

NHS Wales

Specialised Services

Strategy

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Purpose and Summary of Document:

This Strategy has been produced as a response to the Welsh Government's commitment to "require Local Health Boards to produce a national specialist services strategy for Wales". It is a high level strategy and not a detailed action plan. As such, it does not define which services should be provided where, but to provide the framework within which such decisions can be made.

The primary aim of this Strategy is **to ensure equitable access to safe, effective, sustainable and acceptable specialised services for the people of Wales.**

The strategy also aims to raise awareness and understanding of specialised services and ensure that specialised services help meet the IHI 'Triple Aim' to:

- improve the health of the population
- enhance the patient experience of care (including quality, access, and reliability)
- reduce, or at least control, the per capita cost of care

The objectives of this Strategy are to identify:

- how specialised services should be defined
- the mechanisms that should be used to evolve the 'list' of specialised services over time
- the mechanisms that should be used to determine how specialised services should be planned, secured and delivered
- how the specialised services budget should be set and then balanced

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1 Introduction

This Strategy has been produced as a response to the Welsh Government's commitment to "require Local Health Boards to produce a national specialist services strategy for Wales". It is a high level strategy and not a detailed action plan. As such, it does not define which services should be provided where, but to provide the framework within which such decisions can be made.

The Strategy will guide the future plans of the Welsh Health Specialised Services Committee (WHSSC), which was established in 2009 to plan and secure specialised services. In doing this, WHSSC acts on behalf of all seven Local Health Boards (LHBs), who have the statutory responsibility for their populations, including access to specialised services, and ensures a shared national approach to the joint planning of specialised and tertiary services.

This Strategy does not propose that the role or governance arrangements of WHSSC should change. However, the Strategy does define how the scope of WHSSC may develop over time and will inform its future plans and actions in planning and securing specialised services.

This Strategy has been produced under the direction of the Director of Specialised and Tertiary Services, acting on behalf of the Local Health Boards, and has been overseen by the WHSSC Joint Committee.

2 Aims and Objectives

The primary aim of this Strategy is **to ensure equitable access to safe, effective, sustainable and acceptable specialised services for the people of Wales.**

The strategy also aims to raise awareness and understanding of specialised services and to ensure that specialised services help meet the IHI 'Triple Aim' to:

- improve the health of the population
- enhance the patient experience of care (including quality, access, and reliability)
- reduce, or at least control, the per capita cost of care

The objectives of this Strategy are to inform how:

- specialised services are defined in the Welsh context and how the list of specialised services is developed over time
- specialised services are planned, secured and delivered

- the specialised services budget is set and then balanced.

The successful implementation of this strategy will mean that people in Wales will not be unfairly disadvantaged merely because the condition they suffer from is rare and/or requires specialist intervention

3 Context

This Strategy has been produced following the publication of *Together for Health – A Five Year Vision for the NHS in Wales*, which focuses on delivery and aspires to “services best suited to Wales, but comparable to the best anywhere”. This aspiration applies to specialised services, where comparisons can often be readily made, particularly with other parts of the UK.

The Specialised Services Strategy is intended to support the improvements described in *Together for Health*:

- Health will be better for everyone
- Access and patient experience will be better
- Better service safety and quality will improve health outcomes.

The challenges outlined in *Together of Health* all apply to specialised services and this Strategy must address the facts that:

- Health has improved but not for everyone and our population is ageing
- Health care quality has improved but the NHS can do even better
- Expectations are continually rising
- Medical staffing is becoming a real limitation on our services
- Funding is limited.

Of particular importance to specialised services is the emphasis given in *Together for Health* to the need to:

- have one system for health, with clear care pathways
- develop centres of excellence for specialist care, as part of fully integrated networks of care
- ensure ‘excellence everywhere’, including by further strengthening clinical leadership and empowerment and by monitoring quality and testing against evidence
- ensure transparency on performance and the development and implementation of clinically focused targets
- forge a new partnership with the public
- make every penny count.

Each Local Health Board is developing its own plans to reconfigure services to meet the objectives of *Together for Health* and, where relevant, Boards are working in partnership on changes at a regional level.

The financial context, in which this Strategy has been produced, is enormously challenging and difficult decisions will need to be made about the use of NHS resources, including in relation to specialised services.

