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Experiences of faith group members using new reproductive and genetic technologies: A qualitative interview study

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ABSTRACT

This paper explores the experiences of members of faith groups deciding whether or not to use new reproductive or genetic technologies (NRGTs). It is based on 16 in-depth, semi-structured interviews with people with direct experience of NRGTs. Participants identified as members of Christian or Muslim faith traditions and had been faced with deciding whether or not to make use of novel forms of fertility treatment or genetic testing. The findings show that members of faith groups may experience specific barriers of access, and distinctive ethical difficulties, when considering the use of different forms of NRGTs. Both Christian and Muslim interviewees reported difficulties in obtaining information on the official faith teaching, or found that their faith group had not yet crafted an official position. Participants' needs for information, and the opportunity to discuss the faith implications of their clinical choices, were not being met in either the clinic or the faith setting. This paper concludes that clinics should indicate more clearly their acknowledgement of patients' faith concerns. Appropriate training is needed for both healthcare professionals and chaplains, while faith groups should be encouraged to engage with healthcare providers to ensure that guidance is available to their members.

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Introduction

The growing repertoire of new reproductive and genetic technologies (NRGTs), ranging from conventional IVF to the currently experimental and controversial technique of mitochondrial replacement, raises difficult ethical questions for professionals and public alike. These can be especially troubling for members of different faith groups, some of which hold distinct positions on the use of these technologies. However, there is a noticeable gap in our knowledge about the role of religious faith and practice in lay people's use of, and access to, NRGTs. Empirical studies of the influence of religion on attitudes towards NRGTs in Britain have focused mostly on some of the cultural factors associated with membership of an ethnic group, rather than on specifically religious aspects (e.g. Culley, Hudson, & Rapport, 2013; Purewal & van den Akker, 2006; Rozario, 2005). Inhorn (2006) addresses religious aspects, but is based on research in Egypt and Lebanon. In a review of public attitudes to gamete donation, Hudson, Culley, Rapport, Johnson, and Bharadwaj (2009) draw attention to the limitations of

the available studies and argue for research that explores the perceptions of people who tend to be less often included in public consultations, including members of religious groups.

The findings reported here form one part of a 2-year research project funded by the Economic and Social Research Council, "*Faithful Judgements: the role of religion in lay people's ethical evaluations of new reproductive and genetic technologies*" (PEALS, 2014). The overall study consisted of three parts: in the first, we used in-depth, semi-structured interviews with lay people with direct experience of NRGTs; this was complemented by, second, scenario-based dialogue groups with people without direct experience of NRGTs, and third, interviews with faith group leaders. This paper focuses on data from the interviews with lay people. In particular, it examines what lay people who identify as having a faith commitment (hereafter 'religious people') had to say about their experiences within the healthcare services, both as patients and more generally as contributors to the public debate about the use of these technologies. We were especially interested in

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whether participants, as faith group members, encountered distinctive ethical or other difficulties in making use of NRGTS; if they perceived conflicts between what their religion required of them and the wider secular consensus reflected in UK legislation and policy; and whether they felt able (or indeed wanted) to introduce a faith perspective into public consultations and debates on NRGTS. These aims were part of a broader examination of the processes through which religious people form ethical judgements about NRGTS, building on previous work (Banks, Scully, & Shakespeare, 2006; Scully, Banks, & Shakespeare, 2006; Scully, Shakespeare, & Banks, 2006) that showed there can be significant differences between lay people's ethical evaluations of biomedical technologies and those of professional philosophers and clinicians.

Materials and methods

In this paper, we focus on data from 16 qualitative semi-structured in-depth interviews held with people who self-identified as either Christian or Muslim, and who had direct experience of assisted reproduction or prenatal genetic testing. The interview schedules were designed to begin with a question eliciting the narrative of participants' experiences, going on to explore in more detail areas such as (i) the ethical and other considerations that participants found relevant to making their decision about using NRGTS; (ii) whether they found religious resources were helpful to making their decision, and if so what these were; (iii) whether they had received guidance or support from their faith group leader or faith community; (iv) how their clinic responded to any ethical or faith concerns; and (v) whether they had experienced any conflict between the requirements of their faith and the use of NRGTS. Here, we focus on the question of whether ethical and other concerns related to their religion were adequately addressed in the healthcare setting.

