Public Health Agency
Research and Development

HSC R&D Division Final Report

PPI in Research Small Grant Scheme

Updated March 2026

Reports should be submitted via electronic copy to HSC R&D Division within 6 weeks of the request.
The report should be completed on the attached form in Arial 11. Please extend boxes as required. Please adhere to any word limits. These reports may be subject to external peer review.
Details from the Report may be placed on the HSC R&D Division website and shared with appropriate key stakeholders or members of the public.

HSC R&D Division Award Details

HSC R&D File Reference	STL/5562/19
HSC R&D Funding Scheme	PPI in Research Support: Small Grant Scheme
Project Title	Exploring the needs of patients with a Left Ventricular Assist Device (LVAD) in Northern Ireland
Award Holder Name (Employer)	Dr Loreena Hill (Ulster University)
Host Organisation	Ulster University
Award Duration	
Award Start Date	01.08.25
Award End Date	01.11.25

Signature

Award Holder Signature:	[redacted]
	Date: 5th May 2026

Evidence Brief for PPI in Research Small Grant Scheme

(2 pages: which may be used for dissemination by HSC R&D Division)

Why did we start? (The purpose and need for the PPI initiative)	This timely and clinically important initiative aimed to explore the needs of patients with a VAD living in Northern Ireland (NI). In 2021, the technology changed to HeartMate 3, significantly improving patients' clinical outcomes. However, the psychosocial and economic landscapes that patients and their caregivers navigate daily remain complex and unclear. Many patients report profound physical (i.e. Carrying the VAD), psychological (i.e. Anxiety), economic (i.e. travel to consultations) and social (i.e. home adaptations) challenges. Current evidence calls for more than just technical education, rather structured, continuous psychological interventions and improved self-management skills. This would be achieved by the establishment of an inclusive steering group and agreement on steps for future involvement (research, education and practice).
What did we do? (Please comment on how the UK Standards for Public Involvement guided your plans and what you did)	In-person and inclusive workshop with patients (n=10), caregivers (n=5), clinical (n=5) and academic staff (n=4), and two representatives from HF Warriors NI was held on the 20th August. Prof Guy MacGowan attended virtually. Refreshments and informal introductions, enabled a welcoming environment, supporting rapport and honest communications. A brief overview was provided by Prof Hill, before a conversational and open dialogue commenced. Members were keen to engage and share their experiences. Together, they voiced concerns such as 'fear and loneliness' and how access to a 'VAD community' would help. The day was a safe space for all involved to support and learn from each other. Future funding application(s) were discussed, and many wished for continued involvement. Plans were made for the team to develop and share a document/booklet or leaflet outlining the challenges VAD patients and their caregivers encountered, with tips on navigating these and the benefits that evolved, as a method of ensuring sustainable impact.
What did we achieve? (Please describe any outputs and the short and longer-term impacts of this initiative)	The event provided the 1st opportunity for patients and their caregivers to meet and exchange information. Patients were grateful that they had a VAD, but at the same time felt **terrified, fearful over the 'what ifs'** and **lonely.** There was a clear need for more education for future recipients, particularly relating to necessary life adaptations following implantation. Further exploration was warranted on the patients and caregivers experiences during the transition and on return home from the transplant centre in Newcastle. The significant psychological impact on the caregiver was emphasised. One caregiver following the event reported **"I have truly benefitted from meeting other people and having shared their experience and learned a few things along the way".** However, it also left, for the team many unanswered questions concerned with equity of care, isolation, psychological distress and anxiety. The team therefore submitted a funding application to the NI Chest, Heart and Stroke, as many of the issues revolved around living in NI/ at a distance from Freeman's hospital. There were discussions and raised awareness of additional training needed for healthcare professionals to care for patients with a VAD if they present to primary care or hospital. A dedicated VAD clinic and or VAD professional, were considered as possible options to ensure these complex patients received optimal care when they needed it. Finally, contact was made with Electric Cranks https://www.newstartcharity.org/latest-news/the-cranks-on-the-move- to discuss establishing a sustainable presence, which will be facilitated through the HF Warriors NI.

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What should be done now? (Practice/Policy Implications and/or Recommendations for PPI in HSC Research)	This initiative has underscored the inadequate support provided to patients and caregivers living with a VAD living in NI. Despite receiving a life-saving treatment, patients and their caregivers are isolated and often left to deal with adapting to a new home life, one which can bring frightening situations. Their point of contact remains Freeman's hospital, with no sole point of contact in NI. There were a number of key points which emerged, which require further action 1: Increase in education for future recipients of a VAD in NI. Currently there is an increase in interest towards the use of Destination Therapy VADs by NHS England, leading to a potential increase in the number of VADs implanted. 2: Need for a user-friendly document/leaflet outlining practical tips for living with the VAD in Northern Ireland. These may include tips regarding travel (including insurance), battery care, driveline care, suitable clothing to support the carrying of the VAD, follow-up etc 3: Additional training for nursing and medical staff across clinical settings. Many patients with a VAD users have other medical needs alongside HF. Therefore, all professionals who may encounter these patients should be familiar with the VAD and when to refer for help. 4: Consider need for Patient advocate, VAD Specialist within NI and a specific VAD clinic. 5: More psychological care needed for patients and their caregivers, with need for onward specialist referral.
What do you feel has been the **most significant impact** of being awarded the PPI in Research Small Grant?	Undoubtedly the most significant impact was the stark realisation that patients with a VAD and their caregivers feel very isolated when discharged from Freeman's hospital. These findings led to a re-evaluation of the design of a future grant application.
Do you have any **'lessons learned'** from your PPI experiences during your award that would serve as useful learning for others in the future?	Advice for others would be to undertake a PPI activity much earlier when planning a future research application. What clinicians and researchers often perceive are key issues or potential interventions, do not always align to the priorities of patients. In addition, patients who attended the event had an overriding concern for their caregivers, appreciating the dependency they had on them. This underscores the importance of future research into caregivers needs and to emphasize their key role in shared decision-making in patients awaiting for or who have had a VAD implanted.

Word Cloud following PPI event with Patients who had an LVAD, and their caregivers