Heart Conditions
Delivery Plan

Highest standard of care for everyone with or at risk of a heart condition

Produced by the Heart Conditions Implementation Group

January 2017
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Introduction by Judith Paget, Chief Executive of Aneurin Bevan University Health Board and Chair of the Heart Conditions Implementation Group

In this refreshed heart conditions delivery plan, the Welsh Government’s commitment to both minimising the incidence of preventable heart disease and ensuring those affected by any kind of heart condition have timely access to high quality pathways of care, irrespective of where they live and whether these are delivered through hospitals or in the community is reaffirmed.

We have made progress in improving the care of people with a heart condition in Wales. There has been a steady decline in the rate of people in Wales dying from all cardiovascular disease. In 2010 just over 10,000 people died from cardiovascular disease, by 2015 this had fallen to just over 9,000 deaths. The rate of hospital admissions for coronary heart disease has fallen considerably over the last five years, by 21%. The rate of hospital admissions for both cardiovascular disease and coronary heart disease has fallen considerably over the last five years, by 10% and 21% respectively1.

There have been considerable developments in cardiac care across Wales since the original delivery plan. Innovative projects such as the development of the familial hypercholesterolemia programme, community cardiology, enhanced cardiovascular risk assessment, the adult congenital heart disease service in south Wales, direct access for primary care to diagnostics, nurse led diagnostics, and e-referral and e-advice systems have all been supported by NHS Wales resulting in improved outcomes for patients. This is a tribute to all those involved in the planning and delivery of services for people with heart conditions.

However, key challenges remain in maintaining a workforce to provide sustainable service models and unwarranted variations in practice and the delivery of services remain. Comparisons, benchmarks and clinical audit have been difficult to establish and maintain in many areas.

Stakeholders must continue to work together and build on the success to date to continue the improvement seen in recent years. Delivery organisations have already embedded the methodology of the heart disease delivery plan so in this next phase of the plan. I would expect to see health boards and trusts working to improve outcomes for people with heart conditions, reduce clinical variation and work across organisational boundaries. Health board heart condition plans must be fully integrated within health board strategic planning, for national standards and pathways to be fully delivered.

We have an enormous challenge ahead of us with our growing and ageing population, in the context of our socio-economic situation. Cardiovascular disease causes 28% of all deaths in Wales around 8,800 deaths each year2. NHS Expenditure on circulatory problems, including CVD in Wales in 2014/15 was £446 million3. This demand will be set against the finite resources likely to be available for health and care services in Wales, which makes it challenging to simultaneously improve quality and performance.

At the heart of service quality improvement is tackling variation. Incidence of heart

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1 Welsh Government, Together for Health – Heart Disease Annual Report 2015
2 British Heart Foundation/Oxford University in collaboration with the Office for National Statistics
disease varies between most and least deprived areas in Wales. The premature (under 75) death rate for Blaenau Gwent (106 per 100,000) is nearly twice as high as for the Vale of Glamorgan (Bro Morgannwg; 56 per 100,000)\(^4\). As a small country with a small number of providers we can do better to tackle differences in pathways of care and reduce inequalities.

Our vision is for a fully integrated primary, community, 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. Primarily this involves lifestyle choices and participation in programmes to minimise the risk of complications in the years and decades to come. This concept is at the heart of the future of healthcare, co-responsibility and co-production of care.

We need to continue our efforts to tackle preventable heart disease. I know that day in and day out health professionals, management teams, the third sector, patients themselves and carers are working hard to achieve the best outcomes. The purpose of this delivery plan is to support and encourage this effort 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. 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.

The size of Wales 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. We can draw strength from the consistency of our approach by continuing with the delivery plan through to 2020. As well as taking advantage of our ground breaking Well-being of Future Generations Act, our established public health interventions and our world class research base.

Our Heart Conditions Delivery Plan continues to provide a framework for action by health boards and trusts working with their partners. First published in 2013, following significant engagement and formal consultation with key partner agencies, stakeholders, services users and carers, it is a cross-Government strategy that sets out the expectations for people of all ages with heart conditions, wherever they live in Wales and whatever their circumstances. This Plan encompasses a range of actions, to meet the needs of people at risk or affected by a heart condition.

This refreshed plan has been developed through partnership. This continued co-operation between Welsh Government, the Heart Conditions Implementation Group, Wales Cardiac Network, professional bodies and third sector organisations is key to delivering the next phase of working together to achieve the outcomes at greater pace and with greater impact.

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\(^4\) British Heart Foundation/Oxford University in collaboration with the Office for National Statistics
1. Overview and Background

This plan encompasses a range of actions, to meet the needs of people at risk or affected by heart conditions. This plan focusses on heart conditions excludes other cardiovascular conditions such as chronic kidney disease and peripheral artery disease. This plan will focus on the quality of the pathway of care and the outcomes it delivers by looking at compliance with standards, benchmarking with others and identifying areas for improvement.