It must be recognised that the health policy context in England is different from that in Wales and is currently diverging. This will result in increasing differences in the way that specialised services are commissioned and delivered within the two countries. This divergence will often be apparent to the public and will impact directly on Welsh patients treated in England.

A consultation on the *UK Plan for Rare Diseases* is in progress.

In the above context, it is essential that:

- plans for specialised services are developed in close liaison with LHB and regional level planning for non-specialised services
- decisions and choices in relation to specialised services, affecting both individuals and services, are consistent in terms of consideration of risk, impact and value with decision making in other services
- divergence with policy and practice in England is carefully managed
- this Strategy informs NHS Wales' response to the consultation on the *UK Plan for Rare Diseases* and the subsequent implementation of its recommendations in Wales.

4 Specialised Services

There is no set definition of specialised services, but the following have been used at UK level:

- **Specialised Services** - Services, products and health technologies for rare conditions provided in relatively few specialist centres to catchment populations of more than one million people. In the Welsh context such services are normally provided in at least one centre in Wales (although English centres may also be used to facilitate geographic access)
- **Highly Specialised Services** - Services for very rare conditions, concerning no more than 500 UK patients and/or provided in four or fewer specialist centres in England. Relevant Welsh patients are treated in one these English centres.

Specialised services can involve lifetime or episodic care for rare diseases, complete congenital or acquired conditions.

Specialised services typically have many or all of the following characteristics:

- involve high-cost, low-volume interventions and treatments
- expose LHBs to the risk of having to fund expensive, unpredictable activity if such risk is not shared
- require a highly skilled multidisciplinary team and/or specialist equipment and facilities that can only be provided cost effectively in few locations
- require a concentration of experience to achieve clinical effectiveness
- require close monitoring to prevent inappropriate proliferation
- require scarce clinical skills.

The range of services within WHSSC's remit is decided by the Joint Committee; an initial list of services was agreed on its establishment and there have been several transfers, or planned transfers, of services into and out of WHSSC.

It should be noted that some services have been included, for pragmatic reasons, within the scope of WHSSC, without being deemed to be specialised. This includes some services that are pooled for risk management purposes and other recently introduced services that are high volume, but require a carefully managed introduction before being introduced into mainstream clinical practice. Such arrangements may continue to be appropriate.

It is proposed that, in Wales, specialised services should continue to be defined as being those that the LHBs, acting collectively through the WHSSC Joint Committee, deem to be specialised and, as a result, to be commissioned by WHSSC.

The list of existing specialised services, together with new and emerging services that have the characteristics of being specialised, should be formally received and reviewed annually by the Joint Committee, taking into account the guiding principles set out in section 5 below, together with consideration of:

- planning populations
- volumes
- costs
- expertise of providers
- pace of change.

In some cases, services that have previously been deemed to be specialised may reach a level of maturity where they can become part of routine practice.

5 Guiding Principles

Planning, securing and delivery of specialised services must be underpinned by explicit principles. They must:

- must meet a defined need
- must be safe
- must be effective
- must be sustainable
- must be equitable
- must provide the best value for resources used
- should be acceptable to patients and the wider public
- should be part of a continuum of care/pathway.

Taken together, these principles provide a definition of quality that is appropriate for specialised services. They also directly support the achievement of the IHI 'Triple Aim'.

The above principles are central to this strategy and must be used to inform future planning and decision making within specialised services. In particular options in relation to which services will be commissioned and where and how they should be delivered should be assessed against these principles. The principles should be applied in the wider context of all health services, rather than just with reference to other specialised services.

Each of the principles is expanded upon below:

5.1 Meet a defined need

Specialised services must meet a need that is defined in terms of both an assessment of the population's overall needs, (health status) and specific needs assessments for particular services/interventions. This includes the epidemiology of conditions/diseases and appraisal of the evidence for interventions.

Needs must be measurable and defined through calculation of population numbers referred through secondary care and describable with clinical indicators, including severity of disease and thresholds for admission or attendance for investigation.

5.2 Be safe

Specialised services/interventions must be safe. The benefits must outweigh the risks and avoidable harm must be minimised. This depends, in part, on the maintenance of appropriate clinical expertise through the maintenance of sufficient activity levels in individual services.

