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

identifier (to be allocated by JLA team on receipt of final priorities from PSP)	(the unique identifier of the		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)	summary of up to 150 words, explaining key points of the	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, including protocols for future 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, lakovidou 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 actitivies foe 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?		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
		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?		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 additional 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?'		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
		No significant evidence for people with advanced heart failure	13-Feb-19	7	No systematic reviews on this topic in past five years	Cardiovascular
	continue as their heart failure	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	
		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?	1 1	13-Feb-19	17	Rashid M, Kwok CS, Gale CP, Impact of comorbid 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
	management advice for people with	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
		No significant evidence for people with advanced heart failure	13-Feb-19	21	No systematic reviews on this topic in past five years	Cardiovascular

	How do we break down barriers fo patients with advanced heart failur carers and health professionals to enable talking about end of life care.	re, advanced heart failure	13-Feb-19	6	No systematic reviews on this topic in past five years	Cardiovascular
	What is the optimum time to discu deactivation of ICDs (implants) and discuss palliative care with people with advanced heart failure?		13-Feb-19	24	No systematic reviews on this topic in past five years	Cardiovascular
	How do health professionals explain how advanced heart failure progresses and what that means for patients' symptoms?	No significant evidence for people with advanced heart failure	13-Feb-19	15	No definite evidence	

Description of the contraction	n add onside ne end	op 10 questions are highlighted in yellow. dditional 14 questions which were dered out of scope are also included at nd 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.					
Advisit further and content on the second of the time?  Advisit further and the second of the second	there   re 'Po  ubmiss ut the	e possible. Advised minimum requirements opulation' and 'Intervention'. Not all issions may be suitable for PICO structure, ney should be in a format that will ultimately	Original uncertainty	systematic review identified by the PSP, plus a maximum of 2 other systematic reviews, including protocols for future systematic	to show them e.g. 1 x patient, 19 x clinician, 4 x research				
All I writerious fatigue?  All I writerious graves you want and 1 do about a complete form of the complete form of	W	Why do neonle with advanced heart failure	As Why am I so tired no energy just glad to get to hed	I.IBI Database System Rev Implement Rep	4 natients				
As for question 1  Software to manage frague in people with advanced bear afailure?  3. Which approaches are effective in rectangle and the force of the property of the product of the property of the product of the property of the product of the			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	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:					
failure?  C24 How to m the Tatigue be loss treated? C24 How to manage fatigue more effective? C39 What can be done to improve fatigue in heat B35 What can be done to improve fatigue in heat B35 What can he lot me more energy? A36 What can lot on minimise fatigue? A38 How it heart failure less the ent failure less the ent failure less the ent failure less the ent failure less caused by heart failure? C56iii Which are the best approaches to the fatigue of heart failure? A50 What can be done to help me with my tiredness C142 Can we improve the profound tiredness associated with heart failure C167 What rate the best ways to manage breathlessness caused by heart failure? C16ii How can we manage your fatigue best? C16ii How can we manage your fatigue best? C170 Are there any treatments which relative fatigue? B35ii What can help the profound stague? B35ii What can help the physican designed better? B69i What can lot do to help my husband sleep better? A follow that and help the hif patient sleep better? What can help the hif patient sleep better? B69i What can help the hif patient sleep better? What can lot to help my husband sleep better? What can lot to help my husband sleep better? What can lot to help my husband sleep better? What can lot to help my husband sleep better? What can lot to help my husband sleep better? What can lot to help my husband sleep better? What can lot to help my husband sleep better? What can lot to help my husband sleep better?	dvanc ave?	nced heart failure and what impact does it?	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		21 patients, 14 patients, 3 carers				
What can I do to help my husband sleep better &		e?	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 associated with heart failure 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? C151ii How can we manage your fatigue best? C170 Are there any treatments which relieve fatigue? B35ii What can help the hf patient sleep better?						
	. W	Which approaches are effective in helping p	What can I do to help my husband sleep better &	As for question 1	2 carers				
5. Which approaches, in additional to C83iiBreathlessness associated with heart failure C63Patients tend to ask about the practical hints and	. W	Which approaches, in additional to	C83iiBreathlessness associated with heart failure						

6. What amount and type of exercise is safe	A184 What can help me with my tiredness [and will	1. Clin Renabil. 2018 Nov;32(11):1482-1492.	28 patients.22 health				
6. What amount and type of exercise is safe and effective for people with advanced heart	exercise help my heart failure?]	doi: 10.1177/0269215518784345. Epub 2018	professionals, 3 carers ,1 other				
failure?	A40i-iiiWhen getting up in the morning or out of a	Jul 9.The impact of high-intensity inspiratory	prorocolonalo, o caroro , r caror				
Tallare:	chair after a long period of sitting (for example,	muscle training on exercise capacity and					
	watching tv) is it best to wait a while until the	inspiratory muscle strength in heart failure with	1				
	body/heart adapts to the new position before moving	reduced ejection fraction: a systematic review					
	into action? Is it unwise to try to do things as one	and meta-analysis. Gomes Neto M1,2,3,					
	used to do (hurrying upstairs even though this will	Ferrari F4,5, Helal L4,6, Lopes AA2,7,					
	cause tiredness and breathlessness) or should one	2. Int J Cardiol. 2018 Mar 1;254:224-229. doi:					
	move very slowly to avoid the symptoms? How safe	10.1016/j.ijcard.2017.10.114. Epub 2018 Jan					
	is it to drive alone, which 90% of the time I do as I	28.Determinants of exercise intolerance in					
	suffer from breathlessness, swollen ankles, fatigue.	heart failure with preserved ejection fraction: A					
	C7 Does yoga or Pilates started in heart failure	systematic review and meta-analysis.Montero					
	reduce problems with activities of daily livening? C26	D1, Diaz-Cañestro C2.					
	Does more physical activity improve the outcome?	3. Arch Cardiol Mex. 2017 Oct - Dec;87(4):326	i-				
	A10 What exercise I can safely do?	335. doi: 10.1016/j.acmx.2016.12.002. Epub					
	A15 Will exercise really help or hinder?	2017 Jan 5. [The exercise training restores the					
	A19 How to increase stamina in a way that will not	heart rate variability in heart failure patients. A					
	further damage cardiac function	systematic review]. [Article in Spanish] Segovia	a				
	A36 To what extent can exercise improve me, and	V1 .					
	how far can I push myself? What type(s) of	4. Cardiology. 2017;136(2):79-89. doi:					
	exercise/training should I attempt? What can I do to	10.1159/000448088. Epub 2016 Aug 27.The					
	minimise fatigue?	Effect of Exercise Training Intensity on Quality					
	A37 With 40% EF what exercises should I not do in	of Life in Heart Failure Patients: A Systematic					
	the gym?	Review and Meta-Analysis. Ostman C1,					
	A14 Why can we not get better exercise support?	5. Congenit Heart Dis. 2018 Mar;13(2):194-					
	D49i,ii What physical activity would be good for me	202. doi: 10.1111/chd.12586. Epub 2018 Feb					
	and what would be bad for me? How would I know	8.Effects of inspiratory muscle training in					
	when I was doing too little or too much?	chronic heart failure patients: A systematic					
	C52i,ii Can I hurt myself by exercising too much?	review and meta-analysis. Wu J1, .					
