



Llywodraeth Cymru
Welsh Government

Welsh Rare Diseases Implementation Plan

Highest standard of care for everyone with
a rare disease

Produced by the Welsh Rare Disease
Implementation Group

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Introduction by Dr Graham Shortland, Chair of the Rare Diseases Implementation Group and Medical Director of Cardiff and Vale University Health Board

In this updated Rare Diseases Implementation Plan, the NHS and Welsh Government's commitment to both empowering those with a rare disease and ensuring those affected by any kind of rare disease have timely access to high quality pathways of care is reaffirmed.

We have made some progress in improving the care of people with a rare disease in Wales, yet there is still more to do. All stakeholders must continue to work together to build on the progress to date and deliver improved care. Delivery organisations have started to embed the methodology of the Rare Diseases Implementation Plan. In this next phase of the Plan, I expect to see health boards working closely with partner organisations, delivering at greater pace to improve outcomes for people with rare diseases and working across organisational boundaries. I expect health board rare diseases plans to be fully integrated within health board strategic planning.

By their very nature rare diseases offer specific challenges to the NHS. There are many such diseases and in any given area there may be very few people affected by any one disease. Our vision is for fully integrated primary, secondary and specialist pathways of care, designed around the needs of the patient, to provide the support needed for patients to do what they can to manage their condition. People will spend a small proportion of their lives in direct contact with healthcare professionals and so have personal responsibility to do all they can to manage their condition. This concept is at the heart of the future of healthcare, co-responsibility and co-production of care.

We will continue our efforts to raise awareness of rare diseases. I know day in and day out, health professionals, management teams, the third sector and the patients themselves are working hard to achieve the best outcomes. The purpose of this Plan is to support and encourage these efforts by providing national leadership, encouraging collaborative working and planning ahead. We are more likely to get to where we need to be by working together.

We must make the most of our assets in Wales to optimise the outcomes of the Plan. Not least the skill, dedication and hard work of our clinical staff, service managers and third sector organisations. We should also look to create a more equal relationship between patient and healthcare professional, enabling people to co-produce their treatment based on their values, goals and circumstances.

Wales is a relatively small country which allows us to take a population approach with a shared common vision, utilising collaborative and planned approaches. We will continue to bring our providers, stakeholders and commissioners together routinely to deliver this common vision. We will build on our commitment to quality, equity and evidence-based pathways of care to make the most of the resources at our disposal.

The updated Rare Diseases Implementation Plan continues to provide a framework for action by health boards and NHS trusts working with their partners. First published in 2015, following engagement and formal consultation with key partner agencies, stakeholders, services users and carers, it sets out the expectations for people of all ages with a rare disease.

1. Overview and Context

This Plan encompasses a range of actions, to meet the needs of people affected by a rare disease. These will focus on the quality of the pathway of care and the outcomes it delivers.

A rare disease is a life-threatening or chronically debilitating disease that affects five people or fewer in 10,000. There are between 5,000 and 8,000 rare diseases and, while each one affects relatively few people, together they affect the lives of three million people across the UK, which would imply some 150,000 people affected in Wales. Rare diseases can take many and varied forms, including physical and psychiatric disorders. Some 80% are genetic in origin, but that means many are not. Most appear at an early age but again, that means many do not and so services must be alert to the signs at many different stages in people's lives. It is estimated some 350 diseases account for 80% of cases, but it is also estimated over 200 new diseases are identified each year¹.

For some people with a rare disease, it will also be appropriate to refer to other delivery plans such as *Cancer, Respiratory Health, Neurological Conditions, Delivering End of Life Care Plan and the Delivery Plan for the Critically Ill*².

The Rare Disease Implementation Plan puts in place a framework to deliver the Welsh Government's commitment to the vision in the *UK Strategy for Rare Diseases*³. In 2013 all four countries in the UK agreed to:

- promote equity of access – allowing everyone with a rare disease to follow clear, well defined care pathways, providing high quality services for every individual through integrated personal care plans;
- offer a patient centred, coordinated approach to treatment services, specialist healthcare and social care support which takes into account the needs of patients, their families and others who provide essential support;
- deliver evidence-based diagnosis and treatment of rare diseases, developed through the best use of regional and national resources that are easily accessible by patients and professionals;
- support specialised clinical centres to provide expert, high quality clinical care and expertise to patients their families and carers and the patient's, multi-professional healthcare team;
- promote excellence in research and develop our understanding of and treatments for rare diseases;
- deliver rapid and effective translations of advances in the understanding of rare diseases into clinical care by creating appropriate infrastructure, care pathways and clinical competences;
- deliver effective interventions and support to patients and families quickly, equitably and sustainably;
- promote collaborative working between the NHS, research communities, academia and industry wherever possible to facilitate better understanding about rare diseases and how they can be best treated;

¹ [What is a rare disease?](#)

² Annex 2 within this document.

³ [UK Strategy for Rare Diseases.](#)

- support education and training programmes that enable health and social care professionals to better identify rare diseases to help deliver faster diagnosis and access to treatment pathways for patients; and,
- promote the UK as a first choice location for research into rare diseases as a leader, partner and collaborator.

In responding to the Strategy, each of the four countries is taking a slightly different approach, reflecting local resources, priorities and practices. Collectively the plans will aim to improve access to information, services and research, and to bring real, positive change to the lives of people with rare diseases and their families.

An engaged, sustainable and skilled workforce is essential to delivering high standards of care and transforming the way services are delivered to meet the many challenges faced by the NHS in Wales today.

Children living with a rare disease should receive the best possible support and care in Wales in all environments, including schools and in transition to adult services. We must consider how we can better engage with patients and gain an insight into their experience, both nationally and locally, to ensure pathways of care are genuinely co-produced with structured and broad input.

Wales needs consistent and equitable services moving forward to ensure the delivery of integrated quality, affordable care in the face of growing demand, complexity and expectation. We need to deliver on the mandate of improved patient care, safety and experiences underpinned by communication and planning.

The Health and Care Standards, published by Welsh Government in 2015⁴, are designed so they can be implemented in all health care services, settings and locations. They establish a basis for improving the quality and safety of healthcare services by providing a framework which can be used in identifying strengths and highlighting areas for improvement.

Welsh Government is encouraging more open partnership between NHS Wales and industry, the Prudent Healthcare agenda is encouraging NHS Wales to work with industry partners to identify areas of need and opportunity, design and develop new ways of delivering healthcare services and measure the real world improvement impact. This is predicated upon protecting the primacy of public value at all times.

