

## A public health approach to patient-centredness in embryo research

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### Background

Looking at patient-centredness through the lens of public health is needed for responsible governance of human embryo research. This study aimed to explore patients' experiences and perspectives on information about and consent for research with human embryos, to sustain the development of policies and guidelines.

### Methods

An observational and longitudinal mixed-methods study was conducted in a Portuguese public fertility centre with 3 evaluation moments: questionnaire with 313 women and 221 men undergoing In Vitro Fertilization (2011-2012); semi-structured interviews with 34 couples, 3 months after; questionnaires 12 months after baseline (114 women; 107 men). Data on willingness and reasons to donate embryos for research and on opinions about embryo storage were collected. Descriptive and inferential statistics and content analysis were used.

### Results

Most couples were willing to donate embryos for research (87.3%;95%CI:82.1-91.5), but a significant decrease over time was observed (RR = 0.85;95%CI:0.76-0.95). Participants expected benefits for science, health and infertile patients, but reported lack of information about research projects using human embryos. Having experienced at least one previous cycle was associated with agreeing with a duration of storage longer than 5 years, both in women and men (OR = 2.94;95%CI:1.51-5.71 and OR = 2.44;95%CI:1.17-5.08, respectively). Having children was inversely associated with longer duration of storage among women. There were misconceptions and gaps in knowledge about cryopreservation.

### Conclusions

This study points to the need to provide accurate information about embryo storage and expected results from human embryos research more responsively. It also supports the development of guidelines regarding embryo storage limit that consider reproductive trajectories and life conditions of patients. Lastly, it calls for a renewed discussion around the idea of a two/three-stage process to obtain full informed consent.

### Key messages:

- Provision of accurate information and a two/three-stage process to obtain consent on embryo donation for research is needed
- Investing in guidelines on embryo storage limit and research focused on public health is crucial to promote patient-centredness in the field embryo donation for research