

Research Priorities in Advanced Heart Failure: James Lind Alliance Priority Setting Partnership

Taylor et al. (2020)

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For which topic were research priorities identified?

advanced heart failure

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

In the field of advanced HF, research has focused on younger, often male patients. In recent years, national funding bodies have advocated for more involvement of patients in setting the research agenda.

What was the objective?

to determine research priorities in advanced heart failure for patients, carers and healthcare professionals

What was the outcome?

a ranking list of 13 research questions

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: establishing steering group, defining scope. Step 2: identifying unanswered questions: participants were asked three open questions about the physical and emotional impacts of advanced heart failure and the treatment, support or help provided for people with the condition, 489 responses. Step 3: data processing: refining and categorizing submissions, resulting in 65 summary questions. Step 4: interim ranking: participants were asked to choose their top 10 from a list of 65 summary questions, to ensure balance between stakeholder groups top 13 priorities from patients/carers and top 13 from healthcare professionals were included on shortlist. Step 5: final prioritization: workshop: series of small group discussions and rankings, aggregate ranking discussed, final facilitated discussion

Which stakeholders took part?

Patients, carers and healthcare professionals. Survey: 192 participants: 74 patients, 17 carers, 92 health professionals and 9 others. Interim ranking: 128 participants: 17 patients, 15 carers, 96 healthcare professionals. Workshop: 26 participants: 5 patients, 3 carers, 6 GPs, 2 nurse specialists, a cardiologist, a geriatrician, 3 GP cardiologists, a physiotherapist, a cardiology research nurse, 2 charity representatives and a patient and public involvement facilitator.

How were stakeholders recruited?

No information provided.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group and PPIE group. The steering group consisted of 18 members: including 4 patients, 2 carers, 6 healthcare professionals (HF nurse specialist, palliative care nurse, cardiologist, geriatrician, palliative medicine consultant and GP), the 4 core PSP team members, 1 observer. The members oversaw the process, met eight times, designed and piloted the survey, were involved in data processing and observed the workshop. The PPIE group consisted of 7 members. The members worked alongside steering group, provided additional advice from the perspective of patients with advanced HF, provided feedback on the wording of the survey and usability of the online and paper versions.