7. What is the best diet for people with	C52iii What should I eat to help?	10.1038/s41598-018-19708-0. Effects of	3 patients, 2 health professionals				
advanced heart failure? For example to improve	C54ii Has anyone studied dietary changes as	vitamin D supplementation on inflammatory					
condition, lose weight	helpful for heart failure? I have heard anecdotally	markers in heart failure: a systematic review					
	that low carb approaches help HF.	and meta-analysis of randomized controlled					
	A87Does healthy eating help heart failure?	trials.Rodriguez AJ1, Mousa A2, Ebeling PR1,					
	A128Weight gain is a big problem I am fighting	Scott D1, de Courten B3.					
	against, what can help to maintain my weight	2. Nutrients. 2018 Jun 26;10(7). pii: E828. doi:					
	whilst not doing as much exercise?	10.3390/nu10070828. Dietary Patterns in					
	A124iiiWhat is the best diet to follow if you simply						
	can't exercise? (eg my stress echo by the	Systematic Review. Dos Reis Padilha G1,					
		3. Curr Drug Targets. 2011 Jan;12(1):29-41.					
	for someone of my age is extremely poor and only	Vitamin D biology in heart failure: molecular					
	a small % of what it should be)	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	t				
		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	d				
		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.					
8. What is the best way to identify mental	C125 How many patients actually feel depressed and	No direct or sufficient evidence	4 health professionals				
8. What is the best way to identify mental health issues in people with advanced heart	how many have been asked about this by a						
failure?	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						
				I I	1	1	1

O 9 How do psychological emotional or mental	C119What are the main psychological issues facing	1. Eur J Cardiovasc Nurs. 2016 Dec;15(7):478-	6 health professionals 1 carer				
9. How do psychological, emotional or mental health issues affect people with advanced heart		485. Epub 2016 Feb 24. Anxiety in chronic	o ficaltii professionais. I carci				
failure and how do they affect prognosis (their	C125What proportion of HF patients with depression	heart failure and the risk of increased					
future)?	have been offered access to CBT	hospitalisations and mortality: A systematic					
	C179How much does depression confer an adverse	review. Vongmany J1, Hickman LD2, Lewis J2,					
	prognosis in end stage heart failure; how prevalent is	Newton PJ3, Phillips JL3.					
	depression in end stage HF and how should it be best	2. Heart Fail Rev. 2016 Jan;21(1):49-63. doi:					
	managed	10.1007/s10741-015-9517-4. Depression and					
	C180What type of support and how frequent should it	anxiety as predictors of mortality among heart					
	be for low mood in advanced heart failure	failure patients: systematic review and meta-					
	B121iiHow do you help a person with heart failure	analysis. Sokoreli I1, de Vries JJ2, Pauws SC2,					
		Steverberg EW3.	'				
	stay upbeat, especially in the winter, or when they						
	develop other complications?	3. Issues Ment Health Nurs. 2008					
	C139iii Is it safe for me to take antidepressants?	Sep;29(9):1002-17. doi:					
	C26Do the fatigue and breathlessness courses	10.1080/01612840802274867.A systematic					
	offered by hospices help mood?	review of depression in adults with heart					
		failure: instruments and incidence. Delville CL1,					
		McDougall G.					
4 a 40. How son morale with advanced boost failure	B148I,II My husband had advanced heart failure. He	No definitive evidence	C nationta 2 haalth				
10 10. How can people with advanced heart failure	becomes very frustrated when he cannot walk like he	No definitive evidence	6 patients, 2 health				
cope with their emotions, including fear &	used to or do his gardening etc. More difficult to keep		professionals, 2 carers,				
frustration, and what's the best way to support	him cheery although he tries hard to adapt and cope	İ.					
them?	with his disabilities.	İ.					
	A94 How do I deal with the anger? How do I deal with	İ.					
	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 emotionalA9I 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?						
	B78How the person with heart failure copes with not						
	being able to do what they used to do. C24i,ii How						
	best to deal with emotional burden of heart failure? Is						
	CBT an effective alternative to anti-depressants?						
	A95iiil 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?)						
	C161i, ii How do you find strength to cope with the						
44 140 41 41 45 41 4	ups and downs of your condition? Has having heart A127 Help with depression etc caused by heart failure		101 111 1 1 0				
11. What is the most effective treatment,	C179How much does depression confer an adverse		10 health professionals, 3				
including psychological interventions, for	prognosis in end stage heart failure; how prevalent is		patients, 1 other				
people with depression and advanced heart		1 Int I Psychiatry Clin Proct 2019					
failure?	depression in end stage HF and how should it be best						
	managed	Sep;22(3):164-169. doi:					
	C117 Who can best help with my depression? [What						
	is the emotional impact of having an ICD?]	Nov 26. The effect of antidepressant					
	C6 Are there antidepressants that are contraindicated						
	in heart failure?	on outcomes: mortality, cardiovascular function					
	C139iii Is it safe for me to take antidepressants?	and depression - a systematic review.					
	A140 Being depressed and on Fluoexitine I have	Rajeswaran T1, Plymen CM2, Doherty AM3,4.					
	been stuck on it and just left hanging i.e. no follow-	2. J Cardiovasc Nurs. 2016 Sep-Oct;31(5):457-	·				
	ups.	68. doi: 10.1097/JCN.0000000000000274. A					
	C 28ii/iii Is there any evidence to show the impact of	Systematic Review of Relaxation, Meditation,					
	clinical psychology support for patients with heart	and Guided Imagery Strategies for Symptom					
	failure?/	Management in Heart Failure.Kwekkeboom					
	Is there any evidence to show the impact of clinical	KL1, Bratzke LC.					
	psychology support for patients with heart failure?	3. Heaart Fail Rev. 2017 Nov;22(6):731-741.					