The project also held 18 facilitated dialogue groups involving a total of 102 participants (46 Muslim and 56 Christian) who had not themselves had direct experience of NRGTS. These dialogue groups used two short scenarios about egg donation and preimplantation genetic diagnosis (PGD) as initial prompts for discussion in order to gain insights into the process of how people of faith make ethical evaluations of NRGTS. The methodology of the groups was developed in previous work by two members of the current research team (Banks et al., 2006). In addition, we held four interviews and a number of informal discussions with faith group leaders, to gain an insight into how they mediated the official teaching of their faith. In this paper

we concentrate on the analysis of patient interviews, but our interpretations are supported by material from the dialogue groups and faith group leader interviews.

Sampling and recruitment

Our aim was to characterize elements of people's experience and ethical decision-making that relate to identifying as a member of a faith group, rather than to differentiate between different faiths or denominations/traditions within those faiths. We therefore chose to focus on Christians and Muslims, numerically the two largest faith groups in the UK (Christian, 59.3%; Muslim, 4.8%) according to the 2011 UK census (Office for National Statistics, 2012). 'Official' faith positions on different NRGTS vary significantly. For example, Roman Catholicism rejects most forms of assisted conception, as well as the termination of pregnancy that can follow prenatal genetic testing (Congregation of the Doctrine of the Faith, 2008; Ford, 2008; Lanzone, 2013). Conversely, most branches of Islam allow IVF between married couples, although there are significant differences between Sunni teaching and some Shi'a authorities on sperm and egg donation, due in part to different views on whether third-party donation is tantamount to adultery; and there is a diversity of opinion on prenatal genetic testing leading to termination of pregnancy (Albar, 2002; Clark, 2006; Jafri et al., 2012; Larijani & Zahedi, 2008; Serour, 2013; Shaw, 2012). The Church of England does not take tightly defined positions in relation to issues of fertilisation and embryology, recognizing the different views held in good conscience by Christians, and preferring to leave decisions to the informed judgement of individuals and couples (Church of England, 1996). Other Protestant churches tend not to have centralised teaching authorities, though individual churches, congregations or pastors may take a line on particular issues.

'Religion' is a sociologically complex concept embracing multiple aspects of belief, meaning, ritual, experience, belonging and community. In this project, our conceptual and methodological interest was in how individual lay people experience NRGTS as people of faith and how they interpret, transform and experience their faith group's guidance when thinking ethically about NRGTS. We therefore defined 'religious' through self-report and recruited those for whom religious commitment was relevant to forming ethical opinion or making important life decisions, irrespective of whether they prioritised substantive religious content, practice or group identity. Interviewees were recruited by advertising the project through local and

regional faith centres (including churches and mosques), appeals in national media specialising in faith or bioethical issues, on local radio and by word of mouth and snowballing. We anticipated that recruitment to interviews would be challenging, as the research touches on two highly sensitive areas (religion and personal health), and so our inclusion criteria were broad: we appealed for people in Christian or Muslim faith communities who self-identified as religious and who had considered using any form of NRG. Some dialogue groups, but no interviews, required the use of an interpreter. Interviews were carried out by the principal investigator (J.L.S.) and research associate (J.H.). Ethical approval was obtained from Newcastle University's Faculty of Humanities, Arts and Social Sciences (Ref: BH101657; dated 20 September 2011). All interviewees gave written voluntary informed consent to take part.

Data analysis

Interviews were audio recorded with the consent of the participants and the recordings transcribed verbatim. Themes were identified by close reading and an inductive thematic analysis, identifying key features of participants' experiences in the clinical encounter as well as their sources of faith guidance and their processes of ethical evaluation. The identification of themes was initially performed independently by all three members of the research team, and the analysis and interpretation discussed at regular team meetings to ensure consistency and agreement. One team member (J. L. S.) coded the interviews in line with agreed themes using software package NVivo (Gibbs, 2002).