This updated Plan builds on the first phase and gives the NHS and its partners the vital continuity of approach it needs. The Plan is set out in a similar structure, covering the need to empower, diagnose early, provide fast, effective and safe care, treatment, and research. These chapters are underpinned throughout by the need for effective care pathways and quality patient information. It has also been written to reflect the latest strategic drivers, including prudent healthcare, the primary care plan and new legislation.

Since the publication of the first Rare Diseases Implementation Plan there have been a number of strategic and legislative changes that have impacted upon policy and need to be reflected in this updated Plan, these are summarised in Annex 1.

⁴ More information on the health and care standards can be found [here](#).

2. Empowering those affected by Rare Diseases

The UK Rare Disease Strategy aims to ensure improvements across the whole 'patient journey', from the first contact with the GP through diagnosis to ongoing management of a rare disease. The commitments in the Strategy emphasise the fundamental role the patient, supported by their family/carer and/or patient organisation, will play during this journey.

The diagnosis of a rare disease or condition generally marks the beginning of profound changes in the life of the individual and the lives of their family and friends. It may affect relationships, career prospects, income and expectations for the future. Everyone's experience of living with a rare disease will be different, but there will be lots of issues and challenges that are shared by many people living with the condition.

In primary and secondary care, patients, carers and their families are often those with most knowledge about their condition, its management, and the services they require. NHS professionals must be attentive to their views as they will have a much better understanding of the problem and its implications. Even in more specialised centres, within tertiary care, a collaborative relationship between clinicians, patients, carers and families will allow valuable exchange of information.

Understanding the experiences of people at the end of their lives, and their families is fundamental for patient-centred, co-productive services in line with prudent healthcare principles. This understanding is also vital to measuring the effectiveness of services.

Clinicians in local services must recognise the limitations of their own knowledge and when it is necessary to refer on, or seek advice, from specialist centres or experts. Patients and patient third sector organisations play a role in education where there is no specialist clinic for a condition.

A wide range of third sector groups help provide the knowledge and guidance patients use to secure access to health and social care services, and to manage and improve their condition. Many are able to act as the patient's advocate when needed and bridge the gap between patients, their families and the health service.

However improving the patient's experience of care must be a key priority for NHS Wales. A focus on the 'patient experience' plays a vital role in the drive to improve the quality of care. The Framework for Assuring Service User Experience⁵ advocates the need to collect patient feedback from a number of sources, not just surveys. Health boards and trusts should have mechanisms in place to gather views from patients and carers about their experience of the services they have used. To improve services organisations must demonstrate how they respond to user experience; ensuring feedback is captured, published, associated learning and improvement displayed.

Through the *Patient Reported Experience Measures (PREMs)* and the *Patient Reported Outcome Measures (PROMs) National Programme*, health boards and trusts should ensure ongoing patient engagement and empowerment to inform the development, delivery and continuous improvement in pathways for people with rare diseases in Wales. PREMs and

⁵ NHS Wales - [Listening and Learning from Feedback - Framework for Assuring Service User Experience 2015](#).

PROMs should be accessible to patients of all ages, including children, older people, and those with sensory deficits, poor literacy or learning difficulties.

Patients must be at the centre of service development, all patients will be offered appropriate information in the appropriate language and format. Clear information is central to the overall quality of each patient's experience. The provision of quality, accessible health and care information supports people to participate in shared decisions about their care. Patients must also have clear treatment plans to guide them through what can be very complex care processes. Increasingly patients should be able to access their own clinical records and interact digitally with the health service. Information is not just about leaflets and printed information, it can also be through hospital signage, appointment notifications, websites, informed consent, personal health records, patient education programmes and social media.

Key information must comply with the Welsh language standards and be produced in a range of formats to enable accessibility. Health and care information for patients, families, carers and the public needs to be high quality, easy to access and easily understood. It should engage people in their well-being, improve their experience and enable them and their families or carers to make informed choices about their lifestyle, treatment and the services they use. By providing good quality information, we can help to ensure people feel empowered and have greater protection and choice in all key aspects of their healthcare. Information should be planned and coproduced with patients, families and carers to ensure it meets their needs.

Some patients with learning disabilities can deteriorate rapidly and this may be difficult to identify, especially if they are unable to communicate verbally. Carers often accompany patients to hospital appointments and their input may help in identifying where a person is in danger of deterioration. Utilising Learning Disability Liaison Nurses, where they are employed can support staff to ensure reasonable adjustments are made.

Increasingly digital technology is being used to support patients and enable them to play a part in their own care, appropriate use of digital, telehealth and telemedicine wherever possible to help patients deliver self care.

Key actions for health boards in conjunction with WHSSC:

1. Support the inclusion of rare diseases care and treatment within existing patient reported experience measures (PREMs) and patient reported outcome measures (PROMs);
2. Put effective mechanisms in place for seeking and using views of patients of all ages and their carers including the collection of patient feedback from a number of sources such as concerns, complaints, patient stories, compliments and clinical incidents;
3. Ensure people with rare diseases have access to high quality accessible information at all stages of their journey, enabling them to make informed decisions;
4. Ensure they involve patients and their carers in the provision of the service of rare diseases;

5. Ensure with all stakeholders including patient organisations in the development of commissioning policies which provide detail on the referral pathway, clinical indications for the procedure or treatment, and access criteria for the service.

3. Identifying and preventing rare diseases

The UK Strategy noted many rare diseases are present at birth and are either caused by a genetic problem (for example cystic fibrosis), or deficiencies or exposures to substances, around the time of conception or during pregnancy. In this context it considered the role of screening and testing.

The majority of cases of rare diseases are not identified as part of a population based screening programme and the role of screening and carrier testing is limited. The All Wales Medical Genetics Service has a central role in the ongoing carrier testing and counselling of immediate family and relatives following the identification of rare inherited diseases. The provision of accurate information and carrier testing ensures families are able to access ongoing management and make well informed reproductive decisions. Counselling provides accurate information about risk and the availability of prenatal testing options as well as on pre-implantation testing if appropriate.

Public Health Wales and the Welsh Government are both represented on the UK National Screening Committee (NSC) and Wales has representatives on its subgroups across the screening programmes. The Wales Screening Committee takes advice from the NSC and the Welsh Government takes the decisions on implementing screening policy in Wales.

