

(eg, trade, intellectual property, foreign investment, macroeconomic policy, debt and debt-cancellation conditionalities, migration, and human rights). Third, routine public dissemination of all evaluation reports on the performance of signatory Partners to the IHP+, starting with the first progress report. Current and future evidence is vital for the Partnership to show any achievement, as well as to encourage broader commitment to achieving the Millennium Development Goals by parties presently outside the IHP+, such as the USA.

\**Ronald Labonte, Anna Marriott*

Institute of Population Health and Department of Community Medicine and Epidemiology, University of Ottawa, Ottawa, ON, Canada K1N 6N5 (RL); and Development Finance and Public Services Team, Oxfam, Oxford, UK (AM)  
rlabonte@uottawa.ca

We thank Adrienne Germain, Ravi M Ram, Gita Sen, David McCoy, Lola Dare, David Sanders, Gill Walt, Rene Loewenson, and Devi Sridhar for their help with this Comment. We are all members of the International Advisory Group to IHP+ Results. Some International Advisory Group members received an honorarium for their contribution to the IHP+ Results consortium. Our opinions are not those of IHP+ Results or IHP+ signatories.

- 1 IHP+. Welcome to the International Health Partnership and related initiatives. <http://www.internationalhealthpartnership.net/en/home> (accessed Feb 18, 2010).
- 2 International Health Partnership. A global 'Compact' for achieving the millennium development goals. Sept 5, 2007. [http://www.internationalhealthpartnership.net/CMS\\_files/documents/ihp\\_global\\_compact\\_EN.pdf](http://www.internationalhealthpartnership.net/CMS_files/documents/ihp_global_compact_EN.pdf) (accessed April 20, 2010).
- 3 High Level Forum. Paris declaration on aid effectiveness. March 2, 2005. <http://www.oecd.org/dataoecd/11/41/34428351.pdf> (accessed April 20, 2010).
- 4 High Level Forum on Aid Effectiveness. Accra agenda for action. Sept 4, 2008. <http://www.oecd.org/dataoecd/11/41/34428351.pdf> (accessed April 20, 2010).
- 5 Kar D, Cartwright-Smith D. Illicit financial flows from Africa: hidden resources for development. March, 2010. [http://www.gfp.org/storage/gfip/documents/reports/gfi\\_africareport\\_web.pdf](http://www.gfp.org/storage/gfip/documents/reports/gfi_africareport_web.pdf) (accessed April 5, 2010).
- 6 Anon. DAC members' commitments and performance: summary table of OECD Secretariat projections. Feb 15, 2010. <http://www.oecd.org/dataoecd/20/19/44607047.pdf> (accessed Feb 18, 2010).

## Confidentiality and sharing genetic information with relatives

A cluster of reports in the second half of 2009 highlighted the importance of incorporating genetic developments into mainstream medicine,<sup>1-4</sup> and recommended that the ethicolegal implications of so doing are carefully explored. A genetic test in one person can reveal information about risk of disease for relatives and can therefore have important implications for their medical management. The successful and appropriate incorporation of genetics into mainstream medicine depends on clarifying the role and scope of confidentiality in the use of genetics. Interestingly, the General Medical Council's new confidentiality guidelines for the first time make specific mention of the possibility of breaching a patient's confidentiality to share genetic information with relatives.<sup>1</sup> While re-emphasising the public interest in high standards of confidentiality, the guidelines suggest this interest might sometimes be outweighed by a competing public interest in the avoidance of serious harm to relatives.

Until recently, the fact that a diagnosis of a genetic condition offered few options—at best a state of preparedness or an ability to terminate affected pregnancies—combined with concerns about the potential harms of informing relatives and a “right not to know” were generally taken to imply that the doctor's duty to inform at-risk relatives did not outweigh the public interest in confidentiality.<sup>5</sup> Genetic and now

genomic medicine is expanding rapidly, however, and as effective interventions emerge it is reasonable to assume that growing numbers of relatives would wish to be informed of their risks. A UK House of Lords report in 2009 called for greater integration of genetics in all branches of medicine.<sup>2</sup> These developments mean that health professionals will increasingly need to make a judgment about when disclosure of genetic information is appropriate.

Generally, patients in whom inherited conditions have been diagnosed are keen to pass on information about this to relatives. However, geographical, social, and emotional factors can mean that communication does not happen. Although studies have explored the acceptability of contacting relatives directly on behalf of patients,<sup>6</sup> current practice in the UK leaves the onus on the individual to pass on information to relatives. Outright refusal to share relevant genetic information is rare<sup>7</sup> but there are many situations in which health professionals can be left uncertain about the nature of their obligations to family members (panel).

