



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Consultation Response

Department of Health

Equity and Excellence: Liberating the NHS

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 138 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.

Putting patients and the public first

3. We support the concept of a patient-centred approach to service provision as articulated in the White Paper. It is our view that this approach works best in practice when patients and professionals share an understanding of what needs to be done and how best to bring this about given the constraints of current knowledge. It is particularly important in cases where patients have chronic conditions for which no quick-fix intervention is possible, and where the objective is to enable the patient and the family to enjoy as good a quality and quantity of life as possible. This requires a genuine commitment to partnership, with a clear recognition that patients' and families' views must be given due weight in planning and providing care and support; and a recognition that meeting needs may require the crossing of traditional services or speciality boundaries.
4. Achieving a patient centred approach is not just a matter of will power and the institutionalisation of structures and pathways. It requires investment of time, training and professional support mechanisms to bring about the attitudinal changes that are necessary, and to embed them in the everyday work of the NHS.

Shared decision-making: nothing about me without me

5. Genetic Alliance UK welcomes the commitment to shared decision making, and the acknowledgement that this results in better health outcomes, and in reduced costs. It should be

recognised however, that it is not necessarily the case that costs will be lower. It may be that money will be better spent with better outcomes for patients in ways that are intangible but nevertheless important. Difficulty in measurement should not be a barrier to recognition of validity.

6. Creating the opportunity for shared decision making requires not only attitudinal change within the NHS but also investment in capacity building in patient organisations and in patients themselves to develop the skills to bring this about.

An NHS information revolution

7. We welcome the emphasis on the provision of timely information to patients and clinicians. Easy access to timely, comprehensive information presented in an accessible format is particularly important where conditions are rare, and as a consequence their symptoms and implications are not widely appreciated, or where they are genetic and there may be significant implications for other family members.
8. Sources of good quality information outside of the NHS should be recognised, supported and utilised; such as patient organisations and international resources such as www.orpha.net.
9. We support the provisions to allow patients control of their health records. In our experience, patient held records can empower patients with long-term multifactorial conditions; they help integrate inputs from different clinical specialisms and other services, and value patients' time alongside that of clinicians. They can also facilitate the prompt correction of errors and the dissemination of treatment plans across disciplinary boundaries.
10. We support plans for extensive consultation as to what information is collected, and how it is held and made accessible to patients and citizens.
11. We welcome also the recognition of the need for partnership between patients and clinicians in research. Genetic Alliance UK has been working in partnership with other European patient organisations to study the value patients can have in research as part of the Patient Partner project: www.patientpartner-europe.eu, which promotes the role of patient organisations in the clinical trials context. We believe that involving patient organisations as equal partners at all stages in research delivers findings that are better adjusted to the real needs of patients.

Increased choice and control

12. The majority of the patients and families supported by our members require specialist healthcare and often from more than one specialism. While we support the spirit of proposals for increased choice and control, we would like to stress that many of our members need access to care that is only available from one or a few care providers, and they do not have the luxury of choosing where they access their care. Greater control can be provided to patients in this situation by providing easier access to services, such as more flexible appointment times which take account of the availability of a patient's carer(s).

Patient and public voice

13. The proposed HealthWatch England and Local HealthWatch organisations should enable diverse communities and individuals to contribute to the NHS in practical ways. Of key importance to the credibility of the scheme will be the success with which it gives a voice to those who do not currently contribute to public debate about NHS issues; such as those with

direct personal experience of rare genetic conditions, those from minorities, children and stigmatised groups.

Improving healthcare outcomes

14. Whilst an Outcomes Framework is a useful tool, it can be associated with many of the same problems that have affected process indicators: incentives can be created that take people away from their focus on the clinical needs of the patient and move them towards the items which are counted in the outcomes framework.
15. The concepts of overarching indicators, and of improvement areas, unavoidably disadvantage those affected by conditions which are not being highlighted, supported or boosted with these methods of focusing improvement and measuring results.
16. Whilst process driven targets may not be as effective at measuring whether or not the NHS is delivering appropriate outcomes effectively, it should be recognised that in selected instances they give patients a clear indication as to what they can reasonably expect to experience and on what timescale. This can give patients the opportunity to plan and make any necessary arrangements; it can also give a measure enabling early remedial action to be taken.
17. We support a greater emphasis on outcomes, but not at the expense of measures to ensure that processes are appropriate; and only when outcome measures are not selected in such a way as to marginalise those with uncommon or complex conditions.
18. Our examination of these proposals in greater detail in the ‘Transparency in outcomes’ consultation has shown that the current proposals for outcome measurement do marginalise the vast majority of our members. Genetic Alliance UK believes a great deal of work will need to be done to redesign outcome measures in a more equitable way before implementation of these plans.

