



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Consultation Response

Department of Health

Healthy Lives, Healthy People: Our strategy for public health in England

Response by Genetic Alliance UK

1. Genetic Alliance UK (formerly Genetic Interest Group) is the national charity supporting all those affected by genetic conditions. Genetic Alliance UK aims to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them. Our membership represents more than 150 voluntary organisations working for a wide range of conditions, many of which pose complex health and social care needs.
2. A baby with a genetic condition is born every half an hour in the UK; of these only 4 in 10 will have their condition cured or ameliorated, the rest will die or live with a lifelong chronic condition.
3. We are grateful for the opportunity to comment on this consultation.

Public health and genetics

4. Traditionally, public health and the discipline of providing genetic healthcare overlap solely in the area of screening. As our understanding of human genetics changes, this overlap will grow. Traditional “common” conditions, currently recognised as multifactorial conditions, are fragmenting into conditions with a genetic component. This is the case for both cancer and heart disease.
5. Cancer genetics is an established discipline and the list of genes influencing cancer risk is growing. Families affected by inherited cancer mitigate their risk both with increased surveillance for tumours based on knowledge of their genetics, and by observing public health initiatives regarding diet, smoking and exercise.
6. There are many genetic conditions that affect cardiac health, conferring elevated risk of myocardial infarction, chronic heart disease and/or risk of sudden acute episodes. As in the case of cancer, families affected by inherited heart disease mitigate the risks that their genes bring in two ways: with specialist advice and medication from cardiologists, and by observing public health initiatives regarding diet, smoking and exercise.

Screening

7. The key concern for Genetic Alliance UK though remains screening. Screening is the best route to early diagnosis for children affected by genetic conditions. Of the six antenatal and newborn screening programmes running in England, five contribute to the early diagnosis of genetic conditions. The Sickle Cell & Thalassaemia programme and the Newborn Blood Spot programme

screen for specific genetic conditions on the recommendation of the National Screening Committee; the Down's Syndrome and Fetal Anomaly Ultrasound Screening programme and the Newborn and Infant Physical Examination programme offer early opportunities to recognise physical anomalies, many of which are indicative of genetic disease; and the Newborn Hearing programme can deliver early diagnosis of deafness, much of which has a genetic cause.

8. Early diagnosis is vital to the future health of a newborn child affected by a genetic condition. With diagnosis comes effective management of the condition, and access to the best available treatments. Delays in access to treatment can lead to an irreversible deterioration of the child's health, even after intervention.

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9. There is very little mention of screening in the White Paper, other than the statements that: a) screening will be funded by Public Health England, and b) that Public Health England will ask the NHS Commissioning Board to commission screening programmes.
10. There is further mention of screening in the *consultation on the funding and commissioning routes for public health*: that Public Health England will be responsible for the funding and management of pilot screening programmes and the extension of current ones. We have concerns over the division of responsibility between Public Health England and the NHS Commissioning Board, and would like to see more detail as to how this division will be made. Further details of our views on this can be found in our response to the *consultation on the funding and commissioning routes for public health*.
11. We hope that Public Health England will work with, and seek advice from, the National Screening Committee, and will consider the great value of early diagnosis, in making decisions regarding pilot screening programmes.
12. Genetic Alliance UK hopes that the lack of detail regarding screening in the White Paper and its accompanying documents indicates that there are no plans to change the current arrangements for the provision of screening in England.

Endorsements

13. Genetic Alliance UK endorses the responses to this consultation from the British Heart Foundation who are members of Genetic Alliance UK, and the Cardio & Vascular Coalition of whom we are members.



Alastair Kent OBE
Director