Opening Statement by Chris Macey, Director of Advocacy and Patient Support, Irish Heart Foundation (IHF), to the Joint Oireachtas Committee on Health, December 13th 2023

Thank you Cathaoirleach for the invitation to meet the Committee today. I will address three important areas of need in this presentation:

- The chronic lack of investment in community supports for heart and stroke patients and the IHF role in supporting them.

- The lack of a national cardiovascular disease (CVD) policy, the failure to publish the long-awaited National Cardiac Services Review and implementation of the National Stroke Strategy.

- The need to prioritise prevention. Given that 80% of CVD is preventable, there's no measure open to policymakers that will save more lives, prevent more chronic disease and help make the health service sustainable in the long-term.

I'll begin with community services for CVD patients and the solo role played by the IHF in delivering national support services to heart and stroke patients. Since Covid we have built a comprehensive pathway of practical, social and emotional support services running almost literally from the hospital gates for as long as patients need our help.

These services were developed in response to a widespread sense of abandonment among stroke survivors caused by lack of access to community rehabilitation and recovery services. And to help heart failure patients who endure a revolving door syndrome highlighted by a 90 day hospital readmission rate to hospital of 30%, often for the want of basic information and support.

Although our services focus primarily on stroke and heart failure, we also deliver supports across a broad range of conditions, including heart attack, cardiomyopathies, sudden cardiac death, congenital heart disease, Long QT syndrome and people with ICDs.

These services are endorsed by the HSE, but have received no statutory funding to date, apart from partial CHO support amounting to around 7% of their total cost.

Patients describe our practical, social and emotional support services as their lifeline. They revolve around non-medical services and supports delivered by phone, online and face-to-face that can be the difference between living well in the community and long-term dependency or even premature death.

They prevent hospital readmission among heart patients, reduce requirement for nursing home care among stroke survivors and remove a significant burden from frontline services.

Despite psychological impact similar to PTSD that often results from a stroke or heart disease diagnosis, the IHF provides the only access to counselling for many people.

This year around one third of stroke survivors returning home from hospital nationally will be referred to our services, with thousands of heart failure and other cardiac patients also benefiting.

We are more than 90% funded by public and corporate donations and therefore at the mercy of economic forces such as the cost of living crisis.

We are making a difference to thousands of lives, but the continued delivery of these services can never be guaranteed in the absence of statutory funding.

And our limited capacity as a small charity given the scale of CVD means we cannot give many thousands more patients the help they need without ourselves getting help from the State.

Each year there are over 9,000 CVD deaths in Ireland – almost 30% of all mortality. Over half a million people are living with a cardiovascular condition, with 80,000 discharged from hospital each year.

During a meeting with us in 2021, Committee members expressed alarm that there had been no national policy for the world's biggest killer disease since 2019. Despite your subsequent representations and a continuing increase in CVD incidence, driven by age demographics, the Department of Health still has no intention to develop a policy. Although cancer has its own unit within the Department, CVD comes under a broad population health and non-communicable diseases unit.

Additionally, we have a National Cardiac Services Review that began almost six years ago and whose final report has been on the Minister's desk for most of this year, without any indication of a publication date.

The review recommends an updated configuration for national adult cardiac services. Pending implementation, cardiac care will remain in a state of limbo, with unnecessary difficulties in planning and organising services that will inevitably impact patient outcomes. Specific issues include long waiting times for echocardiogram, cardiac magnetic resonance and CT scans and shortages in physiologist posts.

There's also a pressing need for a Heart Failure Registry. Although at least 90,000 people are living with the condition with another 250,000 impending cases, there is a lack of reliable real-time data. This is crucial to give health service planners a better understanding of the causes of high re-admission and mortality rates.

Meanwhile, the National Stroke Strategy 2022-27 has been published, but is not being coherently implemented. Mainly non-recurrent funding was allocated in last year's Budget, so key staffing increases which are its cornerstone were largely unaddressed. And there's growing concern that none of 70-75 posts required under the Strategy will be filled in 2024.

All of this matters. Research shows that stroke units reduce death and long-term disability by up to 20%. But the national stroke unit network is already struggling, with units in Naas and St James' not currently meeting minimum criteria and others under severe pressure. Senior clinicians believe a failure to roll-out the Strategy could result in no stroke units being left in Ireland's inland counties.

We estimate that de-funding the stroke strategy could mean some 500 cases of preventable death and severe permanent disability among patients who aren't admitted to a unit. It could contribute to

bed days increasing by 12,000 a year and additional requirement for long-term care resulting in no net savings in exchange for an enormous human cost.

Whilst we must address current deficits and futureproof services for an imminent upsurge in heart disease and stroke rates, policymakers must also capitalise on the fact that 80% of CVD is preventable.

This means most of its human toll and consequent impact on our health services is unnecessary. By adopting a stronger focus on primary prevention – transforming what is essentially an illness service into a genuine health service – policymakers could effectively tackle the continuing lurch towards unsustainability fuelled by changing demographics.

Crucial to this is political will to address the factors fuelling preventable CVD including obesity, uncontrolled blood pressure, smoking, physical inactivity, excess alcohol intake and air pollution.

To provide a blueprint for policymakers, the IHF commissioned the UCC School of Public Health to set out primary prevention policy responses in a landmark research paper. We have also established the Irish Health Promotion Alliance comprising members across civil society to seek greater policy focus on all chronic disease prevention.

In summary, there are three areas we urge the Committee to champion on our behalf:

1. Support an assessment of patient needs in the community and investment in community CVD services and supports, ensuring the health service puts greater emphasis on patient recovery and wellbeing.

   The assessment should measure the financial burden of CVD. Our recent survey of heart failure patients found 60% suffered a significant drop in income, whilst the vast majority struggled with the additional cost of medical bills, prescriptions, travel and household bills Almost 40% of working-age patients didn't have a medical card or GP visit card. A survey among working-age stroke survivors found that 70% experienced a substantial reduction in income and over 80% faced higher costs.

2. Seek a timebound commitment from Minister Donnelly to develop a new National Cardiovascular Policy, publish and implement the National Cardiac Services Review; and fully roll-out the National Stroke Strategy.

3. To seek priority for population-based strategies for primary CVD prevention on the grounds of health, wellbeing, equity and social justice.

ENDS