Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Cefnogi pobl sydd â chyflyrau cronig

This response was submitted to the Health and Social Care Committee consultation on supporting people with chronic conditions.

CC23: Ymateb gan: | Response from: British Society for Heart Failure

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British Society for Heart Failure

Submission to the Senedd Cymru

supporting people with chronic conditions consultation

The 25in25 initiative

Saving thousands of lives by focusing on reducing heart failure deaths by 25% in the next 25 years

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Executive Summary:

At a Summit held on 9th March 2023, the British Society for Heart Failure (BSH) convened 45+ top health organisations from across the UK, with key roles in diverting the course of the burgeoning heart failure epidemic. Senior representatives from organisations with beneficiaries affected by heart failure including the British Heart Foundation, Diabetes UK, the UK Kidney Association, the All-Wales Heart Failure Nurse Forum, Wales Cardiac Network, the Association for the Study of Obesity and British and Irish Hypertension Society etc. united as leaders to participate in workshops to assess risk factors, diagnosis, treatment and patient empowerment. The results of this intense pooling of expertise will be used to inform a roadmap for the implementation of the 25in25 initiative. The leaders signed a declaration (Appendix 1) and made their commitment to reducing deaths from heart failure in the first year after diagnosis by 25% in the next 25 years. They are the 25in25 Collaborative (Appendix 2).

As malignant as, and with a mortality risk worse than many cancers, heart failure is the destination of almost all cardiovascular disease (which remains the biggest cause of death in the UK). Mortality rates for heart failure patients are high, with 40% of newly diagnosed patients dying within a year, and 50% of patients either readmitted to hospital or dying within a year of admission to hospital. Management of heart failure accounts for ~2% of the entire NHS budget, 70% of which is spent on acute hospital admissions.

Over 1 million people in the UK are known to have heart failure, with 200,000 new diagnoses every year and, right now, an estimated further ~400,000 British citizens with heart failure who are currently undetected, undiagnosed and, consequently, missing out on life-preserving treatments. In Wales, cardiovascular diseases cause around 9,500 deaths each year - a loss of 26 people each day. Approximately 36,000 people in Wales have been diagnosed with heart failure yet estimates suggest there could be thousands more people living with HF across the country. The most disadvantaged in society are at greater risk of developing heart failure and paradoxically, less likely to access the medicines that would improve their lives and their outcomes. 98% of those who are diagnosed with heart failure in the UK live with at least one other long-term condition, such as diabetes, kidney disease, high blood pressure, COPD and depression. From epidemiology to pathophysiology, there are overlaps with many other organ systems and clinical specialities. Across all intersections with heart failure, the immediate issue, where we will have most impact on people and services, is through detecting the people who already have heart failure and don't even know it. It is essential to make every contact count to improve the health of individuals at risk of or already suffering from

heart failure. Preventing and treating heart failure must be considered a shared responsibility across the wider healthcare environment and hence the need for the 25in25 initiative.

For the implementation phase, our research has indicated the ‘Fast-Track Cities’ initiative, successfully addressing the HIV epidemic (as well as tuberculosis, and hepatitis B and C), as the most sustainable and inclusive approach to improve the future health of those at risk of heart failure mortality.

This is a progressive, continuous improvement model which strives towards capturing the following metrics: that 90% of patients with a risk factor for heart failure are identified; 90% of expected patients with heart failure are accurately diagnosed; 90% of diagnosed patients with heart failure are prescribed guideline directed medical therapy; 90% of patients with heart failure have a personalised care plan that addresses quality of life and wellbeing.

A roadmap created by the 25in25 Collaborative will be the foundation of an AI enabled custom platform which will be used by ‘communities’ (localities in priority order based on pre-determined need). These communities will comprise health and social care professionals, local politicians, public health, community groups and faith-based organisations, dependent on demographics and local needs. The platform will identify trends in population health that will inform and future proof community planning and resource allocation.

Adaptable for new and further sites within Wales and other locations across the UK, outcomes of people with heart failure will be assessed, especially those who are currently unaware they have the condition and improvement will be achieved.

Working together with allied organisations focusing on the care of the ‘whole person’ across all ages, genders, races, ethnicities, and socioeconomic circumstances and looking through the lens of our population’s health, the 25in25 Collaborative can accelerate action towards reducing deaths due to heart failure.