Consent processes must be appropriate for both screening and symptomatic pathways to ensure parents or patients are able to have sufficient information on which to make an informed choice.

General Practitioners must be informed of babies identified with a rare disease to ensure they are well placed to provide appropriate generalist support to the family.

Whilst many rare diseases will be identified at or before birth through specialist services, others first appear later, presenting primary and community care services with the challenge of identification and management.

There is a lack of awareness and identification of rare diseases amongst healthcare professionals outside of the specialist services, often resulting in a delayed diagnosis or misdiagnosis in patients. Education in rare diseases should help all health professionals:

- be aware common presentations may include a small number of patients with a rare disease;
- understand the pattern and combination of signs/symptoms across the family rather than in just a single individual may suggest a specific rare inherited disease diagnosis;
- understand the different modes of inheritance and risks of further affected children in pregnancy;
- be able to take and record an accurate family history of disease;
- be aware of clinical genetics services and other services for rare diseases and how these can be accessed;
- be aware of sources of reliable and “just in time” information on rare diseases, such as the online resource Orphanet⁶;

⁶ The UK portal into Orphanet can be found [here](#).

- be aware of the importance of access to research for those with rare diseases and where information on research opportunities can be accessed (e.g. online via National Institute for Social Care and Health Research (NISCHR) and National Institute for Health Research (NIHR) portfolios).

Additionally, medical undergraduates, healthcare scientists and specialist clinicians need to be prepared for the clinical application of sequencing technologies that are expected to change the approach to diagnosis in rare disease. The All Wales Medical Genetics Service (AWMGS) will have a significant role in the education of health professionals in the information and communication needs of patients in relation to delivery of Next Generation Sequencing (NGS) testing and results. In the future this will not be limited to Clinical Genetics, but will extend to how genomics is linked to clinical practice in most other specialties such as paediatrics, cardiology and oncology.

The NHS must be responsive to the different ways in which people may need to obtain information in respect of rare diseases due to rapid changes in technology and biomedical understanding, and the need for reflection and patient interaction. This should be recognised in planning arrangements, contracts and continuing education.

Key actions:

1. Ensure stakeholders in Wales are aware of current UK National Screening Committee consultations via networks and websites;
2. Ensure UK National Screening committee recommendations are considered and implemented appropriately and timely within Wales;
3. Work collaboratively to improve awareness and education regarding rare diseases for healthcare professionals.

4. Diagnosis and early intervention

Early and accurate diagnosis of rare diseases is a prerequisite for the best care and for early intervention. Diagnosis of rare diseases often requires recognition of the possibility of a rare disease as a cause for common symptoms and signs, therefore poses a challenge in non-specialist care. Individuals and their families and carers can experience distress and anxiety while waiting for a diagnosis, especially with a resulting deterioration. Early diagnosis can reduce this and lead to earlier treatment and effective management.

Diagnosis of a rare disease via screening is relatively unusual. Early diagnosis and early intervention may also follow testing because of family history of a rare disease, where no symptoms of disease have yet appeared. Increasingly, early diagnosis and early intervention offer the prospect of prevention of disease prenatally. In the case of IVF, pre-implantation, diagnosis and the prevention of disease complications can be achieved through increased surveillance, prophylactic procedures, chemoprevention or targeted therapy.

Genomic technologies are being used increasingly frequently with newer approaches allowing sequencing of the whole genome (the whole genetic structure of an individual), or part of it (an 'exome'), to try to explain an unrecognised pattern of signs and symptoms and support direct genetic diagnosis of a specific (rare) disease.

Some patients may for a long period lack a clear diagnosis, or indeed never receive one. It is important in cases where a patient clearly has an unusual health problem but no diagnosis he or she receives appropriate support and care.

The principles of prudent healthcare should be used to guide the patient's journey or pathway through the system; including self-care, diagnosis and treatment processes. Utilising multidisciplinary teams (MDT) combining the skills of different clinicians alongside full patient involvement to help achieve the best outcomes.

Peer review of the quality of healthcare to support and inform the planning and delivery of services has strong clinical backing and has proven to be an effective and inexpensive way of evaluating services, making targeted improvements and sharing best practice.

A GP will have very limited experience of rare diseases and it is clearly impossible for any individual to have expertise in every condition. However, since it is estimated one in 17 people will suffer from a rare disease in the course of their lifetime⁷, it is likely primary care teams will develop a generic expertise in the management of cases where it appears difficult to reach a diagnosis and where a rare disease might be suspected.

Where there is uncertainty, patients and their carers should be reassured their concerns are recognised and a shared understanding of the diagnostic difficulties and appropriate actions should be developed. In many cases GPs have a longstanding relationship of care for a patient or their family and this may provide particular support at times of uncertainty.

⁷ [What is a rare disease?](#)

Secondary care services are an important bridge between the primary care team and the specialist service and their role can include:

- initial consideration of and further investigation in secondary care of a rare disease;
- referral for further opinion to specialised services;
- ongoing liaison with the specialised services;
- provision of routine and emergency care local to the patients home;
- access to information and support for patients affected by rare disease and their families.

As is the case for GPs, individual hospital clinicians may have limited experience of a rare disease, but unlike primary care will have prompt access to inpatient/outpatient facilities to manage the condition. The role of primary and secondary care needs to be considered in partnership with specialised services, agreeing individual care pathways for patients so they may move between primary, secondary and specialised care appropriately and without delay, receiving treatment in a timely manner. This may include signposting to relevant electronic/web-based systems and urgent contact telephone numbers for patients. It should include the identification of the most appropriate lead clinician for that patient in secondary care to act as an advocate for the patient and co-ordinate shared care or specialist care where appropriate

Health boards and trusts must consider when managing and creating job plans for clinicians and geneticists managing rare diseases. Education of health professionals, setting standards and developing pathways of care for appropriate use of genetic resources, should be appropriately reflected in job plans.

The Welsh Health Specialised Services Committee (WHSSC) has contracts in place with specialised service providers covering the more common rare diseases. While there is some provision of specialised services for rare diseases by health boards within Wales, many patients with rare diseases may be referred to specialist providers in England for their care. Where there are no contracts in place for providers outside of Wales, in order for a patient to access a service, referrers are required to submit clinical information for consideration by the All-Wales Individual Patient Funding Request panel.

