

More detailed information to be shown on the JLA website for the questions discussed at the final workshop.

PSP unique identifier (to be allocated by JLA team on receipt of final priorities from PSP)	Record ID (the unique identifier of the uncertainty. To be allocated by JLA team on receipt of final priorities from PSP)	PSP Name	Total number of verified uncertainties identified by the PSP	Uncertainty (PICO formatted indicative uncertainty where possible. Advised minimum requirements are 'Population' and 'Intervention'. Not all submissions may be suitable for PICO structure, but they should be in a format that will ultimately be of value to the research community)	Explanatory note (a plain language summary of up to 150 words, explaining key points of the uncertainty and why it is important, for research funders to begin working on. PSPs may wish to include examples of the original survey submissions here)	Date of the priority setting workshop	Rank of the uncertainty at the final workshop. (If no rank was agreed, please indicate)	Evidence (reference, and weblink where available, to the most recent relevant systematic review identified by the PSP, plus a maximum of 2 other systematic reviews, that the PSP considers relevant.)	Health Research Classification System (high level HRCS code to be allocated by the JLA team unless the PSP prefers to complete this)
		Advanced heart failure	25			13-Feb-19			
				Which approaches are effective in reducing fatigue in people with advanced heart failure?	Whilst there is some intervention research focusing on fatigue with advanced heart failure, much of it is not, and there is much more focus on functional improvement and to a lesser extent broad quality of life measures.	13-Feb-19	11	1. JBI Database System Rev Implement Rep. 2016 Mar; 14(3):68-115. doi: 10.11124/JBISRIR-2016-2441. Experiences and management of fatigue in everyday life among adult patients living with heart failure: a systematic review of qualitative evidence. Schjoedt I, Sommer I, Bjerrum MB. 2. Heart Fail Rev. 2016 Sep; 21(5):579-90. doi: 10.1007/s10741-016-9558-3. Effect of cardiac pacing on sleep-related breathing disorders: a systematic review. Anastasopoulos DL, Chalkias A, Iakovidou N, Xanthos T. 3. Sleep Med. 2016 Jan; 17:149-57. doi: 10.1016/j.sleep.2015.10.017. Epub 2015 Dec 2. Nocturnal oxygen therapy in patients with chronic heart failure and sleep apnea: a systematic review. Bordier P, Lataste A.	Cardiovascular

			What helps with symptoms from peripheral oedema experienced by people with advanced heart failure? For example, massage, exercise.	No significant evidence for people with advanced heart failure	13-Feb-19	25	No systematic reviews on this topic in past five years	Cardiovascular
			Can the long-term care needs of people with advanced heart failure be better met by closer co-operation between heart failure and palliative care teams?	No significant evidence for people with advanced heart failure	13-Feb-19	12	1. Ann Intern Med. 2008 Jan 15;148(2):147-59. Evidence for improving palliative care at the end of life: a systematic review. Lorenz KA1, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, Morton SC, Hughes RG, Hilton LK, Maglione M, Rhodes SL, Rolon C, Sun VC, Shekelle PG.	Cardiovascular
			What amount and type of exercise is safe and effective for people with advanced heart failure?	There is a large body of evidence for rehabilitation/supervised exercise as well as 'informal exercise' such as tai chi functional measures e.g. heart capabilities and to a lesser extent quality of life measures but no guidance on which/how much/how often - this lack of evidence is reflected in clinical guidelines. Equally there is no guidance for everyday activities for people with advanced heart failure e.g. going to shops, walking up hills	13-Feb-19	2	Three recent reviews: 1. Clin Rehabil. 2018 Nov;32(11):1482-1492. doi: 10.1177/0269215518784345. Epub 2018 Jul 9. The impact of high-intensity inspiratory muscle training on exercise capacity and inspiratory muscle strength in heart failure with reduced ejection fraction: a systematic review and meta-analysis. Gomes Neto M, Ferrari F4,5, Helal L, Lopes A. 2. Int J Cardiol. 2018 Mar 1;254:224-229. doi: 10.1016/j.ijcard.2017.10.114. Epub 2018 Jan 28. Determinants of exercise intolerance in heart failure with preserved ejection fraction: A systematic review and meta-analysis. Montero D1, Diaz-Cañestro C2. 3. Arch Cardiol Mex. 2017 Oct - Dec;87(4):326-335. doi: 10.1016/j.acmx.2016.12.002. Epub 2017 Jan 5. [The exercise training restores the heart rate variability in heart failure patients. A systematic review]. [Article in Spanish] Segovia V1 .	Cardiovascular

			How can advanced heart failure patients and professionals be helped to communicate about patients' symptoms that are difficult to express such as anxiety and low mood?	No significant evidence for people with advanced heart failure	13-Feb-19	9	1. Eur J Cardiovasc Nurs. 2015 Dec;14(6):525-35. doi: 10.1177/1474515114547648. Epub 2014 Aug 19. The importance of interactions between patients and healthcare professionals for heart failure self-care: A systematic review of qualitative research into patient perspectives. Currie K1, Strachan PH2, Spaling M3, Harkness K2, Barber D1, Clark AM4. 2. Int J Nurs Stud. 2012 Dec;49(12):1582-97. doi: 10.1016/j.ijnurstu.2012.05.010. Epub 2012 Jun 19. Understanding help-seeking decisions in people with heart failure: a qualitative systematic review. Clark AM1, Savard LA, Spaling MA, Heath S, Duncan AS, Spiers JA.	
			What support would be most effective for carers of people with advanced heart failure for example support groups?	No significant evidence for people with advanced heart failure and their carers	13-Feb-19	10	No systematic reviews on this topic in past five years	
			What is the most effective way to use diuretics in advanced heart failure, with respect to, fluid overload, kidney function, survival & quality of life?	No significant evidence for this care in the community for people with advanced heart failure	13-Feb-19	8	Examples from hospital care 1. Heart Fail Rev. 2016 Sep;21(5):611-9. doi: 10.1007/s10741-016-9559-2. Defining the role of ultrafiltration therapy in acute heart failure: a systematic review and meta-analysis. 2. Jain A1, Agrawal N2, Kazory A3. Nephron. 2015;129(3):189-96. doi: 10.1159/000371447. Epub 2015 Feb 27. Effect of ultrafiltration versus intravenous furosemide for decompensated heart failure in cardiorenal syndrome: a systematic review with meta-analysis of randomized controlled trials. Chen HY1, Chou KJ, Fang HC, Chen CL, Hsu CY, Huang WC, Huang CW, Huang CK, Lee PT. 3. Int Heart J. 2015;56(2):192-5. doi: 10.1536/ihj.14-288. Epub 2015 Feb 23. Liberal versus restricted fluid administration in heart failure patients. A systematic review and meta-analysis of randomized trials. Li Y1, Fu B, Qian X.	
			How can healthcare professionals manage the expectations of people with advanced heart failure? For example, uncertainty	No significant evidence for people with advanced heart failure	13-Feb-19	13	No systematic reviews on this topic in past five years	
			Which healthcare professional is most appropriate for people with advanced heart failure to consult with at each stage of their disease journey?	No significant evidence for people with advanced heart failure	13-Feb-19	19	No systematic reviews on this topic in past five years	