This delivery plan, covers heart conditions more broadly, highlighting the importance of providing high quality detection and treatment of all major heart conditions, including:

- Heart failure (predominantly caused by coronary heart disease)
- Rhythm management, including arrhythmia management and atrial fibrillation
- Congenital heart disease (in children and adults)
- Inherited or idiopathic cardiac conditions, including cardiomyopathies

There is much common ground with prevention sections in other Welsh Government Delivery Plans, such as the Stroke and Diabetes Delivery Plans. For some people with heart conditions it will also be appropriate to refer to the Delivering End of Life Care Plan and the Delivery Plan for the Critically ill.

Despite efforts to make improvements in the care of people with heart conditions and ensuring NICE guidelines and quality standards are being followed in providing treatment to reduce mortality rates and improve the quality of life there is a need to raise the profile and deliver a quicker pace of change. We need 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 also need to deliver on the mandate of improved patient care, safety and experiences underpinned by communication and planning.

Children living with a heart condition should receive the best possible support and care in Wales in all environments, including schools. We also need to 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. We must make use of the clinical leaders in this field to drive system change and be responsive to clinical audit and peer review findings, as well as more proactively embedding improvement programmes.

This refreshed delivery 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 prevent the preventable, diagnose early, provide effective and safe care, treatment, and research. These chapters are underpinned throughout by the need for quality patient information and digital tools. This plan includes streamlined introduction and performance reporting sections. It has also been written to reflect the latest strategic drivers, including prudent healthcare, the primary care plan and new legislation.

It is vital services pull together and do everything possible to alleviate future demand and deliver the best outcomes for patients. We are at a point where we need to build upon the foundations laid, but with a focus and determination that will deliver not a gradual sustainable improvement but an immediate and fundamental change in pace for Wales to lead the way in providing care for people, of all ages, at risk or affected by heart conditions within Wales.
Since the publication of the first delivery plan there have been a number of strategic and legislative changes that have impacted upon policy and need to be reflected in this refreshed delivery plan. These are summarised in Annex 1.
2. Preventing cardiovascular disease

Cardiovascular disease (CVD) remains a major cause of ill health and death in Wales. In Wales, more than 1 in 7 men and nearly 1 in 10 women die from coronary heart disease\(^5\). Issues that require addressing include a reduction in risk factors and identifying how improvements can be made to reduce morbidity and mortality associated with cardiovascular disease.

Premature coronary heart disease is a largely preventable condition, significantly influenced by poverty and socio-economic health determinants - as well as factors such as family history, smoking, alcohol consumption above recommended guidelines, obesity, lack of physical exercise and untreated hypertension. Achieving reduction in levels of heart disease will require proactive approaches to tackling the underlying socio-economic determinants of health and promoting healthy lifestyles from childhood onwards. Where appropriate, cross cutting prevention strategies may apply to other specialty plans, not only heart conditions, diabetes and stroke but also cancer.

Resources should be targeted at areas of greatest risk, both on a population level and on the basis of individual interventions sensitive to cultural diversity. A multidisciplinary approach should be adopted to promote healthy living and empower people to engage in self-care from a young age. Individuals should therefore be encouraged to lead healthier lives by increasing their knowledge about risk factors and how to reduce them through provision of support, education and effective signposting to relevant information.

It is important to understand key population risks throughout the life course and then find when changes in behaviour occur e.g. people stop taking physical activity, become overweight or take up smoking. Targeted resources must deliver interventions which prevent the change in behaviour in a timely manner, proportionate to need and inequality in health.

Reduced smoking prevalence and inequality can be achieved through:

- Developing a clear understanding of the social and economic pressures in communities, e.g. deprived communities and age groups where smoking rates are highest.
- Supporting intensive targeted interventions to specifically address smoking prevention and cessation uptake with target groups.
- Advocating increased action at the population level, including increased measures to reduce the affordability, accessibility and attractiveness of smoking.
- Promote smoke free spaces in areas where children congregate to reduce childhood exposure to second-hand smoke and to denormalise smoking as an activity.
- Ensuring that every contact with health and care services is used to both prevent smoking uptake and encourage cessation.
- Ensuring that educational settings implement a whole systems approach which promotes a smoke-free society.

Reducing the proportion of the population who are overweight and obese through:

- A better understanding of why individuals are likely to become overweight or obese in early adulthood and how this can be prevented.

\(^5\) British Heart Foundation, CVD statistics – Factsheet for Wales, December 2016
• Ensuring effective interventions and pathways for prevention, treatment and management of childhood obesity are routinely available and systematically implemented, including antenatal interventions.
• Supporting intensive targeted interventions to specifically address weight and diet issues within deprived communities.
• Advocating increased action at the population level to ensure healthy food is available to all.

Increasing physical activity levels especially in older population groups through:
• Better understanding why individuals stop exercising as they get older and how this can be prevented.
• Supporting interventions within targeted age groups to increase participation in physical activity.
• Better understanding the motivations and barriers for undertaking physical activity.
• Considering interventions within a settings approach.

Reducing alcohol consumption and binge drinking through:
• Better understanding the social changes that cause a demographic shift in alcohol prevalence.
• Advocating increased action to reduce the marketing and promotion of alcohol for home consumption, e.g. multi-buy deals, minimum unit price of alcohol.
• Increasing awareness of harmful alcohol consumption in less deprived areas.