5.3 Be effective

Specialised services must be of proven effectiveness in terms of clinical outcomes, health gain and cost effectiveness. Outcomes should be considered from a clinical and patient and population perspective.

5.4 Be sustainable

Specialised services must be sustainable. Sustainability relates to critical mass in terms of staff, numbers or referrals, training, research and development and interdependency and has a direct relationship with specific consultant and junior workforce numbers and volumes of activity necessary to sustain expertise and clinical competence.

Within NHS Wales, the ability to recruit, train and retain medical staff is increasingly a constraint on the delivery of safe and effective services. There are, however, opportunities for the development of specialised services to facilitate wider workforce modernisation in ways that also benefit non specialised services, through maximising available skill sets and improving career structures and value for money.

Specialised services must facilitate training and stimulate and sustain research and innovation. The clinical undergraduate and postgraduate provision should be explicitly matched to the range of clinical services necessary to support good quality and mandatory teaching and training.

5.5 Be equitable

Specialised services must be equitable. Considerations of equity include multiple dimensions, including equity between patients with the same disease/condition and between patients with different diseases/conditions. Decisions must be reached in a consistent and transparent manner.

People in similar situations must have access to similar services/interventions. Grounds, which are irrelevant to the outcome of care, must not be used to discriminate against individuals in their access to treatment.

5.6 Provide the best value for resources used

Specialised services must provide value for money compared with alternatives, taking into account the overall cost impact and affordability, including the opportunity cost. The services planned must represent the best use of the available resource.

Choices need to be made within and between services/interventions. Prioritisation should ensure that the best outcomes are achieved for the resource available. The prioritisation framework used for specialised services should be consistent with the approach taken by LHBs for other services.

5.7 Be acceptable to patients and the wider public

Specialised services should be acceptable to the public, including in terms of patient experience and accessibility.

Specialised services should be accessible to patients across Wales, taking into account the fact that the annual volume of work presenting to the specialised service from the defined populations must influence the level and location of care where the service is provided. Therefore, rarer low volume specialised needs will be met in fewer centres in Wales, or one only, or not at all and so be delivered in England or elsewhere.

There is, therefore, a trade off between the geographical or local availability of a specialised service versus the need to travel to obtain provision at a distant centre where the volume is sufficient to provide sustained skills and expertise at an acceptable cost of provision.

Because of the potential for increased distance to affect clinical outcomes and reduce access, there should be a presumption that services will be delivered within Wales, where volumes of patients are sufficient to sustain skills and expertise and where the other principles can be met.

5.8 Be part of a continuum of care/pathway

Specialised services should form part of the overall continuum of care and be a defined part of specified care pathways for each disease/condition. This allows consideration of the impact on and interdependencies with other services and facilitates opportunities for more effective use of resource and improved outcomes.

Care pathways must be clearly defined and it should be explicit how patients move into and out of the scope of specialised services as their treatment progresses.

6 Planning, Securing and Delivering Specialised Services

6.1 Planning and Securing (Commissioning) Specialised Services

The guiding principles set out in section 6 must be rigorously applied to planning and securing (commissioning) decisions relating to specialised services.

The processes to determine what is planned and secured must:

- be population based, including coverage of the whole population of Wales
- consider the whole pathway of care, including the impact on other services
- be organised on a programme basis, to promote alignment with non specialised services and facilitate consideration of pathways
- engage clinicians through partnership with individuals and networks as part of the whole system
- be transparent and engage the public and their advocates on both an ongoing and an ad hoc basis
- be consistent with those used by LHBs, particularly when LHBs are considering services across LHB boundaries
- be informed by appropriate horizon scanning in relation to emerging technology and treatments and their potential impact on patients and services
- formally assess new drugs and technologies prior to adoption.

In relation to the final point, it should be noted that Wales has mechanisms for assessing new drugs. However, no equivalent mechanism exists for new technologies and Wales is entirely reliant on mechanisms at the UK level and in the other home nations.