Supporting people with chronic conditions consultation

The British Society for Heart Failure (BSH), the professional association for heart failure care across all nations of the UK, cautiously welcomes the Welsh Government’s proposed ‘Supporting people with chronic conditions consultation’ and requests the opportunity to discuss the potential of our 25in25 initiative within the context of the strategy, alongside future thinking around the National Workforce Implementation Plan for NHS Wales. The consultation and the workforce plan come at a crucial time with many aspects resonating with the ambitions held by the Society in our 25in25 initiative which is also about preserving good health and the early detection and treatment of diseases, neutralising health inequalities and supporting those clinicians working in specialisms.

Hidden in plain sight

Heart failure, an insidious condition, is the destination of almost all cardiovascular disease which, as the Welsh Government should recognise, is still the biggest causes of death in Wales with numbers set to rise even further. Despite the availability of treatments that can extend and improve the lives

of those with heart failure, it remains as malignant and common as the top four cancers and is too often overlooked. The poorest in society are disproportionately affected, are more at risk of having heart failure and yet are less likely to access lifesaving therapies. The 25in25 initiative also seeks to address disadvantage and to narrow the gap in healthy life expectancy.

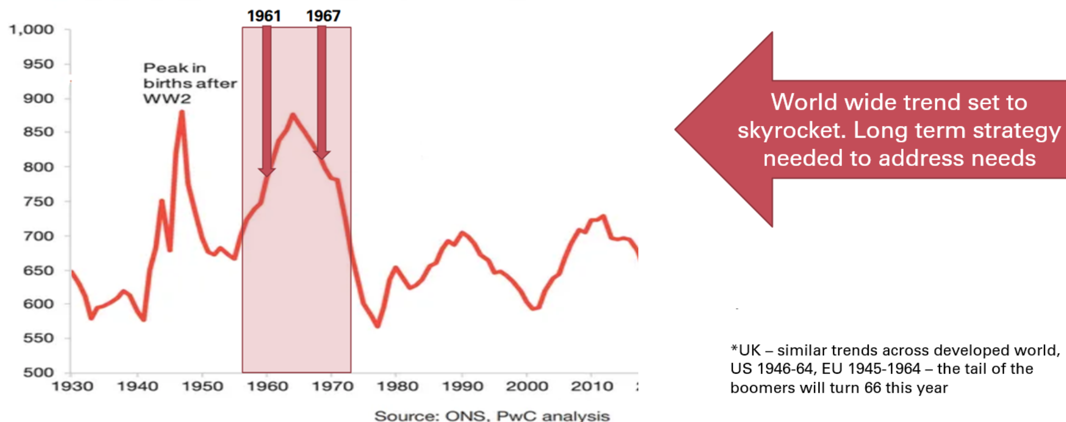
Scale of the problem

- Over 1 million people across the UK live with heart failure
- At least 200,000 are newly diagnosed with heart failure each year
- An estimated further ~400,000 British citizens with heart failure who are currently undetected, undiagnosed and, consequently, missing out on life-preserving treatments
- In Wales, cardiovascular diseases cause around 9,500 deaths each year - a loss of 26 people each day
- Approximately 36,000 people in Wales have been diagnosed with heart failure yet estimates suggest there could be thousands more people living with the condition across the country.
- 80% of people are only diagnosed following an acute admission to hospital despite 40% describing symptoms that should have triggered an earlier assessment in primary care
- Sadly, today across the UK people are waiting up to three years for a first diagnosis
- Acute decompensated heart failure is the commonest cause of emergency hospital admission in patients over >65 years and accounts for 2% of all NHS hospital bed occupancy
- Management of heart failure accounts for ~2% of the entire NHS budget, 70% of which is spent on acute hospital admissions
- Mortality rates for heart failure patients are high, with 40% of newly diagnosed patients dying within a year, and 50% of patients either readmitted to hospital or dying within a year of admission to hospital

And heart failure is skyrocketing to epidemic proportions exacerbated directly and indirectly by the Covid pandemic, by multiple deprivation and because of our burgeoning ageing population, augmented by the ‘Baby Boomer’ generation (1945-1960).

