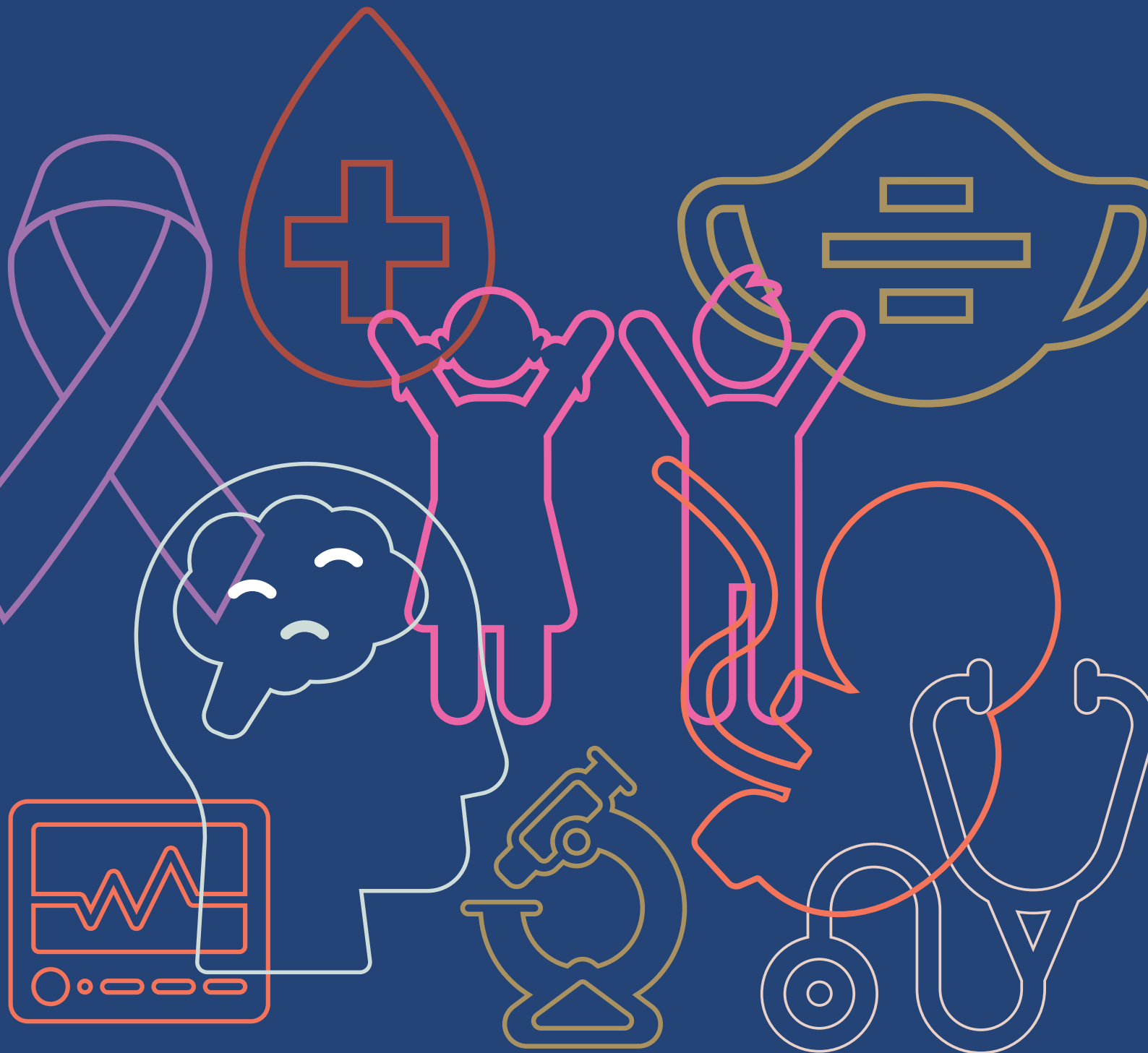GIG
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NHS Wales Health
Collaborative

NHS Wales Health Collaborative
Annual Report 2020/21

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Foreword

Welcome to the third annual report of the NHS Wales Health Collaborative, covering 2020/21. I hope this will give you an insight into the range of our work and the achievements of our teams over this particularly challenging year.

The Covid-19 pandemic meant we had to face a range of new challenges and introduce and adapt very quickly to new ways of working as an organisation. Thanks to the commitment, flexibility and hard work of our externally facing teams and the support provided by our corporate staff, we were able to continue to develop and enhance our support to NHS Wales through the use of technology.

It is difficult to capture all of the work our teams have achieved in one single report, but here we have highlighted the areas that our teams feel are particularly important to them and the NHS services with whom they work.

I thank all Collaborative staff for their dedication to improving health care and services for the people of Wales. They demonstrate every day the importance and value of working in collaboration with a wide range of partners, including NHS Wales, Welsh Government, the third sector, industry, and patient groups to achieve the best outcomes.

I also want to take the opportunity to acknowledge the leadership and dedication of Rosemary Fletcher, who retired from her role as Director of the Collaborative in March 2021 and who oversaw the work summarised in this report.

I hope you enjoy reading this report for 2020/21.

Mark Dickinson
Director

Introduction

About us

The NHS Wales Health Collaborative is a national organisation working on behalf of the health boards, trusts and special health authorities that make up NHS Wales.

Through facilitating engagement, networking and collaboration between our NHS partners and other stakeholders, our teams work to support the improvement of NHS Wales' services across organisational boundaries, in order to improve the quality of care for patients. We help to plan, shape and make recommendations on NHS services across Wales.

Our teams cover a broad range of clinical networks, national programmes and projects, major conditions implementation groups, and support functions. The Collaborative is hosted by Public Health Wales, on behalf of NHS Wales.

Our work

Our work plan is shaped in a number of ways and its scope continues to grow, year on year. The majority of our work plan comprises the priorities agreed through clinical network boards, major conditions implementation groups and national programme boards.

In 2020, we reprioritised our work to focus on providing support to NHS Wales and Welsh Government in the response to the COVID-19 pandemic.

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.

Clinical Networks
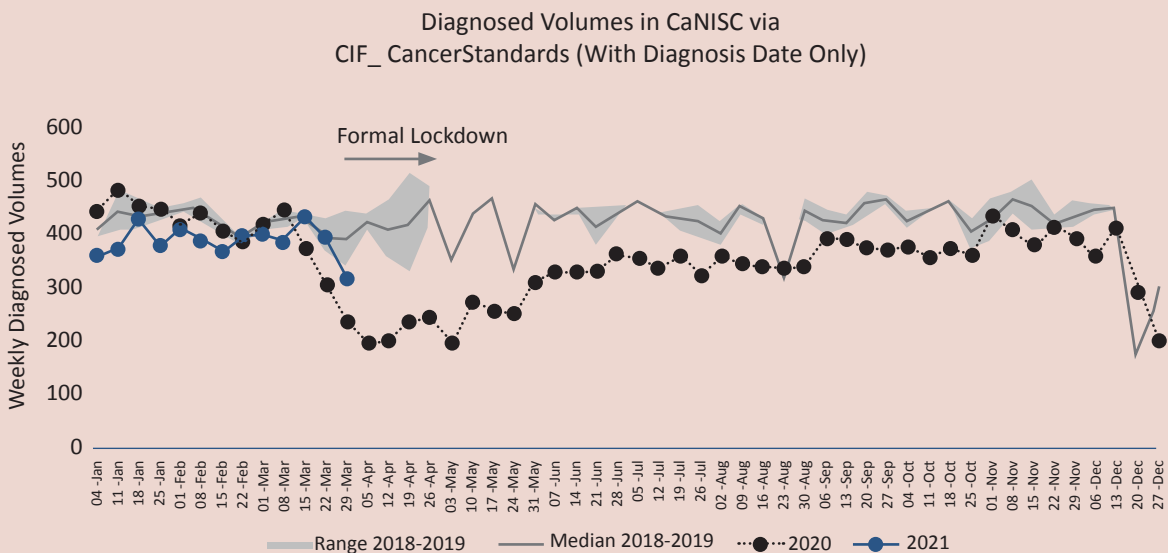
Wales Cancer Network

The Wales Cancer Network provides system leadership for partners to work collaboratively to transform cancer services and improve outcomes for patients.

Our 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**
- **A national programme to develop Rapid Diagnosis Centres that provide early diagnosis for people who have vague symptoms of cancer**
- **Co-ordinating a national approach to digital patient centred care documentation, and the third 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 (Chemocare)**
- **Bowel Cancer Initiative, a 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**
- **Driving improvement by quality assurance through the Cancer Peer Review programme.**

What we achieved in 2020/21

The Covid-19 pandemic has had a profound effect on cancer services in Wales with a reduction of suspected cancer referrals and fewer patients diagnosed with cancer (please see graph below).

Diagnosed Volumes in CaNISC via
CIF_ CancerStandards (With Diagnosis Date Only)

The Wales Cancer Network has been central to the collaborative approach in understanding the challenges facing cancer services through the COVID-19 pandemic.

