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Palliation of heart failure: value-based supportive care

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ABSTRACT

Objectives Heart failure (HF) is a prevalent condition associated with poor quality-of-life and high symptom burden. As patients reach ceilings of survival-extending interventions, their priorities may be more readily addressed through the support of palliative care services; however, the best model of care remains unestablished. We aimed to create and evaluate a cospeciality cross-boundary service model for patients with HF that better provides for their palliative care needs in the latter stages of life, while delivering a more cost-effective patient journey.

Methods In 2016, the Heart Failure Supportive Care Service (HFSCS) was established to provide patient-centred holistic support to patients with advanced HF. Patient experience questionnaires were developed and distributed in mid-2018 and end-of-2020. Indexed hospital admission data (in-patient bed days pre-referral/post-referral) were used allowing statistical comparisons by paired t-tests.

Results From 2016–2020, 236 patients were referred to the HFSCS. Overall, 75/118 questionnaires were returned. Patients felt that the HFSCS delivered compassionate care (84%) that improved symptoms and quality of life (80% and 65%). Introduction of the HFSCS resulted in a reduction in HF-related admissions: actual days 18.3 to 4 days ($p < 0.001$), indexed days 0.05 to 0.032 days ($p = 0.03$). Cost mapping revealed an estimated average saving of at least £10 218.36 per referral and a total estimated cost saving of approximately £2.4 million over 5 years.

Conclusion This service demonstrates that a cospeciality cross-boundary method of care delivery successfully provides the benefits of palliative care to patients with HF in a value-based manner, while meeting the priorities of care that matter to patients most.

INTRODUCTION

Heart failure (HF) is a common condition with progressively poor quality-of-life (QoL) and high symptom burden, often equivalent to metastatic cancer.¹

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Palliative care input is known to offer benefits in symptom control, quality of life, advance care planning and reducing hospital admissions in advanced heart failure patients; however, the optimal model of care is yet to be established.

WHAT THIS STUDY ADDS

⇒ An integrated cospeciality cross-boundary model of supportive care can effectively overcome referral barriers and deliver palliative input in a value-based manner.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This approach may guide future service development and policymaking to extend value-based benefits of palliative care to this and other non-cancer populations.

Palliative care is a relatively new specialty originating through need to improve the suffering caused by cancer; however, as the socioeconomic burden of non-cancer chronic disease escalates, skills of palliative care are increasingly recognised to alleviate suffering for these patients also.^{2–4}

Patients with HF frequently experience a physical and emotional ‘roller-coaster’ resulting from an unpredictable disease trajectory with repeated hospital admissions, creating dependency on acute services by reinforcing cycles of fear and uncertainty.^{5–6} Patients in later stages of chronic disease would instead prefer to feel a greater sense of control with gradual refocusing on enhanced QoL over longevity, improved symptom control and more opportunities to spend time with, and lessen burden on, the people they love.^{7–8} Most people also prefer to spend the last phase of life at home, which is more often achieved if admission is avoided in the months leading up to death.^{9–11} When patients with HF reach ceilings of survival-extending interventions, their

priorities may be more readily addressed through the support of palliative care services.¹²

Despite these advantages, referral rates from cardiology to palliative care have remained low, owing to several referral barriers, including general lack of understanding and education of the role of palliative care; difficult prognostication; apprehension of broaching the subject of palliative care and preconceived views of palliative care predominantly serving patients with cancer or those in the last days of life.¹³

The best model of care, therefore, remains unestablished and value-based service designs that can overcome referral barriers, improve patient experience and deliver care more cost-effectively throughout the whole patient journey, are urgently needed.^{14 15}

OBJECTIVES

To create and evaluate a patient-centred cospeciality service model for patients with HF that better provides for their palliative care needs in the latter stages of life, while delivering a more cost-effective patient journey.

METHODS

The service model

In 2016, a new cospeciality hospital-community service, the Heart Failure Supportive Care Service (HFSCS), was established at the University Hospital of Wales embodying core values of the Cardiff and Vale University Health Board (CAVUHB), including care closer to home; putting patients first and working in partnership.¹⁶ CAVUHB covers a catchment population of approximately 445 000 people, with 350–400 HF admissions each year.

This new model of care centres around cospeciality multidisciplinary team meetings (MDTM) attended by a cardiologist specialising in HF, a palliative care physician, a geriatrician (subspecialising in HF) and clinical nurse specialists in HF and palliative care to discuss appropriateness of referrals; review patient progress and ensure cospeciality expertise is fully integrated into management plans throughout the patient journey.

New patient referrals to the service may be identified through prognostic indicators such as: increasing frequency of hospital admissions; NYHA (New York Heart Association) III–IV symptoms; ejection fraction <30%; hyponatraemia or weight loss >10%.¹⁷ However, expert opinion is taken as the most important determining factor for referral, when anticipated prognosis is 1–2 years of life despite maximum optimised medical and device therapies.^{17 18}

Patients can attend a cospeciality community-based clinic, seeing both specialists together or a parallel clinic accessing both specialities as needed. This model of care is cross-boundary, with patients seen at home visits, during inpatient admissions or when attending other clinics. This approach maximises service contact while reducing unnecessary visits to healthcare settings. If deteriorating

function means attending clinics is too difficult patients are prioritised for home visits or relatively stable patients may be monitored by telephone consultation. The coronavirus pandemic in 2020 restricted face-to-face clinics, nursing home access and home visits, which facilitated an additional opportunity to increase remote-monitoring through virtual platforms and telephone consultations in line with patients' preferences (online supplemental appendix 1).

Fundamental elements of the HFSCS include good rapport-building and compassion-based delivery of care, ideally at face-to-face assessment, where relationships are built more readily and symptom control issues plus factors impacting QoL can be identified and addressed. Involvement and support of the person's loved one(s) are also a high priority. Sensitively exploring understanding of the life-limiting nature of the condition and uncertainty of the disease trajectory/prognosis, while exploring fears are essential elements of communication.

Patients (and carers) are educated that the service model is personalised and responsive to their changing needs, rather than being a rigid structure they must fit into. As patients deteriorate, well-established rapport allows increasing phone monitoring with home visits as needed. Re-empowering patients in this manner ensures economical use of clinical resources and adaptability to an individual's changing condition.

Advance care planning (ACP) is also addressed, but only once there is established trust in the team, a process which is integrated into the model of care at the patient's own pace. This facilitates a compassionate and personalised approach, allowing disease trajectory and modes of death to be fully understood before recommendations regarding ceilings of treatment are explained. Patients are supported to make decisions that are truly in their best interests, which are revisited as needed. Rather than just focusing on completing documentation, ACP is seen as an evolving process of understanding, emphasising rationalising rather than rationing of active management (figure 1).