	How accessible is this for patients?	doi: 10.1007/s10741-017-9640-5.Effects of					
	C180 What type of support and how frequent should	cognitive behavioural therapy for depression in					
	it be for low mood in advanced heart failure	heart failure patients: a systematic review and					
	D32 Psychological services for heart failure are thin	meta-analysis. Jeyanantham K1, Vongmany					
	on the ground any research that would help funding	J1, Hickman LD2, Lewis J2, Newton PJ3,					
	resources in this would be brilliant. Perhaps research	Phillips JL3.					
	into the different approaches of services on heart	4. Heart Lung. 2012 Sep-Oct;41(5):469-83. doi:	:				
	failure patients. And which patients benefit from which	10.1016/j.hrtlng.2012.06.002.Effects of					
	referrals	interventions on depression in heart failure: a					
	OFO Developer de la company de la lace de la company de la	Investment to an investment Walter DOA Observe DW		1			
	C58 Psychological support needs - Impact of	systematic review. Woltz PC1, Chapa DW,			L.	l	1
	C58 Psychological support needs - Impact of uncertainty	Friedmann E, Son H, Akintade B, Thomas SA.					

12 12. Which healthcare professionals are best	C5i-iii What are the best ways to support your No definitive evidence	3 health professionals, 2 patients		
placed to, and should support the emotional	Cor in What are the best ways to support your	o mount professionals, 2 panems		
	emotional needs and who would you want to support			
needs of people with advanced heart failure?	you with this?			
	Would you like your Dr/Consultant to include this in			
	their consultation? Some kind of evaluation looking			
	at physician v nurse psychological/emotional			
	discussions/support/referrals.			
	C7i Does having contact with a heart failure specialist			
	nurse reduce the risk of depression?			
	A126 How can we get our GPs to listen and refer			
	sooner for counselling? How can we get the most			
	impact from counselling?			
	C146i-iii What's the emotional impact of a diagnosis			
	of HFPEF and thus being told ' no you can't access			
	the HF service, and there aren't any well recognised			
	treatment options for you" What's the emotional			
	benefit of support groups? Is there an emotional			
	benefit for patients who have regular contact with a			
	HF clinician (nurse or GP?)			
13 13. What is the right type of counselling for	C108 How do support groups help heart failure family No definitive evidence	1 patient, 1 health professional		
people with advanced heart failure?	carers?			
	A 126 How can we get our GPs to listen and refer			
	sooner for counselling? How can we get the most			
	impact from counselling?			
4 44 Are there were to help mathematical and	A400 Con you identify any analife to the transition to be by Marcha areas with a second the constitution of	1 notions 1 health meeters!		
14 14. Are there ways to help motivate people with	A102 Can you identify any specific techniques to help May be some evidence in the exercise	1 patient, 1 health professional		
advanced heart failure to complete normal daily	improve motivation to complete activities of daily literature - question 6			
activities?	living when living with heart failure?			
	C118 How can we improve patient activation			
	measures in patients with advanced heart failure who			
	often have low mood and depression			
	one have to a most and appropriate			
4 = 45. Do poonlo with advanced beart failure feel	A12 Learnet speak to appear about worries Lam. No definitive evidence	7 notionto		
15. Do people with advanced heart failure feel	A13 I cannot speak to anyone about worries. I am  No definitive evidence	7 patients		
isolated, and how can they be supported?	divorced and do not want to worry my children.			
	Doctors have no time.			
	A16 Nobody to talk to, wife not interested, nhs phone			
	in no use. Very depressing and I believe the more			
	depressed you are the less active you are			
	A11i Why do I feel so alone even when there are			
	plenty of people around?			
	A12 The biggest emotional impact is fear of being left			
	alone to cope. That feeling of being abandoned			
	A31 Social isolation is difficult. When you are a fairly			
	young adult and you look 'normal' it's difficult to			
	explain to people why you can't go to a function or			
	even out for coffee. Help explaining to your children			
	that you have a life limiting condition and how that			
	impacts you, help for them			
	A124 Is it normal to feel isolated when my life seems			
	to have stopped and my friends have moved on			
	without me?			
	A128 There is no one to talk to, I am quite young and			
	feel I am judged, who can I go to for a shoulder to cry			
	on?			
16 How can advanced heart failure patients and	1. Eur J Cardiovasc Nurs. 2015 Dec;14(6):525-	- 3 patients		
professionals be helped to communicate about	A87 Who do I contact if the anxiety is getting too 35. doi: 10.1177/1474515114547648. Epub	•		
symptoms that are difficult to express such as	The state of the s			
	hat was not beat and hardthan and said and			
anxiety and low mood?	A105 Both my heart failure nurses are great yet between patients and healthcare professionals			
	sometimes feel as I do when seeing my cardiologist for heart failure self-care: A systematic review			
	that my concerns and fears are not always of qualitative research into patient			
	addressed. I sometimes feel that I'm been told things perspectives. Currie K1, Strachan PH2, Spaling	J		
	to give me hope. However these things never come M3, Harkness K2, Barber D1, Clark AM4.			
	such as appointments for tests or possible  2. Int J Nurs Stud. 2012 Dec;49(12):1582-97.			
	procedures. As for my GP I tend not to see them as doi: 10.1016/j.ijnurstu.2012.05.010. Epub 2012	2		
	by 40. He denotes the religion of civilians			
	they just do not understand the condition and nover			
	A105 Sometimes I do find it difficult to express my systematic review. Clark AM1, Savard LA,			
	feelings and concerns the impact of the condition has Spaling MA, Heath S, Duncan AS, Spiers JA.			
	on me. I find myself sometimes not mentioning when			
	I'm not feeling to well or get pain as I feel with the			
	condition not been visable I feel like it's not going to			
	be listened to			
	DO IISTOTICA TO			
47 December 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	OUTE D	1		
17. Does understanding prognosis (the future)	C155 Does understanding prognosis and uncertainty no definitive evidence	1 health professional		
I I land magnitude below 10	help mood?			
and uncertainty help mood?	neip meed.			

101	18. What is the impact of advanced heart failure	C163i ⅈ How having a parent or primary carer with	1. J Card Fail. 2014 Jun;20(6):448-55. doi:	1 health professional					
10	on relationships between patients and their	reduced mobility and fatigue due to heart failure	10.1016/j.cardfail.2014.03.010. Epub 2014 Apr	·					
	carer and family?	affects their children on an everyday level.	13. Context matters in heart failure self-care: a						
	•	How does having heart failure affect your	qualitative systematic review.						
		relationships with others? □	Eur J Cardiovasc Nurs. 2015 Feb;14(1):79-						
		'	89. doi: 10.1177/1474515113518434. Epub						
			2014 Jan 6. Caregivers' contributions to heart						
			failure self-care: a systematic review. Buck						
			HG1, Harkness K2, Wion R3, Carroll SL4,						
			Cosman T5, Kaasalainen S6, Kryworuchko J7,						
			McGillion M8, O'Keefe-McCarthy S8, Sherifali						
			D9, Strachan PH6, Arthur HM2.						
10 1	19. How can people explain advanced heart		No definitive evidence	2 patients					
l l l	failure and its emotional impact to their carers	A101 How can I explain heart failure to my family							
a	and close friends and family?	without causing them heart failure!							
