

# NHS Wales Health Collaborative Annual Report 2019/2020



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# Foreword

We are delighted to introduce this annual report, the second produced for the NHS Wales Health Collaborative, through which we have aimed to provide an insight into the work of the Collaborative in 2019/2020.

The scope of the Collaborative's work programme continued to grow in 2019/2020. At the start of the year, the Collaborative took on new responsibilities for the management and support of the major conditions implementation groups and the introduction of a national programme to improve access to and the quality of endoscopy services. This new work, together with priorities for the clinical networks and other national programmes, ensured a busy year for Collaborative staff, working in partnership with NHS Wales, Welsh Government, the third sector, industry partners and others.

By the end of the year, the work of the Collaborative team looked very different due to the need to focus on providing support to the response to the COVID-19 pandemic. Some of the early activities were advising and supporting the critical care response, and providing support to Public Health Wales' response. The Collaborative's role broadened as the pandemic developed and its impact on the focus of the work of the Collaborative will continue through 2020/2021.

The achievements of the Collaborative in 2019/2020 have come from the hard work of the staff, working in collaboration with colleagues across NHS Wales and beyond, and this annual report provides examples of work and achievements identified by staff as important to them and people using NHS services. We would like to offer our thanks to all staff for their commitment and enthusiasm to improving health services and healthcare which will result in improved outcomes for patients.

We hope you enjoy reading this Annual Report for the NHS Wales Health Collaborative for the year 2019/2020.

#### **Ann Lloyd CBE**

Lead Chair and Chair, Aneurin Bevan University Health Board

#### Judith Paget CBE

Lead Chief Executive and Chief Executive, Aneurin Bevan University Health Board

#### **Rosemary Fletcher**

Director NHS Wales Health Collaborative

# Introduction

This is the second annual report published by the NHS Wales Health Collaborative. It provides information about our organisation and our teams that work in support of NHS Wales to plan and improve health care. It provides an overview of the work of our teams and highlights some of our achievements in 2019/2020.

The progress made and achievements through the year are due to the commitment and hard work of all our staff and those who work with us. This annual report has been prepared through contributions from staff and to reflect examples of achievements and case studies important to them.

The Collaborative was established in 2015. We work on behalf of the chief executives and chairs of the health boards, trusts and special health authority that make up NHS Wales. We also work in support of Welsh Government. We help to shape, plan and make recommendations on the future of NHS services across Wales.

As a national organisation, the Collaborative works in areas offering the opportunity for cross organisation improvement. Through collaboration, engagement and facilitation, our teams work to improve NHS Wales' services across organisational boundaries, and improve the quality of care for patients.

Our teams cover a broad range of clinical networks, strategic programmes and projects, implementation groups, and support functions.

The Collaborative is hosted by Public Health Wales, on behalf of NHS Wales. Through our hosting arrangements, the Collaborative is supported by corporate teams within Public Health Wales and works within its standing orders, standing financial instructions and all relevant policies and procedures.

The Collaborative team is accountable for its performance and the delivery of its work plan to NHS Wales' chairs and chief executives. The Collaborative Leadership Forum (chairs and chief executives) acts as the responsible governance group for the Collaborative team and signs off the Collaborative annual work plan. The Collaborative Executive Group (chief executives) is a formal sub group of the Collaborative Leadership Forum and provides more frequent executive guidance to the Collaborative team and more detailed oversight of its work.

About us

# Our values

We have committed to 'work together, with trust and respect, to make a difference' in all that we do as a Collaborative team and in working with our stakeholders. This is consistent with the values of Public Health Wales, our host body.



Our work plan is shaped in a number of ways. The majority of the work plan for 2019/2020 comprised the priorities agreed through the clinical network boards, major conditions implementation groups and strategic programme boards. Details are described through later sections in this report.

We deliver against our priorities through collaboration with our partners across NHS Wales, including health boards, trusts and special health authority and other NHS Wales-wide organisations, and wider stakeholders such as the third sector and industry partners.

Towards the end of 2019/2020, we reprioritised our work to enable our staff to focus on providing support to the response to the COVID-19 pandemic, the impact of which will continue through 2020/2021.





## 6.1 Wales Cardiac Network

The Wales Cardiac Network works with partners at the interface of primary, secondary and tertiary care to provide improved care for people of all ages, at risk or affected by heart conditions. Its work is driven by a strategic leadership group, the Heart Conditions Implementation Group, and it strives to improve outcomes in reducing premature cardiac mortality and morbidity.

The network has developed all Wales care pathways for atrial fibrillation, heart failure and acute coronary syndrome. Data and informatics projects have improved data sources for the Welsh clinical portal, with better access to clinical information and diagnostics, and have supported the development of a heart failure dashboard.

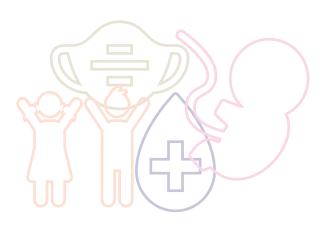
The network also supports the *Save a Life Cymru* partnership, funded by Welsh Government. The partnership brings together NHS, emergency services, third sector, and others, to pool expertise to assist in improving access to CPR and defibrillators in the community to save lives.

#### Atrial Fibrillation: tackling unwarranted variation in care

Atrial fibrillation is a heart condition that causes an irregular and often abnormally fast heart rate which can cause problems such as tiredness, palpitations or shortness of breath. If uncontrolled, it can lead to greater chance of blood clots forming or internal bleeds. Better management will reduce stroke and cardiac complexities for patients.

As one of the priority areas for both the Heart Conditions and Stroke Implementation Groups, and informed by the baseline provided through the Cardiovascular Atlas of Variation, we developed a joint initiative to tackle unwarranted variation in key aspects of care.

Through the shared knowledge from other projects, such as *Stop a Stroke*, and the work of the NHS Wales Informatics Service had undertaken to develop a clinical portal for GP-related atrial fibrillation activity, we had a better understanding of the variation and how to measure improvements.



#### The plan is in three stages:

- **Protect:** Identify and offer treatment to those already known to have the condition and a CHADS, VASC risk score of two or more who are not yet on any medication.
- Perfect: Switch patients who are on Warfarin to other options if it is not helping.
- Detect: Increase opportunistic screening for atrial fibrillation, such as using portable devices in GP clinics or pharmacies for instant ECG.

*Stop a Stroke (SAS)* had already developed a platform and education resources. This had informed the SAS Audit+ tool, now part of the GP IT systems across Wales and facilitated the monitoring of compliance.

The Atrial Fibrillation Pathway provides a means of consistent practice and, through joint partnership with industry and *Stop a Stroke*, training started across Wales.

Moving forward, partnership with industry will give us the option to test initiatives at small scale and share results.



## 6.2 Wales Cancer Network

The Wales Cancer Network provides system leadership to bring together partners to work collaboratively to transform cancer services and improve outcomes for patients. Its priorities are identified and overseen by the Cancer Implementation Group and include:

- National Optimal Pathway development and improvement in support of the Single Cancer Pathway.
- Promoting the development of Rapid Diagnostic Centres to provide early diagnosis.
- Facilitating a national approach to digital patient centred care documentation, and the 3<sup>rd</sup> Welsh Cancer Patient Experience Survey.
- Dataset development for the first time including the Acute Oncology Service within the Cancer Information Solution.

