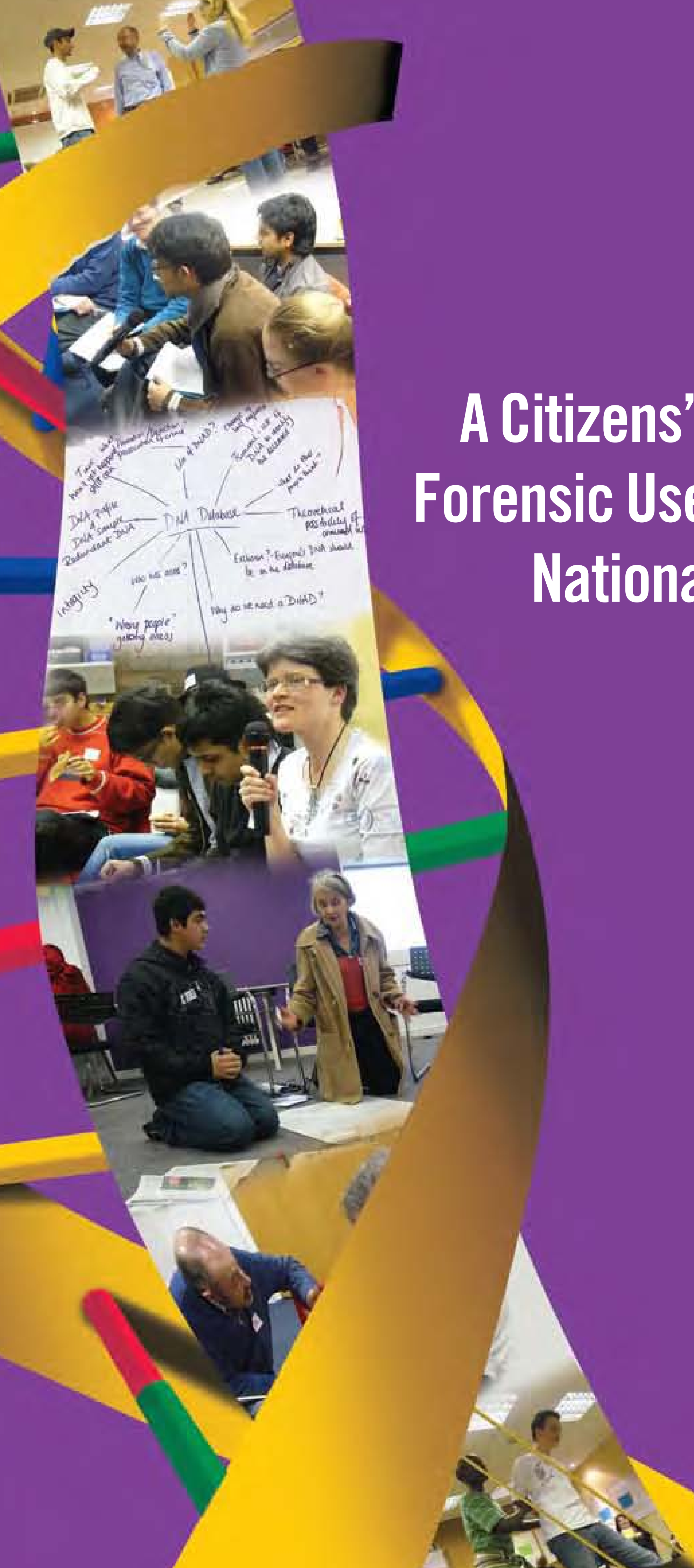

A Citizens' Inquiry into the Forensic Use of DNA and the National DNA Database

Introduction by the HGC Working group

July 2008

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1. Introduction

Most people accept that there needs to be a balance between protecting the public from the effects of criminal behaviour and the infringement of privacy involved in taking and keeping genetic information about individual citizens. However, where that balance should be struck is often keenly disputed.

While there has been no overwhelming groundswell of opposition to the growth of the National DNA Database, the assumption that lack of opposition implies general public approval needs to be examined properly. When prompted, many express the concern that there should be some compelling reason for the state to hold personal information about individual citizens, especially those who have committed no crime. Furthermore, it is difficult to assess the practical utility of the National DNA Database because of a lack of clear evidence, so to the ethical question of its acceptability must be added the practical question of its desirability (as a good use of the resources available for fighting crime).

2. The National DNA Database

The National DNA Database in England and Wales was established in 1995 (a separate database exists for Scotland although profiles are shared with the National DNA Database). The database is populated using biological samples from three sources:

- samples found at crime scenes (for example blood, semen, skin – refinements of technology make it possible to use increasingly small samples comprising only a few cells);
- samples obtained compulsorily from people who are arrested by the police (the police currently have the power to require anyone arrested for a 'recordable' offence to provide a DNA sample); and
- samples provided by volunteers, usually in order to exclude them from a criminal investigation (these can be provided for a specific investigation or included on the database in perpetuity).

