionise the way we experience and understand having babies and creating families. These technologies fundamentally impact some of the most profound aspects of the human experience: personal identity, parenthood, family and kinship.

JG: Bioethics invites analysis of a problem from many perspectives. I’m intrigued by ‘border disputes’ and focus on issues where medicine poses challenges to law and vice versa, such as religious bans on blood transfusion and in-school vaccination, preconception arrangements and regulation of assisted human reproduction.

How can the aspects encompassed by the ‘right to know one’s genetic origins’ be summarised?

VR: The ‘right to know one’s genetic origins’ encompasses two distinct notions; a right to know how one was conceived, and a right to have information (identifying or not) about the donor.

EB: For the donor-conceived individual, the ‘right to know’ means a right not to be deceived either by the state or by professionals operating under state licence about the true nature of their genetic origins. Also, it means that a mechanism should be in place to enable donor-conceived individuals who wish to access information about their donor’s identity and other genetic relatives such as donor half-siblings to do so.

Can you give insight into the debate surrounding the disclosure of donor identity?

BS: The issue is: does it matter who your biological parent is? Does your parentage have any meaning, or is it entirely a social, imaginary construction? We offspring, assert that it does have some meaning. Given what we know about genetic influence on a broad range of things, from disease to personality traits, it would seem reckless and absurd to claim otherwise.

OP: To me there is no debate. Donor anonymity is unethical and irresponsible. It is the deliberate separation of the biological and social parenting tie and it is absolutely unnecessary to continue the practice of anonymity in order to maintain donor conception.

WK: With regards to anonymity in the US, the only entities still promoting it are the people selling donor gametes and their representative...
organisations. Their argument is that if anonymity in the US is banned, fewer donors will be available. However, reported numbers from the Human Fertilisation Embryology Authority (HFEA), since the 2005 banning of anonymity in the UK, show otherwise.

JS: We now have relatively easy access to technologies that accurately identify one’s genetic relatives. Whether or not parents decide to share the donor origins with their child, there is a good chance that the child will at some point identify that a parent is not their genetic parent. Families as a whole may experience the burden of keeping secrets and, when not supported by the reproductive medicine and general communities, the additional burden of possible communication challenges after disclosure.

MG: In the case of families with same-sex parents, our children learn about their origins from the outset. There are never secrets and of course even if we wanted to we could not pretend to be the two biological parents. Because of this, our children grow up at ease with their origins and do not feel they are missing pieces about who they are.

AC: Canadian provinces should develop a donor-offspring registry that allows the disclosure of health and identity information between donors, offspring and siblings. In some ways, it should be similar to the adoption registries, in others it must be very different. For past anonymous donations this must be mutually voluntary. For prospective donations, following family legal reform in each province to clarify parentage laws, the registry should be mandatory, and include the capacity for ongoing disclosure of relevant health information.

How does your collaborative endeavour differ from traditional research projects?

VR: This project is unique in that it does not collect new data but rather brings together all the various relevant stakeholders. These groups never have the opportunity to engage in a direct conversation about the challenges raised by donor conception. These stakeholders are the individuals and families affected by the practice, the donors, the clinicians who work in IVF clinics and use donor conception, the researchers who study empirical and conceptual aspects of the practice, sperm banks and egg donation agencies, policy makers, media, and community organisations who provide support and education.

As a growing issue of public debate, would you say enough research is conducted in the area of donor conception?

VR: There is definitely not enough research on the medical or psychological interests of donor-conceived individuals, nor on the implications of donation for egg and sperm donors. Recruiting participants is difficult in an area shrouded in secrecy and where people value their privacy. We need more funding and more researchers who are willing to take on these challenges.

TENS OF THOUSANDS of babies are born annually from donated sperm and egg. In recent years, a plethora of issues has emerged regarding this practice. Many donor-conceived individuals wish to know more about their genetic origins. They are interested in accessing medical, as well as personal, information about donors in pursuit of psychological wellbeing and a sense of belonging. However, challenges arise in the form of barriers that deny them the right to access medical records or to construct a more complete identity.

With a view to addressing growing concerns, Dr Vardit Ravitsky, Associate Professor in the Bioethics Program at the University of Montreal, organised an international multi-stakeholder workshop in collaboration with experts in various fields and funded by the Canadian Institutes for Health Research (CIHR). The aim was to identify key points of contention and agreement, foster an informed and open conversation about priorities for action and pinpoint further research areas required to better understand this multifaceted topic.

UNDERSTANDING THE INTERESTS OF VARIOUS STAKEHOLDERS

The Canadian Assisted Human Reproduction Act of 2004 declares that ‘the health and wellbeing of children born through the application of assisted human reproductive technologies must be given priority in all decisions respecting their use’. However, following a 2010 constitutional challenge by Quebec, many of the Act’s provisions were declared unconstitutional. The authority to regulate now lies with provincial and territorial governments, yet many aspects of donor conception remain unregulated. This reality creates a unique opportunity for governments in Canada to address key public policy questions such as those surrounding donor anonymity and access to medical records.

