



Consultation Response

Strengthening National Commissioning

Department of Health

Response by the Genetic Interest Group and Rare Disease UK

1. The Genetic Interest Group (GIG) is the UK national alliance for all people affected by genetic conditions. GIG works to raise awareness and improve the health service provision available to those living with and at risk from inherited conditions. Our membership represents 138 voluntary organisations working for a wide range of conditions, many of which are rare and/or pose complex health and social care needs. Many of the organisations and families which GIG represents are affected by conditions that require specialised and tertiary services. It is vitally important that patients can access good quality health services that provide timely and accurate diagnosis; and effective and best practice management from clinicians and health professionals who have the knowledge and expertise in each particular condition.
2. Rare Disease UK (RDUK) is an alliance for people with rare diseases and all who support them. It is a joint initiative of the Genetic Interest Group and other key stakeholders including over 100 patient organisations, clinicians, academics, industry and interested individuals brought together in response to the unmet care needs of the 3.5 million people who struggle to access integrated care and support from the NHS.
3. GIG and RDUK welcome this consultation and the opportunity to respond.

Introduction

4. Commissioning care and treatments for many of the patients that our organisations represent can be complicated and/or expensive. Our organisations therefore have a strong interest in the existence of a commissioning framework which is capable of planning and funding many differing types of care: 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 complex rare conditions are three examples.
5. GIG and RDUK believe commissioning of high cost complex services by an expert body in close contact with ministers is a vital component of this framework. This expert body should be in close cooperation with the bodies responsible for commissioning less specialised services to ensure there is a coherent continuous commissioning structure in England.
6. The commissioning structure should ensure good communication between those commissioning services at the Primary Care Trust (PCT) and General Practitioner (GP) level and those commissioning the most expensive 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 PCT and GP commissioned services throughout their lives as unrelated health care needs arise. A joined up commissioning system is essential for a joined up healthcare service.

7. This consultation affects three key current organisations responsible for commissioning and the successful delivery of these services.
8. **National Commissioning Group (NCG)** is a standing committee of the National Specialised Commissioning Group, composed of clinical representatives, local commissioners, public health representatives and R&D experts. NCG is responsible for advising ministers on which services are best commissioned nationally, and then for the commissioning of those services for the population of England and Wales.¹
9. It is proposed that NCG is dissolved and replaced by the **National Commissioning Advisory Group (NCAG)** which will provide advice to ministers on which services are best commissioned nationally.
10. **National Specialised Commissioning Group (NSCG)**, responsible for coordination between Specialised Commissioning Groups and the National Commissioning Group, coordinating joint working between Specialised Commissioning Groups, and providing advice on specialised commissioning.¹
11. It is proposed that NSCG will contribute members to the NCAG rather than advising ministers directly on which services are best commissioned nationally. The new NCAG will not be a committee of NSCG.
12. **Specialised Commissioning Groups (SCGs)**, responsible for commissioning specialised services in regions coterminous with Strategic Healthcare Authorities, which have populations between 3 million and 7 million.¹
13. There must be no gaps or lack of co-operation between the working of these three bodies, or those bodies that replace them, for specialised healthcare to be delivered in such a way that “nobody is left behind” as the NHS Constitution pledges.

Focus of this review

14. The focus of this review should have been wider. It is GIG and RDUK’s view that it is the role of the NSCG and its empowerment to fulfil this role that is in most need of review.
15. Recommendation 1 of the Review of Commissioning Arrangements for Specialised Services (2006) states that “A National Specialised Services Commissioning Group (NSSCG) [the current NSCG] should be established to coordinate specialised services commissioning across all SCGs where appropriate and to provide a framework within which binding commissioning decisions requiring pan SCG agreement can be made. The NSSCG should act on behalf of all PCTs as represented by their SCGs and be highly influential in representing their interests with national bodies and the DH.” GIG and RDUK do not believe this recommendation has been fully implemented. NSCG does not provide a framework within which binding commissioning decisions requiring pan SCG agreement

Genetic Interest Group:
Rare Disease UK:

mail@gig.org.uk
info@raredisease.org.uk

www.gig.org.uk
www.raredisease.org.uk

Genetic Interest Group is a charity registered in England and Wales (no. 1114195) and in Scotland (no. SC039299) and a company limited by guarantee, registration no: 05772999

Rare Disease UK is an unincorporated association of stakeholders with an interest in rare diseases

can be made. NSCG's influence over PCTs is weak, indeed the influence of PCTs over NSCG is too strong.