			Which treatments have the biggest impact on the quality of life of people with advanced heart failure?	Generally quality of life is not the primary (main)outcome in clinical studies - although it is likely to an outcome in exercise studies as a secondary outcome (not the main focus of study) , self-management and self-care interventions	13-Feb-19	1	No systematic reviews on this topic in past five years	
			What percentage of people with advanced heart failure have advanced care plan (ACP) discussions?	There are risk prediction studies for advancement of disease but with no patient focus	13-Feb-19	16	Risk prediction models for mortality in ambulatory patients with heart failure: a systematic review. Circ Heart Fail. 2013 Sep 1;6(5):881-9. doi: 10.1161/CIRCHEARTFAILURE.112.000043. Epub 2013 Jul 25.	Cardiovascular
			Which approaches are effective in helping people with advanced heart failure to have a good night's sleep?	There is some evidence of people's experiences of sleep problems but no significant evidence on how to tackle it	13-Feb-19	14	1.JBI Database System Rev Implement Rep. 2016 Mar; 14(3):68-115. doi: 10.11124/JBISRIR-2016-2441.Experiences and management of fatigue in everyday life among adult patients living with heart failure: a systematic review of qualitative evidence. Schjoedt I, Sommer I, Bjerrum MB. 2. Heart Fail Rev. 2016 Sep; 21(5):579-90. doi: 10.1007/s10741-016-9558-3.	Cardiovascular
			How do health professionals best manage chronic kidney disease and advanced heart failure? a. What medication is best to use? b. How to manage diuretics c. Is metolazone or iv furosemide better?	The evidence around this topic area is hospital based - the evidence that is lacking is care in the community	13-Feb-19	22	1. Heart Lung Circ. 2018 Aug;27(8):928-939. doi: 10.1016/j.hlc.2017.12.013. Epub 2018 Feb 13.Tolvaptan for Heart Failure in Chronic Kidney Disease Patients: A Systematic Review and Meta-Analysis. 2. J Card Fail. 2007 Oct;13(8):599-608.Worsening renal function and prognosis in heart failure: systematic review and meta-analysis.Damman K1, Navis G, Voors AA, Asselbergs FW, Smilde TD, Cleland JG, van Veldhuisen DJ, Hillege HL. 3. J Am Coll Cardiol. 2006 May 16;47(10):1987-96. Epub 2006 Apr 24.Renal impairment and outcomes in heart failure: systematic review and meta-analysis.Smith GL1, Lichtman JH, Bracken MB, Shlipak MG, Phillips CO, DiCapua P, Krumholz HM.	
			Which approaches, in addition to standard therapies, are effective in supporting breathless people with advanced heart failure?	No significant evidence for people with advanced heart failure	13-Feb-19	5	No systematic reviews on this topic in past five years	
			Do health professionals understand the life / activity / functional consequences of each medicine?	No significant evidence for people with advanced heart failure	13-Feb-19	20	No systematic reviews on this topic in past five years	

				How do health professionals respond when people with advanced heart failure ask 'When am I going to die? Are we talking days, months, years? What about sudden death?'	There are risk prediction studies for advancement of disease but with no patient focus	13-Feb-19	23	Rahimi K, Bennett D, Conrad N, Williams TM, Basu J, Dwight J, Woodward M, Patel A, McMurray J, MacMahon S. Risk prediction in patients with heart failure: a systematic review and analysis. ACC Heart Fail. 2014 Oct;2(5):440-6. doi: 10.1016/j.jchf.2014.04.008. Epub 2014 Sep 3. Alba AC, Agoritsas T, Jankowski M, Courvoisier D, Walter SD, Guyatt GH, Ross HJ. Risk prediction models for mortality in ambulatory patients with heart failure: a systematic review. Circ Heart Fail. 2013 Sep 1;6(5):881-9. doi: 10.1161/CIRCHEARTFAILURE.112.000043. Epub 2013 Jul 25.	Cardiovascular
				What are the benefits of asking a person with advanced heart failure 'what is important to them'?	No significant evidence for people with advanced heart failure	13-Feb-19	7	No systematic reviews on this topic in past five years	Cardiovascular
				How do people get support to continue as their heart failure becomes more advanced?	No significant evidence for people with advanced heart failure - more about access to services which is likely to variable across different geographical regions	13-Feb-19	18	No systematic reviews on this topic in past five years	
				How can the work of heart failure charities be better integrated with NHS services to optimise the care of people with advanced heart failure?	No significant evidence for people with advanced heart failure	13-Feb-19	4	No systematic reviews on this topic in past five years	Cardiovascular
				How can we distinguish between co-morbidities (other chronic conditions) for example: COPD/chest infection & advanced heart failure?	No significant evidence for people with advanced heart failure	13-Feb-19	17	Rashid M, Kwok CS, Gale CP, Impact of co-morbid burden on mortality in patients with coronary heart disease, heart failure, and cerebrovascular accident: a systematic review and meta-analysis. Eur Heart J Qual Care Clin Outcomes. 2017 Jan 1;3(1):20-36.	Cardiovascular
				What is the most empowering and effective education and self-management advice for people with advanced heart failure and carer? For example, dealing with fatigue.	Whilst there is evidence on self-management for heart failure -there is no real focus on patient-related outcomes such as fatigue	13-Feb-19	3	Whilst there are studies/systematic reviews on self-management for heart failure - some are quite old (outside our 5 year search), the outcomes are quite diverse or on very specific issues (cognitive impairment/heart failure and education). No real focus on patient-related outcomes such as fatigue	Cardiovascular
				Is there an 'App' to help people manage advanced heart failure?	No significant evidence for people with advanced heart failure	13-Feb-19	21	No systematic reviews on this topic in past five years	Cardiovascular

Data management spreadsheet for use by Priority Setting Partnerships for all questions received. Spreadsheet to be published on the JLA website at www.jla.nihr.ac.uk on completion of the PSP.

	The top 10 questions are highlighted in yellow. An additional 14 questions which were considered out of scope are also included at the end of the list		It was considered by the steering group that none of the following 65 questions were adequately answered by the systematic review literature. The systematic reviews referenced below are broadly related to the question/topic area.							
ID	Uncertainty (PICO formatted indicative uncertainty where possible. Advised minimum requirements are 'Population' and 'Intervention'. Not all submissions may be suitable for PICO structure, but they should be in a format that will ultimately be of value to the research community)	Original uncertainty	Evidence (reference, and weblink where available, to the most recent relevant systematic review identified by the PSP, plus a maximum of 2 other systematic reviews, including protocols for future systematic reviews, that the PSP considers relevant.)	Source of Uncertainty (if there are multiple sources, a PSP may wish to show them e.g. 1 x patient, 19 x clinician, 4 x research recommendations)						
1	1. Why do people with advanced heart failure experience fatigue?	A8 Why am I so tired no energy just glad to get to bed A9i-iii Why am I so tired all the time? A95ii I sometimes get very tired, what can I do about this? Why do I often feel tired after sleeping and is my poor sleep down to my heart problems? A115iii why do I feel so tired? (This is not a psychological question, it is not about mood or depression, it is a physical question.)	1.JBI Database System Rev Implement Rep. 2016 Mar; 14(3):68-115. doi: 10.11124/JBISRIR-2016-2441.Experiences and management of fatigue in everyday life among adult patients living with heart failure: a systematic review of qualitative evidence. Schjoedt I, Sommer I, Bjerrum MB. 2. Heart Fail Rev. 2016 Sep; 21(5):579-90. doi: 10.1007/s10741-016-9558-3.	4 patients						
2	2. How common is fatigue in people with advanced heart failure and what impact does it have?	C6 What can help with tiredness? C23 How can the fatigue be best treated? C24 How to manage fatigue more effectively? C39 What can be done to improve fatigue in heart failure? B35i What can help them get more energy? A8 Why am I so tired no energy just glad to get to bed A9i-iv Why am I so tired all the time?	As for question 1	21 patients, 14 patients, 3 carers						
3	3. Which approaches are effective in reducing fatigue in people with advanced heart failure?	C6 What can help with tiredness? C23 How can the fatigue be best treated? C24 How to manage fatigue more effectively? C39 What can be done to improve fatigue in heart failure? B35i What can help them get more energy? A36 What can I do to minimise fatigue? A38 How is heart failure likely to affect my day to day life? Is there anything I can do to help with tiredness caused by heart failure? C56iii Which are the best approaches to the fatigue of heart failure? A90 What can be done to help me with my tiredness C142 Can we improve the profound tiredness associated with heart failure C167 What are the best ways to manage breathlessness caused by heart failure? C156 Which interventions work best for fatigue? C161ii How can we manage your fatigue best? C170 Are there any treatments which relieve fatigue? B35ii What can help the hf patient sleep better? B69i What can I do to help my husband sleep better & reduce his tiredness?	As for question 1	11 health professionals, 3 carers, 2 patients						
4	4. Which approaches are effective in helping p	B35ii What can help the hf patient sleep better? B69i What can I do to help my husband sleep better & reduce his tiredness?	As for question 1	2 carers						
5	5. Which approaches, in addition to standard therapies, are effective in supporting breathless people with advanced heart failure?	C83iiBreathlessness associated with heart failure C63Patients tend to ask about the practical hints and tips to overcome the physical symptoms of illness ie around fatigue/breathlessness etc..C155What helps	No definitive evidence	8 health professionals , 2 patients						