		A120 So far there has been no obvious emotional							
		impact and I have learned to cope with the limits of							
		what I can do. My wife particularly and my family							
		show more concerns and worries about my health so something to give them reassurance would be helpful.							
		Something to give them reassurance would be neighb.							
20 2	20. What is the impact of advanced heart	C39 How do carers of people with heart failure feel	Family caregiving for persons with heart failure	4 health professionals, 3 carers			+	-	
20 /	20. What is the impact of advanced heart failure on a carer's emotional wellbeing?	during a hospital admission?	at the intersection of heart failure and palliative						
	and the same of th	B20 Every time my husband has an angina attack,	care: a state-of-the-science review. Heart Fail						
		which is often, I am really frightened that it will be his	Rev. 2017 Sep;22(5):543-557. doi:						
		last.	10.1007/s10741-017-9597-4.						
		B42 As my husband's carer what signs should I be	Kang X, Li Z, Nolan MT. Informal caregivers'						
		aware of that I am suffering or struggling? It's easy	experiences of caring for patients with chronic						
		not to pay attention to self when you are too busy balancing your husband, full time work and other	heart failure: systematic review and						
		commitments. What support is available for Carers	metasynthesis of qualitative studies. J						
		who work full time?	Cardiovasc Nurs. 2011 Sep-Oct;26(5):386-94.						
		A36 It's not so much the direct emotional impact, as	doi: 10.1097/JCN.0b013e3182076a69.						
		the impact on spouse/partner/carer and if that is							
		adverse how it can pull the patient down with it.							
		A61ii-iii What about getting emotional support for							
		patients and significant others, including children.							
		What is the impact on children when one of there							
		parents is diagnosed with Heart failure.							
		C65 What do carers find most difficult about heart							
		failure?							
		B77i-iii As a full time Carer 24/7 life looking after							
		someone who has swollen legs tired no get up and go not wanting to go out to tired to get dressed. They are							
		very strong as you don't want to see your hubby like							
		this I cry every day							
		C157 How are the carers needs different when							
		looking after someone with heart failure							
		C136ii-iii How having a parent or primary carer with							
		reduced mobility and fatigue due to heart failure							
		affects their children on an everyday level. How does							
21 2	21. How does the emotional impact on carers,	A36 It's not so much the direct emotional impact, as	May be addressed in the evidence for question	1 patient			T		
a	affect the patient with advanced heart failure?	the impact on spouse/partner/carer and if that is	18						
		adverse how it can pull the patient down with it.							
22 2	Lo. What support would be intest chestive for	during a hospital admission?	No definitive evidence	5 patients, 6 health	1		Γ		
<u>  '</u>	carers or people with advanced near training for	B20 Every time my husband has an angina attack,		professionals, 6 carers					
e	example support groups?	which is often, I am really frightened that it will be his							
		last.							
		B42 As my husband's carer what signs should I be							
		aware of that I am suffering or struggling? It's easy							
		not to pay attention to self when you are too busy							
		balancing your husband, full time work and other							
		commitments.							
		A36 It's not so much the direct emotional impact, as							
		the impact on spouse/partner/carer and if that is adverse how it can pull the patient down with it.							
		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 there							
		parents is diagnosed with Heart failure.							
		C65 What do carers find most difficult about heart							
		failure?							
		B77i,iiiii in prognosis As a full time Carer 24/7 life							
		looking after someone who has swollen legs tired no get up and go not wanting to go out to tired to get							
		dressed							
		They are very strong as you don't want to see your							
		hubby like this I cry every day							
		A99 There seems to be no help on line for information							
		for partners etc							
<u> </u>		C108 How do support groups help heart failure family				 			

22	23. What is the most effective way to use	C24 is weighing daily an effective monitoring tool?	1. Heart Fail Rev. 2016 Sep;21(5):611-9. doi:	13 health professionals				
23	diuretics in advanced heart failure, with	How to improve balancing the impact on chronic	10.1007/s10741-016-9559-2. Defining the role					
	respect to, fluid overload, kidney function,	kidney disease and heart failure?	of ultrafiltration therapy in acute heart failure: a					
	survival & quality of life?'	C23 What medication is best to use with severe heart	systematic review and meta-analysis.					
	Survivar & quality of life:	failure and renal impairment?	2. Jain A1, Agrawal N2, Kazory A3.Nephron.					
		C60iii How to manage cardio-renal syndrome or those	2015;129(3):189-96. doi: 10.1159/000371447.					
		at risk of this - how best to manage diuretics in late	Epub 2015 Feb 27.Effect of ultrafiltration					
		stage heart failure	versus intravenous furosemide for					
		C134 Should fluid intake be limited? We see patients	decompensated heart failure in cardiorenal					
		with Continence issues so it relates directly to the	· ·					
			syndrome: a systematic review with meta-					
		advice we offer.	analysis of randomized controlled trials.Chen					
		C138 in a community setting (rapid response team)	HY1, Chou KJ, Fang HC, Chen CL, Hsu CY,					
		should we be doing daily weights and monitoring fluid	Huang WC, Huang CW, Huang CK, Lee PT.					
		intake? if a GP/ANP increase or decreases	3. Int Heart J. 2015;56(2):192-5. doi:					
		diuretics how long should this be left before a review?	10.1536/ihj.14-288. Epub 2015 Feb 23.Liberal					
		in the community they often just get left and patient	versus restricted fluid administration in heart					
		becomes overloaded with fluid or dry resulting in a	failure patients. A systematic review and meta-					
		potential admission that could have been prevented?	analysis of randomized trials.Li Y1, Fu B, Qian					
		C161 Do diuretics improve quality of life?	Y					
		C161 Does subcutaneous furosemide improves	4. Minerva Cardioangiol. 2014 Apr;62(2):131-					
		· ·						
		symptoms, C161 quality of life, or prognosis?	46. Efficacy and safety assessment of isolated					
		C167 At what point does peripheral oedema cause	ultrafiltration compared to intravenous diuretics					
		distressing symptoms and how can these be	for acutely decompensated heart failure: a					
		alleviated? (Massage, diuretics, exercise)	systematic review with meta-analysis.De					
		C178 How effective are subcut diuretics in managing	Vecchis R1, Esposito C, Ariano C.					
[		fluid overload in heart failure cp iv	5. Int J Cardiol. 2014 May 1;173(2):139-45. doi:					
[		C178 Evidence for home based support for patients	10.1016/j.ijcard.2014.03.020. Epub 2014 Mar					
		with very advanced disease incl feasibility of iv	14. Hypertonic saline with furosemide for the					
		diuretics in community.	treatment of acute congestive heart failure: a					
		•	systematic review and meta-analysis.Gandhi					
	24 Which treatments have the higgest impact	ÿ		3 health professionals 1 nations			+	
24	24. Which treatments have the biggest impact on the quality of life of people with advanced	C178 Does involvement of a specialist palliative care team in addition to heart failure nurses improve	, ,	3 health professionals, 1 patient				
	heart failure?		trials - it is likely to an outcome in exercise, self- management and self-care interventions					
	heart failure?	quality of life for patients and their carers	management and sell-care interventions					
		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?						
