



Work Package 1:
REACH-HF Feasibility Study Process Evaluation
FINAL Report – September 2014

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EXECUTIVE SUMMARY

This report presents a summary of the data collected during the REACH Feasibility Study. The main aims of this report are to a) assess the feasibility and acceptability of the intervention b) extract ideas to help refine the intervention in advance of the main trial and c) to assess the quality of intervention delivery.

During this study, the REACH HF intervention was delivered to 23 patients (and 12 caregivers) by eight facilitators at three sites (Cornwall, South Glamorgan, Birmingham and York). Data was collected from multiple sources, including recordings of intervention sessions, satisfaction questionnaires and interviews with both patients and caregivers.

We found that there was a high level of satisfaction with the intervention from facilitators, patients and caregivers and good engagement with the intervention by both patients and caregivers. A number of ideas for improving the text of the Heart Failure Manual and for improving the training were identified and are described in detail in sections 2.3 and 3.2. Analysis of the quality of intervention delivery (intervention fidelity), based on applying a checklist to recordings of all the consultations for 18 cases, suggests that the components of the intervention were mostly delivered as intended and with high quality. However, there was room for improvement in terms of addressing caregiver health and emotional health.

1. Introduction

This FINAL report has been compiled to support the development of the facilitator training and materials for the REACH-HF main trial based on the findings of the feasibility study process evaluation. It is based on the data collected from April to beginning of September 2014.

This Final report has two main sections based on the source of data used (1) audios, contact sheets and feedback, and 2) patients and caregivers) with recommendations for training and materials. An additional section reports on the feedback on the text of the HF Manual from Peer Reviewers.

The main body of the report includes learning and recommendations from the final facilitator focus group, the intervention sessions conducted in the latter part of the study (including the important process of 'closing down' the intervention), analysis of intervention fidelity scores, final interviews with patients and caregivers, and peer review. An examination of participants' usage of Progress Trackers (a tool included in the manual to facilitate self-regulation and the learning of self-regulation skills) is included in Appendix 4. Data on participant satisfaction and some feedback on the research processes is presented in further appendices.

1.1 Data sources

Table 1: Data sources

Intervention delivery data	Patient and caregiver data	Peer review
Audio recordings n=147 (of every phone and face-to-face contact between facilitator and patient +/- caregiver)	Satisfaction questionnaires n= 49 – representing 19 participants (completed by patient +/- caregiver following each home visit)	External reviewers n=5 Comments on the manual text
Contact sheets n= 140 (completed by facilitators after every phone and face-to-face contact)	6 week interviews n=13 – representing 13 patients and 9 caregivers	Facilitators n=1 One facilitator provided written comments on the manual text
Facilitator teleconferences n=3 Facilitator focus Group n=1	End of intervention interviews n=13 – representing 13 patients and 7 caregivers	Participants n=1 One patient provided written comments on the manual text
Intervention Fidelity checklist scores n=18 - representing 18 patients, 10 caregivers and 6 nurses)	Progress trackers n=15 – representing 15 participants	
Written formative feedback to facilitators from WP1 team n=16 - based on review of the audio recordings above		
Written comments from CD and JE in response to facilitator feedback and teleconferences		
Email correspondence and phone call feedback from facilitators		

1.2 Questions addressed in this report

- How have the HF Manual and facilitation process been implemented and received?
- What (if any) changes are required to the materials offered to the patients and caregivers?
(HF manual – HFM, Caregiver Resource – CGR, Progress tracker – PT, Relaxation CD – RCD, Chair based exercise DVD – CBE DVD, pedometer)
- What (if any) changes are required for the facilitator training?

1.3 Intervention delivery

It was anticipated that facilitators would have around three face-to-face contacts with participants during the 12 week intervention, and a similar number of phone call contacts in-between visits. Complete data (from start to end of the intervention) on contact time was collected from 16 of the 23 participants, who were treated by six of the eight facilitators (**See Table 2 below and Appendix 1**). The mean number of face-to-face contacts actually made was four (mean 69 mins each), with an

additional four phone calls (mean 16 mins each). The maximum number of sessions (face-to-face or phone) for one case was 11, and the minimum was six.

The Health Economics data will be reported elsewhere, however, descriptive statistics based on the audio data received suggests that total contact time varied from just under two hours to nearly ten hours, with average total contact time being 5 hrs 46 mins (over the 12 week intervention period). Individual sessions varied from being just one minute long (phone contact) to 2 ½ hours long (visit).

The following values are based on the returned audio data from the facilitators. There may be differences in the length of time per session recorded on the contact sheet compared to the length of audio time. For consistency, only the audio times have been used here. No audios were available for n=5 cases so these have been excluded from this section. Two cases were not yet completed so they have also been excluded from this section.

Table 2: Facilitator contacts: number, type and time spent.

Sessions (n=16 cases)

	N	Min	Max	Mean	Median	SD
Total Contact time from audio	16	110	583	345.6		152.003
Number of contacts	16	6	11	8	8	1.41
Number of visits	16	2	8	3.94	3	1.526
Number of phone contacts	16	1	6	4.06	5	1.388
Total visit contact time	16	95	553	284.56		146.78
Total phone contact time	16	12	117	61.09		32.54
Mean time per visit	16	31.6	91.3	68.6		19.49
Mean time per phone call	16	3	27	15.9		7.44

2. Intervention delivery (audios, contact sheets and facilitator feedback)

Eight facilitators (two physiotherapists and six nurses) delivered the intervention in four study sites (Abergavenny, Birmingham, Cornwall and York,). The following comments are based on data from seven of the facilitators (both physiotherapists and five of the nurses). Data from one of the facilitators were limited to contact sheets only, and one facilitator did not return any data. Individual feedback to facilitators (n=16) was based on listening to their audio data (consequently two of the facilitators did not receive individual feedback).

Contact sheets (n=140) were reviewed and audio data from facilitator face-to-face and phone sessions (n=147) were scored by AS, JW and CG using an intervention fidelity (IF) checklist (Section 2.2). *(Note: the numbers of audio files and contact sheets are not the same as not all the contact sheets had been returned at the time of writing.)*

There were three supervision/discussion teleconferences with facilitators and one final focus group.

2.1 Overview

The facilitators were invited to give direct feedback of their experiences of the training, materials and intervention via the facilitator focus group, the contact sheets, and individual communication with the research team. Overall they saw their involvement with the programme as a good experience.

Feedback from facilitators

Training

- The training folder was a useful resource particularly if the patient had a question.
- The facilitators felt well prepared by the training. They also learnt on the job and found the three debriefing teleconferences (x3) invaluable.
- The additional information and paperwork provided following the debriefing meetings (starting questions and advice on prescribing a walk programme) was helpful (N.B. The audio recordings indicate this was used in the sessions.)
- Learning occurred via 'on the job' training.

Resources

- The quotes in the manuals were helpful.
- Some facilitators used the boxes with summarised information to overcome the barrier of poor reading skills or a dislike of reading.
- The progress tracker is a useful tool. Sometimes the caregivers completed the tracker.
- The "having fun" section of the progress tracker was used for goal setting.
- Understanding heart failure chapter helped people manage the 'good days' and the 'bad days'.

Intervention delivery

- It was rewarding to see the progress made in people's home. The facilitators who normally work in a hospital or group setting reported it 'opened my eyes to what people are dealing with at home'.
- The facilitators learnt to encourage 'bite size' reading of the manual. They realised they need to make it clear that not all sections will be relevant for all participants.

Observations from reviewing the audio data:

Overall, the quality of delivery started reasonably well and has developed to a very high standard in our view. The participants in the study have presented the facilitators with a range of challenges to work through together. These include among others: engaging both the participant and the caregiver in the intervention; managing misconceptions about heart failure; awareness of the impact of comorbidities; prescribing exercise; and facilitating the development of monitoring skills.

The participants have a range of ages but tend to be older with co-morbidities including diabetes, myalgic encephalopathy, arthritis, coeliac disease, leg shortening, gout, sleep apnoea, fibromyalgia, CFS and other cardiovascular conditions (e.g. AF, angina, heart valve problems).

We are addressing the pre intervention information needs for the facilitators (led by Prof Patrick Doherty). All facilitators have also found additional information from sources such as the cardiac consultant, a pharmacist, the GP surgery or heart failure nursing service. This includes an up to date medication list, co-morbidities, information about drug stability, and results of investigations.

What has been noticeable is how the balance of power has changed (often dramatically) over time from being with the facilitators in earlier sessions to being with the participants. We observed this trend both within facilitators (over time) and also within cases (from earlier to later sessions). This seems to be as a result of three main reasons. Firstly, the facilitators have become more familiar with the manual and confident in using behaviour change techniques. Secondly, the participants have learnt about managing heart failure and how the facilitation process works. Thirdly, formative feedback from the facilitator de-briefing sessions and individual feedback from JW, AS and CG may have influenced their practice.

Initially, there was a tendency to cover all topics during the first consultation, this changed for later participants. The ask-tell-discuss technique has markedly improved over the weeks and the facilitators have become less didactic in their approach. There is more affirmation /praise for actions and for at least 'giving it a go'. Facilitators have also learnt to ask what the participant will do to overcome a problem rather than telling them what to do.

There has been a focus on exercise, medication and stress management. In the audios reviewed there has been one clear case of depression, several reports of low mood and an exacerbation of heart failure. These have been sensitively and appropriately handled by the facilitators and participants have responded well. These experiences have been used to reinforce learning and behaviour during the following weeks.

Exploration of social support around the patient and /or the caregiver is more often missing or sparsely covered.

The manual has generally been enthusiastically presented and well explained as a 'dip in and out' resource rather than a book. All the facilitators we have heard (n=6) have demonstrated that they care and have developed an excellent rapport with the participants. They adapt their language appropriately and use humour well. There have been examples of very personal information being shared with the facilitator indicating the trust and bond between them. In the follow up consultations the participants sound pleased to see or hear their facilitator, and several have said that they enjoy the facilitator's visits.

The facilitators have sometimes adapted the words they use to suit the participants although at times it has been a little 'medical model' oriented. One aspect that works well is that during the weeks between sessions the participants have been able to think about what they want and prepare questions. The tracker has been useful for this and is often but not always a key tool to guide the consultation. As the facilitators have learnt to ask 'how have you been getting on with....' or 'what have you written in your tracker', the participants have come to expect to use the tracker and have it ready when the facilitator telephones or visits.

One participant does not like to read and felt overwhelmed by the size of the manual. What has worked for him was use of the purple or green boxes and the quotes from people with heart failure and discussions with his facilitator (who never sounded judgemental about him not reading much of the manual). Several participants have had the facilitator use the exercise DVD with them. This gives the facilitator opportunity to encourage engagement and also to correct any actions e.g. when the patient tries to go faster than the demonstrator on the DVD. There have been examples where the facilitator has demonstrated and facilitated the belly breathing exercise, and also where they have accompanied the patient on a walk to check their breathing, intensity etc. These examples show flexibility and an individualised approach by the facilitators.

There have been no audios or contact sheets submitted (so far) from Birmingham, so we cannot yet comment on the critical issue of adaptation to ethnic minority groups.

Goal setting and length of time for the 1st consultation

The first consultations vary in length between 45 minutes and 2½ hours, most are around 1½ hours. They need to be substantial to allow for assessment of needs and HF knowledge and status. Those who are still emotional about their diagnosis or experience may need a longer consultation.

However, there has been a tendency in some cases to go through the whole manual – this is not really necessary as there are 12 weeks.

Initially the exercise programme was prescribed rather than negotiated; this has changed as the programme has continued, perhaps as a result of the feedback the facilitators have received.

Physical activity

There is quite a lot of variation in the way that the exercise aspect of the programme is introduced by the facilitators. There appears to be some implicit decision-making by the facilitators about which activity – walking or the CBE DVD – to offer. Sometimes both are offered as a choice but the amount of information presented about each may not be equal. Also, in some cases both are offered as

interchangeable (“you could walk on Wednesday, do the DVD on Friday...”). Whilst this may help with variety, dealing with the weather etc., it can also lead to an unclear plan.

