

# Genomic Medicine

An Independent Response to the House of Lords  
Science and Technology Committee Report

Background synthesis paper

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The PHG Foundation is the working name of the Foundation for Genomics and Population Health, a charitable organisation (registered in England and Wales, charity no. 1118664; company no. 5823194) which works with partners to achieve better health through the responsible and evidence-based application of biomedical science.

This is a summary of the key findings from the first four data gathering workshops, which were held between November 2009 and February 2010. It was presented in draft form for comment to the final strategy workshop, and provided the basis for formulating the final report. It is organised into six cross-cutting themes that were identified from the four workshops:

1. Scope and Vision
2. Data and Evidence
3. Implications for Health Services
4. Implications for Industry
5. Implications for Research
6. Implications for Public Engagement

## 1. Scope and Vision

### Strategy

The groups thought that there needed to be more clarity about the long-term goals and vision for a strategy for genomic medicine in the UK, and felt that the House of Lords Science and Technology Committee Genomic Medicine Report ('the Report') was 'lacking in evidence'. They thought that the vision should be for health focusing on unmet needs, and should ask the question how genomics can help to address these needs. It should recognise that this is a 'new arena for healthcare innovation'. The vision should be concerned with future society considering 'what we want as society' and 'how it can integrate social and medical health and well being'.

The Genomic Medicine Report suggests that the Office for Strategic Coordination of Health Research (OSCHR) should lead the development of a strategy for genomics. It was agreed that while this was appropriate in relation to research, that the focus of the OSCHR was too narrow if the vision was extended to clinical services and genomic medicine more widely. It was therefore suggested that the Academy of Medical Royal Colleges could work with OSCHR to take the lead on the clinical and public health aspects.

### Genetic exceptionalism

In setting the scope of the strategy it should be recognised that genetics is not special, but is part of a 'wave of discovery'; it should not, therefore be given special status. Although the main focus in the Report was on high-throughput genome sequencing technologies, the following technologies should also be included:

- Array and genomic technologies for measuring chromosomal imbalances
- Other 'Omic' biomarkers, e.g. epigenomics
- Other technologies for measuring phenotype, e.g. biochemical, imaging

It was suggested that 'molecular medicine' (rather than genomic medicine) might be a better term to cover all these technologies.

## Starting point

It was generally thought to be rather unfortunate that the ‘genomic medicine’ envisioned in the Report seemed to be concerned with delivering a future that was not connected with the current work in clinical genetics, which is focused on inherited (single gene) disorders. The Report does not recognise the significant level of unmet needs of those affected by single gene disorders, for whom accurate diagnosis and management of the disorder is currently possible. There will be a massive impact on clinical genetics arising from new genomic technologies and, in this regard, it was generally perceived that there was a much greater level of urgency for development and implementation that did not come across in the Report.

It was thought that the Report over-estimated progress to date and should recognise the limits of complex disease genetics, such as the ‘missing heritability’ of many diseases. In particular, participants emphasised that although research in this area will be important for understanding disease biology, and therefore possibly in the development of future treatments, it will not necessarily be useful for prediction at the individual level. The Report was characterised by too many claims and assumptions about susceptibility testing which many believed would never happen. It ‘over-hyped’ the potential benefits in this regard, which remain to be proven; it also conflated the rate of change of the technology and the rate of realisations of health outcomes. At the very least, the timetable for suggested change was too short. Thus the overall shift to predictive medicine was premature and the focus on genomics and prevention was too polarised; in particular, there needed to be more emphasis on the interactions with lifestyle, and more realism about what might work and how much it would cost before priorities are identified.

## 2. Data and Evidence

### Data generation, storage and Integration

All the groups recognised the central role of data in genomic medicine. A feature of new genotyping and sequencing technologies is their power to generate unprecedented amounts of data about a single individual. But if the technologies are to be useful, (*i.e.* to have clinical utility) data must be integrated from a variety of sources; for example, effective research and clinical practice is likely to arise from the integration of genomic and phenotypic information (namely information about genotype and lifestyle).