Results

Participants

We were able to hold 18 interviews with a total of 21 people. However, two turned out to be unsuitable because participants had not in fact had direct experience of NRGs, leaving us with 16 interviews involving 19 people. Of these, 13 interviews involved participants identifying with a branch of Christianity and three with an Islamic tradition (see Table 1). Most interviews were held in participants' homes. The majority were one to one but on three occasions a married couple preferred to be interviewed together. Participants were assured of complete anonymity, and all transcripts were pseudonymised and had other potentially identifying material removed. Many participants were very concerned that they should not be identified, particularly if decisions they had made or

views they expressed went against their faith community's practices or teaching.

The majority of the interviewees had experienced problems with fertility (12 interviews), with a minority discussing either prenatal testing for a genetic disorder ($n=2$) or postnatal testing for familial cancer ($n=2$). We have included the latter as their considerations included the implications for reproductive decisions by children or other family members. All had faced a decision about whether to pursue treatment for infertility or diagnostic genetic testing. Of the infertility interviewees, eight had gone on to seek treatment while four had not. Of the genetic testing interviewees, three had decided for testing, while one had rejected it (Table 1).

Themes relevant to the clinical encounter

Our analysis identified a large number of themes related to the research questions of the project. Here we consider those themes primarily relevant to the clinical encounter. They are the following: (i) the overall experience of infertility/genetic disease, and of NRGs; (ii) experiences in the clinic; (iii) participants' awareness of constraints on the healthcare services; (iv) guidance and support from faith groups; and (v) contributing to wider public debate.

The overall experience of infertility/genetic disease and of NRGs

Although our focus was on the participants' experience and decisions to use, or not to use, NRGs, these decisions were embedded within the overall experience of infertility and/or genetic disease. Such conditions are difficult for most people, whether or not they have a religious commitment. Nevertheless, it was notable that participants often referred to the extra difficulty that they felt their faith presented. For example, they were confronted with the classic problem of theodicy: understanding suffering in a religious context. None of the participants expressed the belief that their infertility or genetic condition was a 'punishment from God', but several emphasised that they had had to go through a process of making sense of infertility or genetic disease, and the possibilities of treatment, within the context of their religious beliefs and faith group traditions, and that this was an additional step that would not be necessary for non-believers. As this evangelical Christian man said:

There's a scientific aspect and there's a faith aspect that needs to be processed and, for any individual who's coming along, they have an element of both. You still

Table 1. Details of interview participants.

Interview number	Faith group, gender	Condition	Decision
1	Evangelical Christian woman	Infertility	Treatment, successful
2	Anglican Christian couple	Infertility	Treatment, unsuccessful
3	Sunni Muslim man	Infertility	No treatment
4	Evangelical Christian woman	Infertility	No treatment
5	Catholic Christian woman	Infertility	Treatment, successful
6	Catholic Christian woman	Infertility	Treatment, successful
7	Sunni Muslim couple	Infertility	Treatment, unsuccessful
8	Catholic Christian woman	Infertility	Treatment, unsuccessful
9	Catholic Christian woman	Infertility	Treatment, successful
10	Pentecostal Christian woman	Testing for genetic condition	Test taken
11	Pentecostal Christian woman	Testing for genetic condition	Test taken
12	Catholic Christian man	Testing for genetic condition	Test rejected
13	Anglican Christian man	Testing for genetic condition	Test taken
14	Anglican Christian man	Infertility	Treatment, successful
15	Shia Muslim woman	Infertility	No treatment
16	Catholic Christian couple	Infertility	No treatment

have to go away yourself and process that. This [i.e. the clinical information] is what I've been told, but how do I integrate that with my faith?

Participants reported that they wanted to know whether their faith group had a particular position on an NRG and if so, what it was. They also usually pointed out that the faith group position did not determine their decision; rather, it was something they needed to understand and take into account in their deliberations. This had both positive and negative consequences. Some said that the result of this engagement had been a deepening of their faith. However, those who decided to go against their faith group's clear position (in our study, this involved four of seven Roman Catholic individuals) had to consider what this meant for their relationship to their church. At a time when they were already in distress and in need of support, this additional consideration was one of the "hard questions the secular don't face" as one participant put it. However, as we discuss below, the situation was not necessarily any easier for those participants whose faith group did not have a specific position on NRG use (in our study this included the Church of England and the Methodist, Baptist and Pentecostal churches).