We established the Operational Managers Group, bringing together cancer operational managers, Digital Health and Care Wales, Delivery Unit, Improvement Cymru, lead nurses and allied health professionals to understand the challenges facing cancer services through the COVID-19 pandemic and help develop new ways to address some of the issues that COVID was presenting for suspected and confirmed cancer patients. The Group was formed to support the Health Boards and Trusts with

- **Maintaining and reinstating essential cancer services during the pandemic**
- **Developing plans for recovery**
- **Maintaining consistent and equitable access to urgent and essential surgery**
- **Creating designated cancer surgical and/ or diagnostic hubs and recommencing complex surgery either at local or regional basis.**

The group supported the development of the Single Cancer Pathway dashboard to report the performance against the Single Cancer Pathway, which was published in March 2021.

In addition, a Clinical Reference Group was formed to bring together the cancer clinical community leading a unified approach to the response to the COVID-19 pandemic in the development of transparent, consistent and equitable service plans.

The Clinical Reference Group was pivotal in advising Welsh Government around patients being vaccinated prior to cancer treatment, and for developing a framework for obtaining remote informed consent for Radiotherapy and Systemic Anti-Cancer Therapy (SACT) during COVID-19.

The Wales Cancer Network through the Operational Managers Group and Clinical Reference Group were responsible for leading the development of clinical guidelines in response to the COVID-19 pandemic, including a framework for the Recovery of Cancer Services in Wales during COVID-19.

As a response to the fall in suspected cancer referrals in 2020, the Wales Cancer Network and NHS Collaborative led a communications campaign in collaboration with Welsh Government and third sector organisations encouraging the public to seek medical advice if they are experiencing any signs and symptoms of cancer.

We are now seeing around a 40 per cent increase in demand at the end of March 2021, raising new challenges leading into the new financial year.

In addition to this work the Wales Cancer Network achieved other key objectives:

- **In collaboration with Health Boards, we appointed regional project managers and a national programme manager to develop a standardised national approach for the development of Rapid Diagnosis Centres**
- **We published Tranche 2 of the National Optimal Pathways**
- **We provided a total of £100k in funding for 10 improvement or innovation projects across Health Boards and Trusts relating to our four work streams: Person Centred Care; Single Cancer Pathway; Research Development and Innovation; Information and Intelligence.**

Wales Cardiac Network

The Cardiac Network works with partners within primary, secondary and tertiary health services to improve care and outcomes for people of all ages at risk of or affected by heart conditions.

Our work is driven by the Heart Conditions Implementation Group (HCIG), with clinical and managerial representation from health boards, commissioners, professional societies and key strategic partners from across the cardiac communities in Wales.

The HCIG provides leadership and oversight to influence health boards in translating them into their own medium term and annual plans, together with the work programme for the Cardiac Network.

The HCIG priorities for 2020/21 were to support the Delivery Plan:

- **To build on the development of the community cardiology services and all Wales clinical pathways; to deliver value-based healthcare and to implement the pathways for heart failure, atrial fibrillation and acute coronary syndrome**
- **To implement the Out of Hospital Cardiac Arrest (OHCA) Plan for Wales**
- **To improve the Cardiac Informatics Roadmap.**

The impact of the COVID-19 pandemic, however, meant we had to put the majority of our work programme on hold to prioritise essential services.

The National Institute for Cardiovascular Outcomes (NICOR) highlighted concerns about delayed interventions in a report published in September 2020.

These concerns were reflected in the NHS Wales Operating Framework for the following six months, which identified a need to consider re-instating non-essential cardiac services and prompted a revised set of priorities:

- **To share learning from the revised implementation and operational delivery across services in Wales**
- **To develop new models in the provision of cardiac services, promoting agile working and virtual clinics, patient classes and non-direct contact diagnostics**
- **To ensure sustainable fit for purpose workforce for cardiology services in Wales.**

What we achieved in 2020/21

Following the first wave of the pandemic, there was a challenge in re-establishing consultant job plans and demand from acute coronary services escalated rapidly.

As a network, we played an active part in restarting elective activity safely, supporting the development of revised 'clean pathways', which included pre-procedural testing protocols for patients.

Elective activity recommenced with diagnostic angiography only, followed by the re-establishment of PCI services.

Establishing a fit for purpose physiology workforce was essential. This was progressed in collaboration with HEIW and specialists and clinical leads from health boards to address current needs and future training requirements.

As the pandemic continued it proved very difficult to maintain any elective services due to staff absence and sickness.

The network developed an operational managers group consisting of clinical leads, operational managers and planning representatives to help provide guidance for health boards. This was in addition to the guidance provided with the essential services framework.

There were many changes to practice during the pandemic, which included creating new concepts and remote ways of working. To ensure that we held on to the good changes that emerged, the network acted as a repository for shared learning. The further development of Sharepoint options will allow access to these resources.

The use of technology to deliver virtual clinics and working practices were supported though the development of standard operating procedures (SOPs). These new working practices were well received by both patients and staff and effective during the pandemic by reducing patient risk and exposure to coronavirus.

As a network, we helped shape the opportunity to reset the threshold for accepting referrals from primary care to be seen in clinics, as advice and guidance delivered in a timely fashion (for example, using the Welsh Clinical Portal and e-referrals) would be more prudent. This would result in fewer investigations especially among low risk populations and help to reduce waiting lists.

Following clinical consensus, work began on triaging existing and new requests in collaboration with primary care colleagues. This work has informed the risk stratification process currently being developed with Welsh Government.

We re-established the Save a Life Cymru partnership and launched with a successful communication strategy in the autumn including targeted social media campaigns to raise awareness of the need for CPR and defibrillation skills.

Finally, the pandemic highlighted the risk of having both elective and acute services on single sites and that a whole systems approach was needed to progress.

We are therefore working actively with other condition specific clinical leads and the value-based health team to identify a road map for the future. We have embraced an opportunity to radically redesign our future services and the setting up of 'regional or community' diagnostic and treatment hubs is a first step in this separation.

Wales Critical Care and Trauma Network

The Critical Care and Trauma Network provides a framework through which clinical care for the critically ill and traumatically injured can continuously improve across Wales.

The Network began as three regional networks for Critical Care in 2007 and has since evolved to a single Network for Wales with responsibility for Trauma for the north Wales population. In 2020/21, we changed from being 'just' a Network into being a true community, supporting clinicians to work in innovative ways to respond effectively to the Covid-19 pandemic.

At the start of the year, we expected to focus on implementing the recommendations of the 2019 Task and Finish Group for Critical Care overseeing investment of an initial £15 million and planning a five-year phased implementation of the full recommendations. Instead, the Network focused on responding to the Covid-19 pandemic.

Whilst we co-ordinated a Wales-wide critical care pandemic response, the Network continued with the procurement and implementation of the Wales Intensive Care Information System (WICIS), securing capital funding for the national programme and running hundreds of hours of clinical configuration workshops.

What we achieved in 2020/21

In March 2020, our work plan was put on indefinite hold whilst we changed how we operated to support NHS Wales to respond to Covid-19. Within days, the Network moved from a strategic planning role to actively delivering operational co-ordination of the cross-Health Board critical care pandemic response.

The Network team was the link between Critical Care clinical teams and professional bodies, colleague clinical networks and delivery groups such as Renal and Respiratory, Health Board executives, NHS Wales Shared Services Procurement, Public Health Wales and Welsh Government as NHS Wales prepared and then weathered the two waves of the pandemic.

When the pandemic was declared in March 2020, our first action was to bring together senior critical care clinicians, Welsh Ambulance Service Trust and Emergency Medical Retrieval and Transfer Service along with experts from Public Health Wales and policy leads in Welsh Government to assess the situation to start planning a Wales-wide critical care response to the pandemic.

From that point on, we continued to co-ordinate bi-weekly meetings for the duration of the pandemic to steer the planning and delivery of critical care services across health board boundaries.

Early in the outbreak, we brought together representatives from Health Education and Improvement Wales (HEIW), critical care practice development nurses and senior lecturers in critical care from Welsh universities to plan a training syllabus and roll-out programme to upskill the non-critical care workforce that would be required to support critical care units in the pandemic.

Throughout the pandemic, our experienced clinical and management team offered expertise to advise on purchase of ventilators, renal supplies and syringe drivers and working with Welsh Government and Shared Services on distribution of UK-procured stock. Statistical modelling for the second wave predicted greater numbers of patients requiring critical care than in the first wave and the fear was that, even with the extra support from respiratory wards, critical care units would be overwhelmed.

The Network supported preparation by gaining agreement on mutual aid procedures and facilitating the establishment of a critical care transfer service to move critically ill patients from units close to overwhelm to other units in Wales with available capacity.

We established and ran morning meetings seven days a week, at which senior professionals from critical care units, the network, Welsh Government, the Emergency Medical Retrieval Service and the ambulance service could monitor the situation and plan patient transfers.

The Network continues to gather information from health boards on the lessons learned from both waves of the pandemic. These will be synthesised into more effective emergency pressure plans across the critical care system as well as highlighting ways of working that could be embedded into normal services beyond the pandemic.

Wales Maternity and Neonatal Network

Established in 2019, the Wales Maternity and Neonatal Network brings together stakeholders from across Wales to support each other in improving the overall safety and quality of maternity and neonatal services.

By improving the experience and outcomes for mothers, babies and their families, we can help give every child the best start in life and play our part in reducing long term health inequalities.