There have been no notable differences between the facilitation of exercise between the nurses and the physiotherapists once the nurses gained confidence in their knowledge and skill.

Physiotherapists and nurses have taken the time to a) go for a walk with the participant and b) sit through a DVD session with them to make sure they could work the DVD player and to build confidence in doing the exercises correctly. Both these activities were helpful, but also time-consuming

Caregivers

What has been missing to varying degrees has been involvement of the caregivers as co-facilitators when agreeing action plans. This may be in part because the family member is not seen as a caregiver by the participant or by themselves or because actively involving caregivers is not usually part of current clinical roles. The term caregiver has therefore been a barrier to engagement in some cases.

Exploration of the caregivers’ needs has been minimal or non-existent in a number of cases, although there have been some good examples of this.

Caregivers are generally not actively considered in follow ups and are often not included in telephone follow ups. This will need to be addressed in the training programme. There are however some good examples of this (and of the caregiver responding well).

Follow up consultations

At follow up contacts, the focus tends to be on exercise or using relaxation techniques.

Challenges:

Overall, although the feedback was broadly positive, a number of challenges were identified and these are incorporated with the ideas for improving the intervention in section 2.3.

2.2 Intervention Fidelity

Intervention fidelity was checked by applying our 13-item intervention fidelity checklist to all recorded intervention sessions (i.e. all the phone and face-to-face sessions for the 18 participants for whom data was returned). Tables 2 shows the mean intervention fidelity scores and range of scores for each item and Table 3 shows the scores for each facilitator. The scores indicated adequate delivery (defined as a score of 3 or more) for most aspects by all facilitators. However, the mean score for items 10 (ADDRESSING EMOTIONAL CONSEQUENCES OF BEING A CAREGIVER) and 11 (CAREGIVER HEALTH AND WELL-BEING) was less than 3. Analysis of the scores for each facilitator show that only one of the six facilitators delivered these elements of the intervention as intended.

Table 3: Mean Intervention Fidelity scores

	Item 1	Item 2	Item 3	Item 4	Item 5a	Item 5b	Item 6	Item 7	Item 8	Item 9	Item 10	Item 11	Item 12
N	18	18	18	18	18	18	18	18	18	15	15	15	18
Minimum	3.0	3.5	3.0	2.0	3.0	3.0	3.0	2.5	2.0	2.0	.0	.0	.0
Maximum	6.0	5.5	5.0	6.0	6.0	6.0	6.0	5.5	6.0	5.0	4.5	5.0	6.0
Mean	5.056	4.611	4.361	4.250	4.639	4.667	4.611	4.472	4.194	3.800	2.700	2.567	3.583
SD	.6157	.6543	.7237	.8952	.7031	.6642	.7962	.8309	1.1775	1.0657	1.4736	1.635	1.458

Table 4: Mean Intervention Fidelity scores by facilitator

	IF Score	IF Score	IF Score	IF Score	IF Score	IF Score	IF Score	IF Score	IF Score	IF Score	IF Score	IF Score	IF Score
	Item 1	Item 2	Item 3	Item 4	Item 5a	Item 5b	Item 6	Item 7	Item 8	Item 9	Item 10	Item 11	Item 12
	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean
1	5.1	3.9	3.5	3.1	3.9	4.0	3.9	3.4	2.5	3.5	2.2	1.3	2.4
2	5.3	4.2	4.0	4.2	4.5	5.0	4.7	4.5	3.8	3.8	2.5	2.3	3.3
3	5.5	5.2	5.0	5.3	5.5	5.3	5.3	5.0	5.3	3.5	1.5	2.0	5.0
4	5.0	5.1	4.8	4.5	4.8	4.5	4.4	5.0	4.5	5.0	4.1	4.4	4.0
5	5.0	5.0	5.0	4.0	5.0	5.0	6.0	5.0	6.0	.	.	.	6.0
6	4.3	4.7	4.5	4.5	4.7	4.7	4.7	4.5	4.7	2.7	2.3	2.0	2.7
7
8

2.2.1 Inter-rater reliability

The inter-rater reliability (IRR) for the IF Checklist was assessed by having 2 coders independently code a selection of the recorded phone and face-to-face visits. The scores were then correlated using a simple bivariate correlation (Pearson's R). Based on 698 paired observations, the overall IRR for all 13 items was R=0.74. The inter-rater reliability for each item is shown in the table below:

Table 5: Intervention fidelity checklist inter-rater reliability

	Item 1	Item 2	Item 3	Item 4	Item 5a	Item 5b	Item 6	Item 7	Item 8	Item 9	Item 10	Item 11	Item 12
N	69	68	69	69	56	56	56	56	56	47	47	47	55
R	0.54	0.57	0.57	0.57	0.56	0.83	0.64	0.43	0.60	0.89	0.73	0.68	0.67
Sig	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000

The data suggest that, although the IRR was reasonable overall, the IRR for item 7 (ADDRESSING EMOTIONAL CONSEQUENCES OF HEART FAILURE) was poor and the IRR for several other items (1,2,3,4,5a,6 and 8) was less than desirable. The variation may reflect difference in experience and background (1 health psychologist, 1 nurse-researcher and 1 qualitative health services researcher). Inter-rater reliability might be improved by more intensive training and feedback (including independent scoring of 4-6 sessions followed by discussion of any discrepancies between coders), as well as some updates to the definitions and examples provided for each item.

2.3 Ideas for improvement based on the audios, contact sheets, and facilitator feedback

Where there are no comments or changes related to a specific section of the manual, this is indicated by the word “none”.

2.3.1 The Heart Failure Manual

Introductory text

To help uptake and use of the caregiver resource (family and friends resource) it may be helpful to have a short paragraph at the start of the HF Manual about involving/encouraging others to also read the manual and the supporting friends and family resource?

Part 1: Understanding Heart Failure

This chapter is generally well received.

- One facilitator called blood returning to the heart via the superior and inferior vena cava “spent blood” and blood returning from the lungs and going to the body from pulmonary veins and the aorta as “rejuvenated blood” – the participant liked this. Is this something we could add in to the manual diagrams of the heart?

Part 2: Managing Your Condition

The facilitators cover the content in their discussions but no comments have been heard about this section.

No changes recommended.

Taking Medications

No changes recommended.

Keeping Active

This has been a key chapter for both the facilitators and the participants.

- For explaining the importance of warming up, one facilitator uses the analogy of you wouldn't start a car in fourth gear and expect it to go; you start in a lower gear first and move up the gears. This seems to be well received. It could be added to the manual. A cool down using the same approach could also be used.
- More emphasis on the cool down period could be added – especially as this is the risk period for arrhythmia.
- 'Money in the bank' is a good metaphor /explanation for pacing of exertion over the course of a day.
- Need to add in section on swimming (we've heard 4 participants ask). 'Cold water' problems could be addressed with a top or t-shirt? See PD advice on this issue (PD expressed caution on recommending swimming due to the extra haemodynamic load, especially if this is a new activity).
- Need to add in information for diabetics - taking a sugar based supplement with them on a walk, for the insulin dependent diabetics if exercise is new should we recommend checking their capillary blood glucose (finger prick test) is 7 or above? Should we recommend checking after exercise (to check with clinical advisors)?
- Need information on movement and handling –wheel barrow, shopping, boxes, work, avoiding heavy loads.
- Golf has been a common past time – we could add a paragraph about golf being good physical activity but often not at the intensity required to be exercise. However, playing golf does provide an opportunity to fit in some bouts of brisker walking, so could become part of a sustainable exercise plan. Building their fitness may help them complete a round of golf without needing a buggy or feeling so tired – linking motivation with quality of life.
- We could add into the manual decision-making re thresholds of exercise – if meeting the recommended amount for fitness maintenance, why would you want to do more/preserving the rest of your energy for enjoying other activities/parts of your life.
- Consider renaming this section to “Keeping Active and Improving your Fitness”.
- Include information on FITT principle and SMART goals.
- Look at expanding the range of DVDs for which the DVD will play (formatting)
- Include advice on pacing and planning exercise/activities together with household jobs, gardening and work.

- Include more about warming up and cooling down, and other things to be aware of before exercising e.g. not exercising or doing other activities for an hour after meals and (if they still smoke) to avoid smoking for 2 hours before and after exercise (?).
- Add information for patients at risk of over-exercising.
- Add clear information about swimming.
- Emphasise that chair-based exercises are not just for 'older people'/is applicable for people of all ages.
- For people who don't like the idea of either walking or the DVD, give some further examples of other exercise that could be beneficial e.g. WiiFit, other exercise DVDs. (Also, text on pages 44 and 49 refers to a 'table below' with other exercise ideas but there is no table.)
- Pg 53. "no energy" section: include that their exhaustion may be due to housework, gardening, shopping, hobbies, busy/stressful family life, work. They need to balance these activities with exercise and plan when and how to do them.
- Pg 53. "difficult to motivate" section: add that it can be useful to think of exercise like a prescription like medication. With their medication, they don't miss a dose just because they don't feel like it, and they know it has benefits. Exercise has been shown by research that it is as effective as medication in rehab though in a different way and needs to be done regularly to benefit and notice the rewards, even if they don't feel like it.
- Pg 54. "depressed" section: add that exercise has been proven to lift mood as it stimulates "feel-good" hormones. Depression is sometimes due to loneliness or feeling stuck at home. If you try a walk it will get you out of the house for some fresh air, a change of scenery and you may meet others and have a chat. This can all lift your mood.

Managing Your Fluid Balance

- There are some regional variations about the traffic light system. In Wales the trigger seeking help for weight gain is 4 not 5 lbs.
- Could the Traffic Light Plan from the Progress Tracker be duplicated here for ease of reference?

Managing Stress

There has been a mixed reaction to this section. The symptoms of stress and the check list have been well received (except by one patient who felt these reflected his personality/temperament and so he did not need to address them). The most frequently used pages are page 64, 68-74, the STOP and breathing techniques have been practiced by the participants effectively. Some participants feel the section as a whole is too long and one has found it to be a bit 'doom and gloomy'.

- The relaxation CD had a mixed response. Some participants did not like the voices.

Managing Breathlessness

None.

Managing Changes in Your Symptoms

This is used well by the facilitators in setting up use of the tracker and to explain planning or pacing – good days and bad days.

No changes recommended.

Part 3: Further Information

None.

Keeping Your Spirits Up

This has been used by the facilitators effectively, especially the downward cycle of feeling low or depressed

No changes recommended.

Getting Support from Others

We have not heard any examples of this section being facilitated, so no real feedback here.

None.

Managing Your Finances

This section has not been heard being used. One facilitator did discuss and provide an onward referral to a financial advice service but did not signpost to this section of the HFM.

No changes recommended.

Managing Your Home and Work Environment

Not heard being used.

No changes recommended.

Travel

This has been used as some holidays have been taken during the intervention - including abroad.

- We could add a brief paragraph about pacing activities, continuing with exercise, managing risk of dehydration in heat (and fluid monitoring). This latter point has also been important for exercise in the UK.

Sex

One facilitator did facilitate a discussion about sex between the patient and caregiver and this led to an onward referral. However she did not also signpost to the section in the manual.

No changes recommended.

Sleep

None.

Living with Uncertainty

Mixed response but should remain.

No changes recommended.

Implanted Devices

Minimal questions from participants about implanted devices (pacemaker) – facilitator has explained verbally but not signposted to this section in the manual.

No changes recommended.

Alcohol

At least two participants have had alcohol problems.

- Need to clarify the size of the glass to count as a unit.

Smoking

Participants who did smoke had already stopped smoking before the study.

No changes recommended.

Healthy Eating

These sections have been used quite a lot.