Reducing the numbers of people with undetected and untreated high blood pressure with early detection and evidence based treatment:
• Ensure those identified with a higher than expected blood pressure measurement are offered an appropriate referral pathway for management of their condition in order to help reduce the known risks.

Cardiovascular disease risk assessment is a systematic population based risk factor modification programme involving early detection of cardiovascular disease, atrial fibrillation and diabetes in populations aged 40 to 64, prioritising clusters of high deprivation. Two pilot models indicate offering lifestyle modification and behavioural support, linking patients to community support, such as smoking cessation services and/or triggering evidence based treatment via agreed clinical pathways meet planning objectives. Both in respect of supporting primary care capacity and sustainability as well as reducing unnecessary unplanned care admissions based on a prudent healthcare approach.

The priorities for promotion of healthy hearts are closely aligned to prevention across a range of conditions and to the stroke and diabetes delivery plans.

### Key actions

1. Health Boards should have in place a population based approach to cardiovascular disease, diabetes and atrial fibrillation risk assessment including targeted programmes for hard to reach groups

2. Public Health Wales will work with a broad range of partners (including public service boards and the third sector) to:
   • Raise awareness of healthy living
   • Signpost existing sources of information, advice and support relating to lifestyle change
• Develop and deliver local strategies and services to tackle underlying determinants of health inequality and risk factors for coronary heart disease
• Target resources in population areas of high risk (such as areas of deprivation) and areas of high impact (including early intervention actions in pregnancy and with children to tackle prevention from outset of life)

3. Public Health Wales and health boards, supported by Wales Cardiac Network, will support and facilitate GPs, practice nurses and community pharmacists to proactively:
   • Use every opportunity in primary care to promote healthy lifestyle choices and smoking cessation
   • Ensure consistent provision of testing and treatment for risk factors such as high blood pressure and cholesterol

Outcome indicators and assurance measures
• Coronary disease prevalence rates - proportion of patients under 75 living with coronary disease as recorded on GP heart disease registers.
• Outcome indicators for measuring the health of the population of Wales more generally included in the Public Health Outcomes Framework
• For outcomes relating to children, we will consider information available on smoking in pregnancy, perinatal death, low birth weight, breast feeding, obesity in children, smoking at ages 11 and 15, children's drinking and children’s physical exercise.
3. Timely detection, effective and safe care

People suffering with symptoms of heart disease need access to quick and effective diagnosis and treatment including surgical intervention where necessary as close to home as possible. In order to take a holistic and integrated population based approach to supporting improvements in cardiac outcomes we will utilise a whole life pathway model across Wales. This will include primary prevention and early identification of risk factors through to management across sectors and organisations. It will ensure patients are placed at the centre of their care as well as engaging clinical leaders workforce to ensure equity of access and clinical consistency throughout Wales within a once for Wales and prudent healthcare approach.

Referral to treatment times have been shown to be a poor measure of quality. Patients should start treatment within 26 weeks of being referred from their GP to give them the best possible outcomes. This measure misses an important high risk population that need particular components of this target delivered. There are a number of components to the pathway, included in the referral to treatment times. Introduction of component waits for each aspect of the pathway, meeting national standards and integration of care pathways is needed. Work is under way to develop measurements that will better reflect patient experience of the pathway and drive continuous improvement to overcome system delays in line with quality requirements. The heart conditions implementation group will develop proposals for a new approach to managing referral to treatment times based upon clinical need and will support services to plan and work together more effectively.

The Wales Cardiac Network will facilitate this work to bring together those involved in the pathway for a particular condition to develop and implement a quality based pathways. Patients should receive the same quality of care whatever their condition and wherever they live in Wales.

The pathways will identify the quality requirements, an appropriate sequence of interventions, timeframes, milestones and expected outcomes, acknowledging elements of the pathway may be delivered differently locally. Initial pathway review and development will focus on those pathways which will provide the greatest population benefit such as the Acute Coronary Syndrome and Heart Failure Pathways. Once developed, these pathways will inform the planned peer review process.

Community cardiology which whilst varying across health board areas, all models seek to support priorities aiming to improve access to primary and community care. This will look at different ways of treating people, where appropriate, as locally as possible, reduce waiting lists, avoidable pressure on unscheduled care and admissions or re-admissions to hospital particularly for the frail, elderly and those with long term conditions.

Cardiac rehabilitation is an integral part of the pathway and should be offered early, underpinned by individual assessment of patients needs. Timely cardiac rehabilitation is associated with greater patient benefit, currently people in Wales are waiting too long before starting rehabilitation. There is a need to focus on ensuring all people with heart disease can, and do, access good quality rehabilitation with equitable provision to priority patient groups across multiple pathways in Wales.

There are now more people living with cardiac conditions and post-hospital and longer term care needs to match the pace of progress made in hospital based treatment. This plan
seeks to increase the emphasis on longer term support for people living with cardiac conditions, ensuring their psychological and social support needs, as well as their physical needs, are assessed, are met and reviewed regularly.

People living with life limiting cardiac conditions should be supported in having early discussions about escalation and their end of life care. 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.

