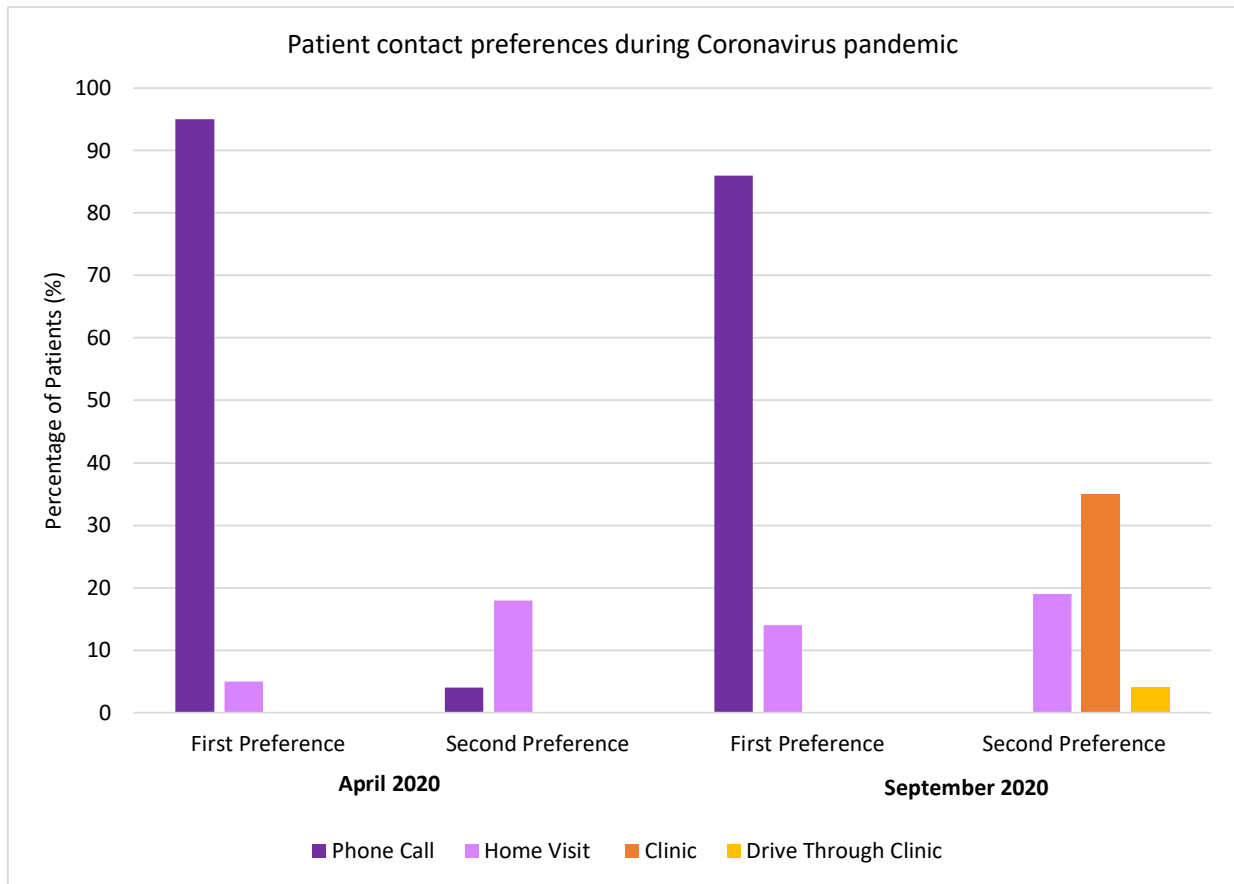


Appendix 1 – Patient contact preferences during Coronavirus pandemic



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

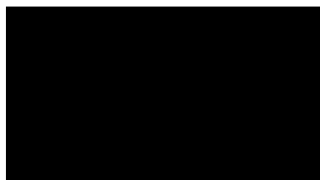
Comments?

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

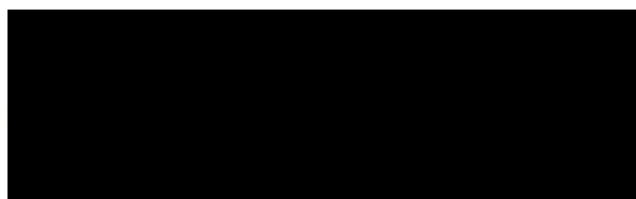
- Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

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/FP team/paramedics	Senior review/plan/ward round reviews
GP/GP OOH				Clinical decision to admit	(£115.00 x 1) + (£115 x 0.5 x 10) = £690.00 (2020: add 4 x 0.5 x £115 = £230)
Ambulance service				Ambulance transport	£100.00 x 1 = £100.00
Junior doctors				Ambulance transport	£250.00 + £30.00 = £280.00
Bed day costs (including nursing path/radiology/path/overheads)				Junior doctor assessment/daily review	(£26 x 1) + (£26 x 19.46 x 0.5) = £278.98 (2020: add 8 x £26 = £208.00)
OT/physio/Social workers/discharge planning team				Pharmacy assessment/daily review	19.46 x £474 = £9224.04 (2020: add 8 x £474 = £3792.00)
Pharmacy				Pharmacy assessment/daily review	(£29 x 3) + (£34 x 7) + (£29 x 1) + (£34 x 3) = £456.00
Phlebotomy				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)
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)