- In a couple of cases, patients have been undertaking weight loss regimes. Do we need to add any more about maintaining weight loss? (It currently just says “stick with any changes you have made”.) Suggestion that Colin Greaves reviews this section.

- Should this section and salt section be moved to the managing your condition chapter?

Managing Your Salt

- Can we develop a credit card sized information card about salt to be used when shopping?

Other Conditions That Might Affect Your Heart Failure

Not heard this section being used.

No changes recommended.

Fluid record

No one has been on a fluid restriction.

No changes recommended.

About Your Medications

None.

Frequently Prescribed Medications

- There are other common medications mentioned that are not currently included in this section. It may be helpful to review whether or not the manual could also include: statins, calcium channel blockers such as verapamil, or amlodipine, amiodarone.

2.3.2 Progress Tracker

- Need to add in sections for weeks 11-12 for the weight charts and week 12 for the exercise chart.

- Need a section for monitoring sleep – how about a page with a section where the participant can describe their current sleep routine and frequency of waking up, document planned changes (change of bedtime drink, relaxing bath, exercise, pain medication, relaxation CD or technique etc.) and finally a section to record the effect. Alternatively, if sleep issues are long-term they may not be related to HF. However, if relatively new, do we want to include a space in the mood and stress weekly progress section where they could be recorded/monitored?
- Provide a photocopiable set of key tracking elements documents – weight, mood and exercise for continued weekly /helicopter-view rather than intensive monitoring.
- Smiley faces for mood is a success.
- Can we move the traffic lights towards the front of the tracker? Sometimes the participants and facilitators are struggling to find it in consultations.
- Look at current traffic light guidelines in relation to local guidelines. Do these need to be changed in the PT, or space left for facilitators to add local guidelines? How should this be managed?
- Should we have a repeated traffic light plan in the main manual under symptom control? This would reinforce the need for monitoring.

2.3.3 Caregiver Resource

- Change title to help engage caregivers (who don't see themselves as "caregivers")
- Facilitators are giving an overall explanation of the resource but are seldom returning to it.
- The name should be changed to 'Family and Friends Resource' and review wording of the manual to be in-keeping with this.
- Add clarification that some sections are for caregivers caring for someone who is ill but there are sections for everyone.

Most used: What to do in an emergency, understanding and managing medicines (caregiver present in consultation when covered), difficult discussions and managing mental wellbeing and health.

Not used: The providing personal care is seen as being less positive.

2.3.4 Pedometers

- Need to discuss the use of pedometers. These are only being supplied as part of a research project at the moment – would they be needed if the trial is successful, if so then they would need to be costed in. HMD - would they also present a problem for packaging when rolled out?
- The pedometers provided do not always accurately record steps. Also, some people have difficulty opening the casing.

2.3.5 CBE DVD

- Chair Based Exercises (CBE) are viewed by some participants as being for people who are infirm – the facilitators have overcome this barrier by discussing the rationale (building muscles, reversing degeneration, enabling activities of daily living) or by completing the CBE with them. They use it as an opportunity to offer praise and to check technique. Also good to practice ‘belly breathing’. Once this barrier has been overcome the CBE was well received.

- There have however been some issues over compatibility of the format of the DVD and some DVD players (the disc does not work on the participant’s player). How could this be overcome?

2.3.6 Relaxation CD

As expected the relaxation CD has been used by some but not all participants. Most only use it a few times. Time seems to be the biggest barrier on top of the exercise programme. Facilitators have encouraged its use by both patients and caregivers, and it has been used and found to be useful by some of the caregivers.

2.3.7 Other issues

- The title ‘Heart Failure Manual’ was seen negatively by some participants and implies it will be hard work. The manual was seen as ‘chunky’ and difficult to hold for the more sick patients. Perhaps “Managing Heart Failure”?

- Consider adding a glossary of terms.

- List of national organisations, addresses, phone numbers and websites eg BHF, CMA, Age UK (Age Cymru) should not just be in the caregivers book, but also in the main HF manual (this makes sense if we are encouraging the patient to self-manage – with support from the caregiver as and when appropriate/available).

- Could have a facilitator summary sheet to keep track of what has been discussed, the plan and the topics for the next session. (Some facilitators used the research contact sheets for this.)

- Pictures (specific feedback from one facilitator): need slightly more variety of pictures/types of people with more positive expressions. Maybe a different style of picture - less “heavy”, not such thick lines and dark colours. Re the picture on the front of the PT - in some ways it looks positive as though she is triumphal, having conquered HF self-management, but I don’t think her pose is appropriate as we don’t recommend patients do things above shoulder height. She is also very heavily dressed. OK, she looks active, like she’s out for a walk in the winter, but her clothing looks very cumbersome/heavy. It doesn’t look very inviting to go for a walk, dressed like that. Maybe OK if using this in the winter but not appropriate for an all year image. (She appears again, arms aloft, on pg 38 of manual.)

- Ensure consistency of heading sizes.

- Provide more scenarios/testimonies in HFM.

- Provide more information for people returning to work: e.g. being realistic, pacing, legalities.
- Can facilitators have a REACH-HF name/ID badge to wear during their visits

2.3.8 Training

Suggestions include:

Fluid management

- It can be difficult to get the patient to see the difference between weight management for monitoring fluids and weight for dietary management.

Psychological support

- Psychological support was at times a challenge especially when the facilitator felt it was a problem but the participant did not. More practical advice would be helpful especially for patients who experience frequent ups and downs. One facilitator found it helpful to use an example from the participant's life to show when the exercises may be helpful.
- Some topics are particularly 'sensitive' (e.g. sex, finance, end of life), could there be additional training on how to handle these topics?
- Concerns about becoming counsellors where there was disagreement between the participant and their caregiver, or when dealing with sensitive topics.

Exercise

- Swimming: give clear advice to facilitators that they can pass on to patients as appropriate.
- Step counting: reinforce how and why this is done; what is considered a fast pace/maximum step count per minute and what to do once/if a patient reaches it (or is already there at the beginning of the intervention).
- Give clear advice about what to do with patients who are already meeting the exercise recommendations (including goal setting, maintenance, working with those who aspire to return to pre-HF activity levels, and helping those who are at risk of over-exercising).
- In cases where e.g. a patient has a valve problem, their condition is unstable, or seems to be very deconditioned, the facilitator may have concerns about the suitability of the exercise programmes. Is there a need to include something more in the training about clinical judgement/seeking additional clinical perspectives in such cases?
- Include the material prepared by Patrick re ISWT scores and walking plans (Appendix 2).
- Discuss with facilitators 'prescribed' exercise versus exercise plans developed collaboratively/negotiated with the patient. This links with motivation and maintaining changes after the intervention ends. How do the facilitators offer the exercise component of REACH? How is a starting point and plan established? We want to make sure it is offered in the context of sustainable behaviour changes rather than e.g. "something we want you to do (for the research)".

- Reinforce SMART goals in exercise planning. This may mean beginning with only one type of exercise (CBE or walking), with introduction of other types later on as appropriate.
- Consider whether to cover low blood sugar in diabetes and exercise.
- It may be appropriate for the facilitator to walk with the patient or do the DVD exercises with them in some cases, but only if the patient really needs help with this and doesn't have a caregiver. If this is the case, it would be sensible to monitor part of a DVD session rather than the whole thing, or engage in a 5-minute walk (plus warm-up and cool down). If using the DVD: check the patient has a player, that they are confident in using it (or have assistance to do so), and that the DVD disc works in their player.
- Can the use of 'steps per minute' be incorporated into the training as a measure of progression that facilitators can discuss with participants?
- Are facilitators aware of the importance of recovery days alongside exercise days? Check that this is covered in the training.
- Where a patient is already hitting the top end of physical activity recommendations when they join the study, the facilitator can focus on helping them to maintain/sustain this, but it may not be appropriate to try and encourage them to further increase their exercise levels. Too much exercise can be unsustainable and potentially detrimental. Therefore, it is useful for facilitators to have a dialogue contextualising activity and recalibrating exercise behaviour.
- Do we want to include use of case studies/group work into the training about issues that may arise in the exercise component? Would these be part of day 2 (Patrick's session) or day 3 (Jenny Elliot's)?

Medications

- Reinforce key questions for the facilitators to focus on during appointments re medications: whether the patient has an effective system for organising their medications; if they have a basic understanding of why they take them; and what to do if they miss a dose.

Caregivers

- The facilitators need more training on how to support caregivers to look after themselves, as well as the patient. Some encouraged the caregiver to take part in the exercise plan.
- It was a challenge to address the needs of caregivers as this is not part of their usual service. Some caregivers were very engaged with the intervention while others were less so.
- More input on caregiver needs: providing psychological support, managing different emotional reactions, dealing with and addressing their own needs.
- The question "how is (caregiver)?" never seems to lead to much more than "oh, she's alright", so we need some kind of follow-up /probing questions to make sure this doesn't get skated over as is the tendency at the moment - e.g. "could I talk to her briefly?" if on a phone call.
- How to make sure that the facilitators are engaging the caregivers as co-facilitators, including the caregivers in the follow-up sessions and phone calls, and signposting to the CGR? - What to do when there is someone present who has a 'caregiving' role but has not been identified as such by the

patient. How can facilitators raise this issue and (where appropriate) how can they draw the caregiver into the intervention?

In the training programme the caregiver's role should be included in all sessions with specific reference to the action plan.

Social Support

- Encourage facilitators to explore and signpost to the social support section.

Bringing the intervention to a close

- Prepare patients and caregivers for the 'loss' of the facilitator at the end of the intervention period. This may include positively reflecting on (and reinforcing) benefits gained and the developing self-management resources (self-efficacy and self-belief) of the participants.
- Preparing for/noting the approaching end of intervention a few sessions in advance
- Discussion of intentions to keep their level of fitness (or progress further), ideally transitioning to activities that are Routine, Pleasurable or Necessary (RPN) – i.e. sustainable activities.
- Forward planning re. next steps, maintenance and overcoming setbacks (including e.g. getting back after a fall).
- Discussion of challenges /barriers to ongoing exercise and how to overcome them (using Ask-Tell-Discuss and OARS).
- Caregivers could be important for monitoring change and offering encouragement for ongoing maintenance of changes.
- Reviewing arrangements for ongoing health care (e.g. cardiology or HFSN service, GP contacts). Being clear about who the participants could contact once the intervention had ended (including support groups as well as health care services).
- Review of progress and any benefits experienced and inviting participants to reflect on this.
- Review of support in the family /community (including any support groups).
- Discussion of what to do if they have any setbacks (start again building fitness slowly /may need to take a few steps back).
- Review of other plans /goals (e.g. managing sleep, stress, losing weight etc).
- Can close by reviewing things they are looking forward to and leaving the door open for future contact (if appropriate).
- Reinforcing the REACH-HF materials as ongoing reference tools.

Adaptation

- Setting realistic goals can be a challenge especially when the patient wishes to return to how they were several years ago.