16. The current system is not working well. There is considerable variation between SCGs in the availability of the services listed in the Specialised Services National Definition Set.² NSCG has struggled to bring SCGs to account over these variations, and lacks the hard edge necessary to do so.
17. Half of the membership of NSCG are chief executives of PCTs; their influence is too strong. The perception of PCTs is that specialised commissioning is a drain on their budgets, rather than a risk sharing structure that allows them to discharge their responsibility of care to a wider spectrum of patients. This misconception perhaps arises from the funding method for national and regional commissioning, by which the funds appear on PCT balance sheets.
18. GIG and RDUK believe that the means by which funds are allocated to national and regional commissioning is an important cause of PCT hostility toward the concept of national commissioning. PCTs should have no control over national commissioning funds and top-slicing for national commissioning should occur before funds appear on PCTs' balance sheets.
19. The funds available to national commissioners should increase annually, at least at the rate of NHS growth. Due to their distinct, discrete nature, nationally commissioned services cannot be offset against other services allocated from the same budget, therefore budgets must expand in pace with the expansion of service provision.
20. Coordination between levels of commissioning in England is necessary to foster cooperation between national, regional and local commissioning. Those treatments that do not meet the criteria for nationally commissioned status fall into the area of responsibility of SCGs at the regional level. If SCGs do not fulfil this responsibility, as set out in the Specialised Services National Definition Set, there will continue to be a gap in availability of specialised services in England.
21. Coordination is necessary not only for coherent commissioning, but also for coherent care delivery. Specialised services can be delivered at specialist centres, but also at PCTs, GPs, and even at a patient's home. Oversight is necessary to ensure care delivery is well planned. This is shown by the experience of a Muscular Dystrophy Campaign (MDC) funded consultant liaison between PCTs and specialised services in Wales. Once the MDC funds expired, the post was not extended. Patients have since reported a drop in care quality, and there has been an increase in hospital admissions.

Genetic Interest Group:
Rare Disease UK:

mail@gig.org.uk
info@raredisease.org.uk

www.gig.org.uk
www.raredisease.org.uk

Genetic Interest Group is a charity registered in England and Wales (no. 1114195) and in Scotland (no. SC039299) and a company limited by guarantee, registration no: 05772999

Rare Disease UK is an unincorporated association of stakeholders with an interest in rare diseases

Replacement of the National Commissioning Group with the National Commissioning Advisory Group

22. The proposals will allow ministers to expect a single clear message from a single body to support their commissioning decision. This is an important component of a transparent and robust decision making process.
23. This single clear message should cover a wider field. NCG/NCAG should also be the single body responsible for advice to ministers regarding services designated in the Specialised Services National Definition Set to which regional commissioners must adhere. Grouping these responsibilities within one body will assist in the creation of a coherent approach to the commissioning of specialised services at both the national and regional level, ensuring strategy is formed by one expert body able to decide at what level services are best commissioned.
24. Concerns arise from the separation of the body responsible for national commissioning decisions from the body responsible for ensuring cooperation between national commissioners and regional commissioners. NSCG is already overly influenced by PCT opinion; the proposal to remove those members of the current NSCG who specialise in national commissioning outside of the organisation will further bias NSCG toward the interests of local commissioners.
25. There is currently no body equipped with the tools, the responsibility, and the impetus to regulate the commissioning of services in the Specialised Services National Definition Set. NSCG is best placed and best equipped to do so, but must first be given the responsibility and the regulatory power to do so. The culture within NSCG of supporting PCT interests should be addressed by properly separating funds for the various levels of commissioning. (*Paragraphs 17-19*).
26. NCG/NCAG should have the remit and the necessary authority to make NSCG work to enforce adherence to the Specialised Services National Definition Set. Similarly, NSCG should be empowered to carry out this duty of enforcement,
27. Concerns arise also from the choice of nomenclature. The National Commissioning *Advisory* Group will replace the National Commissioning Group. There is no mention in these proposals of the secondary function of the current NCG: the practical process of commissioning specialised services for the population of England and Wales¹. We therefore assume that the proposed NCAG will carry out the same function as the current NCG plus the added responsibility of considering a small number of additional drugs and technologies.
28. Whilst the advisory function to ministers is a key component of the proposed remit of the new body, so is the practical commissioning of services in England and Wales. We feel that the insertion of “advisory” into the new title down plays the importance of this second aspect of the group’s role.
29. GIG and RDUK propose that the name of the new body therefore continues to be the National Commissioning Group to avoid any misconception that the new body will have a lesser function or weight than the current NCG.