Establishing patient preferences for place of care/death and wishes regarding avoidance of unnecessary hospital admissions is also essential. Important discussions in advance about modes of death allow patients and carers to feel prepared, so avoiding panic-calling of emergency services. Instead, deteriorating patients are encouraged to alert the HFSCS and community services who may use interventions such as subcutaneous diuretic infusions and anticipatory symptom control medications to avoid unwanted admissions and enabling home-based palliation.

Specialist palliative care unit admission may facilitate some palliative interventions within a community-based setting for example, paracentesis, pleural drainage, iron infusion or occasionally for end-of-life care.

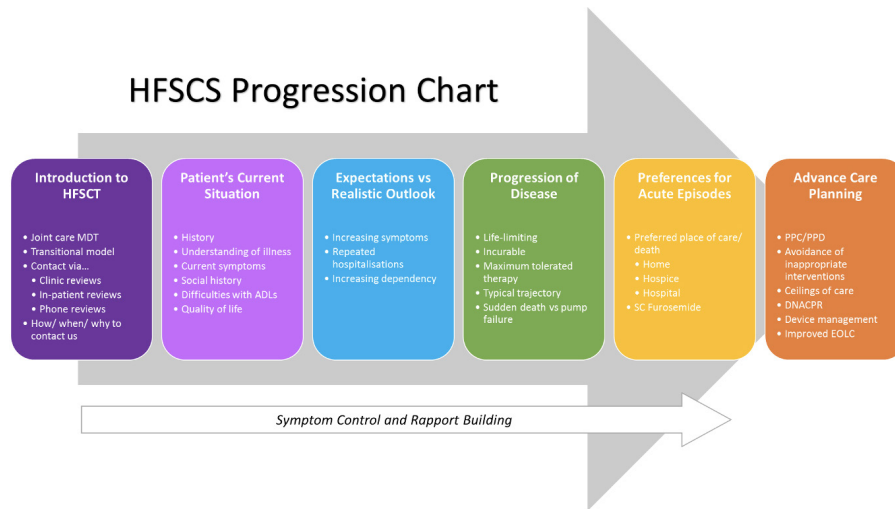


Figure 1 A flow diagram representing the key elements and process of the HFSCS. HFSCS, Heart Failure Supportive Care Service; HFSC, Heart Failure Supportive Care Team; PPC, preferred place of care; PPD, preferred place of death; MDT, multidisciplinary team.

Outcome measurements

Bespoke questionnaires were developed by the HFSCS using patient-reported experience measure (PREM)-based questions (online supplemental appendix 2) because current evaluation tools were found to be inadequate and lacking sufficient fidelity to discriminate QoL and patient preferences in the advanced palliative HF population.

Questionnaires were informed by available amalgamated enquiries from chronic disease patients and thereby more aligned to their needs and priorities and were distributed to patients at two time points: mid-2018 and end of 2020, allowing modification after review by external peers in 2020.^{7 8}

The electronic medical records (EMRs) were used to collect data on all admissions (number of admissions and in-patient bed days) before and after the point of acceptance at the MDTM. In addition, data on the cause of unscheduled admissions (all-cause vs HF-related) were collected for each hospital admission from the primary discharge diagnosis recorded in the EMR.

Service-specific interventions including days spent in the hospice, number of days on subcutaneous diuretic

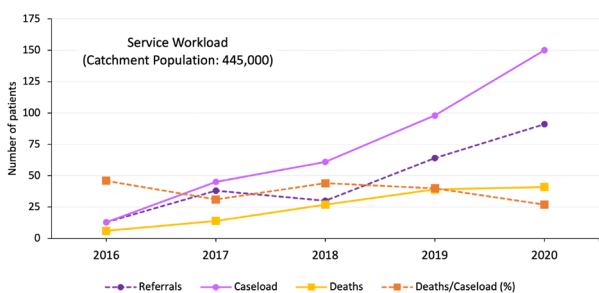


Figure 2 A graphical representation of the evolving case-load of the Heart Failure Supportive Care Service over the first 5 years of the service.

infusion in the community and place of death were also recorded.

RESULTS

Demographics

From 2016–2020, 236 patients were referred to the HFSCS (figure 2): 88 (37%) women, age 80 ± 9 years (range 26–95) and 148 (63%) men, age 79 ± 13 years (range 34–96). Referral source is detailed in figure 3.

Average time under the service was 284 days with 127 (54%) patients dying during the study period. Annual mortality ranged between 27% and 46% and mean interval between time of referral to death was 229 days.

Patient experience

In total, 75/118 questionnaires were returned (20/25 of 2018 cohort), and 55/93 of 2020 cohort (overall response

		Gender		Age	Referral Source				
		Male	Female		HF	Cardiology	Palliative	GP	Medicine
2016 (n=13)	n	6	7	80*	11	2	0	0	0
	*mean								
	% *SD	46	54	11	85	15	-	-	-
2017 (n=38)	n	29	9	77*	29	8	0	0	1
	*mean								
	% *SD	76	24	10	76	21	-	-	3
2018 (n=30)	n	25	5	73*	2	7	0	0	3
	*mean								
	% *SD	83	17	12	67	23	-	-	10
2019 (n=64)	n	41	23	82*	29	19	2	1	13
	*mean								
	% *SD	64	36	8	45	30	3	2	20
2020 (n=91)	n	46	45	80*	49	18	7	9	8
	*mean								
	% *SD	51	49	12	54	19	8	10	9
2016-2020 (n=236)	n	148	88	79*	138	54	25	10	9
	*mean								
	% *SD	63	37	11	58	23	11	4	4

Figure 3 A tabular representation of the demographic variables of the patients under the care of the Heart Failure Supportive Care Service over the 5 years of the service, including referral source.