- All Wales Prescribing Competency Passport, dataset development, and clinical guidance supporting the national e-prescribing solution business case.
- Multi-faceted programme aimed at improving clinical outcomes and reducing variation for people living with bowel cancer in Wales.
- Scoping review on low-dose CT screening for lung cancer.
- Developing clinical leadership in primary care through a Community of Practice of GPs and nurses to support cancer service improvement.
- Cancer Peer Review.

# A Cancer Innovation Challenge to enable improvements in cancer services, patient experience and outcomes

The Cancer Implementation Group challenged the Wales Cancer Network and the Life Sciences Hub Wales to bring research, industry, third sector and the NHS together, fostering innovative solutions to Cancer Delivery Plan priorities. In response, the Research and Innovation Programme was established and, together with the Wales Cancer Research Centre, the following deliverables agreed:

- Multisector partnerships to improve pathways through a Cancer Research and Innovation Industry Forum.
- 2. Cancer Research Strategy for Wales (CReSt).
- 3. Intelligence and evaluation methodology and resources to support service improvement.

To kick-start collaborative innovation and engagement through the industry forum, a *Cancer Innovation Challenge* was developed, using cross-sector expertise to refine a Health-Hack methodology.

Priorities were presented at a two day challenge event. Teams were facilitated to form and develop solutions by the Life Sciences Hub Wales, Wales Cancer Research Centre and Network subject area experts. Partnership solutions were pitched to a multisector panel including Welsh Government and patient representatives. Five projects were awarded funding from a £50k pot, funded by the Cancer Implementation Group and Welsh Government:

- Next generation training for healthcare professionals in dealing with sepsis.
- Enhancing patient pathway efficiency through digital pathology.
- Increasing clinical trial recruitment using artificial intelligence (AI).
- Improving the outcomes and experience of patients undergoing Bone Marrow Transplant: BMT together.
- AI diagnosis of melanoma.

Participant feedback was extremely positive. The Industry Forum has been established with more than 35 members attending an inaugural meeting to identify priority collaborations with the NHS, research and third sector for the immediate future.



# 6.3 Wales Critical Care and Trauma Network

The Wales Critical Care and Trauma Network team is made up of clinicians from health boards in Wales, as well as managers and administrators based in the Collaborative. It covers two separate but interconnected services – critical care and trauma.

The Network brings together 14 intensive care units (ICUs) across six health boards, providing a framework for collaborative clinical quality improvement through regular meetings with clinical and strategic planning colleagues. Peer review provides supportive feedback on ICU provision against accepted standards.

The Network also supports provision of an integrated trauma system in North Wales, linking with the Royal Stoke Hospital as its Major Trauma Centre as part of the North Wales and North West Midlands Trauma Network. This experience has supported planning for the establishment of the South Wales Trauma Network, to serve South Wales, West Wales and South Powys. The Collaborative provided clinical and programme leadership for this significant area of work and, with the support of NHS partners, prepared a comprehensive programme business case. Following scrutiny and peer review, the programme business case was considered within relevant health board and trust meetings during November 2019 and formally approved by the Welsh Health Specialised Services Committee in January 2020. Supported by funding from Welsh Government, implementation work has begun within health boards and the ambulance service, to provide the required workforce and infrastructure, and it is anticipated that the service will commence in 2020.

#### **Critical Care response to COVID-19**

In early 2020, news emerging from China warned of a new Coronavirus that was highly infectious with many sufferers needing a ventilator in intensive care. The Network responded quickly to support health boards in preparation for a new pandemic.

The situation developed rapidly, during which time the Network kept information flowing to critical care teams and health board executives to facilitate planning. The clinical understanding of COVID-19 rapidly evolved as more was learned about this new illness, and the Network used instant messaging to rapidly share emerging evidence with clinicians across Wales.

The Network proved to be a lynchpin in the critical care response to COVID-19 in Wales bringing clinicians together, advising Welsh Government and supporting health boards with operational planning. The Network team has championed a sustainable response to the outbreak focusing on staff wellbeing in critical care units.

The team pulled together representatives from across health boards and Welsh Government to plan surge capacity and advise on elective activity. Admission guidelines were agreed, as well as planning for rehabilitation of COVID-19 patients leaving critical care.

The Network's nursing educational group collaborated with Health Education and Improvement Wales to rapidly plan and deliver training and support for hospital staff redeployed to critical care units.

The Network supported Welsh Government to devise a daily situation report to monitor capacity and demand for critical care through the pandemic. The close working relationships formed across NHS Wales enabled the Critical Care and Trauma Network to safely manage high risk emerging issues relating to supply of ventilators, medicines and vital items needed for renal replacement therapy.



# 6.4 Wales Maternity and Neonatal Network

The Wales Maternity and Neonatal Network was established in June 2019. Through the year, a number of stakeholder events were held to determine key service priorities, driven primarily by the All Wales Neonatal Standards (3rd Edition); Maternity Care in Wales: A Five Year Vision for the Future (2019-2024) and the Royal College of Midwives/Royal College of Obstetricians and Gynaecologists Review of Maternity Services at Cwm Taf Health Board. These priorities informed the work programme, under the following work streams:

- Family centred care.
- Continuity of carer.

- Safe and effective care.
- Skilled multi-professional workforce / sustainable services.
- Timely care.

Neonatal sub groups addressing these themes are well established, particularly around safe and effective care, and we achieved positive engagement in identifying obstetric and midwifery representation for maternity led subgroups. It is intended that these will become joint subgroups delivering a 'Once for Wales' approach.

#### **Collaborative Quality Improvement - Managing Antibiotics Wisely:** Introduction of the Neonatal Sepsis Risk Calculator in Wales (Finalist in the British Medical Journal awards 2020)

Early onset neonatal sepsis is an infrequent but serious illness that has had an aggressive clinical management strategy, including prophylactic antibiotic injections. Evidence shows that antibiotic use in newborns can increase resistant bacteria and cause obesity and serious disease in later life.

Following discussion with the commissioners, and approval by the National Antibiotic Stewardship and Welsh Risk Pool, a collaborative approach to Quality Improvement (QI) was coordinated across the network, aiming to safely reduce antibiotic usage.

The QI project, led by senior consultant Dr Sujoy Banerjee from Swansea Bay University Health Board, was delivered through a network task and finish group. No additional funding was provided to run this project. Standardised training was cascaded through each unit, and fortnightly data on births, antibiotic usage, culture positive sepsis and admissions collected.

The QI project was simultaneously launched across 10 of the 11 units in Wales in April 2019, with data analysis and process reviews undertaken on a monthly basis using Healthcare Improvement methodology through multi-disciplinary meetings.

Results of the project were extremely positive, with a 48.2% reduction in antibiotic usage.

These results were homogenous and consistent across all participating units. In real terms this meant that for every 1000 births in Wales over 34 weeks, 71 infants safely avoided unnecessary antibiotic exposure. Importantly there was no evidence of harm to any infants and no change in the neonatal unit admissions.

This was the first successful UK application of the neonatal sepsis risk calculator (SRC) in a large multi-centre using rigorous QI methodology that shows large scale effect and with extremely positive staff feedback.

## **6.5 Wales Mental Health Network**

The All-ages Mental Health Network is intended to drive, facilitate and enable transformational change and sustained improvement for NHS commissioned and/or delivered mental health services in Wales by promoting a prudent, whole system approach. The network includes four sub groups:

- Perinatal Mental Health.
- Child and Adolescent Mental Health (CAMHS).
- Eating Disorders.
- Adult Mental Health.