Genetic Interest Group:
Rare Disease UK:

mail@gig.org.uk
info@raredisease.org.uk

www.gig.org.uk
www.raredisease.org.uk

Genetic Interest Group is a charity registered in England and Wales (no. 1114195) and in Scotland (no. SC039299) and a company limited by guarantee, registration no: 05772999

Rare Disease UK is an unincorporated association of stakeholders with an interest in rare diseases

Taking full advantage of a comprehensive commissioning framework

30. Commissioning of Specialised services nationally provides a number of benefits to a number of stakeholders. Patients can expect to receive the highest quality of care available in the NHS, from the best healthcare providers, using the best equipment. They can expect healthcare providers to be able to coordinate multidisciplinary care well, based on experience and expertise. Healthcare practitioners and researchers can be sure of a location or locations from which they can expect expert advice or to which they can direct cases in the expectation the best possible treatment, funders of healthcare can be sure that they are receiving all possible economies of scale, and their expenditure is being discharged by practitioners that are best qualified to perform the job.
31. This model brings enormous patient benefit as efficiently as possible. Given these twin benefits, it is our view that NCG/NCAG should be pro-active in seeking out treatments, technologies, and planned expenditure at the regional level that would benefit from this kind of healthcare delivery.
32. Nationally commissioned status is currently only possible given a combination of factors. An energetic, knowledgeable healthcare practitioner must be allied with an energetic, well-funded and well-organised patient organisation to design and temporarily deliver a service that meets national commissioning criteria. None of these factors are trivial, and GIG and RDUK believe the process should be facilitated by national commissioners.
33. To reduce administrative barriers to suitable services achieving nationally commissioned status, NCG/NCAG should also offer a facilitation and advisory service to ensure criteria for designation are properly understood and properly described in applications to the decision making body. NCG/NCAG's criteria should be made publically available online, and organisations should be given assistance with the completion of applications.
34. Cooperation with the devolved nations of the United Kingdom should be investigated as a route by which further cost sharing can be achieved whilst widening the patient population for service provision.
35. Innovative therapies should be fostered and delivered to patients as they become available. The national commissioning decision making body should have access to expertise from the clinical research community, GIG and RDUK would propose the National Institute for Medical Research, and processes should be in place to ensure research is translated into treatments as they become feasible.
36. A position for a representative of NIMR on NCG/NCAG should also deliver specific oversight of research into the poorly understood conditions that the nationally commissioned services tend to treat. These research opportunities need to be systematically analysed and exploited. The benefits of this approach can be seen by the increase in quality and quantity of research into Inborn Errors of Metabolism following the commissioning of specialised services to treat them.

Genetic Interest Group:
Rare Disease UK:

mail@gig.org.uk
info@raredisease.org.uk

www.gig.org.uk
www.raredisease.org.uk

Genetic Interest Group is a charity registered in England and Wales (no. 1114195) and in Scotland (no. SC039299) and a company limited by guarantee, registration no: 05772999

Rare Disease UK is an unincorporated association of stakeholders with an interest in rare diseases

Conclusions

37. Ministerial decisions on the commissioning of specialised services on a national and regional level should be carried out to a transparent and robust framework based on advice from a single expert body.
38. The role and responsibility of all bodies concerned with the commissioning of specialised services should be clearly defined, to ensure that there is a single clear message on national commissioning strategy.
39. The body concerned with advising ministers on their national commissioning decisions and with carrying out the commissioning of those services should continue to be named National Commissioning Group to reflect its continuing responsibilities.
40. The budget for national commissioning should not be subject to PCT control and should not appear on PCT balance sheets. It should increase at least at the rate of NHS growth.
41. The National Specialised Commissioning Group should be empowered to hold Specialised Commissioning Groups to account on their responsibilities to commission the services listed in the Specialised Services National Definition Set.
42. The National Specialised Commissioning Group should be equipped, as proposed in Recommendation 1 of the Review of Commissioning Arrangements for Specialised Services (2006), to ensure there is coordination of commissioning of specialised services across all Specialised Commissioning Groups.
43. The National Specialised Commissioning Group should be responsible for ensuring cooperation between specialist centres and local care providers to ensure coherent care delivery and good quality health care planning.
44. Every suitable service should be commissioned nationally to ensure the benefits of the national commissioning formula are enjoyed by all stakeholders. National commissioners should facilitate the application process by publishing criteria for selection and assisting application preparation.
45. The research community should be represented with membership on NCG/NCAG to ensure research opportunities are systematically analysed and utilised.

-
1. National Specialised Commissioning Group
<http://www.specialisedcommissioning.nhs.uk/index.php/about-us/organisational-structure-whos-who/>
Accessed on 17th February 2010
 2. Survey of Specialised Services Collection Commissioning Arrangements – Intentions for 2008/09
National Specialised Commissioning Group
<http://www.specialisedcommissioning.nhs.uk/index.php/key-documents/specialised-commissioning-groups/>
Accessed on 17th February 2010

Genetic Interest Group:
Rare Disease UK:

mail@gig.org.uk
info@raredisease.org.uk

www.gig.org.uk
www.raredisease.org.uk

Genetic Interest Group is a charity registered in England and Wales (no. 1114195) and in Scotland (no. SC039299) and a company limited by guarantee, registration no: 05772999

Rare Disease UK is an unincorporated association of stakeholders with an interest in rare diseases

Consultation Questions

Consultation question 1: Do you agree to combining this advice into one group? If not why not?

