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## Could Seeking Human Germline Genome Editing Force Journeys of Transnational Care?

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## **Could Seeking Human Germline Genome Editing Force Journeys of Transnational Care?**

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### **Abstract**

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The scope and use of in vitro fertilisation (IVF), a technology which inherently presents gender inequalities, and its platform applications differ across countries according to respective legislation and regulation (Inhorn, 2015). Using the context of human germline genome editing (hGGE) as a framework, this article will explore and discuss whether differences in legislation and regulation across countries force individuals/couples to seek transnational care to fulfil their reproductive desires. This article will primarily focus on regulation and practices in the United Kingdom (UK) and use these as a comparative to regulation and practices in other countries. The primary research upon which this article is based was conducted in the UK between 1st March 2018 – 31st October 2019. The research consisted of a largely qualitative, online public survey with a final data set of 521 respondents, semi-structured interviews with 11 experts/professionals who were/are involved in the scope of hGGE in the UK, and semi-structured/interactive interviews with 21 people affected by a respective range of genetic conditions. The findings reveal that 65.64% of respondents were supportive of people utilising transnational care to achieve their reproductive desires in relation to hGGE and that 76.39% felt they should not be prosecuted if they do.

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**Keywords:** genome Editing, In Vitro Fertilisation, reproduction, transnational care

## **¿Podría la Búsqueda del Uso de Técnicas de Edición de Genoma en un Embrión Humano Forzar los Viajes de Cuidado Transnacional?**

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### **Resumen**

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El alcance y el uso de la fertilización in vitro (FIV), una tecnología que presenta de forma inherente las desigualdades de género, y sus sistemas de aplicación difieren entre los países de acuerdo con la legislación y la regulación respectivas (Inhorn, 2015). Utilizando el contexto de la edición del genoma de la línea germinal humana (hGGE) como marco, este artículo explorará y discutirá si las diferencias en la legislación y la regulación entre países obligan a las personas / parejas a buscar atención transnacional para cumplir sus deseos reproductivos. Este artículo se centrará principalmente en la regulación y las prácticas en el Reino Unido (UK) y las utilizará como una comparación con la regulación y las prácticas en otros países. La investigación principal en la que se basa este artículo se realizó en el Reino Unido entre el 1 de marzo de 2018 y el 31 de octubre de 2019. La investigación consistió en una encuesta pública en línea en gran parte cualitativa con un conjunto de datos final de 521 encuestados, entrevistas semiestructuradas con 11 expertos. / profesionales que estuvieron / están involucrados en el alcance de hGGE en el Reino Unido, y entrevistas semiestructuradas / interactivas con 21 personas afectadas por un rango respectivo de condiciones genéticas. Los hallazgos revelan que el 65.64% de los encuestados apoyaron a las personas que utilizan la atención transnacional para lograr sus deseos reproductivos en relación con hGGE y que el 76.39% sintió que no deberían ser procesados si lo hacen.

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**Palabras clave:** edición genómica, Fertilización In Vitro, reproducción, atención transnacional

This article explores attitudes towards transnational care using technologies for the prevention of genetic disorders as a framework. This article draws upon primary research to question whether seeking to use such technologies could force people to seek transnational care.

In vitro fertilisation (IVF) is a procedure in which eggs are fertilised by sperm outside of the body (Franklin, 1997). This procedure was originally developed to assist couples experiencing difficulties with fertility to have a genetically related child (Franklin, 1997) but is now used as a platform to enable several other reproductive choices (Wang & Sauer, 2006). Such choices include surrogacy (a woman gestating and giving birth to a baby for another person or couple), gamete freezing (freezing egg or sperm cells for later use), gamete donation (donated gametes being combined with a parent's gametes to create embryos), and preimplantation genetic testing (testing embryos created via IVF for a genetic condition of which there is a family history, formally known as preimplantation genetic diagnosis (PGD)) (Zegers-Hochschild et al., 2017). More recently, a genetic editing technique known as CRISPR-Cas9 has been used in conjunction with IVF to enable the genomic material (DNA) in human embryos (germline cells, i.e. cells which are heritable) to be edited (Morrison & Saille, 2019). While this latter application is not widely established, it is highly controversial and has unearthed international discussions on whether its use should be developed and/or permitted among reproductive choices, and if so, to what extent.