25	25. When is weighing a person with advanced		No direct or sufficient evidence	2 health professionals				
25	heart failure daily effective for monitoring?	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						
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		should we be doing daily weights and monitoring fluid						
		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?						
		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						
		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						
		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						
26	26. When can the focus on weighing a person	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?	No direct or sufficient evidence	1 health professionals				
26	26. When can the focus on weighing a person with advanced heart failure be stopped?	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?  C171ii When to take the focus of 'dry weight'.	No direct or sufficient evidence	1 health professionals				
26	with advanced heart failure he stonned?	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?  C171ii When to take the focus of 'dry weight'.		·				
27	with advanced heart failure be stopped?  27. How do health professionals best manage	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?  C171ii When to take the focus of 'dry weight'.  C24 Is weighing daily an effective monitoring tool?	1. Heart Lung Circ. 2018 Aug;27(8):928-939.	1 health professionals 4 health professionals				
27	with advanced heart failure be stopped?  27. How do health professionals best manage chronic kidney disease and advanced heart	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?  C171ii When to take the focus of 'dry weight'.  C24 Is weighing daily an effective monitoring tool? How to improve balancing the impact on chronic	1. Heart Lung Circ. 2018 Aug;27(8):928-939. doi: 10.1016/j.hlc.2017.12.013. Epub 2018 Feb	·				
27	with advanced heart failure be stopped?  27. How do health professionals best manage chronic kidney disease and advanced heart failure? a. What medication is best to use?	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?  C171ii When to take the focus of 'dry weight'.  C24 Is weighing daily an effective monitoring tool? How to improve balancing the impact on chronic kidney disease and heart failure?	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	·				
27	with advanced heart failure be stopped?  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	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?  C171ii When to take the focus of 'dry weight'.  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	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	·				
27	with advanced heart failure be stopped?  27. How do health professionals best manage chronic kidney disease and advanced heart failure? a. What medication is best to use?	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?  C171ii When to take the focus of 'dry weight'.  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?	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.	·				
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20	29. How long after a change in diuretic dose	C178 How effective are subcut diuretics in managing	No definitive evidence	3 health professionals			
29	should person with advanced heart failure be	fluid overload in heart failure cp iv	The definition of the control of the	o noam provide in the control of the			
	reviewed?	C178 Evidence for home based support for patients					
	icvicweu:	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?					
30		C167 At what point does peripheral oedema cause	No definitive evidence	1 health professional			
	coucina experiencea zy people mini auraneca	distressing symptoms and how can these be					
	heart failure? For example massage, exercise	alleviated? (Massage, diuretics, exercise)					
31	31. How does fluid intake affect continence of a		No definitive evidence	2 health professionals			
51	person with advanced 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?					
		potential admission that could have been prevented:					
	32 What is the best way to manage anaemia in	C30i What is the hest way to manage anaemia in	Qian C, Wei B, Ding J, Wu H, Wang Y.The	1 health professional			
32	32. What is the best way to manage anaemia in people with advanced heart failure?	hoort foilure?	Efficacy and Safety of Iron Supplementation in	i ilealtii professional			
	people with advanced neart failure?	rieart failure?	Patients With Heart Failure and Iron				
			Deficiency: A Systematic Review and Meta-				
			analysis Can J Cardiol. 2016 Feb;32(2):151-9.				
			Kansagara D, Dyer E, Englander H, Fu R,				
			Freeman M, Kagen D.Treatment of anemia in				
			patients with heart disease: a systematic				
			review.Ann Intern Med. 2013 Dec				
			3;159(11):746-757.				
			Groenveld HF, Januzzi JL, Damman K, van				
			Wijngaarden J, Hillege HL, van Veldhuisen DJ,				
			van der Meer P.Anemia and mortality in heart				
			failure patients a systematic review and meta-				
			analysis. J Am Coll Cardiol. 2008 Sep				
			2;52(10):818-27.				
00	33 What can help people with advanced beart	B35 What can help with nausea?	Qian C, Wei B, Ding J, Wu H, Wang Y.The	1 carer		+	
33	33. What can help people with advanced heart failure who experience nausea?	200 Triat oan neip with hausea:	Efficacy and Safety of Iron Supplementation in	Validi			
	ianure who experience nausear		Patients With Heart Failure and Iron				
			Deficiency: A Systematic Review and Meta-				
			analysis Can J Cardiol. 2016 Feb;32(2):151-9.				
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1			Kanaanana D. Duan E. Englander H. Ev. B.				
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			failure patients a systematic review and meta-				
			analysis. J Am Coll Cardiol. 2008 Sep				
			2;52(10):818-27.				
1							I

34. What are the commonest and/or worst side					
	A99 Can anything be done about the dizziness?	lo definitive evidence	7 patients, 5 health professionals		
effects of drugs used in with advanced heart	A104 How can dizziness from very low blood pressure				
failure, and what can be done about them?	as a side effect of heart failure medication be				
	significantly reduced, as it can be extremely debilitating?				
	C65ii Which drugs and which side effects are the				
	worst?				
	C56ii In the very elderly and frail which drugs make				
	the most difference for the least side effects?				
	C65ii Which drugs and which side effects are the				
	worst?				
	A95iv My heart failure nurse is supportive and				
	available.				
	My blood pressure is low and so takes only a minimal				
	amount of beta blocker.				
	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?				
	A11 How long does medication take to work?				
	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?				
	C52 I'd like to know more about the pros and cons of				
	my medications				
	C63i Can you explain my medication to me?				
35. Do health professionals understand the		o defintive evidence	1 patient		
35. Do health professionals understand the life / activity / functional consequences of each	consequences of one drug over another when both				
medicine?	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?				
36. How can a person with advanced heart failure take enough beta-blockers without their	in the state of th	lo defintive evidence	1 patient		
	available.				
blood pressure being too low?	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?				
	about this? I take eplerenone. Are there any long term effects				
	about this?				