British Society for Heart Failure

The baby BOOMer* and subsequent generations: the case for ACTION



Our Heart Failure Specialist workforce is not ready for this. Our NHS is not ready for this. Our economy is not ready for this.

Heart failure rarely exists alone

We support the Welsh Government's interest in tackling the growing issue of care of people who are living with more than one condition and the focus on patients with multiple long-term conditions receiving 'whole person' care. 98% of those diagnosed with heart failure in the UK live with at least one other long-term condition, such as diabetes, kidney disease, Chronic Obstructive Pulmonary Disease, and depression. Obesity can also be a complicating factor. Coronary artery disease (where the arteries that supply blood to the heart become clogged up with fatty substances such as cholesterol) and raised blood pressure are two of the most common precursor conditions (see comorbidity graph below).

A heart failure patient with 3 multi-morbidities, such as chronic kidney disease, diabetes and dyslipidaemia, will likely have a length of stay in hospital extended by half a day; have an increased admission cost of £350 and both readmission and inpatient mortality increase by 1%.

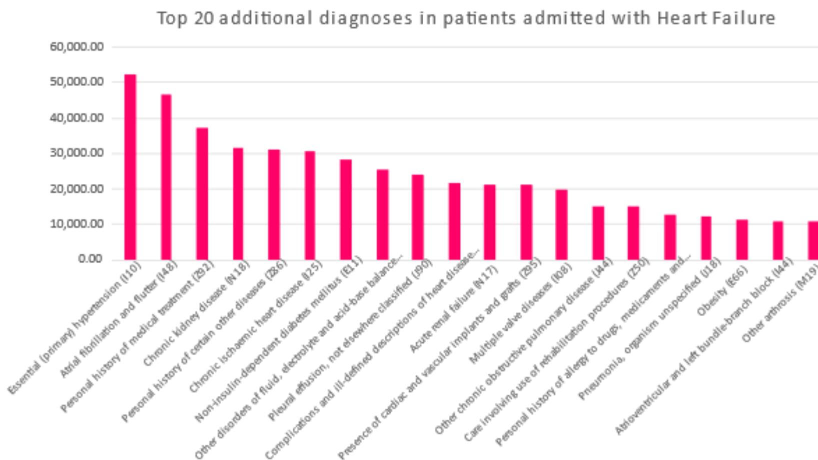
From epidemiology to pathophysiology, there are overlaps with many other organ systems and clinical specialities. Preventing and treating heart failure must be considered a shared responsibility across the wider healthcare environment and hence, the need for the 25in25 initiative. It is essential to make every contact count with individuals at risk of or already suffering from heart failure.

BRITISH SOCIETY FOR HEART FAILURE

British Society for Heart Failure

25IN25

Heart Failure- Comorbidity



The presence of 3 of these comorbidities.*

Average length of stay increases by ½ a day.

Admission cost increases by £350.

Readmission and inpatient mortality both increase by 1%.

* Diabetes, CKD and dyslipidaemia

Adapted from Bragazzi NL, Zhong W, Shu J, Abu Much A, Lotan D, Grupper A, Younis A, Dai H. Burden of heart failure and underlying causes in 195 countries and territories from 1990 to 2017. Eur J Prev Cardiol 2021;28:1682-1690.

Together we can turn the tide on this life limiting condition.

25in25 collaboration to reduce heart failure deaths

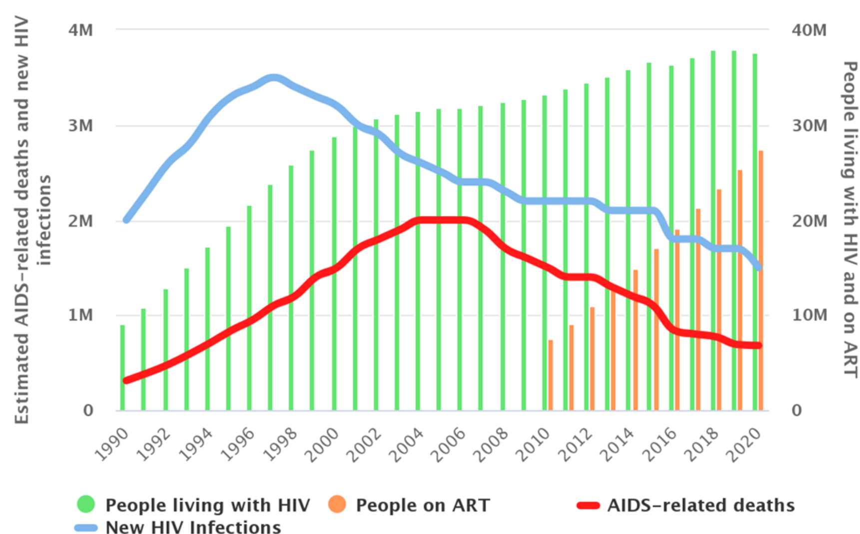
At a Summit held on 9th March 2023, the British Society for Heart Failure convened 45+ top health organisations from the UK, with key roles in diverting the course of the heart failure epidemic. Expert representatives from the 25in25 collaborative united as leaders to sign a declaration and commit to reducing the mortality from heart failure in the first year after diagnosis by 25% in the next 25 years. The 25in25 Collaborative.

