



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Consultation Response

Department of Health

Liberating the NHS

Commissioning for patients

Response by Genetic Alliance UK

Executive Summary

- Patients with genetic conditions make use of the health service at all levels and need a commissioning structure which is capable of planning and funding many differing types of healthcare, from local day-to-day healthcare to multidisciplinary, complex, specialised care.
- Genetic Alliance UK welcomes proposals to give responsibility for commissioning of specialised services to the NHS Commissioning Board, and hopes this measure rightly includes those services previously commissioned at a regional and supra-regional level, thereby alleviating postcode lotteries for specialised services.
- We believe the budgets currently allocated to national and regional specialised commissioning should be directly allocated to the NHS Commissioning Board to ensure services currently commissioned nationally and as part of the Specialised Services National Definition Set are adequately funded.
- Genetic Alliance UK welcomes the extension of public and patient involvement in the NHS through engagement in commissioning decisions and believes this will be best delivered with expert patient involvement at a board-management level.

Alastair Kent
Director



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Consultation Response

Department of Health

Liberating the NHS

Commissioning for patients

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 respond to this consultation. This response has been endorsed by the trustees and members of Genetic Alliance UK.

Commissioning for patients with genetic conditions

4. Genetic Alliance UK would like to see a commissioning structure which is capable of planning and funding many differing types of healthcare, such as: complex therapies for which there will be very few patients; multi-disciplinary care from various specialities for patients with multifactorial conditions; and good quality, timely, expert diagnosis of rare conditions.
5. The majority of the many thousands of single gene disorders that affect patients in the UK are rare, cause multisystem disease, and require specialised treatment. More and more common diseases are being found to have a genetic component; many of these could require specialised knowledge for management. Genetic conditions, and conditions with a genetic component, have implications for families, both now and in their future.
6. Patients with genetic conditions make use of the health services at all levels, from local, everyday health services and social care, to specialised services commissioned on a national basis, and from both a chronic and acute position of need. A commissioning structure that can provide adequately

for those affected by genetic conditions needs to ensure good communication and coordination between those commissioning services at the local level and those commissioning specialised services.

Specialised commissioning

7. Services currently commissioned at a national and regional level are vital to our members. Of the 45 services commissioned nationally, 6 are services for patients with genetic conditions, and 27 of the remainder frequently treat those affected by genetic conditions.
8. Of the 34 defined services in the Specialised Services National Definition Set (SSNDS), currently commissioned on a regional basis, 4 are services for patients with genetic conditions, and 28 of the remainder frequently treat those affected by genetic conditions. Many patients with genetic conditions will need to use more than one of these services.
9. As this consultation document has recognised, the recommendations of Sir David Carter's 2007 review of specialised commissioning have not been fully implemented. In the current commissioning system, patients with very rare genetic conditions, such as lysosomal storage disorders, and Alstrom syndrome, benefit from guaranteed access to nationally commissioned specialised services. Those with slightly less rare conditions, such as cystic fibrosis, haemophilia, or thalassaemia find that their care delivery differs drastically across the country according to whether or not the Specialised Commissioning Group (SCG) covering their area has commissioned the relevant service from the SSNDS.
10. This issue was recognised in the House of Commons Health Select Committee's Fourth Report of Session 2009-10, entitled 'Commissioning'; and the problems identified were accepted by the Government in its response published 2010.
11. This postcode lottery at the regional commissioning level is a major problem with the current specialised commissioning arrangements. The method by which funding for regional specialised commissioning is collected, pooling resources from Primary Care Trusts (PCTs), causes resentment towards a system that should deliver good value for money and better care for patients in PCT catchment areas. This resentment manifests itself as a penny-pinching attitude in SCGs and results in a patchwork of specialised service delivery. Every single SCG currently commissions a different selection of services from the SSNDS, and many pay differing amounts for the same service from the definition set.
12. The process by which specialised services are commissioned with the current arrangements could also be improved. For a specialised service to be commissioned, it must either fit the criteria for national commissioning and be selected, or it must gain a position in the SSNDS. Given the large number of genetic conditions (there are more than 6000 single gene conditions, to which can be added chromosomal disorders and multifactorial diseases with a strong genetic component), there is understandably a large queue for specialised commissioning designation.
13. Genetic Alliance UK believes the system should move towards a more inclusive paradigm for specialised commissioning based around common pathologies. New treatments and services for those with rare conditions, when they arise, can then be housed within services already supported by their SSNDS designation, whose budgets can be expanded to allow for this. Diagnosis and management for genetic conditions will of course continue to require the specialist knowledge provided by genetic services.