O.7. 37 When can/should the following	about this? I take eplerenone. Are there any long term effects of this drug?	lo definitive evidence	3 natients 3 health professionals		
37 When can/should the following medications be stopped for advanced heart	about this? I take eplerenone. Are there any long term effects of this drug?	lo definitive evidence	3 patients, 3 health professionals		
medications be stopped for advanced heart	about this? I take eplerenone. Are there any long term effects of this drug?  N  C173 In the terminal stage which medications can be	lo definitive evidence	3 patients, 3 health professionals		
failure? a) Blood pressure medications b)	about this? I take eplerenone. Are there any long term effects of this drug?  N  C173 In the terminal stage which medications can be safely discontinued?	lo definitive evidence	3 patients, 3 health professionals		
medications be stopped for advanced heart	about this? I take eplerenone. Are there any long term effects of this drug?  N C173 In the terminal stage which medications can be safely discontinued? A104 How can dizziness from very low blood pressure	lo definitive evidence	3 patients, 3 health professionals		
failure? a) Blood pressure medications b)	about this? I take eplerenone. Are there any long term effects of this drug?  C173 In the terminal stage which medications can be safely discontinued? A104 How can dizziness from very low blood pressure as a side effect of heart failure medication be	lo definitive evidence	3 patients, 3 health professionals		
failure? a) Blood pressure medications b)	about this? I take eplerenone. Are there any long term effects of this drug?  C173 In the terminal stage which medications can be safely discontinued? 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	lo definitive evidence	3 patients, 3 health professionals		
failure? a) Blood pressure medications b)	about this? I take eplerenone. Are there any long term effects of this drug?  N  C173 In the terminal stage which medications can be safely discontinued?  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?	lo definitive evidence	3 patients, 3 health professionals		
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failure? a) Blood pressure medications b)	about this? I take eplerenone. Are there any long term effects of this drug?  C173 In the terminal stage which medications can be safely discontinued?  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?  A62i,ii Is furosemide the mainstay of treatment?  Should BP mess & statins be continued until when?	lo definitive evidence	3 patients, 3 health professionals		
failure? a) Blood pressure medications b)	about this? I take eplerenone. Are there any long term effects of this drug?  N  C173 In the terminal stage which medications can be safely discontinued?  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?  A62i,ii Is furosemide the mainstay of treatment?	lo definitive evidence	3 patients, 3 health professionals		
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40. Is there a specialist service that could do	C116 Once the patient with heart failure had their	No definitive evidence - more about access to se	1 health professional one carer		
40. Is there a specialist service that could do medication checks for people with advanced	pharmacological therapy optimised, can he/she be	INO delimitive evidence - more about access to si	i ileaitii professionai, one carei		
heart failure on a regular basis?	discharged from the care of the heart failure specialist				
neart failure on a regular basis?					
	nurse?				
	B44ii Medication doesn't seem to be regularly				
	checked except when my mum goes into hospital and				
	is not increased or decreased - is there a more				
	specialist service that could do this on a regular				
	basis?				
41. How can NHS services (such as	A13 I find it difficult getting a repeat prescription.	King AJL, Johnson R, Cramer H, Purdy S,	6 patients		
appointments, repeat prescriptions, access to a	Something is always missing or prescription isn't	Huntley AL.Community case management and	o panonio		
heart failure nurse) be improved for people with		unplanned hospital admissions in patients with			
advanced heart failure?	appointment unless desperate A88iv Nominated nurse to contact directly email or	heart failure: A systematic review and			
		qualitative evidence synthesis. J Adv Nurs.			
	phone.	2018 Jul;74(7):1463-1473.			
	A88iii Could we have a consistent team approach				
	nurses, doctors, social and consultants?				
	A88ii Communication between consultant and GP				
	could do with improvement				
	A93 Where can I access a helpline 24/7/365 without				
	having to go to A&E. A phone line would really help				
	A102 Can access to heart failure nurses be increased				
	within the UK?				
	How do you best access a heart failure nurse and				
	what is their role with the MDT?				
	mid to their role mar the me :				
40 1411 41 4 4 4 1 1 1110	A404340	N. 1.6.32	4		
42. What barriers are there to accessing NHS	A124 Where do I turn as living in a rural area there	No definitive evidence	1 patient		
services for people with advanced heart failure	are simply no heart failure services available?				
in rural communities and how can these be	Why are rural areas less likely to have support				
overcome?	services available?				
43. Which healthcare professional is most	A102 Can access to heart failure nurses be increased	No definitive evidence	5 health professionals, 2 patients		
appropriate for people with advanced heart	within the UK? How do you best access a heart				
failure to consult with at each stage of their	failure nurse and what is their role with the MDT?				
disease journey?	C108ii How do I get my heart failure nurse if I need a				
anocado journoy.	talk after I am not on her list?				
	C149 Who is best to talk to patients about end of life				
	and advanced care planning? How do we recognise				
	when a patient is becoming palliative and who is best				
	placed to make this decision - GP, heart failure nurse,				
	Cardiologist				
	A62 Can a HF patient be effectively managed by a				
	nurse practitioner?				
	C82 Traditionally not concentrated on in secondary				
	care although very important for patient and relatives.				
	HF nurses do this much better than Drs. would be				
	useful to know what exactly patient want to know and				
	whether the current info is sufficient, who they would				
	like to get this info from				
	C82 Are we doing a good enough job and do patients				
	know who to contact/ what to do when they have a problem				
	C149 Are outcomes for patients with severe heart				
	10 143 Are outcomes for patients with severe near				
	failure hetter if they are made a break failure and		1		
	failure better if they are under heart failure nurse care			1	
	failure better if they are under heart failure nurse care or GP care				
44. How can the work of heart failure charities	or GP care	No evidence	2 patients		
44. How can the work of heart failure charities	or GP care   A88v Make better use of charity organisations and	No evidence	2 patients		
be better integrated with with services to	or GP care   A88v Make better use of charity organisations and the material they produce.	No evidence	2 patients		
optimise the care of people with advanced heart	or GP care   A88v Make better use of charity organisations and the material they produce.  A41 Would like a full integrated team of occupational	No evidence	2 patients		
be better integrated with with services to	or GP care   A88v Make better use of charity organisations and the material they produce.  A41 Would like a full integrated team of occupational therapists, dieticians, psychologists, physios, carer	No evidence	2 patients		
optimise the care of people with advanced heart	or GP care   A88v Make better use of charity organisations and the material they produce.  A41 Would like a full integrated team of occupational therapists, dieticians, psychologists, physios, carer support services, complementary therapists,	No evidence	2 patients		
optimise the care of people with advanced heart	or GP care   A88v Make better use of charity organisations and the material they produce.  A41 Would like a full integrated team of occupational therapists, dieticians, psychologists, physios, carer	No evidence	2 patients		

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	ore about access to se 2 patients, 1 health professional	
46) What are the benefits of asking a person	C39ii Does asking a person with heart failure what No definitive evidence	4 health professionals	
to them"?	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?		