6	<p>6. What amount and type of exercise is safe and effective for people with advanced heart failure?</p>	<p>A184 What can help me with my tiredness [and will exercise help my heart failure?] A40i-iii When getting up in the morning or out of a chair after a long period of sitting (for example, watching tv) is it best to wait a while until the body/heart adapts to the new position before moving into action? Is it unwise to try to do things as one used to do (hurrying upstairs even though this will cause tiredness and breathlessness) or should one move very slowly to avoid the symptoms? How safe is it to drive alone, which 90% of the time I do as I suffer from breathlessness, swollen ankles, fatigue. C7 Does yoga or Pilates started in heart failure reduce problems with activities of daily living? C26 Does more physical activity improve the outcome? A10 What exercise I can safely do? A15 Will exercise really help or hinder? A19 How to increase stamina in a way that will not further damage cardiac function A36 To what extent can exercise improve me, and how far can I push myself? What type(s) of exercise/training should I attempt? What can I do to minimise fatigue? A37 With 40% EF what exercises should I not do in the gym? A14 Why can we not get better exercise support? D49i,ii What physical activity would be good for me and what would be bad for me? How would I know when I was doing too little or too much? C52i,ii Can I hurt myself by exercising too much?</p>	<p>1. Clin Rehabil. 2018 Nov;32(11):1482-1492. doi: 10.1177/0269215518784345. Epub 2018 Jul 9. The impact of high-intensity inspiratory muscle training on exercise capacity and inspiratory muscle strength in heart failure with reduced ejection fraction: a systematic review and meta-analysis. Gomes Neto M1,2,3, Ferrari F4,5, Helal L4,6, Lopes AA2,7, 2. Int J Cardiol. 2018 Mar 1;254:224-229. doi: 10.1016/j.ijcard.2017.10.114. Epub 2018 Jan 28. Determinants of exercise intolerance in heart failure with preserved ejection fraction: A systematic review and meta-analysis. Montero D1, Diaz-Cañestro C2. 3. Arch Cardiol Mex. 2017 Oct - Dec;87(4):326-335. doi: 10.1016/j.acmx.2016.12.002. Epub 2017 Jan 5. [The exercise training restores the heart rate variability in heart failure patients. A systematic review]. [Article in Spanish] Segovia V1 . 4. Cardiology. 2017;136(2):79-89. doi: 10.1159/000448088. Epub 2016 Aug 27. The Effect of Exercise Training Intensity on Quality of Life in Heart Failure Patients: A Systematic Review and Meta-Analysis. Ostman C1, 5. Congenit Heart Dis. 2018 Mar;13(2):194-202. doi: 10.1111/chd.12586. Epub 2018 Feb 8. Effects of inspiratory muscle training in chronic heart failure patients: A systematic review and meta-analysis. Wu J1, . 10.1038/s41598-018-19708-0. Effects of vitamin D supplementation on inflammatory markers in heart failure: a systematic review and meta-analysis of randomized controlled trials. Rodriguez AJ1, Mousa A2, Ebeling PR1, Scott D1, de Courten B3. 2. Nutrients. 2018 Jun 26;10(7). pii: E828. doi: 10.3390/nu10070828. Dietary Patterns in Secondary Prevention of Heart Failure: A Systematic Review. Dos Reis Padilha G1, 3. Curr Drug Targets. 2011 Jan;12(1):29-41. Vitamin D biology in heart failure: molecular mechanisms and systematic review. Meems LM1, 4. J Card Fail. 2015 Dec;21(12):989-99. doi: 10.1016/j.cardfail.2015.10.004. Epub 2015 Oct 23. Nutritional Interventions in Heart Failure: A Systematic Review of the Literature. 5. Abshire M1, Xu J2, Baptiste D3, Almansa JR4, Xu J5, Cummings A4, Andrews MJ6, Dennison Himmelfarb C3. 6. J Gerontol Nurs. 2015 Nov;41(11):50-9. doi: 10.3928/00989134-20151015-06. Nutrition and Cognition in Older Adults With Heart Failure: A Systematic Review. Stewart MW, Traylor AC, Bratzke LC. 7. Curr Atheroscler Rep. 2008 Apr;10(2):117-20. Alcohol consumption and heart failure: a systematic review. Djoussé L1, Gaziano JM.</p>	<p>28 patients, 22 health professionals, 3 carers, 1 other</p>						
7	<p>7. What is the best diet for people with advanced heart failure? For example to improve condition, lose weight</p>	<p>C52iii What should I eat to help? C54ii Has anyone studied dietary changes as helpful for heart failure? I have heard anecdotally that low carb approaches help HF. A87 Does healthy eating help heart failure? A128 Weight gain is a big problem I am fighting against, what can help to maintain my weight whilst not doing as much exercise? A124iii What is the best diet to follow if you simply can't exercise? (eg my stress echo by the transplant team has shown that my activity ability for someone of my age is extremely poor and only a small % of what it should be) □</p>	<p>10.1038/s41598-018-19708-0. Effects of vitamin D supplementation on inflammatory markers in heart failure: a systematic review and meta-analysis of randomized controlled trials. Rodriguez AJ1, Mousa A2, Ebeling PR1, Scott D1, de Courten B3. 2. Nutrients. 2018 Jun 26;10(7). pii: E828. doi: 10.3390/nu10070828. Dietary Patterns in Secondary Prevention of Heart Failure: A Systematic Review. Dos Reis Padilha G1, 3. Curr Drug Targets. 2011 Jan;12(1):29-41. Vitamin D biology in heart failure: molecular mechanisms and systematic review. Meems LM1, 4. J Card Fail. 2015 Dec;21(12):989-99. doi: 10.1016/j.cardfail.2015.10.004. Epub 2015 Oct 23. Nutritional Interventions in Heart Failure: A Systematic Review of the Literature. 5. Abshire M1, Xu J2, Baptiste D3, Almansa JR4, Xu J5, Cummings A4, Andrews MJ6, Dennison Himmelfarb C3. 6. J Gerontol Nurs. 2015 Nov;41(11):50-9. doi: 10.3928/00989134-20151015-06. Nutrition and Cognition in Older Adults With Heart Failure: A Systematic Review. Stewart MW, Traylor AC, Bratzke LC. 7. Curr Atheroscler Rep. 2008 Apr;10(2):117-20. Alcohol consumption and heart failure: a systematic review. Djoussé L1, Gaziano JM.</p>	<p>3 patients, 2 health professionals</p>						
8	<p>8. What is the best way to identify mental health issues in people with advanced heart failure?</p>	<p>C125 How many patients actually feel depressed and how many have been asked about this by a healthcare professional C65 What is the prevalence of depression and mental illness in heart failure patients? C83 Depression associated with heart failure C39 How common is depression, anxiety, stress in carers of people with heart failure</p>	<p>No direct or sufficient evidence</p>	<p>4 health professionals</p>						

