Response to Nuffield Council Consultation Paper

Medical profiling and online medicine: 
the ethics of 'personalised' healthcare in a consumer age

This is a response from the Economic and Social Research Council (ESRC) Centre for Social and Economic Research on Innovation in Genomics (ESRC Innogen Centre), based at the University of Edinburgh and the Open University. The centre, which began in 2002, focuses on research that connects the social with the life sciences. The life sciences have the potential to transform healthcare and food production systems in developed and developing countries and to provide one of the main platforms of economic growth and global competitiveness in the 21st century. Rapid developments in life sciences challenge our existing regulatory systems and raise new ethical and social issues. Innogen’s research aims to provide a sound base for decision-making in science, industry, policy and public arenas related to innovation in life sciences. Staff at the Innogen Centre have, for over twenty years, researched issues of regulation, innovation and engagement in the life sciences (both agricultural and health related), but also in other sciences and technologies of information, communication, energy and environment. The researchers working at Innogen include social scientists, economists, and lawyers. Innogen also engages with a wide range of stakeholders, nationally and internationally, including scientists, industry and private interest groups, policy makers and regulators, and citizens and public interest groups.

Summary of response

The following answers/comments to some of the consultation paper questions draw on Innogen’s research and expertise in social, economic and legal issues around genomics and public health. We have responded specifically to the questions concerning provision of health care services, drug advertising and regulation of DNA and body imaging services.

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This response was submitted to the consultation held by the Nuffield Council on Bioethics on Medical profiling and online medicine: the ethics of ‘personalised’ medicine in a consumer age between April 2009 and July 2009. The views expressed are solely those of the respondent(s) and not those of the Council.

Introduction: Consumer choice

Q1: Health care as a Consumer Good

This question asks whether it is desirable that an increasing number of medical products and services be available as consumer goods (such as full body imaging). There are clearly both positive and negative aspects to this. On the one hand, it can enable individuals to take greater control over their medical care, which supports the liberal notions of autonomy and individual rights. However, the dissemination of clinical data in the absence of follow-up care, counselling if needed; and the provision of context to the information provided is clearly undesirable, even if the individual chooses to purchase the product as a consumer (Mitra, 2007a). Overall, the provision of clinical products as a consumer good might, on balance, be desirable, but only if the market is regulated appropriately. Furthermore, there are a number of more general but equally important questions about commercialisation of health care and healthcare technologies; specifically the potential commercialisation of knowledge gained from public participation in screening services. Innogen researchers have conducted a lot of empirical work on public perceptions or attitudes to genetic knowledge and DNA screening/databases. This research has revealed a complex range of concerns about consent, confidentiality and research governance in the context of “wealth-related ends” of biomedical research (Haddow et al, 2007).

Q2: Validity of Information

A lot of our research has questioned whether new types of genetic information should be treated as special or exceptional (Mitra, 2006). The genetic exceptionalism argument claims that there is something unique about genetic data in terms of its social, legal and ethical status. If we accept this argument, then the provision of low quality or inaccurate genetic health information by lifestyle and health books/magazines does provide some reason to restrict access to DNA profiling and body imaging services, as it is likely that individuals will access data without the appropriate context to understand it. However, this presupposes affirmative answers to two key questions. First, is genetic information substantially different to other forms of predictive clinical data? Second, does the provision of inaccurate or misleading information/knowledge by the media in itself justify restriction of access to these technologies? On balance, our research suggests that there does not seem to be a compelling argument to restrict access in this case (Mitra, 2007b)
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Q3: Prevention

While the promotion of personal responsibility for one’s health is certainly a good thing and should be encouraged, the notion that personal responsibility should extend to the use of DNA profiling and body imaging services is problematic. While there may be no compelling argument to restrict access to these technologies for those who wish to choose them for personal reasons, individuals should not be “expected, encouraged or obliged” to have such tests. Research in law, ethics and social science has tended to argue that there is a “right to genetic ignorance” (Takala, 1999; Laurie, 2002). That is, people should not feel compelled or be coerced to acquire knowledge of their future health risks.

Q4: Who Pays?

This is an interesting and complex question as to whether individuals who choose to pay privately for DNA profiling and body imaging services should then be provided with publicly funded services for follow-up diagnosis and treatment. This is clearly not a black and white issue. In some cases it might be inappropriate to expect the public funder to provide all the follow-up care and diagnosis free of charge, but in cases where the patient presents with an extant medical condition that in all other circumstances would be treated by the health service, it would be inequitable to restrict access purely because the patient initially went down the private route.

Online Drug Purchasers

Q8: Advertising Health Care Products

The idea of advertising prescription drugs direct to consumers has always been a controversial issue and Europe has tended to oppose it. On balance, it seems that allowing direct advertising would bring few benefits, especially since prescription drugs in the UK are paid for and provided through the NHS, and it is unclear whether advertising would enable patients to benefit from greater choice in the range of medications on offer. But this does raise related questions about the acceptability of advertising DNA profiling or body imaging, which the report indicates is not currently prohibited. On balance, it would seem there is something distinct about prescription medicines that require additional limitations regarding marketing. It would seem that access to drugs through the GP continues to be the most appropriate and best approach to drug treatment. Advertising DNA profiling may not require the same restriction since it can be purchased privately outside the NHS and is a diagnostic tool rather than a treatment.
Body Imaging and DNA Profiling Services

Q12: Regulation

The question asks whether it is satisfactory for DNA profiling and body imaging services to have to pass more stringent evaluations before they are provided by the NHS as opposed to the commercial sector. Again, this isn’t a straightforward black and white question. It depends on the kind of evaluations made and their purpose. Some technologies are evaluated by the NHS in terms of cost-effectiveness. Here, sufficient efficacy must be demonstrated in relation to cost per patient. This kind of regulation would not necessarily be appropriate to the commercial provider. If, however, evaluation involves issues around safety, ethics, follow-up procedures etc, then it would seem appropriate to apply the regulations equally to both public and private providers. Inconsistency in the application of regulatory protocols, particularly between different sectors, is a problem in many areas of biomedicine and is generally undesirable.

References