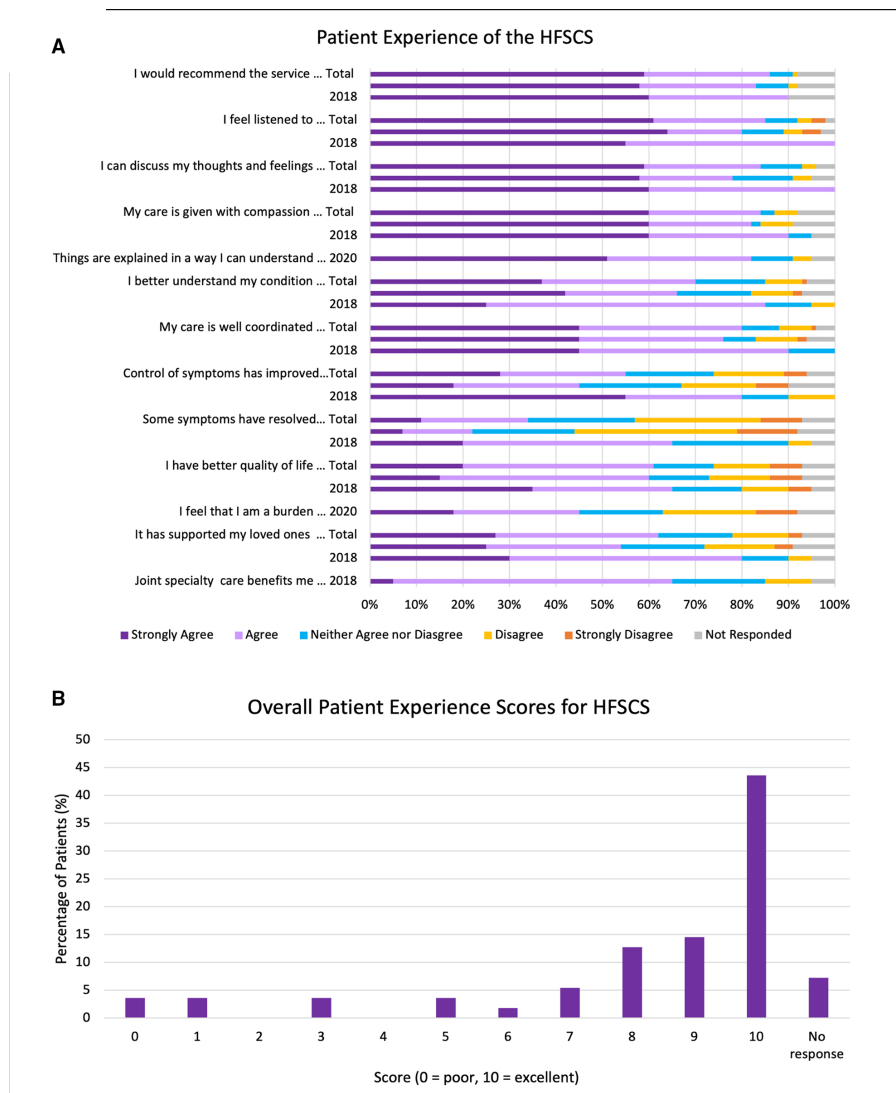


Figure 4 A graphical representation of the patient experience questionnaire responses by theme and year of assessment, including overall responses for themes repeated in both years of questionnaire assessment. HFSCS, Heart Failure Supportive Care Service.

rate 64%). The results of this survey are outlined in [figure 4](#) (A, B) and online supplemental appendix 3.

Hospital admissions and places of care/death

Unscheduled hospital admissions (in-patient bed days) for HF-related and all-cause admission episodes in the 12 months before and after referral to the HFSCS were recorded. As some patients died within 1 year of referral to the service, indexed hospitalisation data (episodes/365 for the 12 months before referral and episodes/days in service until death/end of 2020) were used to allow for statistical comparison pre-referral and post-referral using paired student t tests ([figure 5](#) (A - D)).

Over 5 years, there was a planned admission to the hospice for 23 (10%) patients for an average 3.1 days per patient and 27 (11%) patients were treated in the community with subcutaneous furosemide, averaging 4.9 days per patient.

By 2019, 51% of patients died at home, 10% in the hospice and 39% in a hospital setting, with similar outcomes overall for 2016–2020 (by year referred and year of death: home 49% vs 50%, hospice 8% vs 10% and hospital 41% vs 43%). However, during 2020, there was a change in pattern of place of death compared with previous years (by year referred and year of death: home 18% vs 38%, hospice 0% vs 2.5% and hospice 82% vs 60%) ([figure 6](#)).

In-patient mortality of supportive care patients admitted to hospital during the COVID-19 pandemic (10.2%) was disproportionately higher than in-patient mortality rates observed prepandemic (6.6%). Case note reviews by three clinicians of in-patient deaths (n=25) during the first wave of the COVID-19 pandemic (2020) were undertaken to reach consensus on cause of each death; definite COVID-related (n=2; 8%), probable COVID-related (n=1; 4%), possible

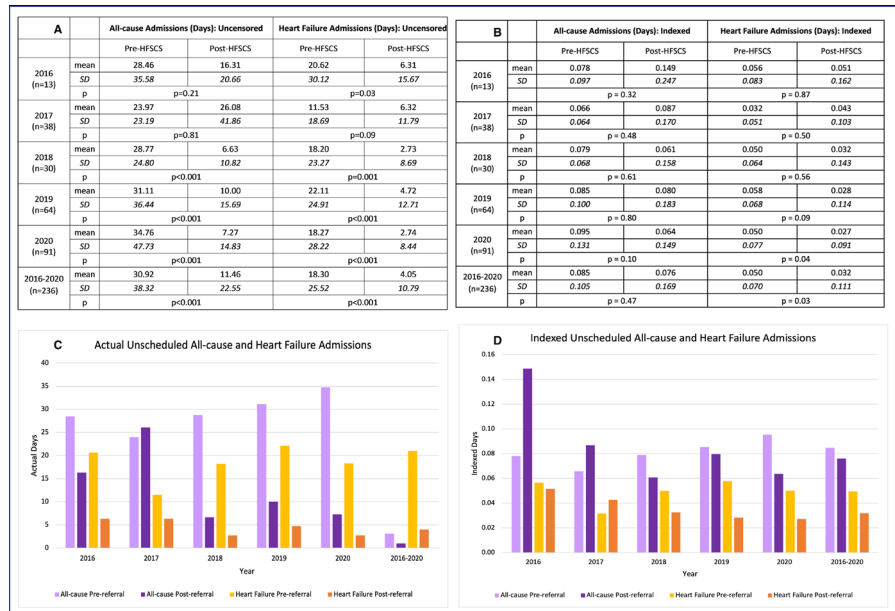


Figure 5 A tabular representation of uncensored unscheduled admissions (both all-cause and heart failure) comparing mean number of inpatient days for patients under the care of the Heart Failure Supportive Care Service (HFSCS) pre-referral and post-referral for each year of the service and overall for the 5 years.

