St Christopher's Cardiovascular Project: April 2023- October 2024

Funded by The Burdett Trust for Nursing

Aims of this project:

People living with and dying from heart failure have a high symptom burden. Based on previous pilot work in one borough, we demonstrated that we can improve access to palliative care and improve outcomes for patients and carers by integrating care across heart failure (HF), general practice and palliative services, and working more effectively across the hospital community divide. We demonstrated reduction in hospital bed days and ED attendances but also an improvement in patient-reported outcome measures despite having a declining health trajectory. [1,2,3] As a result of this work community HF nurses were commissioned and the service continued to run for Bromley.

Currently there is inequity of access to services, and different experiences between those living with Heart Failure with reduced ejection fraction (HFrEF), and those with preserved ejection fraction, right-sided heart failure or valvular heart disease. We recognised from the start that this leads to a very different and challenging approach to their engagement with and experience of healthcare services.

This project aimed to progress further on this work: to continue to explore the benefits of an integrated service, bringing palliative care and heart failure closer together, working collaboratively. But it also aimed to expand, serving a wider catchment area by developing the service in Croydon: an area with a very different demographic, both in terms of ethnicity and socioeconomically.

We wanted to introduce an outpatient infusion service, enabling improved choice for people about how they want their treatment delivered when they have periods of instability.

Whilst having a dedicated heart failure palliative care specialist in both boroughs allowed for the collaborative working, we wanted to ensure that a wider community of health care professionals could come together to learn from each other's experiences and grow together, exploring topics such as symptom control, recognising the uncertain trajectory of heart failure outcomes and the role that palliative care has to play in their patients' journey.

Key Achievements:

We have:

- Continued to run and grow the HF service for Bromley, working closely with the HF team, attending multidisciplinary meetings (MDMs) and working jointly across providers.
- Built a new service covering the borough of Croydon, integrating into their cardiology/HF services, building new relationships and supporting one another. This includes joint visits,

both with internal staff and external professionals, bridging the gap between palliative and HF care.

- Supported 246 patients and their families over an 18-month period across both boroughs.
- Engaged with wider services to improve access for those people who would not normally engage with heart failure services (often with diagnoses of preserved ejection fraction) through links with the complex care team, hospital at home team and rapid response service.
- Developed further our decision support tool and standard operating procedure (SOP) to continue to offer treatment for fluid overload with subcutaneous furosemide in the home setting, enabling people to remain at home and out of hospital.
- Established protocols and governance for a new outpatient day infusion service based out of the hospice to enable people to access iron infusions and with potential to treat with IV furosemide to offload fluid, enabling more choice and reduce burden on acute services. Provided to nine individuals (18 visits).
- Run an online community of practice reaching over 189 individuals from across the globe to share knowledge and skills in palliative care and heart failure. This comprised six sessions focusing on topics such as symptom control, understanding the trajectory of outcomes, and device therapies. The brought together heart failure clinicians and palliative care clinicians, to learn together and share their wealth of knowledge.
- Run focus groups, initially with patients and carers and then solely with carers which has led to a legacy support group for those people caring for someone with heart failure.
- Interviewed patients to explore what living with heart failure is like. The focus of this was to enable us to think about how we shape our services based around lived experience.
- Interviewed and developed a video of a carer's experience for us to share and learn from.
- We organised a 1-day hybrid conference showcasing the benefit of integrating palliative care and heart failure, learnings from the project and also other services across the country who have led the way in providing a truly collaborative approach to their HF care.

Literature review - What has the literature told us so far?

Heart failure is a worldwide health concern, affecting more than 64 million people.[4] Common symptoms including fatigue, breathlessness and oedema, overall reduction in quality of life and the burden of complex decision-making in the face of ever-increasing medical interventions. [5] People living with heart failure are frequently required to make complex decisions regarding their treatment plans, often with limited information pertaining to their likely prognosis, support for decision making and advance care planning. [6]

People living with and dying from heart failure are exposed to numerous physical, emotional, psychological and spiritual consequences as a result of their diagnosis, directly impacting their encounters with acute healthcare through hospitalisation and increased mortality. [7] Alongside this, advancing treatment options lead to more people living with this condition for longer and alongside co-morbid disease into older age. The trajectory of heart failure, whilst challenging to prognosticate, is often characterised by the cycle of decompensation, deterioration and recovery, and is often associated with high healthcare service use, and socio-economic and carer burden . [8]

There is an increasing body of literature identifying the value of palliative care as a critical component of care in its own right, and recommending integrated working between palliative care and heart failure. [9,10] Access to palliative care is now recommended by all major cardiovascular

societies in the management of advanced CHF. [11] Palliative care as an intervention can lead to improved quality of life, with fewer hospitalisations, enabling people to obtain symptom control and psychosocial support through access to community palliative care. [5,12]

However, access to palliative care for people living with heart failure is low due to a multitude of reasons focused around the individual, the system and the disease. [5] In the UK, only 7% of people living with heart failure will be placed on the palliative care register versus 48% for those living with and dying from cancer and we know that although palliative care integration is recommended it continues not to be routinely seen in practice. [13]

Prognostication remains challenging, with services now moving towards a needs-based referral strategy over a prognosis-based strategy (NHS England 2023). [10] Specialised and generalised clinicians who lack understanding of palliative care as a concept can cause poor recognition of palliative care as a valued intervention and critical component of care for people living with heart failure.

Introducing palliative care to people living with heart failure can be challenging due to not only a lack of understanding by healthcare professionals (HCPs) of the role that palliative care has to play, confusing it solely with end of life care, and the difficulty with prognostication, but also due to patients misunderstanding around their diagnosis and implications of this. As a result, although there is a widespread belief that GPs and community nurses may be best placed to introduce palliative services, patients want earlier conversations. As such, cardiologists and HF nurses are best placed to introduce the concept of palliative care into their patients' journey due to their expertise and relationship with the person. [14]

Project Plan

Appendix 1 details the timeline of events to help set up this project.

During the project we held 6 steering groups to reflect on progress and guide next steps (*Appendix 2*). Attendee numbers ranged from 8 to 14, with external members including: ICB transformational leads, ICB heads of community, Heart Failure consultants and/or HF CNSs.

We focussed on relationship building across organisational boundaries, building a network of people with a vested interest in supporting people living with heart failure to access palliative care.

