



Llywodraeth Cymru
Welsh Government

2017 – 2020 Stroke Delivery Plan

A Refreshed Delivery Plan for NHS Wales and its Partners

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Foreword

As Chair of the Stroke Implementation Group and the National Clinical Lead for Stroke, we would like to acknowledge the considerable work undertaken by all those involved in the delivery of the stroke plan to date.

Over the last 12 months, we have made excellent progress in stroke care across Wales. More people are surviving strokes, staff skills and expertise have been enhanced and performance against the Sentinel Stroke National Audit Programme (SSNAP) is improving.

We are in a strong position to move ahead with pace. We have a settled national implementation group steering the plan, an external stakeholder network and are developing clear strategies and treatment pathways for Wales. We have worked with health boards on their stroke delivery plans and have recruited a stroke coordinator whose primary role will be to drive forward the actions within this delivery plan.

There is still much more to be achieved for stroke care in Wales, this includes focusing on participation in research and planning stroke services so that they are more robust and in a position to withstand the challenges of recruitment of specialist staff and to make the best use of finite financial resources using a prudent healthcare approach.

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

Going forward our focus will be upon implementing a stroke pathway to deliver a step change in stroke service planning, facilitated by improving the alignment of health board Integrated Medium Term Plans and local stroke delivery plans. This will empower collaborative stroke delivery planning encompassing the delivery groups and integrated service models with primary and secondary care; as well as creating greater accountability and transparency of progress against local stroke plans. This will be delivered by building on the relationships, systems and procedures already in place. Our collaborative approach among a relatively small number of stakeholders is a great opportunity for Wales to forge ahead in stroke care and support. In particular, our third sector partners make an invaluable contribution to discussions and service provision.

This refreshed delivery plan builds on its predecessor and gives the service the vital continuity of approach it needs. The plan has been refreshed to reflect the latest strategic drivers, including prudent healthcare, the primary care plan and new groundbreaking Welsh legislation.

The challenges ahead are many and significant but we can look to the future with a sense of shared direction and confidence. NHS Wales cannot do this on it's own and

we will continue to develop the co-production of services, working closely with the third sector, stroke survivors and carers. Together, we will maintain the momentum to deliver sustainable improvements to deliver the best possible outcomes for stroke patients throughout Wales.

Fiona Jenkins
Chair Stroke Implementation Board
Executive Director
Therapies & Health Science,
Cardiff & Vale University Health Board

Phil Jones
National Stroke Clinical Lead
Hywel Dda University
Health Board

Introduction and Context

Each year around 7,400 people will have a stroke in Wales and the Stroke Association estimates that there are almost 66,000¹ stroke survivors living in Wales. A stroke can have a very serious and lasting impact on the lives of individuals and their families.

It is estimated that up to 70%² of all strokes could be avoided if the risk factors were treated and people adopted healthier lifestyles. People need to make every possible effort to avoid stroke as, despite improvements in stroke services, there will always be some strokes which are too severe to treat, resulting in lives being shortened or a long term severe disability.

This Stroke Delivery Plan provides a framework for action by health boards and NHS trusts, working with their partners. It sets out the expectations of all stakeholders to tackle stroke in people of all ages, wherever they live in Wales and whatever their circumstances. Stroke is one of the top causes of death and a leading cause of adult disability. The outcomes from this plan will be shared across all health boards in Wales to ensure the lessons learned are publicised and adopted. In this manner investment is being made in our highly valued multidisciplinary staff and ensuring services are working in accordance with the principles of prudent health care.

This delivery plan encompasses a range of actions, to meet the needs of people at risk of ,or affected by, stroke, this includes capturing specific data relating to patient reported outcome and experience measures; (PREMs and PROMs) and the introduction of a peer review process, all designed to improve the patients' experience of care within NHS Wales. The expected outcomes include an improvement in the safety, quality and effectiveness of services; a better experience for patients' and the consistent sharing of good practice.

The workforce is also a critical element of both the NHS and the third sector, and is a key determinant to the success of any organisation. An engaged, sustainable and skilled workforce is essential to delivering high standards of care and transforming

¹ Quality and Outcomes Framework - Wales

² Royal College of Physicians (RCP)

the way services are delivered to meet the many challenges faced by NHS Wales today. The Royal College of Physicians (RCP) guidelines, updated in 2016, set out the basic principles of stroke care in Wales.

There are a number of common prevention themes running across many of the Welsh Government major health conditions delivery plans; for example neurological conditions or heart disease. For some people most severely affected by a stroke it may also be appropriate to refer to the Delivering End of Life Care Plan or the Delivery Plan for the Critically Ill.

