Commit to talks on patient data and public health

Gene-edited embryos are exciting, but the truly urgent conversations concern genomic medicine, says **Vivienne Parry**.

Of course it was going to happen — and now it has. Last week, an international team reported the use of CRISPR–Cas9 gene-editing techniques to correct a heart-wrenching mutation in human embryos. These attempts worked several times more efficiently than previous ones had, and avoided introducing new genetic errors. Although the embryos were never destined to be used for pregnancies (and have now been destroyed), the work — carried out mainly in the United States — makes it easy to foresee practical applications to genetically alter human embryos.

It's a watershed moment. The team picked a compelling glitch to fix, one that kills young athletes without warning. The 'designer babies' headlines and calls for more 'conversations' about the ethical implications of gene-editing were inevitable. Such stories are science clickbait, guaranteed to drive traffic to websites and set social media aflame. Attention will continue to be fixed on this polarizing issue — until the next one comes along.

Don't get me wrong. Dialogue is what we need. The scientific community, haunted by the disastrous crash-landing of genetically modified organisms in Europe in the 1990s and controversies over vaccines, has learnt hard lessons about the need for public engagement when new technologies have societal implications. CRISPR has these in spades. So we do need conversations in which societal views are heard. Jennifer Doudna, a molecular biologist at the University of California, Berkeley, and co-inventor of the CRISPR–Cas9 system, has been exemplary in her insistence on cautious steps, made hand in hand with the public.

Typically, however, conversations are begun but dropped long before they percolate through the many groups and interests that comprise the public. Abandoning these too soon matters because, unlike gene-edited infants, which are still years away, genomic medicine is with us now. The 100,000 Genomes Project, a sequencing initiative that has been recruiting patients with rare diseases and cancer, is enabling Britain's National Health Service (NHS) to incorporate genomic medicine into routine heath care.

The NHS is the first national system to do this. The more people who contribute their data, the more useful those data will be for enhancing care, particularly for patients with rare diseases or unusual variants of common diseases. If the British people lack confidence in the security or use of their data, that distrust will reverberate around the globe. This is the case that must be made to the public, to governments and to those clinicians and scientists who wish to retain their own independent islands of data.

We have an expression here in Britain — 'fine words butter no parsnips'. Essentially, it means that there's a time when talking has to stop and actions begin. We need forums whereby societal views are not simply elicited, but acted upon.

This year, the country's chief medical officer, Sally Davies, produced a report entitled 'Generation Genome'. It is — like the paper that made headlines last week — a watershed publication. Of 16 chapters exploring genomic medicine, Davies singles out the one on ethics as the most important. The report does not lay out pre-ordained principles: it calls for the development of a new social contract between patients and the NHS, as well as for a short and understandable consent process by which patients can choose how their own data are used and protected.

Considerations about an individual's confidentiality and privacy that exist in other areas of medicine cannot always be applied in genomics: one person's genomic data can have implications for other family members. One effort to define these concepts (and to communicate essential information) is under way through a global survey, 'Your DNA, Your Say', being carried out by the Global Alliance for Genomics and Health (GA4GH), a group of large regional initiatives that collect genomic data.

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Delegates representing efforts from Australia, India, Qatar, Turkey, Brazil, the United States and elsewhere met in London this June to collaborate and share experiences. Genomics England, the government-owned company where I work, and that runs the 100,000 Genomes Project, also attended. Its head, Mark Caulfield, was clear that groups should showcase their efforts not just to clinicians and researchers, but to patients and the public, and so encourage further involvement and discourage the locking away of data. Rigorous shared standards and protocols will be necessary across the globe, because no country can do this alone.

Each country must address what, for its constituents, are 'red lines': unacceptable financial or other detriments arising from the use of genomic data by insurers, employers or third parties. They must also deal with qualms about data access by industry.

Genomics is collaborative. Commercial entities will be essential to power research and to manage and interpret data. The social contract through which patients can share their genomic data must include ways of ensuring that benefits are distributed equitably. If conversations to design such mechanisms can build trust that empowers commercial entities to take part, all will benefit.

Keep on talking about what counts, even after the headlines fade: that is surely the message for the public, clinicians, researchers and patients. And that is what GA4GH and Genomics England plan to do. ■

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