COVID-related (n=11; 44%) and definite COVID-19 unrelated (n=11; 44%).

Resource costings

Resource costings were calculated by mapping a typical patient episode (eg, fluid overload), which would usually result in an unscheduled admission, being instead managed by community-based care under the HFSCS. To evaluate approximate cost savings, calculations were based on mean number of admission days saved per year. Over the 5-year study period, the introduction of the HFSCS resulted in an estimated average saving of at least £10218.36 per referral; however, year-on-year savings have increased, and in 2020, this figure rose to £14109.36 per referral. Overall, it is

estimated that the HFSCS has saved approximately £2.4 million over 5 years, with almost £1.3 million saved in 2020 alone (online supplemental appendix 4).

LIMITATIONS

Although patients described NYHA III–IV symptom severity; their performance, QoL and symptom burdens varied frequently within individuals on a daily or weekly basis making meaningful classification and discrimination of interventions difficult.

Exploration of existing tools to evaluate patient experience of the HFSCS including: Clinical Summary Score of the Kansas City Cardiomyopathy Questionnaire; Missoula-VITAS Quality of Life Index and the EQ-5D score, identified no tool sufficiently discriminatory to evaluate this cohort of highly symptomatic and deteriorating patients robustly.^{19–21} Consequently, original PREM-based questionnaires were designed for survey purposes exploring themes pertinent and central to the service. We recognise this as an unvalidated method giving only an observational overview of patients' views and experiences to qualitatively contextualise other data. We anticipate validation of our questionnaires and consideration of other evaluation methods, such as semistructured interviews, as important aspects of future work.

We also acknowledge that an alternative approach might be a randomised study comparing the new service design with 'usual care', but this would be practically and ethically challenging, hence our choice of study design with acceptance of potential bias. However, we believe that the magnitude of benefit seen here in evaluation of this service is of clinical relevance.

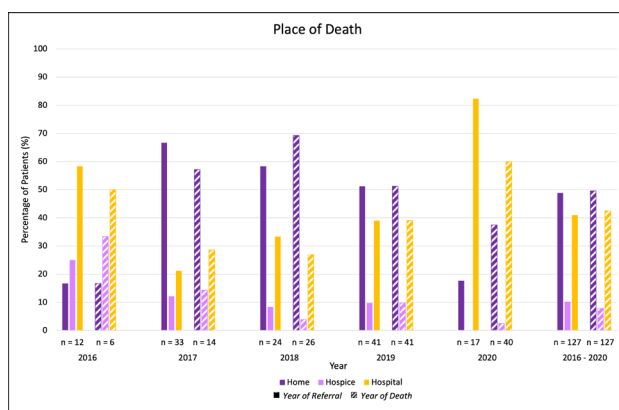


Figure 6 A graphical representation of the place of death of patients under the care of the Heart Failure Supportive Care Service over the 5-year study period, shown as a percentage of all patients for (A—solid) year of referral and (B—striped) year of death.

DISCUSSION

Despite patients with advanced HF often being as symptomatic as patients with advanced cancer and increasing recognition that palliative care input can be beneficial, the service model that can facilitate this most effectively and cost-efficiently remains unclear.¹⁴ This cross-boundary service design demonstrates that highly integrated cospeciality care delivery can successfully provide the benefits of palliative care to patients with HF in a value-based manner, while meeting the priorities of care that matter to patients most.

This model of care was designed to better address patient needs and the high proportion of service users reporting a willingness to recommend the service to others (85%) and rating the service favourably suggest this is being achieved (figure 4(A, B)). Patients with HF experience an inevitable functional decline impacting on their QoL, with emotional comfort, therefore, becoming increasingly important. Recognising the fear experienced by these patients during cycles of frequent admissions and prolonged suffering led us to focus on establishing trusting relationships to support care provision through compassion-based rapport building. This is reflected by most patients reporting feeling listened to (85%), being able to discuss their thoughts and feelings (84%) and perceiving care delivery as compassionate (84%). The value of purposeful use of compassion in healthcare is not extensively studied, but some evidence suggests that this can improve patient anxiety and that a compassionate approach may even improve patient outcomes.^{22 23} It is conceivable that through managing patient fears, improving patient well-being, supporting compliance, reducing symptom-related stress, improving patient mobility and managing depression, there may even be a direct impact on the HF substrate itself.²⁴

Regaining a sense of control is important when facing an unpredictable disease trajectory, which was addressed by improving co-ordination of healthcare provision, increasing patient involvement in their care, educating patients and carers and encouraging patient empowerment in self-monitoring and key decision-making. Effective communication was essential to this approach and is reflected by most patients reporting that things were explained to them in an understandable way (2020, 82%), an improvement in understanding of their condition (70%) and additionally an appreciation of better care coordination (80%). Skilled communication reduces stress during patient-clinician interactions and can thereby help patients with processing of information.^{25 26} In contrast, fear and anxiety can negatively impact on cognition, and studies show that autonomic responses seen in patients during stressful discussions, may be attenuated by clinicians using more patient-centred empathic styles of communication.^{27 28}

Symptom control strongly influences QoL and is an integral aspect of this service.^{29 30} Poorly controlled

symptoms are a constant reminder of illness and reinforce fear. Patients with advanced HF frequently have multiple symptoms including anxiety, breathlessness, pain, depression, fatigue and oedema. These symptoms are among the most difficult to resolve, therefore marginal improvements in as many symptoms as possible must be prioritised.³¹ Patient feedback in 2018 showed good impact on symptom control although this was not fully sustained in 2020, probably as a result of restrictions in face-to-face specialist clinics and home visits (2018, 80%; 2020, 45%). However, despite the impact of COVID-19 on service provision, improvements in QoL were still reported at both time points (2018, 65%; 2020, 60%).

Patients wish to avoid being a burden and by providing increased support to carers, we hoped to ease strain on important relationships. Patient feedback suggests that less than half of the 2020 cohort (45%) felt like a burden yet still the majority recognised the support offered to their loved ones (2018, 80%; 2020, 54%). Patients experience distress when separated from those who matter to them most during unwanted and lengthy hospital stays, which together, with the gradual shift towards greater focus on QoL, gives good reason to reduce unscheduled hospital admissions and avoidance of unnecessary interventions.³² Avoiding hospital admissions also increases the chance for patients to remain at home for end-of-life when this is their wish.¹

Using each patient as their own control prereferral and postreferral allowed evaluation of the impact of the HFSCS on admission rates. Data show a comparative reduction in both actual and indexed bed days before and after referral, with a progressive trend towards significance observed across the 5 years of the service for all types of admission. These benefits have been realised against a background of progressive patient decline, which would typically be expected to increase dependency on acute services.¹⁰ Importantly, since it is well known that these patients have escalating healthcare needs and increased hospitalisations in the last months of life, we believe that the favourable outcomes observed following supportive care intervention are likely to be under-represented.

