Palliative care provision for people with Heart failure: Northern Ireland - *Policy brief*

Context

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 with heart failure may have access to 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.

A recent study mapped the palliative care available for people receiving heart failure care via statutory services in Northern Ireland, to identify any gaps in palliative care provision where more support and resources may be required. 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.

Gaps in palliative care service provision and recommendations for policy and practice:

Gap identified through research (academic findings paper due end of 2025)	Recommendations for policy and practice
1. Lack of identification and routine palliative care holistic needs assessment Lack of a systematic tool/template to guide holistic assessment.	1a. Implement appropriate performance metrics to ensure consistent use of palliative care holistic assessment tools such as ELCOS or SPICT across care settings.
	1b. Embed routine palliative care holistic needs assessments into electronic health records to prompt completion by heart failure clinicians at key stages (including at the point of diagnosis and other stages of deterioration, not only towards 'end-of-life'). With timely referral to the palliative care Key worker (usually the District Nurse) for ongoing community support.
2. Assessment of palliative care needs happening too late (toward a person's end-of-life).	2a. Ensure palliative care education is embedded within pre and post registration curricula for all healthcare professionals, including allied healthcare professionals.
	2b. A targeted public health campaign to improve the public understanding of what palliative care is, its benefits, and when it should be introduced for people with Heart Failure.
	2c. People with Heart Failure should have timely access to rehabilitation throughout their palliative disease trajectory. Palliative Rehabilitation is essential following periods of deterioration to support the person to readjust to any reduction

	in independence by maximising their quality of life and promote self-management where possible.
3. Lack of knowledge around locally agreed eligibility criteria for referral to specialist palliative care.	3a. Ensure that locally agreed referral criteria for specialist palliative care are clearly communicated, regularly reviewed, and embedded into clinical workflows.
	3b. Locally agreed referral criteria for specialist palliative care should be embedded in electronic systems, visible within care settings, and embedded in clinical education, for example, mandatory training at induction when staff are initiated into new roles.
4. Lack of routine Advance care planning (ACP), completed largely by palliative care physicians.	4a. Mandate the implementation of a shared responsibility model to provide people with the opportunity to be involved in advance care planning across all care settings. Tools such as the ReSPECT form will ensure a person's values, wishes and beliefs are understood by all staff involved in a person's care.
	4b. Ensure that General Practitioners (GPs), nurses, and hospital clinicians are trained, supported, and held accountable for offering people the opportunity to be involved in Advance care planning.
5. Lack of routine inclusion of specialist palliative care in multi-disciplinary meetings.	5a. Establish formal requirements for the routine inclusion of specialist palliative care physicians, and/or palliative care nurse specialists in relevant multi-disciplinary team (MDT) meetings.
	5b. Trusts should ensure that meeting structures, referral processes, and communication pathways enable regular palliative care input.
6. Inequity of palliative care provision for those with Heart failure with preserved ejection fraction (HFpEF).	6a. Develop and implement inclusive referral criteria and clinical guidance that explicitly support ongoing timely access to palliative care for people with HFpEF, in particular during periods of increased symptoms/deterioration.
	6b. Palliative care provision should be based on need – not prognosis.
7. Post-code lottery: Palliative care provision based on locality.	7a. All patients should have access to the same service – there should be no postcode lottery.

Final thought:

These findings and implications are not specific to heart failure, but rather also highlight systemic issues across non-cancer life-limiting conditions. Integrating palliative care into heart failure and other chronic disease management aligns with system-wide goals of cost-efficiency and sustainable care delivery. Policymakers should consider palliative care not only as a clinical imperative but also as a strategy for optimising health system performance.

Project Lead: Dr Tracey McConnell

Co-authors: Dr Ashleen Crowe, Prof Joanne Reid, Prof Loreena Hill, Katarzyna Patynowska

These recommendations were co-produced with patient and public partners following consultation on the mapping survey findings.

Special thanks to NI Heart Failure Warriers (people with heart failure and their family/carers), Linda Cooper (Carer partner) and the McGill Charitable Family Trust who made a charitable donation to Marie Curie to fund the mapping survey.