Our priorities are driven by the All Wales Neonatal Standards (3rd Edition) and the Welsh Government's strategy 'Maternity Care in Wales: A Five Year Vision for the Future (2019-2024)' and organised under the following five work streams:

- **Family centred care**
- **Continuity of carer**
- **Safe and effective care**
- **Skilled multi-professional workforce / Sustainable services**
- **Timely care.**

What we achieved in 2020/21

The impact of Covid-19 resulted in considerable pressure on maternity and neonatal services. In addition, part of our workforce was diverted to supporting the wider response to the pandemic, acting on behalf of the Essential Services Cell in providing health boards with an assurance framework to self-assess their services.

Despite these pressures, colleagues remained keen to move ahead with the workplan and we made significant progress, including:

- Launching an interim 24-hour neonatal transport service for south Wales in January 2021

- Advancing work on a maternity performance indicators dataset – all relevant data sharing agreements are now in place and we have data from Digital Health and Care Wales going back to 2014. The aim is to develop a dashboard to allow for real time data to be accessed and necessary assurances be made to ensure safe maternity services in Wales

- Running very positive training and education events over MS Teams addressing topics such as safeguarding, supporting end of life, and results and learning from OBS Cymru, the three-year Obstetric Bleeding Strategy programme

- Using MS Teams to increase colleague engagement with ongoing mortality reviews

- Establishing task and finish groups to take forward areas of work including development of clinical guidelines.

Prior to Covid-19, we had started promoting a two-day Family and Infant Neurodevelopmental Education (FINE) event, which would have cost health boards approximately £600 per candidate.

However due to slippage in our budget and in recognition of our ethos around family integrated care, we decided to fund 42 places on the FINE Level 1 training. FINE is an innovative step-by-step pathway designed to enable neonatal professionals to put the theory and evidence behind infant and family-centred, developmentally supportive care into practice.

Level 1, the foundation toolkit, is an interactive classroom event consisting of lectures and workshops, covering a range of neuroprotective topics that fit into the six core themes:

- **Infant development**
- **Observation**
- **Family**
- **Reflection**
- **Systems**
- **Evidence**

Participants are then able to progress their learning further through Level 2 which invites them to put theory into practice and Level 3 which continues to reference the six core themes but places more emphasis on systems with the completion of two projects, one being a quality improvement project based on the plan do-study-act (PDSA) model.

Doctors, nurses and allied health professionals from neonatal units across the network took part in the level 1 training funded by the Network. Feedback was extremely positive, with 97 per cent of participants describing the content as extremely relevant to their practice and 75 per cent saying that attending the course would change their practice.

Already practitioners are noting evidence of changes in practice, in particular to recognising baby cues, positioning and containment and communication with parents, which will contribute to ensuring outcomes for babies and families across Wales.

Wales Mental Health Network

The aim of the All-ages Mental Health Network is to bring about positive change and sustained improvement for mental health services commissioned or provided by the NHS in Wales.

We promote a prudent, whole system approach and our priorities are guided by the delivery plan for the Welsh Government's 'Together for Mental Health' Strategy 2019-2022 and the suicide and self harm prevention strategy 2015 – 2022, which align to ambitions in 'A Healthier Wales'.

The network includes the following sub-groups and programmes

- **Perinatal Mental Health**
- **Child and Adolescent Mental Health (CAMHS)**
- **Eating Disorders**
- **Adult Mental Health**
- **Together for Children and Young People (T4CYP)**
- **Suicide and Self Harm Prevention.**

Perinatal Mental Health Network

We oversee the planning and delivery of efficient and effective perinatal mental health services for NHS Wales. We focus on prevention, earlier intervention, prudent health care, and ensuring that the right services are provided at the right time and by the right people.

The network supports evidence-based and innovative practice, enabling equitable delivery of services across Wales. Our work centres on implementing the recommendations of the 2018 report by the Assembly's Children, Young People and Education Committee, and 'From Bumps to Babies: Perinatal Mental Health Care in Wales'.

We bring stakeholders together to shape services for parents, with parents, to improve the quality and equity of care.

What we achieved in 2020/21

- We prioritised plans to develop the interim six-bedded Specialist Perinatal Mental Health Inpatient Unit, which opened in April 2021
- We completed the consultation on the content for the new clinical pathway, which is now being designed
- All health boards signed up to the perinatal quality network and will be adopting a quality improvement approach to meeting national standards
- We established links with Health Education and Improvement Wales (HEIW) and Health Education England (HEE) and began the process of developing a national competency framework.

Eating Disorders

The Eating Disorders sub-group brings together clinicians, service managers, service users, carers and third sector representatives. We work to improve services in Wales for people of all ages who experience an eating disorder, and to support their families.

Our aim is to achieve effective and accessible services that provide consistent quality of treatment and care across Wales, with the flexibility to meet the individual needs of service users and their families.

Since 2018, we have been guided by the recommendations of the Welsh Government's Eating Disorders Service Review, informed by ongoing consultation with those providing and receiving treatment across the pathway.

What we achieved in 2020/21

- We appointed a National Lead for Eating Disorders to take forward strategic development of services for people with eating disorders
- With the support of the Welsh Government's mental health improvement funding, we enhanced eating disorders specialist services in line with early intervention
- We carried out online consultation workshops with service users and their families to inform the delivery of the recommendations in the Welsh Government's eating disorders service review
- We monitored the severe impact that COVID19 has had on the rates of eating disorders and specifically the resulting pressures on inpatient services
- We completed an audit of refeeding admissions for young people aged 16 and 17
- We produced training materials based on service user and carer lived experience
- We established a nationwide clinical consultation network to discuss treatment of eating disorders with diabetes.

Adult Mental Health

The Adult Mental Health Services network aims to effect positive change and long-term sustainable improvement in services commissioned or provided by NHS Wales.

We promote a whole system approach that encourages integration of services across the NHS, local government and the voluntary sector, advising partners and stakeholders on planning and providing specialist services and supporting data collection.

What we achieved in 2020/21

- We appointed a National Lead to support the implementation of the actions relevant to adult services in the 'Together for Mental Health' delivery plan
- We completed a review of the published literature in relation to community mental health services
- We established a work programme to support the development of national guidance for community mental health teams, informed by online engagement with service users and carers
- We held a successful online engagement event with key stakeholders including health board representatives, the Royal College of Psychiatrists, the all-Wales Senior Nurse Advisory group and third sector organisations
- In response to concerns about a lack of consistent information regarding the availability of mental health services during the pandemic, we created an FAQ resource that all health boards incorporated into their websites.

Child and Adolescent Mental Health Services (CAMHS)

The CAMHS Network is made up of clinical leaders and practitioners from all health boards and national NHS bodies in Wales and Welsh Government.

We provide the governance and framework mechanisms for organisations to work collectively to improve services, share best practice and provide a collective advisory voice on CAMHS. We also enable meaningful engagement between service providers and children, young people and their families to ensure effective co-production.

One of our key functions is to ensure close alignment between those delivering and managing services in health boards and other elements of work being taken forward as part of the wider whole system approach, in particular the Together for Children and Young People Programme and the development of the Whole School Approach.

What we achieved in 2020/21

- We developed an updated Service Improvement Framework
- We carried out a first cycle of clinical peer review of services to identify and share best practice
- Together with the Adult Mental Health subgroup, we advised on the implications and options to extend CAMHS services to age 25 and manage patients' transition between services
- We contributed to the oversight, management and ongoing recovery of mental health services (as an essential service) during and beyond the Covid 19 pandemic as part of the Welsh Government's governance arrangements
- We supported the development of the Whole School Approach, the early help and support framework, and the neurodevelopment programme
- We provided clinical expertise and experience to support:
    - the development of a Mental Health Workforce Strategy
    - the implementation of the new mental health core data set and outcome measurement tools
    - the development and implementation of Matrics Cymru
    - the further development of Tier 4 services and the bed management panel arrangements.

Suicide and Self Harm Prevention

Since May 2020, the Mental Health Network has worked with partners in health boards to establish a Wales-wide team to fulfil the Welsh Government's 'Talk to Me 2' suicide and self harm prevention strategy.

Key work-streams include the collaborative development of a Wales-wide response to bereavement by suicide, the implementation of a more timely surveillance system for suspected suicides, and the development of a workforce training and development framework or plan.

What we achieved in 2020/21

- We appointed a National Coordinator for suicide and self harm prevention
- We appointed three regional coordinators (north, mid and west, and south east) to support the multi-agency regional suicide and self harm prevention forums, and build links with other partners involved in the work of the strategy
- We facilitated the processing of bids and awarding of Welsh Government grant funding to support suicide and self harm prevention projects across the regions
- We commissioned a listening exercise to gain deeper insights in the experiences of people living with bereavement by suicide.

Together for Children and Young People (T4CYP) Programme

The programme was set up in 2015 to consider ways to reshape, remodel and refocus the emotional wellbeing and mental health services provided for children and young people in Wales.

In December 2019, the Minister for Health and Social Services agreed to extend the Programme until March 2022 with a focus on:

- **Early Help and Enhanced Support**
- **Working with Regional Partnership Boards**
- **Neurodevelopmental services**
- **Governance**

We're committed to communicating, engaging and co-producing with children, young people, their families, and with the organisations and staff who work with them, to ensure that their experiences shape our activities.