Following the birth of Louise Brown in 1978, the first baby born as a result of IVF (Wang & Sauer, 2006), the use of IVF has grown into a global multi-billion pound industry (Grand View Research, 2019). Her birth signified a monumental breakthrough in science and technology and ignited hope for those with fertility difficulties (Franklin, 2013). Prof. Sarah Franklin, an anthropologist turned sociologist with pioneering research in reproductive technologies, thus writes that IVF is a hope technology (Franklin, 1997) and this is reinforced by its surroundings statistics. IVF has a modest success rate of around 24% which steeply declines as maternal age advances (HFEA, 2018b). This means that roughly only 1 in 4 people who utilise IVF services achieve their desired outcome. However, despite this modest success rate, individuals/couples are not deterred from utilising the technology and its continued use has generated a shift in public attitudes towards assisted

reproduction technologies (ARTs) (Bonetti et al., 2008; Fauser et al., 2019). Among the shift in attitudes is trust (Fauser et al., 2019); trust that the use of ARTs will not have catastrophic consequences (presumed by the resulting births of children with no explicit abnormalities) and that such technologies are therefore safe. The assumed safety however does not account for the unequal health and socioeconomic demands contemporary IVF practices place on women or the associated risks they encounter as a result (NHS, 2017b; Inhorn, 2015; Franklin & Roberts, 2006).

Women who undergo IVF are most commonly required to inject themselves with hormones for several weeks before her eggs are surgically removed (Franklin & Roberts, 2006; Stock, 2003). This is so that a menopause-like state can be induced and more than one egg can be stimulated to mature (Fauser & Devroey, 2003). This process presents the woman with several significant risks which men undergoing IVF are not subjected to. The hormone injections can present with unpleasant side-effects which can include changes in mood, headaches, hot flushes and restlessness/irritability (Fauser & Devroey, 2003). While those side-effects may seem minor, the woman is also at risk of ovarian hyperstimulation syndrome which is when too many eggs develop in her ovaries and they become enlarged and often very painful (Fauser & Devroey, 2003). Symptoms of this syndrome can include weight gain (from a build-up of fluid), nausea and vomiting, dehydration, and breathing difficulties (Vlahos & Gregoriou, 2006). Additionally, the syndrome can become so severe that blood clots can form inside the woman and these can have fatal consequences (Vlahos & Gregoriou, 2006). In comparison, men undergoing IVF are simply required to ejaculate into a container and are not subject to any invasive procedures or their associated risks. In this context, IVF is a technology which inherently presents with gender inequalities. Such inequalities are not limited to the process of IVF and can extend to the sociocultural use of them (Inhorn, 2015).

The growth and availability of IVF has seemingly normalised its use regardless of the risks involved (Franklin & Roberts, 2006). According to Prof. Marcia Inhorn, a medical anthropologist, this normalisation can make women feel like they have a duty to subject themselves to the risks and costs of IVF if their quest for a genetically related child is not fulfilled through their sexual practices (Inhorn, 2015). Similarly, women often feel that they are held

responsible for the health and wellbeing of their children (Inhorn, 2015; Franklin & Roberts, 2006; Kerr, 2004). While some factors of a child's health and wellbeing may be controllable and/or influenced by environmental factors such as nutrition and physical activity (Murphy et al., 2018), other factors, such as genetics, are less controllable (Kerr, 2004; Boardman, 2017). In the UK, 30,000 babies and children are diagnosed with a genetic condition each year (Genetic Disorders UK, 2020a). Some of these conditions have no family history and are therefore termed '*de novo*', which means that are new to a person's genetics (Veltman & Brunner, 2012), while others do. In cases of the latter, perspective parents (often the woman to a greater extent) can be faced with difficult choices on how they should form their family (Kerr, 2004).

Advances in healthcare and genetic testing for heritable disorders have enabled an increasing number of diagnoses to be made and for people with genetic conditions to have a wider range of reproductive choices (Kaur & Border, 2020; Boardman, 2017). While adoption or not having children were once generally the only options for such people, perspective parents can now opt to use donated gametes to conceive a child or preimplantation genetic testing (PGT) (Boardman, 2014; Franklin & Roberts, 2006). PGT is currently the only option which can enable both parents to be genetically related to a child without a specific genetic condition being passed on to it (Kaur & Border, 2020), but is reliant on IVF and its associated gender based risks and inequalities. The availability of such choices have been found to impact what people affected by genetic conditions believe people think about them (Kerr, 2004; Boardman, 2014; Shakespeare, 2017). Boardman (2017) found that lived experiences with a genetic condition influence reproductive decisions. This is significant because as advances in genetic testing continue, PGT could become an option for a greater number of conditions and individuals/couples may feel obligated to subject themselves to such services and the gendered inequalities inherent to them (Boardman, 2014, 2017; Boardman & Hale, 2018).

