

Notes on HGC meeting in Manchester on 14 May 2002

Areas considered to be of special interest to the Scottish Executive or NHSScotland are in **red bold type**

Updates to code of practice for direct-to-public genetic testing

- The government is asking for advice. HGC is an advisory body. Strange if it did not agree to advise!
- Are we on the verge of a flood of over-the-counter tests?
 - Probably not, although pharmacogenetic tests might potentially fall into this category
- **Health record underpins genetic test utility and so the role of the GP is very important whether tests being taken are public or private.**
- HGC should not be the regulator; it is an advisory body
- Regulation is hard in a world of international trade and internet availability. However view expressed that we should set standards that balance individual liberty against public protection for UK and give a lead and inform our citizens. Other countries will do the same for theirs.
- Public education (limitations, context) as important as code-of-practice but costs money to do well. Multi-factorial tests are not used in clinical practice as utility not clear. Public should understand this when offered private tests.
- Need to have regard to predictability of tests: not all are the 'disease-specific, highly penetrant and high impact on close relatives' variety
- Need to consider links between tests and services targeted at testees to help them do something to reduce a risk shown by testing (lifestyle, diet etc). "Test is a way of leveraging demand"
- Advice required by end 2002

Genetics and Insurance

- Baroness Kennedy and Mark Bale recently lunched with Institute of actuaries. Institute of Actuaries want to work with HGC and recognise they need to come up with ideas instead of being reactive to others thoughts/actions. Start with life insurance, move later to critical care etc.
- **HGC (and others) need to examine use of family history in underwriting**
- Mythology of genetic testing is worse than actuality. Hypothesis is that adverse testing unlikely to impact insurers (particularly if action taken as result). John Burns asked could insurance companies be source of money for research to examine how predictable tests really are. 1000s of sample are required and this will cost more than current CRUK grant allows. Could charities broker something? Insurance industry would pay, charities insulate to prevent any control of studies?
 - Concerns expressed that research might be compromised by industry trying to control agenda, nominate sympathetic geneticists to steering group. Research must be designed and controlled by clinical investigators. If industry happy to become involved to demonstrate willingness to engage, find out without wanting to control research that would be OK.
 - What if hypothesis is wrong and some test-derived information is highly relevant to underwriting? Would HGC be compromised by seeming to have approved such a study and compelled to then allow use of such test data in insurance decisions? Endorsing search for information may compel HGC to take such information as important factor later
 - HGC should participate in debate and 'not strike a position yet'.

Biobank

- **HGC will arrange workshop for commissioners (also open to public/professionals) in Autumn 2002. This should generate dialogue: Biobank principals to respond to HGC concerns; HGC to learn more**

- **Need to consider ethics of use of info as well as process ethics. For example, what to do with information on individuals revealed by testing. Should that be communicated back? Duty of care and potential liability? Analysis of small sub-groups may inadvertently give feedback to members of those groups**
- **Concern about police subpoena of biobank data. HGC making (in 21 May publication) a strong recommendation for all personal genetic information: “no use for non-medical purposes”**
- **Will the oversight body have teeth? Will it have a remit to oversee both science and social aspects?**
- **Have to be careful with storage of information even if not under names: cross-referencing may inadvertently identify individuals.**

Stem Cells

- Meeting previous day had highlighted how little is known about success, impact and timescales for treatments. Although seems far away, dangerous to so assume. Useful to have time to think before clamour for actual treatments starts
- Diverse opinions/ regulation across Europe. Some countries (e.g. France, Germany, Ireland) prohibit use of embryos to generate stem cells but do not disallow use of cell lines so derived. Ethical tangle: ‘Benefit of wrong-doing’
- **What are implications for life-span: will this accelerate development of aged population?**
- Is ‘stem cells’ genetics anyway: should HGC be deliberating?
 - This is HFEA’s bag but principles developed for personal genetic information may be useful in these deliberations too. Positions taken will reverberate into other areas. Need to clarify division of labour between HGC and HFEA
 - Cell nuclear replacement (Dolly-style cloning) involves perpetuation of personal genetic material
- Mustn’t allow “GM-Food” gap to open up between public and professionals
- Don’t lose sight of the “issues of reproductive choice” arguments
- John Harris will prepare papers on Stem Cells and Pharmacogenetics for the next HGC plenary in September 2002-05-16

Patenting

- **A paper is in preparation on “implications for NHS of patenting” by Margaret Llewelyn (who presented at the HGC patents info-gathering day) – funded through Public Health Genetics Unit**
- Nuffield Council on Bioethics also preparing a report on this (in addition to that on Genetics and psychology – to be released 21 Sep)
- HGC will revisit this topic at future meetings

Reproductive choice (including pre-implantation or pre-natal diagnosis)

- **After discrimination this was viewed as “the big issue” by one commissioner (Bill Albert)**
- **Ian Gibson, chair of HoC S&T committee thinks HGC and his committee should examine together.**
- **This should not be “kicked into long grass”**
- **Should at minimum lay out the issues and arguments for and against, decide who needs to be consulted**
- **Working subgroup of HGC established to examine this in collaboration with HFEA**

Next meeting

- 11 Sep in Belfast with briefing session on pharmacogenetics for HGC on preceding day