

A joint response by the Genetic Interest Group and Rare Disease UK

Executive Summary

1. A world class health service can only be provided with excellence at every level of its planning process, which requires cooperation, world class expertise and world class tools. Services must be planned based on good quality evidence, and commissioners should be equipped to obtain this.
2. Planning and funding of care is now carried out in a hierarchy: at GP, PCT, Regional and National level. This layered approach is necessary for the provision of high quality postcode-blind tertiary and specialised services. Communication between commissioning structures is essential to ensure that coordinated care can be provided at all levels.
3. Following changes made by devolved governments to their health services, commissioning is now solely an English and Northern Irish discipline. These changes provide a unique opportunity to examine which structures provide efficiency and which are wasteful; and to compare the intricate with the streamlined to establish whether intricacy is necessary to deliver health care to all of the population, whatever their health need.

Introduction

4. The Genetic Interest Group (GIG) is the UK national alliance of families and all those 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.
5. 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 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.
6. GIG and RDUK welcome this inquiry and the opportunity to provide evidence.

Specialist Commissioning

7. 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; good quality, timely, expert diagnosis of complex rare conditions for patients approaching primary care; and multi-disciplinary care from

various specialities for patients with multifactorial conditions, are three examples.

8. A particular concern for those that our organisations represent is that services that require the cooperation of multiple specialities within the NHS are facilitated. The commissioning process should be flexible enough to fund integrated care between secondary care specialities for patients with multifactorial conditions and accommodate patient's needs in this complex area. This flexibility should allow for novel entry-points as diagnosis of a multifactorial disease is possible from many angles and healthcare provision for patients such as these should allow for this, and provide a service that looks the same from any angle.

Service Planning

9. Services should be planned using good quality evidence and with proper communication and coordination between different levels of the commissioning framework, to prevent gaps in service provision. The changing rate of demand for services must also be identified as part of a horizon scanning process. Mechanisms need to be developed to ensure that as the demand for a service increases then the planning for the service takes this into consideration.
10. Horizon scanning should also take account of other changes, for example: improvements in healthcare have led to life expectancies rising for many conditions. Conditions that were once solely cared for in the paediatric setting now have patients progressing into adulthood. This has led to young adults sometimes being cared for in paediatric environments, a situation which is not ideal for any party. There is little incentive from commissioners for the development of adult services, and the level of specialisation in adult medicine is such that there is no obvious point from which to develop an adult service for these young adult patients.

Levels of Commissioning

11. Currently, funds in the English NHS follow a convoluted pathway, with commissioning taking place at many levels. The budget is top-sliced to provide funds for the National Commissioning Group, it is then distributed between PCTs, who then top-slice the funds again for Strategic Healthcare Authority level planning (Regional Commissioning), and use the remainder for commissioning of services within their area of remit, including the possibility of another layer of commissioning: practice based commissioning.
12. It becomes necessary to concentrate on recalling that this is a single health service. Whilst on inspection the benefits and reasoning behind planning and funding care at different levels is clear, better communication is perhaps necessary to remind all of the parties of this reasoning. Regional Commissioning can sometimes be regarded as a drain on PCT's resources. In fact the system is in place because decisions are best made at this level for this kind of care provision and the risk of individual PCTs having to fund potentially expensive and unpredictable activity is reduced by commissioning services collectively. Regional Commissioning should be seen as a mechanism which assists PCTs to discharge their obligation to all of their patients, and prevents potentially unfair drains on resources being presented to single PCT.
13. That commissioning should be carried out at more than one level is not in dispute, evidence for the necessity of commissioning at national level is amply provided by the progress made by the National Commissioning Group in safeguarding treatments for some of those with the rarest of conditions. Commissioning of services such as these would be impossible at a local or even regional level.
14. Many patients with a rare disease are already heavy users of NHS resources, but these resources are provided without any strategy, often in a fragmented and uncoordinated manner, that is not always appropriate to the patient's needs. SCGs can provide solutions to patients' needs and enable health gain by ensuring that adequate structures are put in place to deliver integrated care strategies for patients. This should not be seen as a distraction from the day to day business of providing healthcare to the "average" citizen. Specialist services should be considered complimentary to local services as opposed to a threat to local services, and commissioners should be in a position to

facilitate coordination between these areas.