However, PGT is focused upon created embryos not being affected by a given condition in order for them to be considered viable for transfer into a uterus. This means that if all created embryos test positive for the parent's condition, the couple will not have a viable embryo (Franklin & Roberts, 2006). The couple can subject themselves to IVF for PGT again but this is dependent on several factors. Firstly, the couple has to be willing to go through

IVF again, including all the impacts on and risks to the woman (Fauser & Devroey, 2003; Franklin & Roberts, 2006). Second, the couple has to consider the emotional and financial expenses of PGT and whether they can afford them (Franklin & Roberts, 2006). Many researchers have found that the desire to have a genetically related child supersedes most rational decisions and that couples will go through great lengths to achieve their reproductive desires (Franklin & Roberts, 2006). These decisions include accruing debts into the thousands and travelling abroad to access clinics which are perceived to offer greater promise and/or services not available in their country of residence (Inhorn, 2015). The notion of travelling abroad to access ARTs is a form of transnational care which has been termed as ‘reproductive travel’ and shortened to ‘reprotravel’ by Prof. Inhorn (2015a).

Reprotravel is a growing phenomenon which is exacerbated by the variations in legislation and regulation of ARTs in different countries (Inhorn, 2015). In the UK, ARTs are regulated by the Human Fertilisation and Embryology Act 1990, as amended (Parliament UK, 1990). This Act is enforced by the Human Fertilisation and Embryology Authority (HFEA), an independent body established to licence, monitor and inspect all fertility treatment and research involving human embryos outside of the body (Genetic Alliance UK, 2019). Under the Act, PGT is only permitted for medical purposes. In contrast, in the United States (US), PGT can be used for sex-selection and to select embryos based on non-medical characteristics such as eye-colour and hair-colour (Bennett, 2016; Shanks, 2018). While these non-medical possibilities may not seem significant enough to compel a couple to subject themselves to the complexities of IVF for PGT, such choices may appeal to some couples. For example, in eastern countries where sex-selection for non-medical purposes is prohibited, couples have utilised reprotravel to achieve their reproductive desires based on sociocultural expectations (Inhorn, 2015; Rosemann et al., 2019). Such choices are usually motivated by cultural factors such as the historical one-child policy in China (Hesketh et al., 2005), and/or to avoid the expense associated with dowries (Sudha & Rajan, 1999). Considering that individuals/couples are motivated to reprotravel for such factors, the lengths perspective parents may be willing to go through to prevent a child being born with their condition could be even greater.

Many people seek transnational care to access bespoke clinical research trials and innovations (Bell et al., 2015; Rosemann et al., 2019). In such cases, trials often offer hope as a last resort and sometimes they may be the only source of hope (Bell et al., 2015). As indicated above with the IVF industry, people will seek hope and take their chances regardless of projected success rates and the associated gendered risks and inequalities (Franklin, 1997; HFEA, 2018a). A developing biotechnology which could be added to ARTs is human germline genome editing (hGGE) (Ormond et al., 2017). This is when the DNA in egg, sperm or embryo cells is either added to, removed or replaced (Morrison & Saille, 2019). Such edits could change the characteristics of the individual born as a result from them and could be passed on to future generations (Ormond et al., 2019). This means that any potential benefits and/or unforeseen side-effects could both also be passed on to future generations (Morrison & Saille, 2019). For this reason, there is ongoing international contentions on whether this technology should be developed and/or permitted for potential clinical use (Greenfield, 2019; Rosemann et al., 2019).

The most compelling reason advocated for developing hGGE is for the prevention of serious monogenic (single-gene) disorders (Daley et al., 2019). In theory, successful clinical application of hGGE could end a family's prevalence of a disorder for which they have a history (Ormond et al., 2019). This technology could also increase the number of viable embryos following PGT so women may not need to feel compelled to undergo IVF treatment several times to achieve their reproductive desires (Coller, 2019). Potentially, hGGE could therefore alleviate women from undergoing IVF more than once. This could save women from the associated gendered risks and socioeconomic burdens of IVF, should they wish to have a genetically related child to themselves and their child's father free-from their history of a given genetic disorder. In this context, a demand for hGGE should it ever be considered safe enough for clinical application is foreseeable, as is utilising reprotravel to access it (Rosemann et al., 2019).

### **Genetic Disorders and hGGE**

Scientists currently estimate that there are around 10,000 monogenic disorders of which 4,000-6,000 are diagnosable but rare (World Health Organization, 2020; Rare Disease UK, 2020; Nuffield Council on Bioethics, 2018).