Since the publication of the first delivery plan, there have been a number of strategic and legislative changes that have impacted upon policy and are reflected in this refreshed plan. A summary of these changes is included at Annex 1. The relevant links are included at Annex 2.

The Stroke Vision

The common vision is for all people of all ages to have the lowest possible risk of having a stroke, and, when it does occur, to have an excellent chance of surviving, and returning to independence as quickly as possible. NHS organisations, social services and the third sector must work together to continually strive to improve stroke services for all patients across all services in Wales.

The Stroke Implementation Group (SIG)

The SIG was established in 2013 to provide national leadership and support for the delivery of effective person centred stroke care in Wales. The SIG acts as a forum to drive forward change and oversee health boards' efforts to deliver the Welsh Government's vision for improving stroke services in Wales.

The SIG's role is to oversee the national plan and support health boards to deliver their local stroke plans. It brings together the key stakeholders, including all the health boards, informatics and the third sector, primary care and secondary care and

the Welsh Government to work collaboratively. The group develops solutions to common problems; as well as assessing health boards' progress and managing the Welsh Government's £1m recurrent funding for the stroke delivery plan.

Stroke Outcome in Wales

The Welsh Government is responsible for strategic leadership through setting the health outcomes it expects for the people in Wales. It holds NHS Wales to account on how well it delivers the outcomes for stroke patients. The lines of accountability are through the Chairs of the health boards and NHS trusts to the Cabinet Secretary for Health, Wellbeing and Sport. The Chief Executives of the health boards and NHS trusts report to the Chief Executive of the NHS Wales, who is also the Director General of the Welsh Government, Health and Social Services Group. Progress against this plan will be overseen through monitoring and assessment of the specified levels of performance against the agreed SIG priorities.

The last five years has seen progress against the following outcomes:

More people surviving stroke - Stroke survival continues to improve across Wales. Over the last 10 years (2006-07 to 2015–16), survival rates following a stroke for people aged 74 and under has improved by 5.7%, and by 7.3% for people aged 75 and over. The number of people dying from strokes is reducing, deaths from strokes in Wales have fallen by 623 (22%) since 2010.

Improving staff skills and expertise - Funding from the SIG has resulted in staff from all over Wales who are involved in stroke care undertaking training to improve care in the community, accident and emergency departments, therapy services and rehabilitation. This training has included:

- Self management training being delivered in health boards. Such approaches enable health and social care practitioners to support individuals to feel confident to self-manage and become less reliant on their services, enhancing the efficiency and impact of their care and rehabilitation.

- Stroke training for therapists being offered to all health boards to improve outcomes for people following a stroke.
- Advanced Stroke Life Support (ASLS) training being offered to all 1,500 Welsh Ambulance Service paramedics. This course equips participants with additional skills to identify the more subtle presentations of stroke and transient ischaemic attack (mini stroke).
- Provision of training at Prince Charles Hospital to allow nurse-led delivery of administration of thrombolytic medication for suitable patients within A&E. This is now included as part of the 10 week Emergency Care Department training delivered by the health board, which will further improve outcomes for patients and reduce their length of stay in hospital following a stroke.
- Training staff to improve identification of patients with atrial fibrillation who may benefit from anticoagulation has been funded and preliminary results suggest that there would be great benefits across Wales if the findings and actions could be replicated across all university health boards.

Improving performance - *Clinical* audit and outcome review provides a means of demonstrating ongoing service improvements. Each health board in Wales participates in all the national clinical audits and clinical outcome reviews, as set out in the Welsh Government's national annual audit programme, and they are expected to act upon the outcomes. This includes participation in the Sentinel Stroke National Audit Programme (SSNAP) now thrice-yearly clinical audit, the organisational and the post acute audit. These audits are published by the Royal College of Physicians (RCP) and highlight the stroke performance of all health boards in England, Wales and Northern Ireland.

Access for All - Within the refresh of the plan, access for all will be a priority. Both the Mental Capacity Act 2005 and the NHS Wales Standard: Equality, Diversity and Human Rights provide clear direction to embedding the principles of equality and human rights into services. In terms of providing services to Welsh speakers, *More than just words....* the Welsh Government's strategic framework for Welsh language services in health and social services emphasises the importance of providing services in Welsh to meet the care needs of Welsh speakers and to treat them with

dignity and respect. There will also be a need to comply with the statutory Welsh Language Standards for the NHS when they are introduced.

Children and Young People

Childhood stroke is a neglected area, with both professionals and the general public lacking awareness of the problem and its potential consequences. Stroke affects several hundred children in the UK each year, many children who have a stroke have another medical condition (such as a cardiac disorder). Ethnic minority children are subject to a higher risk of conditions such as sickle cell disease and vasculitis, the impact of this means that years of healthy life can be lost which makes stroke in children and young people a significant condition even with small numbers.