46. GIG and RDUK believe that the ministerial decision making process should be robust and transparent, and that a single message from a single body responsible for advice will assist in achieving this aim (*please refer to paragraphs 4, 5, 13, 19, 20 and 22*). We believe this should include advice regarding designating services for inclusion in the Specialised Services National Definition Set for regional commissioning (*paragraph 23*).
47. However we are concerned that the approach taken in this review does not focus on the area that most needs addressing. The current national commissioning process works relatively well, when compared to the coordination of regional commissioning (*paragraphs 14, 15, 16, 17 and 20*).
48. Furthermore we have reservations regarding the proposed new organisational structure, as we believe NSCG bias towards the interest of PCTs will be increased by the separation of NCG from NSCG (*paragraph 24*).
49. This consultation makes no mention of the current NCG's responsibility for the practical commissioning of services in accordance with ministers' wishes. We therefore assume the body replacing the NCG will continue to have this responsibility and propose the new group retains the title *National Commissioning Group* to reflect this. The proposed name of *National Commissioning Advisory Group* could lead to the misconception that the new body's role is solely advisory (*paragraphs 27, 28, and 29*).

Consultation question 2: Do you think [the proposed membership of NCAG] is right? Is there other expertise we should include?

50. GIG and RDUK believe all stakeholders should be represented on NCAG, and therefore propose that the field of research is present to ensure research opportunities are systematically utilised (*paragraphs 29 and 30*).

Consultation question 3: Do you have any suggestions for strengthening national commissioning?

51. The current regional commissioning arrangements are not working well (*paragraphs 14, 15, and 16*). There is hostility from PCTs towards national and regional commissioning and PCTs exert a disproportionately high influence over NSCG (*paragraphs 17, 18 and 24*).
52. It is vital that the NSCG is empowered and coordinated with NCG, to ensure a single coherent specialised commissioning message (*paragraphs 5, 13, 14, 15, 20, 22 and 23*). The National Specialised Commissioning Group should be equipped, as proposed in Recommendation 1 of the Review of Commissioning Arrangements for Specialised Services (2006), to ensure there is coordination of commissioning of specialised services across all Specialised Commissioning Groups (*paragraphs 24 and 25*).

Genetic Interest Group:
Rare Disease UK:

mail@gig.org.uk
info@raredisease.org.uk

www.gig.org.uk
www.raredisease.org.uk

Genetic Interest Group is a charity registered in England and Wales (no. 1114195) and in Scotland (no. SC039299) and a company limited by guarantee, registration no: 05772999

Rare Disease UK is an unincorporated association of stakeholders with an interest in rare diseases

53. The National Specialised Commissioning Group should be empowered to hold Specialised Commissioning Groups to account on their responsibilities to commission the services listed in the Specialised Services National Definition Set (*paragraph 26*).
54. The budget for national commissioning should not be subject to PCT control and should not appear on PCT balance sheets. It should increase at least at the rate of NHS growth. (*Paragraphs 17, 18, 19 and 25*).
55. Commissioning should be coordinated from national commissioning at the very top to practice based commissioning at the very bottom of the commissioning structure in England and Wales, to ensure the provision of a joined up healthcare service (*paragraphs 5, and 6*).
56. The National Specialised Commissioning Group should be responsible for ensuring cooperation between specialist centres and local care providers to ensure coherent care delivery and good quality health care planning (*paragraph 21*).
57. The benefits of commissioning services at a national level are great and should be extended to all services which fit the criteria. The organisations responsible for the process of commissioning at the national level should seek out suitable services and assist them in the process of becoming nationally commissioned (*paragraph 31, 32, 33 and 34*).
58. Relationships with the devolved nations of the United Kingdom should be built and maintained (*paragraph 35*).

Alast Kent

Alastair Kent

Director Genetic Interest Group
Chair Rare Disease UK

19th February 2010

Genetic Interest Group:
Rare Disease UK:

mail@gig.org.uk
info@raredisease.org.uk

www.gig.org.uk
www.raredisease.org.uk

Genetic Interest Group is a charity registered in England and Wales (no. 1114195) and in Scotland (no. SC039299) and a company limited by guarantee, registration no: 05772999

Rare Disease UK is an unincorporated association of stakeholders with an interest in rare diseases