In the clinic

While most interviewees spoke very positively of the clinical aspects of their NRG experiences, they also reported feeling that both public and private healthcare systems tend to be insensitive towards, uncomprehending of, and occasionally even actively hostile to faith issues. Statements of this sort were made in the majority (14 of 16) of interviews, as illustrated by these comments from a Catholic man in a couple interview about a conversation with a consultant:

[W]hen I gave him my reasons [for rejecting IVF] he just patently expressed that he thought it was ridiculous. That was really the worst experience. [As a result] part of us I suppose felt, oh this bit of the NHS doesn't accommodate people like us. And we've just, I guess we accepted that really.

Several participants commented that they felt the onus was on them to raise issues of faith in the clinic, which was not always easy, according to this Shi'a Muslim woman:

There's also the sense that religion and things like fasting and so on, or any worries we had about whether [egg] donation or whatever fits with Islam, that these are matters that don't belong there because it is all clean and medical and religion is not. So you have to bring it in yourself by the scruff of the neck, almost. And I felt awkward doing that. I felt I was being a problem and I would almost, that I would be asked to explain why it was important, to people who didn't feel it was important, and I just wasn't up to it.

Most participants said faith issues had not been raised at any point beyond being asked to state their religion when filling out personal information forms, as this Sunni Muslim man noted:

We didn't have any experience of that, it was never mentioned. None of the literature that we were sent ... nothing was mentioned there.

A minority of participants were more positive about the handling of faith in their clinical encounter. However, even the participant who spoke most positively, a Pentecostal Christian woman, had had to introduce the topic herself:

I suppose really it was myself and my husband... saying, you know, we are strong believers, Christians, and we believe in prayer and, yeah, so they sort of, you know accepted why.

Participants did not expect healthcare staff to have theological information at their fingertips. However,

they indicated that they would have found it helpful if staff were more explicitly open to discussing faith matters, and had been able to point to sources of information about faith groups and NRGTs. This Catholic woman wanted:

... just basic information and something saying, we will consider your faith in looking at treatment options or, maybe in the letter that comes through for the appointment, we invite you to raise any [faith] issues. Just kind of understanding that faith influences medical decisions.

Interestingly, two interview participants suggested that faith issues were not raised because fertility is not felt to be a condition in which religious support is necessary:

I think to some degree [healthcare staff] can understand it if it comes to literally life and death decisions, but fertility is not a life and death issue you see. (Catholic woman).

In some cases, participants felt that any expression of ethical doubt or concern was considered inappropriate by healthcare professionals. This could also happen when, for example, Catholics wanted to discuss alternatives, such as intrauterine insemination, to standard IVF. As this Catholic woman said:

I was chatting to one of the embryologists about how many [embryos] to thaw and I said morally I really struggle with this decision ... [In her response] I just thought she's effectively saying if that's what you struggle with you're probably sitting in the wrong clinic doing the wrong thing. So I just backed down and I didn't say any more about it. But [having ethical reservations about treatment] doesn't mean we don't want to do it. It just means it's adding another dimension to it.

For this woman, and some others, having ethical or religious difficulties did not necessarily mean they would reject an intervention. Rather, they were uncertain or ambivalent, and felt they needed some help while exploring the extent of their ambivalence before they could decide whether to go ahead or not.

Participants' awareness of constraints on the healthcare services

Several participants, like the Shi'a Muslim woman quoted below, expressed their awareness that healthcare professionals who spontaneously raised faith issues in the clinical setting might be seen as behaving inappropriately:

I think religion though is such a touchy subject and I can understand doctors or healthcare people in general, even if they are sympathetic, thinking "just don't go

there" if they're afraid of getting it wrong or touching a nerve.

Participants also recognised that clinicians' apparent insensitivity or disinterest could reflect lack of time, and pressures on the delivery of service rather than healthcare policy:

I would have loved to have spoken to someone there about it, but I mean everything happens in such a rush. (Catholic woman)

Perhaps the people on the ground don't implement the recommendations and the guidance there is. (Sunni Muslim man)

Guidance and support from faith groups

Both Christian and Muslim interviewees were often unclear about the official teaching of the religion on NRGTs. They reported finding it surprisingly difficult to get information on official positions, a finding in line with other research (Shaw, 2012), or alternatively finding that their faith group had not yet crafted a specific view. Often, the most readily available forms of religious guidance were not viewed as authoritative. For example, participants like this evangelical Christian women felt that their local faith leaders lacked relevant knowledge and expertise:

[Our minister] told us very wise things to think through but also, bless him, he was kind of out of his depth. He'd never had a couple come up to him and say, we're thinking of sperm donation.