9	<p>9. How do psychological, emotional or mental health issues affect people with advanced heart failure and how do they affect prognosis (their future)?</p>	<p>C119 What are the main psychological issues facing patients with advanced heart failure? C125 What proportion of HF patients with depression have been offered access to CBT C179 How much does depression confer an adverse prognosis in end stage heart failure; how prevalent is depression in end stage HF and how should it be best managed C180 What type of support and how frequent should it be for low mood in advanced heart failure B121 ii How do you help a person with heart failure stay upbeat, especially in the winter, or when they develop other complications? C139 iii Is it safe for me to take antidepressants? C26 Do the fatigue and breathlessness courses offered by hospices help mood? □</p>	<p>1. Eur J Cardiovasc Nurs. 2016 Dec;15(7):478-485. Epub 2016 Feb 24. Anxiety in chronic heart failure and the risk of increased hospitalisations and mortality: A systematic review. Vongmany J1, Hickman LD2, Lewis J2, Newton PJ3, Phillips JL3. 2. Heart Fail Rev. 2016 Jan;21(1):49-63. doi: 10.1007/s10741-015-9517-4. Depression and anxiety as predictors of mortality among heart failure patients: systematic review and meta-analysis. Sokoreli I1, de Vries JJ2, Pauws SC2, Steyerberg EW3. 3. Issues Ment Health Nurs. 2008 Sep;29(9):1002-17. doi: 10.1080/01612840802274867. A systematic review of depression in adults with heart failure: instruments and incidence. Delville CL1, McDougall G.</p>	6 health professionals. 1 carer						
10	<p>10. How can people with advanced heart failure cope with their emotions, including fear & frustration, and what's the best way to support them?</p>	<p>B148 i, ii My husband had advanced heart failure. He becomes very frustrated when he cannot walk like he used to or do his gardening etc. More difficult to keep him cheery although he tries hard to adapt and cope with his disabilities. A94 How do I deal with the anger? How do I deal with the sense of loss? How do I minimise impact on my family? (Note: I am generally positive and try hard to get on with moving forward with what I've now got). A126 Why and how can we control impatience and short temper following heart attacks? A147 Following cardiac arrest I find it more difficult to cope and I am more emotional. I am very thankful for the medical intervention I had, but I am still sad. What can I do to stop feeling sad about how much my lifestyle has had to change? B78 How the person with heart failure copes with not being able to do what they used to do. C24 i, ii How best to deal with emotional burden of heart failure? Is CBT an effective alternative to anti-depressants? A95 iii I am aware of a lurking anxiety with the threat of depression as a result of my health condition. [I counter act this by being busy and doing things I enjoy and perhaps being over active. Is this sensible?] C108 Is there specific counselling for coping with heart failure? (may be talking about their selves as carers or on behalf of HF person or both?) C161 i, ii How do you find strength to cope with the ups and downs of your condition? Has having heart</p>	No definitive evidence	6 patients, 2 health professionals, 2 carers,						
11	<p>11. What is the most effective treatment, including psychological interventions, for people with depression and advanced heart failure?</p>	<p>A127 Help with depression etc caused by heart failure C179 How much does depression confer an adverse prognosis in end stage heart failure; how prevalent is depression in end stage HF and how should it be best managed C117 Who can best help with my depression? [What is the emotional impact of having an ICD?] C6 Are there antidepressants that are contraindicated in heart failure? C139 iii Is it safe for me to take antidepressants? A140 Being depressed and on Fluoxetine I have been stuck on it and just left hanging i.e. no follow-ups. C28 ii/iii Is there any evidence to show the impact of clinical psychology support for patients with heart failure? Is there any evidence to show the impact of clinical psychology support for patients with heart failure? How accessible is this for patients? C180 What type of support and how frequent should it be for low mood in advanced heart failure D32 Psychological services for heart failure are thin on the ground any research that would help funding resources in this would be brilliant. Perhaps research into the different approaches of services on heart failure patients. And which patients benefit from which referrals C58 Psychological support needs - Impact of uncertainty A86 i Apart from cbt, what other counselling type help</p>	<p>1. Int J Psychiatry Clin Pract. 2018 Sep;22(3):164-169. doi: 10.1080/13651501.2017.1401085. Epub 2017 Nov 26. The effect of antidepressant medications in the management of heart failure on outcomes: mortality, cardiovascular function and depression - a systematic review. Rajeswaran T1, Plymen CM2, Doherty AM3, 4. 2. J Cardiovasc Nurs. 2016 Sep-Oct;31(5):457-68. doi: 10.1097/JCN.0000000000000274. A Systematic Review of Relaxation, Meditation, and Guided Imagery Strategies for Symptom Management in Heart Failure. Kwekkeboom KL1, Bratzke LC. 3. Heart Fail Rev. 2017 Nov;22(6):731-741. doi: 10.1007/s10741-017-9640-5. Effects of cognitive behavioural therapy for depression in heart failure patients: a systematic review and meta-analysis. Jeyantham K1, Vongmany J1, Hickman LD2, Lewis J2, Newton PJ3, Phillips JL3. 4. Heart Lung. 2012 Sep-Oct;41(5):469-83. doi: 10.1016/j.hrtlng.2012.06.002. Effects of interventions on depression in heart failure: a systematic review. Woltz PC1, Chapa DW, Friedmann E, Son H, Akintade B, Thomas SA.</p>	10 health professionals, 3 patients, 1 other						