Questions thus arise regarding what society owes donor-conceived individuals. Do they have a right to know their genetic origins, similarly to adoptees? And what empirical evidence do we currently possess regarding issues such as medical or psychological harm stemming from the protection of donor anonymity? A number of stakeholder groups are involved in this debate: parents, whose interests may lie in the protection of the family sphere and having discretion regarding what to tell their child; donors, and their interest in remaining anonymous or in being identifiable, but in either case in not carrying legal liability for the resulting child; donor-conceived individuals, who may or may not wish to know their genetic origins; the reproductive technology industry, which is in need of effective guidelines regarding best practices; and society as a whole, which allows and enables a practice that may – in the long run – be harmful if not regulated properly.

Key objectives of the workshop were to identify areas of common ground, to reach consensus regarding priorities and to explore what future research may best inform practice and policy.

Wishing to establish effective guidelines and future research directions, a multi-stakeholder workshop organised by the University of Montreal, Canada, is shedding light on the challenges faced by all those involved in donor conception.
INTELLIGENCE

DONOR CONCEPTION WORKSHOP

OBJECTIVES

• To foster informed discussion of donor conception
• To define priorities for research and action

KEY COLLABORATORS

Francoise Baylis, Dalhousie University, Canada • Eric Blyth, University of Huddersfield, UK • Angela Cameron, University of Ottawa, Canada • Raquel Cool, Claire Burns, Egg donors, Co-Founders of ‘We Are Egg Donors’, a self-advocacy community for women who have donated eggs or are considering doing so (Canada and USA) • Lucy Frith, University of Liverpool, UK • Mona Greenbaum, Executive Director, Coalition des Familles Homoparentales du Québec, Canada • Vanessa Gruben, University of Ottawa, Canada • Juliet Guichon, University of Calgary, Canada • Wendy Kramer, Co-Founder and Director, Donor Sibling Registry, USA • Olivia Pratten, Journalist, plaintiff against the Government of British Columbia • Joanna E Scheib, University of California, Davis, USA • Barry Stevens, Filmmaker: Bio-Dad and Offspring, Toronto, Canada • Samantha Yee, Centre for Fertility and Reproductive Health, Mount Sinai Hospital, USA

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GENETIC ORIGINS

Dr Lucy Frith from the University of Liverpool, UK, and member of the workshop organising committee, emphasises the importance of focusing on the intersection between the ethical and social aspects of donor conception. “A key issue is to ensure that reproductive technologies can meet the needs of both those undergoing infertility treatment and those who will be born from the treatments, while being mindful of the families these techniques create,” she explains. This is especially pertinent given that many fertility experts have not foreseen the collateral wave of issues surrounding donation. They focused on helping their patients and thought of donors as crucial but anonymous contributors to achieving a desired pregnancy.

While some sperm banks and egg donation programmes in North America currently offer open-identity programmes that allow full identification of the donor, the majority of sperm and egg donations are still anonymous. However, with the progression of technology, individuals can now search for their genetic origins through organisations such as the Donor Siblings Registry, that have so far helped connect over 8,400 half siblings and/or donors and offspring. Moreover, medical advancements now enable DNA testing to help track donors.

Knowing one’s genetic origins is of great value in the medical context. It is necessary for proper awareness of health risks, taking preventive measures, having better ability to diagnose conditions as they emerge and making informed reproductive decisions. Some donor-conceived individuals are not only denied access to this information about half of their family history, but they also make false assumptions, assuming a social parent is also a genetic one.

While the American Society for Reproductive Medicine (ASRM; see pp6-9) publishes guidelines providing criteria for evaluating donors’ medical history and a list of recommended laboratory tests, the Food and Drug Administration (FDA) requires that donors’ records be maintained for only 10 years, which means that they can be destroyed before the child would need the information they contain. This clinical reality raises many difficulties that need to be urgently addressed.

FOSTERING COLLABORATION

Chaired by Ravitsky, the workshop entitled ‘Donor Conception: Lessons for clinicians, families, policy makers and researchers’ was held in Montreal in June 2013 and served as a platform for exchanging perspectives and ideas. Rather than organising panels around specific topics, discussions were based on stakeholder groups involved in donor conception. “The purpose of the workshop was to engage these various groups (who are not homogenous in themselves) in an informed and open conversation that might lead to better practice and better policy,” Ravitsky elucidates. Key objectives were identify areas of common ground, reach consensus regarding priorities and explore what future research may best inform practice and policy.

Juliet Guichon from the University of Calgary, Canada, and workshop co-Chair, highlights the challenges borne from disparities in how people are affected by not knowing their origins. “Areas of common ground in this field might help facilitate legislation in the best interests of the most vulnerable and most affected; the offspring,” she asserts. Due to the sensitive nature of donor conception, it was important to be aware of the emotional cost for many of those present at the workshop when discussing ethical, medical and legal obstacles.

One of the main limitations was the necessary restriction of the number of attendees – in order to have a fruitful discussion where voices could clearly be heard by those present. This, in turn, limited stakeholder representation: “As a result, we do not pretend that the participants covered every possible perspective out there,” Ravitsky emphasises. The workshop did, however, unite and foster dialogue between stakeholders who do not ordinarily speak directly with one another. Moreover, sharing international perspectives allowed those present to better understand how other countries have overcome similar issues, and how fears and concerns can be managed in effective ways to foster progress, while considering all parties involved.