The burden of childhood stroke on the health services is, numerically, smaller than stroke in the elderly. However, the long-lasting physical, emotional and social effects of stroke on an individual near the beginning of their life affects not only the individual themselves, but also their family and society as a whole.

Many professional agencies can be involved in helping the affected child fulfil their potential and in providing support and advice to the family. These agencies may change in the course of the child's life and it is important that they are all aware of the consequences of childhood stroke, and that their efforts are co-ordinated. The child's cognitive, social and emotional needs are in constant development and the functional impact of childhood stroke may, as a consequence, vary over time.

There is an acknowledged need for multicentre collaboration in such research to enable the design of studies with sufficient power to produce definitive results. The networks necessary for this are beginning to be established.

Guidelines³ have been produced for the treatment and management of childhood stroke and the Royal College of Paediatrics and Child Health is currently consulting

3. The Royal College of Physicians, Stroke in Childhood 2004

on draft clinical guidelines 'Stroke in Childhood'. Once published the SIG will consider them in a Welsh context and encourage health boards to align these to their current and future stroke support services.

The Patient's Voice: PREMs and PROMs

Understanding the experience of living with effects of stroke, and of being an NHS patient or service user, is fundamental for patient-centred, co-productive services. This understanding is also key to measuring the effectiveness of services.

In 2016 the SIG worked in partnership with the Neurological Conditions Implementation Group to develop *Patient Experience Outcome Measures* (PREMs) and the *Patient Related Outcome Measures* (PROMs) for stroke and neurological conditions in Wales. The SIG is currently considering when and how these measures will be implemented.

Working closely with patients, carers and families these measures aim to identify key areas of service and personal importance to individuals and to use this information to develop the appropriate measures to be used by NHS stroke and neurological conditions services across Wales. Gaining insight from a patient's perspective will enable the NHS to use real life information to gain a more insightful understanding to improve services.

The Stroke Pathway

Stroke is a complex condition and recovery and rehabilitation require support from health and social care professionals with specialist knowledge and skills. Many of these specialist skills are transferable across the population living with many other neurological conditions.

Recommendations in the revised stroke guidelines published by the Royal College of Physicians (RCP) in 2016 involve assessments and interventions being undertaken by clinicians with appropriate expertise in neurological disability, rather than in stroke specifically. The community neurological rehabilitation fund, jointly financed by the Stroke Implementation Group (SIG) and the Neurological Conditions Implementation Group (NCIG), is building capacity and expertise across the stroke and neurological rehabilitation workforce in Wales.

Workforce requirements will need to be continually monitored and aligned to support any future service reconfiguration.

Stroke is a condition that encompasses all aspects of health and social care when it occurs. From primary prevention through to acute management, ongoing rehabilitation, life after stroke and the need for social care support are all essential. Our vision for stroke services is set out against each part of the pathway:

Wales Stroke Care Pathway and Priorities

Living Well

Work closely with partner organisations to support and promote initiatives that help people to understand their lifestyles and help them to live healthy and long lives.

Stroke Prevention

Promote primary and secondary prevention through the intervention of treatment and advice to manage lifestyle and provide the appropriate pre-hospital interventions.

Early Recognition and Transition Ischaemic Attack (TIA)

Provide early access to evidence based interventions.

Fast Effective Care

For those with confirmed stroke, rapid access to evidence based interventions, treatments and care in the most appropriate hospital and ward.

Rehabilitation, Recovery and Life after Stroke

Recognising and addressing the life long affects of stroke on the patient and their family and carers and providing the right amount of therapy from the right therapists in the environment, acute hospital, community hospital or home.

End of Life Care

Recognising that stroke is a fatal event for some victims and ensuring that we provide the best palliative care for our patients and the best support to family and friends at this time.

Living Well

A focus on prevention across strategic Welsh Government programmes and policies is wholly consistent with the principles of prudent health care, as it involves taking action at points which maximise the potential for long term benefits, both in terms of health gain and in reducing the higher long term costs associated with preventable ill health. Preventative work is also a crucial component in a renewed partnership between government and the public, whereby the Welsh Government has a responsibility to provide and promote social conditions which are conducive with good health, with a corresponding responsibility on individuals to act in ways which promote and protect their own health and wellbeing. Ensuring accessible information such as electronic signposting is available to help increase awareness and supporting the public to recognise the sign of stroke is therefore vital.

Wearable devices, for example, could be considered to help identify strokes. These devices include gloves and jackets which contain microcontrollers which measure the movements of a patient and feed them to a smartphone, giving the data to patient and doctor alike. This can lead to more interaction between them, with the doctor able to be more involved in helping the patient in between in-person visits.