WHSSC has established clinical leads in a number of specialities related to rare diseases. These leads act as clinical gatekeepers and can authorise referrals to centres outside Wales. Information on the clinical lead and speciality is published on the WHSSC website in a referral management directory⁸.

WHSSC, health boards and trusts must ensure effective governance and reporting arrangements are in place to monitor the provision of safe and effective care. This includes taking into account all relevant evidence and guidance including the National Institute for Health and Care Excellence (NICE) guidelines and professional standards when developing the clinical pathway for people with rare diseases.

The All Wales Medicines Strategy Group (AWMSG) provides clinical expertise, information and advice, as well as genetic testing services, for patients across Wales. Genetic testing is a major development area in diagnosing and treating rare diseases. Each year, as

⁸ WHSSC referral management directory can be found [here](#).

knowledge of genetic disorders increases, new genetic tests are commissioned by the UK Genetic Testing Network (UKGTN). These new genetic tests then become available to patients and their families affected by, or at risk of, the associated rare diseases. The right tests at the right time can improve efficiency and reduce anxiety by ensuring quicker diagnosis and avoiding ineffective treatment.

WHSSC has continued to develop a robust evidence-based process to support its commissioning decisions. This includes the prioritisation of new technologies for inclusion in their annual Integrated Commissioning Plan, and the development of condition specific commissioning policies. The development, review and update of commissioning policies is managed by a dedicated group within WHSSC. All new and revised policies are routinely issued for consultation with key stakeholders, including relevant clinical teams and patient support groups. Each commissioning policy identifies clear inclusion and exclusion criteria for services, as well as the referral pathway and outcome measures.

A new process for appraising orphan and ultra-orphan medicines⁹ was implemented by the AWMSG in September 2015¹⁰.

A review of the Individual Patient Funding Request process (IPFR), through which patients can secure access to treatments not routinely provided, has recently been undertaken. The IPFR report¹¹ was published in January 2016 and recommends replacing the current decision-making criteria, so the decision always relates to the potential clinical benefit for the patient and the value for money of the intervention. The concept of 'exceptionality' was found to often not work for patients with rare diseases, because there was no baseline to establish exceptionality. The review's proposed criteria allows for interventions for rare diseases to be assessed on the basis of whether they offer significant clinical benefit and reasonable value for money.

The development of Next Generation Sequencing (NGS) will enable the development and validation of diagnostic protocols and specialist bioinformatic analysis. This will allow Wales to keep pace with regional genetics services elsewhere in the UK.

Key actions for health boards in conjunction with WHSSC:

1. Develop an agreed single all-Wales care pathways for people with rare diseases, delivered as close to home as possible;
2. Use significant event analysis to identify diagnostic delays and service barriers to identify and address any learning needs in relation to unusual diagnoses in their personal development plans and share learning across practice teams;
3. Develop services to ensure consultation times reflect need and allow sufficient time to address complex care management;

⁹ Orphan and ultra-orphan are drugs that are not developed by the pharmaceutical industry for economic reasons but which respond to public health need. Further Information can be found [here](#).

¹⁰ AWMSG, [Process for appraising orphan and ultra-orphan medicines and medicines developed specifically for rare diseases](#).

¹¹ [Independent Review of the Individual Patient Funding Request Process in Wales](#).

4. Obtain the input of primary care to the development of appropriate pathways for diagnostic, treatment and support;
5. Include peer review of the quality of healthcare to support and inform the planning and delivery of services;
6. Use evidence-based appraisal processes for reviewing treatments to ensure appropriate evaluation of new genetic and genomic tests and technologies;
7. Ensure appropriate and equitable access to genetic testing;
8. Ensure appropriate commissioning arrangements for Welsh genetics services, including monitoring and evaluation of access to testing;
9. Communicate effectively with other specialised services, as required, to ensure high quality care and diagnostic support;
10. Ensure arrangements are in place for identifying and supporting patients for whom no diagnosis can be agreed.

5. Coordination of Care

This section outlines the situation where an individual may need support from different clinicians, possibly far apart or far from home, and covers:

- service specification;
- specialist centres;
- information to support planning and co-ordination of care.

Children and young people with healthcare needs, including those with a rare disease have the same rights of admission to schools as other children. Schools are legally obliged to ensure all children with health care needs are properly supported in school and have full access to education, including school trips and physical education. Schools, local authorities, health professionals and other support services are advised to work together to ensure children with medical conditions receive a full education and reach their academic potential. Future service provision must be informed by the Additional Learning Needs Bill and Integrated Autism Strategy currently in development.

Care needs will change over time, both as people grow older and as their condition develops. The role of the GP and local services is likely to be life-long, for children the role of other professionals, such as health visitors and paediatricians is likely to be considerable. In the case of children there will be issues around transition from services designed for their age group to those for adults, and this should be carefully handled. There must be arrangements in place to ensure the needs and interests of children and families are properly considered and these must be sensitive to different ages. Children's circumstances change with the passing years and services should be able to differentiate between, and appropriately deal with, young children, those who are older, teenagers and young adults.

Poorly planned transition from young people's to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss of follow-up, which can have serious consequences. Services should support children and young people who are moving from paediatric services to access adult services. These should be organised so all those involved in care, treatment and support, cooperate with planning and provision. Services should continue to be appropriate to the age and needs of those accessing them. Care needs to be seamless into adult services across the various stages of transition between locations and services, taking into account any comorbidity.

The *Continuing NHS Healthcare*¹² guidance is designed for use by all those planning and providing services for children and adults with life limiting or life threatening conditions requiring continuing care, by health boards, trusts, local authorities and their partners. It describes the interagency process. All organisations should implement bespoke packages of continuing care for those who require it because their needs cannot be met by existing universal or specialist services alone.

GPs provide continuity of care, which may be particularly important at times of transition between specialist services. GPs will recognise the potential for conflicting advice when

¹² Continuing NHS Healthcare guidance can be accessed [here](#).

many services are engaged in the delivery of care. Patients should be supported to clarify the advice and make choices that meet their needs and personal preferences.

Primary care teams must identify and support the needs of carers and ensure access to social care advice is provided where appropriate. Carers play a vital role in supporting individuals with a rare disease. They often have a detailed understanding of the condition, the individual's experience, and their physical, social and emotional needs. Their role in supporting and delivering direct care and therapeutic interventions must be recognised and supported by multi-disciplinary, multi-agency health, social care teams and third sector organisations. The Social Services and Well-being (Wales) Act 2014 sets out clear expectations for joint working to support the needs of individuals and carers. It must not be forgotten there will be times where carers themselves may need respite, professional advice and support. Special consideration must be given to the needs of young carers.