What we achieved in 2020/21

As the Covid-19 pandemic took hold, we worked with Public Health Wales to develop a toolkit to support people in taking care of their mental health and wellbeing.

The revised and refocused T4CYP has been concentrating on key areas within the Early Help and Enhanced Support workstream and the Neurodevelopmental workstream.

The Neurodevelopmental workstream is committed to:

- **Embedding the National Pathway and Standards**
- **Building a national digital profiler tool to increase efficiencies and enhance clinical acumen across services on a 'Once for Wales' basis**
- **Creating a long term vision for Neurodiversity, including the establishment of cross sector policy alignment.**

The National Neurodevelopmental Pathway and Standards were co-developed in the first phase of the Programme and we worked in partnership with key parties to develop the long term vision.

The Early Help and Enhanced Support workstream focused on the development of the NEST/NYTH National Framework and planning tool, which sets out the early help and enhanced support that should be available in all areas of Wales. We completed the detailed supporting narrative for the framework along with an easy read version and animation and a digital planning tool to support implementation across regional planning boards.

Co-production has been at the heart of the development of the framework. This was further demonstrated at our event in March where representatives from our National Youth Stakeholder Group and Parents and Carers Network shared their views with the Deputy Minister for Mental Health and Wellbeing about the support young people need.

We have secured additional funding to support the implementation of NEST/NYTH across all Regional Partnership Boards during the financial year 2021/22. All of our work this year has been co-produced with our National Youth Stakeholder Group (NYSG), a group of young people who have had experience of using mental health services. We also have very close links with a national parents and carers network, which has been key to informing our work.

National Programmes

National Imaging Programme

The Imaging Programme Team leads a nationally co-ordinated approach to achieving the actions outlined in the Welsh Government's Imaging Statement of Intent. We support the development of high quality, effective and sustainable imaging services across NHS Wales that provide the best outcomes for Welsh patients and future generations.

The programme is structured into four core work streams:

- **Workforce and Education**
- **Quality, Safety and Service User Experience**
- **Strategic Resource Planning**
- **Informatics, Information and Business Intelligence (see Radiology Informatics System Procurement Programme for further information on this workstream).**

Our priorities included:

- Co-ordination of activity in relation to the response, maintenance and recovery planning for essential imaging services not specific to the COVID-19 response
- Developing sustainable workforce arrangements across imaging services in Wales
- Building sustainable models and solutions for the delivery of breast imaging and radiology services in Wales
- Establishing a programme of work that contributes to implementing the NICE guideline for prostate cancer 2019 and agreeing appropriate implementation mechanisms across NHS Wales
- Developing a Quality, Safety and Service User Experience workstream to produce accreditation recommendations for NHS Wales, via the All Wales Imaging Quality Forum.

What we achieved in 2020/21

- We facilitated a co-ordinated all-Wales response to the COVID-19 pandemic via the Imaging Essential Services Group (IESG)
- We developed an Imaging Workforce Development Plan through the Imaging Workforce and Education Group (IWEG) and its strategic partnership with Health Education and Improvement Wales (HEIW)
- We developed a high-level service specification for a formal MRI surveillance programme for women identified at very high risk of developing breast cancer and worked with key stakeholders to identify a preferred delivery model to implement the service across NHS Wales
- We co-ordinated work to review the prostate cancer diagnostiv pathway and encourage adoption of minimum standards and protocols for prostate imaging in Wales
- We continued working towards a national quality framework for imaging services in Wales.

The Imaging Essential Services Group (IESG)

The pandemic had a significant impact on imaging services across Wales.

Rapidly increasing hospital admissions led to all but essential services being suspended to create the necessary capacity to deal with the predicted influx of patients.

Radiology services in Wales were already under significant pressure prior to the pandemic, with many health boards reliant on outsourcing and mobile scanning companies to provide additional reporting and scanning capacity.

A nationally co-ordinated response for imaging services was required to support health board services in the recovery from the effects of the pandemic. For this purpose, the Imaging Essential Services Group (IESG) was formed, with the inaugural meeting held in May 2020.

The group provides leadership and oversight in relation to:

- **Co-ordination of the imaging response throughout the COVID-19 pandemic and the reinstatement of imaging services in the recovery phase**
- **The identification of 'essential services' that should be maintained (or, where stopped, reinstated) to prevent avoidable mortality and significant morbidity and to ensure equity across Wales**
- **The agreement, production, dissemination, and implementation of specific guidance on imaging services for health boards and trusts**
- **The assurance and monitoring of the delivery of imaging services**
- **Communications and engagement with stakeholders and health professionals in relation to the above.**

The IESG advises on cross boundary and regional planning issues, as well as operational implementation relating to the maintenance of essential services, liaising with other clinical groups and informed by specialist advice as required.

The group provides an environment that encourages collaboration, and from day one, involvement and engagement across all health boards has been excellent. As well as providing vital guidance and decision making, the IESG is a forum for discussion, acting as a 'clinical sounding board' for members to share ideas and feed back to their respective organisations.

Members continue to meet bi-weekly, to oversee the contribution and delivery of essential imaging services both during and in the wake of the COVID response to ensure equity of care across Wales, to reflect and learn, and to work in partnership to improve patient outcomes.

National Pathology Programme

The National Pathology Programme Team leads the co-ordination of the actions set out in the Pathology Statement of Intent (2019), enabling the development of high quality, effective and resilient pathology services.

Our work is overseen and managed by a National Pathology Network Strategy Board and prioritised through the mandated National Pathology Network and associated delivery groups.

Improving diagnostic services can help to transform the patient pathway and experience leading to better outcomes for patients and more efficient health services. Our current priorities include:

- **Improving and strengthening the profile of pathology across NHS Wales**
- **Developing sustainable workforce arrangements across pathology services in Wales**
- **Building sustainable and modern infrastructure and facilities for pathology services across Wales**
- **Developing a co-ordinated approach to identifying, evaluating, prioritising, and adopting new technologies including Point of Care Testing**
- **Supporting clinical practice and peer review through standardised, best practice and reduction of unwarranted variance**
- **Improving and strengthening patient involvement in service development.**

What we achieved in 2020/21

We have made significant progress on achieving our programme objectives for 2020/21.

Services, training and accreditation structures were boosted with the establishment of the Centre of Excellence for Precision Medicine Board and Clinical Group, the Point of Care Testing (PoCT) Competencies and Training Group, and the National Pathology Business Intelligence Group. Alongside these, a new Accreditation Forum allows colleagues to share information, best practice and recommendations following recent accreditation visits.

The National Digital Cellular Pathology Programme team completed the connectivity of digital scanners procured by the programme into a hub and spoke model, which enabled some national image sharing ability – an important step forward for patient diagnostics and care in Wales. Following this, Phase 3 of the programme 'National Scale Up' began formally and will procure further digital pathology capabilities for NHS Wales.

The continually evolving nature of pathology requires highly skilled staff and an innovative approach to workforce planning. This year, the Pathology Workforce and Education Group began the vital process of mapping the scientific training and career pathways needed to support a modern, world class pathology service, and provided a workforce planning training course to a cohort of pathology colleagues.

Point of Care Covid-19 Testing

Very early in the pandemic, it became clear that point of care testing would be a vital part of the Welsh Government's overall Covid-19 testing strategy for Wales.

Point of care testing (PoCT) refers to any diagnostic testing that is performed at or near to the patient. It can be carried out by a range of healthcare professionals in a variety of settings, so enabling rapid triage and treatment decisions for improved patient management.

As we had a robust governance structure in place along with a clear stakeholder network and a clinical lead for national PoCT services, the PoCT Strategy Board was ideally placed to take a lead on this aspect.

Working collaboratively with Welsh Government and NHS Wales Shared Services Partnership, we rapidly established the PoCT Covid 19 Testing Board to evaluate, procure, implement and provide training on Covid point of care technologies.

Bringing together colleagues from academia, Welsh Government and NHS Wales pathology and procurement departments, the PoCT workstream quickly expanded beyond lateral flow antibody tests to encompass all Covid-19 point of care tests.

It also collated organisational PoCT data including workforce, sites and equipment to inform options for future service models.

Standardised training and test packaging enabled NHS staff to use the tests correctly, efficiently and with confidence, ensuring that quality was maintained at all times.