All NHS organisations have a role to play in improving the health and wellbeing of the population and developing their workforce to be able to do this. We know that many long-term diseases affecting the population are closely linked to known behavioral risk factors - tobacco, hypertension, alcohol, being overweight or being physically inactive. Health boards and local public health teams should exploit the information hospital systems hold to ensure stroke patients are identified quickly and easily, and are supported to develop and establish programmes of initiatives at a local, cross sector level.

It is evident that a large proportion of people in Wales could do more to reduce their risks of having a stroke. The 2015 Welsh Health Survey (WHS) reported that 59% of adults were classified as overweight or obese, of which 24% were obese; 32% of adults reported eating five or more portions of fruit and vegetables the previous day; 58% of adults reported being physically active (doing at least 150 minutes of

moderate intensity physical activity in blocks of 10 minutes or more in the previous week); and 30% reported being inactive (active for less than 30 minutes in the previous week).

The survey also reported that excessive alcohol intake is widespread; 40% of adults reported drinking above the guidelines on at least one day in the past week, including 24% who reported drinking more than twice the daily guidelines (sometimes termed binge drinking).

The Living Well advice, priorities and preventative measures outlined within this delivery plan are applicable across a range of conditions and are also included in the Welsh Government's heart and neurological delivery plans.

Some risk factors for stroke cannot be controlled, for instance age and family history, but risks related to harmful behaviours can. In particular, eating a healthy diet, being physically active, not smoking and only drinking alcohol within the recommended guidelines can reduce the risk of high blood pressure, a key risk factor for stroke.

Wales has been proactive in tackling tobacco use and the revised Tobacco Control Action Plan will contribute efforts in this area. Similarly, other programmes aimed at increasing physical activity and consumption of healthy diet and reducing alcohol consumption will contribute to stroke risk reduction and will continue to be developed alongside the advice in other plans such as heart and neurological.

The actions to tackle the risk factors specific to stroke include multiple organisations and interventions. The stroke delivery plan does not attempt to own these interventions but to complement and enhance them where possible, by supporting approaches such as Making Every Contact Count and signalling their relevance to the stroke risk reduction agenda. Public Health Wales, in collaboration with local health boards, will lead the charge for these interventions to reduce health-harming behaviours and link to the stroke delivery plan.

Health Boards, Public Health Wales and Third Sector organisations should:

- ***Provide high quality, reliable advice in line with NICE and RCP guidelines.***
- ***Support the ‘Making Every Contact Count’ approach with staff and key partners.***
- ***Recognise and respond to the requirement for continuous service review and improvement.***
- ***In line with the principles of prudent healthcare, ensure that smoking cessation support is offered as a first-line intervention for smokers.***
- ***Implement the Wales Obesity Pathway at all levels, for both adults and children.***
- ***Lead a comprehensive prevention programme to minimise population-level risk of disease, including stroke.***
- ***Use telehealth/telecare to help patients self care and aid rehabilitation.***

Stroke Prevention

Primary Prevention - People should be aware of and supported in the actions they need to take to minimise their risk of stroke through healthy lifestyle choices and medication where appropriate.

Most healthy lifestyle choices are not specific stroke risk factors but should be part of general health promotion. Many of the causes of poor health are deep rooted and difficult to tackle, and reduction in health inequality through the “Inverse-Care Law Programme” can make an important contribution.

Secondary Prevention - Following a stroke, a thorough assessment of the cause and risk factors for recurrent stroke should be undertaken, unless the care is palliative, and those identified effectively managed. This may include advanced brain and vascular imaging with neuro-radiology and neurosurgical advice after cerebral haemorrhage.

Early Recognition of Stroke and Transient Ischaemic Attack (TIA)

TIA is sometimes referred to as a mini stroke because symptoms can resolve within minutes or hours. Stroke and TIA can be caused by a blood clot becoming trapped within part of the brain, blocking the supply of blood to the affected part. The only difference between stroke and TIA is that in TIA, the blockage is temporary. In TIA, the clot may dissolve of its own accord, or move to a part of the brain where it no longer produces symptoms.

Quick recovery or resolution of symptoms can lead patients, carers or relatives to dismiss them as insignificant or put them down as a 'funny turn'. One in 12 people who experience a TIA will go on to have a stroke within a week, with the greatest risk of stroke being in the first few days. It is therefore imperative that people who experience the symptoms of a TIA urgently access further assessment and treatment.

95%⁴ of people who suffer their first symptoms of stroke and TIA will do so outside of hospital. Stroke is a medical emergency, so the role of the public in being the first link in the chain for stroke survival and recovery cannot be understated.

