

Genomic medicine: the future is now

EDITORIAL Lessons for Hong Kong from the House of Lord's Report on Genomic Medicine

The House of Lords Science and Technology Select Committee published its report on genomic medicine, defined as "the use of genomic information and technologies to determine disease risk and predisposition, diagnosis and prognosis, and the selection and prioritisation of therapeutic options", on 7 July 2009 under the guidance of Lord Patel.¹ Its basic message is clear and unequivocal: genomic medicine is already with us and the NHS is not geared up to it. All its recommendations reflect this theme, beginning with the suggestion that the Office for Strategic Co-ordination of Health Research (OSCHR) should "take the lead in developing a strategic vision for genomic medicine in the UK with a view to ensuring the effective translation of basic and clinical genomic research into clinical practice" and inform "the basis of a new government White Paper on genomic medicine".

It was necessary, the report said, that there should be more translational research,² that the regulatory burden on researchers should be reduced and that the importance of bioinformatics and the use of information systems should be better recognised. Genetics had to be integrated into mainstream medicine; the organisation of molecular genetics services had to be rationalised; greater coordination between molecular genetics and other pathology services was needed; genetic tests had to be better evaluated³; doctors and other clinical professionals needed better training in genomic medicine.

These recommendations apply as much to Hong Kong as to the UK, and should be taken as seriously here as in London. Locally, there has been a very prominent and well-established clinical genetics service for over 25 years overseen by Dr Stephen Lam,^{4,5} while internationally respected work has been carried out by distinguished academics. These have included Professor Sir David Todd (haemoglobinopathies), Professor Lap-chee Tsui (cystic fibrosis), Professor Pak Sham (psychiatry), and Professor Dennis Lo (free foetal DNA). Despite this, neither the Hospital Authority nor the Department of Health appear to have accorded any priority to understanding the impact of genomic science on health care within the Special Administrative Region (SAR), nor have they formulated a policy response.

Across departments in both the Chinese University of Hong Kong and the University of Hong Kong internationally recognised research in genomics

is being conducted. A Genome Research Centre with world-class facilities has also been established, providing a research base and technological innovation. In the field of infectious diseases, the role of Hong Kong in the severe acute respiratory syndrome epidemic and in avian flu is well appreciated across the world. The Centre for Health Protection now plays a significant part in global infectious disease control, and in which genomics plays an important role. Yet, no strategy, mechanism or funding exists to ensure the systematic translation of the research into clinical or public health practice.

The Department of Health is responsible for the clinical genetic service, including laboratory and neonatal screening programmes. This is in stark contrast to the other clinical specialties which are provided through the Hospital Authority. These arrangements need urgent review. Clinical genetics is a clinical specialty like all others; laboratory genetics (including cytogenetics and molecular genetics) must serve not just the arena of clinical genetics but the entire health system, including primary care. Its laboratory structure must be rationalised and integrated with other pathology services to ensure maximal efficiency in the use of human and capital resources. Policy makers should recognise that genetic testing now spans a much wider remit than before, moving from paediatric issues and concerns about reproductive choice to cover diagnostic, preventive and treatment services across a range of specialties.^{6,7}

The picture of genomic medicine in Hong Kong, as elsewhere, is of a system characterised by ad hoc developments, some of real excellence. But the system also reveals many gaps. In this area of endeavour, Hong Kong can excel with the right leadership, but the existing 'muddling through' that has characterised genome-based science and services over the last two decades is an impediment that should no longer be tolerated.

As distinct from the implications for service provision, public policy considerations also need to be addressed. The latter include: science and research policy, data protection and confidentiality, intellectual property and the relationship between the commercial and private sectors. The information systems of the future will have to be fit for purpose. In an era of personalised medicine and individualised risk prediction, the family history will be of increasing interest. The family pedigree

may be referred to far more in the next few decades than it is now. It is therefore pertinent to ask, whether the implications of this trend have been taken into account in the design of the new system of electronic health records in Hong Kong, a project that will cost in excess of HK\$1 billion? To whom does the pedigree belong? Who should have access to it?⁸

Genomic medicine is not a panacea for all ills. From a public health perspective, environmental causes of disease will still be of prime importance. From the perspective of clinical practice, a whole range of service provision from primary to tertiary care will still need to be funded. But clinicians, especially those in tertiary centres, are already taking genomics forwards as part of their day-to-day work, and service planners need to be aware that this is taking place. The message is not that genomics should be paramount, nor that it should take priority over the funding of existing services, but serve as a warning that its implications cannot be avoided. The very fact that it is likely to have significant capital and revenue implications argues for a more strategic approach. Fragmented, uncoordinated implementation could prove costly and inefficient. Policy makers must establish a system for considering these implications. In so doing, they must draw on the principles of public health genomics, which may be defined as ‘the responsible and effective translation of genome-based knowledge and technologies for the benefit of population health’.^{9,10}

The scenario that Hong Kong must avoid is the implementation of genomics by default, rather than as part of a carefully considered strategy. Hong Kong, like the UK, must act to develop “a strategic vision for genomic medicine”. The multiple institutions and

actors within the SAR require that a new Steering Group be established to carry out this task. The group could be endorsed by the Secretary for Food and Health, University Vice Chancellors, the Directors of the Centre for Health Protection and the Genome Research Centre, as well as the Chief Executive of the Hong Kong Hospital Authority. Its membership should comprise representatives from the corresponding institutions as well as public health specialists, lawyers, social scientists, ethicists and health psychologists. The Hong Kong Academy of Medicine could also play an important role and should be properly represented. The imperative is for the government to take these matters seriously and to meet the challenges posed by genomics and personalised medicine head on.

The House of Lords report would serve well as a starting point for the deliberations of such a group. Its many recommendations are easily transferable to the Hong Kong context. Medicine in Hong Kong has had a distinguished history. If it is to maintain its position on the international stage, its policy makers will need to act quickly and develop a strategic vision to prepare its health system so as to benefit from advances in genomic science. The future is now. If there is no action, the future will be the past, and all that will remain will be lost opportunity and a health service not fit for purpose in the 21st century.

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