As researchers (and ultimately healthcare professionals) seek to integrate multiple sources of information, there will be an increasing need to share data. Already, new research tools such as the genome-wide association study, have necessitated sharing of data across research groups and jurisdictions, akin to multicentre trials in clinical research. This necessitates the development of processes and procedures for data sharing that are transparent, accountable and robust. Many groups commented that these need strengthening. IT systems will also need to be capable of transferring, archiving and mining relevant data.

## Biomedical informatics

All groups commented upon the challenges posed by interpreting genomic data and the need to develop appropriate informatics algorithms. The groups varied in their perception of the importance of biomedical informatics. Some regarded the need for a new discipline of clinical bioinformatics as being central and self evident; others regarded the emphasis upon bioinformatics as being naïve, and considered that there were other numerical disciplines that were equally important in contributing to the intelligent use of statistics (for example, for modelling the limits of predictability). Opinion was also polarised as to the advisability of supporting a centralised bioinformatics institute. Despite its limitations, it was argued that effective software could aid efficient data integration from multiple sources, and ultimately facilitate the translation of complex input data into a simple binary decision for the healthcare professional. If suitable software could be developed and kept up-to-date, it could prove a practical mechanism for integrating genomic information into numerous clinical specialties.

## Access

As more data is processed across multiple users, there were concerns about what level of data security is proportionate, particularly given that much genetic data will be clinically uninformative. Traditional paradigms for legitimising health interventions - namely seeking consent from individuals to process their genetic data - were seen as being inadequate or impracticable in some contexts. Individual genetic data is also shared by family members, which has implications for concepts of data ownership, data handling and access. Wider restrictions on data processing should reflect a balance between the need to protect individuals from harm by respecting the need for privacy, as against the need for researchers to have access to relevant data. Some felt that the balance was sometimes distorted by the risks of not sharing data being inadequately articulated.

It may also be difficult to obtain a properly informed consent, because the risks associated with sharing data are unclear due to the incomplete state of knowledge about the genome. The scope of legitimate consents (*i.e.* broad or limited) was also questioned, though it was recognised that judgements are difficult to make due to the lack of relevant case-law. Thus new models might be needed which take account of relevant duty of care and professional standards of practice.

## Governance and regulation

There were concerns that data generation coupled with more accessible formats for holding data (such as electronic patient records) would necessitate a more systematic approach to address wider ethical issues, including disclosure of family history or risk data and the generation of incidental findings. As more knowledge is gained about individual genomes, appropriate levels of sharing data must be found in relation to secondary users, such as insurers and employers. In particular, the insurance industry is likely to be affected by developments in genomics, and may even drive the uptake of genetic testing.

Since genotypic knowledge is likely to evolve over time, establishing the parameters of clinical duty and negligence may require reassessment and may need to be supplemented by new forms of decision making tools. In general, existing legislation such as the Data Protection Act is adequate, although some aspects of the Equality Act and Disability Discrimination Act need clarification with regard to genetic discrimination. A more sophisticated solution than simply banning the use of genetic information is needed and it was suggested that legislation should be established that bans all forms of discrimination against future predictive factors; singling out genetic factors would be an unacceptable example of genetic exceptionalism.

### **3. Implications for Health Services**

#### **Clinical genetics versus genomic medicine**

All groups felt that genomic technologies would impact on the provision of health services, but were concerned that the commissioning and provision arms were ‘not fit for purpose’ to cope with this development. Genetic testing is currently still orientated around clinical and genetic services as a small specialty. While this was appropriate when there were a small number of conditions for which genetic testing was available, the burgeoning of applications related to single gene disorders is now putting a strain on the system, which may not be sustainable for a health service in which genomic technologies are more widely embedded.

The Report appeared to assume that the health service currently deals well with single gene disorders and that these services did not require further attention; instead, it seemed to suggest that services should prepare for dealing with genomic aspects of complex disease. All groups noted that, in reality, greater health gain could be achieved through improved provision of genetic testing and clinical services for those with single gene disorders, and single gene subsets of common disorders, where diagnosis and treatment can currently be offered but for which there is under provision and inequity in access.

