



**Genetic Alliance UK**  
Supporting. Campaigning. Uniting.

## Consultation Response

Department of Health

Liberating the NHS

Local democratic legitimacy in health

Response by Genetic Alliance UK

### Introduction

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 130 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. Most of the patients and families supported by our members are frequent users of the NHS and require good quality coordinated care from a wide variety of local, regional and national centres in many areas of specialisation.
3. We are grateful for the opportunity to comment on this consultation. This response has been endorsed by the trustees and members of Genetic Alliance UK.

### Strengthening public and patient involvement

4. Genetic Alliance UK welcomes the proposed strengthening of patient voices through a national roll out of HealthWatch.
5. The focus in this consultation document is on local care, integration between GP consortia and components of care provided by local authorities, and on local oversight by HealthWatch. Speaking on behalf of patients who would expect a component of their care to come from specialised services not necessarily delivered locally, Genetic Alliance UK would like to see the same principles applied to specialised services organised on a national basis. Specialised services should receive the same quality of support and oversight afforded to locally delivered care.
6. Well thought out strategies for organising and delivering treatment, care and support to small populations with special (often complex and challenging) needs would benefit equally from such patient involvement and oversight. A clear distinction between the role of local HealthWatch outlets in overseeing GP Consortia commissioned services and input from patients to services commissioned directly by the NHS Commissioning Board will be necessary to ensure local agendas do not hinder the implementation of these strategies.

### Question 3: What needs to be done to enable local authorities to be the most effective commissioners of local HealthWatch?

7. Genetic Alliance UK awaits proposals for the legal status of local HealthWatch and national HealthWatch, their constitution, powers, funding and accountabilities with interest.

#### Improving integrated working

8. Genetic Alliance UK welcomes the recognition of patient frustration arising from poorly integrated services in paragraph 20. Joined up service provision across boundaries is essential to high quality care. This is not only important between the NHS, social care, and public health at local level, but also within the NHS, "vertically", where elements of care provided in specialist centres are integrated with those provided by GP consortia or other authorities. The NHS Commissioning Board should ensure that its monitoring framework is sufficiently sensitive to capture both the vertical and the horizontal dimensions in good quality care.

9. Genetic Alliance UK has carried out practical research in this area. The 'Family Route Maps Project' is one of these studies: [www.geneticalliance.org.uk/projects/familyroutemap.htm](http://www.geneticalliance.org.uk/projects/familyroutemap.htm). The aim of this project was to assist families' access to care and support in the NHS.

10. Key findings of this work are:

- Communication between healthcare professionals is important to ensure that care is properly coordinated within a multidisciplinary team, and to counter fragmentation through organisational boundaries. The project reported many instances of patients having to repeat themselves to healthcare professionals. This lesson should be carried across to integration of care between the NHS, public health, and social care services.
- Patients' access to information is valuable to assist their navigation between care providers. Both good quality communication from their healthcare provider, and good quality information in material form, allow patients to understand better which components of their care they should be accessing from which care provider. We expect new HealthWatch bodies to contribute to this role.

11. Genetic Alliance UK is continuing this work with the project 'Routemaps for Rare Conditions', a project funded by the Department of Health. This will develop a practical and cost-effective framework for improving information, access and coordination of health and social care services for individuals and families with a wide range of rare genetic conditions. This pilot scheme will support eight user-led support groups to develop a series of condition specific Route Maps. A toolkit and a written methodology will be created alongside the Route Maps so that in the future other groups can develop a Route Map for their own condition.

### Question 7: Do you agree with the proposal to create a statutory health and wellbeing board or should it be left to local authorities to decide how to take forward joint working arrangements?

12. Genetic Alliance UK supports the concept of oversight of integration between NHS, social care, public health and other local services by health and wellbeing boards.

### Question 12: Do you agree with our proposals for membership requirements set out in paragraph 38 - 41?

13. It should be recognised that the majority of patient organisations in England are small, busy, voluntary organisations. They should be empowered to fulfil their role on health and wellbeing boards with funding and training, and be given a statutory right of access to relevant information. To secure patient confidence that they are truly representative of the community their purport to speak on behalf of they will need to have democratic accountability.

### Question 18: Do you have any other comments on this document?

14. A key foundation of the White Paper is the foundation of the NHS Commissioning Board and the protection of the health service from micromanagement from Whitehall. The increasing role to local authorities in the oversight of the NHS and local level will introduce the potential for political (and party political) point scoring and the opportunity for locally elected politicians to pursue specific local agendas which are not necessarily in the best interests of the patients using health care commissioned by GP Consortia.
15. The boundaries of local authorities and GP Consortia commissioning areas are unlikely to be co-terminus, the potential for conflict in areas where there is an overlap should be recognised and planned for. This may be particularly severe when adjacent local authorities have a differing political make up.



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