



Faculty of Public Health

of the Royal Colleges of Physicians of the United Kingdom

Working to improve the public's health

Response from the Public Health Genetics Unit and the Faculty of Public Health to the Human Genetics Commission's consultation on Choosing the Future: Genetics and Reproductive Decision Making

The Faculty welcomes the opportunity to respond to this consultation and our comments have been put together by the Public Health Genetics Unit and the Faculty's lead on genetics.

A1. Various forms of prenatal screening have now become a routine part of medical practice in the UK today. An increasing number of genetic conditions may be included in screening programmes in the future. How do you feel about these developments?

The UK National Screening Committee (NSC) defines population screening as a public health service designed "...to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications."¹ The decision on whether a screening programme should be introduced should be based on whether it meets criteria, such as those from the NSC, for a screening programme, and its effectiveness in meeting its stated objectives.

Whether or not a screening programme should be introduced should be determined by established criteria and not on whether the condition to be screened for is an inherited condition nor whether the technology to be used is based on DNA and related techniques. If a proposed screening programme for a genetic (inherited) condition does meet the criteria, is shown to be beneficial and falls within the NSC criteria, we would welcome its introduction.

European/international considerations, an example of which is the recent publication of 25 recommendations on the ethical, legal and social implications of genetic testing², takes a similar stance. Recommendation 8 stresses that tests should be meaningful, the condition screened for must be serious, the test highly predictive and follow-up actions must be available.

Of course, even if a proposed genetic screening programme satisfies the criteria for assessing the merit of a screening programme, other factors, most notably other competing priorities for scarce health care resources must be considered.

A2. We are interested in the extent to which you have confidence in the current provision of prenatal screening and diagnostic services:

- ***Is adequate counselling provided?***
- ***Is sufficient and appropriate information offered at all stages of the process?***
- ***Is the information provided full accessible to all groups in the community?***
- ***Is counselling non-directive?***

¹ http://www.nsc.nhs.uk/whatscreening/whatscreen_ind.htm

² European Commission. (2004). *25 Recommendations on the ethical, legal and social implications of genetic testing*. http://europa.eu.int/comm/research/conferences/2004/genetic/pdf/recommendations_en.pdf

As noted by the Department of Health in its White Paper on Genetics, more support and funding are needed to train a sufficient number of genetic counsellors in order to meet current and future needs. In addition we believe that training programmes must be established to enable midwives, health visitors, general practitioners and primary care teams to have greater understanding of the genetic conditions covered by national screening programmes. Primary care teams should have an important role in identifying individuals with a family history or other factors that put them at increased risk, and providing initial information and advice. The evidence at present is that the understanding among health professionals is poor and that patients are not always given the best advice. Until this deficit is corrected, mass genetic screening programmes should not be established.

A3. It has been claimed that prenatal screening and diagnosis presupposes that most women and couples will opt for termination if a genetic disorder is identified, some feel this reflects a wider negative assessment in society of the value of the lives of disabled people and/or people with genetic disorders. Do you agree or disagree with this view? And why?

We would first wish to recognise that genetic disorders cover a wide range of clinical manifestation and severity. In our answer to question A1, we referred to recognised criteria for screening programmes. These criteria included a requirement to ensure that the disease is an important health problem. Thus, we would not wish to see screening programmes established where the disease involved does not have significant impact on life expectancy, quality of life etc.

However, with this caveat, we believe the purpose of offering prenatal screening and diagnosis is to give individuals a full and informed choice as to whether they wish to proceed with a pregnancy. The provision of understandable information and non-directive counselling by trained genetic counsellors should help to enable individuals to make the choice best suited for them. The objective of a screening programme should never be to reduce the birth prevalence of children with genetic disorders.

We do not agree with the view that giving parents such a choice devalues the lives of disabled people with genetic disorders. The responsibilities that face parents and families of people with serious genetic disability can be enormous. It is more often than not that having a child with such a disorder leads them to decide to terminate the pregnancies of future affected children. This in no way affects the love and attention that they continue to give to the affected living child. We recognise the importance of services to address the social and healthcare needs of people with disability. When such services are available, the support that they offer may provide parents with a more balanced choice against termination of pregnancy. It is therefore important that such services are widely available.

Those who already have genetic disability are best placed to make the correct choice for themselves that take into account the family member with the disability and the needs of other members of the family.

B4. There are a number of genetic disorders for which embryos and fetuses can be tested. Should the use of PGD to test and select an embryo be governed by the same principles as the use of prenatal genetic testing (PND)? And to what extent should people have the right to request the testing of an embryo or fetus for particular genetic conditions?

PGD is an expensive and complex procedure with a limited success rate that will only benefit a small number of people. It is not practical at this time to devote limited healthcare resources to making it generally available. Under the current system, eligibility is limited to a small group of people who must meet agreed criteria in order to receive approval to take advantage of this

procedure. We support the present regulatory framework for PGD and the requirement for strict control of its use.

There will always be the need to set priorities in the NHS. The concept that an individual has a right to any particular procedure is always limited by considerations of opportunity cost. Commissioners of health services have always had the responsibility of making difficult decisions about what services should be made available to their population. PGD is no different from any other service in this regard. When resources are finite criteria may have to be set that limit the availability of a particular service. This is entirely acceptable provided that such criteria are explicit, equitably applied across the country and using a process that is clear and transparent.

B5. Whilst treatment using donor sperm, eggs and embryos is regulated in the UK, there exist companies outside the regulatory framework who can match potential donors with recipients. To what extent should people be able to choose the characteristics of a donor in the hope that they will conceive a child who inherits these characteristics?

There are serious issues related to ensuring the safety of sperm, eggs and embryos sourced from unregulated companies. Recipients will not know whether donors have been screened for infectious diseases or heritable diseases. There is a suggestion that with the loss of anonymity for egg and sperm donors from April 2005, fewer people will donate forcing women to consider an unregulated option, such as purchasing sperm over the internet. These issues require further consideration.

Choosing an embryo based on its sex is already prohibited unless there is concern regarding a sex-linked genetic disease. There are arguments that the number of people who wish to choose the sex of their child through genetic testing is limited and therefore not a real threat to the population, and that sex selection should be allowed. These arguments will become much more complex as and when genetic testing can indicate other characteristics that might be of interest to parents or when an embryo can be genetically manipulated to change its characteristics as desired. The ability to do this for complex traits such as intelligence or beauty will not become a reality for many decades, but the technology to use PGD to select simple traits such as eye colour is already with us. It is essential that the ethical, legal and social considerations surrounding these issues are addressed early and in advance of the technology.

C6. What, if any, are the potential future developments in this field that give you hope and/or concern? How might your hopes or concerns be addressed most effectively?

Public health has particular expertise in regulatory issues and policy development. It is essential that an appropriate balance be struck between having a regulatory framework that allows proper research and development to occur without incurring too great a burden, yet at the same time is effective in protecting the public. This balance is essential if society is to continue to benefit from developments in genetic science.

C7. Genetics is a rapidly changing field, particularly in relation to reproduction. Are there any issues you would like to raise about the framework and organisation of services in light of potential developments over the next decade?

No

C8. Are there any additional issues or concerns you would like to bring to the attention of the Human Genetics Commission that have not been addressed in this document?

No