#### **Problems and opportunities**

##### *Budgets and silo mentality in commissioning*

NHS financial structures currently present a barrier to innovation and development, and also hamper decision-making across the medical specialties resulting in inefficiencies. The costs of an initial activity may be controlled by a separate budget from that where potential savings may be realised. For example, genetic tests to identify which family members should be monitored and which can be discharged are not undertaken due to budget restrictions within clinical genetics, resulting in increased spending through unnecessary monitoring of patients by other specialties. Current commissioning organisation results in this silo mentality and a lack of integration between different specialties and their budgets. There are also problems with how patients access tests, partly due to silo'd funding so tests are available in some locations but not in others. This inequity of access is exacerbated by devolved commissioning, and therefore equity of access needs to be addressed at a strategic level. Commissioning of specialist services currently causes a bottleneck in the commissioning of genetics services, and engaging with NHS commissioners to address this issue is therefore a priority. Commissioning arrangements are inadequate at responding to innovation and new evidence, and a more effective commissioning model is needed across the whole NHS.

### *Need to restructure clinical science and genetics organisation*

The current paradigm of the NHS does not fit with a workforce that can deliver genomic medicine. It is important that a wedge is not created between traditional clinical genetics and genomic medicine; rather that genomic medicine is seen as an expansion of existing expertise. Genomic medicine is a continuation of genetic medicine and the transferable nature of skills and services from clinical genetics needs to be recognised. As DNA-based tests are increasingly used by other specialties, clinical geneticists will need to move from their current gate-keeping role.

### *Focus initially on delivering services for single gene disorders*

Potential health gains from managing single gene disorders have not yet been fully realised (although this is the assumption of the Report). Currently, greater health gain can be achieved by effective care of patients and families affected by single gene disorders than by focussing on complex disease, where the complexity of the underlying genetic mechanisms is not yet sufficiently understood to be incorporated into clinical practice. Mendelian disorders should therefore be the focus for clinical management where the wealth of knowledge has not yet been fully translated into practice and the potential to develop new treatments has not been realised. For example, the National Screening Committee (NSC) should review the ‘flood’ of developments over the past five years in the characterisation, diagnosis and management of single gene disorders and the potential for extending newborn screening to some of these disorders.

### *Need to assess the effectiveness of clinical practice*

There is a need to generate and assess evidence for the effectiveness of current clinical practice across healthcare, as there is inertia in changing established practice and introducing innovation. This can cause problems in managing public expectations. Conversely the danger of ‘technology pull’ should be recognised - technology should answer clinical questions rather than creating questions simply because the technology can answer them. For example, we need to identify whether there is benefit to the NHS from high-throughput next generation sequencing and, if so, how to manage the introduction of this technology most effectively while addressing ethical considerations such as the implications which may arise for children. It is important to be explicit about what is effective rather than over-hyping what genomics can deliver. The health economic impact of genomic medicine should also be evaluated.

### *Investment in information technology*

Technological advances will not be translated into better healthcare unless there is sufficient investment in IT within the NHS including investment in electronic patient records. Although the NHS Connecting for Health Programme currently offers some direction, issues such as internet bandwidth and local variations in funding still need to be resolved.

## Laboratories

There is a general shift occurring in the use of diagnostics, which will increasingly be at the centre of the healthcare system. The provision of any medical test (genetic or otherwise) can be seen as an integral part of a clinical pathway, and understanding the molecular basis of disease arising from a precise genetic diagnosis is often important for clinical decision-making. The use of genetic tests for diagnosis should be integrated with other tests undertaken within clinical practice, rather than necessarily being treated as special, whilst being mindful of the possible implications for family members and making a lifetime diagnosis. Important new areas where genetic testing may have direct clinical benefit include cancer diagnostics and understanding the spectrum of different responses to old and new drugs (*i.e.* pharmacogenetics). However, the current structures for providing genetic information are not optimal, and high-level laboratory reorganisation and integration is urgently needed; for example, laboratories could share resources and work more efficiently, as is already starting to occur in molecular and cytogenetics.

### *Pathology Modernisation*

There is currently a huge opportunity to develop services for genomic medicine, but it was felt that this would need a radical ‘more aggressive’ and top-down approach to pathology modernisation rather than just an evolutionary one. Because genetic understanding and testing is now relevant to numerous specialties, a small number of genomic laboratories could be established that could serve the whole medical system, with clinical scientists being more independent from clinical geneticists and able to provide supporting advice. Laboratories should be able to serve numerous different clinical purposes, rather than being disease-specific, and some degree of centralisation would avoid unnecessary duplication of services. Importantly, genetics should be considered as part of pathology, rather than separate from it.

