

Case Study

Forensic use of DNA

A Citizens' Inquiry into the forensic use of genetic information and the National DNA Database

Vital statistics

Commissioning body:

Human Genetics Commission

Duration of process:

8 months: December 2007 – July 2008

Number of public participants:

Initially 30: 25 at the end

Number of experts/stakeholders involved:

Experts/stakeholders = 11
Advisory Group members = 14

Cost of project:

£100,000 total,
Sciencewise-ERC funding = £50,000
External funding = £50,000
(Wellcome Trust, ESRC Genomics Forum, HGC)

The National DNA Database (NDNAD) was established in 1995 to hold records of genetic samples from people convicted of a criminal offence. In 2001, the law was amended to allow DNA profiles from people who were arrested or questioned in connection with a crime, even if they were not subsequently convicted. This amendment meant the database expanded to more than four million samples. The Human Genetics Commission (HGC) was aware there were ethical issues to be discussed and concluded there was a need for direct dialogue with the public. Ethical issues included concerns over how the data might be used, who should be on the database, how long the genetic information should reasonably be held and to what use it should be put.

Key messages from the public

The dialogue took the form of a Citizens' Inquiry. The participants developed a set of 29 recommendations linked to particular themes, such as civil liberties and societal rights, education and public information, and future implications of DNA science. Some recommendations were unanimous, some were backed by a majority and a number of minority recommendations were also put forward.

Key issues raised by the public participants in the Inquiry include:

- The DNA of innocent people should be immediately removed from the database
- The length of time that information is held should be proportionate to the seriousness of the crime committed

- The NDNAD should be funded by the Government, but managed by an independent body
- Legislation is needed on who should have access to the information held
- People providing samples should not have their ethnicity recorded.

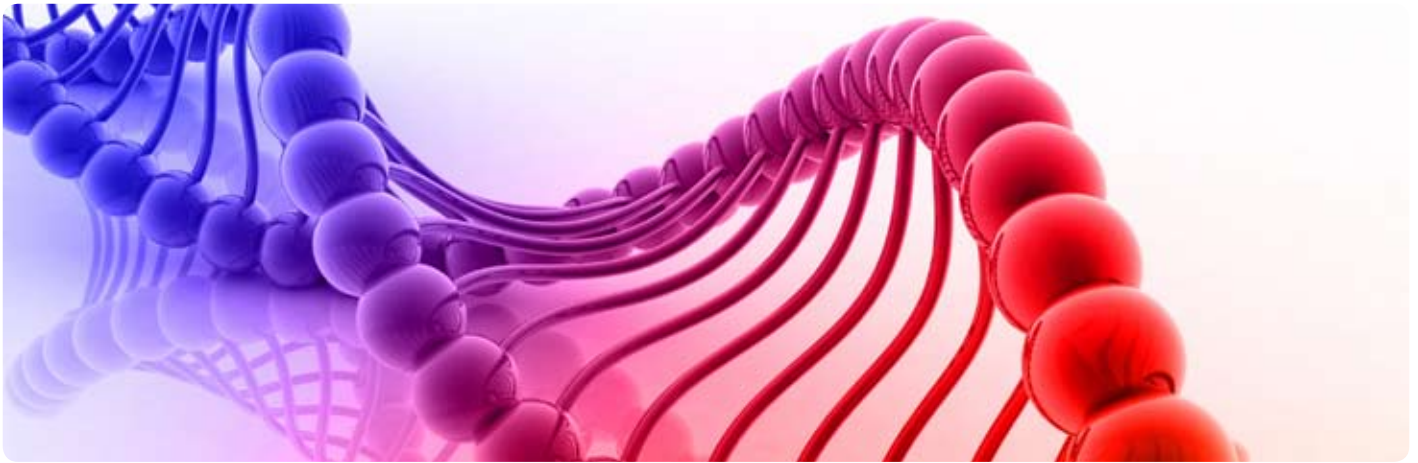
Policy influence

- New questions were developed for the wider consultation that followed. This, in turn, influenced the HGC's conclusions and recommendations to Government in its final report 'Nothing to hide, nothing to fear?'¹ published on 24 November 2009 and its subsequent advice to the Department of Health in December 2009

- The Inquiry strengthened the potential impact of the HGC's conclusions. The HGC view was that the inquiry gave 'much more credibility and legitimacy' to HGC conclusions by broadening the range of views taken into account and, therefore, 'in terms of the quality and robustness' of the recommendations
- The results were acknowledged and taken into account in reports produced by the National DNA Strategy Board, the National Policing Improvement Agency, the NDNAD Ethics Group and the Home Office
- The Government's Green Paper 'Keeping the right people on the DNA Database'², published in May 2009, reflected some of the concerns identified in the Inquiry.

¹To view full report, visit: <http://tinyurl.com/zyzufo3>

²To view full report, visit: <http://tinyurl.com/6dt79tc>



Background

The HGC advises Government on ethical issues surrounding the collection and use of DNA samples. After the law was amended in 2001, the expanded UK NDNAD became the largest database in proportion to population of any country in the world. The creation and management of the NDNAD had not been subject to any previous significant public or Parliamentary debate and a number of high-profile legal stories in the media had brought the debate into sharp focus. The growing public and media interest reinforced HGC's view that there should be a public dialogue to help it address some of the contentious issues involved. The HGC wanted to explore public attitudes so that this evidence could be incorporated into the advice it gave to the Department of Health.