Across the UK, introducing measures to reduce mortality in the first year after diagnosis of heart failure, would result in 5 fewer deaths for every 100 patients newly diagnosed with heart failure every year, translating to over 10,000 lives saved annually.

Working together with allied organisations and looking through the lens of our population's health, the 25in25 collaborative can accelerate action towards reducing deaths due to heart failure. In addition, the 25in25 initiative intends to harness the potential of whole person care, addressing the fact that the health and care system has been built in silos, often focused on specific diseases or organs in the body. Across all disciplines and specialities that intersect with heart failure, the immediate issue, where we will have most impact on people and services, is through detecting the people who have heart failure already and don't know it. Identifying those at risk of developing heart failure and intervening early is key to the long-term management of cardiovascular diseases. Identified early, a huge difference can be made in the lives of those with heart failure. We have the tools and expertise to manage heart failure well and to enable those with the condition to live better.

Implementation - The 25in25 Fast Track Communities Initiative (FTCI)

The 25in25 collaborative is formed, now comes the implementation. Like the Welsh Government's aspiration to see health and care services, local Government and NHS bodies working ever more closely together, the aims of the 25in25 initiative are to be achieved through collaboration. To address the heart failure epidemic, we propose to use a 'Fast Track Communities' model based on the 'Fast-Track Cities' model for reducing deaths due to HIV, established by UNAIDS in 2014.



The global aims for the Fast Track Cities HIV initiative are for 90% of all people living with HIV to be diagnosed, 90% of those diagnosed to receive HIV treatment and 90% of those receiving treatment to achieve viral suppression, by 2020. In 2017, the UK reached 92-98-97. London became the first city in the world to meet the 95-95-95 target demonstrating the significant impact of the Fast Track Cities Initiative (FTCI) on clinical and organisational care.

Unlike HIV, heart failure is complex. Unlike HIV, heart failure is widespread, not as concentrated in cities or urban areas, however the advantages of a Fast Track 'cities/ communities' approach is that it is a 'meeting point' for all stakeholders, across the whole pathway, to come together under political and clinical leadership.

Fast Track Communities is a progressive, continuous improvement model which strives towards capturing the following metrics:

- 90% of patients with a risk factor for heart failure are identified
- 90% of expected patients with heart failure are accurately diagnosed
- 90% of diagnosed patients with heart failure are prescribed guideline directed medical therapy
- 90% of patients with heart failure have a personalised care plan that addresses quality of life and wellbeing

Having identified the priorities across risk, diagnosis, treatment and patient empowerment cross-functionally at the Summit, the 25in25 collaborative will finalise a roadmap over the coming months. This roadmap will be the foundation of an AI enabled custom platform which will be used by

'communities' (localities in priority order based on pre-determined need) to identify trends in population health. It will inform planning for the future. These communities will comprise health and social care professionals, local politicians, public health, community groups, faith-based and Welsh language speaking organisations, dependent on demographics and local needs. The platform will identify trends in population health that will inform and future proof community planning and resource allocation.

Across multi-morbidities, it is essential to make every contact count with individuals at risk of or already suffering from heart failure. This plan will culminate in reducing the unnecessary suffering and deaths due to heart failure and improve population health whilst reducing the burden on health services and professionals. The Fast Track Communities initiative can support the NHS across the UK to achieve essential goals; reducing hospitalisations due to heart failure, improving patient outcomes and quality of life, improved early detection and treatment of those who are currently unaware they have the condition.