A review of the All-ages Mental Health Network Board was undertaken in August 2019. It concluded that the Network Board has facilitated broad discussions across health bodies and provided a forum for shared learning and understanding of policy and strategic direction for mental health services across Wales. There was a clear appetite and ambition to exploit the benefits of a Network, and the review made a number of recommendations.

Following the appointment of the National Programme Director for Mental Health, a high level work plan aligned to the ambitions in A Healthier Wales and the outcomes and priorities in the Welsh Government's *Together for Mental Health* Delivery Plan was confirmed in January 2020.

#### **Review of primary mental health care**

The Child and Adolescent Mental Health Services sub group undertook a review and evaluation of wider primary care mental health teams that provide services to children and young people. The review examined referral pathways, both internal and external to NHS Wales, and key partner agencies, including the third sector. A constructive engagement approach was used, key to which was achieving and capturing the patient experience.

The importance of investing in improving patient experience cannot be understated. An understanding of patient experience was captured through direct feedback from young people, their families, siblings and carers, in person or by telephone.

Alongside clinical outcomes highlighted in the review and other intelligence, feedback will inform quality improvements and help to shape how local services are designed. Other clear key benefits include:

- The impact of experience on organisational reputation.
- That experience is improved when people have more control over their care and have the ability to make informed choices about their treatment.
- The link between experience and health outcomes.
- The link between experience and cost of care.
- The relationship between patient and staff experience.

Health boards and partner agencies have been able to take the recommendations of best practice from the report and consider them in planning future service provision.

#### **Establishment of the Perinatal Mental Health Network**

The aim of the Network is to oversee the planning and delivery of efficient and effective perinatal mental health services for NHS Wales, focusing on prevention, earlier intervention, prudent health care, and ensuring we provide the right services, at the right time and by the right people. The Network supports evidence-based and innovative practice, enabling equitable delivery of services across Wales, with a focus on implementation of the recommendations within the Children, Young People and Education Committee Report, and from Bumps to Babies: Perinatal Mental Health Care in Wales. We bring stakeholders together and shape services for parents, with parents, in order to improve the quality and equity of care.

2019/2020 achievements:

- What we established the Perinatal Mental Health Network, Community of Practice, Quality Network and six professional forums; all health boards have benchmarked against all Wales standards.
- Why collaborative working across Wales is key to improving the quality and standards of care being provided.
- How we identified key stakeholders and parents, connected and engaged with colleagues from all service areas across the pathway.
- Who we engaged with service users, midwives, health visitors, primary care, secondary care, specialist and inpatient clinicians, third sector and voluntary organisations, commissioners and Welsh Government.

#### Supporting mental health services during COVID-19

To support local organisations and provide a single link to the Welsh Government's COVID-19 governance arrangements, a Mental Health Co-ordinating Centre was established jointly between the Mental Health National Programme Director and the National Collaborative Commissioning Unit in March 2020. The mental health teams within Improvement Cymru and the Delivery Unit worked in support of these arrangements.

The Co-ordinating Centre has provided a single point of contact and information source for NHS mental health, learning disability and substance misuse services for both NHS and private providers. Some of the early actions of the centre (agreed under the Welsh Government Mental Health Implementation Group) were:

- Virtual expert group established to provide ad hoc advice and sign off clinical guidance.
- Additional mental health inpatient capacity (surge beds) put in place with central management of deployment.
- Extensive online population mental health and wellbeing self-help and guidance collated and made available via specialist helplines CALL and Hub (and subsequently Public Health Wales).
- Development of a recovery framework and related series of actions put in train.

# 6.6 Together for Children and Young People (T4CYP) Programme

As the T4CYP programme approached its planned close in October 2019, the team focused on transferring legacy projects to their long-term homes and reflected on the programme's impact since 2015. This included a Children, Young People and Education Committee Session, where Carol Shillabeer, T4CYP Programme Chair, gave evidence of our progress against the *Mind over Matter* (2018) recommendations.

Two T4CYP conferences were held in June and October 2019, which brought together a range of stakeholders, children and young people to share updates, knowledge and good practice. The National Youth Stakeholder Group was active throughout the year, including holding a lively 'question time' session with Vaughan Gething, Minister for Health and Social Services, and Kirsty Williams, Minister for Education.

Following a detailed end of programme review, Welsh Government confirmed in December 2019 that a refocused T4CYP (2) Programme, funded until March 2022, will look at Early Help and Enhanced Support, neurodevelopmental services and links with Regional Partnership Boards.

#### Early Help and Enhanced Support Conference - June 2019

Over 90 young people and professionals from across Wales attended the T4YCP Early Help and Enhanced Support (EHES) Conference, co-chaired by Professor Dame Sue Bailey OBE DBE. The event aimed to identify:

- a values-based definition of what EHES for children and young people means
- what the offer should look like, and
- examples of existing services and projects in Wales.

It was an important step in fulfilling a *Mind Over Matter (2018)* recommendation to address challenges faced by children and young people who do not meet the threshold for specialist child and adolescent mental health services (CAMHS), but for whom other suitable therapeutic or additional support is not available.

Delegates attended from 11 local authorities, three health boards, and 12 third sector organisations, together with representatives from the Children's Commissioner for Wales, National Assembly for Wales, Welsh Government, and Cardiff University.

Interactive workshops provided a space to discuss and identify key messages, key ingredients and core values that should be central to EHES. We gained real time responses from delegates at the start and end of the day on key values, defining EHES and critical factors to enable success.

Co-production was at the heart of the event. Young people delivered presentations and co-led workshops, talking about a range of topics including using photography to manage depression and looking after mental wellbeing as a care experienced young person.

The information we gathered is the start of a co-produced EHES Framework, as part of a concerted effort to improve outcomes for children and young people by establishing a whole-system approach, with multi-disciplinary working across health, education, social care and third sector.

# 6.7 National Endoscopy Programme

The National Endoscopy Programme was established in 2019 to drive sustainable improvements in endoscopy services. Its development followed the recognition of the pressures faced by endoscopy services in Wales. The overall aim of the programme is to develop sustainable endoscopy services that provide high quality, timely services to patients and, in particular, to balance demand and capacity, achieve JAG accreditation of units and enable optimisation of the bowel screening programme.

The programme is structured into four work streams:

- Demand and capacity to ensure balanced and responsive demand and capacity planning through a standardised approach.
- Clinical pathways to standardise pathways according to evidence and to achieve optimization and equity.

- Workforce training and development to support local workforce analysis, job planning, recruitment and retention, and to develop national training and development opportunities.
- Facilities and infrastructure to develop a national overview of the physical estate, to achieve JAG accreditation of endoscopy units, and to improve the IT infrastructure.

A national action plan was published in October 2019. Endoscopy services had significant challenges prior to the pandemic and its impact has significantly added to the scale of the challenge. The National Endoscopy Programme will refocus its work plan to develop a national recovery plan to assist health boards and develop a more sustainable service model for the future.

#### **NHS Wales Capacity and Demand Modelling**

The number of diagnostic endoscopy procedures required is increasing due to population changes, a lower threshold for suspected cancer investigation, the demand for surveillance and the need to expand the bowel-screening programme. Demand is currently significantly out of balance with the available core capacity and there is a need to develop solutions that are sustainable.

A key achievement in 2019/2020, vital to the diagnostic phase of the overall programme, was the development of a standardised model for establishing current and future demand and capacity within endoscopy units in Wales, using agreed guiding principles applicable to local solutions.

Following its establishment, the programme worked at pace to design a demand and capacity model. By January 2020, after refinement of the model through work with all Health Boards, data was produced that could describe endoscopy procedure activity, list activity, workforce gaps and the necessary uplift in activity required to address the anticipated increase in volumes of referrals expected over the next few years. This 'modelling tool' was the first nationally produced within Wales.

