# Feedback template

Reforms to health regulation in Victoria – consultation paper – 29 April 2024

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## Submission details

| Question | Your response |
|---|---|
| Name and title (optional) | (Dr) Marilyn Crawshaw |
| Email address (optional) | marilyn.crawshaw@york.ac.uk |
| Organisation / association / peak body / regulator / government agency (if relevant) | PROGAR – UK multi disciplinary and multi agency Project Group on Assisted reproduction administered by the British Association of Social Workers. For details see - https://new.basw.co.uk/support/groups-and-networks/special-interest-groups/project-group-assisted-reproduction-progar |
| Are you authorised to provide this submission on behalf of your organisation (if relevant)? | Yes ☒ No ☐ N/A ☐ |
| Please select which category best describes you (optional). | ☐ Member of the public/health consumer<br>☐ Regulated service or individual<br>☐ Public or health consumer organisation/peak<br>☐ Industry or professional organisation/peak<br>☐ Regulator or government entity<br>☒ Other _____ |
| Is your submission 'private and confidential' and you do not want any part of your submission made public? | Yes ☐ No ☒ |
| Would you or your organisation like to receive project updates via email? | Yes ☒ No ☐ |

# Consultation questions

## Part 1 – Improved compliance and enforcement tools

### Question one

Do you support the Health Regulator having access to the proposed compliance and enforcement tools across the regulatory schemes it is responsible for?

We have only limited comment on much of Part One, especially given that we come under a different jurisdiction to yours.

However we have in our responses used verbatim, or adapted, relevant sections of our submission to the 2023 HFEA consultation on lUK aw reform in order to provide some context for our submission to you. It can be read in full at https://new.basw.co.uk/policy-and-practice/resources/progar-submission-consultation-modernising-regulation-fertility.

'PROGAR has since the 1980s worked on matters concerning assisted reproduction, including surrogacy, in the UK and overseas. We have variously worked in partnership with donor-conceived adults, Barnardo's, Birth Registration Reform Group, Children's Society, Donor Conception Network, British Infertility Counselling Association (BICA), British Association for Adoption and Fostering (BAAF), Coram BAAF, National Association of Guardians ad Litem and Reporting Officers (NAGALRO), Children and Family Court Advisory and Support Service (Cafcass), Children and Families Across Borders (CFAB) and UK DonorLink.

**PROGAR'S core interest is in the long term implications of donor conception and surrogacy for the children and adults conceived through such routes, the families and networks in which they are raised and those that they may later establish as adults. We are also interested in such aspects for gamete donors, surrogates, their families and networks.**

Social work has a strong professional interest in this sector for a number of reasons, including the fact that some social workers are employed in this work. There are also many parallels between this sector and adoption and other alternative care services, not least in relation to understanding of personal identity in complex family relationships. In addition social work has decades of experience of where there are family problems and breakdowns and social workers are involved in providing mental health services to people who have suffered trauma related to their identity and in supporting children and families when relationships fall apart. The experience of social workers is therefore of crucial importance to decision-making and risk assessment in relation to both policy and practice in this field.'

### Question two

Do you agree that these compliance and enforcement powers will enable the Health Regulator to adopt a more graduated, risk-based and proportionate approach to compliance and enforcement?

Similar to our response to Q1, we draw heavily from our 2023 response to the HFEA when we say:

'We strongly believe that there should be a mandated upper limit to the length of time between inspections. Our experience drawn from both the fertility sector and the children's social care sector is that things can change rapidly for the worse (for example with staffing changes, financial pressures) and without regular inspections and with an over-reliance on self-reporting a regulator could fail to pick up on actual or pending problems.

We also said to the HFEA that we believed that the inspection of counselling services should be strengthened. This should go beyond the extent to which the requirement to *offer* counselling is met (as mandated by UK law) and drill down far more comprehensively into both practice standards and levels of take up considered against numbers of treatment cycles provided or donors recruited.

We recognise the pressures related to inspection and the need to ensure that inspection is proportionate, balancing costs, maintaining quality services which adhere to regulations, avoiding unreasonable pressures on agencies and staff and upholding the wider public interest. We would suggest that inspection is an essential safeguard and that, in the private and public sector environments which characterise this sector, a loose touch inspection would result in a fall in standards. It is not reasonable to rely on market factors for regulation because the consequences of poor practice may not be seen for a generation. We therefore veer towards stronger inspection frameworks in the interests of children and all the parties involved'

We add:

'As with other aspects of what happens in clinics, there is a need for good solid regulation that is proportionate from the viewpoint of the person who may be conceived as well as those undergoing treatment or donating gametes. This includes, for example, any poor/non-compliance in completion of donor information. We are aware that the danger still exists that the treating clinic loses sight of the current and long term implications for these groups and hence of the human rights and welfare (including safety and best interests) of the child that might be (or is) conceived and children that might be (or are) affected. *This includes when donor-conceived and surrogate-born people make later approaches for information and help.* In a field dominated by medical science and where the dominant focus of regulation will be on treatment-related processes,, taking account of such matters will always be challenging and needs to be informed by such a long term perspective.