This collaborative work on the research, verification, procurement and distribution of PoCT technologies meant that priority groups could be quickly targeted and reduced variation in provision across Wales.
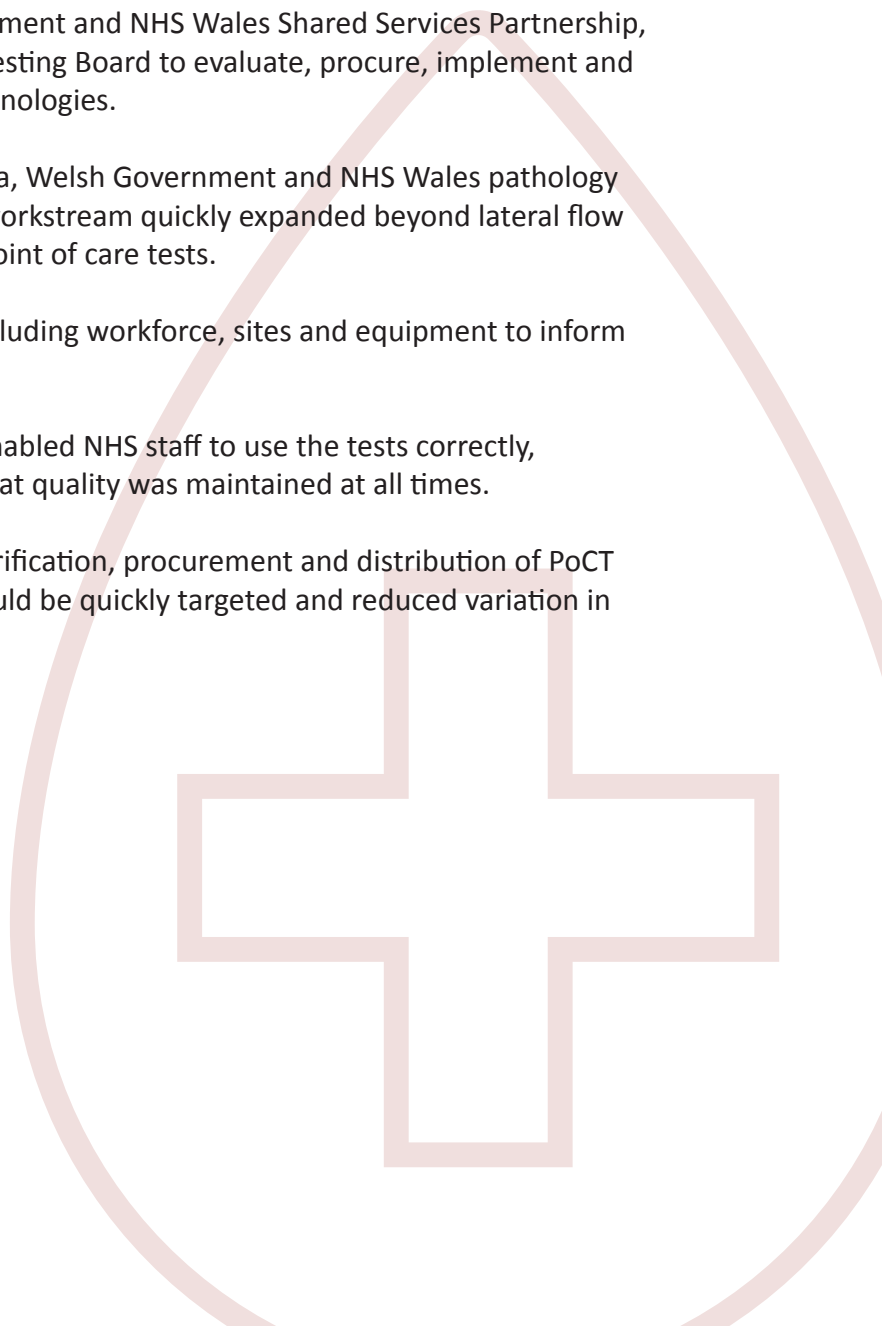
National Endoscopy Programme

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.

Our overall aim is to develop sustainable endoscopy services that provide high quality, timely services to patients, to balance demand and capacity, achieve JAG accreditation, enable optimisation of the bowel screening programme and implement the endoscopy elements of the Single Cancer Pathway.

The programme is structured into four work streams, each with defined areas of focus:

- **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.**

Endoscopy services faced significant challenges prior to the Covid-19 pandemic, and its impact significantly added to the scale of the challenge. The action plan was refreshed in October 2020, to incorporate a national recovery plan that was developed to assist endoscopy services in Wales recover from the pandemic and deliver a more sustainable service model for the future. In anticipation of the approval of this recovery plan, a key priority for the Programme is to ensure services are optimising their current capacity, to aid recovery from the backlog created by the pandemic.
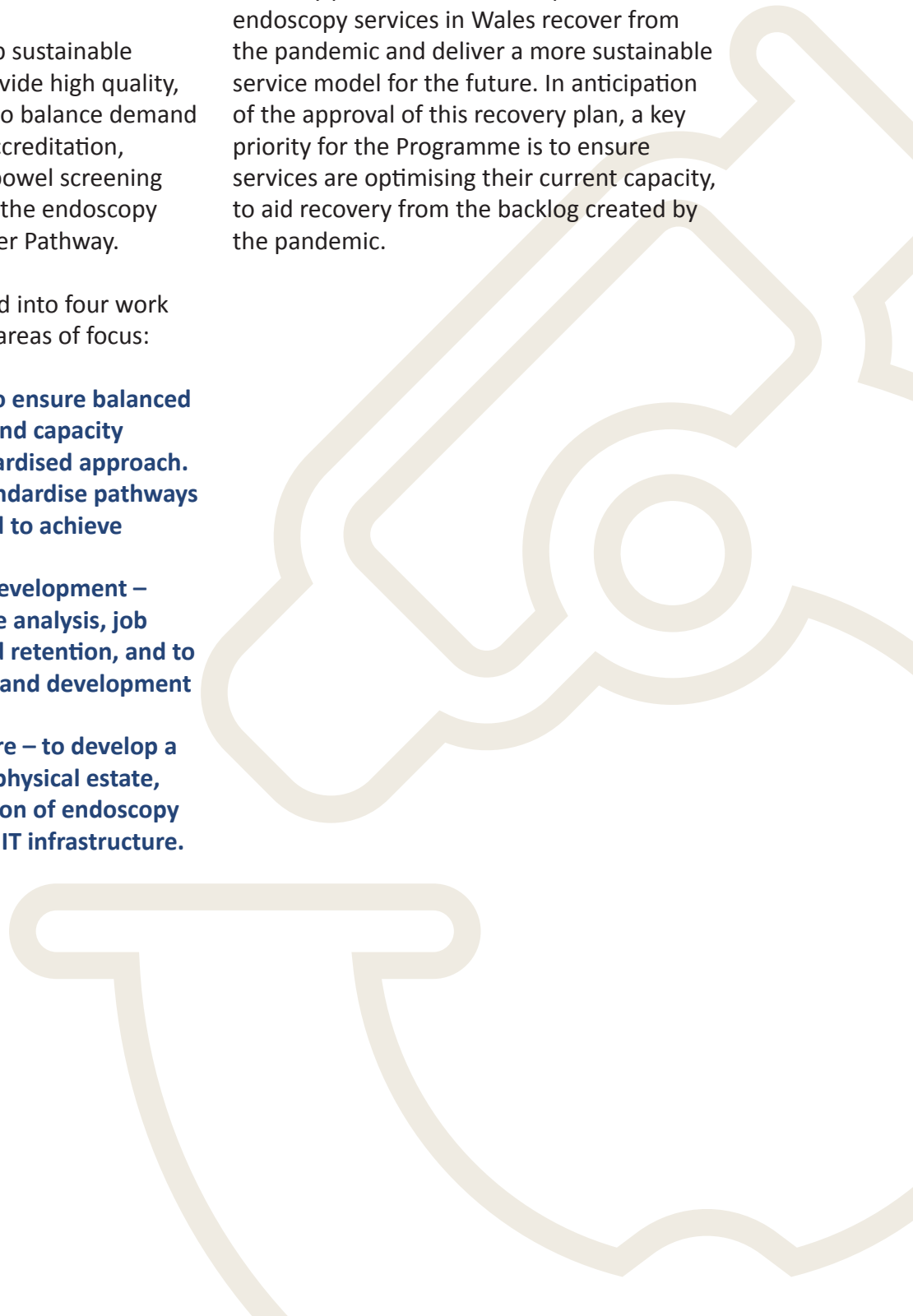
What we achieved in 2020/21

Programme Wide

- We established a new approach to strengthen communication with health board teams and ensure consistent engagement to support delivery of the Programme action plan.

Demand and Capacity

- The creation of a shared national model which continues to be refined to meet ongoing the challenges caused by the pandemic
- The data outputs from this model are fed into the national D&C workstream and regularly updated to support programme decision making and planning.

Workforce Training and Development

- We completed the baseline staffing questionnaire for all units and a process to collate this data on an annual basis is being developed to inform future modelling for all endoscopy staffing groups
- The Endoscopy Training Management Group was established through HEIW to create and manage a centrally governed and coordinated sustainable training programme for endoscopy services in Wales that maintains standardisation and equality for all staff groups
- Recruitment to two Clinical Endoscopist training programmes.

Facilities and Infrastructure

- We have carried out unit visits with all health boards to ascertain the preparedness of local teams in working towards the JAG accreditation
- We have collaborated with Shared Services to undertake decontamination audits within health boards
- We have developed an Informatics workplan to ensure delivery of the action plan
- We have developed a JAG SharePoint facility to support health boards with the accreditation process and enabled targeted support for operational teams form a lead JAG assessor
- Patients' endoscopy results are now available within the Welsh Clinical Portal in Cwm Taf Morgannwg University Health Board and this will be rolled out to other health boards.