External changes:

Croydon

The main route to enabling a collaborative approach was to build a good relationship with the Croydon heart failure team, through a sharing of ideas, discussing ways we could support one another, offering teaching and joint working, and regular attendance at their MDMs.

We also linked in with rapid response as they also attended the weekly HF MDM. Isobel Jackson shadowed them to gain an understanding of how they worked and carried out some teaching with them.

We linked in very closely with the complex care team in Croydon, providing them with teaching about palliative care, attending their MDM on a weekly basis, liaising via telephone or email for advice or to accept referrals and working jointly.

We built awareness through the Croydon EOL steering group and GP meetings to promote the new service.

We developed literature that went out to GP practices to share the details of the new service, and explain who to refer and how to refer them.

We developed our patient leaflets and empowered the HF team to utilise and share them with their patients, to use as an adjunct to their discussions about bringing palliative care alongside their mainstay HF treatment.

An information governance risk assessment was carried out to ensure the safe and legal sharing of clinical information.

Bromley

Our work in Bromley continued with a new palliative heart failure ANP coming into post in June 2023 who was able to continue to attend the weekly cardiology MDM at the Princess Royal Hospital. She was new to this role and required support to build her confidence and competence in supporting people living with heart failure.

Internal changes:

Our patient flow was reviewed as the project developed.

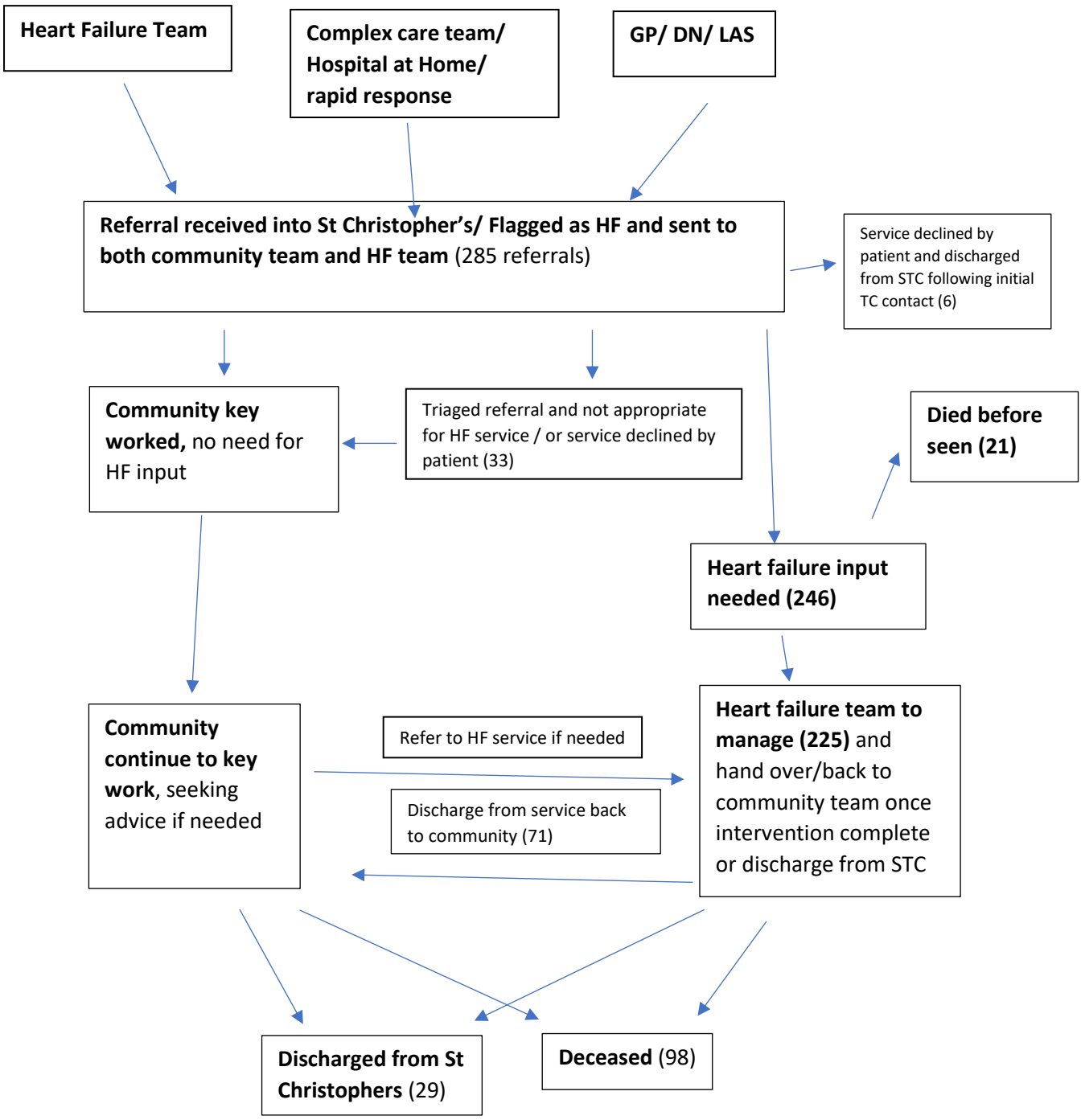
At the start of the project, all new HF referrals were being seen by the St Christopher's (STC) HF team, however after an influx of referrals it became clear this was not sustainable. We continued to review our processes and recognised that for some people the introduction to palliative care and utilising our already established community service was all that was needed, using the HF ANP as a bridge between the 2 services. Therefore, once the referral came through the community team would see the patient first and assess if there was need for specialised HF input, subsequently referring on to the HF service on a needs basis. For others where there was an element of complexity flagged on referral, they were still seen first by the HF ANP. Our admin team would flag when new referrals came through and the HF team would continue to assess the need for HF input, liaising closely with the community team to offer support where needed.

IT system changes made:

We use SystmOne for all patient records and this was utilised to create a new caseload for the Croydon HF team, with pathways set up for internal referrals to come through. The Bromley heart failure caseload was already in effect at the start of the project.

In Bromley, EMIS was utilised to enable a quicker and more stream lined approach for GPs to refer directly into the palliative HF pathway, highlighting to them who they could refer and what information was needed to help provide an efficient service. We were not able to facilitate this change in Croydon unfortunately.

Figure 1 Referral pathway:



Results - Data

This report includes the referral of 246 patients who were accepted onto the service between 01/04/23 and 31/08/24 (17mths). Outcome data has been censored on 10/09/24. 225 patients were seen by the service; 21 patients died after referral before being seen.