The demand and capacity model played a pivotal role in quantifying the size of the challenge faced by endoscopy services across Wales, with its increasing demand and lack of capacity to address it. It has provided the necessary information during the diagnostic phase of the programme that will influence the next phase, the transformation of endoscopy services across Wales.

# 6.8 National Pathology Programme

Though 2019/2020 the National Pathology Network continued its work to:

- Support delivery of the Welsh Programme for Government.
- Develop and implement a programme of strategic work which contributes to delivering the vision of the Pathology Statement of Intent 2019.
- Ensure the adoption of All Wales standards and protocols for pathology services in NHS Wales.

A new National Pathology Network Strategy Board was formed to ensure oversight and ongoing development of the implementation plan. Work is prioritised through the National Pathology Network and delivered through its work streams, e.g. Pathology Workforce and Education Group, Point of Care Strategy Board, National Pathology Operational Managers Group, All Wales Pathology Quality and Regulatory Compliance Group, and the National Digital Cellular Pathology Programme Board.

#### **Point of Care Testing**

Pathology is involved in 70% of all diagnosis made in the NHS. 95% of clinical pathways rely on patients having access to efficient, timely and cost-effective pathology services.

Point of Care Testing (PoCT) produces rapid, accurate results which benefits the patient through the acceleration of both diagnosis and treatment.

Recognising the importance of this continually developing service, a key action of the Pathology Statement of Intent 2019 was *'NHS Wales would establish a formal structured arrangement to deliver Point of Care Testing services in NHS Wales'.* 

Building on work of the National Pathology Modernisation Programme, whilst remaining aligned to delivering the action of the Statement of Intent, there have been several key advances during 2019/20 to develop new national delivery models for PoCT diagnostics. These are:

- The establishment of a Point of Care Testing Strategy Board, providing formal oversight of the National Point of Care Co-Ordinators Group.
- Through a workshop approach to 'Develop a National Roadmap for Point Of Care Diagnostics':
  - Engaged with stakeholders who use pathology and PoCT services.
  - Promoted the idea of a single national PoCT support service, especially to primary and community care.
  - Identified new models for delivering PoCT support services the challenges and barriers.
- The appointment of a National PoCT Lead to provide formal leadership and further develop the identified models for a National PoCT Service.

Next steps will be to further develop the service models identified, providing care closer to home through offering the right care, in the right place, at the right time.

# 6.9 Lymphoedema Network Wales

Lymphoedema is a long-term condition that causes swelling in the body's tissues. It develops when the lymphatic system does not work properly.

Lymphoedema Network Wales, which encompasses all health board lymphoedema services and a small national team, is embedded as a value-based service. In 2019/2020, the network gained approval for investment for its Lymphoedema Value-Based Business Case.

In 2019/2020, lymphoedema services received 7,687 new patient referrals and completed 36,759 contacts. The caseload was 20,616 patients.

The network has three main work programmes: service development, education/audit/research and innovation/technology. Within each are numerous project groups, including: lymphatic venous anastomosis surgery; data performance capacity and demand; pathways and policies; coproduction in prescription films; accredited education/ e-learning and Project B. A cellulitis project started in January 2020 and aims to deliver efficiencies for NHS Wales.

Research and education continues to be a priority and work is underway on the validation of PROMS-LYMPROM<sup>®</sup> and PREMS-LYMPREM<sup>®</sup>.

#### Raising awareness of lymphoedema with care home staff

*Background:* Patients referred to lymphoedema services from care homes (residential and nursing) are often complex cases, with repeated cellulitis, falls and other complications. An education project was initiated to raise awareness of the condition amongst care home staff, with funding from Welsh Government.

*Aims:* To enable care staff to identify residents with lymphoedema, promote prompt referrals, raise the importance of skin care and exercise and estimate the likely costs from complications associated with the condition.

*Methods:* Pilot health boards agreed to participate and 47 care homes were invited. An education tool was developed and a lymphoedema therapist carried out a scoping review of the residents with care home staff. Anonymous data was collected and analysed with support from Swansea University.

*Results:* 44 care homes participated in the project with 1,216 education packs issued to care home staff. Findings suggest that of the 960 residents reviewed, 262 had lymphoedema (27%); 4% suffered with frequent falls, 1% had wounds and 3% had recurrent cellulitis. Only 13% (35/262) of residents with lymphoedema were known to the local service. Of the 31 residents reporting cellulitis, 81% had lymphoedema; of the 11 residents identified with a wound, 100% had lymphoedema and of the 40 residents reporting falls, 70% had lymphoedema. The findings suggest that, in addition to the impact on residents, there are extensive costs attributed to lymphoedema, in particular the high number of district nurse visits and unscheduled care admissions for falls and cellulitis, totalling almost £200k in six months.

*Conclusion:* Education is vital to raise awareness of lymphoedema within care homes. By improving carers' confidence in identifying the condition they were able to refer residents to a local lymphoedema service directly, negating the need for GP visits. Enabling care home staff to understand the importance of skin care and exercises will decrease the risk of lymphoedema in other residents.

# 6.10 National Imaging Programme

The Statement of Intent for Imaging (March 2018) provides the strategic direction for imaging services in Wales. The national imaging programme is overseen by the National Imaging Programme Strategy Board, supported by workstreams:

- Imaging Workforce and Education Group conducted work on demand and capacity, advanced and extended practice, education, training routes and workforce data.
- Imaging Quality Forum undertook peer review, developed a revised procedure on non-medical referrers, and facilitated shared learning.
- Prostate Cancer Diagnostics Pathway group progressed data collation and standardised biopsy protocols.

#### Multiparametric MRI for diagnosis of prostate cancer

The National Institute for Health and Care Excellence (NICE) published the '*Prostate Cancer: Diagnosis and Management*' guideline in May 2019. One of the key changes is the recommendation to introduce pre-biopsy multiparametric MRI (mpMRI) for diagnosis of prostate cancer.

The pathway received considerable political and public scrutiny, and NHS Wales needed to be in a position to implement the recommendations.

The programme strategy board agreed to provide central leadership to support implementation in Wales, and the Prostate Cancer Diagnostics Pathway Subgroup was formed in August 2019. Over the last few years, in line with emerging evidence, there has been a 300-400% increase in prostate MRIs. The NICE guideline also recommended that men with negative MRIs (30%), may avoid immediate biopsy and associated risks. The scans and reporting therefore need to be of high quality. The subgroup was tasked with promoting adoption of minimum standards and protocols across Wales.



With representation from radiology, urology, primary care, National Imaging Academy Wales (NIAW), Prostate Cancer UK (PCUK) and other specialists, the subgroup started to plan a programme of work, reviewing pathway elements to encourage standards based implementation of NICE guideline, including:

- Public and patient information.
- Primary care information, training and support.
- mpMRI protocols.
- Reporting.
- Biopsy technique.

The subgroup offers an environment supporting collaboration and, thanks to the efforts of members and excellent relationship with PCUK (and learning from their work with NHS England), there have been some exciting developments:

- Training and mentoring opportunities with NIAW and PCUK, including a virtual offering via collaboration software.
- Linking with GPs to shape how we standardise patient information and a primary care education programme to update GPs.
- Questionnaires to health boards to understand current practice and inform development of standardised protocols.

Ultimately, the aim is to reduce variation, waste, harm and cost so that patients experience a high quality, equitable service and best possible outcome regardless of where they live.