Commissioning and planning systems for rare diseases must ensure equitable access to evidence-based health services and treatments across the UK, regardless of a patient's location. Specialised commissioning and planning bodies across the country therefore must look to work together to improve accessibility to services for rare diseases, as due to the low numbers of patients affected by individual diseases, it is not possible for services to be established for all rare diseases in each of the four home countries of the UK.

Formal links should be in place between all those involved in the care and treatment of patients to ensure they receive the best possible care and this is optimally coordinated.

Very rare diseases may be best managed and supported by a network of interested and committed clinicians from across the UK, who may not see enough patients on a regular basis to meet the criteria for a specialist centre but are able to initially develop and then follow appropriate best care pathways.

There will be a systematic programme of designation for centres of excellence for rare diseases supported by networks linking into local services throughout the UK. This will result in the development of centres which have expertise in rare diseases and will be able to centrally coordinate care of patients with that disease. They will have in-depth knowledge of the implications of the condition and know what services are likely to be required and when.

Currently, England has a number of Highly Specialised Clinical Service Centres. Wales needs to consider how to participate more closely with existing Centres and develop a small number of such centres for rare diseases in which the UK is leading on research.

Patient organisations are ideally placed to liaise between newly diagnosed patients and the centre of excellence to ensure all patients are aware of the centre's existence and they are accessing the appropriate services.

At present, information on rare diseases is not captured in a consistent and useable way to support planning, treatment and outcome monitoring. There are very few specific registries, the Welsh Congenital Abnormalities Register (CARIS) does capture information on a wide range of cases, and there may be opportunities for development of the role of CARIS in registering cases.

Data around particular individuals can be scattered across GP records and various hospital-based systems, with no routine way of collating data for individuals or for groups with a shared diagnosis. There is a requirement for collated information for individuals, so their overall circumstances and treatment record can be viewed as a whole. This might involve information on activity undertaken at different sites in Wales and outside. Better information on overall numbers affected is needed to support planning.

People living with rare diseases should be supported to have early discussions about the progression of their disease and their end of life care, if appropriate. Individuals, and those important to them, need the opportunity to have open and transparent discussions about personalised plans that enable a holistic approach to promoting their choices of treatment, care and support. This philosophy of care is important to individuals, and the health care system, as it promotes: partnership between all agencies which may be able to help; a reduction of unplanned hospital admissions; the enabling of more people to die in their preferred place and the supporting of care wishes by anticipatory care planning.

Health boards and trusts must ensure effective governance and reporting arrangements are in place to monitor the provision of safe and effective care. This includes taking into account all relevant evidence and guidance including NICE guidelines and professional standards when developing the clinical pathway for people with rare diseases.

Key actions:

1. Ensure Wales is involved as a member of UK development of rare disease healthcare coding;
2. Work with WHSSC and colleagues in Europe on the further development of the European Orphanet to:
 - extend Orphanet listings from genetic testing services to include specialist clinical services;
 - foster better communication between primary and secondary care and support more focused referral using common websites such as Orphanet to improve diagnosis.
3. Develop, change or expand information systems to capture, connect and analyse data about clinical and social care pathways;
4. Work with health boards as providers and NHS England to:
 - develop and agree service specifications;
 - develop an agreed process for monitoring services against specification;
 - implement and monitor services against service specification including outcome and audit monitoring;
 - consider possibility of establishing hub and spoke service delivery.
5. Health boards to ensure the individual care plan considers all aspects of health and social care needs, including access to; medical devices or treatment, benefits advice where appropriate, and in the case of children transition arrangements;
6. Work with international partners wherever possible and develop UK-wide criteria for centres to become part of an expert reference network to increase the flow of information between patients and professionals in a range of disciplines;
7. Health boards to ensure patients with complex needs have appropriate, timely

assessment of their continuing care needs;

8. Health boards to develop and implement integrated and co-ordinated plans for the transfer and provision of care from paediatric to adult services;
9. Health boards to ensure effective governance arrangements are in place to monitor and review the provision of safe and effective care. This includes taking into account all relevant evidence and guidance including NICE guidelines and quality standards.

6. Role of Research

Health and Social Care research is critical to provide effective care for people with rare diseases, generating new insights into preventative approaches, novel treatments and better solutions to care.

Evidence has shown healthcare systems which actively engage in clinical research have better patient outcomes¹³. Therefore, the NHS must facilitate research, ensure appropriate access to clinical trials and respond to the latest research evidence in the planning and delivery of its services. Patients benefit from access to novel therapies and implementation of evidence-based practice and, in the longer-term, benefit from a better understanding of the causes of rare diseases. Additionally, high quality clinical research builds institutional reputation and attracts and retains staff. Innovative healthcare is associated with significant income generation, through the development and exploitation of intellectual property and attracting investment from industry.

Welsh Government has recognised the need to increase research capacity in Wales and outlines a number of initiatives in its *Science for Wales* strategy¹⁴ to enable this, including the *Sêr Cymru* programme¹⁵. The programme aims to support fellowships and bring 'research stars' to Wales. Within the NHS, research is supported by Health and Care Research Wales (HCRW), with each of Wales' health boards and trusts supported by a research and development team. HCRW has highlighted capacity building as a strategic aim in its 2015 – 2020 strategic plan. As part of this work, HCRW funds Clinical Research Time Awards for interested staff, the HCRW Centres and Units researching specific diseases, in addition to Clinical Trials Units that develops new methodologies to assist in clinical trials and other study types. The Wales Clinical Academic Training Programme also funds a genomics post. Building on this, HCRW has implemented a new workstream to investigate the requirements for efficient knowledge transfer to ensure the outcomes of research studies inform and improve clinical services.

In March 2016, the Welsh Government published a Statement of Intent¹⁶ for Genomics and Precision Medicine, recognising the increasing impact genomic technologies is having on the diagnosis and treatment of rare diseases, and healthcare more broadly. Building on this, a wider strategy is in preparation. This aims to create a sustainable, internationally-competitive environment for genomics in Wales through strengthening our genomics services and research, building new strategic partnerships and building the genomics workforce. Genomics will play a key role in our ability to develop a prudent healthcare system, with genomic diagnostics providing evidence to select the most appropriate intervention for individuals, with fewer ineffective and often costly treatments.