Pattern of referrals: (n=246)

Referral volume ranged from 2 to 21 per month. The cumulative referrals by month are shown below; 50% of patients were referred from each borough (Bromley/Croydon).

Figure 2: Numbers of referrals by month, cumulative (blue bars) and by borough (Bromley dark green; Croydon pale green)

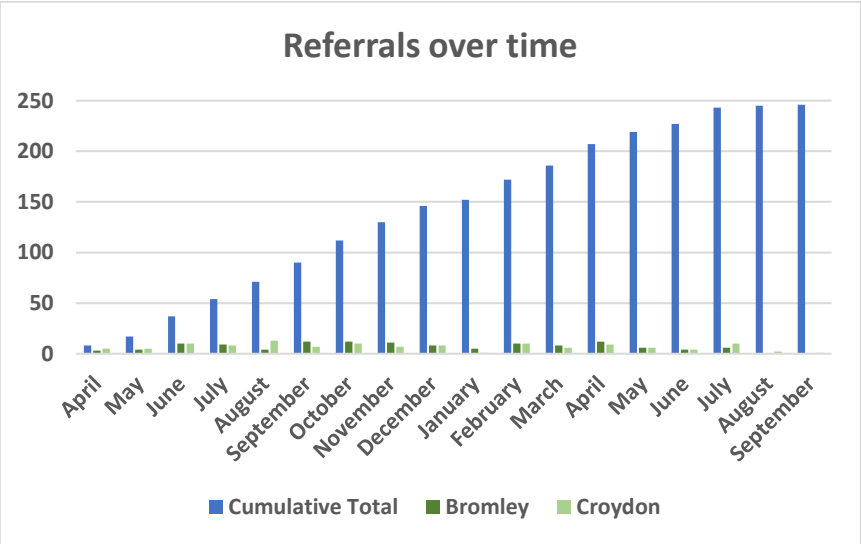


Table 1: Numbers of referrals by month and by borough

Month	Total	Bromley	Croydon
April	8	3	5
May	9	4	5
June	20	10	10
July	17	9	8
August	17	4	13
September	19	12	7
October	22	12	10
November	18	11	7
December	16	8	8
January	6	5	1
February	20	10	10
March	14	8	6
April	21	12	9
May	12	6	6
June	8	4	4
July	16	6	10
August	2	0	2
September	1	0	1

The majority were referred by the Heart Failure teams (35%). A quarter (24%) were internal referrals from the St Christopher's Community Palliative Care Teams (CPCTs). GPs referred 16% of patients, with a further 17% from other community services (Rapid Response, Integrated Care Network, Hospital at Home and 2 patients from LAS and 1 from Care Home staff). 8% were referred by other hospital teams.

Croydon patients were more likely to be referred from HF teams, reflecting the focus of service development to link with this team and the fact that their nurses work across multiple settings (hospital and community). Bromley patients were more likely to be referred by GPs, as this referral pathway is well established having had an established service for many years prior to the project. Alongside this, EMIS (their IT system) was adapted with a new referral pathway for Bromley but we were not able to introduce this in Croydon.

Table 2: Numbers of patients referred by different professionals, by borough.

	Total	Bromley	Croydon
Heart Failure Team	87	34	53
Other hospital	20	10	10
Internal Referral St Christopher's CPCT *	59	31	28
General Practitioner	39	30	9
Integrated Care Network	9	9	0
CCT **/Rapid Response Team (Croydon)	19	0	19
Hospital at Home (Bromley)	10	10	0
Other	3	0	3

* Community Palliative Care Team ** Complex Care Team

58% of the HFrEF patients came via referrals from HF services, whereas they only referred 13% of the non-HFrEF patients. The majority of the non-HFrEF patients came from the CPCT or GPs. This reflects the dilemma of increasing need for specialist HF services to care for non-HFrEF patients who are often more symptomatic and unable to access hospital services.

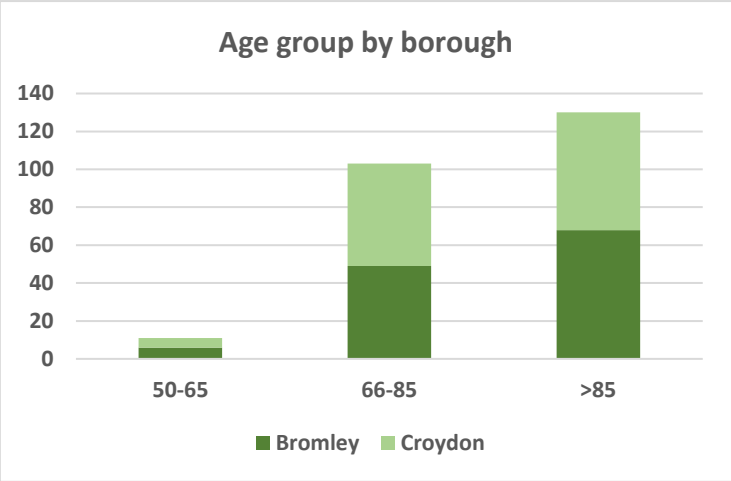
Most patients were referred for symptom control (86%). Additional requests were for advance care planning (25%), emotional and psychological support (9%), rehab (3%), welfare/financial advice (3%) and 5 patients (2%) for end-of-life care. Referrers could identify more than one need on referral.

Patient Demographics: (n=246)

Gender and Age

129 (52%) were male. Bromley patients were more likely to be male (56.5%) and Croydon patients female (52%) but this was difference is not statistically significant. The mean age was 84.0 ± 9.0 yr (median 86 range 52-100 yr). There was no difference between boroughs. The majority of patients (53%) were >85 yrs of age.

Figure 3: Number of patients in each age category, by borough



Ethnicity

75% of the caseload were White British which could be reflective of Bromley being predominantly a White British borough.

9% were Asian, 9% Black, 5% mixed or Unknown and 2% Other- this includes a small gypsy/traveller population.

Croydon has a higher proportion of Asian and Black population compared to Bromley which is reflected in the higher numbers of this demographic on the Croydon caseload.