However, there are a number of issues in developing the forward strategy for pathology modernisation:

- *The technology may not be mature enough to take major strategic decisions.* As technologies get cheaper and simpler to operate the current push towards centralisation will be countered by pressures to build local capacity. As the technology is still developing, it may be impossible to take a firm view on this at present and the model developed will therefore need to be flexible.
- *No formal evaluation system is currently in place to establish the clinical validity and utility of new tests (genetic or otherwise).* In particular, for susceptibility, there are relatively few immediate benefits and so it will be difficult to demonstrate clinical utility quickly. However, it is important that different standards are not applied to the evidence required of genetic and genomic tests than is applied to medicine as a whole. Therefore an evidence base needs to be established for all tests that are available within the NHS, including those based on the analysis of DNA.
- *Private laboratories may be used for sequencing, data storage and interrogation.* Caution should be exercised by the NHS when using such services, particularly whilst the technology is in flux, to ensure that only clinically and cost-effective tests are offered.

## Professional education and training

Training of the wider workforce will be needed to build capacity and expertise within the UK. To date, the public health community has not engaged with genetics and there needs to be further consideration as to how genomic medicine fits in with medicine as a whole and with public health in particular. However, not everyone needs immediate training in genomics; it is more important to provide education on what currently is effective, such as taking a good family history, rather than focussing on future possibilities. There are, nonetheless, some specific educational needs:

### *Education for scientists*

More clinical scientists will be needed to interpret increasing volumes of genotype information, which is partially being addressed through the Modernising Scientific Careers (MSC) initiative. However, there is also a need to attract individuals from computing and numerical disciplines into biomedical informatics to prepare the NHS for genomic medicine. These professionals will develop tools to enable clinicians to translate the 'omics' datasets into clinically actionable information.

### *Education for mainstreaming*

There needs to be infrastructure to translate research into clinical practice. Genotype-based medical advice may answer a wide range of clinical questions, which will change over time as the patient develops new health problems or the knowledge base develops, and infrastructure will need to be created so that clinicians can use genotype information effectively. Part of the challenge will be to provide up-to-date information at an appropriate level to physicians, nurses and allied healthcare professionals; the Royal Colleges will need to be engaged in this process, and the role of the National Genetics Education and Development Centre (NGEDC) will also need to be defined.

### *Education for primary care providers*

Support is needed for primary care providers around the role of genomics in both rare and common disorders, including encouraging GPs to take and make use of family history. Quality and Outcomes Framework (QOF) incentives could be used to reward GPs where they can have the biggest impact on health gain - for example, in identifying patients with inherited cardiovascular disorders. As primary care practitioners are the first point of contact for patients who have purchased genetic tests directly and accessed other online genetic information, training is urgently needed to deal with patients' concerns.

## 4. Implications for Industry

### UK Plc

The groups recognised that there are potentially large benefits for the UK economy from developments in genomics. Through investment in technology, research and development, the UK should aim to be an international leader and ensure that it is a competitive, attractive and rewarding place to invest. To achieve this end, effective public-private partnerships will be crucial, both between commercial and public sectors within the UK (including academia, service and industry) and with international collaborators (including developing economies such as China). In addition, there are various commercial obstacles that need to be addressed, including developing incentives for innovation, reducing the regulatory barriers to translation, achieving an appropriate balance of private versus public interests, and understanding the impact of intellectual property rights.

Despite the potential financial benefits of genomics, the relationship between the commercial and public sectors needs careful consideration. A balance must be reached between the commercial interests of UK Plc and the potential of genomic medicine to yield health benefits and improvements in patient care through the NHS. Although some developments might be justifiable on purely financial grounds, it is important to be clear that the role of the NHS in genomic medicine is to provide effective translation of scientific understanding into health gains for patients using public money, rather than to create the ideal opportunity to generate products that can be sold for money. To this end, those involved in developing and advocating genomic medicine should be explicit about any vested interests.