It is vital that patients who have a mini stroke or TIA have rapid access to specialist vascular services, so a swift decision can be made as to whether or not they should have surgery.

Receiving early supportive therapies within 72 hours following a stroke increases the potential for patient independence. In Wales all patients should be assessed within 72 hours and individual goals should be agreed by 5 days of admission.

⁴ *Royal College of Physicians (RCP) CP 2012*

Fast Effective Care

Both stroke and TIA are medical emergencies and 999 should be called for any person who is showing or experiencing FAST (Face, Arm, or Speech and Time) problems. If symptoms disappear or resolve quickly, they must not be ignored because of the potential for the patient to go on to have a full stroke. Patients who describe resolved FAST symptoms during home or practice consultations should be considered for referral to TIA clinics.

FAST is part of a pre hospital bundle of care that is administered by paramedics. The RCP guidance states that following a stroke all patients should be directly admitted to a stroke unit within 4 hours of arrival. There is a review of stroke services underway which is considering the most appropriate hyperacute stroke pathways in Wales. The impact of this work may provide a more rapid assessment of patients in the emergency department and direct transfer to a hyperacute stroke unit (HASU).

This review will require some re-defining of the current Wales stroke units, with timely repatriation to local stroke services and better configuration models of care.

NHS organisations and third sector should:

- ***Continue to work towards achieving fast effective care for stroke patients across all services in Wales. This includes taking into account all relevant evidence and guidance, including the National Institute for Health and Care Excellence (NICE) guidelines and quality standards.***
- ***Ensure equitable access and parity for people with protected characteristics, such as people with a learning disability on antipsychotic medication etc.***
- ***Deliver continued improved compliance against the SSNAP indicators.***
- ***Deliver high quality, pre-hospital interventions to all potential stroke patients.***

Atrial Fibrillation – A specific risk factor for stroke is atrial fibrillation (AF). This is an irregular heart rhythm that increases the chances of a clot forming in the heart to cause a stroke. This condition increases with age and is often unrecognised and, even when identified, not treated with blood thinning until the stroke has occurred.

NICE recommends the use of novel (or direct) oral anticoagulants to facilitate the process and safety of anticoagulation treatment for people with AF (NICE Clinical Guideline CG180).

Paroxysmal Atrial Fibrillation (PAF) - PAF occurs when the atria (upper chambers of the heart) lose their normal rhythm and beat chaotically. When this happens, blood isn't flowing through the heart and body efficiently. This inefficient flow can cause blood to pool inside the atria, increasing the risk of blood clots.

The current recommendation of 24 hours or longer monitoring may miss this important risk factor, particularly in strokes where the cause is uncertain, extended monitoring may be required for optimal ascertainment.

Carotid Stenosis - Prompt patient access to carotid imaging (a test for narrowed carotid arteries, which increases the risk of stroke) is an important aspect of the stroke pathway treatment. Where significant narrowing is found the patient should have access to carotid surgery within seven days of onset. This action reduces the further risk of stroke within five years by 16%.

Thrombolysis - Thrombolysis is an effective treatment for patients suffering from ischaemic stroke providing it is given soon after the onset of symptoms and within a maximum of 4.5 hours following a stroke. The earlier the thrombolytic treatment is delivered the better the outcome, particularly if delivered within 90 minutes of symptom onset.

Thrombectomy is a developing, evidence based treatment for acute stroke where thrombolysis is either contraindicated or ineffective. Thrombectomy involves expert neuroradiology intervention to remove a clot from the blood vessels in the brain using a wire passed through the arteries to get to the brain. Currently there are

insufficient trained neuroradiologists to perform this task across the UK. Wales like many other sites in the UK, has a service that does not yet provide 24/7 access. Work is in hand to improve the availability of this service which is heavily dependent upon the time needed to train the specialists.

NHS organisations and the third sector should:

- ***Review the National Vascular Registry annual reports and implement recommendations on safe and effective practice related to stroke. These recommendations should be adhered to by all Vascular Units in Wales.***
- ***Review and, when necessary, improve the time it takes to diagnose and treat carotid endarterectomy.***
- ***Ensure stroke services have access to evidence-based and prudent systems for long-term monitoring for detection of hidden PAF.***
- ***Ensure that personalised secondary prevention is discussed with stroke survivors at regular reviews, including six month reviews.***
- ***Continue to provide education and public awareness campaigns on stroke prevention and risk factors.***
- ***Measure the outcomes of these primary care interventions and assess the effectiveness of this strategy on stroke prevention via effect on stroke incidents.***

Rehabilitation, Recovery and Life after Stroke

Rehabilitation and Recovery - Since 2013, significant work has been undertaken to improve rehabilitation services and long term support for stroke survivors. This area of work has remained a priority for SIG and NCIG who are working collaboratively to develop local interventions and services based around the common impairments of both stroke and neurological disorders.