Community-based diagnosis of heart failure is a public health priority for the NHS Long Term Plan and recent evidence strongly suggests the need for new approaches to increase community-based diagnoses which would unlock longer, healthier lives for patients while substantially reducing the heart failure cost burden. We believe 25in25 Fast Track Communities initiative is an opportunity for the 25in25 Collaborative to work in support of, and hand in hand with, the NHS to achieve this. We believe that collaboration is the key to supporting clinical professionals to heal with whole person and to change the trajectory of heart failure.

We ask that the Welsh Government:

- Recognises and acknowledges heart failure as a growing societal problem and the endpoint of almost all cardiovascular disease and, as such, prioritises heart failure as a chronic condition that requires action now
- Prioritises prevention, detection, diagnosis, and treatment of heart failure across diverse communities, particularly the traditionally lesser engaged communities and that the BSH is involved in stakeholder forums and engagement/ Public Health Wales around health inequalities in chronic conditions, particularly with respect to the Fast Track Communities
- Asks that the Minister for Health and Social Services takes a cross Government approach to address heart failure prevention, diagnosis and treatment, and includes heart failure in operational guidance and frameworks for the Health Boards, Trusts and primary care to drive better outcomes in this insidious chronic condition

Request for dialogue:

- The BSH would welcome a meeting with the Welsh Government Health and Social Care department to discuss heart failure and the 25in25 initiative within the context of the chronic conditions consultation

- We further request for the BSH to be involved in stakeholder forums and engagement around the implementation of the chronic conditions consultation and future thinking/ roll out of the National Workforce Implementation Plan

- We request that the Minister for Health and Social Services joins a one-hour briefing with senior members of the BSH and the 25in25 Collaborative to discuss how the 25in25 initiative will influence good clinical practice and support achievement for the quality statement for heart conditions and chronic conditions consultation

Working together

It is important that we focus on ways to deploy our existing and future workforce more effectively. As mentioned in the Wales workforce implementation plan and originally stated in the Health Education England's 'Multi-professional framework for advanced clinical practice in England' report of 2017, "New solutions are required to deliver healthcare to meet the changing needs of the population". This will include:

- enhanced use of multi professional teamworking, with service, team and role redesign deploying new roles
- use of technology and efficient process thinking to deploy people more flexibly, through effective rostering and work scheduling, enabling flexible employment across professional and organisational boundaries and reducing any delay or barriers in our employment systems and processes
- the opportunity for digital solutions to release time to care, to support scarce workforce expertise and to enable people to work more effectively to improve services and reduce workload
- Like the Fast Track Communities Initiative, the Implementation Plan will need to be an agile plan capable of reprioritising during delivery and updated regularly
- New priorities will emerge from the all-Wales programmes and networks for major conditions such as cardiac/heart disease and should prioritise heart failure

The Welsh Government has stated that the workforce model needs to adapt, reflecting that NHS Wales is caring for patients with increasingly complex needs and with multiple chronic conditions. We concur. It is well evidenced that heart failure specialist care drastically improves outcomes for those with heart failure. However, having just completed the first ever UK Heart Failure Service Mapping Survey, we know we do not have enough heart failure specialists to manage the case load of diagnosed heart failure patients now, let alone into the future with the growing burden. With support from national bodies across England, Wales, Scotland and Northern Ireland, this survey, to be audited on an annual basis, will be critical to support service planning, development, and research and for evaluation of services for request of adequate resources to better serve our heart failure patients.

That there are too few heart failure specialists in the UK for the caseload now is one of the drivers for the 25in25 collaborative. Working together as multi-professional teams across healthcare settings and disciplines towards the common 25in25 goal will lead to sustainable wins for heart failure and across other diseases. Sharing the responsibility of identifying those with risk factors for and detecting heart failure earlier, at any and every possible point of care, is paramount to success. But better awareness and education is essential – for the public, policy makers, healthcare practitioners and all.

Collectively, we can leverage our reach, infrastructure, and human capacity to build a more equitable, inclusive, prosperous, and sustainable future for all those in danger of dying from heart failure, regardless of circumstances. Together, we can turn the tide on this life-limiting condition and benefit our communities.

References and evidence to support available on request.