15. Understanding between levels of commissioning in England is necessary to foster cooperation between national, regional and local commissioning. There are over 6000 rare diseases, not all rare diseases are so complex that the day to day management needs to be delivered through specialised services. The patient will always begin their pathway at the local level, they may need to progress to a nationally commissioned service for a diagnosis, but treatment thereafter will involve a combination of specialist and local care.
16. Good quality communication and understanding between the levels is necessary on both the clinical side and the financial side. There should be no barrier to referrals outside of a particular funding area. Referrals to a service outside of a PCT should be just as seamless as those made within the organisation. A clear framework should be in place which allows clinicians to make appropriate referrals with no unnecessary bureaucratic hurdles. Investment is needed to foster a culture of co-operation and allow integrated solutions to emerge.

The rationale behind commissioning: has the purchaser / provider split been a success and is it needed?

17. With the advent of devolution and the changes made by devolved governments to their health services, commissioning is now solely an English and Northern Irish discipline. This direction of travel from Scotland and Wales raises questions; and the evidence which will accumulate as the new system in Scotland and the soon to be new system in Wales become mature has the potential to provide answers. Should policy formation be so far removed from funding decisions in the English NHS? Does the purchaser / provider split generate efficiency and choice or does it waste money and discourage cooperation within the English NHS?

Wales - the new structure

19. The structure of the NHS in Wales that will be adopted on October 1st 2009 is simple in comparison to that of NHS England. The healthcare budget for Wales will be divided between seven Local Health Boards (LHBs), each responsible for healthcare provision in their constituency. These funds will then be top-sliced, and pooled for tertiary and specialised services. Governance of the spending of this top-slice pool will be from the Welsh Health Specialised Services Committee (WHSSC), composed of LHB Chief Executives. All planning and fund allocation for healthcare in Wales will therefore be carried out by the LHBs.
20. This model, when compared to the structure of the NHS in England is straightforward, and gets funds to primary and secondary care at an appropriate level for the population size in a streamlined manner. This plan does bring concerns for the community of patients that our organisations represent. Our concerns are that the top-sliced funds should be distributed by a dedicated body, which is perhaps further removed than the LHBs than is currently the plan.
21. This point illustrates a facet of the structure of the NHS in England which we particularly appreciate and support, top-sliced funds for specialised and tertiary services, are governed by the National Commissioning Group, a dedicated group who provide expert guidance on the types of services that can be funded in this way and provide support for those services once founded. Details of the role that the WHSSC will fill and how they will interact with commissioners in the English NHS to facilitate cross-border access to specialised care is yet to emerge.
22. The purchaser / provider split was originally implemented to encourage efficiencies and deliver cost savings. The advent of Payment by Results, Practice Based Commissioning, Foundation Trusts, Regional Commissioning and National Commissioning creates an altogether more complicated landscape. Planning and funding of care is now carried out at many levels, GIG and RDUK believe that, for the patient communities that we represent: those requiring tertiary and specialised care, this

layered approach between Regional Commissioning and National Commissioning is necessary for the provision of high quality postcode-blind care and services.

23. The specific question “has the purchaser / provider split been a success and is it needed?” can only be answered with comparison between the four health services of the United Kingdom.

"World-Class Commissioning": what does this initiative tell us about how effective commissioning by PCTs is?

24. World Class Commissioning is essentially an initiative aimed at providing a world class health service at a local level. This is a laudable aim and one to be supported, at least until the initiative just entering its second year is in a position to be judged. However, the initiative does aim to provide a world class health service to all; we hope that this response has demonstrated that commissioning at a Primary Care Trust level, even when overseen at a Strategic Health Authority level, is not enough to provide a world class service to all patients.

25. Commissioning must take place at appropriate levels matching the population and complexity of the health care need, sharing risk and ultimately ensuring that no one misses out from treatment because their condition is rare. A world class health service can only be provided with excellence at every level of its planning process, which requires cooperation, world class expertise and world class tools.

26. NHS England can provide a lead, not only for the Home Nations, but for the rest of the developed world as health care systems struggle to cope with rising demand and constrained resources.

27. The Genetic Interest Group and Rare Disease UK are grateful for the opportunity to comment and welcome further communication on the issues discussed here.



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