Information about such disorders continues to advance and geneticists are working towards understanding the genetic bases of these disorders in greater depth (Nuffield Council on Bioethics, 2018). Disorders are usually the result of a mutation in a person's DNA (Lovell-Badge, 2019). DNA is represented by four letters, A, C, G, and T, the sequence of which determines the characteristics and functions a person has and/or exhibits (Komor et al., 2016). By knowing the general sequences of DNA for respective characteristics and functions, deviations from these can be identified as mutations and disorders can be diagnosed (Komor et al., 2016; Ormond et al., 2017). A recent project in the UK named the 100,000 Genomes Project, looked at the entire DNA sequences (the genomes) of 85,000 people, 15,000 of which were explored twice to generate a database of 100,000 genome sequences (Genomics England, 2014). Analyses of the sequences in the database (among other objectives) are hoped to reveal the genetic foundations for more of the 10,000 monogenic disorders thought to exist so that these can be tested for and diagnosed (Genomics England, 2013).

In the UK, to access genetic testing an individual/couple must request a referral from their general practitioner (GP) or have tested positive for a condition during routine pregnancy screening (NHS, 2019). A referral can take several weeks before a date for an initial consultation with a genetic consultant is booked (Genetic Disorders UK, 2020b). At a consultation, the individual's/couple's family history will be taken, a physical examination will be conducted and blood or saliva samples will be taken for analysis if a test is requested (NHS, 2019). A referral to a genetic counsellor will also be made if genetic tests are requested by the consultant (NHS, 2019). If a consultant does not share the individual's/couple's concerns of having a possible genetic link to a condition, they can refuse to request tests or to test for specific genes (Genetic Disorders UK, 2020b). If specific genes can only be tested for in specific countries, this can be another reason for transnational care being sought and/or utilised. However, in England, in continuation from the 100,000 Genomes Project, a genomic medicine service was launched in 2018 which offers whole genome sequencing (NHS England, 2019). This could also serve as a route through which testing can be sought (NHS, 2019). These services are currently available to UK citizens via the UK's national health service (NHS) if requested by a consultant, however, due to the UK's political

economy this may not be sustainable. Should an individual/couple choose/need to access genetic testing services privately, these can cost between £500-£2000 or more (NHS, 2017a). There are also direct-to-consumer genetic testing services such as 23andMe but results from these may not be considered reliable (Genetic Disorders UK, 2020b). In any case, obtaining results from genetic tests can take several months but are important for diagnostic reasons (Genetic Disorders UK, 2020b).

A diagnosis can be imperative for an individual's/a couple's reproductive choices (Nelkin & Lindee, 2004). A diagnosis can be given with a risk percentage of an individual's/couple's offspring being affected by a given condition and this can influence family planning decisions (NHS, 2019). For example, if there is 25% chance a child may be affected by a condition, the individual/couple may opt to conceive without ARTs, while if there is 75% chance, ARTs may be chosen instead. However, while a diagnosis can be made without knowing the exact gene for a condition, a risk percentage cannot be determined without it (Genetic Disorders UK, 2020b). In this context, knowing the gene for a condition can be vital for considering options, choices and possible interventions which is why data from the 100,000 genomes project could prove to be invaluable (Genomics England, 2014). The same data could also be used to develop treatments and preventative interventions such as hGGE once gene associations have been identified. A gene for a condition would have to be identified for hGGE to be developed as an intervention for it and for it to be a possible intervention to prevent a given condition (Ormond et al., 2017).

hGGE has gained widespread attention in the past eight years due to the discovery of a genome editing technique called CRISPR-Cas9 (Ormond et al., 2017). CRISPR is the abbreviation for clustered regularly interspaced palindromic repeats (Morrison & Saille, 2019). This is reference to how the technology essentially works, i.e. bacteria are programmed to locate a specific sequence of DNA and bind itself to it (Ormond et al., 2017). The 'Cas9' component, which is an enzyme, then breaks the strands of DNA so that repair mechanisms are activated (Anzalone et al., 2019). As the repairs are made, the targeted sequence of DNA can be modified (Anzalone et al., 2019). This technique is far more efficient, methodologically and financially, than other genome editing techniques (Morrison & Saille, 2019). This efficiency has widened the potential applications for genome editing and has enabled

scientists across the globe to develop its uses, one of which is for hGGE (Ormond et al., 2017). However, while the technology could be used to prevent genetic disorders, if people have access to and are willing to use it, hGGE could also be used to generate genetic disorders, both unintentionally and intentionally (Ormond et al., 2019). The fear surrounding the latter possibilities continue to influence policies, legislation and regulation of hGGE across the globe.