At an early stage in the Inquiry process, the HGC identified other Government departments, such as the Home Office, which also had questions that could be usefully addressed during the project. Therefore, representatives from a number of departments became engaged at various stages as the Inquiry progressed.

The dialogue activities

The aim of the Inquiry was to find out the views of those who have been particularly affected by the existence of the NDNAD so that the results could inform its policy development planning, including the development of a wider consultation exercise.

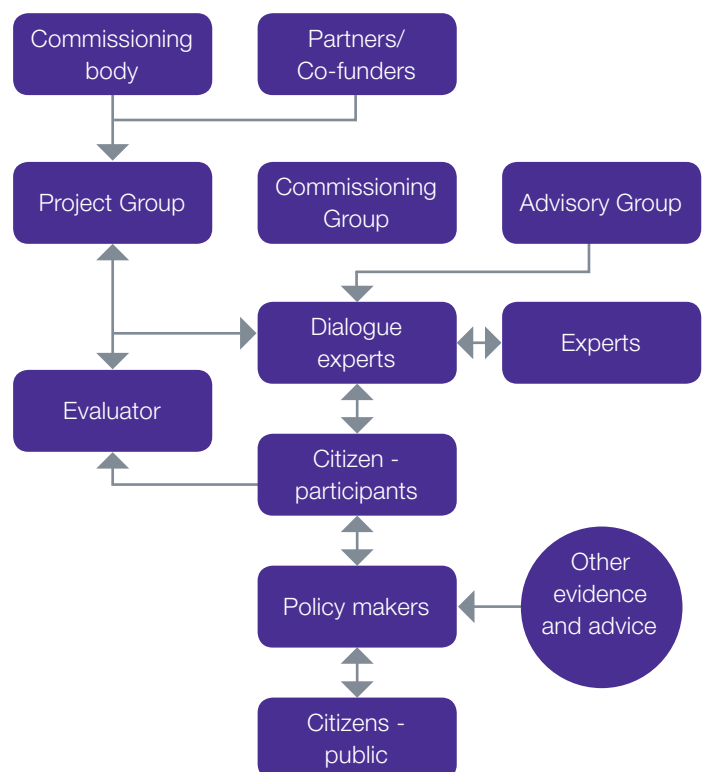
The specific objectives of the Citizens' Inquiry were to:

- Increase awareness of the social and ethical challenges, opportunities and uncertainties provided by the forensic use of DNA
- Broaden the range of informed views to be fed into strategic policy decisions
- Encourage two-way discussion and mutual learning processes between all stakeholders
- Visibly demonstrate that the public's views and concerns have been heard and acted upon, particularly those who have experience of the use of the database
- Provide a solid foundation on which to build a sustainable plan of dialogue and communication activities in this area of policy
- Contribute towards a long-term increase in the involvement of the relevant actors in the use of DNA for forensic purposes in public engagement and dialogue.

The Citizens' Inquiry involved two groups, one in Birmingham and another in Glasgow, made up of a total of 30 people who had personal experience of the NDNAD. The groups were recruited to provide a diverse mix of participants with a significant black and ethnic minority membership. Each group met weekly over a period of six weeks to hear evidence from experts and discuss the issues involved.

On some occasions, the groups in the two locations were joined together by a 'live' video link. In addition, both groups went on regional visits to meet policy makers and communities. Members of the HGC's Working Group, set up to oversee the project, attended some of the sessions alongside other scientists and experts involved in forensic science.

Figure 1. Stakeholders involved



The Inquiry deliberately set out to reflect the views of people most affected by the database. As a result, the process created a high level of 'ownership' among the participants. They learned a great deal about the forensic use of DNA, which gave them confidence to question and challenge experts and decision makers on complex ethical issues, and come to their own conclusions and recommendations about what was needed in future policy.

Participant commitment was fostered through the flexibility of the Inquiry approach, which allowed participants to shape and focus the workshop sessions. They recognised that their views would genuinely be heard by those involved in setting future policy on the NDNAD. This trust was helped by two key factors: the involvement of representatives from the commissioning partners at one of the weekend residential sessions; and the opportunity to present the findings of the Inquiry to a public plenary meeting of the HGC itself. Together, these provided a very direct method of engagement. The whole Inquiry process was genuinely appreciated by participants, many of whom said they would be willing to participate in similar activities in the future.