47 Do we have patient centred outcomes for	C5How are we assessing outcomes for patients with <a href="https://www.ichom.org/port">https://www.ichom.org/port</a>	tfolio/heart-failure/ 2 health professionals	
advanced heart failure?	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		
48) How do we design a key worker	B20 It would be so helpful if there was a person who  1. J Adv Nurs. 2018 Jul;74		
(coordinator) role that is effective, has sufficient time and knowledge to be able to assess a person with advanced heart failure holistically?	was your own personal contact, who knew the history and condition, that you could contact directly, will this ever happen?  884 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 welcome with that my Cardiology problem is more important than Rheumatology. I would like a dedicated number to	professionals  professionals  professionals  professionals  professionals  professionals  professionals	

49) How do people get support to continue as		No definitive evidence- more about access to	1 patient, 1 health professional			
their heart failure becomes more advanced?	C133 patients with heart failure usually have lots of	services				
	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					
	given pine and told to come back in our months.					
50 Can advanced heart failure outpatient care	C149 How do we build communication links between	As for question 48	8 health professionals , 2 patients			
50 50) Can advanced heart failure outpatient care	primary care, heart failure nurse teams and	AS for question 46	o nealth professionals , 2 patients			
be better co-ordinated, e.g. by ensuring an	Cardiology to ensure timely management of unstable					
relevant professionals are kept in the loop of	patients					
communications?	C152 Viii Viii) Patients would benefit from an MDT					
	approach to HF. Perhaps a HF rehab group					
	1					
	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 over					
	sight (in my case haematology and cardiac)					
	A88ii Communication between consultant and GP					
	could do with improvement					
	C185 Best links between hospital staff and primary					
51) Can the long-term care needs of people	C56 What patterns of care enable more people to die	to the first of the state of th	5 health professionals			
with advanced heart failure be better met by	in their preferred place?		_			
closer co-operation between heart failure and	C125 What proportion of patients with HF have been					
palliative care teams?	offered access to palliative care to try to improve their					
pamative care teams:	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					
				<u> </u>	<u> </u>	
52 Would overall provision for people with	A96 As a retired Academic Social Worker I am	No definitive evidence	1 patient			
52 Would overall provision for people with advanced heart failure be improved by closer co	dismayed at the state of Social Care in these early.					
operation between social care and heart failure						
professionals, including joint funding?	is far more coherent and appropriately trained. Joint					
professionals, including joint running!	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.					

53 What do carers need in terms of information	B121 As the daughter of a person with heart failure,		1 carer			
about advanced heart failure?	and not involved in physician consultations, how do I	1. Int J Nurs Stud. 2018 Jan;77:232-242. doi:				
	find accurate information when my father (the patient)	10.1016/j.ijnurstu.2017.10.007. Epub 2017 Oct				
	is trying to be upbeat, and my mother insists on	19. A systematic review of heart failure dyadic				
	4	self-care interventions focusing on intervention				
		components, contexts, and outcomes. Buck				
	what's going on with my father?	HG1,				
		2. Heart Fail Rev. 2017 Sep;22(5):565-580.				
		doi: 10.1007/s10741-017-9596-5. Psychosocial				
		needs and interventions for heart failure				
		patients and families receiving palliative care				
		support: a systematic review. Cagle JG1,				
		3. Patient Educ Couns. 2016 Mar;99(3):326-				
		338. doi: 10.1016/j.pec.2015.10.009. Epub				
		2015 Oct 22. Heart failure family-based				
		education: a systematic review. Srisuk N1,				
		Cameron J2, Ski CF3, Thompson DR3.				
		Cameron 52, Okt Or 5, Thompson Dito.				
= 4 E4 How do you inform poonlo with advanced	D22 What interventions help with compliance to		1 notions 1 other			
54 How do you inform people with advanced	D32 What interventions help with compliance to		1 patient, 1 other			
neart failure about their medication in a way that	t therapies and advice? Provision of education to help					
empowers them to take it conscientiously and	patients be empowered to make decisions about their care					
manage it well?	A103 How do you inform patients about their					
	medication in a way that empowers them to take it					
	conscientiously and manage it well?					
		Dookid M. Kurak CC. Cala CD. Impact of as may	d haalth mustanaianal			
55 How can we distinguish between co-morbidities	C60ii How can I distinguish between co-morbidities	Rashid M, Kwok CS, Gale CP, Impact of co-mor	i i neaith professional			
(other chronic conditions) for example: COPD/ches	eg COPD / chest infection / heart failure					
infection & advanced heart failure)?	il.					
To Mississian the manufacture and effective	A103 How do you inform patients about their	Wiled the second of the second	0			
56 What are the most empowering and effective education and self-management advice for	medication in a way that empowers them to take it	Whilst there are studies/systematic reviews on self-management for heart failure - some are	1 *			
people with advanced heart failure and carer?	conscientiously and manage it well?		professionals, 1 carer			
	A103 How can you support people from the point of	quite old (outside our 5 year search), the outcomes are quite diverse or on very specific				
For example : dealing with fatigue	diagnosis to understand and work through the	issues (cognitive impairment/heart failure and				
	emotional adjustments/loss that their 'life changing					
	condition' will involve (bearing in mind each person's	education ). No real focus on patient-related outcomes such as fatigue				
	condition and adjustment is unique)?	outcomes such as latigue				
	A96i So much of the impact is dependent upon ones					
	own knowledge base at the time of diagnosis and					
	subsequent 'downstream ' events in the heart disease					
	/ heart failure					
	A96ii Again, self-awareness and knowledge base are					
	for me, key to coping. Also, seeking help and helping					
	others via web-based portals such as 'Patient' and					
	various 'Facebook' forums such as Pumping					
	Marvellous'. Signally I have personally found					
	'Wikipedia' an immensely useful resource. My limited					
	recent experience with HF Specialist Nurses has					
	been very supportive as well as the fundamental					
	support through the years via my local hospital					
	Cardiology Department.					
	A36 Why does the process of assessment post					
	diagnosis take so long? Why is HF treated as if it's					
	all a fait accompli and you are where you are? I have					
	felt as if I've had to get on with it myself, and if my					
	wife and I hadn't had the good level of knowledge we					
	have about nutrition and exercise, I'd be a great deal					
	worse					
	A38 What happens if you are discharged from your					
57 57 Is there an 'App' to help people manage		No definitive evidence	1 health professional			
advanced heart failure?	failure? Who should I first contact if I am worried I am					
	getting worse?					

58 How do we break down barriers for patients					
	C23 is there really an open discussion with most	No definitive evidence	11 health professionals, 2		
with advanced heart failure, carers and health	patients about prognosis?		patients, 1 carer		
professionals to enable talking about end of life	B77iii They don't want to tell me hubby has heart		panono, i ouici		
	failure but with swollen legs tired no get up and go				
care?	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				
	<u> </u>				
	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				
59 How can healthcare professionals manage	A94 Why does everything take so long? Why do you	No definitive evidence	1 patient, 1 health professional		
the expectations of people with advanced heart		25	- Fancing . Mounti professional		
the expectations of people with advanced heart					
failure? For example uncertainty	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.				
