

## Impact case study (REF3)

<b>Institution:</b> London School of Economics and Political Science		
<b>Unit of Assessment:</b> 18 - Law		
<b>Title of case study:</b> Reforming the law on storage time limits for frozen eggs		
<b>Period when the underpinning research was undertaken:</b> 2008-2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b> Emily Jackson	<b>Role(s) (e.g. job title):</b> Professor of Law	<b>Period(s) employed by submitting HEI:</b> 1998-2004; 2007 to present
<b>Period when the claimed impact occurred:</b> 2016-2020		
<b>Is this case study continued from a case study submitted in 2014?</b> No		
<b>1. Summary of the impact</b> (indicative maximum 100 words)		
<p>Professor Emily Jackson's research, arguing that storage time limits for frozen eggs should be amended so as to not breach the human rights of "social" egg freezers, has underpinned policy interventions intended to reform the law. With direct input from Jackson, the Storage Period for Gametes Bill was introduced to the House of Lords in June 2019 and, if passed, will provide the option of extended storage for women who have not yet completed their families. Her research has also informed <i>Timeless</i>, an innovative public engagement campaign which has improved public awareness of egg freezing and reproductive rights.</p>		
<b>2. Underpinning research</b> (indicative maximum 500 words)		
<p>Professor Jackson has been carrying out research into the ethical, legal, and social implications of assisted conception techniques since the late 1990s. A key theme of her first monograph, <i>Regulating Reproduction: Law, Technology and Autonomy</i> [1], and of subsequent publications, has been the need to take seriously reproductive autonomy and to recognise that both infertility and its treatment are stressful and difficult, and that prospective patients and their partners need help and support in order to make sense of their options.</p> <p>Jackson's recent research has focused on the commercialisation of assisted conception services. Most fertility treatment in the UK is provided in the private sector and has become "big business". In addition to the strain of infertility, patients are often also under considerable financial pressure and, as a result, may be willing to try anything in order to increase their chance of success. It is recognised that fertility clinics can oversell and overtreat, perhaps by offering services for which the evidence base is either poor or non-existent. As well as the risk of overselling, the new option of "social" egg freezing for women concerned about their age-related fertility decline raises important ethical and legal issues. Perhaps most pressing, as it is currently causing real hardship, is the question of the storage time limits for frozen eggs.</p> <p>In her 2016 <i>Journal of Medical Ethics</i> article [2], Jackson raised, for the first time in the literature, the unfairness of the statutory storage time limits when applied to social egg freezers. The Human Fertilisation and Embryology Act 1990, as amended, set a ten-year limit for the storage of embryos and gametes. Regulations passed in 2009, before developments in vitrification techniques meant social egg freezing became a routine clinical option, allow for the possibility for extended storage, up to a maximum of 55 years, for patients who are, or are likely to become, "prematurely infertile". This works well for men who freeze their sperm because they are about to undergo medical treatment which may leave them infertile. Women's age-related fertility decline is not "premature" infertility, and hence most social egg freezers are ineligible for an extension and can store their eggs for ten years only. If a woman froze her eggs at age 25, she would face their mandatory destruction at 35, before she is likely to want to use them.</p> <p>These rules were not drafted with the interests of egg freezers in mind, and Jackson argues that they are – unintentionally – contrary to their interests and to good clinical practice, as well as representing a breach of their human rights. First, the rules create an incentive for women to freeze their eggs in their late 30s, after their fertility is already in decline. If a woman in her late 30s freezes her eggs, she may have until her late 40s to use them, but she is likely to need to undergo more cycles of egg retrieval in order to have a sufficient number of eggs to freeze. Second, if a woman struggles to conceive after her own eggs were destroyed, she will be advised to use donor eggs. Not only is the unnecessary use of donor eggs likely to be contrary to the egg freezer's</p>		

wishes, it will also cost more and pointlessly expose the donor to the risks of an invasive procedure. Third, the forced destruction of a person's gametes undoubtedly represents an interference with her Article 8 right to private and family life. In order to be justifiable under Article 8(2), it would have to be established that the ten-year limit, with no extension for social egg freezers was "necessary in a democratic society" either "for the protection of health or morals, or for the protection of the rights and freedoms of others". It is impossible to see how permitting time-limited extensions to the storage of eggs to ensure that women can use own their frozen eggs in their 40s would pose a risk to the rights of others, or to "public safety" or "health and morals".

The solution, Jackson argues, is not to get rid of the storage time limit altogether. There is evidence that former patients find it difficult to make decisions about their stored gametes and embryos and, without a time limit, clinics might be obliged to store them indefinitely. Instead, the solution is to amend the Human Fertilisation and Embryology (Statutory Storage Period for Gametes and Embryos) Regulations 2009, by providing an option for extension for women who have not yet decided whether they want to use their frozen eggs in treatment.