People were not asked directly in their interviews about how their particular faith group was responding to the challenge of NRGTs, but in 11 of the 16 interviews this was mentioned spontaneously. The key theme here was that the faith groups were not responding very actively for people in these situations in terms of teaching or pastoral care. Interviewees reported that their faith communities had not yet had much direct experience of either infertility or genetic conditions or their treatment and diagnosis, nor did they discuss them. Their faith groups were not (yet) engaging with NRGTs or their contemporary use by members:

It's not an area the church has really thought through very much, we're playing catch-up a lot, I think ... actually I think a lot of churches are assuming Christians don't do that kind of thing [i.e. egg donation] on the ground level, when actually Christians are starting to do this kind of thing because that's their best option. (Evangelical Christian woman)

In these circumstances, participants often reported feeling frustrated and abandoned in their attempts to

reconcile their healthcare decisions and their faith lives. In consequence, they frequently turned to the Internet for information, including seeking advice and support from online communities for infertility or genetic disease. Even here, however, participants found that in fact faith was rarely mentioned in these online self-help groups, which parallels the lack of discussion within faith communities themselves.

Contributing to wider public debate

Most interview participants accepted that any divergence between the official teaching of faith groups and the wider secular consensus on and regulation of NRGTS simply reflects the diversity of contemporary UK society. Some, however, felt that faith perspectives were more actively excluded from policy deliberations. When asked directly, the majority of interviewees (and also of dialogue group participants) said they would feel able to introduce their own faith perspective into public debates on NRGTS. Nevertheless, a significant minority felt that comments from a faith perspective would be rejected or would attract hostility, as this Shi'a Muslim woman said:

If I were to be taking part in a debate or discussion or in public, I would sort of feel almost dishonest not outing myself [as a Muslim]... On the other hand, I would be afraid of that change in people's attitudes, yes. Even if it's not hostility there is also the dismissive side. "Oh she believes this stuff, she must be mad or stupid." So your views have less weight.

Discussion

For at least some people facing issues of fertility or familial disease, religious belief and practice is an important area of their lives, impacting on their health and healthcare in a variety of ways. When considering various forms of NRGTS, study participants wanted to know if the ethical position they adopted, or the personal decisions they made about use, could be reconciled with the tradition of their faith group. These dilemmas, in which members of faith groups seek to reconcile their religious commitments with the demands on them posed by new technologies, are characteristic of the issues of autonomy and identity faced by adherents of religious traditions in the conditions of modernity (Day, 2008; Taylor, 1989, 2007; Tipton, 1982).

Until faced with these questions participants generally had little or no knowledge about their faith group's actual thinking about different NRGTS, particularly in the case of more recent developments such as

PGD or egg donation. Lack of knowledge about faith group teaching was also shown not only by participants in the dialogue groups that were held as part of the larger research project, but also – and perhaps more problematically – in our parallel series of interviews with faith group leaders such as church pastors or local imams.

Most interviewees reported experiencing a lack of awareness of, or sensitivity to, faith issues in their clinical encounters. Although both NHS and private clinics routinely have guidelines about respecting the religious belief and practices of patients, participants' accounts suggest that such guidance may be poorly or inconsistently put into practice. A possible explanation of this is that a vicious circle develops, in which these issues are not raised by clinic staff, patients themselves feel inhibited about raising them, so clinics feel they are not relevant to most of their patients, and do not encourage their discussion. Whether or not this holds, it remains the case that the majority of interviewees felt that they had had no opportunity *in the clinic* to think through their treatment choices from a faith perspective.

Many of the lay interviewees were, therefore, effectively unable to find information or guidance about the faith aspects of possible treatment in either the clinical or the faith setting. From the point of view of the healthcare services, it can be argued that the clinic is just not the place for discussion of faith issues and that these belong in the church, synagogue, temple or mosque. However, as our findings also show, participants were generally unable to raise questions about the religious context of their infertility, and particularly their treatment options, in faith settings either. This could lead to delays in seeking treatment and affected their relationship with their healthcare professionals, as well as causing significant emotional distress on top of the stress of the infertility or genetic condition itself.