Table 3: Ethnicity by Borough

Ethnicity	Croydon (n)	Bromley (n)
Asian	18	5
Black	20	3
White	75	109
Other	9	7

Heart Failure Aetiology

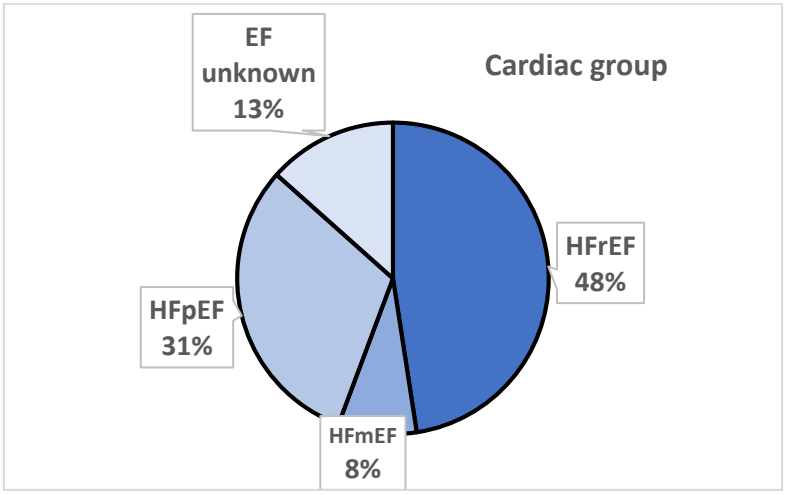
48% had HF with reduced ejection fraction (EF). The remaining 52% who are often not seen by community heart failure teams were split between 8% with HF with moderately reduced EF (40-50%) and 31% with HF with preserved EF (>50%).

The remaining patients (13%) did not have ECHO results with EF recorded but were a mixture of those with valvular heart disease, pulmonary hypertension and right sided HF or unclear aetiology.

Patients with HFrEF were more likely to be younger, comprising 85% of those <65yr vs 50% of those 66-85yr vs 42% of those >85yr. The older frail patients are therefore more likely to have HF without reduced EF, and therefore not be under the care of community heart failure nurse services.

Some degree of valvular dysfunction (moderate to severe) was present for 68% of patients, with 42% in atrial fibrillation. A history of ischaemic heart disease (CABG/PCI/NSTEMI) was present for a third, and 39% had a background of hypertension. 15% had established pulmonary hypertension and small numbers of patients had cardiomyopathy (5%) or amyloid (5%) causing their heart failure.

Figure 4: Number of patients with Heart Failure and reduced, moderately reduced or preserved ejection fraction



Other co-morbidities

193 (79%) of patients had additional co-morbidities including: respiratory (29%), cancer (17%) or endocrine (33%) diagnoses. In addition, 33 (13%) had dementia and 41 (17%) had clinical diagnoses of anxiety and/or depression with 5 other patients having other mental health diagnoses (schizophrenia, alcohol dependence, adjustment disorder and PTSD).

Three quarters of patients (74%) had significant renal impairment (CKD 3 or above), with a fifth (21%) having stage 4/5 where eGFR <30 which has implications for tolerating evidence-based medications (ACE and MRA) or diuretics, and influences which opioids can be given to achieve symptom control.

Clinical frailty scores at baseline were documented for 212 of the 216 patients ≥65yrs age who were seen by the service. 4 patients had missing data. Three quarters of these patients were severely frail (CFS 6-8). Just over half (51%) had no change in CFS, a few improved (8.5%), with the remaining declining during their time in the service.

Figure 5: Number of patients with baseline Rockwood clinical frailty scores 3 to 9

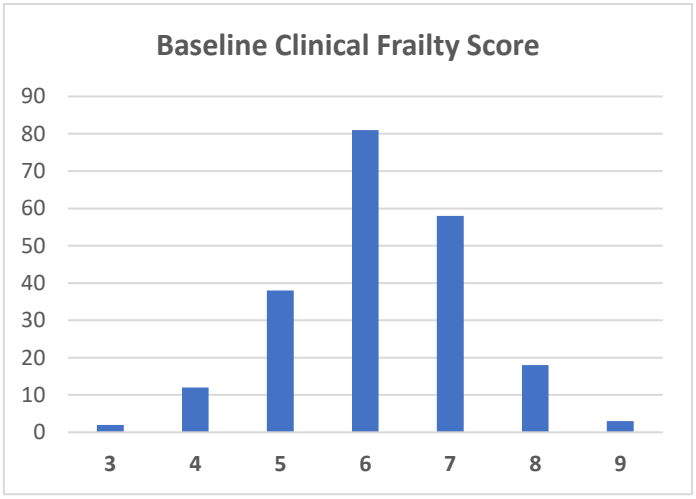
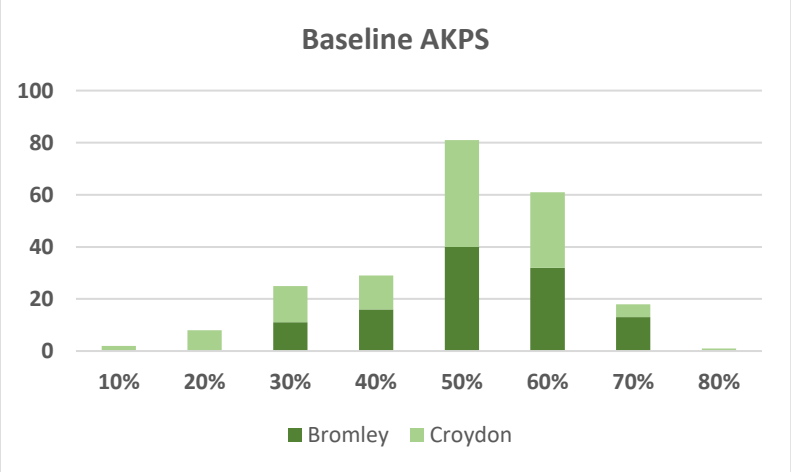


Table 4: Number of patients with no change (grey), improvement (green) or deterioration (blue) in Rockwood clinical frailty score whilst under heart failure service

change in CFS	Number of patients
-3	1
-2	2
-1	14
0	109
1	56
2	19
3	6
4	3
5	1

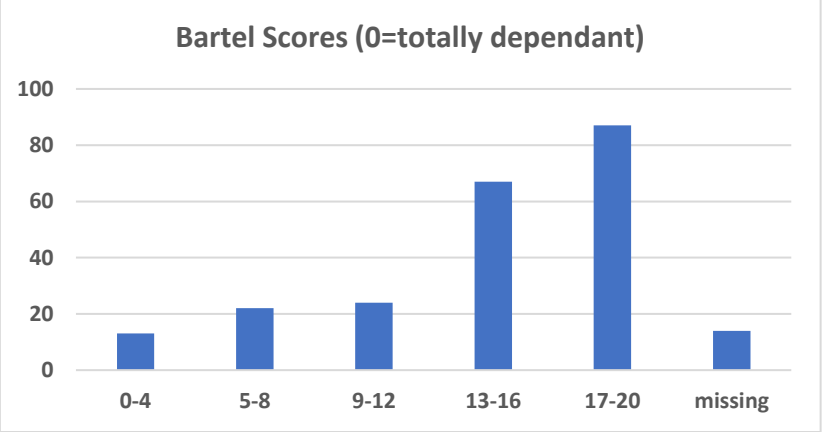
At baseline on first assessment, 64% of patients had a performance status (AKPS) of ≤ 50% requiring considerable assistance or care, with 15% mostly bedbound. N=225, and 2 patients had missing data.