### **Legislation and Regulation**

Most scientists err on the side of caution when genome editing techniques are considered for applications involving hGGE. This is because the invasive technology could have unforeseeable side-effects that could transcend into future generations (Coller, 2019; Ormond et al., 2019). However, in November 2018, on the eve of an international summit on human genome editing, news broke that twin girls had been born in China following the use of hGGE (Lovell-Badge, 2019). The unexpected news was received with palpable shock and horror, and scientists at the summit were quick to scrutinise and publicly condemn the work of the lead scientist responsible for the twins' birth (Daley et al., 2019). Scientists continue to claim that the methods used to make the edits meant that they could not have been successful and that the technology is yet to be considered safe for any clinical trial (Daley et al., 2019). Additionally, the couples involved in the research are thought to have been misled and consequently the women would have been unnecessarily subjected to the gendered risks of IVF. As such, following the news, several international initiatives were launched in response to it and the Chinese scientist who instigated the birth of the twin girls has been sentenced to serve three years in prison (Sample, 2019). However, these advances have not deterred a Russian scientist from wanting to conduct similar research (Cyranoski, 2019), and many countries still do not have clear legislation and/or regulation for hGGE (Yotova, 2017).

Due to the variations in legislation and regulation across countries, such research is currently possible in many countries through public and/or private funding. Scientists in the US and other countries where research involving hGGE is not carefully regulated and/or have strong underlying histories

involving eugenics, such as China and Germany, have called for a global moratorium on hGGE (Lander et al., 2019). The political and economic structures in such countries perhaps explain their motivations and support for this call. In comparison, the UK, who would have no need to participate in a moratorium due to its own fairly robust legislation and the HFEA have no intention of participating in any such moratorium (Kaur & Border, 2020). These differences mean that the development of hGGE if added to ARTs could motivate perspective parents with genetic conditions to utilise reprotravel to access hGGE to achieve their reproductive desires (Rosemann et al., 2019). In this context, international initiatives launched in 2019 could serve to generate a shared grounding for all involved in the development of hGGE regardless of the country in which they work and/or reside. Such initiatives could potentially alleviate some of the socioeconomic and cultural inequalities that could surround accessing the technology and the implications, as detailed above, these have for women.

The first initiative was convened by the UK's Royal Society, the US National Academy of Science and the US National Academy of Medicine in March 2019, and is the International Commission on the Clinical Use of Human Germline Genome Editing (The Royal Society, 2019). The commission have held several public meetings and webinars to address issues surrounding hGGE, in Washington and London, which will inform its work and conclusions (The National Academies of Science, Engineering, and Medicine, 2019; The Royal Society, 2019). It is aiming to develop principles, criteria and standards for the clinical use of genome editing of the human germline and is anticipated to publish these in 2020. While countries may choose not to adopt the commission's conclusions, many anticipate that they will be widely welcomed and adhered to. The second initiative is led by the World Health Organization's Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing. The committee has developed a global registry which aims to track all clinical trials and research involving human germline cells, and launched this in August 2019 (World Health Organization, 2019b). The committee also aims to advise and make recommendations on mechanisms for governance of hGGE in 2020 (World Health Organization, 2019a). The committee's recommendations may be more relevant to some countries than others, but are

hoped to even transnational inequalities regarding access to and the use of hGGE.

There are several countries which, under the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, commonly referred to as the Oviedo Convention, have agreed not to utilise hGGE, but these are few in a global context (Council of Europe, 2011). Article 13 of the convention states that ‘An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants’ (Council of Europe, 1997). Article 13 therefore prohibits hGGE as modifications could be introduced to future descendants as a result of utilising the technology. UK legislation currently intends to prohibit all clinical applications of hGGE but this needs to be readdressed if the UK is aiming to robustly uphold this stance (Kaur & Border, 2020). This is because the prohibitions in the HFE Act specifically relate to women who have been female from birth (i.e. ciswomen) (Parliament UK, 1990). As such, because of ongoing scientific advances with womb transplants, transwomen and/or men could choose to gestate and birth children which have had their germline cells edited. Such possibilities would not be prohibited from being licenced by the HFEA under the Act so long as the embryo is transferred within 14 days from its creation (Kaur & Border, 2020). Nonetheless, legislation in the UK is otherwise relatively clear and the HFEA are renowned for its regulation of ARTs. In the above context, the committee’s recommendations may not hold much relevance to these countries.