This study is the first to attempt to look at the implications of faith group membership in clinical encounters relating to NRGTS. Previous work in this area has tended to focus more on ethnic or cultural differences that are associated with religious identity. We argue that the factor of faith group membership in itself is both distinctive and important, particularly against a background of the broadly secular society of contemporary Britain. While we acknowledge the complexity of disentangling cultural, social and ethnic factors (as discussed in Mitchell, 2006), our analyses focused on the specific contribution of religious commitment. The approach we have taken in the project as a whole, using both interviews and dialogue

groups, generates distinct types of data with different strengths and weaknesses (Mitchell, 1999). In this paper, we have focused chiefly on the data from qualitative interviews with participants with direct experience of NRGTs, which have the advantage of allowing for the discovery and detailed exploration of novel, unanticipated insights. Interviewees can give in-depth subjective accounts of direct personal experience, but only from their own perspectives. In the wider study, we have complemented this with data from dialogue groups made up of participants without direct experience of NRGTs (PEALS, 2014). These participants lack knowledge of the realities of NRGTs, but their more theoretical evaluations may better represent the perspectives of the faith group overall.

The faith groups we studied reflect significant theological, structural and cultural diversity. Our focus on individual lay people (who are less likely to use highly technical doctrinal arguments) mitigated theological diversity. The significant structural differences between faith groups (e.g. in status of religious leaders, and in how religious commitment is lived out) were taken into consideration in our interpretation of the data. Religious groups in the UK are also culturally diverse, and we attempted to account for this as far as possible in the larger research project where we were able to control the composition of the dialogue groups.

As is generally true for qualitative research, we cannot make any claims to statistical representation. Our study is a small-scale project that contributes to identifying key areas of difficulty and suggests areas for further research. Only a minority (four) of the interview participants were Muslim, although in the dialogue groups the contributions of Christian and Muslim participants were more evenly balanced. There may have been selection bias of interviewees, if those with less satisfactory experiences were more willing to volunteer for interview. Nevertheless, our findings show that at least some patients face unexpected difficulties in accessing relevant information and in having their faith group membership accommodated appropriately within the healthcare system.

Although small scale and exploratory, these findings provide a basis for future, larger scale research that should cover a more comprehensive range of faith groups and more denominations and traditions within them. Among the key research questions to be answered are precise delineations of how information about positions on NRGTs are conveyed to members of different faith groups, by which authority in each case, and what, if any, are the channels of communication between faith groups and NRGT healthcare providers.

In terms of recommendations for practice, it is clear that participants were in need of more information about faith group positions and, equally importantly, the opportunity to discuss the implications of their clinical choices in a faith context. These needs are not being met in either the clinic or the faith setting. It is possible that although they may be following guidelines on respect for patients' religious views, clinics may still need to indicate more clearly their willingness to acknowledge patients' faith concerns, and to refer them to appropriate resources such as healthcare chaplains. Information about resources (such as leaflets or online resources for patients and faith group leaders) may need to be more clearly signposted: one model for this is the NHS organ donor website, which outlines the teachings by different religious groups on organ donation, and provides links to more detailed information (NHS, 2015). Appropriate training in faith perspectives and in NRGTs may, therefore, be needed by both healthcare professionals and chaplains. To provide all this requires financial and other resources, and we recognise the constraints on these. But crucial to remedying the concerns identified in this paper is a heightened alertness to faith issues on the part of healthcare professionals, and a willingness to engage with patients on these issues where appropriate (Dutney, 2007; Lemons, Ragsdale, Vaughn, & Grossoehme, 2012).

In many cases, faith groups do not yet have a clear policy on a specific NRGT (especially the more novel ones such as egg freezing or mitochondrial replacement), either because they have not yet developed a position or because pastorally they would be inclined to leave it to the individual's own discernment. Some participants were particularly critical of the faith group's 'lagging behind' developments in healthcare. We suggest that faith groups should also be encouraged to engage with healthcare providers, to ensure that information and guidance is readily available to their members faced with these situations. Finally, we note that chaplaincy services are a key resource, which may be under-utilised at present.

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Disclosure statement

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