

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



Meade, T (2001) Safeguards for research using large scale DNA collections. Study will not be started before suitable arrangements are in place. *BMJ (Clinical research ed)*, 322 (7285). p. 551. ISSN 0959-8138 DOI: <https://doi.org/10.1136/bmj.322.7285.551>

Downloaded from: <http://researchonline.lshtm.ac.uk/12829/>

DOI: [10.1136/bmj.322.7285.551](https://doi.org/10.1136/bmj.322.7285.551)

Usage Guidelines

Please refer to usage guidelines at <http://researchonline.lshtm.ac.uk/policies.html> or alternatively contact researchonline@lshtm.ac.uk.

Available under license: Creative Commons Attribution Non-commercial
<http://creativecommons.org/licenses/by-nc/3.0/>



Letters

Safeguards for research using large scale DNA collections

BMJ 2001; 322 doi: <http://dx.doi.org/10.1136/bmj.322.7285.551> (Published 03 March 2001) Cite this as: BMJ 2001;322:551

Study will not be started before suitable arrangements are in place

Tom Meade (Susan.J.Matthews@mds.qmw.ac.uk), director

*Medical Research Council Epidemiology and Medical Care Unit, Wolfson Institute of Preventive Medicine, St Bartholomew's and the Royal London School of Medicine and Dentistry, London EC1M 6BQ
Clinical and Molecular Genetics Unit, Institute of Child Health, London WC1N 1EH*

EDITOR—As chairman of the expert planning group set up by the Medical Research Council and Wellcome Trust, I can reassure readers of the article by Kaye and Martin that all the issues they raise about the proposed population study in the United Kingdom involving genetic information have been fully recognised.¹ The study will not and cannot be started until arrangements acceptable to all concerned are in place. These arrangements are currently being actively developed and entail consultation with lay and professional advisers.

The two main reasons behind the high degree of public concern and debate about the study in Iceland were the initial proposal for an “opt out” approach to consent for collection of some of the data and the decision to license the databases exclusively to a commercial company. Neither of these has ever been considered as a possibility in the British study. Consent to take part will be on an “opt in” basis only after full verbal and written explanations and guarantees on confidentiality. The availability of fully anonymised material to others in order to pursue the full scientific and therapeutic potential of the study will be tightly controlled.

The study will be overseen and regulated by a publicly accountable and independent body responsible for reviewing all its procedures and activities. In addition, full ethical approval will of course also have to be obtained. The United Kingdom has well developed, high quality expertise in both genetics and population based research, and its diverse population and healthcare system are additional advantages. Others have emphasised the importance for future health care of deriving the full benefit from recent and future developments in genetics.²

While the appropriate regulatory procedures are being put in place we should not lose sight of the willingness of many people in this country to take part in research, including work likely to benefit others perhaps more than themselves. We must ensure that they can express this readiness through their

contribution to important studies such as the one the Medical Research Council and Wellcome Trust are setting up.

References

- 1.Kaye J, Martin P.Safeguards for research using large scale DNA collections.*BMJ*2000; **321**:1146–1148. (4 November.)
- 2.Fears R, Roberts D, Poste G.Rational or rationed medicine? The promise of genetics for improved clinical practice.*BMJ*2000; **320**:933–935.

Educational initiatives are essential for success of population genetic studies

Ian Hopkinson (i.hopkinson@ich.ucl.ac.uk), honorary consultant in primary care genetic medicine

*Medical Research Council Epidemiology and Medical Care Unit, Wolfson Institute of Preventive Medicine, St Bartholomew's and the Royal London School of Medicine and Dentistry, London EC1M 6BQ
Clinical and Molecular Genetics Unit, Institute of Child Health, London WC1N 1EH*

EDITOR—I was delighted to see the article by Kaye and Martin on the proposed population health and diversity study of the Medical Research Council and the Wellcome Trust.¹ This proposal involves the recruitment of around 500 000 patients through primary care for DNA isolation and genotyping, to be linked to their medical records and family histories. These will be correlated with the prospective collection of changes in patients' lifestyles and important health events over several years.

This project may well represent the next major advance in clinical medicine, but several matters arise from the proposal. The active participation of all the relevant professional groups and the patient population is a prerequisite for the success of the project, both to enable the successful recruitment of patients and to maintain the momentum required to sustain such a long-term study. There are important educational issues that should be addressed as a matter of urgency to enable professionals in primary care to recruit patients, to obtain their informed consent, and to answer questions that arise during the course of the study.

Current and emerging technologies will allow rapid identification of mutations causing well described single gene disorders, single nucleotide polymorphism profiling, and genomic sequencing. These powerful technologies may enable the identification of predispositions to common, multifactorial disorders and predict individuals' responses to conventional therapeutic interventions. On the basis of discussions with general practitioners and practice nurses, and the findings of a recent informal survey among general practitioners in South Wales about attitudes and knowledge of genetics (unpublished data), I think that few professionals in primary care would be confident in explaining the nature of these techniques and the importance and implications of the data that would be generated. This would seriously limit the ability of professionals in primary care to obtain informed consent and answer questions that arise over the years of the study. The long term nature of the proposals reinforces the view that education and training in genetics, and particularly in the basic science that underpins the subject, are a priority for medical, nursing, and associated professions at the basic, specialist, and continuing education stages. The success of the proposed study and future population genetic studies

are dependent on this educational need being immediately and effectively addressed.

References

1. Kaye J, Martin P. Safeguards for research using large-scale DNA collections. *BMJ* 2000; **321**:1146–1148. (4 November.)