23	<p>23. What is the most effective way to use diuretics in advanced heart failure, with respect to, fluid overload, kidney function, survival & quality of life?</p>	<p>C24 Is weighing daily an effective monitoring tool? How to improve balancing the impact on chronic kidney disease and heart failure? C23 What medication is best to use with severe heart failure and renal impairment? C60iii How to manage cardio-renal syndrome or those at risk of this - how best to manage diuretics in late stage heart failure C134 Should fluid intake be limited? We see patients with Continence issues so it relates directly to the advice we offer. C138 in a community setting (rapid response team) should we be doing daily weights and monitoring fluid intake? if a GP/ANP increase or decreases diuretics how long should this be left before a review? in the community they often just get left and patient becomes overloaded with fluid or dry resulting in a potential admission that could have been prevented? C161 Do diuretics improve quality of life? C161 Does subcutaneous furosemide improves symptoms, C161 quality of life, or prognosis? C167 At what point does peripheral oedema cause distressing symptoms and how can these be alleviated? (Massage, diuretics, exercise) C178 How effective are subcut diuretics in managing fluid overload in heart failure cp iv C178 Evidence for home based support for patients with very advanced disease incl feasibility of iv diuretics in community. C170 How best to manage resistant fluid retention in</p>	<p>1. Heart Fail Rev. 2016 Sep;21(5):611-9. doi: 10.1007/s10741-016-9559-2. Defining the role of ultrafiltration therapy in acute heart failure: a systematic review and meta-analysis. 2. Jain A1, Agrawal N2, Kazory A3. Nephron. 2015;129(3):189-96. doi: 10.1159/000371447. Epub 2015 Feb 27. Effect of ultrafiltration versus intravenous furosemide for decompensated heart failure in cardiorenal syndrome: a systematic review with meta-analysis of randomized controlled trials. Chen HY1, Chou KJ, Fang HC, Chen CL, Hsu CY, Huang WC, Huang CW, Huang CK, Lee PT. 3. Int Heart J. 2015;56(2):192-5. doi: 10.1536/ihj.14-288. Epub 2015 Feb 23. Liberal versus restricted fluid administration in heart failure patients. A systematic review and meta-analysis of randomized trials. Li Y1, Fu B, Qian X. 4. Minerva Cardioangiol. 2014 Apr;62(2):131-46. Efficacy and safety assessment of isolated ultrafiltration compared to intravenous diuretics for acutely decompensated heart failure: a systematic review with meta-analysis. De Vecchis R1, Esposito C, Ariano C. 5. Int J Cardiol. 2014 May 1;173(2):139-45. doi: 10.1016/j.ijcard.2014.03.020. Epub 2014 Mar 14. Hypertonic saline with furosemide for the treatment of acute congestive heart failure: a systematic review and meta-analysis. Gandhi</p>	13 health professionals					
24	<p>24. Which treatments have the biggest impact on the quality of life of people with advanced heart failure?</p>	<p>C178 Does involvement of a specialist palliative care team in addition to heart failure nurses improve quality of life for patients and their carers C106 How can we most effectively improve survival and quality of life in people with HF? A127 I want my quality of life to get better so I am able to do these day to day tasks and more C161 Do diuretics improve quality of life? □</p>	<p>Generally QoL is not the primary outcome in trials - it is likely to an outcome in exercise, self-management and self-care interventions</p>	3 health professionals, 1 patient					
25	<p>25. When is weighing a person with advanced heart failure daily effective for monitoring?</p>	<p>C24 Is weighing daily an effective monitoring tool? How to improve balancing the impact on chronic kidney disease and heart failure? C138 in a community setting (rapid response team) should we be doing daily weights and monitoring fluid intake? if a GP/ANP increase or decreases diuretics how long should this be left before a review? in the community they often just get left and patient becomes overloaded with fluid or dry resulting in a potential admission that could have been prevented?</p>	<p>No direct or sufficient evidence</p>	2 health professionals					
26	<p>26. When can the focus on weighing a person with advanced heart failure be stopped?</p>	<p>C171ii When to take the focus of 'dry weight'.</p>	<p>No direct or sufficient evidence</p>	1 health professionals					
27	<p>27. How do health professionals best manage chronic kidney disease and advanced heart failure? a. What medication is best to use? b. How to manage diuretics c. Is metolazone or iv furosemide better?</p>	<p>C24 Is weighing daily an effective monitoring tool? How to improve balancing the impact on chronic kidney disease and heart failure? C23 What medication is best to use with severe heart failure and renal impairment? C60iii How to manage cardio-renal syndrome or those at risk of this - how best to manage diuretics in late stage heart failure C170 How best to manage resistant fluid retention in advanced disease: 1. Parenteral furosemide or Metolazone: Which is more efficacious and less likely to worsen renal function? 2. Is SC Furosemide as effective as IV?</p>	<p>1. Heart Lung Circ. 2018 Aug;27(8):928-939. doi: 10.1016/j.hlc.2017.12.013. Epub 2018 Feb 13. Tolvaptan for Heart Failure in Chronic Kidney Disease Patients: A Systematic Review and Meta-Analysis. 2. J Card Fail. 2007 Oct;13(8):599-608. Worsening renal function and prognosis in heart failure: systematic review and meta-analysis. Damman K1, Navis G, Voors AA, Asselbergs FW, Smilde TD, Cleland JG, van Veldhuisen DJ, Hillege HL. 3. J Am Coll Cardiol. 2006 May 16;47(10):1987-96. Epub 2006 Apr 24. Renal impairment and outcomes in heart failure: systematic review and meta-analysis. Smith GL1, Lichtman JH, Bracken MB, Shlipak MG, Phillips CO, DiCapua P, Krumholz HM.</p>	4 health professionals					
28	<p>28. Are intravenous diuretics feasible (practical) to use in the community for people with advanced heart failure?</p>	<p>C178 How effective are subcut diuretics in managing fluid overload in heart failure cp iv C178 Evidence for home based support for patients with very advanced disease incl feasibility of iv diuretics in community. C138 in a community setting (rapid response team) should we be doing daily weights and monitoring fluid intake? if a GP/ANP increase or decreases diuretics how long should this be left before a review? in the community they often just get left and patient becomes overloaded with fluid or dry resulting in a potential admission that could have been prevented?</p>	<p>No definitive evidence</p>	3 health professionals					

34	34. What are the commonest and/or worst side effects of drugs used in with advanced heart failure, and what can be done about them?	<p>A99 Can anything be done about the dizziness?</p> <p>A104 How can dizziness from very low blood pressure as a side effect of heart failure medication be significantly reduced, as it can be extremely debilitating?</p> <p>C65ii Which drugs and which side effects are the worst?</p> <p>C56ii In the very elderly and frail which drugs make the most difference for the least side effects?</p> <p>C65ii Which drugs and which side effects are the worst?</p> <p>A95iv My heart failure nurse is supportive and available.</p> <p>My blood pressure is low and so takes only a minimal amount of beta blocker.</p> <p>A95iv My heart failure nurse is supportive and available. My blood pressure is low and so takes only a minimal amount of beta blocker. My nurse implies that the more beta blocker I can tolerate the better it is for me. Can anything be done about this? I take eplerenone. Are there any long term effects of this drug?</p> <p>A11 How long does medication take to work?</p> <p>A40 I take a 'water' tablet and sotalol, among other medication for various conditions including ataxia, osteoporosis, blood thinning and high blood pressure. Are any of these unnecessary or harmful?</p> <p>C52 I'd like to know more about the pros and cons of my medications</p> <p>C63i Can you explain my medication to me?</p>	No definitive evidence	7 patients, 5 health professionals							
35	35. Do health professionals understand the life / activity / functional consequences of each medicine?	<p>A115 [My comments are around the huge consequences of one drug over another when both are in the same class. Specifically, how bisoprolol acted like a cosh whereas carvedilol was just pulled you down a little. There seemed to be little appreciation (or sympathy) for the difference in effect, and the life consequences. Being on Bisoprolol meant I couldn't walk 50 metres without sitting on a neighbour's wall with a heaving chest. Carvedilol meant I could cycle 5km to my cardiology appointment.] In sum the question is do clinicians really appreciate the life/activity/functional consequences of one medicine over another and the effects of titration of a given drug?</p>	No definitive evidence	1 patient							
36	36. How can a person with advanced heart failure take enough beta-blockers without their blood pressure being too low?	<p>A95iv My heart failure nurse is supportive and available.</p> <p>My blood pressure is low and so takes only a minimal amount of beta blocker.</p> <p>My nurse implies that the more beta blocker I can tolerate the better it is for me. Can anything be done about this?</p> <p>I take eplerenone. Are there any long term effects of this drug?</p>	No definitive evidence	1 patient							
37	37 When can/should the following medications be stopped for advanced heart failure? a) Blood pressure medications b) Statins c) medication therapy	<p>C173 In the terminal stage which medications can be safely discontinued?</p> <p>A104 How can dizziness from very low blood pressure as a side effect of heart failure medication be significantly reduced, as it can be extremely debilitating?</p> <p>A62i,ii Is furosemide the mainstay of treatment? Should BP mess & statins be continued ... until when?</p> <p>A95iv My heart failure nurse is supportive and available. My blood pressure is low and so takes only a minimal amount of beta blocker. My nurse implies that the more beta blocker I can tolerate the better it is for me. Can anything be done about this? I take eplerenone. Are there any long term effects of this drug?</p> <p>C122 When should quadruple therapy cease? What is the optimal service to provide in people's own homes</p> <p>C171i What is the best range for BP in palliation? When patients are past active treatment, do they still have to so many medications they get dizzy?</p>	No definitive evidence	3 patients, 3 health professionals							
38	38. To what extent should heart failure nurses take into account other concurrent cardiac conditions in the patient - particularly in the context of medication, dosages, and exercise?	<p>A104 To what extent should heart failure nurses take into account other concurrent cardiac conditions in the patient - particularly in the context of medication, dosages, and exercise?</p>	1. Eur Heart J Qual Care Clin Outcomes. 2017 J	1 patient							
39	39. Once a person with advanced heart failure had their medicines optimised, can they be discharged from the care of the heart failure specialist nurse?	<p>C116 Once the patient with heart failure had their pharmacological therapy optimised, can he/she be discharged from the care of the heart failure specialist nurse?</p>	No definitive evidence	1 health professional							