The General Medical Council's guidelines<sup>1</sup> state that in such cases doctors must judge whether their “duty to make the care of the patient [their] first concern is greater than [their] duty to help protect the other person from serious harm”. Sometimes, serious harm might be avoided through prophylaxis or increased surveillance;

**Panel: Anonymised examples, from real cases****Case 1:**

Peter (aged 36 years) is diagnosed with long QT syndrome after investigations for blackouts. A mutation is found in one copy of his *LQT2* gene. He has no known family history of this syndrome but his father died suddenly in his 40s. Because of the father's early death, Peter and his siblings have lost contact with his family, but there were possible further sudden deaths in distant relatives. Peter has three siblings who are all at risk (50%) of having the same condition, and nine nephews and nieces who might also be at risk. The first presenting feature could be sudden cardiac death. An implantable cardiac defibrillator, drug treatment, or both might prevent this outcome. Peter says he will tell his relatives if they also have blackouts, but otherwise he does not want to worry them. He knows that one brother, Sam, is worried about insurance issues and therefore does not want his information passed on to anyone. Although the health professionals involved know the names and dates of birth of Peter's siblings, and could locate them, they are unsure whether doing so would be appropriate, yet are concerned that they might be considered liable should a preventable cardiac event occur in uninformed relatives. Such a dilemma might be more acute when one health professional looks after both Peter and Sam. If Sam's risk is known to be increased, should he be told about it?

**Case 2:**

Helen is referred to a genetics service by her general practitioner because she is concerned about her family history of breast cancer. She is not aware of any family members who have sought genetics advice or had genetic testing. However, through details of her family history, it is apparent to genetics professionals that a pathogenic mutation in *BRCA1* has been identified in another member of her family, Angela, even though this information has not been disseminated to Helen. Knowledge of this mutation makes an accurate predictive genetic test in Helen possible because without knowledge of a familial mutation, genetic testing in an individual at risk is less informative. Using the genetic mutation from Angela to facilitate the test will not necessarily point to her. However, because the information is the result of Angela's test, the health professionals involved believe the information is confidential and that they need to obtain consent from Angela to use the result for the benefit of Helen. Without consent they do not feel able to tell Helen about the familial mutation.

or more simply, through awareness of potential health problems. In case 1 (panel), there are interventions that might reduce the risk of premature death but these interventions would usually only be offered to those known to be at risk. The variability of a genetic diagnosis (eg, the type and/or location of a gene mutation) and

lack of long-term follow-up data in such cases mean that the magnitude of risk reduction might not be easy to assess. Any judgment about risk will therefore have a broad confidence interval and whether or not a breach in confidentiality is appropriate is likely to be a complex judgment.

Implicit in the General Medical Council's guidelines<sup>1</sup> is a requirement for health professionals to make judgments about what kinds of genetic information are to count as confidential and covered by the guidelines (case 2, panel). On one interpretation, the case's test result is confidential and subject to the guidelines. But on another interpretation, confidentiality is not an issue here at all because, although originating from one family member, the information is not revealing about a particular individual and is better thought of as part of a familial "joint account". On this interpretation, the mutation details that make it possible to offer a test (or other intervention) should be available for use in the treatment or testing of family members without having to meet the seriousness criterion.

The fact that such situations are increasingly likely to arise in practice means that, in addition to judgments about when it is appropriate to breach confidentiality, health professionals will also need to reach a view about the scope of confidentiality in the context of genetic information. Much genetic information, although originating from an individual, does not identify that individual and could be considered to be part of a joint account and available for use in the care of other family members unless there are very good reasons to do otherwise.<sup>8</sup>

Some of these issues have been debated by genetics professionals,<sup>9-11</sup> but the debate needs to be widened to include other health professionals for whom such issues will increasingly arise in practice as genetic and genomic medicine expands. Although the title of the UK's General Medical Council's press release<sup>12</sup> suggested that breaches of confidentiality might become routine, the guidelines themselves offer a more considered view and argue that only under rare circumstances would a breach of confidentiality be appropriate. When specific risks to specific persons are known, consideration should also be given as to whether this knowledge can be used in the appropriate care of family members without this constituting a breach of confidentiality.

\*Anneke Lucassen, Michael Parker

University of Southampton School of Medicine and Wessex Clinical Genetics Service, Princess Anne Hospital, Southampton SO16 5YA, UK (AL); and Ethox Centre, University of Oxford, Oxford, UK (MP)  
annekel@soton.ac.uk

We declare that we have no conflicts of interest.