General points

- Using real life examples in training: could use some of the good practice examples (e.g. on adaptation) – either play the audio clip (would need facilitator’s permission) or present a transcript – maybe as a “Stop the Tape” exercise – give them the pre-ambule from the transcript and ask them as a group – what might you say at this point? Then present what the facilitator actually said.
- The training is intensive but the facilitators feel they are unlikely to be released for more days.
- How to manage people who are clearly overdoing things /really pushing themselves (most likely in an attempt to get back to ‘normal’) – e.g. 12 hr shifts, large amounts of activity, over-ambitious DIY projects etc. Need to reflect on this /get them to make the connection between overdoing it and poor health – e.g. can ask “what effect does it have on you the next day when you *do the excessive activity*?” and “Can you see a pattern here?” and use guiding reflections (e.g. “it sounds like you are pushing yourself quite hard” – “It sounds like you are trying to get back to the same level of workload as you had before your heart condition started?” “Having read a bit now about what HF is, do you think that is a realistic goal?”). Ultimately they need to work towards acceptance of some limitations now and “find a new normal” as one of the facilitators put it. If they are stuck, could try a bit of re-framing: e.g. "Another way to think about this is if it was your wife or friend who had had a heart attack and come back with heart failure, would you encourage them to (for example) be getting back to work and working 12 hour days and doing shift work?"
- Good to reinforce links between exercise and mood and sleep quality and HF symptoms – they are all linked together. Poor sleep leads to low mood and stress – it also makes symptoms worse, which leads to more stress and worse sleep – it’s a downward spiral. Doing exercises helps reduce stress and improves sleep quality – it can also have a positive effect on mood, so this is a really good way to break the cycle and start making it work in a more positive direction.
- The “doing it for the research” justification was sometimes used to help engagement with the materials e.g. “what we are asking you to do in this project is ... ”. This was not appropriate and needs to be prevented via the training.
- It is excellent practice to take opportunities to reflect on /reinforce positives (e.g. pain subsiding, enjoying work, new hobby) and things people have to look forward to (e.g. holidays, family weddings).
- In terms of discussing future maintenance of self-care (esp. PA), we could include a bit in the Psychology day about the use of relapse prevention /coping planning techniques.
- Develop methods for keeping track of previously identified problems (e.g. sleeping, managing stress).
- How to manage setbacks in health.
- It can be challenging to deal with a variety of presentation styles. One participant and his wife used a ‘jokey’ style when discussing serious issues making it difficult to discern what was, or was not, important to them.
- Referral information could be more detailed: this is being reviewed for the main trial (new outline needs to be incorporated into the training).

- Facilitators do not need to try and cover all the topics in the first session.
- Add 'starter questions' notes (Appendix 1).
- Further develop ask-tell-discuss skills.
- Discussion around number of face-to-face and telephone sessions during the intervention period, and also how much time is spent on these (balancing participant needs with facilitator time, plus providing an intervention that is feasible in terms of time efficiency).
- When a topic has been discussed in a session, reinforce this with signposting to the relevant section in the manual for future/further reference.
- Would a topic guide/checklist/crib sheet be helpful for facilitators for both face-to-face and telephone sessions? This may be a helpful prompt for facilitators whilst not being a 'script'. If yes, is this something offered at the training?
- Emphasise that preparation is vital prior to seeing a patient and/or caregiver. This includes accessing the information provided at point of referral plus any other information the facilitators feel is necessary e.g. results of tests.
- Emphasise that it is good to encourage the patient to use the PT right from the first session in order to become familiar with using it and to make it part of their routine.
- At the end of every session, it is important to summarise what's been covered/agreed and to be clear about any goals (SMART goals). (Consider whether a summary sheet for the action plan of each session would be helpful – for participants and facilitator to refer back to.)
- Examples of good practice and challenging scenarios from the feasibility study can be included in the training. Need to consider whether these will be case studies, transcripts, sections of audio, or other; how many are needed and where they will appear in the training (and training folder).
- Guidance on goal setting – does this need to be increased in the training? If yes, how and where?
- Cover use of HADS with the caregiver as well as the patient.
- How to encourage self-reflective/self-evaluation practice and learning? *To be discussed: will trained facilitators receive feedback from the research team, from peers (e.g. buddying up), or other?*

3. Data collected from patients and caregivers

(Data from April to end of August 2014)

Satisfaction questionnaires: 83% (19/23) of participants (patients +/- caregivers) completed at least one satisfaction questionnaire (representing seven facilitators), and 65% (15/23) of participants completed at least two satisfaction questionnaires.

The responses from a total of 40 post-visit and 9 post-intervention questionnaires have been included in these findings.

Participants are asked to give an overall 'satisfaction' rating of the REACH-HF programme: 84% rated the programme as 'excellent' or 'very good'; 14% as either 'good' or 'satisfactory'; and only one participant rated the programme as 'poor' (their rating increased to 'good' in their final questionnaire).

Table 6: Participant's overall satisfaction rating

(n= 19 participants / 49 questionnaires)

Rating	n=49 questionnaires	%
1=excellent	16	33%
2=very good	25	51%
3=good	4	8%
4=satisfactory	3	6%
5=poor	1	2%
6=very poor	0	0%

The rating from the first and last questionnaires returned by each participant (where available) have been compared (**NB:** last returned questionnaire may not be the post-intervention questionnaire).

The average (mean) number of days between the first and last questionnaire was 56 (median=75, range=0-92).

Table 7: Comparison of ratings of first and last completed questionnaires

(n=15 participants who completed at least two questionnaires)

n=15 participants	First questionnaire rating	Last questionnaire rating
Highest rating	1 (excellent)	1 (excellent)
Lowest rating	5 (poor)	3 (good)
Mean	2 (very good)	2 (very good)
Median	2 (very good)	2 (very good)
Standard deviation	1.14	0.57

(See Appendix 2 and Appendix 3 for full details of satisfaction ratings)

Interview data: A sub-sample of 14 patients and 10 caregivers was purposively selected to provide a range of participants based on: location, facilitator, age, those with and without caregivers, and gender. Interviews were conducted at approximately 6 weeks into the intervention period, and then following the last facilitator contact (at approximately 12 weeks). The findings are based on the 6 week interviews with 13 patients and 9 caregivers and the end of intervention interviews with 13 patients and 7 caregivers (two caregivers were unavailable for the second interview, and one patient and caregiver were not able to be contacted in time for this report).

3.1 Overview

The overall feedback from participants was positive. The facilitators were generally very well received by both patients and caregivers. One caregiver noted that it was a relief to have someone taking an interest in her for a change – not just the patient. Another described how much more confident and reassured she felt having had the facilitator’s input. Several patients commented that they would be sad/miss the facilitator when the intervention ended. It was apparent that a few patients welcomed the social contact from the facilitator’s visits in addition to finding the programme helpful.

Reasons for participating (other than wanting to be helpful to the research) included: wanting to reduce breathlessness; to help slow down deterioration (cough developed and made him realise he was on a “downward spiral”); “what can I still do...what are the dos and don’ts” of living with HF; wanted to find a safe form of exercise (to help with weight loss); hope – a vision of how life could be better. The usefulness of the intervention was felt to be partly determined by how long ago the person had received their diagnosis, what had happened in the interim, and what other support and information they had already received.

Initial reactions to the intervention varied. Two patients with lots of comorbidities said that their heart failure was the ‘least of their worries’ and felt that other aspects of their health needed more input than their heart failure (however both did then go on to engage with the intervention). One patient and caregiver stated that they only wanted a safe exercise programme - and are not really interested in engaging with any of the other aspects of the resources. Another patient said that he was “fairly sceptical” when he first started REACH but could now see the relevance and would continue “putting lessons into practice” once the intervention had finished.

In a very small number of cases, the patient has entered the study with anger and denial about their diagnosis and the proposed self-management. One patient who did react in this way noted that acceptance and managing his limitations have been a key outcome of the intervention. More commonly, patients have noted that they realise their health and wellbeing are ‘in their hands’ and have appreciated the provision of information and also the personal insights they have experienced.

Most patients and caregivers reported that the number and length of facilitator contacts was appropriate and being able to contact the facilitator between sessions (although rarely done) was appreciated.

- One caregiver suggested that the intervention period be increased to 24 weeks with decreasing frequency of appointments over time. She felt this would help people to feel

more supported and reassured in making and maintaining changes. She felt particularly isolated in her role as caregiver and would have liked more ongoing support.

- One patient with a young family felt that the facilitator visits had been too long (the first visit was two hours, followed by two more visits of under an hour each).
- Another patient had known her facilitator for many years and was aware that she had a lot of demands on her time. This patient would have welcomed more than the two visits and three phone calls she received but felt unable to request more.
- One further patient chose to see the facilitator at the hospital (rather than at home). He made five visits to the hospital but did not have phone contact in-between. He said he would have liked to have had the additional phone contact but it was not offered.

Some read the whole HF manual from start to finish and then went back again to read specific sections, whilst others have dipped in and out. The caregiver resource has been used to varying degrees: this is complicated by whether or not the patient and/or caregiver perceive the person offering support as a 'caregiver' and therefore whether the materials will be relevant or not.

3.1.1 Materials and facilitation

Regardless of the extent of use of the written materials, the role of the facilitator has been seen as very helpful to both patient and caregiver. Having someone who can answer questions and give support has also been reassuring. One caregiver noted that, if the facilitator wasn't involved, she would have had concerns about the patient exercising (because he wouldn't pace himself appropriately). Others noted that they looked forward to the facilitator visits and enjoyed her company. There have been no negative comments about the facilitators or about the way they delivered the manual.

NB Comments and feedback from different participants may be contradictory.

Participants particularly liked and commented on:

- Having the programme of support explained at the initial visit.
- The facilitator giving useful information and encouragement on exercise, diet, weight control and relaxation.
- The facilitator giving clear explanations and answering any questions well.
- Being able to discuss any problems and how to improve the situation.
- Facilitator listening as well as giving advice, i.e. patients liked having the opportunity to contribute and ask questions.
- Talking things through in a relaxed atmosphere.
- Phone calls from facilitator between visits.
- Working through the manual in small readable parts.
- Involvement of caregivers and thinking about differing perspectives of caregiver and cared for person.
- Explanation of workings of the heart by the facilitator and in the manual (and the effects of medication on this).
- Setting realistic goals with the facilitator and progressing through the exercise.

- Use of pedometer to monitor walking activity.

Participants particularly liked and commented on:

- Involvement of caregivers in facilitation and thinking about differing perspectives of caregiver and cared for person
 - This included one patient who did not have a caregiver but read the Caregiver Resource to view the condition from a different perspective
 - Reassuring the caregiver that the patient does not need to be ‘wrapped in cotton wool’
- Ways to maintain activity outside of the REACH-HF programme - one facilitator gave information on joining a local gym or health club.
- Facilitator helping to come to terms with the condition and helping to learn “when to rest if I have done too much”.
- Use of pedometer to monitor walking activity. Pedometer was a visual reminder for one patient to continue physical activity. Another participant stated, “As a result (of the exercise programme) I am now walking much further than I was when I came out of hospital.”
- Phone calls from facilitator between visits:
 - Keeping up to date with visits to GP/use of other services
 - Referral by the facilitator to relevant sections of the manual after discussing particular issues
 - Discussed a problem with the facilitator by phone instead of visiting the GP. Facilitator advised when to seek help from GP.
 - Facilitator acted as backup.
 - Motivational and encouraging
 - Helpful advice and guidance on equipment such as rails.
 - Facilitator convinced one patient to use Chair-Based Exercise DVD in addition to the walking programme agreed at meeting.
 - One patient stated that at the end of the intervention the facilitator prepared them to manage independently and trained them to find their own way around the manual with ease and confidence
- At end of intervention, going back over previous concerns and issues discussed and reviewing progress was helpful, as well as encouragement by facilitators to set new goals and use the manual independently.

Specific sections/resources used included:

- Understanding HF
- Quizzes
- Medication
- Salt
- Relaxation
- Stress
- Breathing exercises
- Relaxation CD
- CBE DVD

- Progress tracker
- Recording medications in the PT

Areas which were less liked/disliked included:

- Too much information in the HF manual.
- The manual appears to target a wide spectrum of people: age e.g. some sections (such as work) seem to be targeted at younger people; people who are unfit (“Not fit people like me”). Consequently, it can be difficult to see where one fits in.
- Illustrations on covers and in manual:
 - Mainly focuses on older people
 - Easy to confuse booklets
- Too much information on functions of medications and side effects.
- ‘Living with Uncertainty’ section.

Specific sections not used/not helpful included:

- Medication section: “So what. I’ve read it. I know what pills I take and what they are supposed to be doing, and I assume they are doing it.”
- End of life section and reference to Age UK made it seem like it was focused on older people.
- Managing stress and anxiety (in the PT) – the checklist could be considered personality traits.
- Reading the sections on stress, anxiety and depression can trigger feelings of low mood.