# 6.11 Radiology Informatics System Procurement Programme

The Radiology Informatics System Procurement Programme will lead to the procurement of an end-to-end diagnostic radiology system to meet the needs of imaging services across Wales. This national programme is overseen by the Radiology Informatics System Procurement Programme Board and will include a fully functional

electronic requesting service and development of information and business intelligence services. Through 2019/2020, supplier pre-market engagement sessions and workshops were held to share findings and gather user comments. This programme of work will continue as a priority through 2020/2021.

# 6.12 Healthcare Science

In March 2018, Welsh Government published the Healthcare Science in NHS Wales – *Looking Forward Framework*, describing activities designed to lead healthcare science in NHS Wales into the future, and embrace the opportunities within 'A Healthier Wales'. It sets out a vision and direction of travel for the healthcare science workforce and, to achieve this, we work with our diverse range of professions, to enable NHS Wales to be safer, more sustainable and innovative, and provide increased value for the citizens of Wales. We work to highlight healthcare science as a rewarding career choice, working at the edge of science to improve patient care across a range of disciplines and clinical pathways. Amongst its activities through 2019/20, the programme team:

- Produced guidance on the role, recruitment and training of Consultant Clinical Scientists in Wales, as the start of a series of guidance on career grades within healthcare science.
- Developed a national plan for neurophysiology to address some of the acute staff shortages.
- Worked with local primary schools under the 'See-Science' umbrella to engage young people and increase awareness of professions within healthcare science.

#### Engaging the healthcare science workforce

A key purpose of *Looking Forward* is to harness the potential within the healthcare science workforce through an ambitious workforce plan to allow healthcare scientists to provide an increased contribution towards clinical delivery, and transform future services. Raising the profile of the strategy and providing an opportunity for the healthcare science workforce to unite and speak with 'one voice' was central to the aim of engagement events, to unlock the potential of healthcare science.

In order to publicise *Looking Forward* and engage the healthcare science workforce, the programme team facilitated stakeholder workshops, centred around key themes:

- Workforce.
- Applied research and innovation.
- Service redesign and transformation.
- Culture and integration.
- Quality and service improvement.

The programme team worked with the Healthcare Science Network, the Executive Directors of Therapies and Healthcare Science, Welsh Government and a range of other partners, to address challenges within healthcare science, and inspire cross-disciplinary and multiple stakeholder engagement in delivering the vision for healthcare science.

# 6.13 Laboratory Information Network Cymru (LINC)

LINC is a transformational programme to support delivery of a modern, sustainable pathology service as part of the Pathology Statement of Intent. A key objective is the procurement and implementation of a new laboratory information management system (LIMS) service for Wales.

With a high level of engagement from the pathology service, LINC completed an Outline Business Case. Following business case approval by all health boards, trusts and Welsh Government, a contract notice was published in January 2020 and five suppliers were longlisted. The procurement process will continue through 2020/2021, with the aim of awarding the contract for the new LIMS by June 2021.

Alongside the procurement, a service led Standardisation Strategy Group is leading the standardisation of pathology tests and workflows with only warranted variation. A master catalogue is being developed to provide to the successful supplier to develop the new LIMS service once for Wales.

# Better patient outcomes and improved patient safety through standardisation of pathology test for coeliac disease

Coeliac disease is an autoimmune disorder in which the immune system mistakenly thinks that gluten — a protein in wheat, barley, rye, and oats — is a foreign invader. The immune system makes antibodies that attack an enzyme in the intestines called tissue transglutaminase (tTG).

This can cause a range of symptoms from abdominal pain, diarrhoea and constipation to vomiting and mouth ulcers.

Coeliac disease can be diagnosed by a blood test that detects an immune reaction to gluten. For unclear results, a follow up endomysial antibody test can be undertaken that will inform a decision to biopsy in patients with a positive result.

Across Wales, each health board had its own criteria for undertaking the second endomysial antibody test. The Immunology Standardisation Group had agreed to adopt the guidelines recommended by NICE, but this had not been put into place. The LINC Strategy Standardisation Group identified it as a priority for standardisation. The group supported the Immunology Standardisation Lead who reviewed the latest guidance and proposed three options to colleagues from all health boards and they collaboratively reached a decision for one standardised workflow for the tTG test for Wales.

This has now been implemented in the current laboratory information management system, tested by the immunology service in Aneurin Bevan University Health Board and rolled out across Wales. The standardisation of this test has led to better patient outcomes, improved patient safety, and has driven forward the standardisation work in immunology.

# 6.14 Implementation groups

A number of national major conditions implementation groups were established to support the Welsh Government's 2011 health strategy *Together for Health*.

The implementation groups were tasked with the ongoing development and implementation of national delivery plans. The delivery plans run until the end of 2020/21, whilst funding for implementation groups has recently been confirmed until the end of 2021/22.

Each implementation group is chaired by a lead chief executive or other health board executive director. Three implementation groups (Cancer, Heart Disease and Critical Illness) are closely aligned with, and supported by, clinical networks within the Collaborative, with the implementation group also acting as the network board and are covered in earlier sections of this report. In 2019/2020, the Collaborative took on responsibility for managerial and administrative support to those implementation groups without clinical networks and existing staff in these roles transferred to the Collaborative. As our role continues to evolve, there are different levels of support required by and provided to each of the implementation groups. Whilst many activities are led by health boards, for completeness the following sections provide an overview and example of the work for all implementation groups, supported through the coordinators and support staff.



# 6.15 Diabetes Implementation Group

2019/20 was a busy and rewarding year for the Diabetes Implementation Group. Developments included:

- A service in Swansea Bay University Health Board to prevent type 2 diabetes in high risk people, based on a highly cost-effective and clinically effective model.
- Remission of type 2 diabetes services in four health boards.
- A type 1 diabetes peer review programme.
- A new *SERENConnect* education programme for young adults.
- The Children's Network made excellent progress in early diagnosis work, SEREN education and improved audit outcomes.

- All health boards now trained to deliver the DAFNE (Dose adjustment for normal eating) patient education programme.
- Online education modules procured for health care professionals in Wales.
- A new focus on mental health issues with the development of psychological support materials and eating disorder support.
- National guidance to support all aspects of diabetes footcare.
- All Wales Patient Reference Group formed.

#### Awareness of Type 1 Diabetes in Children campaign

The following fictitious case study illustrates the improvements in care that the campaign is working to achieve as a young patient transitions to adulthood:

Ffion is 15 when she starts to feel unwell with tiredness, weight loss and thirst. Her mother takes her to her GP who recognises the symptoms of diabetes and the need for same day referral due to the Awareness of type 1 diabetes in Children campaign. She starts treatment with support from the paediatric diabetes team. Her specialist diabetes nurse supports her, her family and her school. The award-winning SEREN education programme helps her feel more confident and knowledgeable in managing her diabetes. At the age of 16, diabetes is causing family anxiety and conflict, and they receive support from the psychologist.

When Ffion is 16, the transition service, restructured in line with the All-Wales Standard for People Moving from Paediatric to Adult Services in NHS Wales, prepares her over the next two years for the transfer to adult services. She actively engages with the Diabetes Youth Worker who supports her with college applications and participates in the SERENConnect programme, a group education programme centred on the issues and interests of young people, designed to promote peer support. She learns to drive and is supported by the Talking Type 1 driving booklet, one of a series developed for young people with diabetes.