Clinical Pathways

- The national FIT framework was published
- We published guidance for risk stratification of the surveillance waiting list to support health board teams
- We completed the mapping of referral pathways
- We have developed a shared guidance for the implementation of new British Society of Gastroenterology surveillance guidelines
- We supported the Cardiff and Vale UHB team to develop and implement an enhanced FIT pilot
- We scoped the provision of specialist services to inform future developments across Wales.

Radiology Informatics System Procurement (RISP) Programme

The RISP Programme is leading the procurement of an end-to-end diagnostic radiology system that will meet the clinical requirements of a modern and sustainable imaging service and support the best care, safety, and outcomes for patients in Wales.

Our programme board has representatives from each health board, trust and professional groups aligned to radiology services. The Board reports directly to the Collaborative Executive Group.

Our vision is to deliver a seamless end-to-end electronic solution, from the point when a patient referral is received to the delivery of a radiology report.

To achieve this, our procurement includes the following four systems:

- **Picture Archiving and Communication System (PACS), storing all diagnostic imaging files**
- **Radiology Information System (RIS), allowing users to track patient records**
- **Patient Dose Management System (PDMS), to monitor and manage patient radiation dose**
- **Electronic Test Requesting (ETR), an optional requirement to enable clinicians to request diagnostic imaging procedures.**

The systems will integrate with each other and other NHS Wales applications to ensure that information is easily transferred and updated, so patients can be monitored through their diagnosis, treatment, and recovery pathways.

Our main objectives in 2020/21 were to:

• Produce an Outline Business Case (OBC) by the end of March 2021, using the Welsh Government Five Case Model. However due to availability of resources caused by COVID-19, the OBC was not able to be completed during the financial year and will be completed later in 2021

• Gather the requirements to develop the Output Based Specification (OBS) for the new radiology informatics solution

• Refine the governance structure by the establishment of a new Programme Board to reflect the scale and complexity of the RISP Programme.

The RISP team adapted well to the changes in working practices forced by Covid-19, carrying out much of our work through virtual meetings and workshops.
We ran workshops to develop elements of the OBC, including the appraisal of the longlist of options. The OBC continues to develop at pace as we work in partnership with consultancy firm Archus.

We also used virtual workshops to gather the user requirements necessary to develop the Output Based Specification (OBS), as well as establishing virtual clinical and technical subject matter expert sub-groups.

In line with our growing business needs, we expanded our programme team, to include a Clinical Lead, a Radiology Subject Matter Expert Lead, two additional Project Managers and an additional Senior Project Support Officer.

Reflecting these additional business and administrative demands, we set up a Programme Management Office to ensure a structured and coordinated approach to managing the projects within the Programme.

Laboratory Information Network Cymru (LINC)

LINC is a transformational programme that underpins the delivery of the Welsh Government's Pathology Statement of Intent.

LINC will develop safe, sustainable and standardised pathology services through end-to-end information and communication technology systems and services.

A key driver is the need to procure and implement a national laboratory information management system (LIMS) to ensure business continuity of pathology services as the contract for the current LIMS is ends in 2025.

Our objectives
The LINC programme has been set up with ten overarching objectives:

1. Learn the lessons from WLIMS1

2. Deliver benefits that improve patient care, safety, and outcomes

3. Engage with the Pathology service and wider NHS to ensure commitment

4. Procure a new LIMS service to replace the three current LIMS

5. Ensure long term ownership and management of the service

6. Deliver a seamless end-to-end electronic Pathology solution

7. Standardise Pathology services with evidence-based warranted variation

8. Establish a national quality management service and system

9. Develop information and business intelligence services

10. Develop a different approach to integration services.

What we achieved in 2020/21

We have made great progress during the last year, despite the pandemic, thanks to the commitment and engagement of the LINC team, Digital Health and Care Wales (DHCW) and the pathology service.

We have:

- Completed to plan the procurement of a new LIMS service
- Defined all the current state LIMS configuration comprising nearly 14,000 items and extracting and documenting 96 per cent of these
- Developed a national benefits register of 30 benefits from which each health board will develop their own benefits plan
- Procured, validated and implemented an electronic Quality Management System (QMS) to underpin a national QMS being certified to ISO9001.

As part of the upgrade of the current LIMS, we have led the development of the new InterSystems IRIS business intelligence (BI) system, known locally as DeepSee2.

Phil Waters, the LINC Pathology Subject Matter Expert for BI, chairs the National DeepSee Development Group, comprising colleagues from health boards and trusts all over Wales.

The original DeepSee product was very limited although the group had worked hard to develop it as far as possible. DeepSee2 offers new capability and acts as an information portal, allowing staff to filter for data relevant to them without the need for complex data querying skills. This allows laboratory staff to quickly search for relevant data. Phil has led a collaboration of nearly 50 pathology staff from Wales with InterSystems and DHCW.

A key aim of the project was to develop easy to use BI dashboards, with an intuitive design, customisable to meet the current and future needs of the service.

This has allowed for the dashboards to be standardised across Wales and provide the basis for defining the future state requirements for the new LIMS service. In addition, the platform contains a DeepSee Analyser that allows data scientists and analysts to produce complex queries.

DeepSee2 is now live across Wales planned further enhancements will provide new dashboards including:

• Electronic Test Requesting (ETR) dashboard to monitor the uptake of ETRs across the health boards and trusts
• Covid dashboard – A live list of recently produced Covid-19 results filtered by hospital or user defined group of patient locations.

Phil has been supported by Juber Islam, LINC Pathology Informatics Officer, who has developed a live dashboard to monitor outstanding work, known as Outstanding Test Lists (OTL).

Most laboratories in Wales rely on manually run reports or an ad-hoc system to monitor their outstanding tests. LINC funded two pilot projects providing large screens, which have been installed in biochemistry and haematology laboratories within Cwm Taf Morgannwg and Hywel Dda health boards.

The OTL dashboard provides a live, colour coded update on outstanding work using data directly from the LIMS and can be fully customised to suit the needs of individual laboratories.

The OTL dashboard will save time for laboratory staff, removing the need for manual reports and providing an easy, visual method of tracking tests to be processed and improving the overall turnaround times. Statistics can be produced to measure these benefits and assist audits going forward.

Implementation Groups

The Collaborative provides managerial and administrative support to several major conditions Implementation Groups that do not currently have clinical networks.

The Implementation Groups are chaired by a lead chief executive or executive director and bring together representatives of health boards and trusts, patient groups, the third-sector, academia and other key stakeholders to support the ongoing development and implementation of National Delivery Plans.

In 2020/21 the Welsh Government confirmed that the delivery plans would be extended to the end of 2021/22, whilst the proposed National Clinical Framework was developed.
In common with other services, the workplans of the Implementation Groups were significantly disrupted by the pandemic as staff were mobilised to the Covid-19 response and day-to-day services for people with major conditions were severely affected.

The Implementation Groups played an important role both in directly supporting the Covid-19 response, such as the work undertaken by the Respiratory Health and End of Life implementation groups, as well as in supporting health boards and clinical staff to maintain essential services and to develop recovery plans.

Respiratory Health Implementation Group

The Respiratory Health Implementation Group (RHIG) was established to support patients and healthcare professionals across Wales.

In this context, support is an active process. Through creating high quality interventions and getting these quickly and directly to the people who need them, we are generating actions and behaviours that enable optimum value healthcare.

RHIG is underpinned by a digital strategy to generate scale and pace and to ensure that patients and healthcare professionals are supported wherever they live or work in Wales.

As a result of the unique digital implementation system that we have created, we expect to see population level improvements in health outcomes in respiratory illness, and to set the standard for the new norm of innovation in Wales.

Our priorities were to:

- **Move into the next phase of implementation, scaling up the adoption of national standards and guidelines and quality improvement across primary and secondary care**
- **Update and broaden the roll out of the NHS Wales self-management apps to give patients the resources to manage their conditions and raise expectations of healthcare in Wales**
- **Embed national data collection and audit as part of usual practice to drive respiratory and COVID services.**

What we achieved in 2020/21

This was a remarkable year for the RHIG, as we balanced being part of the frontline response to COVID-19 with our commitments to scaling up national programmes. Our greatest success has been demonstrating through our response to the pandemic that the respiratory model can be replicated in a different setting and context.

We developed a communication platform to disseminate national guidance, standards and patient self-management support. This enabled us to respond directly to COVID-19 through implementing a national hospital guideline and education package.

Following the successful implementation of the national hospital guideline, we developed an equivalent guideline for primary care, following the same principles – a single page colour poster with QR links to high quality education delivered by the experts from across NHS Wales, with weekly updates and communications to those registered.

The guideline was implemented across Wales reaching over 90 per cent of GP practices quickly, despite the fact it was published late into the second wave.

Just prior to this we pushed forward the launch of three NHS Wales self-management apps to support people with asthma and COPD, many of whom were self-isolating, generating several thousand active users during the peak of the COVID-19 pandemic.

A unique implementation framework supports this delivery model to increase impact, enable better alignment, and ensure that we embed a sustainable system of high quality, high value and easily accessible interventions to support our population.

In the last quarter of the year, we also launched the NHS Wales COVID Recovery App, soon followed by a Long COVID guideline as part of the Welsh Government Adferiad (Recovery) programme.