Perceived positive outcomes of the programme:

Having a positive experience of making changes during the intervention (including changes to attitudes and feelings as well as activity etc.) increased their confidence in being able to have a good quality of life while living with heart failure. Both patients and caregivers reported feeling better about the future having taken part in the REACH-HF programme:

“I feel so much more confident about managing my condition and I intend to keep active and keep improving my level of fitness.”

“Having (the facilitator) visit gives me confidence... I feel more at ease about myself now”.

“The facilitator has provided us with the knowledge that we can be positive about the future”.

“We both feel more positive now about what we are dealing with and how to enjoy certain experiences”.

Confidence in being able to maintain changes was generally high: having done it once, people felt confident in being able to maintain/do it again. This included one woman who had a fall prior to the end of the intervention. Although this was a setback to her walking, she was actively problem-solving about how she could restart her exercise programme through using the CBE DVD.

Several patients were aware of improvement in their fitness and/or breathing.

The manuals and materials were seen as being there for ongoing and future reference as required.

After the intervention had ended, several patients were still actively monitoring themselves (including weight and step count) and recording using their own systems (diary/calendar).

Time since diagnosis ranged from a few months to over 10 years. There was a general feeling that the intervention would be most helpful closer to diagnosis, however, those who had been diagnosed for longer noted that it could be a helpful reminder, encouraged new ways of looking at things, and could be helpful for getting out of a 'rut' (both emotionally and physically).

3.1.2 Progress Tracker

The Progress Trackers (PTs) were copied at the end of each patient's intervention as part of their final research clinic visit. Patients retained the original. As at 15/9/14, 19 interventions had been completed and 15 PTs had been copied and sent to the research team (**See Appendix 4 for full details**). The following comments are based on these 15 PTs.

Engagement by a few of the participants focused mainly on using the PT and talking with the facilitator, but not reading the HF manual.

For some, completing the PT initially felt like 'homework' and a burden, however, filling it in became less arduous as it became routine and they determined which sections were most useful to complete.

Overall, the PT was felt to be helpful: "Keeping track of progress helps us to move forward towards our goals... We can't keep everything in our minds so having it on a piece of paper helps."

Completing the PT at the end of the day allowed participants to monitor retrospectively. This seems to be a more common approach than using it as a planning tool (*- however this can be explored in more depth in the final report and when all the completed PTs are available for review*).

The sections most commonly used were:

- My exercise record (15/15) – the most consistently used section with most patients using for the majority of the intervention.
- My weekly progress (12/15) – used consistently by most of the patients but several used sporadically or had gaps in the record. There were a limited number of comments, with the majority simply circling the faces for physical and mental progress.
- My walking speed (12/15) – mixed use: some recorded for several consecutive weeks, whilst others recorded only at the beginning of the intervention. Only one patient recorded walking speed for the whole 12 weeks.
- My weight and symptoms record (12/15) – most patients recorded consistently and for the 10 weeks provided in the PT. Some used this section consistently but did not record daily. One patient added in a table to continue recording for week 11.
- My priorities (9/15)

- My health care (9/15) – in three cases the facilitator had filled in her contact details and this was the only part completed in this section. Other patients included contact details for other healthcare providers too. Only two patients made a note in the ‘cause of my HF’ space and no patients recorded in the ‘specific advice for my HF’ space.
- My medication (8/15)

The sections least commonly used were:

- Managing my stress and anxiety (6/15)
- My appointments (6/15)
- Is it time to have some fun (4/15)
- Traffic light contact details (3/15)
- My questions (2/15)

It is worth noting that no individual patient used all of the sections of the PT. Also, some sections were used but not for the full duration of the intervention.

Noted reasons for not completing the PT included: patient being away on holiday; unable to weigh themselves safely; and having alternative recording systems already in place (e.g. using a calendar for appointments).

3.1.3 Caregiver involvement

The term ‘caregiver’ does not always seem relevant/appropriate to the participants. Alternative terms used include: minder, supervisor, family and friends, and supporter. Participants are in favour of this term being changed and are in support of “family and friends” being used as an alternative.

In addition to feedback about the terminology, there was also a general feeling that roles within a family/marriage/partnership often evolve over time in a more organic and less defined way. Participants talked about their relationship role including aspects of the ‘caregiver’ role but not being defined as such. e.g. “I’m a normal wife...he’s a normal husband – he does his bits around the house and I do mine...I don’t have to take him to the toilet or wash him – that’s what I call a carer.”

Reasons for not using the caregiver resource (CGR) included not identifying as a caregiver, lack of time (especially if working or managing other aspects of the household), and feeling that it wasn’t necessary at this time: “If he was really bad I would, but we seem to be getting on okay.” There was also some evidence of stoicism regarding the caregiver’s own health and wellbeing: “I just get on with it.”

One participant who had read the whole CGR felt that the knowledge and practical skills were helping her to cope better and had given her reassurance: “I’m not so panicky over things now, having taken it and read it”.

The information in the CGR was felt to be easier to understand than information obtained from the internet, however, the information in the CGR can be a lot to take in/remember: “I had to take it to bed and read it, and re-read it, go over things...At early/mid 60s, trying to retain it in our head is a problem...things don’t tend to stay in your mind”.

There are examples of the caregiver taking a lead role in recording in the PT: “If it was up to [patient] there would be nothing written down because he’s not in a good place physically or mentally.” There are also examples of the caregivers using the relaxation techniques and increasing their exercise (either with the patient or on their own).

Caregiver responses to the facilitator have generally been good: they appreciate having someone to talk to, to offer reassurance and support, and also to be something of an ally when supporting the patient: “If I said to do something, he’s reluctant to do it. But if [facilitator] and the book tell him to do something, he does it...It means I don’t have to nag him so much.”

When the patient has low motivation, low mood, or is physically unwell, the caregiver may need more active support from the facilitator: both in the co-facilitator role and looking after their own health and wellbeing. It is important that the caregivers get enough attention from the facilitator, as one caregiver noted: their experience of the facilitator role and REACH-HF programme was “more centred around [patient] – that’s how I feel my life is too.”

3.2 Recommendations based on questionnaire and interview feedback from patients and caregivers, and completed Progress Trackers

3.2.1 Manual and materials

The Heart Failure Manual

- Include more testimonials particularly around relaxation/managing stress and managing changes in symptoms/ups and downs.
- Additional advice for people who are returning to work after a period of long term sick leave.
- - Size of manual could be off-putting/overwhelming/daunting for people who are not used to doing a lot of reading. It may also be difficult/tiring to hold for some people (depending on levels of fatigue, comorbidities etc.). Could the volume of information in the manual be reduced? Or the split into smaller bound sections?
- - Consider providing a 1-2 page summary of the manual for people who don’t like reading – so they can grasp the main points and identify areas for further discussion and information.
- - Ease of navigating around the manual/finding relevant sections could be improved (by adding more tabs).
- - Could the HFM be re-ordered: managing breathlessness, changes in symptoms and fluid balance at the start of part 2, then meds, stress, keeping active, DVD and walking later – so if they do try to read manual from start to finish, they cover other relevant information before trying to tackle exercise.
- - Could the cover of each book be made more different to help with easy identification – the repeated use of the lady in green was confusing.
- - Change images of people to illustrate broader range/less assumptions re older people/more younger people.

- - Repetition in the text – the danger is the patient may think “I’ve read this before” and skip it (but then also miss out on new information).
- - Some errors (grammatical) in the text – leads to potential distrust of the materials. (See Appendix 3 for one participant’s proofreading comments)
- - The technical diagrams could be clearer for those with no/limited previous anatomy/physiology knowledge.
- - Add the traffic light system to the manual.
- - Could there be a section on exercising post-op?
- - Include information for those who have had heart surgery.
- - One participant found the ‘Living with Uncertainty’ section negative (after reading the rest of the manual and feeling that they could get a better quality of life). They suggested this section could go in a separate book.
- - The detailed functions of the medications may not be necessary/may be too long (patients either look at the information leaflet that comes with their medication, or prefer to simply trust their prescription) and could cause anxiety if a patient’s medication is not on the list. Could this be replaced with a simple statement about ‘what to do if you have side effects’? (One example where use of the PT identified where a dose had been mis-prescribed.)

Caregiver Resource

- - Change the term ‘caregiver’ to ‘family and friends’.

Progress Tracker

NOTE: We do not have a complete data set of end of intervention PTs (n=15/23), in addition, different facilitators may have placed differing emphasis on completing the PTs (some requesting that the patient did it ‘to help the research’ and others focusing on the benefit and appropriateness for the individual). Therefore it is suggested that the following recommendations be interpreted within this context.

- Ensure all sections have space for a full 12 week record.
- Review whether to include cause and specific advice in the ‘My health care’ section.
- Consider renaming ‘Is it time to have some fun?’ to e.g. ‘leisure and fun’.
- - Put traffic lights earlier in PT.
- - Add space in the PT to write in the exercise programme starting level.
- - Request for a template of the PT so can continue to use beyond the 12 weeks.
- - One participant said it would be helpful to have a ‘practice week’ to get used to completing the PT.

Pedometer

- - The type supplied can be unreliable and difficult to open. It was appreciated by those who did use it – could an alternative type be provided?

CBE DVD

- If the DVD doesn’t work or the patient doesn’t have a player – could there be written/picture-based instructions for the CBE available as well?

Other issues

- Give an indication of the timeframe for taking part in the research at the outset (including when to expect the first facilitator visit).
- Some sections had a negative tone: end of life and living with uncertainty sections – it was suggested that it could be a separate section for people it is more relevant for. Difficulty in feeling hopeful and positive from majority of HFM and then being 'brought down' by that section.

3.2.2 Training

Facilitator role

- Check time availability, preference, expectations and other commitments with participants before beginning the intervention. E.g. Is it realistic to have sessions that last for more than hour?
- How to make sure that caregivers are involved: both as co-facilitators but also to focus on their own health and wellbeing. Plus ensuring that the caregiver feels involved and supported by the facilitator (so it's not "all about" the patient).
- How to offer the intervention to people with different needs and expectations – helping them to create their own 'bespoke' package from all the different sections in the manual (without getting overwhelmed by the volume of information), and to see themselves reflected in/able to benefit from the materials.

Progress Tracker

- If cause and specific advice in the 'My health care' section is to remain, reinforce in facilitator training re encouraging patients to complete this section (i.e. facilitators help patients to understand the benefit of using it).
- Emphasise in facilitator training the need to complete the contact section on the Traffic Lights page.
- Emphasise that not all sections need to be completed: it is up to each individual patient to identify the most relevant and helpful sections for them. However, we may want to emphasise use of the weight, weekly progress, and exercise records (as a minimum) to focus on – in keeping with the aims of the intervention.

Other issues

- Where a facilitator had another role as HFSN there was potential for some ambiguity at the end of the intervention regarding whether the patient could still contact them or not. This led to some differences in how the facilitator ended the intervention and whether the patient +/- caregiver still felt supported by the same person. This distinction may be worth exploring more/being made more explicit.

- One participant's lifestyle did not allow them to complete the requests in the manual as s/he was also a carer for partner and friends.

3.2.3 Recommendations on the research process

- Some participants reported a long delay between being invited to participate and the first visit from the facilitator.
- Several patients noted that they found the ISWT easier at the second clinic visit as they knew what to expect. Some also believed that they had done better on the follow-up test and this increased their confidence in their fitness gain (- we do not know if this was a perceived or actual fitness increase as the test results are not available). While most gave feedback that the research questionnaires had been okay to complete, a small number of patients +/- caregivers reported that they had found the research questionnaires complex, repetitive or not applicable.
- Several participants noted that they would like some feedback at the end of the study: both their individual outcomes in terms of the fitness test, and also to know more about the outcomes of the study overall.
- Issue where recruited patient had a planned surgery/hospital admission during the intervention period – should they have been eligible?