Welsh Ambulance Service NHS Trust figures show around 8,000 victims of out of hospital sudden cardiac arrests occur annually in Wales\textsuperscript{6}. Survival rates are low and compare unfavourably to a number of other countries. There is the potential for many more lives to be saved if cardiopulmonary resuscitation (CPR) and early defibrillation were undertaken more often, and if the whole pathway of care from successful resuscitation to subsequent rehabilitation were improved. Patient management following return of spontaneous circulation (ROSC) requires greater uniformity of practice. Whilst accepting individual circumstances often dictate some variation, greater uniformity potentially could improve survival rates and allow clinical services to be better aligned.

People who have very high cholesterol levels, or who have a personal or family history of premature vascular disease, should have access to familial hypercholesterolaemia (FH) services where close members of the patient’s family may also undergo testing.

People with a family member who died suddenly of a suspected cardiac cause and those with family members with inherited heart conditions should have access to appropriate genetic advice and testing.

Over a quarter of women who died during pregnancy or up to six weeks after pregnancy died from a cardiovascular cause. This represents the leading cause of maternal death in the UK Pre-pregnancy counselling should be available both within the paediatric cardiology transition service and to women of childbearing age with known cardiac disease. Lack of co-location of obstetric and cardiac services jeopardises interdisciplinary working and communication. Measures such as joint obstetric cardiac clinics, multidisciplinary care plans, copying letters to the woman and all clinicians involved in her care, as well as staff from all specialties writing in the woman’s hand held notes may mitigate against the inherent risk of inadequate communication between specialists.

### Key actions

1. Develop evidence based pathways for specific heart conditions which set out the quality standards or requirements, interventions, timeframes, milestones and outcomes.

2. Health boards, trusts, WHSSC and Wales Cardiac Network must plan and deliver services, in line with appropriate clinical pathways, to meet the ongoing needs of people with heart disease as locally as possible to their home, including:

\textsuperscript{6} Welsh Ambulance Service NHS Trust management data
• Ensure there are agreed evidence based referral and treatment pathways
• Ensure prompt (less than 8 week) and equitable access to appropriate interventions, including new diagnostic procedures, technologies, treatment and techniques, in line with the latest evidence
• Communicate effectively and appropriately with other specialised services as required
• Provide safe, effective and evidence based services as locally as possible
• Agree treatment plans with patients and their carers taking account of co-morbidities and polypharmacy
• Ensure co-ordinated care throughout the entire pathway, so people feel supported and informed
• Provide evidence based follow-up in the community where possible including access to cardiac rehabilitation (including psychological management and exercise) and guidance on healthy lifestyle and self-care to minimise further ill health
• Ensure effective drug and device management in line with quality requirements, including regular reviews
• Ensure effective discharge arrangements including referral to cardiac rehabilitation or other community exercise programmes
• Provide an individualised palliative care plan, where appropriate, in line with the Delivering End of Life Care Plan
• Provide good patient experience, prioritising appropriate information to patients
• Systematically measure and act upon patient experience and satisfaction

3. Co-ordinate effective discharge and timely repatriation of patients to local hospitals as soon as clinically appropriate, following treatment in line with discharge plans and the All Wales Repatriation Policy

4. Ensure cardiac rehabilitation teams are British Association for Cardiovascular Prevention and Rehabilitation certified and provide consistency of care across Wales

5. Ensure equitable access and parity for people with protected characteristics such as people with a learning disability on antipsychotic medication etc.

6. Ensure pathways are in place for people with rhythm disorders which include appropriate advice and access to genetic testing, where appropriate

7. Ensure pathways are in place to identify and treat individuals with Familial Hypercholesterolaemia and reduce the risk of this group developing early onset heart disease

8. Develop and implement an out of hospital cardiac arrest plan for Wales, ensuring there are clear pathways for patient management following return of spontaneous circulation (ROSC)

9. Ensure availability of pre-pregnancy counselling to women of childbearing age with known cardiac disease

10. Ensure a clear pathway is in place for pregnant women with a known or suspected heart condition including rapid diagnosis, multi disciplinary working, improved communication, inputting in the woman’s hand held notes and birth planning
Outcome indicators and assurance measures

- Circulatory disease mortality rates under age 75 per 100,000 population
- Percentage of patients waiting more than 26 weeks to be outpatient triaged and diagnosed
- Percentage of patients waiting for diagnostic tests longer than 8 weeks for each referral pathway
- Percentage of patients waiting more than 10 weeks for stage 4 (treatment or surgical intervention)
- Percentage of patients waiting less than 26 for the complete referral to treatment pathway
- Percentage of patients requiring Primary Percutaneous Coronary Intervention admitted to a coronary intervention centre
- Survival following out of hospital cardiac arrest
4. Children and Young People

Children and young people with heart conditions achieve the best survival, lifespan and quality of life, through the provision of excellent diagnosis, investigation, intervention, management and information. Heart defects are diagnosed in at least 1 in 180 births - that’s an average of 16 each month in Wales - with more diagnoses later in life\(^7\). The incidence of these disorders in Wales is about 1% with over 80% of children born with congenital heart disease will survive to adolescence and young adulthood\(^8\).

