



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Consultation Response

Department of Health

Consultation on the funding and commissioning routes for public health

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 patient 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.

Response to the White Paper

4. This consultation response should be read alongside our response the White Paper: Healthy Lives, Healthy People, in which we highlight the value of national screening programmes and comment on the lack of detail regarding screening in the White Paper and its accompanying consultations.

Question 7: Do you consider the proposed primary routes for commissioning of public health funded activity (the third column) to be the best way to: a) ensure the best possible outcomes for the population as a whole, including the most vulnerable; and b) reduce avoidable inequalities in health between population groups and communities? If not, what would work better?

5. There will be a number of organisations involved in the planning, funding, commissioning, and piloting of screening programmes in the proposed new arrangements. Public Health England will be responsible for the funding of national screening programmes, and for the management of pilot schemes for new screening programmes; but the NHS Commissioning Board will be responsible for the commissioning of screening programmes in the NHS.
6. We are concerned that this division between Public Health England and the NHS Commissioning Board, particularly between piloting and commissioning, may lead to duplication of work and/or inconsistencies in the methods of screening provision; and we are concerned also that information, valuable for the planning of pilot screening programmes, may not flow efficiently between the two organisations.

7. The task of reducing and preventing birth defects will be split between genetic services, and Public Health England and local authorities; rightly so, as birth defects can be a result of genetic causes and environmental factors. This task must take account of the incidence of birth defects, reported by national screening programmes. We hope that adequate measures are put in place to ensure information flow between all of the entities that have a stake in screening.
8. The National Screening Committee is not mentioned in the White Paper or in this consultation document. We believe their expert advice is essential in selecting new screening programmes for pilot, and for the supervision of screening programmes in England.

A handwritten signature in blue ink that reads "Alastair Kent".

Alastair Kent OBE
Director