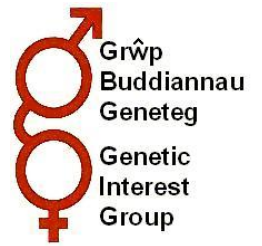


Consultation Response

Proposals for the Future of Specialised and Tertiary Services

Welsh Assembly Government

Response by the Genetic Interest Group



Introduction

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. GIG welcomes the Welsh Assembly Government's consultation on reforming the provision of specialised and tertiary services in Wales.

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. Not addressing individuals' healthcare needs properly can have a negative and potentially devastating effect on their lives, affecting their quality of life and their length of life. Patients may have to manage their condition by accessing emergency services in hospitals with a heavy burden on health and social care services. It is vitally important that those people needing specialised and tertiary services living in Wales can access them appropriately and in a timely manner.

Many people with rare conditions are already accessing and benefiting from excellent levels of care from tertiary and specialised health services. We applaud the dedication of the professionals who deliver and provide these vital services. However, excellent care in Wales is not available to all, and improvements need to be made from the present system.

We are pleased to contribute constructively to this consultation. Our response focuses on the needs of our member organisations and the individuals and families that they represent.

I. Do you agree overall with the proposals contained in this Consultation Paper?

Overall GIG agrees with the proposals. We have concerns about lack of detail regarding the processes involved and believe they need to be set out in a clear framework in order that those needing to access specialised and tertiary services are aware of what is available to them.

The consultation document highlights that in the past patients have fallen through the gaps when Local Health Boards and Health Commission Wales have both refused to cover the cost for certain interventions. We are concerned that such gaps will not disappear in the new

system, and may simply reappear between planning at the local and national level. We would wish procedures to be in place to monitor the system for such gaps to ensure they are filled.

2. Do you agree with the retention of a national All-Wales approach to the planning and securing of certain specialised and tertiary services?

Critical mass

For rare conditions, due to low population levels, the planning of health services is often only economically feasible at a national level. The consultation document makes provision for the possibility that some services may be transferred from national to local planning, but does not make mention of the potential requirement for a service to be upgraded from a local to national basis. The population level of a certain condition may vary and local planning may become impractical, difficult and/or costly. We believe that such a situation should be allowed for and the mechanisms to be put in place to monitor the effectiveness of planning at both an all-Wales and at a local level.

Cross Border Services – the UK

The Welsh Assembly Government must consider the mechanisms necessary to work with clinical colleagues outside of Wales, in other areas of the UK as for some conditions, a centre of excellence, providing a specialist with the expertise and knowledge required to provide the best possible management is only available at a UK level. This is most likely for ultra orphan conditions (prevalence of less than 1 in 50,000).

We urge the National Committee to ensure strong working relations with colleagues within the Department of Health's National Commissioning Group. Procedures must be put in place and strengthened so that families from Wales can access both existing and new developing services in the future that are provided in England, to reduce inequity of access between health services.

Cross Border Services – Europe and beyond

The consultation document makes no mention at all of the requirement to establish a process to enable patients to access services outside of the UK. Although highly unusual, some extremely rare conditions require collaboration with European clinicians with expertise on diagnosis and management, particularly if there is no established treatment already in place. One example of this is sending a diagnostic test to a laboratory to the EU.

The Joint Committee needs to be able to accommodate this requirement to provide patients with the expertise available wherever it may be. By utilising the best level of expertise, the Joint Committee will provide patients with the correct and best level of care.

3. Do you agree with the proposal for a single funding mechanism for services across the full patient pathway?

Full patient pathway

A single funding mechanism should make it clearer to patients, their families and their clinicians about who is (or is not) funding and providing their healthcare.

Funding for the care of patients, particularly those with life-long conditions that need specific interventions and management, needs to be in place and available to them. Provision must be made for the full patient pathway. For example, providing for a patient to have a specialised intervention at a tertiary centre (e.g. neurosurgery) is a waste of resources when provisions for the necessary continuing care or rehabilitation to ensure the patient makes as best a recovery as possible, are unavailable.

4. How should accountability mechanisms be constructed, so as to ensure clarity for the public and patients?

GIG is concerned that the proposals for the Joint Committee do not include membership of an important stakeholder – the patient. Although we welcome public consultation in shaping the Joint Committee, we believe that this should continue through the actual lifetime and work of the Committee itself. The patient viewpoint cannot be second guessed. We recommend a representative from a voluntary organisation to be nominated.

5. Do you have any comments on the Schedule of Services to be transferred to LHBs – Annex A?

6. Do you have any comments on the Schedule of Services to be retained at a National level – Annex B?

Definitions

We are concerned that the Schedule of Services for both national and LHB planning are not comprehensive and that many services will fall through the considerable gap between the two. The Joint Committee should first of all refine their definitions to prevent particular services being interpreted differently, with the potential of a postcode lottery across Wales according to differing interpretations.

Assurance on equitable local planning

GIG is concerned about the lack of information regarding the process of ensuring effective planning by LHBs for certain services. Will it be mandatory for LHBs to plan for particular services and how will this be monitored and assured? A major issue here will be for services designated into Annex A, but with small local populations requiring that LHBs will need to work together to provide services. For areas of medicine such as cancer and cardiac – where networks exist to facilitate this work, this would be less of a problem, but for areas such as neuroscience, which have no coordinating network, we are very concerned that such services will not be sufficiently planned.

