

Advanced Heart Failure: Setting the Research Agenda

Clare Taylor, Alyson Huntley, Amy Gadoud, Richard Lehman, Mary Brice, Nicholas R Jones, FD Richard Hobbs, Gene Feder, Jonathan Mant, Rachel Johnson

Heart failure (HF) is a complex clinical syndrome affecting 1-2% of the adult population.¹ It places a heavy burden on both patients and their families which often increases in the later stages of the illness yet studies to date have not focused on the complexity of advanced disease.² Indeed, the definition of 'advanced HF' is still debated in both clinician and patient communities.³

Research priorities have traditionally been set by researchers and funders but involving those directly affected by the condition in the process can lead to more valid, credible and relevant research findings.⁴ We want to set the research agenda for advanced HF by undertaking a prioritisation exercise involving patients, carers and frontline clinicians.

The James Lind Alliance (JLA) is a non-profit making initiative which aims to identify unanswered research questions by facilitating Priority Setting Partnerships, or PSPs, to engage with those most affected by a particular condition.⁵ The Universities of Oxford, Bristol and Cambridge have been working collaboratively, under the guidance of the JLA, to establish the advanced HF PSP. A steering group of 16 people directly affected by advanced HF including patients, carers and clinicians are overseeing the project.

The steering group have defined the scope of the PSP as there is no universally agreed definition of 'advanced HF' amongst professional groups. Cardiologists and HF nurse specialists may recognise 'advanced' as patients requiring tertiary referral for consideration of devices or transplantation whilst generalists, such as geriatricians or general practitioners, may consider 'advanced' HF in those patients with significant and progressive symptoms, and in the context of frailty, multimorbidity and polypharmacy. For the purposes of the PSP, patients with advanced HF are 'people who know they have HF, may have had it for some time and find their condition has a significant impact on their life. They may need to take a lot of medication, or have needed hospital admission because of their HF, but are not currently in hospital'.

An online survey has been designed to ask patients, carers and frontline clinicians what they think the priorities for advanced HF research should be. The survey, which launches in May 2018, asks what research is needed on the impact of HF on physical health, emotion wellbeing and the treatment and support provided to people with advanced HF.

The members of the steering group will promote the survey through their wider partner networks, which include patient groups and healthcare clinics, and through relevant websites such as HF charities and local NHS trusts. A review of the literature will be carried

out to identify where priorities have already been addressed, and where research gaps exist. Priorities will then be sorted to generate a shorter list for discussion at a final workshop in early 2019 where a 'Top 10' priority list will be agreed. The priorities will be disseminated widely to researchers and funders to ensure this project has the maximum impact on the advanced HF research agenda.

To find out more about the advanced HF PSP, and to complete the survey, please visit:
<http://www.jla.nihr.ac.uk/priority-setting-partnerships/advanced-heart-failure/>

References

¹ Roger VL. Epidemiology of Heart Failure. *Circ Res* 2013;113:646-659

² Ponikowski P, Voors AA, Anker SD, et al. 2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure: The Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC) Developed with the special contribution of the Heart Failure Association (HFA) of the ESC. *Eur Heart J* 2016

³ Abouezzeddine OF, Redfield MM. Who has advanced heart failure? Definition and epidemiology. *Congest Heart Fail* 2011;17(4):160-8

⁴ Partridge N, Scadding J. The James Lind Alliance: patients and clinicians should jointly identify their priorities for clinical trials. *Lancet* 2004;364(9449):1923-24

⁵ James Lind Alliance. Accessed on 27.03.18 at: www.jla.nihr.ac.uk