Stroke rehabilitation is a process of assessment, treatment and management by which the patient (and their family / carer) are supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living. It is not time limited as recovery from stroke can continue for months or years after a stroke.

The most recent RCP guidelines recognise that rehabilitation and recovery can take place in a variety of settings and that the nature of rehabilitation will shift from restorative to compensatory and adaptive approaches over time. However, the guidelines state that rehabilitation should not end solely because natural recovery appears to have reached a plateau. The guidelines include detailed recommendations on interventions for a wide range of specific impairments (e.g. spasticity), activity limitations (e.g. driving), and restricted social participation and quality of life (e.g. vocational training).

Health boards and the third sector should:

- ***Follow the RCP rehabilitation and recovery guidelines and measure progress through the SSNAP clinical audits and participation in the Patient Experience Outcome Measures (PROMs) and the Patient Related Outcome Measures (PREMs) programme.***
- ***Explore the benefits of an inpatient stroke unit capable of providing stroke rehabilitation for all people with stroke admitted to hospital;***
- ***Have a specialist supported discharge service to enable people with stroke to receive rehabilitation at home or in a care home;***
- ***Have specialist rehabilitation services capable of meeting the specific health, social and vocational needs of people with stroke of all ages; and***
- ***Develop services capable of delivering specialist rehabilitation in out patient and community settings in liaison with in patient settings.***

Life after Stroke - Building on progress made over the past three years there are several elements of services for people living with stroke that still need improvement. These include: improved access to six month and annual review services; better self management and peer support; lifelong access to specialist assessment and treatment in a timely way.

There are many conditions that may occur after stroke. Most are common and will improve with time and rehabilitation. However, stroke can, in around 20% of people, cause people to develop dementia, which is a progressive condition. This means the symptoms will gradually get worse over time. Multiple small strokes can also cause dementia to develop.

The way someone experiences dementia will vary and professionals in specialties that work with people at higher risk of dementia, such as stroke services, should be appropriately trained and have access to relevant tools and referral pathways. The Welsh Government's Dementia Strategic Action Plan 2017-22 issued for consultation on 9 January 2017. This plan sets out a range of actions to support people living with dementia⁵.

Up to 30% of people who have a stroke may develop depression. It is important for the individual's wellbeing and rehabilitation that this is identified and treated with appropriate psychological therapy and / or medication. Untreated it can worsen, causing common post stroke conditions such as pain, fatigue, sleep insomnia and lack of appetite.

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 in hospital and listening to their concerns may help in identifying where a person is in danger of deterioration in their condition. Accessing the learning disability liaison nurses, where they are employed can support staff to ensure reasonable adjustments are made.

⁵ The Welsh Government's Dementia Strategic Action Plan 2017-22

Funding made available by the Welsh Government and allocated by the SIG has specifically focused on post stroke support for stroke survivors and their families.

Six month and annual reviews - Across Wales health boards are increasingly providing six month stroke reviews, however, provision is not yet consistent across all health boards.

All stroke survivors should receive a six month post stroke review of their health and social needs. Six month and annual reviews should provide a mutually agreed way forward with the service user. The risk of a secondary stroke can be reduced through this post stroke review service, and regular reviews also reduce the need for hospitalisation, severe psychological problems, carer breakdown or increased social care.

The reviews provide the vehicle to meet the key principles of co-production and wellbeing contained in the Social Services and Wellbeing Act 2014. The aim is that the reviews should give people affected by stroke a stronger voice and control over the services they receive, in a co-productive approach with professionals.

Self management and peer support - Stroke survivors, their families and carers often feel unsupported in the months and years following a stroke, a time during which many experience changes in their needs and struggle to adjust to the often devastating impact of their stroke.

There is good research⁶ evidence that self management programmes for stroke survivors improve the quality of life for people who are living with the effects of a stroke. The research shows that people with stroke who have been involved in self management programmes report improvements in their ability to live the way they want and that they feel more empowered to take charge of their lives, rather than be dependent on other people for their happiness and satisfaction with life. All health

⁶ *Cochrane review annex 2*

boards should consider how to deliver self management programmes for stroke survivors and funding from Welsh Government has supported training for some health boards to pilot self management programmes.