This model of care also appears to better enable patients with HF to die at home, almost tripling the proportion of home deaths and reducing hospital deaths by up to one-third when comparing 2016 to 2016–2020 overall, with inpatient deaths approximately 50% lower than usual anticipated rates.³² However, growing service demand and expanding caseload over 5 years have likely contributed to an apparent upward trend in the reduced percentage of hospital deaths between 2017 and 2020. Despite these findings, the cost-benefits are still being realised by this maturing service through increasing reductions in hospital admissions and length of stay.

During 2020 (the first year of the COVID-19 pandemic), a disproportionately greater in-patient mortality rate was observed for supportive care patients compared with annual mortality prepandemic (10.2% vs 6.6%). Reasons for these observations are speculative but could relate to restrictions placed on usual service delivery, fears around COVID-19 triggering admissions and reduced availability of primary care. Furthermore, our interrogation of the cause of each death during the COVID-19 period suggests that the apparent increased in-patient mortality during 2020 may in part be due to COVID-19 infection itself in this group of exceptionally vulnerable patients (>50% of deaths either definitely or possibly/probably due to COVID-19 infection).

Embedding of gradual ACP within the patient journey and enhanced patient understanding through compassionate listening and support allows rationalising of care goals helping to avoid unnecessary use of acute services. While the benefits of ACP are not fully established, there is evidence in patients with HF of benefit in QoL, patient satisfaction and quality of communication, although timing of discussions and involvement of family/MDT remains fundamental.³³ Successful implementation of ACP within this model of care has aided reduced hospital admissions and deaths. However, reductions in hospital bed days are not accounted for by an equivalent number of days of community-based subcutaneous diuretic infusions or hospice admissions. This suggests that by delivering care holistically, the HFSCS addresses a multitude of patient needs in various ways, including use of compassionate communication, which has been shown to influence readmission rates in some studies.²³

Effectiveness of palliative care input probably results from several factors, including proficiency in rapport building, expert symptom control, skilled communication and purposeful use of compassion. However, there appears to be additional benefit from a cospeciality approach, with the integration of two specialities possibly offering a synergist effect that is valued by patients (65%). The cospeciality model offers a team approach, mutual learning, improved understanding of fellow specialty expertise and enhanced collaboration.³⁴ Ability of specialities to integrate and work in conjunction with each other seems to offer additional benefits through development of interspeciality trust and respect apparently overcoming several historical barriers of referral to palliative care, as shown by increasing referral numbers. Recasting the model of care as the HFSCS allows referrers' opportunity to perceive the service differently to traditional palliative care provision, which may previously have been seen as only 'end-of-life-care' with limited engagement.

Introducing the service earlier in the disease trajectory, as an additional layer of support alongside the referring team, makes certainty of exact prognosis less necessary. Referral is offered at a time when further

active management options are nearly completed and explained as a refocusing on QoL alongside maximising survival, without compromising either objective. Overlapping care between specialities is especially important, ensuring that expertise of the referring team is drawn on throughout the gradual transitioning towards a more palliative care approach and offering referring teams an experiential understanding of palliative care skills, which may otherwise be too subtle to fully appreciate.³⁴ Furthermore, consistent cardiology input helps support palliative care providers who may be daunted by managing patients with HF alone.

Although increasingly complex management of patients with HF has gradually moved largely into secondary care, cross-boundary working allows expertise to be taken from secondary care back to community, enhancing support of primary care teams caring for advanced patients with HF at home.³⁵ This model of care has been beneficial in facilitating multiprofessional working with gradual widening of referral sources seen over 5 years, including increasing referrals directly from general practitioners, suggesting this service is seen as advantageous (figure 3).

The economic impact of HF is substantial, accounting for 2%–4% of the total National Health Service budget, with approximately 50% of expenditure incurred in the last 12 months of patients' lives. The HFSCS's integrated cospeciality and cross-boundary approach appears to not only address needs of patients with HF more holistically compared with previous best available care but also delivers a more cost-effective patient journey, saving approximately £2.4 million over 5 years (almost £1.3 million in 2020) (online supplemental appendix 4).³⁶

CONCLUSIONS

Everyone at the end of life deserves to experience optimum care regardless of underlying diagnosis. Despite increasing recognition of the advantages of palliative care input for patients with HF, the ideal service model to realise these benefits most cost-effectively has been unclear.^{14 37} This service design shows effectiveness in lessening symptom burden and improving QoL, with responsiveness to the unpredictable, fluctuating disease trajectory of HF. Patients are thereby assisted in achieving meaningful goals, including spending more time with loved ones, avoiding unnecessary time in hospital, easing of carer burden and achieving end-of-life at home. By appreciating what matters to patients most, this approach achieves greater personalised value.

This service evaluation suggests that cospeciality cross-boundary care delivery can overcome long-held referral barriers and successfully provide the benefits of palliative care to patients with HF in a cost-effective and value-based manner. The essential elements of this approach are likely to include cospeciality working, re-empowering of patients to work in partnership,

specialist palliative care skill and a compassion-based approach. However, the extent of overlapping cospeciality involvement and integration, throughout the entire patient journey, likely underpins the observed outcomes of this model by offering synergistic benefits. This model has increased scalability by avoiding need for specialists to adopt expertise of a second speciality.

Correction notice This article has been corrected since it was first published. The open access licence has been updated to CC BY.

Collaborators N/A.

Contributors All authors (CA, SH, IJJ, JP, LR, VMFS, ZY) were involved in the development of the new service (led by CA and ZY) and provision of care to patients under the care of the Supportive Care Service. All authors were instrumental in the subsequent generation of data over the 5-year study period. The manuscript including analyses and presentation of data was prepared and revised by CA, IJJ and ZY equally. All other authors (SH, JP, LR, VMFS) reviewed the paper and advised on amendments resulting in the final copy of the manuscript as published. CA is the guarantor author.

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Competing interests All authors have completed the Unified Competing Interest form (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years, no other relationships or activities that could appear to have influenced the submitted work.

Patient consent for publication All patients that participated in this project were fully informed and consented with regards to ongoing evaluation of the service during their period of care.