In contrast, countries such as the US and China may substantially benefit from the recommendations that the committee makes. These countries are highlighted as the unregulated practices in these countries are of global concern to humanity (Baylis, 2019). In the US biohackers conduct unregulated experiments using genome editing technologies in the belief that they are advocating for fairer access to the technology (Baylis, 2019). While biohackers may facilitate fairer access, they cannot ascertain whether their followers and audiences have considered the repercussions and consequences of experimenting with genome editing technologies to the extent they have. In such cases later regret is too late to undo the catalyst to events that could

unfold. In China, as mentioned above, scientists have already unsuccessfully trialled hGGE (Lovell-Badge, 2019; Daley et al., 2019) and consequently women have been unnecessarily subjected to the associated gendered risks. This was possible due to the nuances of legislation and regulation in China (Sample, 2019). While the consequences of experiments and research in these countries cannot be undone, further premature applications of hGGE could be prevented and women could be spared from the gendered risks associated with IVF, if such countries adopt the recommendations that WHO's expert advisory committee publish.

### **Methodologies**

In order to ascertain UK public's views on reprotravel, part of a mixed-methods, online public survey conducted between 1<sup>st</sup> March 2018-31<sup>st</sup> May 2018, questioned respondents' views on reprotravel and prosecution. The survey was titled 'Understandings of Genetic Editing and its Potential Uses with Human Reproduction'. The survey was designed using Qualtrics software and was aimed at people living in the UK aged 16 or over, who were willing to participate voluntarily. To avoid any potential bias, respondents were given no incentive or compensation for their time taken to complete the survey. The respondent sample was weighted on four demographic factors; gender, age, religion and whether the respondent is affected by a genetic condition. The latter two demographics were deemed significant as they are often anticipated to have strong views on genome editing (MacGillivray & Livesey, 2018).

The final sample consisted of 521 respondents, 52% of which self-identified as female, aged 16-82, (rounding the numbers) 37% of which self-identified as religious and 29% as being affected by a genetic condition. Respondents were also asked to state their occupation, which to an extent could indicate their socioeconomic status and/or level of education. Respondents included professionals, skilled workers, some who were unemployed at the time of completing the survey and some who were retired. These demographics are detailed alongside respondents' answers shared in the findings section in this article. The majority of respondents had no direct expertise or professional interest in hGGE technologies and are therefore

considered to be the wider public in the UK. The findings from the survey were reached using mixed-method analysis via SPSS and NVivo software.

The survey consisted of four sections; the first was on knowledge and understanding of genome editing, the second on hypothetical practical applications relating to factors of disease, the third was on regulation and ethics, and the final section captured the demographic information shared above. Findings from the survey were used to inform 11 semi-structured interviews with professionals/experts who could speak to the future of hGGE in the UK and/or who could provide the most up to date information on hGGE. The semi-structured interviews sought to ascertain the existing scientific and legal parameters of hGGE in the UK and to explore how they could expand to enable hGGE for clinical applications. Data from some of these interviews informed the questions and activities for 11 interactive interviews with a total of 21 people affected by a respective range of genetic conditions. Some of these interviews were conducted in groups of 4-5 people, in pairs or one-to-one depending on the participants health and availability either via Adobe Connect software or in accessible public meeting rooms.

All the interviews were transcribed and then imported to NVivo software for analysis. Analysis consisted of core themes being identified and then transformed into overarching categories for further exploration and/or consideration, such analysis would traditionally be considered a mix between grounded theory and thematic analysis (David & Sutton, 2004; Mason, 2017). Findings from these interviews will also be discussed in this article. All the primary research detailed in this section received ethical approval from the University of Cambridge's Department of Sociology's Ethics Committee prior to being conducted, and conformed to the British Sociological Association's guidelines on conducting ethical research (British Sociological Association, 2017). As such, all participants and respondents provided informed consent for the research they chose to be part of and where appropriate/possible participants were given the right to withdraw to a specified date.

## **Findings and Discussion**

4.8% (25/521) of respondents to the survey felt that hGGE should not be legalised in the UK for clinical application. The remaining respondents were either supportive of hGGE being legalised in the UK for clinical application, such as preventing children being born with a given genetic disorder, without reservation or supportive depending on various factors. These findings support findings from a survey commissioned by the Royal Society (van Mil et al., 2017) and suggest that a significantly large majority of the UK population are supportive of hGGE for clinical applications. A large proportion of the support for clinical application of hGGE did however come with several reservations. Respondents felt that robust regulation to prevent misuse of hGGE, i.e. any use that is not for medical benefit, is primal to it being permitted beyond research purposes. This is evidenced by the following answers from respondents:

It [hGGE] has the potential to make a huge difference to the quality of life of so many people. However, it would need legislating really really carefully in order that it not be misused.

