An exploration of the factors that shape public perceptions on human gene therapy

Rachel Iredale, G. Dolan, M. Kirk, K. McDonald
Genomics Policy Unit, School of Care Sciences, University of Glamorgan, Pontypridd, CF37 1DL

Aim
The aim of this study was to explore what the public think about gene therapy, why they think the way they do and investigate what forces are shaping their beliefs.

Method
A small-scale qualitative study. Semi-structured interviews with participants from four groups:
- People with cystic fibrosis
- Family members of people with CF
- People randomly selected from a local GP practice
- Students from an evening class in science

Objectives
These groups were selected in order to compare the opinions of those who have no personal interest in a therapeutic breakthrough for CF with those who do in order to assess whether:
- attitudes differ between focus groups
- opinions are determined by the availability of other therapeutic options
- the acceptability of the technique is contingent upon one’s health status
- opinions on gene enhancement vary

Interview Topics
- Overall understanding of the term genetics
- Genetics in the media
- Participants’ health status
- Making decisions about healthcare
- Perceptions of somatic and germ-line therapy
- Awareness of gene therapy trials
- Willingness to participate in research
- Perceptions of enhancement therapy
- Availability on the NHS
- Regulation of gene therapy
- Future policy making in genetics

Results
- Participants became more optimistic about genetics generally over time
- There was an increase in self-rated knowledge about gene therapy
- Participants’ willingness to undergo gene therapy and their views on its acceptability did not change significantly over time
- Only 3 participants would consider enhancement therapy for themselves
- The majority were in favour of germ-line gene therapy

“I think if you were to start to say to some people “yes you can have better hearing in order for you to be more musical”, then somebody else can say “oh my child needs to be more dextrous” or something. And it would just get to a point where you want somebody to be perfect - perfect hearing, perfect pitch, incredibly dextrous and intelligent. If you can do one thing …..” [CF patient]

“I don’t think that human beings are really meant to suffer …. You get a rogue gene or something has gone wrong …. If you can eliminate it ... well ... get rid of it”. [CF family member]

“I’d like to see the day when genetic diseases can be cured. That would be fantastic. I don’t know whether I will see that in my lifetime. It would be brilliant, but somehow it seems a long way off”. [CF patient]

“If other people wanted it [enhancement therapy] done to themselves then they can do it. I personally wouldn’t have it done to myself. I wouldn’t have plastic surgery or anything”. [Lay participant]