In her 2018 *Biosocieties* article [3], Jackson tackled some of the broader ethical issues raised by social egg freezing. This article described egg freezing as an ambiguous technology. Looked at positively, it could be said to liberate women from the biological constraint of age-related fertility decline. More sceptical commentators have suggested that it represents a medical solution to a social problem, that it reinforces motherhood as women's essential destiny and widens the gap between rich and poor women's experiences of childbearing. Jackson argued that while providing women with more options is positive, at the same time, women need clear and robust advice about the likelihood that they will use their eggs in the future, and the fact that IVF fails more commonly than it succeeds. Egg freezing is expensive and invasive, and it is important that it is not oversold to women as a guaranteed way to preserve their fertility indefinitely.

### 3. References to the research (indicative maximum of six references)

- [1] Jackson, E. (2001). *Regulating Reproduction: Law, Technology and Autonomy*. Hart/Bloomsbury. ISBN: 9781841130545. Winner of the 2002 Society of Legal Scholars' annual book prize.
- [2] Jackson, E. (2016). "Social" egg freezing and the UK's statutory storage time limits. *Journal of Medical Ethics*, 42(11), pp. 738-741. DOI: 10.1136/medethics-2016-103704.
- [3] Jackson, E. (2018). The Ambiguities of "Social" Egg Freezing and the Challenges of Informed Consent. *Biosocieties*, 13, pp. 21-40. DOI: 10.1057/s41292-017-0044-5.
- [4] Jackson, E. (2019). *Medical Law* (5<sup>th</sup> edition). Oxford University Press. ISBN: 9780198825845. Winner of the British Medical Association "Basis of Medicine" Book Award (for the 4th edition).

### 4. Details of the impact (indicative maximum 750 words)

This research [2] [3] has formed the basis of Jackson's contribution to policy interventions intended to effect a change to the law, and so provide women with the option to extend the storage of their eggs. It has also underpinned her involvement in the *Timeless* project, which used novel public engagement techniques to communicate accurate information about egg freezing and improve awareness of fertility issues more generally.

#### Reforming the law on the storage time limit

Since 2018, Jackson has been actively involved in a campaign to change the law on gametes storage periods, working closely with Baroness Ruth Deech, former Chair of the Human Fertilisation and Embryology Authority, lawyers from Bindmans (who are acting for women bringing an application for judicial review of the time limit on human rights grounds), and the Progress Educational Trust. With direct contributions from Jackson, Baroness Deech introduced the Storage Period for Gametes Bill to the House of Lords, which requires the government to consider amending current regulations to permit the extension of the storage period for those who have not completed their family. The government has since launched a public consultation.

Baroness Deech first asked the question of what plans the government had to review the 10-year limit in the House of Lords on 12 July 2018 [A]. At that point, it was not clear whether a change to storage limits would require primary legislation. Jackson advised that, as the option to extend the limit in cases of premature infertility is already set out in the 2009 Regulations, to add another

option for extension could be done through amending the same Regulations, obviating any need for primary legislation [B]. Regulation-making powers exist precisely to allow legislation to respond to new scientific developments such as improved vitrification techniques, in this case.

In September 2018, Baroness Deech moved for a debate in the House of Lords to mark the 40<sup>th</sup> anniversary of In Vitro Fertilisation (IVF). Ahead of this debate, Jackson provided a parliamentary briefing note to be distributed to peers, outlining the background, rationale, problems, and proposed solutions for the current gametes storage limit. During the debate, Baroness Deech argued for urgent review of the storage limit, citing the possible breach of human rights law previously identified by Jackson [2]: *"The regulations as they stand are discriminatory and may be contrary to Article 8 of the European Convention on Human Rights because sperm can be stored for 55 years"* [A].

As well as advancing the issue in parliament, Baroness Deech also made representations to the Department of Health and Social Care in autumn 2018. In correspondence with Jackie Doyle-Price MP, Parliamentary Under Secretary of State at DHSC, Baroness Deech sought Jackson's input, including in a detailed response to the minister's initial letter, outlining the problems with the current storage limit and its inducements to poor clinical practice, as first described in [2], and also appending a simple suggested draft regulatory change [B].

In February 2019, Baroness Deech again raised the matter of the 10-year storage limit in the Lords, this time explicitly asking whether the government had plans to review its compliance with human rights law. Speaking in the debate, Baroness Deech asked: *"Will the Government not enact a simple regulatory change, costing nothing, which will end this interference with private and family life under human rights law - and the indirect discrimination - and give hope to thousands of women?"* [A]. Baroness Deech has subsequently confirmed the importance of Jackson's research to this intervention: *"it was Prof Jackson who clarified that the law was discriminatory when compared with the storage limit of sperm, and that it was likely to face a human rights law challenge... Her authority as a former member of the Human Fertilisation and Embryology Authority is acknowledged and preeminent"* [B].