Figure 6: Number of patients at baseline in each Australian Karnofsky Performance Status group, by borough (ref AKPS)



Bartel Scores at Baseline

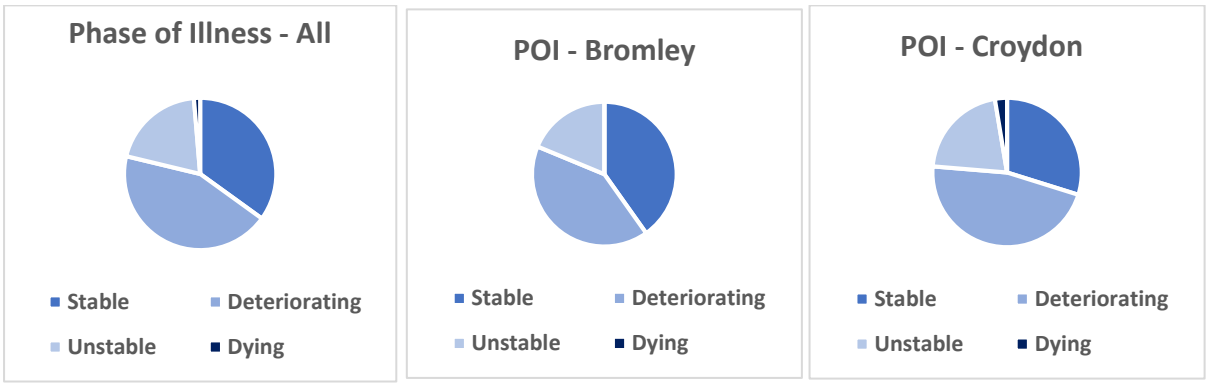
Figure 7: Number of patients at baseline in category for Bartel score



Phase of illness (n=225)

The largest number of patients were in the deteriorating phase of illness (43%) on referral, followed by stable (35%) and then unstable (21%) with only 2 patients in the dying phase. There were some differences between Croydon and Bromley as shown below.

Figure 8: Number of patients in each phase of illness, total and by borough

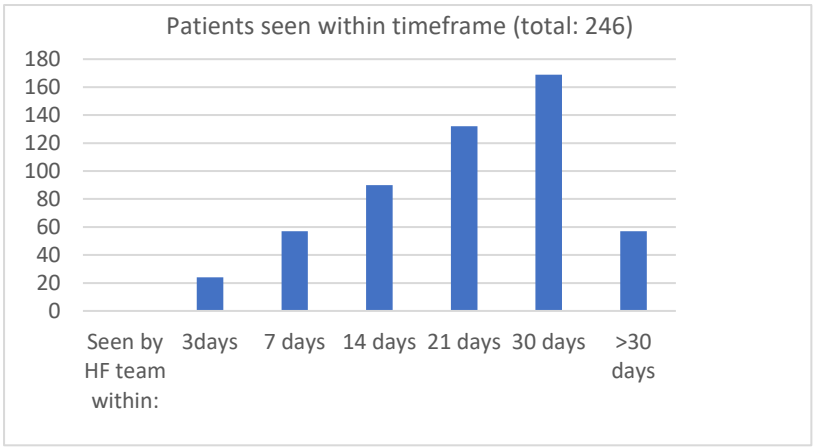


Support Network

Over half of the patients were living with family (55%) and 2 patients had live-in carers. A third (34%) were living in their own home but living alone. Small numbers of referrals (8.5%) were in either Care Homes or Extra-Care housing.

Time to seen (from referral)

Figure 9: Time from referral to review by heart failure ANP



For those patients who were not seen within a month of referral we reviewed individual cases; below is a summary of the mitigating factors behind this:

45 were seen by the community team prior to the HF team seeing them, and for 18 there were delays in the first face-to-face due to either difficulty getting hold of them, family members rearranging home visits or patients changing their choice about when they wanted to be seen.

Looking further at other mitigating factors, 18 patients had low symptom burden or were deemed stable following first community review, 8 patients had support over the phone or advice given to them by the heart failure team, and hospital admission delayed the first assessment in 10 patient cases. In 6 cases lack of awareness of the referral by the patient or family led to them asking for time to process this before having a full assessment or home visit (HV).

Staff sickness impacted 5 patients' first review as HVs were rearranged due to clinical need.

It is worth noting that from halfway through the project onwards referrals were being seen by the community team first, and the HF team second if needed. As such, time between referral and being seen by the HF nurse may have been longer than at the start of the project, and if patients were deemed stable by the community team it may have taken additional time for the HF team to book them in for a review.