### Diagnostics Industry

New genome sequencing technologies are likely to drive uptake of genomic medicine, and there may initially be more genomes sequenced commercially than within NHS. Biotechnology companies focused on developing novel sequencing technologies and providing genotyping services are therefore likely to be important to both health and wealth. Although, the pace of change of genomic technologies is extremely high, developments in genomic medicine will have implications across the whole diagnostics industry, in terms of both research and service provision.

There is an urgent and pressing need to develop a roadmap for R&D in diagnostics, somewhat akin to Phase II and III trials for pharmaceuticals. In particular, frameworks should be established to generate data and create an evidence base for tests, in addition to developing standards for assessing clinical validity and utility, which can then be used to establish the quality, efficacy and safety of novel tests and biomarkers. Funding is therefore required for clinical trials to enable evaluation and implementation of new diagnostic tests and any accompanying software. Because tests are part of a clinical pathway, rather than an end in themselves, their validity and utility is highly dependent upon the context in which they are used. Thus the appropriate trials are frequently too expensive for the diagnostics industry to fund alone, and public-private partnerships may be needed.

Regulation of testing is also important, and a balance should be struck between being too lax in industry's favour versus ensuring high quality research to improve patient care without being too restrictive or stifling innovation. Greater incentives for getting approval, particularly for orphan diseases, may be more effective than over-regulating, and streamlining the regulations may even save costs through reducing bureaucracy. In particular, proportionality is needed for the regulation of genetic tests relative to other *in vitro* tests; rather than simply classifying all genetic tests as medium risk simply by virtue of the fact that they involve DNA (as is recommended in the Report), classification should be risk-based, through a scientific assessment of the potential harms on a test-by-test basis. This notwithstanding, post-marketing surveillance of all treatments and tests would be informative.

### **Pharmaceutical Industry**

Pharmacogenetic testing and the development of targeted treatments and companion diagnostics will be important to pharmaceutical companies, and a clear regulatory framework for trials and commissioning will be needed in this area. It is currently unclear how patent issues are likely to impact upon the diagnostics industry and in particular the development of biomarkers and companion diagnostics. Testing (or analysis) at the point-of-care may also be increasingly useful for guiding treatment strategies, particularly in cancer and infectious disease diagnostics.

### **Consumer testing services**

The development of genetic tests that are sold direct-to-consumer (DTC) over the internet raises a number of important unanswered questions: will health testing become a commodity? Will consumers drive the uptake of genetic testing? Should personal genomes be considered as products? The main concern in this area is how to ensure quality and transparency in terms of the evidence behind a particular test, the interpretation of the results and the information provided to consumers. Clarity is needed about the true uptake of tests, rather than the hype, in order to determine what specific problems and potential harms a regulatory code should aim to prevent. Ultimately, DTC testing may be offered through private medical intermediaries who are able to ensure that the consumer understands the results and limitations of a particular test.

The possibility of purchasing tests over the internet from a different country, and then sending a sample overseas, raises questions about how to regulate such tests. In general, if the test is safe, it should be allowed on the marketplace, but regulation may still be needed with regards to the information provided in order to reduce the potential harms. Although this may primarily be a consumer protection issue based on the claims made by a particular company, exactly what constitutes an unfair claim in this area, the extent of legal redress for unsubstantiated claims, how important proven clinical utility should be for DTC tests, and who is responsible for 'missing' information are issues that may be too complex for existing legal mechanisms. Moreover, the ethical, legal and regulatory requirements on the quality of information provided, and the interpretation and disclosure of the results are currently unclear.

## 5. Implications for Research

### Focus and expectations

There needs to be clarity about the outcomes that are likely to be generated by genomic research to avoid exaggeration or hyped claims. In the research context this means that those engaged in genomic research must be realistic about the predicted outcomes, and recognise that the likely impact of genomics may be to contribute to a greater understanding of disease processes rather than leading to a genotype-driven health service. Thus personalised medicine - at least in the near future - is likely to be 'the exception rather than the rule'.