Shortly after this debate, Baroness Deech began the process of introducing a Private Member's Bill to effect the amendment of the storage limit in the 2009 Regulations. Jackson was again consulted and provided recommendations on the drafting of the crucial amendment to Regulation 4. This included a provision introducing a new exception to the 10-year limit, in respect of any person to have provided a gamete who *"has expressed that they have not yet completed their family"* [C]. This is consistent with an alternative approach outlined in the Jackson research [2]. This, crucially, provides for those women who wish to freeze their eggs for social reasons at a time of relatively high fertility, and brings them into parity with those likely to become prematurely infertile, negating the human rights implications. Again, Baroness Deech has attested to the value of Jackson's expertise in the drafting of this Bill: *"[Jackson's] drafting was far superior to anything I might have obtained from counsel because of her unrivalled knowledge of the law and clarity in explaining it"* [B].

The Bill introduced to the House of Lords by Baroness Deech on 6 June 2019 [C] also contained a requirement for DHSC to open a consultation. The Gamete and Embryo Storage Limits Consultation - initially delayed by recess, prorogation, and purdah - was launched on 11 February 2020 [D]. Speaking about the consultation to the BBC, Caroline Dinenage, a DHSC minister, said she was *"particularly concerned by the impact of the current law on women's reproductive choices"* [E]. Indeed, within the consultation document itself the government acknowledges having been *"persuaded that there is a case to consider a change to the legislative framework"* and that there are *"important arguments to consider about reproductive choice for women and how the current legislation may affect that"* [D].

Alongside these legislative efforts, the Progress Educational Trust (PET), a UK charity working to advance public understanding of, and engagement with, science, law, and ethics in the fields of human genetics, human reproduction, embryology, and stem cell research, has been spearheading a parallel advocacy campaign. PET published a press release to coincide with the Bill, urging the government to seize the opportunity and act quickly, and directly quoting Jackson

when setting out the arguments in favour of amending the Regulations to give an option for extension to women who have frozen their eggs [F].

On 28 October 2019, to coincide with National Fertility Awareness Week, PET formally launched its #ExtendTheLimit campaign, reiterating its plea to government to extend the storage limit for non-medical (social) reasons. PET director, Sarah Norcross, articulating why the current legislation is unfair, again drew attention to the human rights implications first raised by Jackson [2]: *"The 10-year storage limit for social egg freezing is a very clear breach of human rights: it curtails women's reproductive choices, harms women's chances of becoming biological mothers, does not have any scientific basis (eggs remain viable if frozen for longer than ten years), and is discriminatory against women because of the decline in female fertility with age"* [F].

Speaking as the public consultation was launched, Norcross welcomed the government's action and the importance of the progress made to date: *"This is of huge significance for many women, not just those who have frozen their eggs, but women who are considering doing so. [Extending the storage limit] will enable women to exercise reproductive choice, freeing women from the shackles of an outdated, discriminatory, and unscientific law"* [F]. Indeed, egg freezing cycles have increased precipitously (by 256% from 2012 to 2017) and this removal of limitations encourages more women to avail of the option and reestablishes their reproductive autonomy. It also ends the costs and waste of mandatory destruction and serves to reduce the frequency donor eggs are required. Norcross has subsequently underlined the importance of the Jackson research to the #ExtendTheLimit campaign:

*"Her writing on the inequity of the ten-year limit on social egg freezing is one of the key foundation stones upon which the materials for our campaign have been built. Prof Jackson has been involved in the campaign from the outset, advising on the law, [and] drafting documents and letters to be sent to government ministers... She has provided robust legal opinion which we have shared with DHSC. Her contribution has helped PET attract and retain government interest in this issue at the highest level."* [G]

In April 2020, in the wake of the Covid-19 pandemic, all fertility treatment in the UK was suspended. Those people for whom the 10-year limit was imminent when treatment was suspended were faced with the distressing prospect of seeing their gametes or embryos mandatorily destroyed, before these gametes or embryos could be used in treatment. To address this, the government introduced new Regulations, which came into force on 1 July 2020, granting a temporary two-year extension to the 10-year legal limit. Coverage of this announcement cited the #ExtendTheLimit campaign. Jackson has provided advice to those who were and were not able to take advantage of this [B].

In September 2020, the Nuffield Council on Bioethics published a policy briefing on egg freezing in the UK in response to increased interest in the topic and the ongoing Government review. Jackson's research [2] [3] was cited five times and she was also personally acknowledged [H]. This will be used by Nuffield to brief parliamentarians, respond to consultations, and in direct engagement with policymakers. The policy briefing concluded that *"there are few arguments against increasing storage limits for social egg freezing"*, describing the way social egg freezing is presented and marketed as potentially concerning and meriting closer attention [H].