Comments about the ISWT results from facilitators

- The 1st line: "Unable to complete the test? Y or N" seems to be a double negative, if Y means they were unable to complete the test. Completing a test also implies that they reached the end of level 12. It would be clearer if the Q was "Able to attempt test" Y and N.
- What do the start and end times signify?
- There seemed to be no consistency of the timings written down and what they were timing.
- They varied greatly between tests: once it was the same before and after, a few times it coincided with the no. of minutes which the pt walked, otherwise, the length of time varied. Was this the time the 1st and last HR and BP were taken?
- Not sure why effort was recorded before the test as there is no effort at rest. If they were recording breathlessness before and after, that would be a useful comparison.
- Was the end BP taken immediately after the walk or after a cool-down period? If it was after a c/d period it would be useful to know how long that period was. If it was straight after the test it would be useful to have another HR and BP after a 5 minute c/d to see what their recovery was like. All this helps us to gauge our exercise prescription.

4. Peer Review

The written manual materials were sent to a range of experts for external peer review. Five provided comments, which are summarised in Table 8 below. In addition, one participant (separate document available on request) and one facilitator (**see Appendix 5**) spontaneously sent comments.

Table 8: Reviewer comments on the text of the HF Manual

Name:		
Organisation:		
Section	Page Number	Comments
		Please insert each new comment in a new row.
Understanding HF	18	Need to emphasise the importance of following through with cardiac rehab phase 1 – 3, following procedure. This service is not universally promoted or well managed and in some areas patients aren't always offered rehab and guidelines aren't always followed. At what stage will the facilitator be involved? Can the facilitator play a part in the patient's right to rehab? Some Trusts don't feel rehab is necessary for device implantation or primary prevention procedures. Evidence shows rehab will prevent readmissions in following 5 years. Also worth highlighting the importance of phase 4 as an ongoing lifestyle choice.
Managing Your Condition	23	
Medications	32	Again poor example bisoprolol rarely used bd should be bisoprolol 5mgs once daily
Medications Appendix	120	Captopril and enalapril rarely used these days please add perindopril and consider deleting captopril and enalapril
Medications Appendix	122 and 123	Digoxin use should be relegated to behind diuretics as rarely used in Hf now unless rate control in AF – the order should reflect importance of use, ACEi/betablocker/diuretic/ARB/MRA etc
Medications Appendix	126	Please add apixaban to dabigitran and rivaroxaban
Medications Appendix	127	Isosorbide mononitrate used a lot more than dinitrate
Physical Activity		The manual should emphasis the benefits of Cardiac Rehab, including Phase 4 as an ongoing lifestyle choice

Name:		
Organisation:		
Section	Page Number	Comments Please insert each new comment in a new row.
General		GP's in many localities do not have sufficient training to recognise and treat patients with HF. This is left to consultants in acute services and so it becomes difficult to obtain continuity of care between the GP and consultant. The proposed facilitators will therefore need to be aware of this whilst they offer advice and guidance. For example, my cardiac relationship is with the consultants in the hospital rather than my GP, who appears to do little more than prescribe & manage my medication, including warfarin. Members in our patient community also say it is difficult to obtain information about their treatment from the GP and their decisions are not shared. Information is only shared if patients ask, it is not freely offered. This will not be the case everywhere, but it is an issue that the facilitator should be aware of
General		The manual should emphasis the benefits of joining a support group for all the reasons already stated in my comments
Medications	29	Poor example of medication – 4 x 10mgs simvastatin never used – needs to be “real” e.g. simvastatin 40mgs take one at night – similarly in progress tracker booklet
Salt	113	Lots of controversy around this – ESC HF guidelines based on a recent study do not recommend low salt diets – I think this whole section needs to come out
Comment only		Otherwise excellent but does it differ much from similar manual which I reviewed for York many years ago?

Name:		
Organisation:		
Section	Page Number	Comments Please insert each new comment in a new row.
Caregiver HF Manual	28	Emphasis the benefits of joining a support group. Not all will benefit, but most will. My experience and those of my members evidence a better recovery and quality of life. Sharing experiences and learning about conditions and how others manage their conditions and deal with adversity can be inspirational. It can also be a rich source of information (heart friendly health insurance, DVLA restrictions, hospital stats, benefits, retirement, pensions, hobby clubs etc etc) Carers in particular, have a way of sharing, discussing their needs and learning from how others cope. This provides them with an outlet to reduce stress and improve wellbeing. This is also a social environment and I know many who have developed friendships and confidence to move forward.
Useful contacts		BHF insurance link would be helpful, maybe could be more on advance directives and paperwork involved, info about TEP, EOL issues, Palliative care services etc
Manual	Overview	Really well done – lots of very useful information. What follows is a critique of things that I thought could be improved, but of course it will depend on your patient feedback as that is the most important response.

Name:		
Organisation:		
Section	Page Number	Comments Please insert each new comment in a new row.
	General	First reaction – very heavy! The paper is incredibly thick, was there a reason for this? The side tabs were bent and looked shabby. I thought perhaps the manual could be printed as three separate booklets (similar way to the tracker etc.) that deal with the three sections of the manual. Then the person receiving the manual wouldn't feel that they have a very long and heavy book to read. This may add to the cost, but the paper thickness could be reduced substantially and they would be stapled rather than wiro bound which will lead to savings so the cost may be neutral.
How to use this manual	2	No mention of caregiver resource on this page.
Tabs	General	Not a fan of the pictures on the tabs – but understand this is personal preference.
Manual part1	10	Right column, 3 rd para, 2 nd line: change “speak” to “speaking”
	11	Right column, 1 st para, 10 th line: “ejection fraction” – not explained. Link to page 9 1 st para, and use the actual term ejection fraction there if wish to retain it on page 11.
	12-15 (and elsewhere)	Too text heavy, can this be reduced? Or diagrams added?
	12	Fluid retention/congestion scenario – too long and convoluted, please simplify.
	14-15	The purple boxes don't link well to the text. Can the one on breathing problems just go under the Left column, and move the box on page 15 to the bottom of the right column on page 14.

Name:		
Organisation:		
Section	Page Number	Comments Please insert each new comment in a new row.
Manual Part 2 (self care)	25	Right column, 1 st para (about heart failure): much of this detail is also given elsewhere, so could be précised to make the message sharper.
Taking Medications	28/29	Purple box: should be under the questionnaire to link better. Slight reduction in the space for each line of the questionnaire and around the box message would enable its fit.
Taking Medications	32	Needs a bolder “strike-through” on the first bisoprolol to make it clearer that it is deleted.
Keeping Active	38-39	Detail re exercise to slightly out of breath given 3x on these pages and 2x on page 41 – understand the need for repetition but think this is probably overkill.
Keeping Active	44	Left column, bottom para: reference to table below – but no table.
Keeping Active	40-50	Repeated sections for walking and seated exercise. Can’t they be combined – they say virtually the same thing?
Fluid Balance	57	Bullet point 3: change “you” to “your”
Managing Stress	73-74	Disconnect between the “Managing Demands” section and the suggestions and practical exercises, which are overleaf on page 74– but it wasn’t immediately obvious that these are what was referred to on the previous page. The table interrupts the flow.

Name:		
Organisation:		
Section	Page Number	Comments Please insert each new comment in a new row.
Managing Stress	74	Scheduling. "Get a piece of paper and write three headings..." Which headings? Do you mean the ones on the table at the top of the page, as there is no title to the table? I think the table should be at the bottom of the page rather than the top. And the paragraphs describing the table should be linked – I looked at the different cells and tried to work out what was meant. It didn't immediately click that the vertical cells were referring to the same thing.
Managing Stress	76-77	Link the table directly to Jim McClure, as you seem to be suggesting that gardening is an unpleasant stressful activity, which for many it isn't.
Managing Stress	77	"Why not try this for yourself" – ? "Why not try THESE for yourself"
Managing Stress	77-78	Page 77 finishes with the "Five Rules ..." but turning over you meet the stress management example for the progress tracker (which is referred to on page 77, but doesn't mention there is an example overleaf). The five rules are under the tracker. The linkage is confused, I suspect from the designer not fully understanding which text links to which diagram / table. The Progress tracker stress management section doesn't signpost to this example.
TRACKER	General	This is printed on gloss paper – which is difficult to write on – ball point pens quite often fail, and pencils may not properly mark. This would be better printed on matt paper.

Name:		
Organisation:		
Section	Page Number	Comments Please insert each new comment in a new row.
TRACKER	General	There are lots of different record pages for each week – weekly progress, exercise, walking speed, weight and symptoms, stress and anxiety, fun Can't these be combined into a weekly record page – I suspect that people won't fill in all of the relevant sections, so how will they track progress across different goals/check symptoms?
CAREGIVER resource	General	Loved this.

5. Appendices

APPENDIX 1: Facilitator contact time and number of sessions per case

(n=16 completed cases)

Sorted by Facilitator ID

Patient ID	Facilitator ID	Total number of contacts	Total contact time (mins)	Number of home visits	Average length of visit (mins)	Total time spent home visits (mins)	Number of phone calls	Average length of phone calls (mins)	Total time spent phone calls (mins)
FP1001	1	7	139	2	48	95	5	9	44
FP1002	1	9	289	3	66	198	6	18	91
FP1012	1	8	116	3	32	95	5	4	21
FP1016	1	7	110	3	33	98	4	3	12
FP1014	2	11	579	8	69	553	3	9	26
FP1018	2	11	287	5	57	229	6	12	58
FP1019	2	11	509	5	78	392	6	23	117
FP2003	3	8	398	4	66	332	4	22	66
FP2005	3	6	226	3	58	173	3	18	53
FP2007	3	9	394	4	70	281	5	23	113
FP2011	3	6	352	3	78	274	3	13	78
FP2001	4	8	323	3	86	259	5	13	64
FP2004	4	8	297	3	73	220	5	13	77
FP4003	5	8	446	4	91	351	4	26	95
FP4004	6	8	483	5	82	456	3	11	27
FP4005	6	8	583	6	88	547	2	19	36

APPENDIX 2: Satisfaction ratings for individual participants at first and last completed questionnaire time points*

n=15

Participant ID	First questionnaire rating	Last questionnaire rating	Difference between first and last rating	Number of days between ratings
FP1001	2	2	0	92
FP1002	2	1	1	81
FP1012	2	2	0	76
FP1014	2	2	0	27
FP1018	2	1	1	81
FP1019	4	2	2	81
FP2003	1	1	0	44
FP2005	2	2	0	81
FP2007	2	1	1	80
FP2011	3	2	1	31
FP3002	1	1	0	0
FP4001	4	2	2	37
FP4003	2	2	0	75
FP4004	1	2	1	34
FP4005	5	3	2	21

*Please note: data for participants who had completed at least two questionnaires only

APPENDIX 3: Number of satisfaction questionnaires returned by participants.

n=23

Participant ID	Number of post visit questionnaires returned	Number of post-intervention questionnaires returned	Total number of questionnaires returned
FP1001	2	1	3
FP1002	3	1	4
FP1012	2	1	3
FP1014	3	0	3
FP1016	0	0	0
FP1018	3	1	4
FP1019	5	1	6
FP2001	1	0	1
FP2003	1	0	1
FP2004	1	0	1
FP2005	2	1	3
FP2007	3	1	4
FP2008	0	0	0
FP2011	1	0	1
FP3002	2	1	2
FP3008	0	0	0
FP3009	0	0	0
FP3010	1	0	1
FP3014	0	0	0
FP4001	2	0	2
FP4003	2	1	2
FP4004	3	0	2
FP4005	3	0	1
TOTAL	40	9	49

APPENDIX 4: Progress tracker usage

n=23 (15 returns to date)