(Respondent 63: Female, 31, Midwife, not religious, not affected)

[There] Needs to be very careful control of the process. Once it [hGGE] is tried and tested for preventing disease and illness where is the line drawn? Could make arguments for all sorts of ‘improvements’ and move towards some dystopian future.

(Respondent 56: Male, 22, Undergraduate Student, not religious, not affected)

Professionals/experts in the field assert that any future amendments to the HFE Act would only permit hGGE for medical purposes, and that should it be permitted, this would initially only be for ‘serious monogenic disorders’ and where there is ‘an unmet medical need’. This intention however only pertains to the UK. The WHO’s expert advisory committee’s forthcoming recommendations (World Health Organization, 2019a) may assist on addressing this reservation on a wider scale if they support this assertion and if the recommendations are adopted by other countries.



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Respondents also held reservation towards the potential clinical application of hGGE on there being proven, transparent, safety and success of the technology, this included highlighting the risk of any negative side effects hGGE could have. The following answers from respondents evidence this claim:

If it is safe, affordable and the level of success is high.

(Respondent 50: Male, 41, PhD Student, not religious, not affected)

If genetic editing works efficiently and safely, it should be available to all people who can benefit. If there are risks, these should be well understood and explained so that an informed choice can be made.

(Respondent 323: Male, 56, Computer Programmer, religious but no influence, not affected)

Scientists in the UK are very mindful of this reservation and continuously proceed with extreme caution when addressing the efficacy of current hGGE techniques. Discussions with Professor Robin Lovell-Badge and Dr Kathy Niakan, Biologists at the Francis Crick Institute in London, reassure such caution. While both of these prominent scientists are supportive of permitting hGGE for potential clinical application, neither hesitate to emphasise that current hGGE are still developing and are not yet efficient enough for clinical application. Their cautious manners speak to ethical, moral and scientific principles which were lacking in the research conducted in China, and which Biohackers in the US seemingly do not prioritise (Baylis, 2019). While the UK population may be assured that scientists in the UK are capable of governing themselves in accordance to widespread ethical, moral and scientific principles, this is evidently not true of scientists in some other countries (Lovell-Badge, 2019). The suggested moratorium outlined earlier in this article may have been one way of acknowledging this matter, but the International Commission's work towards developing standards for clinical uses of hGGE is perhaps a more pragmatic approach. The commission's forthcoming standards, if they are adopted, could ensure that hGGE is not prematurely used in clinical applications in countries where ethical and moral principles are not at the core of scientific practices. These could also serve to protect women from unnecessary gendered risks associated with IVF, pregnancy, and childbirth, and the impacts these can have on their long-term

health and the gendered unequal expectations of rearing and caring for any resulting children (Coller, 2019).

Inspired by Inhorn's (2015) research, a subsequent question in the survey queried views on whether people living in the UK should be allowed to travel abroad to access hGGE if it was not legalised in the UK for clinical applications. 65.64% (342/521) of respondents were in favour of this proposition and only 7.49% (39/521) of respondents were explicitly against it. This suggests that the majority of respondents hold fairly liberal views towards reprotravel in relation to it being utilised to circumvent UK legislation. The remaining 26.87% (140/521) of respondents held reservations based on several factors. Such factors included the intent for seeking genome editing, the reason why hGGE was not legal in the UK, the safety of hGGE outside of the UK, how follow-up care would be navigated through transnational borders, and the difficulty of preventing people from utilising reprotravel. These factors are evidenced by the following answers from respondents.

Should be depending on the reason for wanting genetic editing. Travel and being able to travel abroad is usually only available to those who are wealthy. Becomes a rich man's game.

(Respondent 144: Female, 34, Manager, religious but no influence, not affected)

It will depend on the reasons for why it is illegal. Would legislators have a reason to think that this would interfere with domestic welfare, health, or security?

(Respondent 320: Male, 28, Researcher, not religious, not affected)

Safety. We have an NHS which puts the welfare of the patient first. Some other countries operate healthcare on who can afford it, which creates a culture of huge disparity in access to quality healthcare options. If it is available, it should be available to all who need it not just those with money.

(Respondent 173: Female, 44, Professional, not religious, has condition)

Availability of trained professionals to be able to deal with any follow up care/intervention back in the UK. Cost would also be a bit of an issue if the person could not self-fund the treatment.