There was extensive discussion about what the focus for research should be. Some groups argued that research should focus on single gene disorders and single gene subsets of common disorders (especially those found to be at high risk). Better understanding of genotype/phenotype correlations in these patients provide a more patient centred approach with clinical utility at its centre. Another theme was the need for a more structured research pathway for diagnostic developments (in terms of clinical utility, R&D input, cost benefits and education) and in particular being mindful of including genomic components from the outset. Researchers should take account of all predictive biomarkers, not just genes, and guard against genetic exceptionalism. More research is also needed into health psychology and the science of behaviour change, including behavioural responses to testing and the effective communication of risk.

### Ensuring effective translation

Successful translation of research depends upon standards and outcomes for clinical utility and clinical validity in translational research being made transparent and explicit. It also requires a sustained programme of investment in the infrastructure of the NHS to support the integration of genetic data from research with clinical data, and the development and maintenance of an evidence base for the clinical effectiveness of new tests arising from these data. Research to generate evidence on clinical validity and utility of genomic information in the relevant population groups is critical.

Engaging sufficient investment is also crucial. Given the effectiveness of the NIHR in catalysing collaborative translational research, there is a need to maintain and expand this scheme. However the existing timeframe of five years is inadequate to take initial findings through to the clinic. There needs to be more integration of research outcomes into practice so that innovation is more effectively rewarded in industry and academia whilst bearing in mind the potential distortions that research agendas may have on services. Development of public-private partnerships may help streamline and fund the translation process.

### Ensuring a proportionate regulatory environment for research

Effective research will depend upon the development of robust processes for accessing data from a variety of sources and then integrating it at a number of different levels (*i.e.* from the individual, population and service diagnostic interface). A prerequisite for this is a regulatory environment that is not unduly restrictive or burdensome, and a workforce of sufficient expertise and size. Other factors such as the need to avoid duplicating processes between different agencies may also be relevant, including research ethics, R&D and health technology assessments.

A minority of participants felt that the prevailing balance currently is in favour of research, while others felt that major barriers remain which hamper research and that there is still room for improvement. At the outset of the research process, difficulties remain in obtaining access to data and samples which could be eased by a more systematic combination of incentives and anonymisation.

The processes involved in obtaining ethical and R&D approval for research still cause delays; the ethical approval takes too long, and changes to R&D have resulted in delays to the initiation of research projects. Ethical committees sometimes impose appropriately restrictive safeguards on the use of genetic data, which is problematic in epidemiological research. Another area of concern was the breadth and nature of the informed consent used in research, as were more conceptual issues around the ownership of genetic samples and data, and how research findings should be fed back to participants.

## **6. Implications for Public Engagement**

### **General public**

The need for wider public understanding of genomics was recognised in terms of awareness, engagement and education. In addition to a better understanding of single gene disorders, the public needs to appreciate the limited predictive utility of genetics for complex diseases in order to use DTC tests in an informed manner and interpret them appropriately. Suggested methods to improve public education varied from increasing the content of genetics and genomics on the national GCSE curriculum, to engaging in public debate about the ethical implications of whole genome profiling. However a simple deficit model of public engagement through education was felt to be inadequate. It was suggested that, in addition to educational programmes, the opinion of the general public should be sought over matters such as where genetic information would be stored (e.g. within or separate from medical records) and the level of information required to achieve informed consent for genome profiling.

There was general agreement that the public needed to be more engaged in research studies (whether through biobanks or cohort studies). Some participants reported existing high levels of public engagement with research, and suggested that many members of the public are less worried than is sometimes thought about the need to anonymise their data. The broader issue of consent for genetic information or material to be used for research purposes was also raised; should individuals need to explicitly consent to this or do the public expect that this type of research will and should occur without specific consent being sought?

### **Patients and families affected by inherited disorders**

Questions arise as to what the public want to know, what sort of information they want and how this should be delivered; this may vary for those individuals with a family member affected by a genetic disease compared to those where this is not the case. Patients and families affected by single gene disorders have a unique perspective upon genetics and are often extremely well informed about various aspects of genomics and health. They are well aware of many issues such as consent and confidentiality, the need for service development, the importance of new technologies for improved diagnosis, as well as the potential for discrimination and stigmatisation. This group could therefore be engaged separately from the wider public.



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