

14th May 2025

Committee Clerk: Keith McBride
Room 410, Parliament Buildings,
Ballymiscaw, Stormont,
Belfast, BT4 3XX

Dear Health Committee,

Regional Mapping exercise: palliative care provision for those with heart failure.

We are aware that the Health Committee is currently undertaking an inquiry into access to palliative care - this is an extremely important exercise which we understand is reviewing current provision and quality, accessibility and equity, coordination and Integration and Future Planning, amongst other things.

With this in mind, we would like to make you aware of a Marie Curie Funded Regional Mapping exercise we are currently undertaking looking at palliative care provision for those with heart failure. The aim of this study is to map the supportive, palliative, and end-of-life care services available for people with advanced heart failure in Northern Ireland, and to determine how palliative care access for people with advanced heart failure is implemented across the country. The study is being supported by a steering group involving stakeholders from heart and palliative care services, specialist charities and those with lived experience. (fuller details of the study are attached).

The final report is due to be published in 2025/early2026, however we wanted to make the committee aware of emerging findings from our Mapping exercise. These include suggested gaps in knowledge around palliative care provision for people with heart failure within and across trusts, which has implications for the equity of palliative care provision for people with heart failure and their families across Northern Ireland.

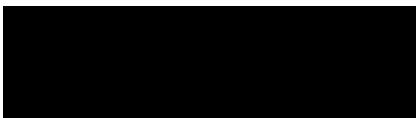
Other emerging findings suggest that there is a lack of integration between heart failure and palliative care services, impacting upon access to palliative care for people with heart failure who could benefit from palliative care support.

Another finding is that advance care plans are not being completed consistently for those with heart failure, leaving those with heart failure without a clear plan for what their end-of-life care can look like or what choices they have when it comes to their end-of-life care.

I hope this information is useful. We will get in touch again once the report is published. However, should you require further information please feel free to contact me.

Yours sincerely,

Dr Tracey McConnell.



Mapping survey Northern Ireland – Palliative care service provision for people with Heart failure

Background

Although access to palliative care for people with heart failure is recommended in national guidelines, there is no national standard to inform how integration between palliative care should be delivered or resourced for those with heart failure. Currently, some individuals may receive excellent care whilst others do not. Therefore, we need to understand how palliative care services are currently being made available for people with heart failure and to identify examples of good practice.

Thus, we are conducting a regional service evaluation to gain an improved understanding of the current provision of palliative care for people with heart failure in Northern Ireland (NI). It has been endorsed by the Department of Health, and as pointed out by the Department, this survey will provide valuable insight into the current provision of palliative care for people with heart failure across the region and will help to identify where more support is needed.

The mapping exercise has been conducted via a questionnaire survey sent to all Heart Failure Clinical Service Leads across all Trusts to gain an understanding of the current provision of palliative care for people with heart failure in NI across community and acute services. The survey is based on a recent NHS England commissioned mapping exercise and piloted with Consultants in Palliative Medicine and Heart Failure Nurse Specialists for adaptation to the NI healthcare context.

Aim

The aim of this study is to map the supportive, palliative, and end-of-life care services available for people with advanced heart failure in Northern Ireland, and to determine how palliative care access for people with advanced heart failure is implemented across the country.

Advisory Board

A number of very valuable stakeholders are involved in steering this project, ensuring it is grounded in practice and policy. These include the British Heart Foundation, Marie Curie, Chest Heart and Stroke, NI Heart Failure Warriors, PCiP, NHS Trust representative, and people affected directly by heart failure including people having heart failure and caregivers.

Practical Outcomes / Impact

- Develop an understanding of where there are gaps in integrated palliative care and heart failure services.
- Work with Marie Curie Policy Team to redress the gaps and inequalities in integrated palliative care and heart failure service provision.
- Impact on practice *via* a service evaluation report for service providers so they can see clearly where there are gaps in supportive, palliative and end-of-life care services for people with heart failure in their trust.
- Steps are needed to improve knowledge, access and integration.

We hope the data obtained from this research will support advocacy calls for improvements in palliative care service provision for people with heart failure. Improved palliative care provision, through the prevention and relief of suffering, will improve the quality of life of patients and their families facing the complex and difficult problems associated with living with heart failure.

This mapping survey of palliative care provision for people with heart failure in NI is due to complete by end of August, with dissemination of findings planned within the following months. This project links to a wider UK NIHR funded study which started January this year, focused on optimising delivery of integrated palliative care and heart failure services – link here:

<https://fundingawards.nihr.ac.uk/award/NIHR161150>