The NHS Outcomes Framework

19. We welcome the recognition that for patient outcomes it is essential that health and social care services are better integrated at all levels of the system and we look forward to more detail on how both will work together.
20. Many families with genetic disorders rely on both health and social care to provide the long-term care they need to preserve and enhance their quality and quantity of life. Current distinctions between that which is deemed “medical” and that which is said to be “social” are frequently arbitrary, and there is an urgent need to eliminate boundaries that make access more difficult than it needs to be.
21. Plans for translation from outcomes to a commissioning framework are valuable and welcome. In carrying out this plan, it should be recognised that outcomes emerge over differing time horizons, especially when chronic disease is involved; and that benefit can be measured in terms of things that don’t happen as well as things that do. For example, the provision of effective genetic counselling to a couple who have just given birth to a child with an inherited disorder can help them appreciate and plan in the light of what has happened, an immediate benefit; but it can also help them to avoid the birth of a second child with that condition if they so wish, a deferred benefit which current systems do not capture at all.

22. International comparisons can help benchmark practice and provision in the NHS, but care must be taken to ensure that like is being compared with like. For example; in Germany the number of genetic tests/unit of population is much higher than in the UK, but the number of clinical geneticists is fewer, making comparison between the effectiveness of clinical genetic services hard to establish. Also, cultural differences, and differences in reimbursement methods can make it hard to draw comparisons. The opportunity for patients to go “doctor shopping” in France leads to higher patient satisfaction than in the UK with its GP gatekeeper system, but whether or not this satisfaction is reflected in better clinical outcomes is difficult to establish evidentially.

Developing and implementing quality standards

23. NICE has played a major role in establishing cost and clinical effectiveness as a legitimate area of health care decision making. It has also developed methods for measuring these dimensions. However the disciplines of health economics and HTA have been frequently criticised by patients and families as being too rigid, and for excluding elements that they feel to be significant for consideration. If these standards are to retain patient and public confidence, particularly at a time of change and significant resource pressure, then the weight given to measures deemed to be important by patients and families must be clear and agreed upon.
24. We are concerned at the lack of commitment to patient involvement in the design of quality standards. NICE's track record on patient involvement is not exemplary. In Genetic Alliance UK's, and our members' experience, the level of patient involvement, whether cursory or genuine, in NICE's work varies according to the ethos of those leading meetings and processes. Patients should be allowed to contribute to the design of quality standards on an equal basis to other stakeholders.
25. In addition to these concerns, we believe the production of just 150 quality standards will leave the majority of health conditions unsupported. All patients should be able to access a pathway outlining the quality of care they can expect.
26. The extension of NICE's remit to social care is to be welcomed, subject to the above caveats. Patient centred quality standards, particularly when these relate to families with lifelong conditions and those of paediatric origin are particularly important. They must incorporate social and psychological aspects of care as well as physical support for the preservation of physical independence.

Research

27. We welcome the recognition of the importance of research, the contribution it makes to patient care and to the UK economy. The NHS is almost uniquely able to support clinical research as it is a single healthcare system for more than 50 million people.
28. Systematic data collection is essential if this potential is to be realised, and future commissioning structures must not jeopardise the potential to collect and analyse relevant data centrally, both to support planning and commissioning and to facilitate research and development. Central collection of data is even more essential for patients with rare genetic diseases if there is to be the possibility of creating a strategic response to their needs.
29. In particular the development of ICD-11, the latest revision of the International Classification of Diseases, which makes a greater granularity in rare disease classification possible, will

provide a crucial opportunity for capturing data and experience in ways that will facilitate research and make planning and commissioning more effective.