ID	Section used: Yes or X (=no/missing)											
	My priorities p3	My questions p4	My weekly progress p5-8	My exercise record p10-15	My walking speed p16	My weight and symptoms record p17-22	Managing my stress and anxiety p23-24	Is it time to have some fun? p25	My medication p27-28	My health care p29	My appointments p30-31	Traffic light contact details p9
FP1001	Yes	Yes	X	Yes week 1-11	Note recorded for week 8&9 (not walking speed)	Yes week 1-10	Yes	Yes	Yes	Yes	yes	X
FP1002	yes	X	Yes week 1-12	Yes week 1-11	Yes week1-12	Yes week 1-10	Yes	X	Yes	yes	X	X
FP1012	X	X	Yes week 1 only	Yes week 1-10	Yes week1-9	Note recorded re one 'steady' weight	X	X	X	Yes (facilitator details only)	X	X
FP1014	X	X	Yes week3-8	Yes week3-11	X	Yes week 1-10 and patient added chart for week 11	X	X	Yes	X	X	X
FP1016	No data											
FP1018	Yes	X	Yes week 1-12	Yes week 1-11	Yes week 2 only	Yes week 1-10 (but not daily)	Yes	X	Yes	Yes	X	X
FP1019	Yes	yes	Yes	Yes	Yes	Yes	X	yes	yes	yes	yes	yes

			week 1-10	week 1-10	week 2-9	week 1-10						
ID	Section used: Yes or X (=no/missing)											
	My priorities p3	My questions p4	My weekly progress p5-8	My exercise record p10-15	My walking speed p16	My weight and symptoms record p17-22	Managing my stress and anxiety p23-24	Is it time to have some fun? p25	My medication p27-28	My health care p29	My appointments P30-31	Traffic light contact details p9
FP2001	X	X	Yes week 1-9	Yes week 1-11	Yes week 1-10	Yes week 1-10	yes	X	X	Yes (facilitator details only)	yes	X
FP2003	No data											
FP2004	X	X	Yes week 1-9	Yes week 1-9	X	Yes week 4-10	X	X	yes	Yes (facilitator details only)	yes	X
FP2005	yes	X	Yes Week 1 & 10 only	Yes week 1&3 (week 10 &11 used for weight and exercise target)	Yes week 1 only	Yes week 1-4 (not daily)	X	Yes	yes	yes	Yes	X
FP2007	yes	X	Yes week 1-7 &10-12	Yes week 1-10	Yes week 1-5	Yes week 1-10	yes	yes	yes	yes	yes	X
FP2008	No data											
FP2011	No data											
FP3002	No data											
FP3008	No data											
FP3009	No data											

FP3010	No data											
ID	Section used: Yes or X (=no/missing)											
	My priorities p3	My questions p4	My weekly progress p5-8	My exercise record p10-15	My walking speed p16	My weight and symptoms record p17-22	Managing my stress and anxiety p23-24	Is it time to have some fun? p25	My medication p27-28	My health care p29	My appointments P30-31	Traffic light contact details p9
FP3014	X	X	X	Yes week 1-3 only	X	X	X	X	X	X	X	X
FP4001	X	X	Yes week 1-10	Yes week 1-10	Yes week 1-9	Yes week 1-10	yes	X	X	X	X	X
FP4003	yes	X	Yes week 1-3 only	Yes week 1-11	Yes week 1&3 only	X	X	X	X	X	X	yes
FP4004	yes	X	Yes week 1,4&7 only	Yes week 1-10	Yes week 1-4 & 8-9	Yes week 1-6 daily, week 7-8 weekly	X	X	X	X	X	X
FP4005	yes	X	X	Yes week 1-11	Yes week 1&3 only	X	X	X	X	X	X	Yes
TOTAL number who used this section at all	9	2	12	15	12	12	6	4	8	9	6	3

APPENDIX 5: Patient information for facilitators

(Comments from one facilitator)

- Once patient has been recruited, provide facilitator with a diagnosis and cause of HF i.e. HF due to IHD or AF, or DCM due to viral illness or alcohol-related, etc . Pg1 of 15 – the classification only gives the degree of symptoms, not the severity of the disease. There is no EF% or other echo findings such as RWMA or valve Dx. This would all be very useful and save us looking through old records of letters or admissions. If they have a device e.g. PPM, CRT, ICD and when implanted and any trigger rates.
- Med history – more detail would be appreciated e.g. form of arthritis, type 1 or 2 DM, when they have had other illness or operations e.g. CABG, or joint replacements, how long they have had symptoms e.g. angina. If any other illnesses are current and if they are receiving treatment e.g. cancer and chemo, or asthma and which inhalers
- How long do they have the accelerometer on for and can we have the results of this. It would be useful again for exercise prescription.
- Med lists and Blood test results. These could also be useful when discussing meds with patients.

APPENDIX 6: Intervention Fidelity Checklist (SUMMARY VERSION)

REACH-HF FIDELITY MEASURE

The rating scale

The six point scale (i.e. a 0-6 Likert scale) extends from (0) where the facilitator did not deliver the intervention element appropriately - either they didn't do it well or didn't do it sufficiently (low fidelity) to (6) where there is the element is delivered appropriately (high fidelity). Thus the scale assesses a composite of both adherence to the intended intervention techniques and the skill of the facilitator in delivering the techniques. To aid with the rating of items, an outline of the key features of each item is provided at the top of each section. A generic description of the rating criteria is given in Figure 1.

Adjusting for the presence of patient difficulties

Adjustments may be needed when patient difficulties are evident (e.g. excessive avoidance or resistance). In such circumstances, the rater needs to assess the facilitator's therapeutic skills in the application of the methods. Even though the facilitator may not facilitate change, credit should be given for attempting to use the intended techniques and demonstrating appropriate /skillful interaction.

Figure 1: The scoring system

Competence level*	Scoring	Examples
Incompetent	0	Absence of feature and /or highly inappropriate performance
Novice	1	Minimal use of feature and /or inappropriate performance,
Advanced beginner	2	Evidence of competence, but numerous problems
Competent	3	Competent, but some problems or inconsistencies
Proficient	4	Good features, but minor problems or inconsistencies
Expert	5	Very good features, minimal problems or inconsistencies
	6	Excellent performance

* The scale incorporates the Dreyfus system (Dreyfus, 1989) for denoting competence. Please note that the 'top marks' (i.e. near the 'expert' end of the continuum) are reserved for those facilitators demonstrating highly effective skills, particularly in the face of difficulties (i.e. patients with high resistance to change; high levels of emotional expression; and complex situational barriers). Please note that there are 5 competence levels but six potential scores.

When rating the item, you should first identify whether some of the 'Key Features' are present. If the facilitator includes most of the key features and uses them appropriately (i.e. misses few relevant opportunities to use them

and delivers them well), the facilitator should be rated very highly. It is important to remember that the scoring profile for this scale should approximate to a normal distribution, with relatively few people scoring at the extremes.

Dreyfus, H. L. (1989). The Dreyfus model of skill acquisition. In J. Burke (ed.) Competency based education and training. London: Falmer Press.

ITEM 1: ACTIVE PATIENT INVOLVEMENT

Key features: The facilitator should encourage the participant to be actively involved in the consultation. The idea is to maximise the participant's autonomy as the main agent of change, developing intrinsic rather than extrinsic motivation, and encouraging her /him to be the person coming up with ideas for improving the situation. However, the participant should not be allowed to ramble in an unstructured way and the consultation should be guided. A collaborative /shared decision-making style is appropriate and the facilitator may share his /her own expertise and ideas (as below). Overall, the participant should be increasingly empowered to take control of her /his self care behaviour. Interactions should be encouraging, respectful and non-judgemental (the opposite of a didactic, telling or persuading style of interaction). The participant should ideally talk for at least half of the time. The interaction should also be *individually tailored* to the patient's specific information needs, beliefs, motivations and barriers. The facilitator should engender a clear sense of warmth, genuineness and empathy (within professional boundaries).

Intervention techniques: OARS (Open questions, Affirmation, Reflective listening, Summaries). Reflective listening may include simple reflections of content but may also be more sophisticated (e.g. amplified reflection; reflection with a twist) and used to direct the conversation or highlight key strengths or barriers. Summaries to reinforce patient choices and acknowledge patient effort are particularly desirable. Individual tailoring of techniques and responses to the individual patient's existing knowledge, skills, current activity levels, needs and preferences are also desirable. The Ask-Tell-Discuss technique should be used to exchange information (e.g. to address misconceptions, or offer helpful new information). The above empathy-building techniques and individual tailoring should be used throughout the consultations - from the initial consultation through action-planning through to review /maintenance sessions.

ITEM 2: ASSESSING THE PATIENT'S CURRENT SITUATION AND NEEDS

Key features: The facilitator should work with the participant to assess the patient's current situation. They should seek to identify ALL of the following over the first 1-2 sessions: Identify and discuss the most important issue currently for the patient, how well are they managing their fluids, how appropriately are they using medications, is there any obvious immediate clinical need, how much stress or anxiety do they have, how much physical activity are they doing, and what other concerns or questions they may have.

Intervention techniques: Facilitators will use patient-centred communication techniques (as above) which may include the Ask-Tell-Discuss and 'tell me three things' technique to explore the patient's current situation.

ITEM 3: FORMULATING AN APPROPRIATE (INDIVIDUALISED) TREATMENT PLAN

Key features: The facilitator should work with the participant to formulate an appropriate treatment plan based on the patient's current situation. This should aim to address (as a minimum) ALL of the following over the twelve weeks

of the programme: What is the most important issue currently for the patient, are they managing their fluids well, are they using medications appropriately, any clinical needs identified, how much stress or anxiety do they have, how much physical activity are they doing, and any other concerns or questions they may have. The treatment plan will be staged over time, aiming to work on a few topics initially and introducing other elements as the programme continues.

Intervention techniques: Facilitators will use patient-centred communication techniques (as above) to discuss and agree what issues to address first and what order to do things in. An element of guiding to ensure the inclusion of clinical priorities (e.g. medication issues, physical activity, psychological well-being) as well as patient priorities may be appropriate. The facilitator will advise the patient (and caregiver if appropriate) to read relevant sections of the manual ahead of their next meeting.

ITEM 4: BUILD THE PATIENT’S UNDERSTANDING OF HEART FAILURE /THEIR SITUATION

Key features: Participants’ ability to make sense of how HF works and how self-care behaviours might influence the course of the illness will be crucial for the success of the intervention as belief in the benefit of the suggested self-care activities will increase motivation to engage in them. The facilitator should elicit the patient’s current understanding of heart failure and seek to build their ‘illness model’ in terms of understanding the Identity, Causes, Consequences, Cure /control options and Timeline^[1] associated with the condition. This process may take several weeks and should be reinforced as the programme progresses.

Intervention techniques: Facilitators will provide the REACH-HF Manual, provide a brief overview of how the manual works and, after assessing the patient’s individual needs and concerns (as above), they will identify some key sections for the patient to read before the next contact, specifically including the Understanding HF section. Facilitators will use patient-centred communication techniques (as above) to elicit and build understanding. This should include the use of the Ask-Tell-Discuss technique and reflective listening to reinforce elements of the patient’s understanding that are factually correct or which predispose towards positive self-care behaviours. They should seek to reframe negative attitudes and exchange information (Ask-Tell-Discuss) to address any misconceptions or to fill any important gaps in understanding. The facilitator will advise the patient (and caregiver if appropriate) to read relevant sections of the manual (including the Understanding HF chapter) to build and reinforce understanding /to address misconceptions. The way HF works should be explicitly discussed and referred back to /reinforced at subsequent sessions when this reinforces perceived benefits of the proposed self-care behaviours.

1. Leventhal H, Nerenz DR, Steele DJ: Illness representations and coping with health threats. In: *Handbook of Psychology and Health*. Volume IV. Edited by Baum AE, et al. Hillsdale NJ: Lawrence Erlbaum; 1984: 219-67.