In support of the development of person centred self management programmes the Welsh Government is working with health boards and others on plans to support the adoption of technology enabled care services at scale across Wales. Technology enabled care services can support new ways of working and aim to provide forms of remote patient monitoring services that are designed to improve the patient's health, independence and quality of life. Care technology has already been shown to help people with diabetes self manage their condition and stay at home, whilst reducing the need to travel to access specialist advice, and should be an important element of the future stroke pathway plans. In some parts of Wales stroke rehabilitation services have developed innovative peer support initiatives to foster recovery and rehabilitation. Other peer support initiatives and groups have been facilitated by the third sector. Evidence emerging from these demonstrates that stroke survivors can reduce post stroke anxiety, gain confidence and social connectivity as a result of peer support participation.

Stroke survivors' value forming friendships with people experiencing similar situations post stroke as they can show higher degrees of empathy. Access to activity based sessions is equally valued. This includes: exercise/ balance classes, gardening, sports, the arts, joining an aphasia choir (for those whose symptoms include speech impairment) and taking up voluntary work.

Lifelong access to specialist assessment and treatment in a timely way -

Recovery after stroke can be variable and does not always follow a predictable course. Research evidence shows that some people can make further functional gains with targeted interventions several years after a stroke, while others are unable to maintain the level of function they achieved during early rehabilitation.

Improvements and loss in function are dependent on a combination of physical, emotional, psychological and social factors. To achieve and maintain optimal

functional ability and independence, stroke survivors should continue to have lifelong access to specialist assessment and interventions in a timely way.

The close link between stroke and socio-economic disadvantage is a recognised key factor. Having a stroke often results in an increase in personal financial expenses and, for many, it can also be the loss of employment and a significant reduction in income.

Employment and specialist vocational support as well as volunteering opportunities act to positively support and impact many stroke patients recovery and should form part of the services stroke survivors receive.

Assessing and meeting the housing needs of stroke survivors must form part of any strategic approach. Ensuring that the appropriate agencies can engage in providing housing options advice as well as the needed adaptations will be key to ensure the home environment is accessible and conducive to dignified living.

Health, social care and third sector services should work together to:

- ***Develop structured services for patients who have had a stroke at six months and one year after the stroke, and then annually.***
- ***Actively signpost patients who have been affected by stroke to relevant support services.***
- ***Ensure appropriate education and self management programmes are in place.***
- ***Increase opportunities for improving opportunities for peer support amongst stroke survivors.***
- ***Ensure clear strategies on what physical and psychological support is available in their area and how people living with stroke and their families can access it regardless of where they are living, in the community or in nursing or residential homes.***

- ***Improve vocational rehabilitation and provide opportunities for volunteering.***

End of Life Care

People approaching the end of life need access to the appropriate care and support. The access to health and social care and support must be the same wherever they die - at home, in hospital, in a care home or a hospice. These services need to be well coordinated across primary, community, social and hospital care, and between statutory and third sector organisations. It is hard to identify those likely to die within 12 months and initiate the necessary conversations. It requires considerable skill and experience. However, the right support can transform the end of life experience for everyone – the patient, family, carers and friends. For patients with acute stroke appropriate end of life care should be provided, taking into account the effect that stroke can have on speech, communication and swallowing. In this situation the knowledge of any advance directive or explicit wishes of the patient will be also be taken into consideration

Health boards and trusts will:

- ***Plan and deliver services, in line with appropriate clinical pathways, to meet the ongoing needs of stroke patients, including providing an individualised palliative care plan, where appropriate, in line with the Delivering End of Life Care Plan***

Research and Development (R&D)

R&D in health and social care is central to driving innovation, improving care and improving population health and well-being. It is, therefore, vital that R&D is included within this plan and acts as a key enabler to the delivery outcomes.

It is well established that active research programmes are essential to move care forwards and that the research projects of today will become the treatment standards of tomorrow. Patient access to stroke research needs to be a fundamental part of

their journey. Recognising the importance of research, the SIG has established a research sub-group and appointed a specialty lead through Health and Care Research Wales. Representatives of each health board in Wales and Wales Ambulance Services Trust (WAST) are members of this group with the remit of increasing Welsh participation in stroke research. This research is active along all points on the stroke pathway.

Health boards, Higher Education Institutions and Third Sector Organisations will:

- ***Increase the number of well-designed stroke studies undertaken in Wales. Work with Health and Care Research Wales researchers and Centres to increase the number of Wales led studies in addition to those undertaken in Wales but led from elsewhere.***
- ***Increase the number of individuals actively taking part in stroke research. Work with Health and Care Research Wales Support and Delivery Service to develop the additional infrastructure required for the delivery of complex intervention studies across care settings, including home. This includes ensuring that patients and carers have access to well design studies across Wales and across care settings whilst minimising the impact on their daily lives.***
- ***Increase the number of members of the public (to include patients and carers) involved and engaged in research activity. Create a robust and meaningful process for involvement of patients and carers with stroke needs at all stages of research activity, from study design to implementation and dissemination.***
- ***Ensure arrangements are in place allowing research to feed into organisations' mechanisms for uptake of best practice and service change, improving clinical practice and patient outcomes.***
- ***Monitor the key performance indicators set out in the Delivery Framework for the Performance Management of NHS R&D that are***

relevant to this Delivery Plan.