60 Why do we use the term heart failure?		Bjork JB, Alton KK, Georgiopoulou VV, Butler	2 health professionals		
60  ,	C50i Wish we could change the name!	J, Kalogeropoulos AP.Defining Advanced Heart			
	C53 Why do we use the word failure- very negative	Failure: A Systematic Review of Criteria Used			
	and emotive?	in Clinical Trials. J Card Fail. 2016			
		Jul;22(7):569-77.			
61 What is the optimum time to discuss	C153 Can patients have more information about their	No definitive evidence	3 health professionals		
deactivation of ICDs (implants) and discuss	ICD's prior to being implanted as many seem		_		
palliative care with people with advanced heart	shocked when discussions take place about				
pamative care with people with advanced heart					
failure?	deactivating them at the end of their lives				
	deactivating them at the end of their lives C154i,ii At what stage to patients want to discuss				
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63 How do health professionals response when	1	Rahimi K, Bennett D, Conrad N, Williams TM,	4 patients, 2 health		
people with advanced heart failure ask 'When	D42 Con you be mare one iff a should not be a continued in		professionals, 1 carer		
am I going to die? Are we talking days months,	B42 Can you be more specific about prognosis?	McMurray J, MacMahon S. Risk prediction in	,		
years? What about sudden death?'	A16 How long will I live? How can I improve?	patients with heart failure: a systematic review			
,	A19 Can I be given a provisional timeline of cardiac failure?	and analysis. ACC Heart Fail. 2014			
		Oct;2(5):440-6. doi: 10.1016/j.jchf.2014.04.008.			
	A102 How can I best deal with coming to terms with	Epub 2014 Sep 3.			
	my mortality following a poor prognosis for my heart failure?	Alba AC, Agoritsas T, Jankowski M,			
	A105 [I have stage 3 HF and was diagnosed 3yrs	Courvoisier D, Walter SD, Guyatt GH, Ross HJ.			
	ago. Although I'm on a good mixture of medications.	Risk prediction models for mortality in			
	No one is able to give me or are unwilling to give me	ambulatory patients with heart failure: a			
	an idea of life expectancy. Or how it progresses how	systematic review. Circ Heart Fail. 2013 Sep			
	much further I will be unable to do daily things	1;6(5):881-9. doi:			
	A105 Both my heart failure nurses are great yet	10.1161/CIRCHEARTFAILURE.112.000043.			
	sometimes feel as I do when seeing my cardiologist	Epub 2013 Jul 25.			
	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? □				
64 How do health professionals explain how	C117i How likely are my symptoms to get	No definitive evidence	7 health professionals, 1 patient		
advanced heart failure progresses and what that			,, p, , . p		
means for their symptoms?	C118 How can we better prognosticate in patients				
means to their symptoms.	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?				
65 What percentage of people with advanced	C125 What proportion of patients with HF have had	Risk prediction models for mortality in ambulatory	1 health professional		
heart failure have advanced care plan (ACP)	advance care planning discussions	patients with heart failure: a systematic review.			
discussions?	January and Grands	Circ Heart Fail. 2013 Sep 1;6(5):881-9. doi:			
4.664.56.6.16.1		10.1161/CIRCHEARTFAILURE.112.000043. Epub			
		2013 Jul 25.			
		2013 Jul 23.			
The following 14 guestions were eliminated but he					
The following 14 questions were eliminated by the					
steering committee just prior to the second survey					
as it was decoded that either there was sufficient					
evidence present for these questions or other					
reasons stated.					

1. What emotional support and psychological					 	 
Triat emotional support and psychological	C28i, Is there any evidence to show the impact of	This question was removed as it was about it is	6 health professionals, 4	no meaningful answer		
treatments for advanced heart failure are	clinical psychology support for patients with heart	about availability and access to services	patients, 1 other			
currently available (for all stages of heart failure						
diagnosis and treatment and for those with	C180 What type of support and how frequent should					
depression and anxiety) and how easily can the	it be for low mood in advanced heart failure					
be accessed?	D32 Psychological services for heart failure are thin					
be decessed:	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?					
2 What current is evailable for carers of needle	A114 Who is available to talk to me about how I feel?	This question was removed as it was shout it is	2 nationts 2 serves 2 health	no magningful anguar		
2. What support is available for carers of people	B42 What support is available for Carers who work	This question was removed as it was about it is		no meaningful answer		
with advanced heart failure?	ruii time:	about availability and access to services and	professionals			
	C61ii,iii What about getting emotional support for	also it was covered by an effectiveness				
	patients and significant others, including children.	question (q22 above)				
	What is the impact on children when one of there					
	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					
	B145 As a patient my relative is very matter of fact about his condition to the point where he often					
	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					
	B145 As a patient my relative is very matter of fact about his condition to the point where he often					
	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???					
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3.When should fluid intake he limited /	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?	NICE Guidance on this already exists based on	2 health professionals	evidence		
3.When should fluid intake be limited /	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?	NICE Guidance on this already exists based on evidence	2 health professionals	evidence		
monitored for a person with advanced heart	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?  C134 Should fluid intake be limited? We see patients	NICE Guidance on this already exists based on evidence	2 health professionals	evidence		
	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?  C134 Should fluid intake be limited? We see patients with Continence issues so it relates directly to the	-	2 health professionals	evidence		
monitored for a person with advanced heart	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?  C134 Should fluid intake be limited? We see patients with Continence issues so it relates directly to the advice we offer.	-	2 health professionals	evidence		
monitored for a person with advanced heart	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?  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)	-	2 health professionals	evidence		
monitored for a person with advanced heart	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?  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	-	2 health professionals	evidence		
monitored for a person with advanced heart	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?  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	-	2 health professionals	evidence		
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7.Are outcomes better heart failure if there is specialist heart failure	greater access to	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	1 health professional	evidence			
8.Would advanced hea	nrt failure hospital		failure. Slyer JT et al. JBI Libr Syst Rev. (2011)  There is evidence to suggest co-ordinated care	6 health professionals	evidence			
between different tean		C56 Does fragmentation of care lead to excess admission? C157i 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?	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)					
9.What can help the he		B35 What can help their heart get stronger?	It was felt that this question could not be	1 carer	no meaningful answer			
how long does it take 10.Do people with adv commonly develop oth For example: kidney fa	anced heart failure ner serious complications,	B121 Do people with heart failure commonly develop other serious complications, e.g. kidney failure?	meaningfully answered 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 increas prevalence) of advance		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			
		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 pro care to all (including h ejection fraction)?	fessionals deliver quality eart failure with preserved	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		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)	professional	evidence			
15. What are the long- eplerenone in the treat advanced heart failure	tment of people with	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			