¹³ [Research Activity and the Association with Mortality:](#)

Baris A. Ozdemir , Alan Karthikesalingam, Sidhartha Sinha, Jan D. Poloniecki, Robert J. Hinchliffe, Matt M. Thompson, Jonathan D. Gower, Annette Boaz, Peter J. E. Holt
Published: February 26, 2015.

¹⁴ [Science for Wales - A strategic agenda for science and innovation in Wales.](#)

¹⁵ [Sêr Cymru programme.](#)

¹⁶ [Statement of Intent – Genomics and precision medicine in Wales.](#)

Wales has recently joined the 100,000 genomes project and is establishing a strategic partnership with Genomics England. A total of £3.4m new funding from the Medical Research Council and Welsh Government will establish the Wales Genomic Medicine Centre. This virtual Centre will work across Wales with the Wales Gene Park, the NHS All Wales Medical Genetics Service and experts from Welsh higher education institutions to recruit Welsh patients with rare diseases and their families into the programme and interpret and apply genomic data in healthcare. Patients will benefit from the potential to receive more accurate and quicker diagnoses and improved services through research and its translation to clinical application. Health boards across Wales should consider how to work with the Genomic Medicine Centre to enable patients with rare diseases to take part.

Data collected within the health system holds enormous value for health research. It helps to answer questions about disease prevalence, patient outcomes and the effectiveness of new treatments; ultimately informing the development and delivery of better patient care. The Welsh Secure Anonymised Information Linkage (SAIL) databank is a anonymous data linkage system that securely brings together the widest possible array of routinely collected data for research, development and evaluation. The Wales Genomic Medicine Centre will work with SAIL to investigate linking genomic data to other health and social care data to improve the care of patients with rare diseases. Health boards and social care organisations should further consider how they can use SAIL in rare diseases research and consider outcomes from SAIL when planning services and care.

Recruitment of patients to rare disease research poses special challenges and clinical trials often operate out of multiple sites or require patients to travel to specialist centres. However, it is important all patients affected by rare diseases are able to access and participate in high quality research, either within Wales, or outside if there are no active research programmes for their disease in Wales. Wales is represented on the National Institute for Health Research (NIHR) Genetics Specialty Group and health boards should work with Wales' paediatric, neurology and oncology specialty leads to increase patient access to UK studies. Children and young people are under-represented in research and this balance should be addressed. Other partnerships include research with commercial entities such as the Pfizer Rare Diseases Division and Genzyme®, these initiatives are being run for example in Hywel Dda University Health Board and as part of the Academic Collaboration in Health (ARCH) in West Wales.

Other research collaborations are with the third sector, include the Motor Neurone Disease Society and Duchenne's Muscular Dystrophy Society.

Disease registries play an important role in rare diseases research. The Welsh Congenital Abnormalities database (CARIS) is a comprehensive reporting register that includes many rare congenital and childhood diseases stretching back to 1998. CARIS is a member of the European network of congenital anomaly registers (EUROCAT). The proposed Respiratory Innovation Centre has research themes in particular on precision medicine, including genomics and population health informatics where prevalence and outcomes of rare respiratory diseases can be monitored. Health boards and social care organisations should support the use of these registries in research.

Key actions for health boards to:

1. Work with the Health and Care Research Wales (HCRW) genetics speciality lead, researchers and the HCRW Support and Delivery service to increase the number of rare disease research studies undertaken in Wales;
2. Encourage more people with rare diseases in Wales to participate in research activity, for example through working with the Wales Genomic Medicine Centre to enable patients across Wales to take part in the 100,000 genomes project;
3. Create more opportunities for people affected by rare diseases to be involved and engaged in research activity;
4. Ensure arrangements are in place to ensure research feeds into organisations' mechanisms for uptake of best practice and service change to improve clinical practice and patient outcomes;
5. Monitor the relevant key performance indicators set out in the Delivery Framework for the performance management of NHS R&D;
6. Ensure a R&D lead is identified and provides visible R&D leadership for the Plan;
7. Promote the importance of R&D through participation in studies, including HealthWise Wales, and recognition and understanding by all NHS and other staff of the role that research plays in increasing and delivering good quality care, including staff recruitment, retention and development;
8. Ensure arrangements are in place to support clinicians and healthcare staff to engage in research, including application of protected time for research and clinical trials;
9. Work with HCRW, the HCRW ethics and permissions services to develop risk-proportional permission systems to enable researchers and patients to take part in UK-wide / international studies;
10. Work with HCRW, the third sector and other organisations to support patients to register on disease registries and promote the use of registries in research.

7. Implementing the rare diseases implementation plan

In response to this updated Plan, health boards are required to identify, monitor and evaluate actions required to deliver the Plan in health boards Integrated Medium Term Plans (IMTPs) (*NHS Wales Planning Framework 2017-20*). It may be useful to also have a detailed action plan for the local delivery plan which can be regularly monitored at health board level.

This Plan has set out our vision and ambitions for people, of all ages, affected by a rare disease within Wales. Doing this will involve joint working between all those responsible for the care of people with rare diseases in Wales.

This Plan has set out the health outcomes expected for the people of Wales. The Rare Diseases Implementation Group and the Welsh Government will hold the NHS to account to ensure the actions in this Plan and the health outcomes desired are achieved.

Health boards and trusts are accountable to both the Cabinet Secretary for Health, Well-Being and Sport and the Chief Executive of NHS Wales.

Wales is in a strong position to move ahead with pace, a national implementation group steering the Plan and developing solutions to support health boards.

The role of the Rare Diseases Implementation Group is to oversee the national plan and support health boards to deliver their local plans. The implementation group brings together the key stakeholders, including all the health boards, trusts, the Third Sector, primary care, secondary care, specialist care, government and managers to work collaboratively.

The Rare Diseases Implementation Group will review progress against this Plan at least once a year. The group will support delivery of the Plan and ensure a focus on working across traditional boundaries to deliver improvements in the care for people with rare diseases.

Health boards are responsible for planning; securing and delivering local services ensuring those people who require care can access the right care at the right time and place. Each health board will have a local planning and delivery group. These groups should plan services effectively for their population. Building and leading coalitions with other health boards, trusts in Wales and England, GPs, local government and the third sector organisations as required. Health boards must integrate their plans for rare diseases into the overall health board IMTP planning and ensure all aspects of the Plan are included in their planning process.