(Respondent 327: Male, 34, Cancer Research Nurse, not religious, not affected)

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Impossible to police.

(Respondent 281: Male, 32, Driving Instructor, not religious, has condition)

These factors are translatable to citizens in other countries as the same considerations are accountable. The specific sociocultural, political and economic contexts which influence individuals'/couples' motivations to utilise reprotravel may differ according to the countries in which they reside but these are likely to be pertinent to the sociocultural context of a given country (Inhorn, 2015). For example, hGGE is not being used in clinical applications in the UK because it is not yet considered to be safe enough, but if UK citizens travelled abroad to access the technology, upon return, medical professionals in the UK may not have the expertise to deal with complications arising from it (Bell et al., 2015; Rosemann et al., 2019). In this scenario, the lack of availability in the UK, in addition to other factors, is designed to protect its citizens from adverse side-effects for which its healthcare system and professionals are not yet prepared, circumventing this through reprotravel therefore threatens this ability. As such, individuals/couples may benefit from taking the underlying context of practices in their country of residence into consideration before accessing transnational care. This could prove to be particularly sagacious in relation to the growing industry of reprotravel and the upcoming risky possibilities that could be made available through it (Grand View Research, 2019; Ormond et al., 2019). Women can prevent themselves from being subjected to the gendered risks of IVF and the risks of its platform applications by challenging the necessity if accessing them and critically assessing the safety of them, in their country of residence and/or abroad.

Perhaps surprisingly, 76.39% (398/521) of respondents felt that even if hGGE were to remain illegal in the UK for clinical applications, people who live in the UK should not be prosecuted if they were to travel abroad to access it. This is because respondents largely felt that only people who are really desperate to have a genetically related child without their disease are likely to utilise reprotravel to fulfil that desire. Respondents therefore also felt that hGGE would not be sought abroad for reasons that do not align with ethical and moral principals in the UK, i.e. for non-medical purposes such as eye-colour or other aesthetic characteristics (Coller, 2019). However, a converse

reason for not wanting people to be prosecuted was because it would be difficult to police. This was also relayed by professional/experts in the field who highlighted that UK legislation is yet address reprotravel for purposes not supported in the UK and that people who do utilise reprotravel are hard to track. Respondents who felt that people should be prosecuted cited fines, imprisonment, refused re-entry to the UK and a ban from accessing care via the NHS as possible sanctions, but also recognised that enforcing these would be a challenge for the UK judicial system. In this context, while current legislation, regulation and/or practices in the UK could force its citizens to access hGGE abroad, acts to prevent children being born with genetic disorders would still be supported by the wider public in the UK. However, support towards such acts is also reserved due to their potential to exacerbate socioeconomic and gendered inequalities associated with ARTs and reprotravel.

### **Conclusion**

This article detailed how IVF is considered to be a technology of hope and how such hope is reflected in its uptake despite its modest success rates (Franklin, 1997; HFEA, 2018a). This article then outlined the gendered risks that are inherent to current IVF practices (NHS, 2017b). It also claimed that the normalisation of IVF has led to a sociocultural discourse of women feeling a duty to utilise the technology to have a genetically related child if this desire is not fulfilled through their sexual practices (Inhorn, 2015). This article then argued that developments in genetic testing and diagnoses being made have increased reproductive choices for people living with genetic conditions (Genomics England, 2014; Wang & Sauer, 2006; Boardman, 2017). Such choices could expand to include hGGE, which in addition to preventing children being born with their parent's condition, could mean that women do not need to undergo IVF multiple times to achieve their reproductive desires, thereby reducing the gendered risks and inequalities they are subjected to.

However, the legislation and regulation of hGGE differs across countries (Yotova, 2017) and because of this some individuals/couples may feel forced to access transnational care. The forthcoming recommendations from two international initiatives launched in 2019, one regarding the governance and oversight of hGGE (World Health Organization, 2019a) and the other

regarding clinical standards (The Royal Society, 2019), are therefore duly anticipated and are hoped to even practices across countries. Findings from a survey which questioned UK publics' views on reprotravel and interviews with professionals/experts in the field of hGGE revealed that a majority would support the clinical application of hGGE for medical purposes. They also revealed that the UK public largely feel that people should be able to travel abroad to access hGGE should it not be legalised for clinical application in the UK, and those that choose to do this, should not be prosecuted if they do. This support is nonetheless reserved on hGGE being robustly regulated and safe (Kaur & Border, 2020), and with caution that limited access to the technology could exacerbate socioeconomic and gendered inequalities within society.

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