Ethics approval This is a service evaluation and does not require ethical approval exempted this study. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All participants are aware that the results of this project would potentially be published, quoted presented and be made publicly available. N/A.

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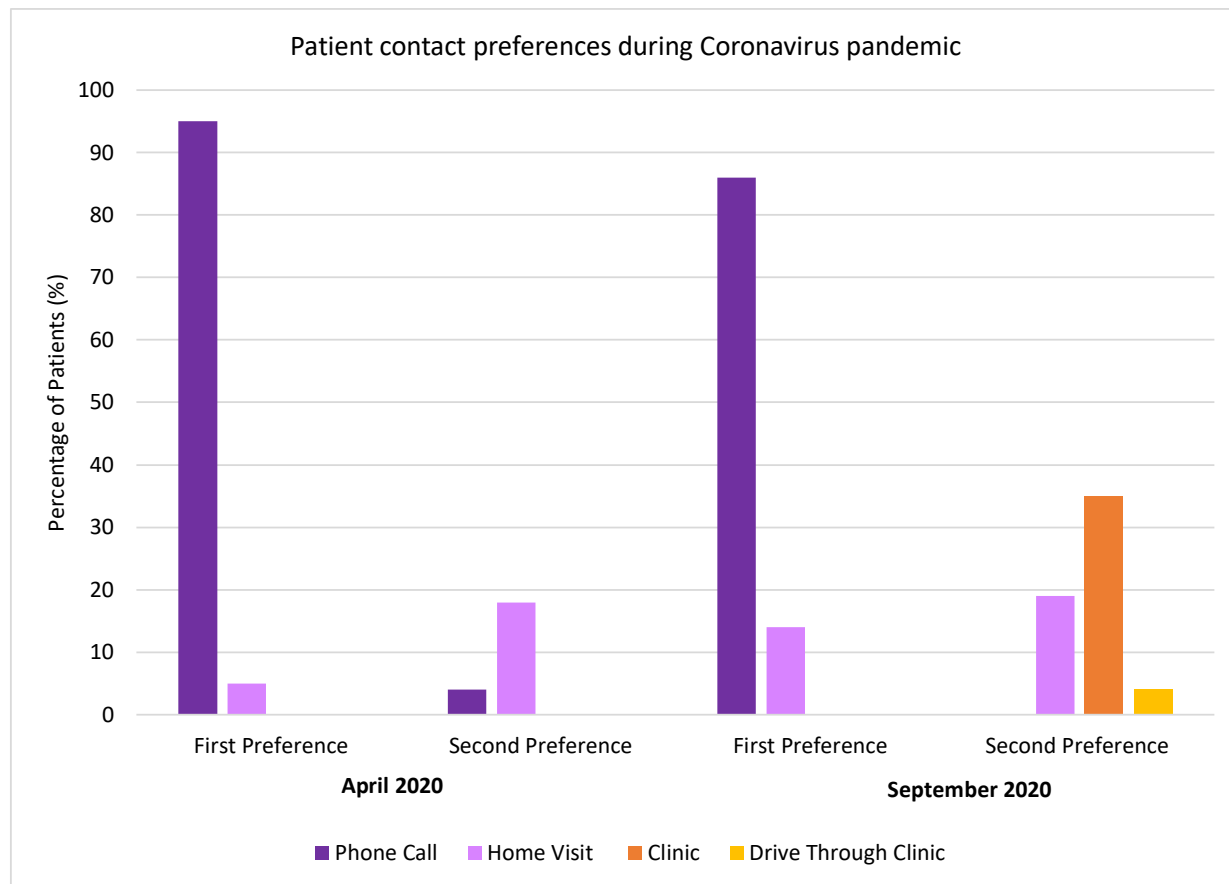
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Appendix 1 – Patient contact preferences during Coronavirus pandemic



Appendix 2 – Patient Experience Questionnaires

2018 Questionnaire

HEART FAILURE SUPPORTIVE CARE FEEDBACK QUESTIONNAIRE

Please tick the box that best reflects your thoughts and feelings about the statement.

This may be completed by a carer on behalf of the patient.

I am the patient I am the patient's carer

1. Some of my symptoms have resolved since the Heart Failure Supportive Care service has been involved in my care.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

2. The Heart Failure Supportive Care service has not improved the control of my symptoms at all.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

3. The information provided by the Heart Failure Supportive Care service has improved my understanding of my heart failure.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

4. Attending the clinic has in no way improved my quality of life.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

5. I feel able to **discuss** my thoughts and feelings with the Heart Failure Supportive Care team.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

6. I do not feel my thoughts and feelings are **listened** to by the Heart Failure Supportive Care team.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

7. I feel this service has improved the co-ordination of my care.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

8. The service helps to support my family and carers.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

9. The clinic is difficult for me to access.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

10. The Heart Failure Supportive Care team delivers compassionate care.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

11. Having both supportive care and heart failure clinicians involved in my care is not beneficial to me.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

12. Have you received subcutaneous infusions of Furosemide at home?

Yes No

If yes, please answer the following: How would you rate this element of the service?

Excellent Good Neither good or bad Poor Extremely Poor

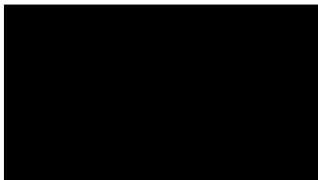
Comments?

13. I would recommend this clinic to other patients in my position.

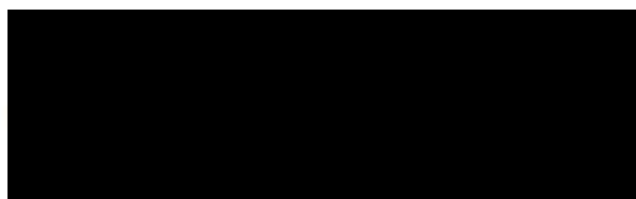
Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

14. Any further comments?

Once completed please return the questionnaire using the pre-paid envelope. If you have lost the envelope, the address is as follows:



2020 Questionnaire



Supportive Care Service Patient Experience Evaluation



PLEASE TICK ONE BOX FOR EACH QUESTION	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I would recommend the Supportive Care Service to someone with the same condition	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
The Supportive Care clinic is easy to access	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
The time between appointments is suitable	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I feel listened to during my appointment and/or home visits	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I feel well cared for by healthcare services in general	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I feel the care I receive is given with compassion	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
My care is well coordinated	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
The Supportive Care team have helped me to better understand my condition and what is happening in my care	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I feel able to discuss my thoughts and feelings at my appointments	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Things are explained in a way I can understand at my appointments	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
My overall understanding of my condition has improved	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I am involved as much as I want to be in decisions about my care	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I feel that I am a burden on my family/carers	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
The Supportive Care service has helped support my family or caregivers	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
The overall control of my symptoms has improved	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Some of my symptoms have fully resolved	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
I have a better Quality of Life as a result of input from the Supportive care team	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Using a scale of 0 – 10 where 0 is very bad and 10 is excellent, how would you rate your overall experience of the Supportive Care service so far?