The future for specialised commissioning

14. Genetic Alliance UK welcomes the proposal to give responsibility for commissioning specialised services to the NHS Commissioning Board. There is little further detail in the consultation document as to how specialised commissioning will be organised in the future though.
15. The National Specialised Commissioning Group (NSCG), NHS Specialised Services (NSS) and the National Specialised Commissioning Team (NSCT) have amassed a considerable amount of experience and expertise in this area. Genetic Alliance UK would like to see this expertise preserved, and housed within the new body overseeing specialised commissioning to ensure continuity and consistency.
16. The proposed new commissioning structure for England contains no analogous bodies to the Strategic Healthcare Authorities, SCGs, and PCTs. In our view, there is therefore no logical reason for retaining a separate regional layer for commissioning specialist services. All services in the SSNDS, currently commissioned on a regional basis should be commissioned on a national basis. Demand and need are constant across the population, and the critical mass necessary for effective patient care and efficient use of resources is best achieved with a common framework across the country.
17. A centralised system for the commissioning and planning of services in the SSNDS will allow for the best geographic distribution of centres appropriate to their catchment population; will end the postcode lottery apparent in the current system; and will allow contracts with care providers to be negotiated with one body.
18. The current budget for specialised commissioning, i.e. the budget for services commissioned by SCGs and the NSS should be preserved and protected. This budget for specialised commissioning should be supplemented to reflect the fact that SCGs do not currently commission the full portfolio of services in the SSNDS. This fund should be directly allocated to the NHS Commissioning Board to avoid any argument from GP consortia that these funds should be allocated differently. Any other service or group of services (e.g. maternity services) that will also be commissioned by the NHS Commissioning Board should have a separate budget.
19. The budget assigned for specialised commissioning should be flexible and allow for expansion when new candidate services for SSNDS designation or national commission appear. Those services in the SSNDS which care for those affected by conditions grouped according to their pathologies, such as the specialised neurosciences services, renal services, endocrinology services and services for metabolic disorders, should be funded in such a way that they are able to provide new services to those affected by particular conditions, as an alternative to an addition to the SSNDS or a new nationally commissioned service. This funding strategy would go some way towards solving one of the problems with the current system; that of a long queue for nationally commissioned status.

Local commissioning for patients with genetic conditions

20. Local healthcare provision is just as important to patients with genetic conditions as specialised services. All patients contact this level of healthcare provision in the first instance and most will receive a component of their specialised service locally from locally commissioned healthcare providers. Indeed, patients will continue to use locally commissioned services throughout their lives as unrelated health care needs arise. A commissioning system in which distinct commissioning bodies communicate well with each other is essential for a joined up healthcare service.
21. We welcome proposals for close links between GP consortia, social care and local authorities. Current distinctions between that which is deemed “medical” care and that which is said to be “social” care are frequently arbitrary, and there is an urgent need to eliminate boundaries that

make access more difficult than it needs to be. Genetic diseases can be complex, difficult to describe, rare, and often do not fit neatly into distinct types of condition understood by social care services. These difficulties can make access to social care for families affected by genetic conditions difficult, leaving families without vital support.

22. Genetic Alliance UK hopes to see closer links between social care and local commissioners ensuring social care providers have a better understanding of individuals' health problems and creating a route for appeal where families feel their health problems are poorly understood.

Comments and answers to questions

Scope of GP Commissioning

23. Paragraph 3.4 states that GP consortia will have the freedom and the responsibility to decide at what level low-volume services will be commissioned. Genetic Alliance UK believes it is vital that services of with a volume of use comparable to those defined in the SSNDS should be commissioned by a national expert body. The commissioning of those services that fall between the thresholds for specialised commissioning and GP consortia commissioning should be carefully monitored to ensure they are commissioned, and that access to those services is equitable across the nation.

In what practical ways can the NHS Commissioning Board most effectively engage GP consortia in influencing the commissioning of national and regional specialised services and the commissioning of maternity services?

24. GP consortia should have representation on committees responsible for the commissioning of specialised services. There should be means by which GP consortia can propose to this body services that might be more appropriately commissioned by the NHS Commissioning Board for adoption as a specialised service.
25. In many cases, the argument for commissioning a specialised service on a national level are irrefutable, and an enormous benefit in terms of quality of service and economies of scale. In these cases the GP consortia representatives on the NHS Commissioning Board should ensure that they communicate these benefits back to consortia.

How can the NHS Commissioning Board and GP consortia best work together to ensure effective commissioning of low volume services?