Interventions and joint working

Advance care planning (n=225)

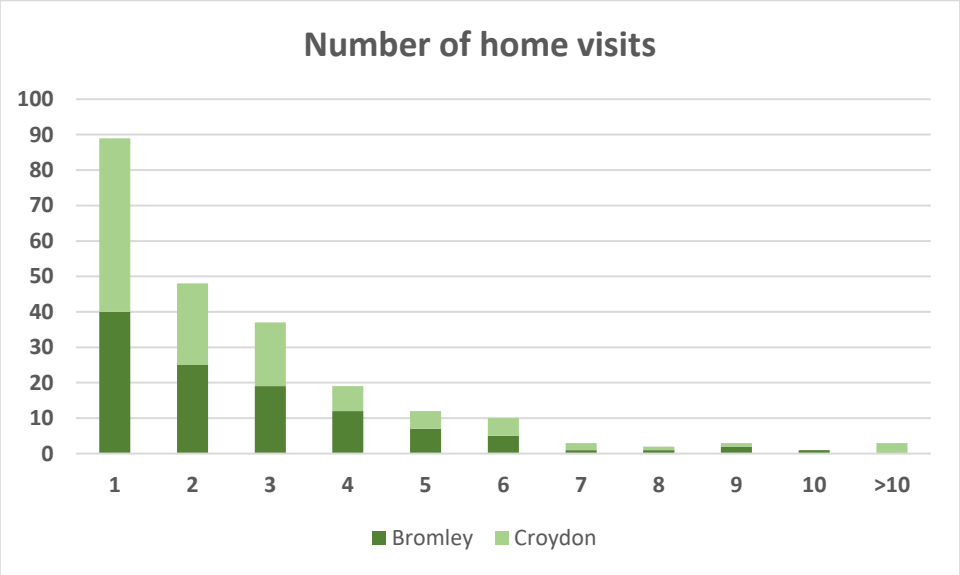
Advance care planning was considered for all patients. At time of analysis, DNACPR decisions/forms were in place for 186 (82%) of patients, with treatment escalation plans (TEPs) agreed for 201 (89%), of whom 20 (10% of TEP population) recorded that the patient remained for active resuscitation. Decisions around preferred place of death were documented for 190 (84%). These advance care planning decisions/discussions were recorded in shared online Universal Care Plans for 176 (78%) of patients following informed consent.

Appendix 3 *Case study of a patient where ACP was challenging and needed a full MDT involvement.*

MDMs and Joint Visits

The number of home visits ranged from 1-16 per patient. 39% of patients had one visit, 21% needed 2 visits, 30% needed between 3 to 5 visits, 8% 6-10 visits and 3 patients had >10 visits.

Figure 10: Number of home visits per patient by borough



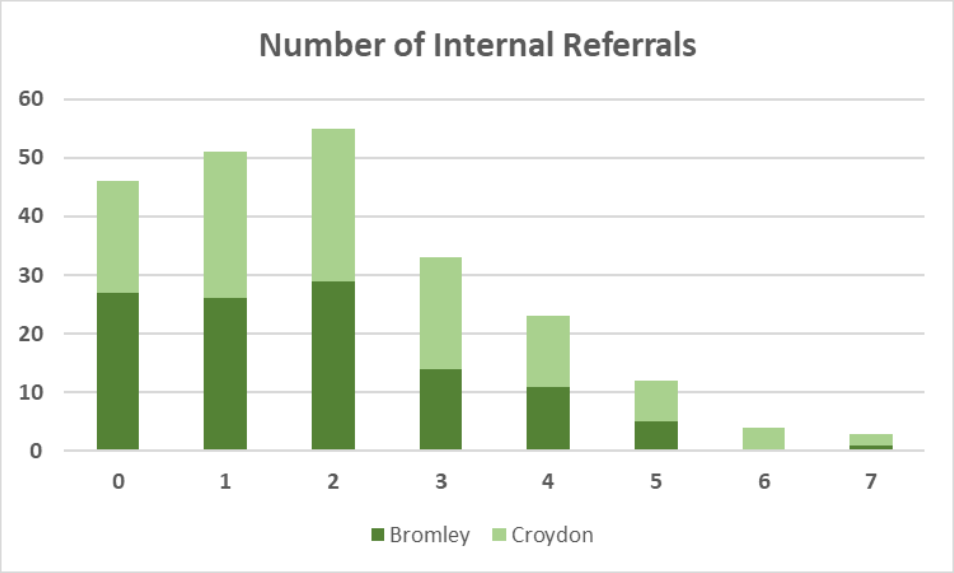
61 patients (27%) had a joint visit with another professional, 11% with external professional and 18% with an internal colleague. 2% had visits with both an external and internal professional.

MDM discussions were had for 164 (72%) of patients. These included GSF meetings with GPs, joint Cardiology and Palliative Care MDMs, and St Christopher's internal MDMs.

Internal Referrals

181 (80%) of patients were referred to other services within St Christopher's. The number of referrals to other services ranged from 1 to 7 per patient.

Figure 11: Number of patients with internal referrals (0 to 7), by borough



Referrals were to a variety of services, most commonly to Rehab (54%), followed by Care Navigators (36%) and Welfare (21%). Details of referrals to other services are shown in the table below where >5 patients were referred. Small numbers (13 patients in total) were referred to other services including Spiritual Care, Bereavement, Liaison Psychiatry, Creative Arts and Biographer.

Table 5: number of patients referred to other St Christopher's Services by borough.

Internal Referals	Rehabilitation Therapies	Care Navigator	Welfare	Complimentary Therapy	Psychological Therapy	Social Work	Wellbeing	Dietician	Choose Home	Inpatient Unit	Speech and Language Therapy	Hospital at Home
Total	123	82	47	36	33	27	24	23	22	23	7	6
Croydon	59	41	26	22	21	12	14	20	14	13	5	0
Bromley	64	41	21	14	12	15	10	3	8	10	2	6

IPU admissions:

25 patients were referred to the IPU. 1 patient died in hospital while awaiting admission, 1 patient was agreed, then improved and subsequently declined admission.

23 patients were admitted to the IPU of which 4 patients had 2 admissions. Therefore there were 27 total admissions.

13 patients died while on the IPU (56% of those admitted), 2 were discharged to NH (1 of which was out of area) and 12 were discharged home.

Time on the IPU ranged from 1 day to 95 days. The average length of stay was 19 days.

Subcutaneous Furosemide

A protocol and decision tool to aid clinicians in deciding when to use subcutaneous furosemide was developed and used as part of this pilot, with a new standard operating policy developed in close alignment with Croydon community SOP to aid consistent practice (*appendix 4*). Subcutaneous furosemide was given to 24 patients, or 10% of those referred to the service, with 26 episodes of care as 2 patients received this intervention on 2 separate occasions. 14 patients were in Bromley and 10 in Croydon. For those treated, average age ±SD was 84 ±10yrs, 58% male, 38% with diagnosis of HFrEF. In half the patients, eGFR was ≤30 (stage 4/5 renal impairment) and a third had systolic blood pressures <100mmHg.

Starting doses of furosemide ranged from 80mg to 230mg over 24hrs. Furosemide was given for a median 8 days (range 2-39). For 3 patients, oral metolazone was also added during treatment to promote offloading of fluid. 13 (50%) of episodes were deemed successful with improvement in symptoms and oedema, although one of these patients later died while on treatment (day 39). Those who responded were converted back to oral diuretics.