ITEM 5a: SUPPORTING SELF-REGULATION SKILLS (PLANNING AND PROGRESS-TRACKING)

Key features: The facilitator should agree a verbal plan of action for the following week(s) with the patient. S/he should set this up as an experiment to see how feasible the proposed actions are and whether they help the patient’s situation. He /she should discuss the use of the progress-tracking tools in the HF Manual to keep track of progress and as a way of recording any problems in completing the activities and any benefits that might be associated with the planned activities.

Intervention techniques: The facilitator should encourage (verbal) action-planning and encourage the participant to monitor /keep track of their activities using the progress-tracking tools in the HF Manual.

ITEM 5b: REVIEWING PROGRESS, IDENTIFYING AND ADDRESSING ANY PROBLEMS ENCOUNTERED AND SEEKING TO PREVENT RELAPSE

Key features: The facilitator should work with the participant to review progress with all planned changes and with achieving the behavioural targets set out in the action plan. The facilitator should celebrate and reinforce and reflect on any successes. The participant and facilitator should discuss any setbacks and the patient's plans should be revised.

Intervention techniques: The facilitator should reinforce any self-monitoring activity /use of the progress-tracking tools in the HF Manual and any successes in behaviour change (by giving praise/ using Affirmation techniques). Reframing should be used to normalise setbacks and see them as an opportunity to learn from experience (trial and error) rather than as failures. Problem-solving should use OARS (Open questions, Affirmation, Reflective listening, Summaries) and information exchange (Ask-Tell-Discuss) techniques to identify barriers and explore ways to overcome them. Problem-solving may specifically focus on issues of connectedness (social influences, involvement of others in supporting activities) and sustainability, or on breaking the problem down into more manageable chunks. Goals /action plans should be reviewed and revised if necessary.

ITEM 6: MAKE A SPECIFIC ACTION PLAN FOR PHYSICAL ACTIVITY, BASED ON THE ACTIVITIES SELECTED BY THE PATIENT

Key features: Using the template in the HF manual, the facilitator should work with the participant to agree a written plan of action for engaging in one of the physical activity /exercise options over the following week(s).

Intervention techniques: Making a written action plan, using the planning tool in the manual. The facilitator should ensure that goal-setting is realistic. The facilitator may also employ some problem-solving techniques at this stage to pre-empt and address potential problems.

ITEM 7: ADDRESSING EMOTIONAL CONSEQUENCES OF HEART FAILURE

Key features: The facilitator should help the patient to recognise and address any significant stress, anxiety, anger or depression that is related to having heart failure. S/he should seek to normalise such feelings and help the patient to access and work through relevant sections of the manual. If these problems are severe or prolonged the facilitator should facilitate a referral to relevant care services.

Intervention techniques: Patient centred counselling techniques (OARS) for assessment and exchanging information to build patient's understanding of the situation. Facilitation of cognitive behavioural therapy techniques and stress management techniques contained within the manual.

ITEM 8: ADDRESSING MEDICATION ISSUES

Key features: The facilitator should help the patient to recognise and address any significant problems or concerns relating to the patient's heart failure medications. S/he should help the patient to access and work through relevant

sections of the manual. This might include problems in organising /taking the medications, knowing what to do if they get a cold or forget a dose, identifying possible side effects and seeking help to minimise them, avoiding over-the-counter medications. For some patients, it may include discussing self-titration of diuretics (water tablets) in response to symptoms /swelling (using the Traffic Light plan as a guide).

Intervention techniques: Patient centred counselling techniques (OARS) for assessment and to exchange information to build patient’s understanding of the situation. Facilitation of medication planning /monitoring tools (in the Progress Tracker) and tips provided in the manual.

ITEM 9: CAREGIVER INVOLVEMENT (as applicable)

Key features: The facilitator should engage the caregiver as much as possible as a co-facilitator of the intervention. S/he should tailor the intervention to work with the caregiver’s abilities and availability to provide support to the cared for person with self-management of their heart failure. Facilitators will provide the Caregiver Resource, a brief overview of what it contains, and identify some key sections for the caregiver to read.

Intervention techniques: Person centred counselling techniques (OARS) for assessment and to exchange information to build the caregiver’s understanding of the situation and their ability to support the person with heart failure with their self-management. The facilitator should facilitate a conversation between the patient and the caregiver to agree their roles and responsibilities and how these might change if the patient’s condition declines. Attention should be given to the caregiver’s needs and concerns about being a caregiver /providing care as well as those of the patient.

ITEM 10: ADDRESSING EMOTIONAL CONSEQUENCES OF BEING A CAREGIVER (as applicable)

Key features: The facilitator should help the caregiver to recognise and address any significant stress, anxiety, anger or depression that is related to becoming a caregiver and supporting someone with heart failure. S/he should seek to normalise such feelings and help the caregiver to access and work through relevant sections of the Caregiver Resource. This includes facilitating a referral for a carer’s assessment if the caregiver wishes, plus referral to other relevant care services as appropriate.

Intervention techniques: Person centred counselling techniques (OARS) for assessment and to exchange information to build the caregiver’s understanding of the situation. Facilitation of cognitive behavioural therapy techniques and stress management techniques contained within the manual.

ITEM 11: CAREGIVER HEALTH AND WELL-BEING (as applicable)

Key features: The facilitator should help the caregiver to prioritise and look after their own health and well-being.

Intervention techniques: Person centred counselling techniques (OARS) for assessment and to exchange information to build the caregiver’s understanding of the situation – helping them recognise and manage their own health needs including mental health, physical health, and social needs. This may be a separate conversation with the caregiver alone.

ITEM 12: BRINGING THE PROGRAMME TO A CLOSE

Key features: Progress should be consolidated and reinforced. Plans for long-term sustainability of activities and strategies learned for managing heart failure should be discussed.

Intervention techniques: The facilitator will review progress since the start of the intervention and reinforce what has been learnt. Useful strategies that were helpful should be identified. Plans to stay well /prevent relapse should be discussed as well as 'cues for action' and plans to revisit the manual in the future. The facilitator will discuss plans to sustain any new activities, identifying any potential problems and coping strategies to overcome these. The possibility of good and bad days should be discussed and normalised.

APPENDIX 7: Possible questions for use in the assessment stage of the REACH-HF intervention

Please note that this is not intended to be a 'script', but is just a set of ideas to prompt coverage of the key bases

Some ideas for approaching assessment are as follows ...

1. *"To start with, can you tell me about your situation?"*

2. *"What is your main concern about having heart failure?"*

3. *"What do you know about heart failure - what it is (or how it works)?"*

4. *Assess the "big 4" = physical activity; stress /anxiety; medication use; and managing your fluid balance. Possible opening questions mightbe ...*

- *What do you know about how your physical fitness affects your heart failure symptoms?*

- *What do you know about fluid build-up in relation to heart failure?*

- *How are you (both) coping mentally/emotionally with all this?*

- *What medications are you using? Are you taking them all?*

- *Do you have any concerns about using your medications? If so what are they?*

For the caregiver:

1. *What do you see as your role in all this?*
2. *What is your main concern about the situation /X's heart failure?*
3. *What are you doing to look after yourself?*

It is important to seek to address the patient's main concern from the start. The same goes for the caregiver

OTHER IDEAS

- Provide a brief overview of what the HF Manual is—*it a resource to help you (both) to understand better what HF is and what you can do about it to hopefully improve your situation. My role is to help you to use it to suit your own particular situation and to address your main concerns.*
- Summarise the goals agreed and next steps at the end of the session
- May need to specifically mention /invite talk about low mood (*e.g. do you ever feel down or depressed about your situation?*)

APPENDIX 8: Overview of walking and chair-based exercise programmes for use in the REACH-HF study

A suggested procedure for both programmes is as follows ...

1. Discuss the link between physical fitness and heart failure: Need to make sure they understand why maintaining a basic level of physical fitness is important.

e.g. *“What do you know about how your physical fitness might affect your heart failure symptoms?”* (refer to the text in the manual (pages 38, 39) and seek to reinforce the potential benefits)

2. Explain the aims of the exercise programme:

“The manual has a whole chapter on physical activity – the aim of this section is to help you to build up your basic fitness over the next 10 to 12 weeks and then find ways for you to keep you fitness up in the long term.”

3. Explain that we have a choice of two programmes – one based on walking outdoors and one which can be done at home following an exercise programme on a DVD. *Which of these appeals to you more?*

4. Set a starting point using the table overleaf.

5. Cover the most important principle -*working at a moderate intensity* (see bottom of page 38 in the manual and below¹): In the DVD there is also a “Perceived Effort Scale”.

6. Reinforce the need to warm up and cool down.

7. Encourage use of the Progress Tracker: *“We need a basis for reviewing your progress next time we talk.”*

8. Review progress at each subsequent visit. If their exercise capacity (from the shuttle walk test) is low (less than Stage 7) to start with, seek to build up duration, then focus on building intensity. Check they are monitoring the intensity and doing the warm up and cool down.

9. At the end, discuss how they will maintain their fitness. This could involve keeping going as they are, or doing other (especially enjoyable) activities. It should always involve getting a decent amount of moderate intensity activity each week, as part of their routine. Maybe revisit the reasons for doing this (pages 38, 39).

Using the results from the patient's Incremental Shuttle Walking Test (ISWT) to set a starting point for the exercise programme.

The initial walk duration (excluding warm up /cool down) or the initial level on the CBE programme should be based on the results from the patient's baseline Shuttle Walking Test, as follows. This is a guide only, so please use clinical judgement to adjust for individual circumstances (e.g. you may wish to step down a level or two if the patient reports significant angina on exercise or CFS):-

NB: Please use the second SWT test result to guide your choice.

ISWT Stage	Speed (mph)	ME Ts average	*Proposed CBE level	*Proposed initial walk time
1	1.12	1.75	One (half)	-
2	1.50	2.15	One (full)	-
3	1.88	2.4	Two	-
4	2.26	2.75	Two	5 to 10 minutes
5	2.64	3.5	Three	5 to 10 minutes
6	3.0	3.6	Three	5 to 10

	0 2			min utes
7	3 . 4 0	3.8	Four	5 to 10 min utes
8	3 . 7 8	4.1	Four	10 to 15 min utes
9	4 . 1 6	4.3	Five	10 to 15 min utes
10	4 . 5 4	4.4	Five	10 to 15 min utes
11	4 . 9 2	4.7	Six	10 to 15 min utes
12	5 . 3 0	5.0	Six	10 to 15 min utes
*The proposed level will start patients at around 65 to 70% of their ISWT MET score.				

People who are unable to do the SWT or those with a capacity below 2.5 METS (stage 3 SWT or less) should be steered towards doing the CBE intervention, starting at level one or two.

Progression

Over time, the patient will be encouraged to increase the duration or intensity of exercise by

- Increasing walk duration as effort scores stabilise, working toward 15 to 20 minutes (although recognising that not everyone will be able to achieve this)
- Adding an interval training component to the walking, where a higher intensity (more steps per minute) is interspersed with natural walking speed
- Increasing the DVD level as effort scores stabilise, working toward Levels 5 to 7 (although recognising that not everyone will be able to achieve this)

Throughout, take any opportunities to check and reinforce patient confidence about being able to exercise independently and any perceptions of benefit from the patient (e.g. sleeping better, having more energy).

Maintenance

Once the patient has achieved a level where he /she is walking at a therapeutic intensity for 15-20 minutes three times per week, or has progressed by three levels on the CBE programme (or if level 6-7 on the DVD is comfortable), OR after 10 weeks of engaging with the programme, the facilitator should discuss options for ongoing maintenance of their basic fitness. This will involve either continuing with the walking or CBE programme, or planning of other forms of 'lifestyle based' physical activity that are likely to fit one of the following criteria

- Routine (easy to build in to a routine, such as taking the dog for a walk)
- Pleasurable (including social activities such as joining a walking or exercise group) or
- Necessary (e.g. shopping for food).

Maintenance of physical activity should be monitored by the patient and also by the nurse at the 3-month (post intervention) review /any other post-programme contacts.