The commissioning process is a cyclical process, which must involve:

- an initial health care needs assessment
- prioritisation
- the development of agreed service standards and patient outcome measures, including standards derived from the above guiding principles
- the development of an agreed service strategy involving providers and patient representatives in its development

- the conducting of equality impact assessment
- the rolling out of the consequent implementation and investment plans
- the agreement of service agreements/contracts with providers
- the monitoring and evaluation of the quality of services against agreed standards
- robust monitoring of activity and financial information
- benchmarking against other services inside and outside Wales
- managing demand
- monitoring the overall health benefit (including safety, quality, process, outputs and patient outcomes)
- reviewing whether services meet health needs.

Commissioning of specialised services is heavily dependant on access to robust and timely public health and clinical advice. This includes the epidemiology of conditions/diseases and appraisal of the evidence for interventions.

Despite the potential for divergence in policy between Wales and England, as mentioned above, there is great value in maintaining and developing strong links between commissioners of specialised services across the UK.

6.2 Location of Specialised Services for Wales

For each specialised service, decisions need to be made about:

- whether the service can and should be delivered in Wales or whether it is necessary to commission the service from England or elsewhere
- how many centres in Wales should deliver the service
- where those centres should be
- when these arrangements should change
- opportunities to deliver services in Wales for patients from Wales and parts of England.

These decisions need to be transparent and based on clear criteria derived from the guiding principles set out in section 5. Where relevant, clinical interdependencies with non specialised services must be taken into account. There should be a presumption that, where the guiding principles can be met, services should be provided within Wales.

The focus on decisions should be on 'services', rather than 'sites'. In many cases it may be possible to provide a single managed service from

multiple sites, provided that this is compatible with the guiding principles. Also, in other cases where there is only a single site with specialised facilities, the service must be managed in a way that facilitates the access of patients across Wales.

7 Delivering Specialised Services

The guiding principles also need to be applied to the management, organisation and delivery of services.

As in the commissioning process, patients, their advocates and the wider public must be involved in decisions around the ongoing delivery of specialised services. The formal consultative processes of the LHBs should be used when required.

Patients and carers are often well placed to comment on the design and delivery of care. Patients' organisations have important roles in protecting the vulnerable and improving standards.

8 Funding Specialised Services

There is not a rigid boundary between the funding for specialised services and that for other NHS Wales services. That is appropriate as the financial consequences of commissioning specialised services will evolve over time.

Each year the LHBs, through the WHSSC Joint Committee, agree the budget and financial risk sharing arrangements for WHSSC to fund those services agreed to be within its remit. This process appropriately takes place within the wider financial context of NHS Wales.

In allocating funding to WHSSC, it is essential that LHBs:

- take the above guiding principles into account
- make choices that are consistent with the choices they are making in other parts of the system , in terms of risk, impact and value.

In 2011/12, WHSSC had a budget of approximately £524 million, representing approximately 10% of the NHS Wales budget of £5 billion.

In commissioning specialised services, WHSSC must ensure that efficiencies are pursued in specialised services, as with other services. This includes steps to:

- increase price efficiency
- increase service efficiency through more efficient service delivery and through the development of better and more complete care pathways
- better manage referrals

- repatriate services from England to Wales, where costs can be reduced whilst meeting the above guiding principles.

There is a need for:

- more robust financial monitoring and a greater understanding of costs and cost pressures
- a clear business framework to ensure the appropriate management of risk
- clear payment and contractual mechanisms.

Benchmarking should be used where relevant and comparable data can be obtained, although it is difficult to benchmark the amount and proportion spent on specialised services across the UK, as definitions vary widely.

9 Next Steps

Informed by this Strategy and, in particular, by the guiding principles, WHSSC should be tasked with:

- developing and maintaining a strategy and action plan for each specialised services programmes within its remit
- ensuring that the list of services within its remit is formally reviewed by the Joint Committee on an annual basis
- ensuring that plans for specialised services are developed in close liaison with LHB and regional level planning for non-specialised services
- ensuring that an appropriate business framework is developed and implemented, to ensure the appropriate management of risk
- report annually on performance in relation to each of the guiding principles set out in this strategy, in the context of the 'Triple Aim'.

The Strategy should be applied to all services within the WHSSC remit by the end of 2012/13.

It is also recommended that:

- this Strategy is used to inform NHS Wales' response to the consultation on the *UK Plan for Rare Diseases* and the subsequent implementation of its recommendations in Wales
- consideration be given to developing a new technology appraisal process for NHS Wales.