

Tackling community concerns about commercialisation and genetic research: A modest interdisciplinary proposal

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Abstract

In recent years, there has been a rise in the creation of DNA databases promising a range of health benefits to individuals and populations. This development has been accompanied by an interest in, and concern for the ethical, legal and social aspects of such collections. In terms of policy solutions, much of the focus of these debates has been on issues of consent, confidentiality and research governance. However, there are broader concerns, such as those associated with commercialisation, which cannot be adequately addressed by these foci. In this article, we focus on the health–wealth benefits that DNA databases promise by considering the views of 10 focus groups on Generation Scotland, Scotland’s first national genetic database. As in previous studies, our qualitative research on public/s and stakeholders’ views of DNA databases show the prospect of utilising donated samples and information derived for wealth-related ends (i.e. for private profit), irrespective of whether there is an associated health-related benefit, arouses considerable reaction. While health–wealth benefits are *not* mutually exclusive ideals, the tendency has been to cast ‘public’ benefits as exclusively health-related, while ‘private’ commercial benefits for funders and/or researchers are held out as a necessary pay-off. We argue for a less polarised approach that reconsiders what is meant by ‘public benefits’ and questions the exclusivity of commercial interests. We believe accommodation can be achieved via the mobilisation of a grass roots solution known as ‘benefit-sharing’ or a ‘profit pay-off’. We propose a sociologically informed model that has a pragmatic, legal framework, which responds seriously to public concerns.

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Introduction

In this article, we examine the recent international trend of creating DNA databases and ask, ‘What

should be done with any (monetary) benefits that arise from these endeavours?’ Since the mapping of the human genome, there has been a significant increase in research into the role of genetic factors in the aetiology of complex diseases. DNA databases are constructed for such research and are defined as

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...large-scale banks which contain either tissue samples, from which genetic material might be or

has been extracted or genetic information, which may be coded and stored in various forms; and in addition, health and ‘lifestyle’ information pertaining to the sample donors (Williams & Schroeder, 2004, p. 90).

In most population or disease-based DNA databases, individuals are asked to donate their DNA, to provide information on their lifestyle, and to allow researchers access to information held on their medical records throughout the life course. People are expected to donate their DNA material voluntarily, often anonymously, and without expectation of any direct benefit to themselves; any benefit is to some unknown other in the future. There is an institutionalised tendency to talk of the contribution of the public as a ‘gift’ with all the assumptions that this entails, i.e., that it is given freely and for no return. For example, the Medical Research Council (MRC, 2001) recommend, in light of legal uncertainty about who or in what circumstances one can ‘own’ human biological material, that tissue samples should be treated as conditional gifts or donations (Medical Research Council (MRC), 2001, p. 8).

We review previous research and thinking on the social and ethical issues relating to DNA databases with a particular focus on issues of profit and commercialisation. After reviewing previous consultations, we then present findings from research we conducted with a range of public/s about a proposed Scottish DNA database called ‘Generation Scotland’. Here, we outline our methods and present our analysis around the following themes of: (i) access, (ii) ownership, and (iii) control. We then broaden our discussion to consider the morality of economic input before presenting a proposed solution to the problem of profits through a ‘benefit share’ model. In conclusion, we consider whether we are witnessing the end of the traditional gift relationship between participant and researcher and suggest that legal solutions can be grounded in public concerns.

Promise and profits

DNA databases promise future health benefits to individuals, families and whole communities. However, such promises are vague with an indefinite future time frame. A degree of controversy has surrounded the scientific value of some of these projects, with doubts expressed in various quarters

as to whether these ‘promises’ can ever be realised (Barbour, 2003). Nevertheless, expectations of future benefit help shape the scientific domain and participant motivation. This promise is, explicitly or implicitly, relied upon by scientists involved in the projects whenever they speak of engaging with the public.

Like the notions of ‘gift’ and ‘gifting’, there is likely to be cultural variation around expectations about what a benefit is, as well as differences in the way benefits can be delivered (Wilson, 2004). For example, the HUGO Ethics Committee defines individual and community benefit as social goods:

A benefit is a good that contributes to the well being of an individual and/or a given community (e.g. by region, tribe, disease-group...). Benefits transcend avoidance of harm (non-maleficence) in so far as they promote the welfare of an individual and/or a community. Thus, a benefit is not identical with profit in the monetary or economic sense. Determining a benefit depends on needs, values, priorities and cultural expectations (HUGO Ethics Committee, 2000).

These social goods do not include direct monetary return to participants. Indeed, HUGO states there should be no financial gain from participation in genetic research. The organisation does not, however, preclude potential monetary return to others. In this view, ‘benefits’ divide along blurred, yet discernible lines: ‘public’ benefits in the form of (potential) public health improvement and ‘private’ benefits in the form of (potential) private commercial gain. Generally, this is viewed as potential future health improvements, through research into the prevention, diagnosis and treatment of illness and disease; however, it may also include potential improvement to the health infrastructure. Aside from rewards to the scientific community of academic and commercial return, there are at least two discourses of ‘promise’ at play: the promise to the public of better health and the promise to private parties of commercial reward for their efforts.

A large part of making the wider health benefits a reality is the involvement of commercial and pharmaceutical companies. It is argued that commercial companies should be granted access and that they should be entitled to seek exclusive rights over the products of their work with the data or samples from DNA databases. It is only by these means will new drug therapies or health benefits be

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