In the young adult clinic, she finds the DAFNE structured education programme very helpful. At university, she is supported by texts and e-mails from the Young Adult Diabetes Nurse but finds it difficult balancing her glucose with her work and playing hockey, so is helped by the Insulin Pump Team to use a hybrid closed loop insulin pump and is much happier with this. A year later however, she feels increasing strain from the daily focus on her diabetes and is diagnosed with "burnout" and is helped by the Diabetes Burnout workbook, part of a series created in Wales.

# 6.16 End of Life Care Implementation Group

During 2019/2020, the priorities for the End of Life Care Implementation Group focussed on:

- Advance and Future Care Planning, and the production of a vision document for Wales.
- Compassionate Communities, with the agreement by the Minister for Health and Social Services to 'A Compassionate Country – A Charter for Wales'.
- Bereavement, with the findings from a study of services forming the basis of the Welsh Government Bereavement Programme.
- Paediatric services: working in partnership with voluntary children's hospices to develop a sustainable model for Wales. This has resulted in the development of a full service specification which will be considered by the End of Life Care Board in 2020/2021.

#### A Scoping Survey of Bereavement Services in Wales

**Background:** The End of Life (EOL) Board acknowledges inequity of access to bereavement care across all ages, particularly for those affected by sudden death, where loss is unexpected. It is widely acknowledged that bereavement care should be accessible to those in need of support following the loss of a loved one, as this can reduce the emotional, physical and mental impact of grief.

As described by the National Institute for Clinical Excellence, adequate bereavement care requires:

- Information offered regarding the experience of bereavement and people sign-posted to further support.
- Provision to access formal opportunities, reflecting on grief, which may involve individual or group sessions.
- **3.** Specialist interventions, involving mental health services, psychological support and specialist counselling.

Comprehensive knowledge of local services is essential to delivery.

**Methodology:** Marie Curie Research Centre was commissioned to conduct a survey of bereavement services provided across Wales. This comprised a literature review, surveys and consultation with bereavement care experts, healthcare professionals and academics. 250 responses were received.



**Results:** Respondents described gaps and challenges in bereavement provision, similar to those in other UK/European surveys, for example:

- Lack of a clear framework for commissioning/delivery of bereavement services and included non-prioritisation of bereavement care within organisations.
- Lack of access to funding and restricted access to training and facilities.
- Challenges in the accessibility of specialist support, waiting lists/inability to meet demand, restrictive eligibility criteria, unclear referral pathways and challenges of rurality/ geographical access.

Lessons Learned: A need to provide:

- Equity/access to appropriate types and levels of support.
- Referral and risk assessment with clear referral pathways.
- Development and maintenance of a bereavement directory to create a more seamless and sustainable service model.
- Improved access to training for staff/volunteers.
- Improvements in how services are evaluated and assessed.

**Outcome:** The development of a national framework for bereavement care, promoting prioritisation of bereavement support at organisational and regional level, delivering a sustainable, motivated workforce, delivering effective and efficient bereavement support throughout Wales.



# 6.17 Liver Disease Implementation Group

During 2019/20, the Liver Disease Implementation Group continued to work with NHS and third sector colleagues to implement the key recommendations of the Liver Diseases Delivery Plan. Amongst its priorities for 2019/20 were:

- Prevention of liver disease
  - continued support for Alcohol Care Teams established in all district general hospitals in Wales.
  - continuing work to eliminate blood borne viral hepatitis.

- Early detection of liver disease.
- Supporting all liver services in Wales to work towards Level 1 and Level 2 accreditation under the IQILS (Improving Quality in Liver Services) accreditation programme.
- Developing the Welsh Liver Disease Registry.

#### **Rapid Testing for Hepatitis C**

Hepatitis C is a significant issue within prisons. Many prisoners have a history of intravenous drug abuse, and close to 50% of people who inject drugs and 30% of former injecting drug users are believed to have hepatitis C.

Although simple and effective treatments are now available, prisoners have had to wait several weeks for test results and to begin treatment, meaning that many prisoners were transferred or released prior to getting their results or treatment, which had negative consequences for their health and increased the risk of transmission in the community and in other prisons. This is a particular problem in a remand prison where there is a very high turnover of prisoners.

The Viral Hepatitis Subgroup, working with HMP Swansea, Swansea Bay University Health Board and Public Health Wales, established a pilot rapid testing and treatment system in HMP Swansea. Point of Care Testing enables successful initiation of hepatitis C treatment in prisoners within a day or so of their entry to the prison.

In September 2019, it was announced that all men in HMP Swansea Prison had been tested for hepatitis C and were found to be either negative or already on treatment, essentially eliminating hepatitis C, a UK first for a remand prison.



# 6.18 Neurological Conditions Implementation Group

Priorities for 2019/2020 were to:

- Implement a co-productive approach to raising awareness of neurological conditions.
- Implement a co-productive approach to service development.
- Develop clear pathways and models of care based on best practice and research evidence.

The clinical lead took forward work to improve clinical and organisation engagement, with task and finish groups established for Seizures, Neuro-rehabilitation and Paediatric Neurology Services. Places were secured on the Clinical Leadership Programme delivered through Stroke Education for Wales, and two places were allocated to each of the task and finish groups to support clinicians to deliver on the objectives of the groups.

Funding was allocated to the Wales Neurological Alliance to develop a Patient Reported Experience Measure and awareness raising programme.

The group has continued to work with the Value Based Health Care team to implement the agreed Patient Reported Outcome Measure across all health boards. Work is ongoing to have this work added to the national platform for services for people with neurological conditions.

#### **Seizures Task and Finish Group**

Epilepsy is one of the most common neurological conditions, and presents to primary care, acute unscheduled care, outpatient clinics, and community services. It has a disproportionate impact in areas of high deprivation, is associated with significant premature mortality, and can be a common secondary problem in a number of other neurological conditions, such as post acquired brain injury, brain tumour, stroke and MS.

The Seizures Task and Finish Group was established in July 2019, chaired by Dr Rob Powell, consultant neurologist in Swansea Bay University Health Board. It is a multi-professional group, with representation from all health boards, the third sector and Swansea University and its priorities are:

- Development of a standardised all-Wales pathway for the management of epilepsy and first seizures, covering primary and secondary care.
- Development of a national epilepsy Patient Reported Outcome Measure.
- To improve reporting and raise awareness of Sudden Unexpected Death in Epilepsy (SUDEP).



Two specialist epilepsy nurses have taken forward projects as part of the Clinical Leadership Programme:

- Development of all-Wales pathway for first seizure to be used in emergency departments and primary care to improve patient outcomes.
- Development and delivery of a sustainable model of care at the Welsh Epilepsy Centre by implementing a patient-led see-on-symptom service, providing a seamless transition across primary and secondary care.

Epilepsy/SUDEP is now to be included in the Wales National Bereavement Pathway which is being developed.

The group have also had preliminary discussions with the value based healthcare team about developing a national data dashboard for seizures and epilepsy. This will inform and support the development of a national dashboard for neurological conditions more broadly.



# 6.19 Rare Diseases Implementation Group

A rare disease is defined as one that affects fewer than 1 in 2,000 of the general population. There are between 5,000 and 8,000 known rare diseases and 7% of the population will be affected by a rare disease at some point in their lives. During the year, the Rare Diseases Implementation Group has continued to work to improve services for children and adults with a rare disease concentrating on delivering a number of key priorities:

• Identifying and improving the pathway for patients with unknown or delayed diagnosis.

- Ensuring better use of patient feedback, best practice and evidence to improve pathways for primary, secondary and specialist services.
- Improving reporting of rare disease information including epidemiology, significant event analysis and shared learning.