Appendix 1

The 25in25 Declaration

DECLARATION

REDUCING HEART FAILURE DEATHS BY 25% IN 25 YEARS

Cardiovascular diseases are the leading cause of death globally[i] and in the UK, accounting for around a third of lives lost through ill health each year[ii,iii]. We are at a crucial point in time for those with cardiovascular diseases such as heart failure.

Over one million people in the UK have heart failure, with 200,000 new diagnoses every year. Estimates suggest there are a further 385,000 people with heart failure who are currently undetected and undiagnosed, and who are missing out on life-preserving treatments. Heart failure prevalence is set to increase dramatically due the rapid aging of the population anticipated over the next 25 years. Heart failure is not only a primary endpoint for almost all cardiovascular diseases but also a significant cause of mortality across the wider cardiorenal-metabolic spectrum, and from epidemiology to pathophysiology, there are overlaps with many other organ systems and clinical specialties.

Currently, 80% of heart failure is diagnosed during an acute hospital admission, despite 40% of these having presented with symptoms in primary care[iv]. Mortality following an acute admission for heart failure is 1 in 3 in the year after discharge[v]. The human and economic costs are huge with heart failure consuming 2% of the entire NHS budget[vi].

Identifying people at risk of developing heart failure is key to prevention, which is needed to slow the growing burden of heart failure on public health services. Early detection and intervention will reduce hospital admissions and free up valuable resource.

* References on request.

Despite growing success due to incredible scientific breakthroughs, increasing awareness and understanding, we must take the opportunity now to change the trajectory of heart failure, which will lead to sustainable wins across other diseases and specialties.

Working together, we can accelerate action towards reducing deaths due to heart failure in the next 25 years. As a collective, we will leverage our reach, infrastructure, and human capacity to build a more equitable, inclusive, prosperous, and sustainable future for all those in danger of dying from heart failure, regardless of circumstances.

Together we can turn the tide on this life limiting condition. To achieve this we will:

1. ***Take collective action for change***
2. ***Bring together our specialist knowledge and professional expertise***
3. ***Support implementation through localised communities***
4. ***Embed prevention and early detection programmes thereby improving population health***

That is why we commit to unite as leaders towards a common goal to reduce heart failure deaths by 25% in 25 years. In witness thereof, the undersigned, being duly authorised to that effect, have signed this agreement...

Signed ....

Organisation ....

BRITISH SOCIETY FOR HEART FAILURE

25 IN 25

British Society for Heart Failure

Appendix 2

The 25in25 Collaborative – list of participating organisations:

- Atrial Fibrillation Association
- All-Wales Heart Failure Nurse Forum
- Association of Nephrology Nurses
- Association for the Study of Obesity
- British Adult Congenital Cardiac Association
- British and Irish Hypertension Society
- British Association for Cardiovascular Prevention and Rehabilitation
- British Association for Nursing in Cardiovascular Care
- British Cardiovascular Society
- British Geriatric Society
- British Heart Foundation
- British Heart Rhythm Society
- British Heart Valve Society
- British Society of Echocardiography
- Canadian Heart Failure Society
- CaReMe
- Cardiorenal Forum
- Cardiomyopathy UK
- Catalan Society for Heart Failure
- Diabetes Africa
- Diabetes Specialist Nurse Forum UK
- Diabetes UK
- Faculty of Public Health
- GIRFT
- Global Heart Hub
- Heart Failure Association of the European Society of Cardiology
- Heart Failure Policy Network
- Heart Failure Society of America
- HeartLife Foundation, Canada
- Heart UK
- Heart Valve Voice
- hFRenDs
- Irish Association of Heart Failure Nurses
- Kidney Care UK
- NHS Wales
- NI Chest Heart and Stroke
- NI Heart Failure Nurse Forum
- Nuffield Health
- Primary Care Cardiovascular Society
- Primary Care Pharmacy Association
- Pumping Marvellous Foundation
- Royal College of General Practitioners
- Scottish Heart Failure Nurse Forum
- Society of Endocrinologists
- Society for Acute Medicine
- Spanish Society for Heart Failure
- Heart Failure Hub Scotland
- UKATPA – amyloid patient charity
- UK Clinical Pharmacy Association
- UK Kidney Association
- Wales Cardiac Network