45	45. What happens if a person with advanced heart failure is discharged from their cardiologist? How is their condition monitored and managed?	A38 What happens if you are discharged from your cardiologist? How your condition is then monitored and managed? A120 I was originally referred to a heart failure nursing team for regular check-ups. This stopped after 2 years and referred back to my GP I only have one blood test a year and the nurse I see is not a cardiac nurse and gives limited feedback on the blood test results. I would like to have more details on results of tests and not sure how to prompt this through NHS services. I recently had a brief meeting with my GP to ask about increasing the dose of Ramipril as suggested when possible at discharge by my consultant 5 years ago. My GP was reluctant to do this. Also asked my GP if I could be remeasured for ejection fraction which was 30% when discharged. He said this would not be possible. I would like to know if there is any way of seeking a more informed decision on these matters. C122 When should quadruple therapy cease? What is the optimal service to provide in people's own homes	No definitive evidence- more about access to se	2 patients, 1 health professional						
46	46) What are the benefits of asking a person with advanced heart failure "what is important to them"?	C39ii Does asking a person with heart failure what matters most to them help improve their sense of wellbeing, of control? C5How are we assessing outcomes for patients with heart failure that are actually related to the patients needs/outcomes? ie returning to work, walking across the room, going in their garden etc. Rather than the outcomes 'we' tend to be focussed on/commissioned for. C125 What are the most important physical symptoms of heart failure to the patient C161 Is it important to you to know the underlying cause of your heart failure? What are the most important symptoms of advanced heart failure for patients? □	No definitive evidence	4 health professionals						
47	47) Do we have patient centred outcomes for advanced heart failure?	C5How are we assessing outcomes for patients with heart failure that are actually related to the patients needs/outcomes? ie returning to work, walking across the room, going in their garden etc. Rather than the outcomes 'we' tend to be focussed on/commissioned for. C125 What are the most important physical symptoms of heart failure to the patient	https://www.jchom.org/portfolio/heart-failure/	2 health professionals						
48	48) How do we design a key worker (coordinator) role that is effective, has sufficient time and knowledge to be able to assess a person with advanced heart failure holistically?	B20 It would be so helpful if there was a person who was your own personal contact, who knew the history and condition, that you could contact directly, will this ever happen? B84 No help at all for patients with complex conditions with other hospitals and clinics involved - all say GP should be the focal point but the GPs are too busy/ not interested/ out of their depth and the named GP system is just a admin process these days - you just see whoever is free. C108i Can I request the same gp each time one with an interest in heart failure? C133 I think that HF patients get support and help in the early stages but can seem to me to be abandoned C108ii How do I get my heart failure nurse if I need a talk after I am not on her list? A16 My GP not very informed and no time to spare. Hf nurses are in a different area so not much communication, they normally phone back in a couple of days. A98i, There is no dedicated telephone helpline linked to Cardiology here. But I was given a number to phone if I required advice from the Rheumatologist NOT Cardiologist. I feel that my Cardiology problem is more important than Rheumatology. I would like a dedicated number to phone as I don't want to bother my GP and I don't feel welcome with that my Cardiology problem is more important than Rheumatology. I would like a dedicated number to phone as I don't want to bother my GP and I don't feel	1. J Adv Nurs. 2018 Jul;74(7):1463-1473. doi: 10.1111/jan.13559. Epub 2018 Apr 6. Community case management and unplanned hospital admissions in patients with heart failure: A systematic review and qualitative evidence synthesis. King AJL, Johnson R, Cramer H, Purdy S, Huntley AL. 2. Fam Pract. 2013 Jun;30(3):266-75. doi: 10.1093/fampra/cms081. Epub 2013 Jan 12. Review.Is case management effective in reducing the risk of unplanned hospital admissions for older people? A systematic review and meta-analysis.Huntley AL, Thomas R, Mann M, Huws D, Elwyn G, Paranjothy S, Purdy S.	9 patients, 3 carers, 3 health professionals						

49	49) How do people get support to continue as their heart failure becomes more advanced?	C133 patients with heart failure usually have lots of experiences of hospital admission that has helped so when they become 'end of life' it is harder for them to see that hospital admission would not help and in some cases when they have been told this it turns out to be wrong. We have a more distinct pathway for cancer patients and I would like it to be looked at differently and more training around the differences to support us looking after end stage heart failure patients. C133 I think that HF patients get support and help in the early stages but can seem to me to be abandoned A88i Post diagnosis review by consultants should be as meaningful as possible. I sometimes felt I was given pills and told to come back in six months. .	No definitive evidence- more about access to services	1 patient, 1 health professional							
50	50) Can advanced heart failure outpatient care be better co-ordinated, e.g. by ensuring all relevant professionals are kept in the loop of communications?	C149 How do we build communication links between primary care, heart failure nurse teams and Cardiology to ensure timely management of unstable patients C152 Viii Viii) Patients would benefit from an MDT approach to HF. Perhaps a HF rehab group combining specialist nurse/physio/OT/Dietician/social support info etc C152iii,Vii iii)Is there a domiciliary service for people who cannot get out of the house due to their physical ability. Vii) How many HF nurses are there and what patch do they cover? Is this a domiciliary service? C152i, Iv, v, vi i) What services are there to improve patient's physical ability? iv) Why is there no HF physiotherapy service?v) Are there any services to help with the emotional impact of HF? Vi)Is there a HF consultant or a GPwSI? C171 Why is it so split in the community, with heart failure teams, ACMs, DNs, GPs, & hospice CNSs? C172 how to link palliative care and heart failure services together to provide the best support possible C175 How can staff coordinate their efforts to reduce the number of professionals, and all know the plan for my care? A19 Need to have appropriate multi-disciplinary oversight (in my case haematology and cardiac) A88ii Communication between consultant and GP could do with improvement C185 Best links between hospital staff and primary	As for question 48	8 health professionals , 2 patients							
51	51) Can the long-term care needs of people with advanced heart failure be better met by closer co-operation between heart failure and palliative care teams?	C56 What patterns of care enable more people to die in their preferred place? C125 What proportion of patients with HF have been offered access to palliative care to try to improve their quality of life C55v what is the best model for shared care between heart failure teams and palliative care teams C171 Why is it so split in the community, with heart failure teams, ACMs, DNs, GPs, & hospice CNSs? C172 how to link palliative care and heart failure services together to provide the best support possible		5 health professionals							
52	52) Would overall provision for people with advanced heart failure be improved by closer co-operation between social care and heart failure professionals, including joint funding?	A96 As a retired Academic Social Worker I am dismayed at the state of Social Care in these early, hopefully 'post-austerity' days. The health service side is far more coherent and appropriately trained. Joint funding and services planning is a 'must'. Addressing futures it would be very helpful if adaptive exoskeleton technology were available and designed for domestic and walking assistance for those with low LVEF and similar conditions. Also it would be great if, like beta blocker development moved into highly selective products, calcium channel blockers followed a similar route, able to differentiate at the level of pulmonary cilia, to facilitate better airway clearance.	No definitive evidence	1 patient							