- 1 General Medical Council. New guidance—confidentiality. Oct 12, 2009. [http://www.gmc-uk.org/guidance/news\\_consultation/confidentiality\\_guidance.asp](http://www.gmc-uk.org/guidance/news_consultation/confidentiality_guidance.asp) (accessed Jan 28, 2010).
- 2 House of Lords Science and Technology Committee. Genomic medicine. Volume 1: report. July 7, 2009. <http://www.publications.parliament.uk/pa/ld200809/ldselect/ldsctech/107/1071.pdf> (accessed Jan 14, 2010).
- 3 Secretary of State for Health. Government response to the House of Lords Science and Technology Committee inquiry into genomic medicine. December, 2009. [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_110005.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_110005.pdf) (accessed Jan 14, 2010).
- 4 Human Genetics Commission. Confidentiality and information sharing in clinical genetics. December, 2009. <http://www.hgc.gov.uk/Client/document.asp?DocId=232&CAtegorId=9> (accessed Jan 14, 2010).
- 5 Laurie G, Kerzin-Storarr L. Discretion and not duty: why there should not be an obligation on healthcare professionals to share genetic information with family members. Sept 17, 2006. [http://www.bionews.org.uk/page\\_37898.asp](http://www.bionews.org.uk/page_37898.asp) (accessed Oct 28, 2009).
- 6 Suthers GK, Armstrong J, McCormack J, Trott D. Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder. *J Med Genet* 2006; **43**: 665–70.
- 7 Clarke A, Richards M, Kerzin-Storarr L, et al. Genetic professionals' reports of nondisclosure of genetic risk information within families. *Eur J Hum Genet* 2005; **13**: 556–62.
- 8 Parker M, Lucassen A. Genetic information: a joint account? *BMJ* 2004; **329**: 165.
- 9 Ashcroft R, Parker M, Widershoven G, Verkerk M, Lucassen AM. Case analysis in clinical ethics. Cambridge: Cambridge University Press, 2005.
- 10 Joint Committee on Medical Genetics, Royal College of Pathologists. Consent and confidentiality in genetic practice: guidance on genetic testing and sharing genetic information. April, 2006. <http://www.rcpath.org/resources/pdf/GeneticsConsentAndConfidentiality-JCMGreportJul06.pdf> (accessed Jan 28, 2010).
- 11 Human Genetics Commission. Inside information: balancing interests in the use of personal genetic data. May, 2002. [http://www.hgc.gov.uk/UploadDocs/DocPub/Document/insideinformation\\_summary.pdf](http://www.hgc.gov.uk/UploadDocs/DocPub/Document/insideinformation_summary.pdf) (accessed Jan 28, 2010).
- 12 General Medical Council. Doctors told to warn patients of their genetic risks. Sept 28, 2009. <http://www.gmc-uk.org/news/4128.asp> (accessed Oct 28, 2009).

## F1 designed to save lives

Formula 1 (F1) is a high-speed union of teamwork and advanced technology, which enables maximum performance in high-pressure environments. These F1 skills and technology have been harnessed by doctors to streamline working practices, help to monitor and diagnose patients, improve mobility, and prevent injury. At the Science Museum, London, UK, the exhibition *Fast Forward*<sup>1</sup> explores how F1 technology is being applied elsewhere, with many examples in medicine.

F1 cars are monitored in and out of the garage like a patient, to ensure that all systems are functioning accurately. The telemetry has been applied to remote monitoring of patients in clinical trials to record outcomes for transmission to the clinic. Furthermore, cyclists are benefiting from adaption of this technology for training bikes, to allow the performance of the bike and rider to be monitored on the road.

In F1 the precision and timing of a pit stop, which usually takes less than 5 s, can decide who wins. Similarly, the precision and timing of handover from theatre to intensive care can decide whether a patient lives or dies. Doctors from Great Ormond Street Hospital, London, UK, have spent time with top pit-crews to hone their skills, with great success in streamlining the handover and a reduction in errors.

F1 technology has also been used to improve mobility and prevent injury. Wheelchair design has benefited from the sculpted monocoque construction of F1 racing-car seats, which need to be strong and comfortable for long periods, and use of a lightweight carbon-fibre shell makes wheelchairs easier to manoeuvre. Additionally, ambulance services previously found that the weight of metal incubators made them hazardous for moving newborn babies by road and air. The BabyPod II<sup>2</sup> has since been developed, which is lighter and smaller, and protects the baby in the same way as the driver in an F1 cockpit.

Technology developed for F1 has been widely used to improve medical techniques and devices. It is so advanced that even the US Marines have tested a leg brace, which is based on hydraulic dampers and has reduced injuries caused by riding in fast-moving inflatable boats.

Alexander Phillips

Queen Elizabeth High School, Hexham NE46 3JB, UK  
Alexander\_jp@hotmail.co.uk

- 1 Science Museum. Fast forward: 20 ways F1 is changing our world. [http://www.sciencemuseum.org.uk/visitmuseum/galleries/fast\\_forward.aspx](http://www.sciencemuseum.org.uk/visitmuseum/galleries/fast_forward.aspx) (accessed April 26, 2010).
- 2 Advanced Healthcare Technology. BabyPod II. <http://www.babypod.com/products/babypod.php> (accessed April 27, 2010).



Corbis