## Question three

Can you provide examples of a regulator that has used similar compliance and enforcement tools in a manner that you consider to be effective, or ineffective?

## Question four

Are there any other matters that should be considered in implementing the proposed compliance and enforcement tools (including any specific impacts or benefits for you, your sector or the regulated services you use)?

See our responses to Qs 1 and 2

## Question five

Do you have any feedback on the penalties that are proposed to apply in relation to the new compliance and enforcement tools?

See our responses to Qs 1 and 2

## Question six

Do you have any other feedback or suggestions in relation to the Health Regulator's compliance and enforcement approach or other related matters?

See our responses to Qs 1 and 2

# Part 2 – Reforms to the regulation of assisted reproductive treatment (ART)

## Question one

Do you have any feedback on the proposals for the management of regulatory and other functions under the *Assisted Reproductive Treatment Act 2008* (including the transfer of regulatory functions to the Department of Health and donor registry functions to the new Donor Conception Registrar)?

We are covering our main concerns under Q3. Given the very short timescale for consultation, we have not provided references but can do so on request

## Question two

Do you support the proposed compliance and enforcement powers for the Health Regulator under the ART Act?

## Question three

Are the proposed matters included in the information provision requirements in relation to accessing information on the donor conception registers appropriate? Is there anything that should be added?

Last year we, along with several other professional bodies from outside and within Australia, raised concerns with the VARTA CEO, Trustees and the Minister of Health about the significant change to the services provided by VARTA in relation to information release & donor linking and, in particular, to the demise of the professional psycho-social support services. As we said then, VARTA has been an international leader in this field and the decision to remove the services was very worrying. We were pleased at that time that our concerns were taken seriously and moves made to reinstate the services. We remain of the view that it is crucial that psychosocial support is made available to those seeking information from the Registers, especially donor-conceived adults and donors, and to those seeking help with exchanging information or making contact with genetic relatives.

Victoria and the UK were among the first jurisdictions to bring in progressive legislation, recognising the rights of donor-conceived people to have access to knowledge of their origins, including the identity of their donor(s), their genetic parent(s). When Victoria went further and brought in retrospective access, this was welcomed by many of us though, sadly, not widely adopted elsewhere. Opening up information systems in this way comes, however, with responsibilities in our view. While some individuals may be well placed to manage these processes both practically and emotionally, others can benefit from professional support. They may also benefit from peer support. The two are not mutually exclusive. To remove the option of professional support being provided is of grave concern.

The consultation document only refers to 'counselling' and this is problematic in its limitations. Counselling is a term that means different things to different people. Hence why we prefer to use the term psychosocial support in relation to information release and donor linking, i.e. support provided by qualified psycho-social professionals with the appropriate skills mix for their role. For some (typically a fairly small number according to existing research and knowledge) the need will be for therapeutic counselling. For others, the need will be for such as the provision of a safe space to think things through, help and guidance with navigating the processes involved, and help with mediating information exchange and contact with genetic relatives where required. The latter work will involve the use of advanced counselling skills but is not

therapeutic counselling and hence draws on a different set of knowledge and skills and takes a different shape in its delivery. A recent study concluded that:this professional role was: '……complex and multifaceted, encompassing psychoeducation, mediation, advocacy, facilitation, relationship counselling, and therapeutic intervention'.

Donors as well as donor-conceived people have consistently reported that they welcome having the option, the choice, of taking up psychosocial support. By your proposal to remove the service, that choice is removed. The consultation suggests that those involved can be referred elsewhere but it is not clear where that would be or whether this assumed other organisation would have the skills, knowledge and experience to provide it. In addition it is known that in any service that signposts on to another for a need to be met, a significant number of people never make it and instead get lost in the transfer. Indeed if we remember correctly, an earlier decision to move some of the information release functions from VARTA to BDM staff did not go well and resulted in their return to VARTA. One of the strengths of VARTA has been that its service has been seamless. Neither is it clear if any alternative service will be provided free, thus raising important questions of equity. Indeed not only does it raise questions of equity but also goes against the reported views of donor-conceived people in particular who say that they should not have to pay for services that arise from the decisions of others before they were conceived.

The HFEA has recently made the decision to sop funding professional support services to those seeking information from its Registers. As in the proposals set out in your consultation, the HFEA has said it will provide web-based information in its stead and refer enquirers on to outside specialist services (though we are not aware of any such services in existence in the UK). That the two past most progressive jurisdictions internationally are now looking to turn away from any professional responsibilities to donor-conceived individuals and donors at the very point at which the information release services are maturing is very worrying indeed.