Congenital heart disease (CHD) is one of the major categories of illness that, if treated, can restore health and improve quality of life. It constitutes the bulk of the paediatric cardiac workload. Between 2001 and 2011 there has been an increase of 22% in the national birth rate in England and Wales with a corresponding rise in the number of paediatric cardiac surgical procedures taking place of 27%\(^9\).

National guidelines set out the Welsh Government’s expectations of effective care. These include the National Institute for Health and Care Excellence (NICE) guidelines, care pathways and professional standards such as the NHS England Congenital Heart Disease Standards for children, young people and adults. Young people with heart conditions should have equitable access to high quality seamless care across the pathway which meets the relevant guidance or standards.

The Healthy Child Wales programme was 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 7\(^{th}\) birthday. Interventions are targeted at supporting women to have healthy pregnancies, identify and address risks which predispose to low birth weight and lifetime cardiovascular risk.

Services must be flexible to ensure that all young people are treated by the most appropriate professional and in the most appropriate setting. This will depend on the young person’s mental, emotional and physical development.

Children and young people with healthcare needs, including those with heart disease, or at risk of sudden cardiac death, have the same rights of admission to schools as other children. Schools are legally obliged to ensure that 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 that children with medical conditions receive a full education and reach their academic potential.

The \textit{Children and Young People’s Continuing Care Guidance} is designed for use by all those planning and providing services for children 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 children and young people who require it because their needs cannot be met by existing universal or specialist services alone.

\(^7\) British Heart Foundation/Oxford University analysis of BINOCAR congenital anomaly registers 2006-10
\(^8\) All Wales Paediatric and Congenital Cardiac Standards for Children and Young People’s Specialised Healthcare Services
\(^9\) NHS England – Paediatric congenital heart disease specification
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 to follow-up, which can have serious consequences. When children and young people who use paediatric services are moving to access adult services these should be organised so that all those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services. Care needs to be seamless into adult services across the various stages of transition between locations and services taking into account any co-morbidities.

**Key actions**

1. Fetal, neonatal, paediatric and adult services for Welsh residents need to work together with specialist centres to deliver care, including to:
   - Ensure there are agreed referral and treatment pathways
   - Communicate effectively with other specialised services as required to ensure high quality care for children with co-morbidities
   - Coordinate services with education and social care for children in all circumstances supporting children to reach their academic potential and lead healthy active lives
   - Provide age-appropriate, safe and effective services as locally as possible
   - Agree treatment plans with patients and their families
   - Ensure that parents and children have co-ordinated care throughout the entire pathway, and feel supported and informed during their cardiac journey
   - Provide appropriate counselling and psychological support to patients and their families
   - Provide an individualised palliative care and bereavement service, where appropriate
   - Provide good patient experience, including information to patients and their families and consideration of access and support to families when they have to be away from home;
   - Systematically measure and act upon patient outcome, experience and satisfaction and contribute to patient surveys, ensuring children are appropriately represented.

2. Ensure patients with complex needs have appropriate, timely assessment of their continuing care needs

3. Develop and implement integrated and co-ordinated plans for the transfer of care from paediatric to adult services

**Outcome indicators and assurance measures**

- Risk adjusted: outcome at 30 days after procedure
- Antenatal diagnosis of congenital heart disease
- Referral to treatment time for children with cardiac conditions
5. Enablers for Delivery

Health boards and trusts should embrace a culture of innovation and new ways of working so that where appropriate, patients can be treated closer to home. This plan supports the development of transformative care, for example the development of community cardiology clinics where early diagnosis and treatment can be offered to patients. Patients will receive earlier detection of a range of common and important cardiovascular conditions in the community. Where patients are referred to hospital, the timely detection will support reduced waiting times.

Cost pressures and ageing populations provide key drivers for the need to focus on the management of population health by working together to respond to patients needs in the most clinically and resource appropriate manner.

There are a number of key actions described in this plan to help people who may be at risk or affected by a heart condition to get the best advice and timely treatment in the most appropriate setting and to be seen and treated by the most appropriate health professional. This plan by targeting resources at prevention and providing information for people to make informed lifestyle choices aims to reduce the burden of heart disease on patients, families and the health service. It also reinforces the importance of person-centred care in line with prudent healthcare principles.

The health and care standards, published by Welsh Government in 2015, are designed so that 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.

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 heart patients.

The primary purpose of the Wales Cardiac Network is to bring together and work in partnership with providers, professionals and third sector across Wales, supporting their strategic planning and decision making within the context of the key challenges facing NHS Wales around finance, workforce and recruitment and meeting rising demand for healthcare and public expectations. The Wales Cardiac Network works collaboratively with third sector partners to support a culture of involving and empowering patients.

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 Experience 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.

Through the Patient Report 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 heart conditions in Wales. PREMS
and 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 appropriate language and format. Clear information is central to the overall quality of each patient’s experience. 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 isn’t just about leaflets and printed information; it can be 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 of 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.

