



## Briefing for Policymakers

### A Call to Action to Support Patients with Heart Failure in Northern Ireland

By Nicole McKelvie, on behalf of Heart Failure Warriors NI

Heart failure (HF) affects nearly 1 million people in the UK and at least **23,000 in Northern Ireland (NI)**, with another 20,000 estimated to be undiagnosed. Despite having **worse survival rates than many cancers**, HF often lacks the visibility, investment, and urgency it demands within our health system.

As policymakers, you are in a unique position to support the citizens of Northern Ireland who are living with heart failure. Having a better understanding of what patients, like myself, are experiencing from the moment of diagnosis to long-term management, funding more specialist heart failure nurses and commissioning more cardiac rehabilitation services, will help improve outcomes, reduce costly hospitalisations, and ensure patients live longer and better.

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### Understanding Heart Failure

Heart failure is a **progressive, incurable condition** in which the heart cannot pump enough blood to meet the body's needs. It is often caused by heart attacks, high blood pressure, or congenital disease. Common symptoms include **breathlessness, fatigue, and fluid retention**.

But it is **treatable**. With early diagnosis, effective treatment, access to cardiac rehabilitation, and person-centred, joined-up care, people with HF can have better quality of life for longer.

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### Nicole and Farrah's Stories: A Tale of Two Pathways



I, Nicole (Southern Trust), was active and fit, yet undiagnosed for over a year despite symptoms. Eventually diagnosed during an A&E admission, she received coordinated care, early access to rehab, and emotional support.

My twin sister Farrah, in another Trust, was diagnosed through family screening. Her diagnosis was delivered over the phone. She waited **eight months** for specialist input and **never accessed rehab**. The emotional toll was profound.

These contrasting experiences highlight **inequities across Trusts**—a postcode lottery that must be addressed.

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### Heart Failure in Northern Ireland: The Reality

- **23,000+ diagnosed**, with a further 20,000 likely undiagnosed
  - **6,400+ hospital admissions** annually—many preventable
  - **Only 49%** referred to cardiac rehab
  - **98%** live with at least one other long-term condition, with half living with 5 other long term conditions
  - **HF prevalence is projected to rise 92% by 2040**
  - Significant gaps in palliative care planning and delivery
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### System Failures and Inequities

Disjointed care pathways and regional variation in service provision impact outcomes:

- People in deprived areas face **20% higher risk** of hospitalisation
  - Access to Heart Failure Specialist Nurses (HFNS) and cardiac rehabilitation is inconsistent
  - End-of-life care is often delayed or poorly coordinated
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### A Call to Action: What the System Needs

Led by Professor Patricia Campbell, the **NI Regional HF Transformation Project** is working to improve equity and standards of care. But progress depends on investment, leadership, and multi-sector collaboration.

### Key Policy Recommendations:

1. **Reframe HF as a long-term condition** (like diabetes or asthma)
2. **Standardise care** across all Trusts
3. **Expand the HF specialist workforce**
4. **Ensure universal access to cardiac rehabilitation**

5. **Collect and act on data to reduce disparities**

6. **Continue clinical leadership beyond 2025**

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**Immediate Asks for Policy Makers**

- Support ongoing HF transformation projects
  - Urge Trusts and commissioners to prioritise:
    - Workforce expansion
    - Rehab access
    - Seamless, person-centred care
  - Involve patients in service planning
  - Raise awareness in Stormont and the media
  - Improve public understanding of HF symptoms
  - Explore all-island care pathways for advanced HF in Ireland
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**Summary of Facts and Asks**


FACT	ASK
HF has worse outcomes than many cancers	Commission specialist-led HF services
HF care varies across NI	Standardise and invest in equitable care
Rehab reduces admissions and improves QoL	Ensure universal access to rehab
Patients have complex, long-term needs	Commission integrated care pathways
HF is rising	Invest in prevention and early diagnosis
Advanced HF care isn't available in NI	Explore all-island care options


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**About Heart Failure Warriors NI**

We are a **patient-led charity** advocating for earlier diagnosis, better care, and improved quality of life for people living with heart failure. We work in partnership with clinicians, policymakers, and communities to raise awareness and drive meaningful change.

 Nicole McKelvie, Chairwoman

 [nicole@heartfailurewarriorsni.com](mailto:nicole@heartfailurewarriorsni.com)

 Watch our story: #FindMe

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## **Final Word**

Heart failure doesn't mean you just give up as there is no hope. With the right support, patients can recover confidence, function—and even enjoy better quality of life. Policymakers have the power to change lives by helping to fund improvement in HF provision. Let's act together now to ensure no one in Northern Ireland faces heart failure alone, misdiagnosed, or unsupported.