#### All Wales Infants' and Children's Genome Service (WINGS)

The All Wales Medical Genetics Service have developed the All Wales Infants' and Children's Genome Service (WINGS) which provides whole genome testing for acutely unwell babies and children with unexplained rare diseases. There are between 6,000 and 8,000 known genetic diseases, but many people with rare illnesses have to wait a long time for answers, as experts try to pinpoint which genes might be responsible. This new service will help to dramatically increase the ability to identify a genetic cause for rare diseases, and shorten what is often a lengthy 'diagnostic odyssey', enabling clinicians, parents and carers to make evidence informed decisions and reducing the anxiety of uncertainty. This service will be available from April 2020 and is the UK's first diagnostic rapid Whole Genome Sequencing service for paediatric patients.



# 6.20 Respiratory Health Implementation Group

The Respiratory Health Implementation Group has focused on innovation, new ways of working, and a novel national programme for respiratory care across Wales.

It has developed a suite of digitalised interventions, which have been embedded within a structured implementation framework. It has aligned health strategy at government and health board level whilst supporting frontline healthcare workers in primary and secondary care, and providing health solutions directly for patients themselves.

• National databases and patient management systems.

- TV shows embedded within a range of national guidelines featuring interviews with the authors – national guidelines that are the first of its kind.
- Supporting blended educational programmes aligned with the Respiratory Delivery Plan work streams - with the latest evidence and strategy delivered by disease and service specific specialists.
- Structured quality improvement opportunities delivered with the Royal Colleges.
- Dual language NHS Wales self-management apps for asthma and COPD.

#### National respiratory pathways

By creating national pathways, £10 million has been saved in inhaler spend in only four years. The principles, processes and speed of delivery are perhaps most widely illustrated in the development of the COVID-19 hospital guideline, which was implemented within every hospital in Wales. The platform was created from scratch in just three weeks. Within two months it was scaled up in size 25-fold from its original design, to include over 150 educational videos delivered by experts from across Wales. This is now available for primary care, as well as a specific platform for care home staff.

Over 4500 clinicians are registered, 60% of which are senior clinical decision makers. Clinicians will continue to receive updates throughout the pandemic. The platform is also being utilised internationally, it has been endorsed in independently written peer-reviewed publications, and has featured on ITV news.

What the implementation group has developed is accessible for everyone in Wales. It is available to access anytime, anywhere and through any device. The whole infrastructure is seamlessly linked in principle and in practice, so we achieve the important outcomes from everyone knowing, learning and doing the things that really matter.

# 6.21 Stroke Implementation Group

The stroke pathway describes six steps that are regarded as important within the overall pathway for stroke care:

- Living well.
- Stroke prevention.
- Early recognition and transient ischaemic attack.
- Fast effective care.
- Rehabilitation, recovery and life after stroke.
- End of life care.

The Stroke Implementation Group has funded and supported projects aimed at delivering improvements across all elements of the stroke pathway:

 Hyper Acute Stroke Units remain a priority and funding has supported projects to enable a move towards this enhanced model with sites offering 24/7 multidisciplinary stroke expertise.

- National Patient Reported Outcome Measure (PROM), working with the value-based health care team.
- Self-help book produced by psychology colleagues in Wales "Rebuilding your life after stroke".
- Bridges Self-Management an evidenced-based, person-centred approach to self-management of symptoms for patients living with stroke and other long-term conditions.
- In partnership with Cardiff Metropolitan University, continued support for the Stroke Hub, the home for stroke education, research and innovation.
- Multidisciplinary places on the Clinical Leadership Programme delivered by Swansea University to develop the next generation of stroke leaders.

#### Stop a Stroke Campaign

The Stop A Stroke campaign is a project to reduce the incidence of stroke in patients with atrial fibrillation (AF), by ensuring that each patient with AF across Wales has a review of their stroke risk and anticoagulation status in line with the latest NICE /All Wales Medicines Strategy Group guidance. The project also forms an integral part of the Quality Assurance Improvement Framework AF QI Project.



Across Wales the project has been able to:

- **1.** Provide primary and secondary care clinicians with:
- Education regarding the risk of stroke and AF.
- An online resource **www.stopastroke.co.uk** to support risk assessment and safe prescribing.
- A model enabling primary care colleagues to effectively and sustainably review patients.
  with AF and initiate prescribing of appropriate anticoagulation, which has worked well across diverse GP clusters in Cardiff and Vale.
- The SAS Audit + tool, deployed to 416 GP practices, providing each with a dashboard that allows them to identify patients with AF and their current treatment (warfarin, Direct Oral Anticoagulant (DOAC) or antiplatelet or not currently on treatment).
- A dashboard (Primary Care Information Portal) that allows all cluster leads and health board leads to view cluster/health board data to identify variance.
- Provide the Audit+ tool and primary care dashboard which allows easy identification of all patients:
- With AF who are at risk of stroke based on their CHA2DS2-VASc score.
- Receiving antiplatelet monotherapy for stroke prevention in AF.
- Implement an E-advice system within Cardiff and Vale University Health Board which has led to a reduction in out-patient haematology referrals and appointments.
- 4. Every health board now has a local enhanced service in place with GP practices for the initiation of Direct Oral Anti Coagulants (DOAC) for AF. This has been a main driver for the prescribing of DOACs in primary care across Wales.



# 6.22 Women's Health Implementation Group

Following its establishment in 2018, the Women's Health Implementation Group delivered a number of achievements in 2019/20, which included:

- Baseline demand and capacity activity commenced to make recommendations for a future Pelvic Floor pathway.
- Co-productive communication with patient groups and networks; namely Welsh Mesh Survivors Group and Fair Treatment for the Women of Wales.
- NHS Wales commitment to a national provision of Sacral Nerve Stimulation to treat severe faecal incontinence.
- Launch of the *Better for Women* Report by the Royal College of Obstetricians and Gynaecologists.

- Improved awareness throughout Wales, presenting at various opportunities within health boards, All Wales forums and UK meetings.
- Improving public awareness of endometriosis and period health.
- Revised approaches to data collection and analysis with new NHS Wales Informatics Service clinical mesh procedure codes.
- Visits to multi-disciplinary teams throughout Wales to share best practice.

# How we can deliver value and improve patient outcomes to the women of Wales suffering with severe faecal incontinence

It is estimated 1.4% of the population experience severe faecal incontinence; 44,800 people in Wales. Patients experience an average seven episodes a day.

NICE approved treatment is sacral nerve stimulation (SNS) where conservative management has not improved outcomes. SNS is a "minimally invasive" treatment and without SNS a patient may have a stoma which is irreversible.

The greatest cause of faecal incontinence is obstetric injury, trauma through vaginal childbirth.

In Wales:

- Approximately 11,000 vaginal birth deliveries per year.
- Obstetric anal sphincter injuries reported to occur in approximately 3.7% of vaginal birthsbut this may be as high as 6.1% in first time mothers = between 407 – 671 mothers injured each year.
- 80% can be managed via conservative methods, 20% may be suitable for SNS.
- Patient Episode Data Wales in 2014/15, 122 hospital admissions due to faecal incontinence that accounted for 346 bed days. Average bed day cost £220 is a £76,120 cost to the NHS.

This treatment has been a non-commissioned service in Wales, where patients have received the treatment in England – costing health boards up to 30% more versus providing the treatment 'inhouse'.

Following analysis and gathering patient experience data, the Women's Health Implementation Group presented their findings to NHS Wales Chief Executives.