Workforce strategy and planning at local level is vital to support a safe and quality service for patients. All health boards and trusts should review their workforce planning to ensure that strategies are in place so that services meet the growing demand in healthcare, covering the full age range from childhood to older age groups, and addressing the demands of comorbidity. Robust plans must ensure services have sufficient staff with the appropriate skills and competencies for the role with adequate succession planning and resilience. Staff should be supported to undertake continuing professional development of relevance to their work and patient group. Health boards and trusts should have appropriate infrastructures and services to attract and retain high caliber staff. Workforce plans must ensure staff are seeing sufficient patients and undertaking sufficient procedures to maintain their competence and to offer people who are affected by heart disease a safe and sustainable service.

Comprehensive cardiac imaging and diagnostic tests fulfils the principles of prudent healthcare and should be provided as early and as locally as possible. Providing appropriate imaging and diagnostics makes sure people receive the minimum investigation necessary to obtain an accurate diagnosis. By doing so, some patients will avoid unnecessary treatments. Increasingly, national and international guidelines recommend the use of newer imaging. Health boards and trusts will be required to review their imaging strategy in order to keep pace with new developments. Cardiac Magnetic Resonance Imaging (MRI) and Computed Tomography (CT) are now part of the core curriculum for the training of cardiac specialist trainees and this needs to be factored into the medical workforce plans.

There is a seismic shift in the way information can improve the experience, quality and outcomes of services for people with heart conditions. Quality information will empower health boards and trusts enabling a culture of shared decision making. Information will
facilitate and drive integration across services as well as informing health and well-being strategies which meet the needs of local communities.

Delivering a national cardiac informatics service through the Wales Cardiac Network provides a number of significant advantages including enabling health boards and trusts to make the best use of specialist skills, resources and experience.

The all Wales accelerating cardiac informatics (AWACI) project will support clinical pathways and processes enabling proactive, coordinated care and visibility of clinically meaningful data. It will support improved communications and collaboration between health professionals. The AWACI project will support an accelerated schedule of development and implementation within the Welsh clinical portal programme with cardiac as a trailblazer speciality enabling patients to receive their diagnosis and care, from the right clinician, in a shorter time within a safer auditable pathway.

Participation in national clinical audits has a number of benefits including allowing healthcare professionals to review the management of patients and utilise the findings to improve the quality of care as well as providing evidence of the effectiveness of services. Full (100%) participation in national clinical audits is required to effectively monitor progress in the delivery of heart care, to provide comparative outcome data and allow effective benchmarking. It is essential this data is used for direct pathway improvement, to look at clinical performance, improve quality and for research. Health boards should have the capability to analyse local data to see and assess the services they provide to their population. Linking clinical audits with peer review will benefit health boards and trusts to evaluate the quality of the services they provide.

Peer review of the quality of healthcare to support and inform the planning and delivery of services has strong clinical support. Welsh Government has established a Peer Review Steering Group to consider proposals and facilitate peer reviews into a variety of services provided by the NHS in Wales. Peer reviews should now be embedded as part of the quality improvement drive with resources being made available from the outset. Peer reviews have proven to be an effective and inexpensive way of evaluating services, making targeted improvements and sharing best practice. All clinical networks, implementation groups and other service representatives are expected to undertake a peer review of their services. They should carefully consider how best to pursue a peer review, and approach the Peer Review Steering Group for authorisation and support to ensure the reviews are undertaken in a consistent and reliable standard.

The Heart Disease Implementation Group will develop a performance framework which sets out the key performance and outcome indicators.

<table>
<thead>
<tr>
<th>Key actions</th>
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<td>1. Health boards and trusts must have effective governance arrangements 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</td>
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<tr>
<td>2. Health boards, trusts and WHSSC working with the Wales Cardiac Network must develop demand and capacity plans based on local needs assessments which take account of workforce, evidence, informatics, innovation advances and research</td>
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3. Ensure people with heart conditions have access to high quality accessible information at all stages of their journey, enabling them to make informed decisions.

4. Implement a peer review programme for cardiac services provided for people of Wales.

5. Ensure full (100%) participation in mandatory national clinical audits, delivering significant improvements on current low participation rates - to support pathway improvement and support medical revalidation of clinicians – and ensure that findings are acted on.

6. 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, compliments and clinical incidents.

7. Continue to pursue an integrated and consistent approach to accelerate cardiac informatics viability across the total pathways of clinically meaningful information.

8. Develop a performance framework which sets out the key performance and outcome indicators.

**Outcome indicators and assurance measures**

Percentage compliance with national audit at all patient ages.
6. Targeting Research

Research is critical to effective care for people with a heart condition and the NHS must respond to the latest research evidence in the planning and delivery of its services. Heart research in Wales is also vital in attracting investment and first class NHS staff. Wales already has an excellent reputation in this area.

Cardiac research results in ongoing improvements in patient outcomes. The NHS must promote research and ensure appropriate access to clinical trials. Patients benefit through the ongoing implementation of evidence based best practice. In the longer term, patients also benefit from better understanding of the causes of heart conditions. Promoting a research culture in hospitals attracts highly-skilled personnel to Wales, providing opportunities to develop skills and gain experience of delivering innovative treatments.

Investment in research taking place across both the university sector and the NHS is important to help ensure that discoveries made in the lab are turned into new treatments and better care for people living with heart and circulatory disease.