The Rare Diseases Implementation Group will support health boards and their local delivery groups through the provision of strong and joined-up leadership and oversight. They will co-ordinate national priorities and actions in a strategic way. The Implementation Group will develop a set of key performance and outcome indicators.

The Rare Diseases Implementation Group will:

- Work in a co-ordinated way, at an all Wales level, to support health boards to deliver the actions within this Plan and achieve the desired outcomes;
- Agree a focus for delivery each year for each health board and provide clear guidance to health boards to support the production of their three years integrated medium term plans, ensuring rare diseases are fully embedded within their plans;
- Facilitate the sharing and implementation of best practice;
- Identify constraints and develop national solutions to common issues where a strategic approach is needed;
- Review and critically assess health board delivery plan actions in light of progress and new developments;
- Review appropriate outcome and performance measures annually;
- Monitor the performance of one or two key indicators at each meeting and escalate areas of concern to the Welsh Government;
- Produce an annual update highlighting progress made throughout the year;
- Develop a performance framework which sets out the key performance and outcome indicators.

The Welsh Government will continue to maintain oversight of delivery and assurance framework and issue an update of progress annually, in addition to supporting and enabling liaison between the Implementation Group and Welsh Ministers.

Annex 1 - Supporting Strategic and Legislative Documents

Since the publication of the first Rare Diseases Implementation Plan there have been a number of strategic and legislative changes that have impacted upon policy and must be reflected in this updated Plan.

New Programme for Government and the NHS Plan

The Welsh Government's *Programme for Government* and NHS Plan set out an ambitious programme for health and well-being in Wales focussing on improving our healthcare services; our healthcare staff; being healthy and active; our mental health and well-being; the best possible start for children and care for older people.

Achieving Excellence: The Quality Delivery Plan for the NHS in Wales for 2012-16

Outlines actions for quality assurance and improvement and a quality-driven NHS that provides services which are safe, effective, accessible, and sustainable. This plan is currently being updated.

Well-being of Future Generations (Wales) Act 2015

The Welsh Government published the Well-being of Future Generations (Wales) Act in April 2015 to improve the social, economic, environmental and cultural well-being of Wales. It aims to make public bodies think more about the long-term, work better with people and communities and each other and look to prevent problems and take a more joined-up approach. The Act sets out seven well-being goals, and five ways of working in order to support the implementation of these goals:

- a prosperous Wales
- a resilient Wales
- a healthier Wales
- a more equal Wales
- a Wales of cohesive communities
- a Wales of vibrant culture and thriving Welsh Language
- a globally responsible Wales

The Act also establishes Public Services Boards (PSBs) for each local authority area in Wales who must prepare and publish a local well-being plan setting out its objectives and the steps it will take to meet them. It is expected these plans inform local priority setting.

Social Services and Well-being (Wales) Act 2014

A number of actions in this delivery plan have been developed to further embed the requirements of the Social Services and Well-being (Wales) Act 2014 which came into force on the 6 April 2016. The Act places a duty on health boards and local authorities to jointly undertake an assessment of the local population's care and support needs, including the support needs of carers. The population assessment is intended to ensure health boards and local authorities produce a clear and specific evidence base to inform various planning and operational decisions, including Integrated Medium Term Plans.

Population Needs Assessment

Population needs assessments are critical to the development of good long-term strategies. The Well-being of Future Generations Act makes it clear that this needs to be done in conjunction with other public service bodies, such as local authorities, education and housing. Population needs assessment should underpin the local well-being plan, developed by public service boards.

The 64 primary care clusters are the mechanism for this collaborative approach to integrated service planning and delivery. Making best use of available financial, workforce and other resources, not just those of the NHS but of local authorities, the third and independent sectors and the assets of local communities.

Prudent Healthcare

In addition, the plan has also been underpinned by the principles of Prudent Health and Care. The way in which services have been shaped and delivered in recent years provide good evidence of prudent health and care in practice and this delivery plan aims to strengthen that approach through a greater emphasis on prevention, integration and long term sustainability. Placing the needs of service users at the heart of service design, co-production in care and treatment planning and delivering services by professionals in both the statutory and third sector are good examples of how the prudent health and care principles underpin service delivery.

Health and Social Care Inequalities

Delivering the actions set out in the plan will make a positive contribution to the Welsh Government's equality agenda objectives through a commitment to identify and meet the needs of all groups in relation to stroke, including those from disadvantaged backgrounds who are statistically more likely to be living in poverty and be at greater risk of heart disease. This has also included consideration to the articles contained within the United Nations Convention on the Rights of the Child (UNCRC).

Welsh Language

The objectives of 'More than just words' the Welsh Government's strategic framework for Welsh language services in health, social services and social care have also been embedded into the plan through actions that make it clear all organisations associated with service delivery must ensure services are available to those who wish to communicate in Welsh.

Informed health and care – A digital health and social care strategy for Wales: The Welsh Government has outlined its commitment to providing access to the best possible services to the public by enabling health professionals to access the most up-to-date technology in its digital health strategy published in 2015. This provides the driver for development and innovation in the use of information technology in critical care for the benefit of patients.

Building a Brighter Future

A coordinated programme to ensure children have the best possible start in life through early intervention, family support and integrated services, focused on achieving better outcomes and reduced inequality for children.

Healthy Child Wales programme

Commenced in October 2016 to offer a coordinated, Wales wide universal core programme of interventions in the first 1000 days from conception, continuing up to the child's 7th birthday.

Developing a Skilled Workforce

The workforce is the most critical element of both the NHS and the third sector and is the key determinant to the success of any organisation. An engaged, sustainable and skilled workforce is essential to delivering high standards of care and transforming the way services are delivered in order to meet the many challenges faced by NHS Wales today. Workforce must be planned and developed around the prudent healthcare principles (i.e. how is the profile of your workforce going to change to allow professionals to concentrate on where they can add the greatest value).