Your consultation paper asserts that the use of ART is an increasingly normalised route to starting or growing one's family. It also acknowledges in particular the importance of donor-conceived and surrogate-born people knowing about and having access to information about their origins. However it goes on to say that because the *ART* route to parenthood is increasingly common and normalised, the support for those involved or impacted may not require legislated functions that are delivered by a regulatory agency (or, presumably, that those affected may not need a mandated right to such provision which is, of course, not quite the same). Without such legislated rights, there is of course no accountability for provision.

Unfortunately the document does not cite evidence to support its assertions about the normalisation from ART use and indeed does not deal separately with any distinct potential needs of those affected by DC or surrogacy, merely stating the importance of access to information. In fact, there are **no** recent research studies internationally or in Australia itself into levels of openness with the donor-conceived or surrogate-born offspring by either recipient parents or surrogates or donors or into associated family relationships. So it is simply not possible to gauge to what extent to which their needs, well-being and rights as adults are being met either by VARTA currently or can be predicted to be met in the proposed reconfiguration. It remains likely, for example, that significant numbers of those directly affected will only learn of their origins outside of infancy or childhood and there is evidence that this can be emotionally and otherwise destabilising.

The suggestion (p17) that information currently covered in counselling can be provided instead through written information seems to miss completely the relationship aspect and value of contact with psycho-social professionals, in what you refer to as 'counselling' (see our earlier comments about the use of the term 'counselling').

While the experience of donor conception starts with medical treatments, its impacts continue across the lifespan and beyond for those affected – recipients, donor-conceived people, donors and their family and social networks. Indeed it has now been argued that we need to move beyond thinking of DC as a medical intervention, and beyond being a family building option to acknowledging that it is something that affects networks both vertically and horizontally. The proposal to remove services in this consultation fail to recognise this.

## Question four

Do you have any feedback on the proposed criteria that must be addressed in the certification for bringing donor gametes/embryos into/taking them out of Victoria (see Appendix 2)? Are there any that should be added, amended, or removed?

Our comments here relate to the central importance of decisions being made that:

- pay full attention to the lifespan impacts of the use of donated gametes
- keep low the numbers of individuals being conceived using the same donor, including worldwide numbers
- ensure that prospective donors are aware of (i) the lifespan implications for themselves, their current and future families of donating, including their responsibilities towards those that will be conceived and (ii) the lifespan implications of how many individuals may be conceived through their donation. This includes the importance of being open about their involvement.
- ensure that prospective parents are aware of (i) the lifespan implications for themselves and their children of using donor conception and (ii) the lifespan implications of how many others may be conceived using the same donor and the lifespan implications of them. This includes the importance of being open with their children about their origins and the importance of knowing whether the donor they use has donated elsewhere (including overseas) or is eligible to do so. We have recently raised concerns with the HFEA, for example, of UK-based gametes bank being granted export licences to sell on gametes if the 10 family limit is reached within the UK. Our concerns (apart from the complexity for offspring of having multiple siblings) is that some recipient parents may choose to use a UK donor in the belief that the gametes will not be exported – and have no right to know if this happens or might do so. You may wish to consider this in any import or export decisions.

## Question five

Do you have any comments on the operation of the certification process for bringing donor gametes/embryos into/taking them out of Victoria?

## Question six

Are there any transitional matters that you think should be considered as part of the transition of VARTA's functions under the proposed reforms?

## Question seven

Are there any other matters you think should be considered in implementation of the reforms?

It has always seemed to those of us following VARTA from a distance that the public education, community consultation and promoting research aspects of its role are important. As far as we can see, these will disappear completely under the proposals. What a loss!

In addition, as far as we could see, the following services currently delivered by VARTA look set to disappear and this would be a worrying withdrawal of important functions:

- VARTA's annual report which includes ART rates by age, average number of eggs collected by age, and cumulative live birth rate for IVF by age;
- VARTA's website which includes:
    - patient resources on understanding success rates, health effects of IVF and ICSI, pros and cons of PGTA;
    - independent resources on considering gamete donation for prospective recipient parents and donors
    - resources on Donor conception Linking which do not exist elsewhere
- The website is used by those directly affected and by professionals both within the State of Victoria but also from elsewhere, including internationally.
- There is already a dearth of supportive literature and resources available to the DC community, past and present, from 'trusted sources' (so important in today's age). The proposed demise of VARTA will also mean that the development of future resources will be majorly affected with no obvious successor to take this on.
- We understand that Victoria recently announced the funding a public egg and sperm bank to assist more Victorians to access treatment. Withdrawing access to the resources currently provided by VARTA is all the more surprising given the apparent policy decision to encourage more domestic provision of DC.

## Question eight

Are there other reforms relating to ART that you would like the department to consider as part of any future reforms?

To receive this document in another format, email the Department of Health's Legislative and Regulatory Reform Team at <legandregreform@health.vic.gov.au>.

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