The police usually take samples from individuals using a mouth swab. The sample is then analysed in a laboratory and a numerical code (the 'DNA profile') is derived. This profile does not contain any usable information about an individual (about their appearance or medical status, for example) except whether they are male or female. It serves simply as a code by which an individual can be identified. (Both the sample and the profile are routinely kept, although the terms under which this occurs differ within the different jurisdictions within the UK). The profile is used to match individuals recorded on the database to samples found at crime scenes. The sample can be used for quality assurance purposes but it is also possible to carry out further analysis to obtain or infer additional information (such as a person's eye colour, their likely ethnic background or whether two samples come from people who are members of the same family). These further analyses are not routinely carried out in police investigations at present.

As a result of the accumulation of these samples and profiles, it is estimated that the National DNA Database currently holds genetic information from over 4 million people, representing the highest proportion of any population on a forensic DNA database in the world (over 5%).[1] It has been predicted that 25% of the male population and 7% of the female population will soon be represented, with the proportions of certain groups, for example, young black males, already being much higher. These disproportions are potentially discriminatory – perhaps in reality, but certainly in perception. The database is not founded on legislation, and neither its creation and subsequent enlargement, nor the way it is used has ever been put to a vote in the UK Parliament.

3. The Citizens' Inquiry

In the view of the Human Genetics Commission (HGC), the growth and development of the National DNA Database has not been subjected to adequate debate. The HGC believes that such a debate could beneficially be had in public, and by the public, because the database affects all UK citizens. Furthermore, the debate should be had now, before even further expansion results in ever larger proportions of the population being on the database, and ever greater use of the information thus derived.

In order to stimulate this debate, the HGC and its partners, the Economic and Social Research Council (ESRC) Genomics Policy and Research Forum and the Policy, Ethics and Life Sciences (PEALS) Research Centre,[2] collaborated to commission a 'Citizens' Inquiry' to bring together a small group of UK citizens to consider key social and ethical issues involved in the current and future use of DNA for forensic purposes. (The Inquiry was also generously supported by funding and advice from the Department for Innovation, Universities and Skills' Sciencewise programme and the Wellcome Trust.)

As the government's advisory body on developments in human genetics and their impact on individual lives, the HGC is uniquely placed to carry forward this debate. The HGC made a number of recommendations about the National DNA Database in its first major report *Inside Information* (2002).[3] These included a strong recommendation that the database should be subject to independent oversight which led, in turn, to the involvement of HGC commissioners as members of the National DNA Database Strategy Board and, later, to the establishment by the Home Office of an independent National DNA Database Ethics Group.

For the HGC working group, comprising the funders listed above and others with experience relevant to the Inquiry (see Appendix), the key aims of the Citizens' Inquiry were, first, to create an environment in which people from diverse backgrounds could come together as a group and develop their understanding of the main issues and, second, to create opportunities for genuine engagement between those whose voices were not routinely heard in debates on public policy and those who advise governments and set the public policy agenda. This dialogue has only just begun but all the funding partners in the Citizens' Inquiry process are explicitly committed to carrying this forward as an ongoing activity – a dialogue *with* the public rather than a dialogue *of* the public at which the policy-makers are merely spectators.

4. The Approach Taken

The HGC working group had in mind a number of indicative questions that it wanted the participants to address.[4] However, it believed that the subject and scope of the Inquiry should be co-determined with the Inquiry participants themselves: by their information needs, by the nature of their concerns, and by their preferred ways of engaging with the issues and with each other. This was one of several ways in which we attempted to produce an inquiry that was genuinely participatory. We hope that the process has encouraged participants to become actively and creatively involved in this Inquiry but also that they will want to extend such involvement to similar debates in the future.

In particular, a deliberate decision was made to try to maximise the range of perspectives that participants would bring to their debates by recruiting a diverse panel, including people who may not always have an input into such debates. This did not mean a representative panel but rather one that brought together different people in a way that would support an empowered dialogue. We were mindful of the need to recruit both men and women, of different ages, social groups and different minority ethnic groups. In order to ensure all voices could be adequately heard, the panel comprised a higher proportion of participants of black and other minority ethno-cultural heritage than would be found within the population as a whole. In this way, the Inquiry took the need for inclusivity as a central concern.

The Inquiry process was intended to be deliberative, with participants coming face to face with those who had professional expertise or could bring a relevant personal perspective to their discussions. Plenty of time, over a number of weeks and weekends, was devoted to participants discussing and developing their ideas together. There was also a requirement that the different arrangements for the National DNA Database and the Scottish DNA Database were taken into account, which suggested a need to convene groups in distinct geographical locations before bringing them together in person to deliberate and develop their conclusions. The HGC Working Group has encouraged direct involvement of some Inquiry participants in dissemination and discussion of the Inquiry's findings; we would also hope that participants will want to be involved in further work in this area, for example by following the HGC's ongoing consultation process and contributing to future debates.

5. The Inquiry’s Findings

The outcomes of the Inquiry are represented in the following reports. The *Contractor’s Report* from Vis-à-Vis, the independent consultants whom we commissioned to facilitate the Inquiry, contains an extended reflection on the Inquiry process, while the *Citizens’ Report* sets out, in their own words, the findings that emerged after the citizens had reflected on the evidence they had heard and the discussions that had taken place during the Inquiry process. (Also included is an *Independent Evaluator’s Report*, which provides an assessment of the success of the Inquiry as an exercise in public dialogue.)