Incentives for quality improvement

30. The refinement of current tariffs should take into account those with complex, multi-system disorders who need integrated care from different clinical specialities where small numbers of patients are affected. Rather than promoting innovation and patient centred responsiveness, current tariffs inhibit joined up working and can result in multiple appointments, repeated investigations, delayed diagnosis and inappropriate interventions. This is bad for patients and families and wasteful for the NHS.
31. We believe the concept of valued based pricing for pharmaceuticals could be valuable, providing that the model for establishing value reflects patients' preferences and experiences. Given that the NHS provides only a small part of global pharmaceutical sales the introduction of a value based pricing systems for drug reimbursement must not lead to a reduction in available therapies due to companies choosing not to launch innovative products here. This is likely to impact disproportionately on patients with rare and genetic diseases where evidence of effectiveness is often only accumulated after the introduction of a therapy, enabling considerable gaps in the evidence base to be filled in gradually.
32. Properly implemented, a value based pricing system for drugs and therapies should encourage the development of interventions targeted at currently unmet health needs. However it should not be overlooked that, in many cases "first in class" is not automatically "best in class", and incremental innovation can play a significant role in patient care.

Autonomy, accountability and democratic legitimacy

33. Whilst the principle of local accountability and service planning is a worthy one for many aspects of health and social care, there are some types of service which cannot sensibly be planned or delivered at local level. Genetic Alliance UK believes the White Paper has not described plans for the organisation of commissioning for specialised services in enough detail.
34. We welcome the recognition in the White Paper to the importance of making separate arrangements for services provided nationally and under the Specialised Services National Definitions Set (SSNDS), and we look forward to seeing the detailed arrangements to be set out in the forthcoming consultations. Effective arrangements for commissioning specialist services are an essential component of an equitable NHS. However those elements commissioned at national or regional level must also integrate effectively with those aspects of care for the patients and families involved that are best provided at local level through the proposed GP consortia.

GP commissioning consortia

35. In principle GP consortia must be sufficiently large to secure sufficient resources to support the full range of services needed at community level, whether community based, primary or secondary care level. They must demonstrate that their commissioning decisions are based on a robust needs analysis that is publicly available and subject to challenge and appeal through well defined criteria.
36. Commissioning arrangements need to take account of the input from other professionals: pharmacists, community nurses and others (such as specialist nurses for cancer, diabetes, motor

neurone disease etc) and there should be representation from patients and patient organisations as full members of commissioning consortia boards as an absolute requirement.

An autonomous NHS commissioning board

37. We welcome the proposed establishment of an autonomous NHS Commissioning Board. Patient and carer membership of the Board at the highest level should be enshrined in legislation creating the Board alongside other membership categories.
38. We welcome the recognition of the need for services specified in the Specialised Services National Definition Set (SSNDS) to be a direct responsibility of the Board. There is little scope for variation in the level of provision of these services, and the adoption of a single national framework will help eliminate the postcode lottery commonly experienced today. We are not convinced of the need for regional commissioning of services encapsulated in the SSNDS, and in our view they should be nationally commissioned.

Freeing existing NHS providers

39. We are concerned that the proposed increases in the freedom of Foundation Trusts will create the potential for gaps in service provision. There should be a clear strategy, enforced and policed, for ensuring that the full range of services is available to patients through a proper combination of local, regional, national and (where necessary for highly specialised services) international providers.
40. Experience to date of the tariff system has shown that Foundation Trusts can be reluctant to develop services which are complex, expensive and only address a small patient community without specific incentives such as those provided by NHS Specialised Services. In freeing Foundation Trusts to take greater charge of their own development, care must be taken not to introduce perverse incentives that will promote the avoidance of certain types of service development.

Conclusion

41. Many of the proposals in the White Paper are valuable and if implemented properly will deliver benefit to patients and families affected by genetic conditions. However, there are many areas in which further detail is required, and where greater consultation will be necessary. We have major concerns in the important area of outcome measures, where further work is essential to ensure the whole patient population of England is treated fairly and equitably.
42. Genetic Alliance UK looks forward to future cooperation with the Department of Health to ensure the needs of patients and families affected by genetic conditions are met during and following this reorganisation of the NHS.



Director
Genetic Alliance UK