Within the university sector, Welsh researchers are producing high quality research. In the most recent UK-wide assessment of research quality, over three quarters of the research in Welsh universities was seen as world-leading or internationally excellent. However, it has been identified in a number of reports that Wales attracts a lower percentage of competitive research funding than it should, given its population size. According to a recent report by the Leadership Foundation for Higher Education, this may be down to the fact that Wales has a shortfall of around 600 academics, largely across Science, Technology, Engineering, Mathematics and Medicine (STEMM) disciplines.

Welsh Government has recognised the need to increase research capacity in Wales and outlines a number of initiatives in its Science for Wales strategy to enable this, including the Seer Cymru programme, which aims to bring 'research stars' to Wales.

Within the NHS, research is supported by Health & Care Research Wales, with each of Wales’ seven health boards and three trusts supported by a research and development team. The need to build research capacity has also been identified as a priority for health and social care research, with health and care research Wales highlighting capacity building as a strategic aim in its 2015-2020 Strategic Plan.

It also needs to be recognised that the third sector are key partners in the development of research, both as a funder of research and supporting patient involvement in clinical trials and social research.

There needs to be support across the whole research pipeline with strong interactions between academia and the NHS to ensure an enhanced translation of research discoveries into better patient care. Children and young people are underrepresented in research programmes and drug development programmes, and this balance should be redressed.

Data collected within the health system holds enormous value for research. It helps us to answer questions about disease prevalence, patient outcomes and the effectiveness of new treatments, ultimately informing the development and delivery of better patient care. Health Boards should consider how they can utilise the Secure Anonymised Information Linkage Databank (SAIL) in their research and consider outcomes from SAIL research when planning services and care. SAIL is a world class, anonymous data linkage system.
that securely brings together the widest possible array of routinely collected data for research, development and evaluation. Health and social care organisations should continue to work closely with SAIL to ensure we can maximise the use of routinely collected health data for the benefit of patients, while ensuring that appropriate patient safeguards are in place.

Over the next four years, we will sharpen our focus on the quality and impact of our research. We need to ensure that we enable all researchers to pursue and produce their best work possible, publishing in the highest quality places, working with the best partners both inside and outside the health sector and addressing the major challenges our communities face. Clear expectations about research performance will be set and, at the same time, the mechanisms will be created to support and develop a culture of research excellence.

**Key actions**

1. Work with the Health and Care Research Wales specialty lead, researchers and the Health and Care Research Wales support and delivery service to increase the number of heart condition research studies undertaken in Wales

2. Encourage more people with heart conditions across Wales to participate in research activity

3. Create more opportunities for people with and affected by a heart condition across Wales 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 so that patients get quicker access to innovative new diagnostic tools, treatments and medical technologies


6. Require research ethical approval to justify excluding children and young people from research projects.

7. Ensure a R&D lead is identified and provides visible R&D leadership for the delivery plan

8. Expand and develop new partnerships, both locally and globally, that enable our research to make a difference, improving the lives of people living in Wales and others around the world

9. To ensure arrangements are in place to support clinicians to engage in research, including application of protected time for research and clinical trials

10. To ensure arrangements are in place to develop the skills and experience of clinicians to enable them to engage in research and clinical trials

**Outcome indicators and assurance measures**

- Percentage of people with cardiac conditions by age group entered into clinical trials
7. Implementing the heart conditions delivery plan

This delivery plan has set out the vision and ambitions for people, of all ages, at risk or affected by heart conditions in Wales. Doing this will involve joint working between all those responsible for the care of people with heart conditions in Wales.

It sets out the health outcomes expected for the people of Wales and the Heart Conditions Implementation Group and the Welsh Government will hold the NHS to account to ensure that the actions in this plan and the health outcomes we desire are achieved.

The lines of accountability will be through the Chairs of the health boards and trusts to the Cabinet Secretary for Health, Well-Being and Sport and, with the Chief Executives of the health boards and trusts reporting to the Chief Executive of the NHS Wales, who is also the Director General of the Welsh Government’s Health and Social Services Group.

We have a national implementation group steering the plan and developing once for Wales’s solutions to support WHSSC, health boards and trusts. We have network clinical leads working with the health boards, supported by an all Wales network.

The role of the Heart Conditions Implementation Group is to oversee the national plan, support health boards to deliver and critically assess their local plans. The implementation group brings together the key stakeholders, including all the health boards, trusts, the third sector, secondary care, government and managers to work collaboratively.

The Heart Conditions Implementation Group will review progress against this delivery plan at least once a year. The national clinical lead roles will support delivery of the plan and will work closely with the implementation group with a focus on working across traditional boundaries to deliver improvements in the care for people with heart conditions.

Health boards and trusts are responsible for planning; securing and delivering local services ensuring that those people who require care can access the right care at the right time and place. Each health board and trust will have a local planning and delivery group. The local groups will need to plan services effectively for their population and build and lead coalitions with Welsh Ambulance Trusts, other health boards and trusts in Wales and England, GPs, local government and the third sector voluntary bodies. Health boards and trusts will need to integrate their plans for heart conditions into the overall health board integrated medium term plan and ensure that all aspects of the delivery plan, informed by their local needs assessment, are included in their planning process.