Throughout the pandemic, a wide range of respiratory programmes has continued to evolve and increase their reach, demonstrating equal engagement between north and south Wales.

This has paved the way for the next phase of adapting and implementing the respiratory apps and for our work to update the asthma and COPD guidelines to address the decarbonisation agenda, where we aim to reduce 80% the carbon footprint of inhalers across Wales by 2025.

Diabetes Implementation Group (AWDIG)

What we achieved in 2020/21

A major achievement for us was our success at the 2020 Quality in Care Diabetes Awards, which recognise initiatives that improve the quality of life for people living with diabetes, as judged by the NHS, patients and industry.

SEREN Connect, the diabetes education programme funded by AWDIG to support young people with Type 1 diabetes as they move to adult services, scooped both the Diabetes Education Programmes: People with Diabetes award, and the Judges Special Award.

The judges commented that the programme was:
"… very impressive, with remarkable results. It is a most effective use of clinical time, money and resource, demonstrating notable involvement from a difficult to reach patient group. It is a carefully developed resource involving a wide range of stakeholders, including young people, that fills a gap in the service and is reducing variation in transition care. It is clearly well received by all, and the numbers of health professionals trained is a reflection of how widely it has spread."

The All-Wales Quality Assured Brief Intervention Pre-Diabetes Pilot won the Prevention, Remission and Early Diagnosis award. Funded by AWDIG, the pilot is a joint project run by Cardiff and Vale University Health Board and Swansea Bay University Health Board and has achieved significant results in preventing people from developing diabetes and improving their health outcomes.

The Talking Type 1 programme, funded by the Welsh Government through AWDIG, was highly commended in the Mind and Body Healthy Together category, with the judges noting it as *"an innovative and novel approach and something that is really needed. It fills a gap within psychological support and had a good range of feedback from different users."*

In April, as part of the programme, a new picture book for children with Type 1 diabetes was published in partnership with the Children and Young People's Wales Diabetes Network.

'How to Manage a Mammoth', written by Dr Rose Stewart and illustrated by Richard Dwyer follows Jake, an eight year old boy with Type 1 diabetes as he learns to live with a mammoth called Mel and talks about the ideas and tips that help him manage.

In January 2020, we began work on the implementation of the all Wales Diabetes Remission Pilot Project to test the real world implementation of delivering a Total Diet Replacement (TDR) based intervention to help people with Type 2 diabetes achieve remission through weight loss.

Dietetics departments within four university health boards (Cardiff and Vale, Betsi Cadwaladr, Hywel Dda and Aneurin Bevan) agreed to deliver the service to a total of 90 participants across Wales.

This work along with the research evidence will inform the future direction for Wales. We hope a positive outcome will open this up to be an option for all eligible people with Type 2 diabetes in Wales. We recognise that 'no one size fits all' and this approach will not be suitable for everyone but will provide the supportive environment needed to implement this approach in a safe and effective way.

Stroke Implementation Group

What we achieved in 2020/21

Despite the challenging circumstances this year, we made progress in several priority areas and adapted quickly to new demands prompted by the pandemic.

We appointed a new national clinical lead and reached an agreement to appoint both a national lead nurse and national lead allied health professional for stroke in 2021/22. Our stroke teams in Wales played a pivotal part of the home nations discussions into maintaining stroke services during the pandemic, coordinating a national response in Wales.

We established a task and finish sub-group with the aim of improving the thrombectomy intervention rate for Welsh patients. Thrombectomy is a procedure that involves using a specially designed device inserted through a catheter to remove a blood clot. It has been shown to be very effective in reducing the severity of disability that a stroke can cause, although it is not suitable for all stroke patients.

The task and finish group comprises representatives and stakeholders from a range of disciplines and organisations from across Wales and our tertiary centres in England.

The ultimate goal is to establish a Wales-wide thrombectomy service, with the initial milestone of increasing uptake of thrombectomy in eligible patients from its current rate of less than one per cent to ten per cent.

The sub-group is focusing on the following areas:

- **Implementation of a multi-disciplinary thrombectomy network to work across organisational and regional boundaries**
- **Development of the thrombectomy pathway, initially to tertiary centres in England**
- **Implementation of an all-Wales image transfer system**
- **Procurement of an artificial intelligence system to support the identification of eligible thrombectomy patients**
- **Undertaking a gap analysis for thrombectomy training in particular CTA (computed tomography angiogram) and CTP (computed tomography perfusion) and identify training opportunities for stroke physicians**
- **Delivering a long term plan to deliver thrombectomy services in Wales.**

Stroke Leadership Programme

This year saw the conclusion and evaluation of the initial three year leadership programme funded by the Stroke Implementation Group.

The evaluation showed that delegates highly valued the design, structure, organisation and delivery of the programme, both in its original form and through the adaptations made as a consequence of the pandemic.

These adaptations included sessions on topics such as the psychological impacts of crisis and uncertainty on themselves and their teams, and sharing and consolidating learning about service changes.

The programme has given a group of senior clinical leaders the skills to step up and effect positive, long-term change, supported by a strong peer network.

Community support

During the pandemic, we quickly reprioritised our agreed funding for the year in order to provide much needed support in the community through the following:

- **Rebuilding Your Life After Stroke – an accessible book/toolkit based on Acceptance and Commitment Therapy**
- **Implementing 'Here for You', the Stroke Association's volunteer telephone peer support service, in Wales – so far 76 stroke survivors and carers have been referred to the service**
- **Funding a Stroke Association 'Connector' to provide information and support for newly diagnosed stroke survivors in Newport, the only area in Wales without this type of service – to date 110 people have received support**
- **Implementation of a helpline service provided by the Stroke Association – 345 stroke survivors from Wales have contacted the helpline either by phone or email.**

Case study - Here for You

Stroke survivor Mr K was referred to his local coordinator in early 2020, suffering from communication difficulties, fatigue, anxiety, depression and isolation.

The officer working with Mr K introduced him to the Here for You service and he began receiving weekly calls from a volunteer who was trained to work with stroke survivors with communication difficulties.

As the weeks passed, Mr K became more and more comfortable with the conversations and as his confidence grew, he joined online groups offered by the Stroke Association.

He said: *"I was very nervous. I wasn't at all sure how it was going to go. Listening to everyone else made me feel at ease and I realised that they felt the same as me. After that I felt a lot better. I blew myself away when I spoke to strangers. I enjoyed it."*

Without the funding from the Stroke Implementation Group, Mr K would not have been able to take his first steps to regaining his confidence which has in turn reduced his feelings of isolation and anxiety.

Next step

In 2021/22, we will be focusing on:

- **Setting up a new stroke programme board**
- **Developing stroke networks to deliver regional comprehensive stroke centres**
- **Drafting the Quality Statements for Stroke**
- **Development of the new Delivery Plan for Stroke**
- **Procuring a national AI system for Stroke**
- **Continuing the work of the Thrombectomy Task & Finish Group**
- **Addressing the findings of the Cross Party Group on Stroke**
- **Developing high quality pathways as set out in the National Clinical Plan.**

Neurological Conditions Implementation Group

The Neurological Conditions Implementation Group provides national leadership to improve the quality and provision of services centred around the needs and experience of those with a neurological condition and their loved ones.

The pandemic placed considerable pressure on neurological services, especially those involving rehabilitation.

Despite this, we were able to make progress on two of our three priority areas – Seizures and Neuro-Rehabilitation.

The Seizures Task and Finish Group

This centred on three deliverables:

1. The Development of an All Wales Epilepsy Pathway.

The pathway provides support to primary care and emergency departments, on when patients needed to be referred to specialist services and helps determine what investigations are needed. The pathway will be launched in the Senedd in September 2021.

2. Epilepsy Mortality and Sudden Unexpected Death from Epilepsy (SUDEP)

The group was successful in raising awareness of the issue of SUDEP through the Chief Medical Officer and Lead Medical Examiner in Wales to ensure effective communication to epilepsy teams across Wales. The group also worked closely with the End of Life Care Board to ascertain how SUDEP can be reflected within the National Bereavement Pathway.

3. Epilepsy PROMs and PREMs

Five epilepsy Patient Reported Outcome Measures and Patient Reported Experience Measures were agreed and implementation across health boards is ongoing. A national data dashboard is planned for 2021/22 to monitor services nationally and identify inequalities in services across Wales.

Neuro-Rehabilitation Task and Finish Group

The group had two main priorities for 2020/21 and will continue to work as a community of best practice in the future:

1. The development of an evaluation framework for neuro-rehabilitation services, which was completed and fed into national guidance on the Evaluation of Rehabilitation Services post-Covid.

2. The Directory of Neuro-Rehabilitation Services across Wales - a workshop was held in February 2020 to discuss the evaluation framework; this work also fed into national guidance on the evaluation of rehabilitation services post-Covid. The evaluation framework for community rehabilitation services has been made compulsory for those services funded through NCIG with the view to developing a much needed data dashboard during 2021/22 to better evaluate the performance and needs of the service.

The Assembly Cross Party Group enquiry into the implementation and effectiveness of the Neurological Conditions Delivery Plan published its report in December 2020.

The Deputy Chief Medical Officer and the National Clinical Lead for Neurological Conditions responded, accepting six key areas in full and two in part. They acknowledged that while progress had been slow due to the complex nature of the group, improvements in some areas such as epilepsy and community neuro-rehabilitation had been made.