Additionally, such services such as neuroscience will therefore not be given priorities or incentives towards their planning. Without NICE guidelines or a National Service Framework standards policy such areas will not be championed. E.g. We presume that neuromuscular services are currently banded under 'neuroscience' and therefore will be planned at the LHB level (Annex A), but with low numbers (approximately 3000 patients in Wales), LHB collaboration would be required, but the plans described in this consultation do not reassure us that such services will be funded. Additionally we are concerned that schemes such as

Annual Operating Frameworks may facilitate the prioritisation of certain services, resulting in the de-prioritisation of those services not included.

7. Do you support the proposal for a Joint Committee?

We are concerned about the funding mechanisms that will exist for specialised and tertiary services. This is the most crucial part of the Committee's work, and it is vital that this information is made public so that all stakeholders can respond to it.

8. Do you have any views on the proposal for Cwm Taf LHB to host the Joint Committee?

We have no objections about this proposal. If costs are saved through this model, then this is a positive venture. We would however request that clear objectives are established between the teams and the staff of the LHB and of the National Team so that neutrality is assured with no conflict of interest.

9. Do you have any comments on the Criteria for Assessment of Specialised and Tertiary Services?

Process of designation

It is unclear from the consultation how the process of designating a service as specialised or as tertiary will function. Will this process take place annually? Will potential services be invited to apply for designation? Will there be an upper limit or how many services a year that may be designated? These are important matters that should be consulted on with stakeholders.

For certain rare conditions, the services that exist for them in Wales are those which have been developed on an *ad-hoc* basis by clinicians with a research interest or by undertaking a clinic within their own training time. Without these clinicians families would not receive any regular management and consequently such services are not sustainable, and fall apart when a clinician moves out of area or retires. This particular situation has been observed with neuromuscular services.

This consultation does not detail sufficiently how existing 'unrecognised' services can be designated as specialised, so that they may be planned formally and sustainably. A process is required to ensure that such 'stealth services' can be formally recognised.

For many of these services, particularly those that cater for patients with rare conditions, there is no policy for their introduction – such as NICE guidelines or the absence of a National Service Framework, therefore no incentive to plan and fund services for those patients.

Admin support

The administrative / strategic support for accomplishing this designation should also be considered. In certain areas, for example oncology and cardiology, the clinical networks are in place to assist in the lengthy and detailed administrative work to fully cost the implementation of such 'new' services; however for certain areas, such as neurosciences, this infrastructure

does not exist and therefore would not be available, leading to a disadvantage for this area of medicine to have services appraised by the Joint Committee.

Priorities

This consultation does not provide enough detail on the processes of Assessment Criteria, nor does it also deal with the priorities used. Within the HCW framework, high priority / weight has been given to new services that will reduce waiting times. While this is an important strategy, for many unrecognised services, the patients are already seen by a clinician and therefore are not 'new' – meaning that funding such a service would not reduce waiting times. Such services are already at a disadvantage to be assessed as specialised.

Horizon Scanning

The consultation briefly mentions the Joint Committee's intention of horizon scanning. The consultation document makes no mention of how the horizon-scanning will take place. We urge the Welsh Assembly Government to consider working with the other health services in the UK to work together in identifying these areas, to share expertise and to reduce the cost of the work.

As well as horizon-scanning for future developments, we recommend the Welsh Assembly Government develops the processes required to identify new generation technologies and facilities for existing services so that there may be advances and improvements in existing services. Such short-term capital expenditure will often result in long-term efficiency savings in addition to better quality of care for patients.

An example of this short term expenditure resulting in long-term efficiency savings is pertinent in medical genetics: The medical genetics service now requires investment to transform their service from manual to the use of automated machines, which will result in better services to patients as it decreases in efficiencies through manual work and increases efficiencies in technician redeployment elsewhere.

Medical genetics services in England have already received investment from the Department of Health and are now providing automated genetic tests, turning around genetic tests for inherited breast and also bowel cancer to eight weeks (meeting NICE guidelines), in Wales the turn-around time is two years (outside NICE guidelines), this trend is set to continue and lengthen as new cases are referred to the service.

The changing rate of demand for services must also be identified in such horizon scanning processes. 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. Would an 'annual designation' review take this into consideration? What would be the processes for this and how would the Joint Committee take this into account?

Medical genetics is a good example here too: Once a small and complex area of medicine, genotyping is now a routine diagnostic method which is available to clinicians. Standards including NICE guidelines and National Service Frameworks require this technology to be used to confirm diagnosis for conditions such as familial hypercholesterolaemia (inherited high cholesterol) and for inherited cardiac conditions such as arrhythmias.

Planning for new services provided in England

The process by which a patient can gain access to new specialised services commissioned in England by the National Commissioning Group is unclear. How might an individual living in Wales with a very rare condition have access to a commissioned service at a centre of excellence in England?

10. Is there anything else you would like to comment on?

Budgetary Cuts

An area not discussed at in this consultation is the proposals on funding cuts that will be made to specialised and tertiary services. The current system sees Health Commission Wales levy its Strategic Change Efficiency Programme (SCEPs) on services, and Trusts imposes its Cash Release Programme (CRPs) to local services. We seek clarification on the future of these two initiatives – will they both continue and therefore impose a ‘double-hit’ on particular services?

As this process is a reality in the current system and is likely to exist in the future in some form, it is reasonable for consultees to be given the details about it.

The Genetic Interest Group is grateful for the opportunity to comment and welcomes further communication on the issues discussed in this document.