Annex 2 – Links to Reference Documents and resources

Congenital Anomaly Register and Information Service

<http://www.caris.wales.nhs.uk>

EURORDIS

<http://www.eurordis.org/about-eurordis>

Health and Care Research Wales

<https://www.healthandcareresearch.gov.wales>

Independent Review of the Individual Patient Funding Request Process in Wales - January 2017

<http://gov.wales/docs/dhss/publications/170117ipfrreporten.pdf>

Newborn Blood Spot Screening

<http://www.newbornbloodspotscreening.wales.nhs.uk/>

NHS Wales - Continuing NHS Healthcare guidance

<http://www.wales.nhs.uk/continuingnhshealthcare>

Orphanet - The portal for rare diseases and orphan drugs

<http://www.orpha.net>

Policy Innovation Research Unit report - Diagnostic odyssey for rare diseases: exploration of potential indicators

<http://www.piru.ac.uk/assets/files/Rare%20diseases%20Final%20report.pdf>

Rare Disease UK – The rare reality an insight into the patient and family experience of rare disease survey report

<https://www.raredisease.org.uk/media/1588/the-rare-reality-an-insight-into-the-patient-and-family-experience-of-rare-disease.pdf>.

Rare diseases list

<https://globalgenes.org/rarelist>

The All Wales Medicines Strategy Group

www.awmsg.org

The Genetic Alliance

<https://www.geneticalliance.org.uk>

UK Rare Disease Advisory Group (RDAG)

<https://www.england.nhs.uk/commissioning/rdag>

UK Rare Disease Forum

<https://www.gov.uk/government/groups/uk-rare-disease-forum>

UK Rare Disease Forum - Delivering for patients with rare diseases: Implementing a strategy - A report from the UK Rare Disease Forum

<http://gov.wales/docs/dhss/publications/161020ukrarediseaseforum-progress-report-2016en.pdf>

UK Strategy for Rare Diseases

<https://www.gov.uk/government/publications/rare-diseases-strategy>

Welsh Health Specialised Services Committee (WHSSC) referral management

<http://www.whssc.wales.nhs.uk/referral-management>

Welsh Rare Disease Implementation Plan Annual Report 2016

<http://gov.wales/topics/health/nhswales/plans/rare/?lang=en>

Other documents:

Cancer Delivery Plan

<http://gov.wales/topics/health/nhswales/plans/cancer-plan/?lang=en>

Delivering End of Life Care Plan

<http://gov.wales/topics/health/nhswales/plans/end-of-life-care/?lang=en>

Delivery Plan for the Critically Ill

<http://gov.wales/topics/health/nhswales/plans/delivery-plan/?lang=en>

Diabetes Delivery Plan

<http://gov.wales/topics/health/nhswales/plans/diabetes/?lang=en>

Heart Conditions Delivery Plan

http://gov.wales/topics/health/nhswales/plans/heart_plan/?lang=en

Liver Disease Delivery Plan

<http://gov.wales/topics/health/nhswales/plans/liver-disease/?lang=en>

Neurological Conditions Delivery Plan

<http://gov.wales/topics/health/nhswales/plans/neurological/?lang=en>

Respiratory Conditions Delivery Plan (to be updated during 2017)

<http://gov.wales/topics/health/nhswales/plans/respiratory/?lang=en>

Stroke Delivery Plan

<http://gov.wales/topics/health/nhswales/plans/plan/?lang=en>

A framework for delivering integrated health and social care for older people with complex needs

<http://gov.wales/topics/health/publications/socialcare/strategies/integration/?lang=en>

Achieving excellence - The quality delivery plan for the NHS in Wales

<http://gov.wales/topics/health/nhswales/plans/excellence/?lang=en>

All-Wales Policy on Do Not Attempt Cardiopulmonary Resuscitation

<http://www.wales.nhs.uk/news/35793>

Children and young people's continuing care guidance

<http://gov.wales/topics/health/publications/socialcare/guidance1/care/?lang=en>

Delivery Framework for the Performance Management of NHS R&D

<http://www.healthandcareresearch.gov.wales/nhs-randd-funding-policy/>

Framework for Assuring Service User Improvement and Core Questions

<http://www.wales.nhs.uk/governance-emanual/public-and-patient-involvement>

Health and Care Research Wales Performance Management Framework

<http://www.healthandcareresearch.gov.wales/performance-management/>

Health and Care Research Wales Strategic Plan 2015

https://www.healthandcareresearch.gov.wales/uploads/Policy%20&%20Strategy/Health_and_Care_Research_Wales_Strategic_Plan_2015_2020.pdf

Health and care standards (April 2015)

<http://gov.wales/topics/health/publications/health/guidance/care-standards/?lang=en>

Improving general hospital care of patients who have a learning disability

<http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/How%20to%20%2822%29%20Learning%20Disabilites%20Care%20Bundle%20web.pdf>

Industry Engagement in Wales

<http://www.healthandcareresearch.gov.wales/industry-engagement/>

Informed health and care – A digital health and social care strategy for Wales

<http://gov.wales/topics/health/nhswales/about/e-health/?lang=en>

Lasting Power of Attorney

http://www.olderpeoplewales.com/en/Publications/pub-story/16-01-04/An_easy_guide_to_lasting_powers_of_attorney.aspx#.VoprFWcqXcs

More than just words.... Follow-on strategic framework for Welsh language services in health, social services and social care

<http://gov.wales/topics/health/publications/health/guidance/words/?lang=en>

NHS Wales Planning Framework

<http://gov.wales/topics/health/nhswales/organisations/planning/>

Patient Consent

<http://www.wales.nhs.uk/sites3/page.cfm?orgid=465&pid=11930>

Primary Care Services Plan

<http://gov.wales/topics/health/nhswales/plans/care/?lang=en>

***Safe Care, Compassionate Care*: National Governance Framework to enable high quality care in NHS Wales**

<http://www.wales.nhs.uk/sitesplus/documents/888/Appendix%20Item%206%20Safe%20Care%20Compassionate%20Care.pdf>

Self care and care plans

<http://gov.wales/docs/dhss/publications/100102frameworkselfcareen.pdf>
<http://gov.wales/topics/health/nhswales/healthservice/chronic-conditions/?lang=en>

Social Services and Well-being (Wales) Act 2014

<http://gov.wales/topics/health/socialcare/act/act-nhs/?lang=en>

The All Wales Standards for communication and information for people with sensory loss

<http://wales.gov.uk/topics/health/publications/health/guidance/standards/?lang=en>

Well-being of Future Generations (Wales) Act 2015

<http://gov.wales/topics/people-and-communities/people/future-generations-act/?lang=en>