26. Genetic Alliance UK strongly supports the concept of specialised commissioning. It is the best means by which quality and accessibility of specialised services can be assured. The system brings with it an inherent problem, that of a threshold: there must be a set of criteria which services must meet to be commissioned in this way, and inevitably some services will fall close to the edge of this criteria set. It is vitally important that those services, for which volume is at or around the threshold for specialised commissioning, do not fall between commissioning entities. There should be a system by which services around the threshold can be judged according to other criteria (such as route of diagnosis, pathology, relation to other specialised service), and commissioned by the appropriate body in a consistent way across the country.
27. Patients needing services that are too high-volume for specialised commissioning, but too low-volume for GP commissioning are vulnerable to the effects of a postcode lottery if there is variation in how they are commissioned between different groups of consortia. Genetic Alliance UK regards this area of the proposed new commissioning framework with a great deal of concern.
28. Best practice in commissioning at the level above individual GP consortia should be collected as and when it arises, and quickly replicated across the country. A key component of the duty of the NHS

Commissioning Boards to hold consortia to account should be to ensure that patients of consortia have access to services commissioned at the level above a consortium-unit volume of population.

Are there any services currently commissioned as regional specialised services that could potentially be commissioned in the future by GP consortia?

29. Genetic Alliance UK is not aware of any services currently in the SSNDS that should be commissioned in the future by GP consortia. (This statement assumes that GP consortia will be closer in size to PCTs than to SHAs.)
30. Just as there should be measures in place to decommission services that are not working; there should be measures in place which ensure that services are being commissioned at the level most appropriate to the population requiring the service. As populations and health service provision evolve, this level is likely to change for certain services. Very specialised services may become more widely used in the future, and commonly used services may become unnecessary for the majority of the population.

Relationship between consortia and individual GP practices

31. We welcome the recognition in paragraph 3.18 that “the effective identification and management of long-term conditions, the accessibility and responsiveness of GP services, and decisions on referrals and prescribing all have a major impact both on the overall quality of patient care”, and that GP consortia can play a key role in driving up this quality.
32. For patients with genetic disease key issues affecting quality of life are effective management of long-term conditions, and access to diagnosis. Whilst monitoring performance in these areas, it is our view that GP consortia can ensure excellence by identifying and disseminating best practice both within and outside their consortium. Access to good quality diagnosis from GP surgeries, be it through referral or not, will benefit from expert oversight, which could be provided by GP consortia.

The role of the NHS Commissioning Board

33. To carry out its role, the NHS Commissioning Board must have a good understanding of the users of the systems it presides over. From the perspective of members of Genetic Alliance UK, we would like to see a position for a designated expert on specialised commissioning. Specialised commissioning is important, but it is often poorly understood by providers of local, high volume healthcare. It is important that the specialised commissioning structures, which have improved so much over the past few years, have an advocate on the NHS Commissioning Board. This member should work closely with the National Clinical Director for rare diseases, as proposed in the Chief Medical Officer’s report of 2009.
34. Specialised services are used by populations outside of England. Scottish, Welsh and Northern Irish patients travel to access treatments that are provided in centres of excellence in England, and vice-versa. It is important that the systems by which health authorities in the Home Nations negotiate contracts for cross-border healthcare delivery continue to be effective after and during this period of reorganisation. Measures should also be taken to ensure that priorities and measurements of care delivery are compatible across borders and that there is no unfairness in the system that prioritises any nation’s patients over others.

i) providing national leadership on commissioning for quality improvement

35. Paragraph 3.27 of the consultation document states that the NHS Commissioning Board will design the structure of tariff and other financial incentives whilst the economic regulator will be responsible for setting tariff levels. It is important that the economic regulator is aware of nuances that affect this pricing and that tariff prices reflect the realities of clinical service delivery.

36. For example, clinical genetics works on an outpatient basis but with a comparatively long typical appointment time of three quarters of an hour. Standard outpatient tariff notes make this economically unviable for the Trust hosting the service unless special arrangements are made to avoid this. Professional groups such as the British Society for Human Genetics have generated expertise on tariff issues and this should be used by the NHS Commissioning Board when developing frameworks and model contracts.

37. Genetic Alliance UK welcomes the NHS Commissioning Board's role in determining technical and data standards to ensure there is consistency in the information that commissioners and providers are using, and compatibility between information systems.

38. Systematic data collection is essential to compare service provision between GP consortia and support planning and commissioning, but it is also vital to progress in research in the NHS. The NHS is almost uniquely able to support clinical research as it is a single healthcare system for more than 50 million people. Central collection of data can facilitate research and development, and is essential for patients with rare genetic diseases if there is to be the possibility of creating a strategic response to their needs. In particular the development and implementation of the International Classification of Diseases (ICD) 11, which makes a greater granularity in rare disease classification possible, will provide a crucial opportunity for capturing data on the incidence and natural history of rare genetic diseases that are currently poorly understood.

ii) promoting and extending public and patient involvement and choice

39. Genetic Alliance UK welcomes the extension of public and patient involvement in the NHS through engagement in commissioning decisions. We believe this will be best delivered with expert patient involvement at a board-membership level, and with consultation of appropriate patient organisations relevant to specific commissioning decisions. Patient and carer membership of the Board at the highest level should be enshrined in the legislation that creates the Board alongside other membership categories.