3 (12%) of episodes were unsuccessful with one patient readmitted to hospital for IV treatment. In 10 cases (38%), the patients died (7 within 10days; 3 after 12-39 days) although one had good symptom benefits as above. 3 patients discontinued treatment due to the burden of the CSCI. One developed hypokalaemia treated with sando K, and one patient had a site reaction which then resolved.

25 (96%) of these episodes resulted in hospital avoidance; 5 (19%) were treated in the hospice inpatient unit with the remaining 21 (78%) successfully treated in the community setting with liaison with GP and District Nursing teams. Only one patient was transferred to hospital. For four episodes, delays in obtaining subcutaneous furosemide influenced care. For those patients in Croydon, ongoing failure to resolve blocks to prescription of furosemide in the community setting has meant the burden of issuing furosemide from hospice stocks remains a challenge.

Iron infusions/outpatient service

Iron infusions were completed for 9 patients: 5 from Croydon and 4 from Bromley. This was piloted in a nurse-led outpatient setting, with support from our physicians' associate.

5 patients were HFrEF, 2 HFpEF and 2 had valvular heart disease

5 patients had received treatment previously in the acute sector, either during an admission or at a planned infusion unit under the frailty service.

100% of patients reported that fatigue was their main symptom of concern and why they had been referred for IV iron.

Doses were 500mg as a one-off dose (2 people) 1500mg as a split dose (4 people) up to 2000mg split across two infusions for 3 people.

IPOS ranged from 1-2 for energy levels pre-infusion with 3 patients showing a reduction from 2 to 1 for their energy level IPOS post-infusion.

1 patient died before they had a full IPOS done after infusion, however reported briefly feeling better after infusion.

7 patients subjectively reported to feeling they had more energy after infusion. 1 patient managed to go on holiday abroad and 1 patient felt better after 1 week of infusion and started baking cakes on a daily basis again. 1 patient didn't report any change, and 1 patient reported mild improvement, though not as much as she hoped for.

Every patient was given an evaluation to complete and reported that they felt they had enough information before during and after the treatment. Everyone felt the service met their needs.

We asked people their feelings about attending the service prior to their first infusion and then again after having had their treatment. People ticked more than one option.

Table 6: patient feedback from outpatient attendance

	Pre treatment	Post treatment (2 visits)
Anxious about coming	1	0
Familiar and no concerns	5	8
Comfortable attending		5
Please to have it somewhere other than hospital	4	6
Pleased with the service		5

Some of the other comments included:

"Everyone put me at ease", "I was very happy with the care and support for both of us (patient and carer)", "very helpful staff and really cheer up patients with their help", "excellent staff, explained the whole procedure clearly which made mum feel at ease".

The process for setting up the service:

We scoped the number of patients that would potentially benefit from this service and estimated that between 13 to 16 patients could benefit from either iron and furosemide.

The first step was to decide on location: a SWOT analysis was conducted for a couple of options. We had originally felt that a space on the IPU would be best due to ease of access to staff. However, on review, it was felt that as part of the service was to try and break down barriers and myths around hospice care, there would be the potential for people to come across distressed family members

which would not be beneficial for them. Alongside this we considered the added technicalities of taking bed space away and how to coordinate that when the referrals would not be predictable.

We agreed on utilising the clinic space already set up and agreed on one of the clinic rooms liaising closely with other services to ensure there was space and it would not interfere with other services already set up.

We needed to consider patient safety especially with a medication which holds a risk of anaphylaxis. We liaised with our pharmacy service to ensure that a dedicated anaphylaxis kit was available during each infusion and anaphylaxis training was completed. Allied teams such as the IPU staff, the referrals team and the outpatients team were aware of when each infusion was being carried out to ensure sufficient staffing in case of an emergency. It was also ensured that all patients were fully counselled on the risks of the treatment and the measures put in place for their safety, what would happen in the event of a reaction or they became unwell, and consent was gained prior to each individual infusion.

The pharmacy team was also linked in with to ensure a smooth process for arrangement of the medications. The ward was liaised with to ensure IV pumps were available as well as all the allied equipment (such as needles, gauze, cannulas etc.).

A standard operating policy (*appendix 5*) was written and agreed at the care directorate meeting. SystmOne was set up with an individual outpatient heart failure service diary so patients could be booked in.

We shared this part of the project with the wider community, helping to cement relationships further with an offer for patients to utilise our service rather than take up acute care.

Learning

We have not been able to utilise the service for IV furosemide. Part of this is due to the nature of the service and the need to balance a community caseload with a treatment that could potentially take up 5-10 mornings of outpatient time depending on the individual. We also did not have the need for IV furosemide during this time frame, as utilising sub-cutaneous furosemide was effective at home which enabled people to stay in their preferred place. For both Bromley and Croydon we also had access to hospital at home or rapid response (though no Croydon patients required IVs at home during the time frame) for IV furosemide if needed although the doses for this would be limited.

The service was being led by a band 8 nurse due to the pilot nature of the service and initial thoughts around managing the complexity. On reflection, the complexity centred on the reviews of people prior to coming to the outpatient infusion service, ensuring the bloods are done and reviewed and assessing suitability, which was all carried out prior to them coming to the service. The administration of the infusion itself would therefore not warrant that level of nursing expertise and it may have been better to consider utilising the outpatient nurses already in situ with support from the HF nurse.

One patient who attended came for 200mg of ferinject for fatigue. He was a gentleman living with HFrEF but also advanced COPD and increasing frailty. He used to enjoy baking cakes most days, and watching baking shows on the TV. His ferritin level was 32 and therefore within the guidelines for administering IV iron. He attended for 100mg ferric carboxymaltose on two occasions one week apart as per the guidelines. He was brought by his daughter and was happy to come having had good

experiences of the hospice beforehand. Within one week of his first infusion he reported his energy levels had improved enough for him to be able to get back into the kitchen to do his daily baking, and he promptly turned up to his second infusion with bags of cakes for the nurse and physician associate to enjoy.

Devices

No patients were referred back to Cardiology for insertion of a device, but a number had devices in situ on referral. One patient from Bromley was referred for a 24-Hour Cardiac Monitor Tape to help decision-making re ongoing care.