0	1	2	3	4	5	6	7	8	9	10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very Bad					Average					Excellent

Is there anything particularly good about your experience that you would like to tell us about?

How could the Supportive Care service be changed to improve your experience?

If you felt the time between contacts with the service is unsuitable, please can you explain why?

Many thanks for taking the time to complete this questionnaire.

Best wishes



Appendix 3 – Patient Experience Questionnaire Free Text

2018 Questionnaire Free Text Responses

Any further comments?

- My heartfelt thanks to [the team]. The care my husband received was quite humbling to witness. Of all the aspects of his care you guys took the time to listen, to explain and to care. Thank you.
- It's not the drugs or the treatment that make it worthwhile, it's the staff. The interest they take in all patients, the support given and the humour and light-hearted atmosphere in clinic. It's a pleasure to attend.
- At the heart support/ palliative care clinic I have been able to discuss my concerns and fear about my health conditions with dedicated and empathetic clinicians who listen and helped to alleviate pain in my spine and legs with medication and they explained so much of the things I was worried about. I am grateful for their help. While I have been attending this clinic my condition changed and I was nauseous and vomiting daily. The team managed to help with this to control my sickness. My GP had said there was nothing he could give me because of the medications I was on. I am so pleased for all they have done for me at the heart failure support team.
- The service had made all the difference. My husband had responsive, co-ordinated, timely and co-operative care from the team. It is a great relief to me that my husband's death was comfortable and dignified. The knowledge of this will help me to accept his passing without trauma. I cannot thank [the team] enough.
- The doctors and nurses of this service are of much more importance to them as a patient than could be expressed buy the box ticking questionnaire. Contact by telephone always brings support and help. To know they are there is like having a reliable, knowledgeable, loving friend. This help is making my remaining days of life easier and less daunting than otherwise.
- I am not aware of any co-ordination between cardiology, GP surgery and palliative care team. But this supportive care teams clinics provide some comfort.
- I suffer from AL amyloidosis and have stage 3 heart failure, so I feel this is the norm, but this service has helped me.
- [The team] have been very supportive and helpful. The improvement in my quality of life has been tremendous. Although there is not cure the improvement in how I feel is marvellous.
- I am very grateful for the service provided. Thank you.
- It took a little too long for the [furosemide] infusion to be fitted which was frustrating and almost catastrophic! Once fitted care was excellent. The care provided by individuals involved has been exceptional in terms of their professionalism and personal care.
- My only criticism of the service is that they do not seem to use the main hospital compute system so that my letters are incorrectly addressed with the wrong spelling, and that letters from the consultant/ nurse do not seem to get to my GP, so that changes on my medication are not recorded.
- Once I go on the driver at home it does make an excellent improvement, nurses are always on time and always give a good service. Even though I had different nurses they have all been good. [The team] are always there when you need them. They are out the same day and will sort you out within hours. They work hard between them.
- Furosemide not mentioned
- Before seeing the heart failure team I was ready to give up. I almost sat back waiting to die. But they helped me understand how to deal with it and want to live.

*2020 Questionnaire Free Text Responses***Is there anything particularly good about your experience that you would like to tell us about?**

- Quick response from any telephone message left. Excellent rapport with [the team].
- When seen helpful and very easy to chat to. I don't ever like to complain about being unwell I just dislike talking about myself and just try to get on with it.
- The information given on my condition and advice given was really helpful.
- [The team] does listen with a sympathetic ear and does do [their] best to solve any problem I have sometimes even if it is only in the shape of a referral the referrals appear to work.
- If I've got a problem one phone call and the ball is rolling straight away to solve my problem. It could be a home visit arrange bloods but I know it is taken care of for me and I don't need to worry.
- I felt abandoned. Now at least I feel someone is listening!
- [The team] have been excellent to all my needs and are very supportive to my wife.
- Since the team have supported my mum her health has greatly improved. Thank you.
- I have not experienced supportive care.
- The level of care and genuine interest in me as a patient and as I was before my heart went wonky!
- Friendly, supportive and made me feel at ease.
- The experience my husband has had from [the team] has been a blessing. I don't know what we would have done without [them]. In fact they have become more friends and very easy to speak to. They are a credit to the heart failure clinic.
- I have the utmost appreciation of the care team; particularly [the team member], who has visited me at my home, many times. Thank you!
- Stop pain feet hands
- Not being admitted again after 5 days of being released after pneumonia. Only being in hospital for 3 days with pneumonia!! Then being told she had only months to live at the time my wife was at her lowest.
- Referred to this clinic around March? Feeling a lot better had home visits from [the team]
- [The team] always listen to me and "think outside the box", suggesting things to improve my quality of life.
- Being able to talk to someone who listens to you.
- One thing I would like to tell you is the way [the team] always seemed to find the time to explain things in simple terms for my benefit and for that I will always be grateful. It has helped me better understand my condition.
- The nurses are very caring and listen to me problems.
- [The team member] of all the others was very, very supportive. [The team member] was excellent contact to have.
- My husband is now in palliative care at home, thank you.
- I have only had one appointment – very satisfactory discussion – followed up concerns about my parkinsonism and have an appointment at the end of the month.
- Before COVID the service and support was excellent. The staff and consultants were very caring and supportive. COVID put a stop for most of this although contact was still possible by phone, so I'm very grateful for that.
- Happy with all care.
- I always feel much better after contact and my wife feels the give her information/ support when needed
- [The team] were very kind gentle and supportive
- Having care provided at home and an easy way to contact the team for help has been and continued to be invaluable
- No continuity
- I find everybody very caring
- Very responsive to issues. Well supported and excellent access to medication which has been very lacking at GP level (poor access to GP during pandemic)
- I have not sent back as I do not remember having any particular support from a support team. I did have help from hospital for a few weeks with care and dressing and preparing meals but no other support.

How could the Supportive Care service be changed to improve your experience?