Final reports can perhaps never do full justice to the breadth of dialogues such as this Citizens’ Inquiry and to the energy and commitment that those running such processes display and inspire. Members of the working group were also able to attend part of one of the weekend residential elements of the Inquiry process, to observe and take part in a question-and-answer session, and the HGC was fortunate to be able to hear first-hand from some of the participating citizens at a plenary meeting in May 2008.

We did not expect the participants to reach a consensus on the answer to each question they addressed. It is unsurprising, therefore, that among the Inquiry’s findings, while some suggestions secured the unanimous agreement of participants, many had both adherents and detractors. These divisions reinforce, for us, the difficulty and interdependency of the issues, the diversity of opinion and the ambivalence that some have about how to tackle public concerns about the collection, use and storage of human DNA samples for forensic purposes.

6. The End of the Beginning

We hope that the publication of these reports does not mark the end either of the citizens' engagement with the issues they have identified during the Inquiry process or of our engagement with the public and other stakeholders on these issues.

The Inquiry has already achieved a number of the aims set out in the original specification document,[5] as the *Independent Evaluator's Report* shows. However, a number of the aims are more long-term, relating, for example, to ongoing communication around the findings and issues highlighted in the Inquiry, and the influence of these on public debate and the development of public policy.

The publication and dissemination of the Inquiry findings represents, therefore, both the culmination of an initial phase of public engagement and the beginning of a broader inquiry by the HGC. A new HGC working group has already been established to examine a full range of evidence (including the findings of the Citizens' Inquiry) and to draw up conclusions and advice for the government on the National DNA Database. To this end, the HGC is also beginning a wider consultation, via its website (www.hgc.gov.uk), stimulated by specific questions, to assist it further in carrying forward this work.

It is expected that the HGC's final report will be published in early 2009.

Notes

1 Latest available figures are given in *The National DNA Database Annual Report 2005-2006*, available at www.homeoffice.gov.uk/documents/DNA-report2005-06.pdf?view=Binary.

2 Latterly the Newcastle–Durham Beacon for Public Engagement; both the Beacon for Public Engagement initiative and the Policy, Ethics and Life Sciences (PEALS) Research Centre are partnerships between Newcastle and Durham universities and the Centre for Life, Newcastle upon Tyne.

3 *Inside Information: Balancing interests in the use of personal genetic data* (HGC, 2002) available at: www.hgc.gov.uk/Client/document.asp?DocId=131&CategoryId=10.

4 These were set out in the specification documents (para.8) as:

- (i) How and from whom, if anyone, should DNA be taken for the National DNA Database?
- (ii) How long should samples be kept and information held on the Database (including views on the different approaches in Scotland compared to England and Wales)?
- (iii) Who should have access to information contained on the Database and for what reasons?
- (iv) How should issues of consent be dealt with?
- (v) Views about the involvement of the private sector.
- (vi) Views about how the Database should be controlled and governed.
- (vii) Views about how the governing bodies should relate to the media and wider public.
- (viii) How should we assess value for money regarding the National DNA Database and the possibility of alternatives?
- (ix) What are the perceived risks and benefits of the National DNA Database?

5 See www.hgc.gov.uk/Client/document.asp?DocId=130&CategoryId=8

Appendix: Members of the Working Group

The Citizens' Inquiry was commissioned by the HGC in collaboration with the Department for Innovation, Universities and Skills' Sciencewise programme, the ESRC Genomics Policy and Research Forum and the Policy, Ethics and Life Sciences (PEALS) Research Centre, and with additional funding from the Wellcome Trust. Members of the working group were:

Dr Alice Maynard (Chair) – HGC Commissioner

Professor Stephen Bain – HGC Commissioner

Sarah Connelly (to August 2007) – HGC Secretariat

Professor Sarah Cunningham-Burley – HGC Commissioner

Ros Gardner – HGC Commissioner

Dr Peter Mills (from August 2007) – Head of HGC Secretariat

Carl Reynolds (to August 2007) – Sciencewise

Dr Tom Wakeford – Director of the Newcastle – Durham Beacon for Public Engagement and Director of Co-Inquiry and Public Engagement, PEALS Research Centre

Geoff Watts – Journalist

Pat Wilson – HGC Media Advisor

Professor Steve Yearley – Director of the ESRC Genomics Policy and Research Forum

Human
Genetics
Commission

ESRC genomics network
genomics forum

wellcometrust

Policy
Ethics
And
Life
Sciences

PEALS Research Centre

beacons
for public
engagement

at newcastle and
durham universities

VIS-À-VIS|RC

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The Inquiry was funded by the Department for Innovation, Universities and Skills' Sciencewise Programme and the Wellcome Trust, with additional support from the ESRC Genomics Policy and Research Forum and from the Policy Ethics and Life Sciences (PEALS) Research Centre and the Newcastle-Durham Beacon for Public Engagement.

The Inquiry was facilitated and delivered by independent public dialogue consultants Vis-à-vis Research Consultancy Ltd.

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