Baroness Deech has been unequivocal in describing the indispensability of the Jackson research to progress made towards reforming the law on the storage time limit:

*"[Jackson] has masterminded the plan of action to change the law, and she is undoubtedly the leading reproductive medicine lawyer of this generation. She has demonstrated a combination of scholarship and practical action, putting that scholarship to use in order to benefit the thousands affected by the law. I have the greatest admiration for her work and her powers of persuasion, and she deserves the highest recognition."* [B]

### **Improving public awareness of egg freezing and reproductive rights**

In March 2016, Jackson was an advisor to the *Timeless* project, created to inform and engage women in thinking about their options in relation to social egg freezing and fertility, whilst also raising public awareness about a topic that could have a significant impact on women and society in the future. Designed by creative consultancy The Liminal Space, with additional research

expertise from Professor Anne Phillips (LSE) and Dr Yacoub Khalaf (Assisted Conception Unit, Guy's and St Thomas' Hospital), *Timeless* was a fictional beauty brand created to engage and educate the general public on the legal, ethical, and social issues raised by egg freezing.

A novel output of this project was a pop-up “shop” in Old Street Underground Station, London. The shop featured a range of *Timeless*-branded beauty products intended to communicate the facts around egg freezing in a visually arresting way and inform women of, for instance, the chances of social egg freezers using their eggs in future or the varying likelihood of success in fertility. For example, the *Eau so Pressured* perfume range dramatically illustrated women’s declining ovarian reserves with a number of bottles corresponding to a woman’s age from 12 to 50, each filled with red fluid proportionate to her remaining quantity of eggs. Drawing on research described in [3], Jackson contributed to the short film shown at the shop - and promoted alongside other “products” on the website - and was a panellist for an on-site event, “Should You Freeze Your Eggs?”, which intended to cut through the confusion and misinformation surrounding egg freezing and look frankly at the pros and cons from a medical, social, and personal perspective. Ipsos MORI conducted a series of in-depth interviews intended to establish how effective the pop-up shop approach had been in fostering dialogue with the public about this ethically and practically complex issue. Interviews revealed that attitudes towards family and careers are changing, and that it was felt that policy and legal structures should also change to keep up [I]. The project was found to be a “good way to kick-start public dialogue and bring home abstract ideas to people’s everyday reality” [I].

More than 1,200 people visited the shop, with approximately 5,000 accessing the *Timeless* website during the same time. The project was the subject of 54 pieces of media coverage, with a reach of 11.8 million people across print, radio, and TV, and over 335,000 online [J], including an *Observer Magazine* cover feature and live broadcasts on BBC Radio and Sky News. In the *New Scientist*, Agatha Haines hailed *Timeless* as a good beginning to addressing the knowledge gap on this subject: “this pop-up provocation provided women with an opportunity to discuss an intimate issue in an intimate setting. Time spent here showed me how to think about an idea whose revolutionary promise is matched only by the dearth of public information about it” [K]. BioNews, which specialises in news and comment on genetics, assisted conception, embryo/stem cell research, and related areas, described it as “informative, and the idea behind it was original and fun, making the shop well worth the visit” [L].

#### 5. Sources to corroborate the impact (indicative maximum of 10 references)

[A] Hansard, House of Lords debates on Human Fertilisation and Embryology: [12 July 2018](#); [13 September 2018](#); and [20 February 2019](#).

[B] Supporting statement from Baroness Ruth Deech, 8 October 2020.

[C] [Storage Period for Gametes Bill \[HL\] 2017-19](#), introduced 6 June 2019.

[D] Department of Health and Social Care, [Consultation document: gamete \(egg, sperm\) and embryo storage limits](#), 11 February 2020.

[E] “[Frozen-egg storage 10-year limit 'could be extended'](#)”, BBC News, 11 February 2020.

[F] Progress Educational Trust press releases: [19 June 2019](#); [28 October 2019](#); and [11 February 2020](#).

[G] Supporting statement from Sarah Norcross, Director, Progress Educational Trust, 6 October 2020.

[H] Bioethics Briefing Note: [Egg freezing in the UK](#), Nuffield Council on Bioethics, 30 September 2020.

[I] “Fertile thoughts: how a pop-up shop can bring egg freezing to life and engage the public in dialogue”, Ipsos MORI, April 2016.

[J] *Timeless*, a case study report, The Liminal Space, February-March 2016.

[K] “[Pop-up show apes beauty brands to highlight egg-freezing issues](#)”, *New Scientist*, 9 March 2016.

[L] “[Event Review: Timeless pop-up shop](#)”, BioNews, 14 March 2016.