THIS WEEK

Incidental benefits

Scientists who screen the genes of volunteers for research should tell participants if they find information relevant to their health.

All research studies on humans can uncover facts relevant to a volunteer's health — at initial screening, during the study itself, or even after the study finishes, when other researchers review the data or conduct their own analyses.

For the most part, researchers have opted not to reveal these potentially important 'incidental findings' to participants. This has been to protect the research process, and to prevent coercing people into studies by unwittingly eliciting the 'therapeutic misconception' — the incorrect assumption on the individual's part that participating in a study will help their own health.

But the emergence of high-throughput genomics, with its ability to catalogue vast amounts of information that may have a bearing on a person's health, has prompted a rethink of this convention.

A working group funded by the US National Institutes of Health (NIH) in Bethesda, Maryland, has recommended that biobanks and archives that house large genetic data sets introduce policies to encourage the return of incidental findings to research subjects (see page 387).

The impact of these recommendations should not be underestimated. As genetics invades every branch of medicine, no field is likely to be exempt from ethical standards introduced to cover genetic data. The recommendations are likely to have their most immediate influence in discussions on the topic now under way at the US Department of Health and the NIH.

There is a precedent for returning information to the subjects of a study. In imaging studies, for instance, a radiologist often reviews patients' scans for incidental findings before they are analysed by researchers. Support is growing for the idea that genetics researchers should similarly review a selected set of genes with known impacts on health before undertaking their own research.

Implementing this will not be easy. Defining appropriate sets of genes is problematic, and any list will need to be constantly updated. And to return the information to an individual in a way that avoids unnecessary anxiety and medical expense is a huge issue. Opponents of the idea point out that it contravenes standard practice in medicine itself, because doctors do not routinely sift through patients' records for old test results that may carry new significance in the light of more recent research.

Perhaps the most visible example of the need for this debate comes not from science, but from commerce. Companies routinely mine vast quantities of consumer information to influence marketing decisions. Governments have not been able to keep pace with standard business practices, and most consumers are unaware of the breadth and depth of information that companies gather on them from Internet searches, social networks and supermarket purchases.

In testimony before the US Presidential Commission on Bioethics in February, John Wilbanks, who runs the project Consent to Research, noted that this pattern is likely to repeat itself in the era of electronic medical records and genomics. "My sad realization is that whether it's your genome or your health information, anyone who really wants to screw you will probably be able to get a copy of the data they need to do so, and the people who are least likely to get a copy are the people who can do something amazing with it, like researchers," he said. Companies are lining up to market products to consumers on the basis of their genomes. Law-enforcement agencies already use DNA left at crime scenes to find suspects and their relatives, and are funding programmes to create physical profiles of suspects on the basis of their DNA. In other words, people now have incomplete protection for their own DNA, and this lack of privacy is likely to increase in the future.

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In this free market, how sure can researchers be that they are truly doing no harm to their study participants when they take a cheek swab? People thinking of entering a study will assess the risks of how their volunteered genetic information might be used, and this might make them more reluctant to participate. Researchers could help to counter this by offering them medically relevant information back in exchange. ■

Flight risk

As the campaign against animal research intensifies, so must the response.

Picture a crowd of scientists waving placards plastered with photographs of stroke victims and sufferers of Parkinson's disease. They are demonstrating outside the corporate headquarters of British Airways, Lufthansa and Delta, demanding that the airlines stop impeding the biomedical research that could deliver big advances against these and other diseases.

Seem far-fetched? Maybe. But if scientists want continued access to animals as research models, they will have to appear on the front line with every bit as much visibility, determination, organization and persistence as animal-rights activists now muster.

In a renewed campaign targeting transportation companies, protestors have found a public pressure point so effective that only a few major airlines still agree to transport non-human primates bound for research labs (see page 381). Nor is the focus confined to primate transportation: earlier this year, the last ferry company that was willing to carry research rodents into the United Kingdom stopped doing so. Such blocks, scientists warn, could shift much animal work to countries where regulations are more lax.

But there is a silent majority for whom the activists do not speak.