Summary of good practice and innovation

- Involved a 'diverse' group rather than aiming for demographic representation, focusing on bringing those most affected by the issues into the Inquiry and enabling resources to be focused on in-depth discussions between participants rather than large-scale events
- Facilitators created a highly productive atmosphere for discussion in a situation that could have engendered social conflict and distrust
- The depth of public engagement produced strong group relationships, and robust conclusions and recommendations that had been thoroughly debated
- The Inquiry was co-designed with citizens; they developed the detailed scope of the meetings, taking into account the type of information they wanted to gather, how they wanted to engage and which experts they wanted to hear from. Each group produced a set of conclusions and the two panels came together on two residential weekends to compile a final report
- Evening Inquiry sessions were held in front of a small audience of other interested people, which contributed to openness and transparency
- The small groups meant this was a very cost-effective approach for HGC
- The Citizens' Inquiry produced its own report and presented its findings to an open plenary session of the HGC in May 2008
- Citizen participants attended the media launch events organised by the HGC to present their own findings
- For maximum openness and transparency, the outcomes of the inquiry were published on the HGC's website and sent to a large number of other interested stakeholders. In November 2009, the HGC published its report 'Nothing to hide, nothing to fear?', which set out the conclusions of the Citizens' Inquiry and the wider public consultation exercise
- Independent evaluation completed and published.

Lessons for future practice include:

- Potential conflicts between project and funding partners over dialogue approaches need to be resolved at an early stage

- The specification for contractors delivering the process should be tightly set out including exact deliverables, such as the level of analysis and reporting required
- The scope and nature of the outputs should be determined before the dialogue begins
- Preparation is vital in reaching diverse communities and in securing considered input from advisory group members
- Live video-conferencing proved an effective way of 'gelling' the two groups together without the need to travel
- The roles and responsibilities of the various commissioning and funding bodies should be made clear when results are presented to the media and public.

Impacts

Influence on policy is covered in the summary on the front page. This section describes the impacts of the Inquiry on all those involved.

Impacts on policy makers and policy organisations

- The Inquiry was used as an example of good practice by the House of Lords Constitution Committee. The Committee went on to reflect some of the inquiry's findings in the 'Surveillance: Citizens and the State'¹ report
- The Inquiry raised the profile of the HGC and its work on the DNA database through media coverage of the Citizens' Inquiry's findings
- The Inquiry provided a good foundation for future dialogues and communications in this field
- It created awareness among all stakeholder groups and interested publics on the use of DNA for forensic purposes
- The Inquiry strengthened the HGC's reputation 'as an organisation that engages with the public'
- Increased skills and knowledge of the HGC in commissioning and managing a national public dialogue.

Impacts on public participants

- There was personal development for the citizen participants, who learned a lot about the subject as well as new skills – writing their own reports, presenting to the HGC (including in front of Japanese TV) and questioning experts
- Participants highly valued the process and were more willing to participate in future as a result of taking part. They were very positive about the whole process and new relationships were built.

Impacts on scientists/experts and other stakeholders

- Increased expert and partner knowledge of dialogue processes.

Wider impacts

- The launch of the Inquiry results attracted considerable media interest, and helped to raise the overall level of public knowledge and understanding about the information held on the NDNAD and how it could be used
- As a result of the Inquiry, a number of Government departments/bodies worked together, including the HGC, Department of Health, the NDNAD Strategy Board and the Home Office.

¹To view full report, visit: <http://tinyurl.com/cwluao>

“ We are impressed by the use of this technique (the HGC Citizens’ Inquiry) for eliciting informed opinions by citizens and thus helping to shape policies...We recommend that the Government should undertake an analysis of public consultations and their effectiveness, and should explore opportunities for applying versions of the Citizens’ Inquiry technique to surveillance and data-processing initiatives involving databases. ”

House of Lords Constitution Committee report,
‘Surveillance, Citizens and State’

“ We allowed participants a lot of scope in defining the issues and got a report out of it written very much in their own words, so it wasn’t necessarily easy to map this onto the policy questions we wanted to answer...There is no perfect way of doing it, but the virtue of doing it the way we did was that you get an understanding of the language and values through which the participants approached solutions. ”

Policy maker

Overall impacts

- Although the Citizens’ Inquiry was carried out on a relatively small scale, it has, nevertheless, had a significant impact on policy and on debate in the media about the future of the NDNAD. The Inquiry process proved to be robust, involving a diverse group of citizens, experts and decision makers at the right levels to influence policy directly. It provided valuable insights into how much people knew about the database, and their views and concerns over the use to which the data is put. The Inquiry has also given an insight into the way that people articulate and debate issues relating to the forensic use of DNA and the NDNAD itself. More specifically, it provided direct recommendations from the public on future policy development, which influenced the advice the HGC subsequently gave to the Government
- The Inquiry gave the HGC the process and information that it required, not only on people’s views about the database but also on the reasons why they held those views and what they felt was necessary in future policy to reflect those views. This valuable evidence gave the HGC much more credibility and legitimacy in its conclusions by broadening the range of evidence taken into account
- The process provided a good opportunity for scientists to understand the concerns of individual citizens, particularly those scientists involved in developing forensic techniques that potentially rely on the resources of the NDNAD. However, the Inquiry participants were more interested in meeting and questioning stakeholders involved in the governance of the database, rather than those responsible for the science that lies behind it. This reflects the findings from other public dialogue processes on science and technology that equity and good governance are major concerns.

Contacts and links

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Reports

Full project and evaluation reports available from Sciencewise-ERC on www.sciencewise-erc.org.uk/cms/Forensic-use-of-DNA-Citizens-Enquiry