40. We welcome the proposal for the NHS Commissioning Board to design patient-reported experience and outcome measures. We have commented further on patient-reported experience and outcome measures in our response to 'Transparency in outcomes – a framework for the NHS'.

iii) ensuring the development of GP consortia and holding them to account

41. The duty of the NHS Commissioning Board to hold GP consortia to account is essential for the success of the proposals in the White Paper.

iv) commissioning certain services that are not commissioned by consortia

42. We support strongly the recognition in paragraph 3.3 that it makes sense for the NHS Commissioning Board to have responsibility – and the accompanying share of the NHS budget – for national and regional specialised commissioning. In paragraphs 14-18 above we have described the changes necessary in the framework for commissioning of specialised services to create equitable provision of services across the nation at a level and availability proportional to the volume of need in the population.

43. Implementation of the new commissioning structures should take care to ensure those services that are currently commissioned by SCGs continue to be commissioned at a level appropriate for their level of specialisation. Genetic Alliance UK believes services such as these, for example the NHS Fetal Anomaly Screening Programme which coordinates screening for structural anomalies and Down's syndrome, should be commissioned by the NHS Commissioning Board.

Are there other activities that could be undertaken by the NHS Commissioning Board to support efficient and effective local commissioning?

44. The proposals to allow Foundation Trusts greater autonomy to develop services create the possibility of a dearth of some services that for whatever reason are not in the interests of care providers to provide. It cannot be left to market forces alone to ensure availability of all services that GP consortia wish to commission. There therefore needs to be adequate safeguards guaranteeing patient access to services should a Foundation Trust decide that a particular area of care is insufficiently attractive for it. This role, to ensure there are services to commission, should be provided by the NHS Commissioning Board.

What are the key elements that you would expect to see reflected in a commissioning outcomes framework?

45. We welcome the proposal in paragraph 5.15 that the NHS Commissioning Board should work with patient groups to develop a commissioning outcomes framework that measures health outcomes and quality of care, including patient-reported outcome measures and patient experience. We regard this as an opportunity to create, for the first time, robust outcome measures capable of truly capturing the patient experience.

46. Issues and measures traditionally not considered, and usually left out of NICE assessments, should be included such as patient comfort, ease and flexibility of treatment access, and necessity of carer support.

47. Any commissioning outcomes framework developed must be sufficiently fine textured and granular to capture outcomes relating to specialist services for rare and/or genetic conditions. The introduction of ICD 11 in 2015 will create the opportunity for systematic data capture of outcomes in rare diseases. This will allow the planning of resource allocation on an evidence based framework as outcome data accumulates in respect of the conditions identified.

Patients and the public

48. Genetic Alliance UK welcome proposals in paragraph 6.2 for greater patient, carer and public involvement in decision-making, and for a greater responsiveness to their views and feedback.

How can GP consortia and the NHS Commissioning Board best involve patients in making commissioning decisions that are built on patient insight?

49. We believe this will be best delivered with expert patient involvement at a board-membership level, and with consultation of appropriate patient organisations according to specific commissioning decisions.

50. Patients and carers have a great deal of expertise to contribute to designing and improving healthcare delivery. Members of smaller patient organisations are busy, and tend to be staffed by volunteers with many other commitments. Commissioners should ensure that there is sufficient flexibility in meeting and consultation arrangements to allow groups such as these to contribute.

51. Consideration should be given to how volunteers will be recompensed for their time spent contributing to commissioning decisions. A stipend will facilitate participation from members of voluntary organisations, and place patients and carers on a level playing field with their fellow contributors.

How can we build on and strengthen existing systems of engagement such as Local HealthWatch and GP practices' Patient Participation Groups?

52. Commissioners should recognise that local groups such as HealthWatch will only be able to provide information and advice regarding more common conditions; other groups with a national focus such as ours, should be consulted also to establish a picture of healthcare needs too infrequent to appear in a local context.

Conclusion

53. Genetic Alliance UK welcomes proposals to give responsibility for commissioning of specialised services to the NHS Commissioning Board, and hopes this measure to rightly include those services previously commissioned at a regional and supra-regional level, thereby alleviating postcode lotteries for specialised services.

54. We believe the budgets currently allocated to national and regional specialised commissioning should be directly allocated to the NHS Commissioning Board to ensure services currently commissioned nationally and as part of the Specialised Services National Definition Set are adequately funded.

55. Genetic Alliance UK welcomes the extension of public and patient involvement in the NHS through engagement in commissioning decisions and believes this will be best delivered with expert patient involvement at a board-management level.



Alastair Kent
Director