The Heart Conditions Implementation Group will support health boards and trusts including 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:

- Work in a co-ordinated way, at an all Wales level, to support health boards and WHSSC to deliver the actions within this plan and achieve the desired outcomes
- Agree a focus for delivery each year and provide clear guidance to health boards to support the production of their three years integrated medium term plans, ensuring heart conditions and its priorities are fully embedded within their plans
- Develop a performance framework which sets out the key performance and outcome indicators
• 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 statement to Welsh Government that highlights progress made throughout the year informed by local progress reports

Health boards and trusts are required to monitor their performance against the heart conditions delivery plan against a set of nationally specified performance measures and report them to implementation group and the Welsh Government annually.

Welsh Government will continue to maintain oversight of delivery and assurance framework and issue a national statement of achievement annually. It will also enable and support liaison between the Implementation Group and Welsh Ministers.
Annex 1 – Supporting Strategic and Legislative Documents

New Programme for Government and the NHS Plan
Welsh Government’s Programme for Government and NHS Plan set out an ambitious programme for health and wellbeing in Wales focussing on improving our healthcare services; our healthcare staff; being healthy and active; our mental health and wellbeing; 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 outlined actions for quality assurance and improvement. A commitment to a quality-driven NHS that provides services which are safe, effective, accessible, and sustainable. This plan is currently being refreshed.

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 that 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, trusts 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 that health boards, trusts 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 to achieve optimal outcomes for those at risk of developing or have heart conditions.

**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 Welsh Government’s equality agenda objectives through a commitment to identify and meet the needs of all groups in relation to heart disease, 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). The latest CMO Annual report focusses on rebalancing healthcare – working in partnership to reduce social inequity and exploring the effects of the social gradient on the people of Wales, and what can be done to address it.

**Welsh Language**
The objectives of ‘More than just words’ 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 that such services are available to those who wish to communicate in Welsh.

**Informed health and care – A digital health and social care strategy for Wales**
It outlines the 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 cardiac care for the benefit of patients.

**Building a Brighter Future**
It sets out a coordinated programme to ensure that 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.

**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).

Other legislation and policies
Account will need to be taken of relevant new legislation and policy during the lifetime of this plan, particularly in relation to public health.
Annex 2 – Updated Links to Reference Documents

Delivering End of Life Care Plan (refreshed plan to be published January 2017)

Delivery plan for the critically ill (refreshed plan to be published January 2017)
http://gov.wales/topics/health/nhswns/plans/delivery-plan/?lang=en

Diabetes Delivery Plan
http://gov.wales/topics/health/nhswns/plans/diabetes/?lang=en

Stroke Delivery Plan (refreshed plan to be published January 2017)
http://wales.gov.uk/topics/health/publications/health/reports/plan/?lang=en

Rare Disease Implementation Plan (to be refreshed during 2017)
http://gov.wales/topics/health/nhswns/plans/rare/?lang=en

Organ Donation Action Plan
http://gov.wales/topics/health/nhswns/organ/transplantation/?lang=en

Congenital Heart Disease Services Standards
https://www.england.nhs.uk/commissioning/spec-services/npc-crg/chd/

Bristol Review
http://www.thebristolreview.co.uk/Bristol-Review--FINAL-REPORT.pdf

National Confidential Enquiry into Patient Outcome and Death: Time to Intervene (2012)
http://www.ncepod.org.uk/2012cap.html

Programme for Government
http://gov.wales/about/programme-for-government/?lang=en

Embedding of the prudent healthcare principles
http://gov.wales/topics/health/nhswns/prudent-healthcare/?lang=en

Securing Health & Wellbeing for Future Generations- February 2016

Health and care standards (April 2015)

Achieving excellence - The quality delivery plan for the NHS in Wales
http://gov.wales/topics/health/nhswns/plans/excellence/?lang=en

NHS Wales Planning Framework
http://gov.wales/topics/health/nhswns/organisations/planning/

Primary Care Services Plan
http://gov.wales/topics/health/nhswns/plans/care/?lang=en

Well-being of Future Generations (Wales) Act 2015

Social Services and Well-being (Wales) Act 2014
Informed health and care – A digital health and social care strategy for Wales
http://gov.wales/topics/health/nhswales/about/e-health/?lang=en

Health and Care Research Wales Strategic Plan 2015

Public Health Outcomes Framework

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

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

Peer review (still to be published)

Framework for Assuring Service User Improvement and Core Questions

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

Delivering Local Integrated Care

Improving general hospital care of patients who have a learning disability

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

Children and young people’s continuing care guidance

Self care and care plans
http://gov.wales/topics/health/nhswales/healthservice/chronic-conditions/?lang=en

Patient Consent

All-Wales Policy on Do Not Attempt Cardiopulmonary Resuscitation
http://www.wales.nhs.uk/news/35793
Lasting Power of Attorney

NHS Wales Workforce Review

Health and Care Research Wales Performance Management Framework

Industry Engagement in Wales
http://www.healthandcareresearch.gov.wales/industry-engagement/

Delivery Framework for the Performance Management of NHS R&D