In 2021/22, we will be focusing on drafting our Quality Statements and updated delivery plan as per the National Clinical Plan.

Next steps

Over the next year the Neurological Conditions Implementation Group will focus on:

- **Drafting the Quality Statements for neurological conditions**
- **Development of the new delivery plan for neurological conditions**
- **Development of a neuro-rehabilitation data dashboard**
- **Addressing the findings of the Cross Party Group on Neurological Conditions**
- **Developing high quality pathways as set out in the National Clinical Plan.**

End of Life Care Board

Our priorities were:

- End of Life Delivery Plan 2017-2022
- Allocation of Covid-19 Emergency Funding Voluntary Hospices
- Production of guidelines: Palliative Care information and resources during Covid -19
- Development of an All Wales Electronic Advance and Future Care Planning Application
- Review of Specialist Palliative Care Services in Wales 2010-2021
- Overseeing transition of work programme of the EOLB into the End of Life National Programme Board as described within the National Clinical Framework (NCF)
- Compassionate Cymru work programme
- National Bereavement Framework.

What we achieved in 2020/21

It was a year of change of the End of Life Care Board, due both to significantly increased work pressures and the start of our preparations for moving to National Programme status in 2022, as confirmed in the National Clinical Framework.

A Programme Board steering group has been established; overseeing the transition of our ongoing work programme and a key priority of the new group will be to begin work on the End of Life Quality Statement.

A review of specialist palliative care services in Wales between 2010 and 2021; exploring the progress made since the Sugar Review recommendations in 2008. This review demonstrated significant progress with the implementing of the recommendations but also demonstrated areas for improvements going forward into the next decade. The report recommendations contribute to the work of the new National Programme Board and will be made available in August 2021.

Alongside this, we focussed on supporting voluntary hospices during the Covid-19 pandemic, overseeing the allocation of £12.3m emergency funding provided by the Welsh Government.

We appointed a strategic manager for the Compassionate Cymru project, with funding from Macmillan Cancer Support and began the process of developing a comprehensive work plan covering events, communications, initiative mapping and building networks within the UK and Ireland.

Compassionate Cymru is a national movement to help people access and offer information, care and support in a compassionate way within their communities, with a particular focus on care and support at the end of people's lives.

Following the review we commissioned of bereavement services in Wales, carried out by the Wales Marie Curie Palliative Care Research Centre, we established the National Bereavement Steering Group in December 2020 to produce a National Bereavement Framework.

The draft framework went out to consultation in March 2020 with responses invited from members of the public, health boards, the Royal Colleges, General Medical Council, the Children's Commissioner for Wales, local authorities, the Welsh Language Commissioner and many third sector organisations.

Rare Diseases Implementation Group

What we achieved in 2020/21

The Rare Diseases Implementation group (RDIG) seeks to improve services for people with a rare disease. A rare disease is defined as one that affects less than 1 in 2,000 of the general population. There are between 5,000 and 8,000 known rare diseases and seven per cent of the population, will be affected by a rare disease at some point in their lives.

In common with all other disease areas, the Covid-19 pandemic placed additional pressure on services, especially as many patients with rare diseases were classified as at 'extreme risk' and 'shielding'.

We continued, however, to work to improve service 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 - 'The Diagnostic Odyssey'**
- **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.**

New-born Blood Spot Screening

Despite the restrictions and problems caused by Covid-19, as a result of the hard work of midwives and screening teams across Wales, the programme was able to continue to provide a full screening programme with only a minimal impact on its targets.

Proposal for a SWAN (Syndrome Without A Name) Clinic

There can be significant challenges in achieving a correct diagnosis for patients and their families. Often a diagnosis cannot be achieved and when a diagnosis is possible, it can take an average of four years.

As well as ensuring optimal management and care, a diagnosis can be a reality check for patients and their families, bringing hope and reassurance and enabling them to plan and make appropriate decisions.

In 2020/21, we developed and submitted a proposal to Welsh Government for funding to establish a Syndrome Without A Name (SWAN) clinic for Wales.

This service would bring together a multi-disciplinary team of specialists to improve diagnosis using advanced techniques such as genetic testing, but also by providing a network of care co-ordinators to support patients and their families both during their 'Diagnostic Odyssey' and following diagnosis. This one-stop approach would be an all Wales service, with the aim of increasing the number of people who receive a correct diagnosis and decreasing the time taken to achieve a diagnosis.

In June 2021, the Health Minister agreed to fund a two-year pilot of a paediatric and adult SWAN clinic

Adult Rare Diseases Register

During the pandemic, we played an important role in advising Welsh Government on those patients who should be identified as being 'clinically extremely vulnerable' and therefore advised to shield.

The Congenital Anomaly Register and Information Service (CARIS) used the existing paediatric registry to identify patients, but also worked to identify adults who should be placed into this category because of a rare disease.

This work is now developing into an Adult Rare Diseases Register and will be continued in and expanded in 2021/22.

UK Rare Diseases Framework

This framework, published in January 2021, sets out a national vision on how the UK will improve the lives of those living with a rare disease.

The four nations have agreed to develop action plans which will set out how the priorities identified in the framework will be addressed.

Next steps

In 2021/22, we will be focusing on:

- **Developing an Action Plan for Wales which will set out how the priorities identified in the UK Rare Diseases Framework will be addressed in Wales**
- **Appointing a new national clinical lead and a programme manager to lead our work, funded by Welsh Government**
- **Working with WHSSC to establish an all-Wales paediatric and adult SWAN Clinic as part of the two year pilot announced by Welsh Government**
- **Developing plans to upscale the WINGS service to meet the requirements of investigating developmental delay**
- **Further developing the Adult Rare Diseases Registry**
- **Investigate the potential use of genomic testing in new-born screening.**

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 throughout our work.

Since May 2019 and the publication of our 2019/20 Welsh Language Standards Annual Report, the Collaborative has been implementing its Welsh Language Standards We have also been exploring 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 together with other national strategies where Welsh could be promoted and developed.

We have appointed a full-time, permanent, Welsh Language Support Officer who works within and across the organisation. The Senior Management Team receives regular updates on compliance with Welsh Language standards and regularly reviews and implements relevant opportunities to further help increase and improve the use of Welsh in the organisation. In 2020, we published our first Welsh Language Standards Annual Report to help us self-assess our progress and plan our future work.

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 and the South East 'More Than Just Words' regional board, which share best practice and collaborate to improve Welsh language provision on a national and regional 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 for our stakeholders and we are now in a position to focus further on embedding Welsh language within and during our core National Network and Programmes work beyond the Welsh Language Standards.

Over the next period there will be sustained focus and momentum with regards to achieving and improving how we deliver 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 again publish a Welsh Language Annual Report for 2020/21 alongside this report on our website.

2020/21 Financial Performance

The 2020/21 Collaborative annual net outturn was **£24.6m**.

The agreed 2020/21 forecast financial position for the NHS Wales Health Collaborative was an underspend of **£700k**.

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 £700k 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 2020/21 year end. The tables below include a summary and details of the 2020/21 financial outturn:

Summary of 2020/21 outturn

Type	2020/21 actual levels	
	£000s	**%**
Income	-24,650	50.00%
Pay	8,442	17.12%
Non pay	16,208	32.88%
Total	**0**	**100.00%**

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 now make up 35% 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

NHS Wales Health Collaborative - Summary of 2020/21 net spend

Teams/Clinical Networks	2020/21 net spend	
	£000s	%
Business, Governance and Finance	768	3.1%
Planning	249	1.0%
Programmes	877	3.6%
Director	1,294	5.3%
Endoscopy National Programme	801	3.2%
Lymphoedema	362	1.5%
LINC	1,212	4.9%
Radiology Information Systems Programme	129	0.5%
Women's Health	259	1.0%
Mental Health Network	876	3.6%
Implementation Group Coordinator	163	0.7%
Cancer Network	6,271	25.4%
Cardiac Network	623	2.5%
Critical Care and Trauma Network	431	1.7%
Maternity and Neonatal Network	527	2.1%
End of Life Care One Wales	1,083	4.4%
Cancer Delivery Plan	1,030	4.2%
Critical Illness Implementation Group	925	3.8%
Diabetes Implementation	965	3.9%
End of Life Care Implementation Group	1,051	4.3%
Heart Conditions Implementation Group	922	3.7%
Liver Disease Implementation Group	852	3.5%
Neurological Conditions Implementation Group	832	3.4%
Respiratory Illness Implementation Group	1,426	5.8%
Stroke Implementation Group	723	2.9%
2020/21 total net spend	**24,650**	**100.0%**

The total net spend of £24.6m in 2020/21 represents an increase of £9.1m (58%) compared to the 2019/20 annual net spend.

The main reasons for the increased turnover in 2020/21 relate to the Collaborative's additional responsibilities and new areas of work including the initiation of the Radiology Information Systems Programme and the Major Conditions Implementation Group financial allocations in relation to:

- **Critical Illness**
- **End of Life Care**
- **Heart Conditions**
- **Liver Disease**
- **Neurological Conditions**
- **Respiratory Illness**
- **Stroke.**