58	58 How do we break down barriers for patients with advanced heart failure, carers and health professionals to enable talking about end of life care?	C23 Is there really an open discussion with most patients about prognosis? B77iii They don't want to tell me hubby has heart failure but with swollen legs tired no get up and go they are wonderful checking but I wish they could just come out with it C100 I get asked, 'is what I am doing going to make me fall down dead.' also 'am I going to make my heart failure worse by doing exercise', C125 How many patients actually feel depressed and how many have been asked about this by a healthcare profession C125 How many patients have been given advice on how to manage fatigue C125 What proportion of patients with HF have had advance care planning discussions C138 I think patients hear heart failure and think they are automatically going to die or will be listed for a transplant, could more discussion/education take place at initial diagnosis? A142 Heart failure is a terminal disease, should patients be counselled and prepared for palliative care, or are they already, a lot of the correspondence from HF nurses and cardiologist is about the treatment plans only. C153 Why don't more heart failure teams/cardiologists refer their patients earlier to palliative services C154i,ii At what stage to patients want to discuss deactivation of ICDs and what are their thoughts on	No definitive evidence	11 health professionals, 2 patients, 1 carer						
59	59 How can healthcare professionals manage the expectations of people with advanced heart failure? For example uncertainty	A94 Why does everything take so long? Why do you think its okay to leave people in limbo without clear explanations and/or expectations so they can plan their lives? Who treats the person as a whole and not the element of the condition or disease they're responsible for? C172 How to balance the expectation that 'there is always something else that can be done' (ie in hospital) with planning for end of life care.	No definitive evidence	1 patient, 1 health professional						
60	60 Why do we use the term heart failure?	C50i Wish we could change the name! C53 Why do we use the word failure- very negative and emotive?	Bjork JB, Alton KK, Georgiopolou VV, Butler J, Kalogeropoulos AP. Defining Advanced Heart Failure: A Systematic Review of Criteria Used in Clinical Trials. J Card Fail. 2016 Jul;22(7):569-77.	2 health professionals						
61	61 What is the optimum time to discuss deactivation of ICDs (implants) and discuss palliative care with people with advanced heart failure?	C153 Can patients have more information about their ICD's prior to being implanted as many seem shocked when discussions take place about deactivating them at the end of their lives C154i,ii At what stage to patients want to discuss deactivation of ICDs and what are their thoughts on this? Ditto question to cardiology teams? What is the optimum time to refer for palliative care input? How can we support heart failure specialists to embrace future care planning discussions and recording these wishes? C161 How and when should we discuss ICD deactivation? <input type="checkbox"/>	No definitive evidence	3 health professionals						
62	62 How should a person with advanced heart failure prepare for the future and who can help them with this?	B42 Can you be more specific about prognosis? A16 How long will I live? How can I improve? A19 Can I be given a provisional timeline of cardiac failure? A102 How can I best deal with coming to terms with my mortality following a poor prognosis for my heart failure ? A105 [I have stage 3 HF and was diagnosed 3yrs ago. Although I'm on a good mixture of medications.] No one is able to give me or are unwilling to give me an idea of life expectancy. Or how it progresses how much further I will be unable to do daily things A105 Both my heart failure nurses are great yet sometimes feel as I do when seeing my cardiologist that my concerns and fears are not always addressed. I sometimes feel that I'm am been told things to give me hope. However these things never come such as appointments for tests or possible procedures. As for my GP I tend not to see them as they just do not understand the condition and never take any notice of what I have to say. C112 We cannot talk about the possibility of death as my Dad does not want to be old or ill and cannot discuss death. How do I bring this up or should I/we continue to ignore it? C175 How long have I got to live? <input type="checkbox"/>	Diop MS, Rudolph JL, Zimmerman KM, Richter MA, Skarf LM. Palliative Care Interventions for Patients with Heart Failure: A Systematic Review and Meta-Analysis. J Palliat Med. 2017 Jan;20(1):84-92. Epub 2016 Dec 2.	5 patients, 2 health professionals, 1 carer						

63	<p>63 How do health professionals respond when people with advanced heart failure ask 'When am I going to die? Are we talking days months, years? What about sudden death?'</p>	<p>B42 Can you be more specific about prognosis? A16 How long will I live? How can I improve? A19 Can I be given a provisional timeline of cardiac failure? A102 How can I best deal with coming to terms with my mortality following a poor prognosis for my heart failure ? A105 [I have stage 3 HF and was diagnosed 3yrs ago. Although I'm on a good mixture of medications.] No one is able to give me or are unwilling to give me an idea of life expectancy. Or how it progresses how much further I will be unable to do daily things A105 Both my heart failure nurses are great yet sometimes feel as I do when seeing my cardiologist that my concerns and fears are not always addressed. I sometimes feel that I'm am been told things to give me hope. However these things never come such as appointments for tests or possible procedures. As for my GP I tend not to see them as they just do not understand the condition and never take any notice of what I have to say. C112 We cannot talk about the possibility of death as my Dad does not want to be old or ill and cannot discuss death. How do I bring this up or should I/we continue to ignore it? C175 How long have I got to live? □</p>	<p>Rahimi K, Bennett D, Conrad N, Williams TM, Basu J, Dwight J, Woodward M, Patel A, McMurray J, MacMahon S. Risk prediction in patients with heart failure: a systematic review and analysis. ACC Heart Fail. 2014 Oct;2(5):440-6. doi: 10.1016/j.jchf.2014.04.008. Epub 2014 Sep 3. Alba AC, Agoritsas T, Jankowski M, Courvoisier D, Walter SD, Guyatt GH, Ross HJ. Risk prediction models for mortality in ambulatory patients with heart failure: a systematic review. Circ Heart Fail. 2013 Sep 1;6(5):881-9. doi: 10.1161/CIRCHEARTFAILURE.112.000043. Epub 2013 Jul 25.</p>	4 patients, 2 health professionals, 1 carer						
64	<p>64 How do health professionals explain how advanced heart failure progresses and what that means for their symptoms?</p>	<p>C117i How likely are my symptoms to get worse/better? C118 How can we better prognosticate in patients with advanced heart failure in light of new treatments and interventions. A124ii Will my symptoms be an indicator that my condition is deteriorating? C131 How do we diagnose/predict end of life in HF? TO guide when to get palliative care support, reduce treatment burden, prepare relatives, etc. C150 What are the most reliable prognostic parameters? C58 Nature of symptom burden, particularly how it changes over the course of disease C168 What is the prevalence of symptoms What are the priority ones which have greatest impact C46ii,iii Are patients given enough information about what symptoms to expect such as leg swelling, breathlessness, cough? pts often present with a cough or leg swelling and they don't seem to know this is a symptom of their heart failure?</p>	No definitive evidence	7 health professionals, 1 patient						
65	<p>65 What percentage of people with advanced heart failure have advanced care plan (ACP) discussions?</p>	<p>C125 What proportion of patients with HF have had advance care planning discussions</p>	<p>Risk prediction models for mortality in ambulatory patients with heart failure: a systematic review. Circ Heart Fail. 2013 Sep 1;6(5):881-9. doi: 10.1161/CIRCHEARTFAILURE.112.000043. Epub 2013 Jul 25.</p>	1 health professional						
<p>The following 14 questions were eliminated by the steering committee just prior to the second survey as it was decided that either there was sufficient evidence present for these questions or other reasons stated.</p>										