- ***When data is required to be captured ensure a R&D lead is identified and provides visible R&D leadership for this Delivery Plan.***
- ***Promote the importance of R&D through participation in studies, 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.***

Implementing the Delivery Plan

Health boards are required to identify, monitor and evaluate action required to deliver this Stroke Delivery Plan in the health board integrated medium term plan (IMTP).

The Welsh Government will hold the NHS to account to ensure that the actions in this plan and the health outcomes desired 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.

Health boards are responsible for planning, securing and delivering local services to ensure that those people who have had a stroke can access the right care at the right time and place. Each health board has 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 Service Trust, other health boards in Wales and England, primary care, local government and the third sector voluntary bodies.

Health boards will need to integrate their plans for stroke care into the overall health boards' integrated medium term plans.

The Stroke 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.

Annex 1

STRATEGIC AND LEGISLATIVE CHANGES SINCE FIRST STROKE DELIVERY PLAN WAS PUBLISHED IN 2013

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.

New Programme for Government and the NHS Plan

The Welsh Government's new Programme for Government *Taking Wales Forward 2016-21* and NHS Plan set out a 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.

The Health and Care Standards – April 2015

The Health Care Standards 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 achieving excellence.

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

The quality delivery plan outlines actions for quality assurance and improvement and for the delivery of a quality-driven NHS that provides services which are safe, effective, accessible, and sustainable, and that comes with an excellent user experience. 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 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 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). The latest CMO Annual report focusses on 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.

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

Building a Brighter Future is a coordinated programme to ensure that children have the best possible start in life through early intervention, family support and integrated services, focusing on achieving better outcomes and reduced inequality for children.

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 that such services are available to those who wish to communicate in Welsh.

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).

Website Links:

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

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

Delivery plan for the critically ill (refreshed plan to be published January 2017)

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

Heart Condition Delivery Plan

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

Diabetes Delivery Plan

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

Congenital Heart Disease Services Standards

<https://www.england.nhs.uk/commissioning/spec-services/npc-crg/chd/>

Sentinel Stroke National Audit Programme

<https://www.strokeaudit.org/>

National Confidential Enquiry into Patient Outcome and Death: Time to Intervene (2012)

<http://www.ncepod.org.uk/2012cap.html>

Cochrane

<http://www.cochrane.org/what-is-cochrane-evidence>

SSNAP website: <https://www.strokeaudit.org/>

Programme for Government

<http://gov.wales/about/programme-for-government/?lang=en>

Embedding of the prudent healthcare principles

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

Securing Health & Wellbeing for Future Generations- February 2016

<http://www.prudenthealthcare.org.uk/securing-health-and-wellbeing-for-future-generations/>

Health and care standards (April 2015)

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

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

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

NHS Wales Planning Framework

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

Primary Care Services Plan

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

Well-being of Future Generations (Wales) Act 2015

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

Social Services and Well-being (Wales) Act 2014

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

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

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

Public Health Outcomes Framework

<http://gov.wales/topics/health/publications/health/reports/public-health-framework?lang=en>

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>

Framework for Assuring Service User Improvement and Core Questions

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

***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%2C%20Compassionate%20Care.pdf>

Delivering Local Integrated Care

<http://gov.wales/topics/health/publications/socialcare/strategies/integration/?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/integ>

[ration/?lang=en](#)

Children and young people's continuing care guidance

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

Stroke in Childhood

http://www.rcpch.ac.uk/system/files/protected/page/RCP%20-%20Stroke%20in%20childhood%2020015_0.pdf

Self care and care plans

<http://gov.wales/docs/dhss/publications/100102frameworkselfcareen.pdf>

<http://gov.wales/topics/health/nhs/wales/healthservice/chronic-conditions/?lang=en>

Patient Consent

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

All-Wales Policy on Do Not Attempt Cardiopulmonary Resuscitation

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

Lasting Power of Attorney

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

NHS Wales Workforce Review

<http://gov.wales/topics/health/publications/health/reports/workforce/?lang=en>

Health and Care Research Wales Performance Management Framework

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

Industry Engagement in Wales

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

Delivery Framework for the Performance Management of NHS R&D

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

The Nurse Staffing Levels (Wales) Act 2016

<http://www.legislation.gov.uk/anaw/2016/5/enacted>