

Genome Editing for Human Benefit: Ethics, Engagement and Governance

Singapore, 12 – 13 November 2019



Case study: An unprecedented outreach event in Argentina to raise awareness about gene editing: A communication challenge to engage the general public

Sebastián Barbosa, Ministry of Science Technology and Productive Innovation, Argentina

Brief description of the research project

In December 2018, a consortium of Argentine government organisations co-convened the first public symposium on gene editing (GE) in Argentina. The partners were the Ministry of Science, the Ministry of Health, the Ministry of Agroindustry and three partnering organisations including: the National Council of Scientific and Technical Research; the National Institute of Agricultural Technology and; the National Administration of Laboratories and Institutes of Health. The event was aimed at engaging with the general public on issues of societal importance. The experience was both challenging and exciting in that the organisers were tasked to deliver an event without precedent and without previous experience to draw from. The primary objective of this event was to engage the public on the status of gene editing in Argentina.

The event was transmitted via streaming and social media networks, mostly Twitter. Being co-organised by six separate government entities, the communication focussed on multiple contexts: health research, food technology and agriculture - three examples most likely to attract research interest and progress in the area of CRISPR technology.

In total, nine invited speakers, many of them researchers working with CRISPR in health research, agriculture, and food technology sectors, along with decision makers in policy matters spoke at the event. The information presented was targeted for the general public. The event attracted 452 attendees, 196 participants viewed the event via live streaming and the tweets generated from the Twitter account of the Ministry of Science and Technology (MINCyT) received over 40,000 impressions. The event attracted broad interest in the mainstream media with 19 news stories written in major national newspapers two days after the event. The coverage also included participation of journalists and foundations related to health and food technology who tweeted during the symposium, helping to increase the impact of the message.

This case report shares our challenges and lessons in organising and delivering a large-scale public event designed to communicate information about the status of gene editing in Argentina to a diverse audience.

Background

In recent times, Argentina has acquired extensive knowledge in molecular biology representing a solid base from which to advance in the development of GE. It also has an adequate regulatory framework to accompany such developments. In November 2018 and March 2019, Argentina declared its support for GE to the World Trade Organization, which has strong support and consensus.

Given this setting, and with the intention of informing the public with reliable information on the country's position, current technological advances and potential benefits, the project coordinators decided to convene the symposium. Our approach was designed to counter any misinformation that existed in our country and in other Latin America countries relating to biotechnology, and especially transgenesis. For us, the greatest challenge was to define the information to be

communicated and the most suitable forms of communication to achieve our objective of providing reliable information on GE.

Ethical issues

The great advantage our project presented was that never before had topics of GE been directly communicated to the general public by government institutions. While this presented a great opportunity to shape the event, it also presented a challenge given that no previous comparable events had been held to guide us. We were however driven by a desire to communicate the issues surrounding GE well. Our challenges included:

- *How do we empower the audience?* We had to counter existing prejudices that people associated with biotechnology, including transgenesis. We decided to use simple concepts, to use language that could be understood, focusing on the benefits but also mentioning aspects for improvement. We demonstrated national developments and resisted making comparisons to other applications of engineering, like GMOs.
- *Preparing to communicate a unified message.* Everybody was in possession of the same information, we worked with a single message and with a clear purpose. This was appreciated during the event and in the social media discourse, before and after the event. Knowing that speakers were going to be received by the press as expert spokespeople, we focused on providing speakers with training. All aspects of the presentations were coordinated. While this was a huge challenge, it was fundamental to be able to achieve our goal.
- *The more stakeholders and participants included, the better.* Working collectively allowed us to present a strong message, allowing for deeper impact and demonstrating coherence in governance of the issue. It was important that these initiatives did not occur in isolation but informed and involved stakeholders broadly.

During the event the public was invited to ask questions. The questions asked included: *What will the first treatments using GE be? When will therapies based on GE be available? Will therapies based on GE be safe?*

We were committed to resist making promises which could diminish trust in our message. Our responses included: that it was important to have greater control of the processes of GE and every investigation or possible therapy would be evaluated as the technology develops. In relation to whether the therapies and products were safe, we assured the public that regulatory agencies were assessing each development. For research that was carried out in the health industry, pharmacovigilance was observed and for medicines already on the market, such control measures assessed safety and efficiency.

The same questions were raised in relation to food and GE. We provided participants with similar responses. GE products would be evaluated through several safety tests before being approved for production and consumption. At the present moment, there are no products available in the market but that we expect this to change in the near future.

Conclusions and recommendations

This experience was extremely positive and enriching for us and for the public. We received many positive comments on the day and following the event. The science minister congratulated us on our success in person. The event received wide coverage in the media including radio broadcast and since the event, two speakers have been invited on two occasions to speak on the radio after the host read about the event on twitter.

As everything that is done for the first time, there are many things to be improved. For us, one of these relates to the planning of a post-event communication strategy.

Drawing on our experiences, paying attention to design aspects that kept accountability, trust and transparency at the centre, has served us well. Our recommendations for others attempting to convene similar events are as follows:

- Communication methods must be tailored to the audience you wish to reach. It is important to define communication objectives, the focus of content, and the mechanisms of communication. Nothing should be left to chance.
- CRISPR should not be shown as a super technique that has the potential to make rapid impact on every aspect of society. This will undermine public perceptions and trust in the future.
- Resist making comparisons between CRISPR and other genomic techniques to highlight CRISPR. Each technology and application has a purpose, along with distinct benefits and disadvantages. Communicating truthfully but simply has proved to be successful for us.