<p>1. What emotional support and psychological treatments for advanced heart failure are currently available (for all stages of heart failure diagnosis and treatment and for those with depression and anxiety) and how easily can they be accessed?</p>	<p>C28i, Is there any evidence to show the impact of clinical psychology support for patients with heart failure? C180 What type of support and how frequent should it be for low mood in advanced heart failure D32 Psychological services for heart failure are thin on the ground any research that would help funding resources in this would be brilliant. Perhaps research into the different approaches of services on heart failure patients. And which patients benefit from which referrals C58 Psychological support needs - Impact of uncertainty A86i, Apart from cbt, what other counselling type help is there A10 I would like to see more support emotional between hospital tests and appointments. The silence is deafening whilst waiting to get things sorted. It would be good to have someone to talk to, not to solve anything but just as a listening service C58 Psychological support needs - Impact of uncertainty C61i What specific emotional support there is for patients with heart failure? C28,ii Is there any evidence to show the impact of clinical psychology support for patients with heart failure? How accessible is this for patients? A107 Is there anyone to see regarding mental health specific to heart failure? A114 Who is available to talk to me about how I feel?</p>	<p>This question was removed as it was about it is about availability and access to services</p>	<p>6 health professionals, 4 patients, 1 other</p>	<p>no meaningful answer</p>						
<p>2.What support is available for carers of people with advanced heart failure?</p>	<p>B42 What support is available for Carers who work full time? C61ii,iii What about getting emotional support for patients and significant others, including children. What is the impact on children when one of their parents is diagnosed with Heart failure. A99 There seems to be no help on line for information for partners etc A114 How can I help my family to get advice on how to help me and understand better? C125 What proportion of carers have been offered cater support B145 As a patient my relative is very matter of fact about his condition to the point where he often neglects himself, but it is his wife who worries constantly and it is her who needs the support. is there support for relatives??? A14ii What support can family get to cope with our fears and negative thoughts?</p>	<p>This question was removed as it was about it is about availability and access to services and also it was covered by an effectiveness question (q22 above)</p>	<p>3 patients, 2 carers, 2 health professionals</p>	<p>no meaningful answer</p>						
<p>3.When should fluid intake be limited / monitored for a person with advanced heart failure?</p>	<p>C134 Should fluid intake be limited? We see patients with Continance issues so it relates directly to the advice we offer. C138 in a community setting (rapid response team) should we be doing daily weights and monitoring fluid intake? if a GP/ANP increase or decreases diuretics how long should this be left before a review? in the community they often just get left and patient becomes overloaded with fluid or dry resulting in a potential admission that could have been prevented?</p>	<p>NICE Guidance on this already exists based on evidence</p>	<p>2 health professionals</p>	<p>evidence</p>						
<p>4.Does oxygen help people with advanced heart failure</p>	<p>C166 Does oxygen help?</p>	<p>NICE Guidance on this already exists based on evidence</p>	<p>1 health professional</p>	<p>evidence</p>						
<p>5.How do health professionals decide who to treat with extracorporeal oxygenation (EPO)?</p>	<p>C60i How do I decide who to think about treating with e</p>	<p>NICE Guidance on this already exists based on evidence</p>	<p>1 health professional</p>	<p>evidence</p>						
<p>6.Why is Co-Enzyme Q10 not offered to people with advanced heart failure?</p>	<p>C113 Why is Co-Enzyme Q10 not offered to patients, when clinical studies have shown that heart failure patients are deficient and that in 87% of patients it greatly improves the pumping action of their hearts?</p>	<p>No convincing evidence to date despite research - that is - current research indicates this has no impact on AHF. Question considered answered by SG. Coenzyme Q10 for heart failure.Madmani ME, Yusuf Solaiman A, Tamr Agha K, Madmani Y, Shahrou Y, Essali A, Kadro W.Cochrane Database Syst Rev. 2014 Jun 2;(6):CD008684. doi: 10.1002/14651858.CD008684.pub2</p>	<p>1 health professional</p>	<p>evidence</p>						

7.Are outcomes better for people with advanced heart failure if there is greater access to specialist heart failure/ function nurses?	C149 Are outcomes for patients with severe heart failure better if they are under heart failure nurse care or GP care	There is evidence to support the benefit of AHF nurses for patients The effect of nurse-led education on hospitalisation, readmission, quality of life and cost in adults with heart failure. A systematic review. Rice H et al. Patient Educ Couns. (2018) Effectiveness of heart failure management programmes with nurse-led discharge planning in reducing re-admissions: a systematic review and meta-analysis. Lambrinou E et al. Int J Nurs Stud. (2012) A systematic review of the effectiveness of nurse coordinated transitioning of care on readmission rates for patients with heart failure. Slyer JT et al. JBI Libr Syst Rev. (2011)	1 health professional	evidence						
8.Would advanced heart failure hospital admissions be reduced if there was better communication, co-ordination and co-operation between different teams, e.g. HF medical, social care, palliative teams, and the patient and their family?	C56 Does fragmentation of care lead to excess admission? C1571 What interventions prevent inappropriate hospital admissions? C159 How to avoid admission. How to get palliative care and cardiology working closer together C172 is it even possible to avoid hospital admissions towards the end of life? or is that just the right thing for many people with heart failure? C179 Does involvement in community heart failure services reduce readmission in patients with non-LVSD (ie HFpEF, RVSD) C180 what research is there about how frequently patients should be seen by a healthcare professional to improve outcomes and reduce hospital admissions?	There is evidence to suggest co-ordinated care between primary and secondary care reduces admissions and that case management involving social care is part of this. Community case management and unplanned hospital admissions in patients with heart failure: A systematic review and qualitative evidence synthesis.King AJL et al. J Adv Nurs. (2018) Does case management for patients with heart failure based in the community reduce unplanned hospital admissions? A systematic review and meta-analysis.Huntley AL et al. BMJ Open. (2016)	6 health professionals	evidence						
9.What can help the heart grow stronger and how long does it take to work?	B35 What can help their heart get stronger?	It was felt that this question could not be meaningfully answered	1 carer	no meaningful answer						
10.Do people with advanced heart failure commonly develop other serious complications, For example: kidney failure?	B121 Do people with heart failure commonly develop other serious complications, e.g. kidney failure?	The link between AHF and CKD is well established Heart failure and kidney dysfunction: epidemiology, mechanisms and management.Schefold JC et al. Nat Rev Nephrol. (2016)	1 carer	evidence						
11. How do we increase awareness (and the prevalence) of advanced heart failure?	A10 I would prefer to find out all the information from talking to people who specialise in HF. Most of the stuff I know has been from Google. GP and A&E seem to have limited knowledge of HF	It was felt that this question could not be meaningfully answered nor that the information would be useful	1 patient	no meaningful answer						
12.Do 'experienced' people with advanced heart failure contribute enough to the formal training of doctors?	A103 How do you get support to newly diagnosed patients from more 'experienced' patients who can show them there is a life possible living with heart failure, albeit one that may have major changes and losses? Do/can 'experienced' patients contribute enough to the formal training of doctors?	Important question but out of scope	1 patient	out of scope						
13.How can health professionals deliver quality care to all (including heart failure with preserved ejection fraction)?	This question appears to have come from the broad category of education & information and was actually created by the steering group	This question was considered very broad and it was felt that it could not be meaningfully answered	the steering group	no meaningful answer						
14.Is there a link between memory problems/dementia and advanced heart failure?	D51 Does dementia come on more quickly? C56i Does heart failure increase the rate of cognitive decline? B78 Cognitive changes in heart failure D51 What is the most common psychological impact? [Does dementia come on more quickly?]	The link between AHF and cognitive decline is well established Cognitive Impairment and Heart Failure: Systematic Review and Meta-Analysis. Cannon JA et al. J Card Fail. (2017) Incident Heart Failure and Cognitive Decline: The Atherosclerosis Risk in Communities Study. Bressler J et al. J Card Fail. (2017) Cognitive decline in heart failure.Alagiakrishnan K et al. Heart Fail Rev. (2016)	2 others, 1 carer, 1 health professional	evidence						
15. What are the long-term effects of eplerenone in the treatment of people with advanced heart failure?	A95iv My heart failure nurse is supportive and available. My blood pressure is low and so takes only a minimal amount of beta blocker. My nurse implies that the more beta blocker I can tolerate the better it is for me. Can anything be done about this? I take eplerenone. Are there any long term effects of this drug?	well known evidence of side effects of the drug. Dr Eleanor Wicks Consultant Cardiologist and Clinical Lead in Heart Failure and Inherited Cardiac Conditions (ICC)	1 patient	evidence						