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Bringing the People Back In : Public Consultation in the UK and France

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Theda Skocpol, Peter Evans, *Bringing the State Back In*, Cambridge University Press, 1985.

In the realm of bioethical issues, the vast majority of modern democratic states have been searching for ways to improve and increase participation by its citizens in the framing of new regulatory systems.

This talk will present two examples of such initiatives, one created in France and another launched and repeated on several occasions in the United Kingdom.

Both France and the United Kingdom have top-down regulatory systems in these areas, but have different ways of soliciting participation from the public, both with strong and weak points.

FRANCE

« Les états généraux de la bioéthique »

General Public Discussion on the Revision of the French Bioethics Law

The 1994 French bioethics laws regulate access to:

=> ART, PGD practices, organ and gamete donation, stem cell research, and the use of genetic information.

First voted in 1994, they are meant to be revised every 5 years.

Prior to the 2009 revision, then President Sarkozy launched the first General Public Discussion / “Les états généraux de la bioéthique”, a hybrid consultation producing:

- Several institutional reports.**
- An interactive internet site.**
- Organized debates within regional ethics committees.**
- Three “Consensus Conferences” taking place in different cities and focusing on one or two particular issues.**

France - Modalities

For each “Consensus Conference”, a representative sample of 25 citizens was chosen using an opinion-poll method.

They first attended 2 week-end seminars, receiving instruction on procedures and issues presented by a multidisciplinary team of experts. The latter had been chosen by an organizing committee mandated by the government.

The “Consensus Conference” citizens were then invited to a general public debate where “key witnesses” - important figures known for their expertise on the topic - would answer their questions.

At the end of this process, each of the three groups of citizens drafted a list of recommendations. These were in turn synthesized in the consultation’s final report drafted by a philosopher, Alain Graf, mandated by the government for the task (2009).

France – Evaluation 1

CITIZEN RECOMMENDATIONS =>

1. The only recommendation that was followed in the subsequent revision of the laws was maintaining the anonymity of gamete donation albeit with more access for ART children to donor medical files.
2. Other recommendations - including that “All couples, without discrimination, have a right to be parents” - were not adopted.

CRITICISMS =>

1. Timid and inconclusive; a “flabby consensus”.
2. Disappointing to participants because most of the previous laws were upheld despite general feeling that they did not address the society’s broader concerns.

Main problem with this type of consultation => It asked citizens to discuss and validate universal principles that were already in place in the 1994 FBL, *i.e.* anonymity, non-commodification, “unavailability” of the human body, meant to incarnate the national common interest, without exposing contradictions and difficulties present within these very principles.

France – Evaluation 2

CONSTRUCTIVE POINTS =>

1. An obvious improvement from the past seeing that the 1994 FBLaws were essentially drafted based on recommendations from the French National Bioethics Committee created by President Mitterrand for the very purpose of guiding legislators, a group made up of doctors, researchers in biomedicine, philosophers, and representatives of religious denominations.
2. The fact that “new values” presented by consulted citizens, *i.e.* the importance for children to know their history, importance for any committed couple no matter their sexual orientation to access ART, were expressed in an official public forum and mediatized.
3. From the *Etats généraux* on, a national discussion was launched in the public arena and partly contributed to the “Same-Sex Marriage Law” voted in 2013.

UNITED KINGDOM

Public Consultation on Mitochondrial Transfer

The Human Fertilisation and Embryology Act 1990 (HFEA) is the primary legislation that governs assisted reproduction and embryology procedures in the UK.

In 2009, following a review of the Act, a power was introduced into the 1990 Act to enable the Government to make regulations to allow the use of eggs and embryos in treatment in which the affected mitochondria is replaced by mitochondria from a donor that is free of any DNA disorder.

The intention is that these techniques would prevent the transfer of serious mitochondrial disease from mother to child whilst allowing the mother to have her own genetically related child.

HFEA Consultation

The HFEA decided to conduct a public consultation exercise via public workshops, public debates and forums, interactive internet sites. They focused on the ethical issues these treatment techniques raise, including whether these techniques should be permitted for use in clinical practice in the UK.

Nota bene: The UK had already carried out public consultations, notably a twelve-week public debate - April 26th to July 20th 2007 - on the creation of hybrid embryos for research purposes.

The HFEA reported the outcome of this exercise in March 2013. Overall, the balance of views from stakeholders and the members of public who took part was that the treatment techniques should be allowed but that their use should be carefully controlled.

United Kingdom: Modalities

The consultation exercise ran from February 27th to May 21st 2014, and set out a number of key questions on which responses were invited.

To ensure that the consultation receive as large an audience as possible, a wide range of organizations were solicited: patient groups, professional bodies, research bodies, genetic interest and faith and community organizations as well as individuals were alerted to the exercise.

1,857 responses were received from the aforementioned range of interested parties as well as a large number of individuals giving their personal views on the draft regulations online.

United Kingdom: Evaluation 1

CITIZEN RECOMMENDATIONS =>

Though the purpose of the consultation was to invite views on the detail of the draft regulations, the majority of respondents simply expressed a view for or against the principle of mitochondrial donation/transfer.

Those supporting the introduction of regulations did so because they felt the treatment techniques offered the only hope of avoiding children being born with serious mitochondrial disease - a view often reinforced by personal experience.

Amongst those opposed, most believed that the techniques crossed unacceptable ethical lines and should never be allowed. Some felt it created children with three genetic parents or was a form of genetic modification. A smaller number felt that the safety of the techniques was not yet proven and that the pace of introduction was inappropriate.

United Kingdom: Evaluation 2

CRITICISMS =>

- 1. The HFEA consultation processes and modalities were rule-guided and strategic, and not based on dialogue and deliberation.**
- 2. Lack of identifiable links between the consultation and the ultimate legislative outcome.**
- 3. Consultation relative to safety issues only lasted two weeks.**

STRONG POINTS =>

- 1. Multi-site public forums.**
- 2. Larger citizen panels than in the French case.**
- 3. More focused recommendations due to the single-issue nature of the consultation.**

Conclusion

Despite the aforementioned shortcomings of both the French and UK experiments in public consultation, it seems obvious that some form of public consultation in the realm of CRISPR/cas09 regulation is required.

By learning from the French and UK examples (as well as others) and relying on available technological resources including all forms of media/the internet, an improved, more inclusive and meaningful consultation process can certainly be devised.

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