- Be available.
- Not too sure what the situation would be should I require support for my husband after 18:00hrs or on weekends. Need more information re: O.O.H.'s support.
- I don't think it can.
- Could they provide either a small dog or a good looking chap about 35 who likes older women - I'm only 80!
- In my husband and I experience we would like to see the heart failure clinic open at weekends on a rota basis (i.e.) Sat / Sun. We had an experience one Saturday morning when my husband didn't feel well and I was at a loss who to phone, eventually I spoke to a doctor who didn't know my husband's history which was very scary. If the heart failure clinic had been there we would have been reassured and the situation sorted. I think with the world moving in 7 day week in all aspects today we both feel there is a need for this clinic, not just for us but for all the heart failure patients - thank you.
- It's rather a long way to walk to the clinic (and e.g. to x-ray, phlebotomy) and I don't like to use a wheelchair.
- I'm not sure.
- In my case - none.
- I can't think of anything to be changed at the moment.
- Contact with the supportive care service has stopped. No contact has been made to check on current status. Staff are very good but not maintaining contact with me at all (commented no appointment for some time/ 2 years on front of sheet).
- I would like the service to return to pre-covid excellence and one to one contact resumed.
- More money.
- Only if they could wave a magic wand!
- A separate session for my family to understand more about palliative care and end of life.
- Very happy with current care.
- Continuity of care, no regular contact. I've initiated the contact 3 visits. No follow upon bloods tests. No phone calls as scheduled.
- The clinics are too far from the entrance from someone with limited mobility as I have at the moment. The waiting time to see the cardiologist at heath was so long I almost gave up as my wife was waiting parked up in the heath park for two hours by that time.
- More frequent appointments would be appreciated.
- I always enjoy having a coffee and chat with the carers.
- It's OK.
- Access service nearer to home. Helped when clinic was at hospital more local to home.

If you felt the time between contacts with the service is unsuitable, please can you explain why?

- Always on annual leave.
- We talk through the contact times, it suits us both. I know that support and advice is available during the day time, I do wonder about O.O.H.'s support.
- I know I can contact team easily if I need to. Thank you.
- I've not had a problem.
- Knowing that contacts between apps is possible all has been great and I try to keep everyone happy!
- Too infrequent.
- I am visiting the clinic on a monthly give me more confident knowing I am being kept an eye on with genuine care.
- I would like to be seen more often.
- For me the 3 months between appointments was reassuring and I felt I was being kept safe. Now that we seem to be beating COVID I hope we can return to this.
- I'd love to have more regular contact but I do realise they do have other patients to support – many probable in much worse states than I.
- Is it once a month, once every two months or only if you ring. No-one reads the notes that include the surgery. ???
- Seeing someone more often would boost my confidence.

Appendix 4 – Costings Overview

Patient perspective		Home based treatment		Return to oral medication if stabilises	Process costs per patient
Supportive Care CNS			Supportive care patient monitoring/regular telephone review/home visit /cross-boundary co-ordination		(£34 x 3) + (£34 x 14.25 x 0.25) = £223.13 (2020: add £34 + (£34 x 7 x 0.25) = £93.50)
Supportive Care Consultant		Phone call from patient	Medical assessment and prescribing of s/c infusion	Phone call to DN team	(£115 x 1) + (£115 x 7 x 0.25) = £316.25 (2020: add £115 x 4 x 0.25 = £115)
GP/GP OOH					£100.00 x 1 = £100.00
District nursing team		Clinical decision for home management	District nurse assessment/set up s/c	District nurse home visit e.g. to replenish s/c diuretic infusion/monitoring/increased care if patient deteriorating	(£23.00 x 1) + (£23.00 x 14.25 x 0.5) = £186.88 (2020: add £23 x 0.5 = £11.50)
Cardiology Consultant				Cardiology advice x 1 per week	£115.00 x 2 = £230.00 (2020: add £115)
Blood lab teams/phlebotomy				Blood tests x 2 per week	£14.00 x 2 = £28.00 (2020: add £14)
Community Palliative Care				Communication to make CPCT aware in case of deterioration OOH	£34.00 x 1 = £34.00 (2020: add £34)
Hospice at home carers (double-handed)				Optional carer double-handed input from Hospice at home team bd e.g. if patient is deteriorating	£23 x 2 x 0.5 x 7 = £161.00 (2020: add £23 x 2 x 0.5 x 4 = £92)
Resource costing per average patient episode (home based management):					
2016-2020: 19.46-day episode of home-based care (inclusive of 14.25 days treatment of fluid overload) =					£1279.26 (2016-2020)
2020: 27.49-day episode of home-based care (inclusive of 15.53 days treatment of fluid overload) =					£1754.26 (2020)
Total estimated overall cost savings:					
2016-2020: (£11 497.62 - £1279.26 = £10 218.36) x 236 referrals =					£2 411 532.96 (2016-2020)
2020: (£15 863.62 - £1754.26 = £14 109.36) x 91 referrals =					£1 283 951.76 (2020)

Patient perspective		Hospital admission		Return home	Process costs per patient	
Heart Failure nurses					£34 x 1 = £34.00	
Cardiology/Gen Med Consultant		Phone call from patient	Home review	Liaison between patient/HF team/GP/PP team/paramedics	Senior review/plan/ward round reviews	(£115.00 x 1) + (£115 x 0.5 x 10) = £690.00 (2020: add 4 x 0.5 x £115 = £230)
GP/GP OOH					Clinical decision to admit	£100.00 x 1 = £100.00
Ambulance service					Ambulance transport	£250.00 + £30.00 = £280.00
Junior doctors					Ambulance transport	£26 x 1) + (£26 x 19.46 x 0.5) = £278.98 (2020: add 8 x £26 = £208.00)
Bed day costs (including nursing path/radiology/path/overheads)					Junior doctor assessment/daily review	19.46 x £474 = £9224.04 (2020: add 8 x £474 = £3792.00)
OT/physio/Social workers/discharge planning team					Pharmacy assessment/daily review	(£29 x 3) + (£34 x 7) + (£29 x 1) + (£34 x 3) = £456.00
Pharmacy					Admission/regular blood tests	(£40 x 1) + (£40 x 0.25 x 18.46) = £224.60 (2020: add £40 x 0.25 x 8 = £80)
Phlebotomy						£14 x 15 = £210.00 (2020: add £14 x 4 = £56)
Resource costing per average patient episode (inpatient-based management):						
2016-2020: 19.46-day episode (inclusive of 14.25 days treatment of fluid overload) =					£11 497.62 (2016-2020)	
2020: 27.49 day episode (inclusive of 15.53 days treatment of fluid overload) =					£15 863.62 (2020)	