- Analysis of AS-IS and TO-BE procedures, medication, treatments and consumables, costs can be reduced to £14,210.
- With SNS cost reductions, patients also receive better outcomes.
- SNS treatment can cause reduction of 50-70% episodes of faecal incontinence per week, and in some patients it can be 100% reduced.

The Women's Health Implementation Group and Pelvic Floor Co-ordinators are continuing their work to develop proposals to commission the treatment in Wales.



Collaborative-wide developments

# 7.1 Welsh language

We recognise the importance of the Welsh language in Wales and we are committed to meeting the language needs and preferences of our stakeholders as well as promoting its use within our work and processes.

Since May 2019, the Collaborative has been implementing its Welsh Language Standards and, more recently, has been looking at how we can further contribute to the Welsh Government's '*More Than Just Words*' Strategic Framework for Welsh Language Services in Health, Social Services and Social Care.

We appointed a full-time Welsh Language Support Officer who works within and across the organisation. The Senior Management Team receive a regular monthly update on compliance with Welsh Language standards and regularly review and implement relevant opportunities to further help increase and improve the use of Welsh in the organisation.

The Collaborative has established a Welsh Language Implementation group with Welsh language representatives from across networks, programmes and teams. This group coordinates and progresses Welsh language matters and provides a forum for staff to share best practice, challenges and opportunities for improvements.

The Welsh Language Support Officer collaborates regularly with Public Health Wales' Welsh Language team to share progress and to work to resolve issues, and is an active member of its Welsh language Group. The Welsh Language Support Officer is also a member of the All Wales NHS Welsh Language Officers Group who share best practice and collaborate to improve Welsh language provision on a national basis. Active membership of these groups provides further opportunities to embed Welsh language into the work of the Collaborative.

We have made good progress in improving the availability, quality and equality of our Welsh medium services, however we recognise that there is still much to do to further embed Welsh language in our work. Over the next period there will be sustained focus and momentum with regards to achieving our obligations under the Welsh Language Standards (No. 7) Regulations and further embedding Welsh into our work and processes. In recognition of the importance of the Welsh language to our work, we will publish a Welsh Language Annual Report for 2019/2020 on our website.



# 7.2 Planning arrangements

The 2019/2020 Work Plan set out ways to maximise the collective impact of the Collaborative. Mechanisms were established to strengthen cross-organisational working and outputs will inform the development of a longerterm plan, in alignment with national planning frameworks and the priorities of NHS Wales.

Engagement with staff, the staff forum and senior management team identified a number of common themes:

- Technology and Business Intelligence.
- Quality and Safety.
- Pathways.

Each of these themes is the subject of a working group populated from our teams to ensure full organisational representation and engagement. The groups are supported by an overarching Collaborative Planning Group. These groups provide a practical opportunity for wider staff to get involved, find out about what is happening across the organisation and NHS Wales, and develop new skills and experience.



# Valuing our staff

The progress made and achievements through the year are due to the commitment and hard work of all our staff and those who work with us. This annual report has been prepared through contributions from staff and to reflect examples of achievements important to them.

A staff forum was established in 2019 as one of our actions in response to the 2018 NHS Wales Staff Survey, and with the primary objective of taking forward and monitoring the implementation of the Collaborative staff survey action plan. The action plan has, as priority themes, values, staff wellbeing, team working, diversity and communications. The staff forum provides a two-way communication process between staff across all sites and senior managers. It has representation from all teams and has had positive engagement since its first meeting in April 2019.

During its first year, the staff forum delivered a number of actions, its main achievement being the successful delivery of a staff away day featuring key aspects from the domains highlighted within the survey; especially around collaborative working, resources and communication. Members of the staff forum worked well together to plan and deliver the day. Feedback from staff was positive and further events are planned. The staff forum also coordinated lunch and learn sessions throughout the year and raised funds to support local flood victims following the devastating floods in February 2020.



# 2019/2020 Financial Performance

# 9.1 2019/2020 Financial performance

The 2019/20 Collaborative annual net outturn was £15.6m.

The agreed 2019/20 forecast financial position for the NHS Wales Health Collaborative was an underspend of £584k. This net underspend position related to part year vacant posts within the Collaborative and slippage against planned projects. In line with the requirements of the hosting agreement, the £584k forecast underspend was returned to health boards and trusts in proportion to their original contributions to the Collaborative Team budget. As a result, the Collaborative Team achieved a break-even position at the 2019/20 year end.

The tables below include a summary and details of the 2019/20 financial outturn:

# 9.2 Summary of 2019/2020 outturn

Туре	WTE	2019/20 actual levels		
		£000s	%	
Income		(15,571)	50.0%	
Рау	114.31	7,291	23.4%	
Non pay		8,280	26.6%	
Total	114.31	0	100.0%	

The core budget for the Collaborative includes the agreed legacy budgets of those parts of the Collaborative that were previously in Public Health Wales, together with a number of additional programmes and the following clinical networks which make up 55% of the overall annual Collaborative budget:

- Wales Cancer Network.
- Wales Cardiac Network.
- Wales Critical Care and Trauma Network.
- Wales Neonatal and Maternity Network.
- Wales Mental Health Network.

# 9.3 NHS Wales Health Collaborative -Summary of 2019/2020 net spend

	2019/2	2019/20 net spend	
Teams/Clinical Networks	£000s	%	
Business, Governance & Finance	761	4.9%	
Cancer Delivery Plan	1,084	7.0%	
Cancer Network	6,380	41.0%	
Cardiac Network	453	2.9%	
Critical Care & Trauma Network	707	4.5%	
Diabetes Implementation	910	5.8%	
Director	651	4.2%	
Endoscopy	793	5.1%	
Implementation Group Coordinators	306	2.0%	
LINC	1,041	6.7%	
Lymphoedema	363	2.3%	
Maternity & Neonatal Network	421	2.7%	
Mental Health Network	574	3.7%	
Planning	207	1.3%	
Programmes	635	4.1%	
Women's Health	286	1.8%	
2019/20 total net spend	15,571	100.0%	

The total net spend of £15.6m in 2019/20 represents an increase of £3.9m (33%) compared to the 2018/19 annual net spend and the staffing levels in 2019/20 increased by 25.84 (29%) compared to 2018/19.

The main reasons for the increased turnover in 2019/20 relate to the Collaborative's additional responsibilities and new areas of work including the Nationally Directed Programme for Endoscopy, Implementation Group Co-ordinators, Diabetes Implementation Group funding, Mental Health Network and the ramping up of the LINC Programme.



Forward Look – 2020/2021 2020/2021 began with exceptional demands being placed on the NHS to respond to the COVID-19 outbreak.

As a result, we initially focused our attention on:

- Providing specific national support and coordination in the areas covered by our various programmes and networks (to directly support the COVID-19 response or to maintain other, essential health services).
- Supporting the Public Health Wales response (as our host organisation).
- Direct support by individual members of staff to health board/trust services to enable service continuity.
- Maintaining urgent, core Collaborative business.

We have reviewed our work programme in the context of the challenging and uncertain environment created by COVID-19 and we will continue to provide a flexible response, through 2020/2021, in support of NHS Wales.

#### For further information, please contact:

NHS Wales Health Collaborative River House, 1<sup>st</sup> Floor Ynys Bridge Court Gwaelod y Garth Cardiff CF15 9SS

NHSWHC.ContactUs@wales.nhs.uk

We welcome correspondence in Welsh and English – we will respond equally to both and will reply in your language of choice without delay.