11 patients had CRT-Defibrillators (7 Croydon, 4 Bromley). We coordinated 5 deactivations (3 Bromley, 2 Croydon). For one patient it was not appropriate to deactivate and he has been discharged from STC with it active and is doing very well. One patient consented to deactivation, but unfortunately died suddenly while making arrangements for formal deactivation – a magnet was available but not needed. We discussed deactivation with four patients who declined to consent. For those who died with a CRT-D device, 5 patients died having had their CRT-D deactivated. Two had active devices, and in one case the patient declined to deactivate following discussion, while the other had a sudden event (he had consented and we were in the process of arranging formal deactivation).

8 patients had ICDs (3 Croydon, 5 Bromley). We coordinated 3 deactivations (2 Bromley, 1 Croydon), in the case of two patients it was not appropriate to deactivate and they declined discussion, one of which has been discharged from St Christopher's, and for three patients it was discussed but they declined to consent. For those who died with an ICD, two were deactivated and one was still active, however a discussion had been had with the patient and they declined to consent.

10 patients had CRT-Pacing devices (of which 2 were CRT-D that had been deactivated prior to referral). Permanent pacemakers were in situ for 17 patients. 2 loop recording devices were in place.

In total, device deactivation was successful for 8 patients (5 CRTD- 3 ICD); 3 in Croydon 5 in Bromley. If patients have their devices implanted under KCH or the PRUH then they have to be well enough to attend an outpatient appointment at the PRUH for formal deactivation. If they have had their device implanted under GSTT or CUH/SGH then home deactivation can be facilitated if needed. In an emergency we use magnets but try to avoid these situations due to the burden and anxiety it places on family members. *Appendix 6 gives two Case History of cardiac deactivation, one from each borough.*

Outcomes

Died /Discharged (n=225)

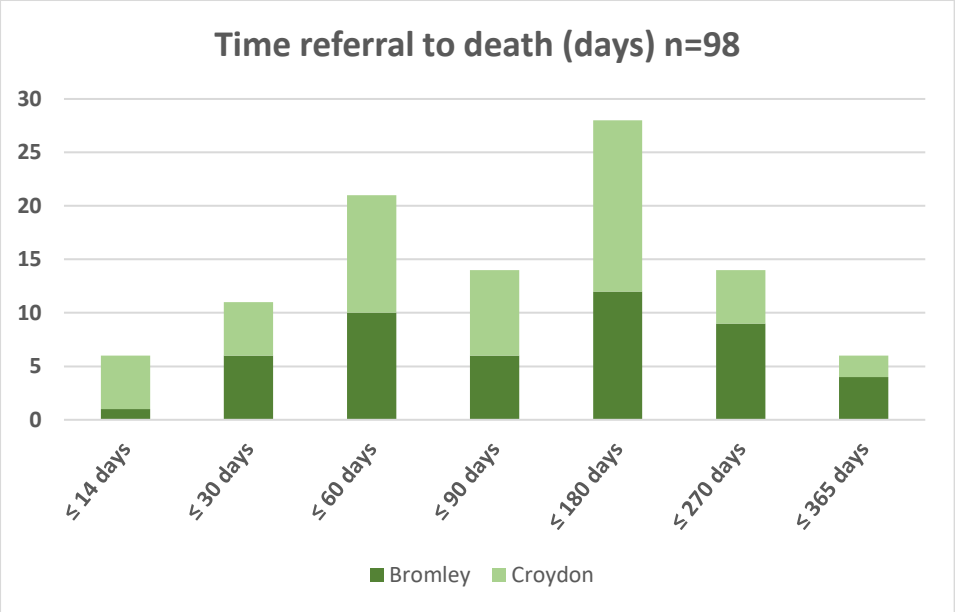
98 (44%) of patients referred to the service had died at time of censor 10/09/24 – 50 patients in Croydon, 48 in Bromley. Preferred Place of Death was achieved for three quarters of these; for those who did not achieve PPD 23 died in hospital, 1 died in a nursing home awaiting admission to the hospice, and 1 PPD was unknown. The majority (72%) were still under the HF service at time of death, 12% had been transferred to the hospice inpatient unit, and 16% had been discharged to the hospice community palliative care teams.

28 (12%) patients were still alive at the time of the censor, a further 99 (44%) had been discharged from the heart failure service of whom 71% remained under St Christopher's community palliative care teams, and 29% had been discharged from St Christopher's' care back to General Practitioners and other community heart failure services.

For those who died, 63% died in their home/nursing home, 25% in hospital and 12% in the Hospice inpatient unit. Place of death was not significantly different between Croydon/Bromley.

Median time to death was 84 days (range: 7-361). This differed between Bromley and Croydon, with median range 92 (10-361) versus 78 (7-346) respectively.

Table 7: Time of referral to death (days) by borough for n=98 patients who died after referral to the HF service.



Outcome Measures (n= 225)

Integrated Palliative Outcome Score (IPOS)

Table 8 - Baseline IPOS scores

Ipos score	Pain	SOB	Weakness	Nausea	Vomiting	Appetite	Constipation	Dry Mouth	Drowsiness	Mobility	Total
0	98	40	30	190	206	99	162	156	101	30	1112
1	55	58	57	20	12	71	35	46	52	48	454
2	56	81	81	12	3	46	22	14	57	93	465
3	11	36	7	0	1	5	2	3	11	45	121
4	2	7	7	0	0	1	1	2	1	6	27

IPOS Score	Anxiety-self	Anxiety-family	Depression	At Peace	Sharing info	Enough information	Practical problems	Total
0	98	78	130	110	139	155	142	852
1	50	62	41	58	46	41	54	352
2	46	52	31	39	28	18	20	234
3	22	24	17	7	4	4	3	81
4	5	5	2	8	4	3	3	30

Table 9 – Final/End IPOS scores

Ipos score	Pain	SOB	Weakness	Nausea	Vomiting	Appetite	Constipation	Dry Mouth	Drowsiness	Mobility	Total
0	104	84	48	202	214	111	174	169	104	65	1275
1	67	77	62	12	3	56	25	29	55	50	436
2	44	43	67	4	1	41	15	16	41	70	342
3	4	15	35	1	1	9	3	4	13	30	115
4	0	0	7	0	0	2	2	1	6	4	22

IPOS Score	Anxiety-self	Anxiety-family	Depression	At Peace	Sharing info	Enough information	Practical problems	Total
0	100	98	142	127	152	158	173	950
1	58	55	37	56	45	47	33	331
2	39	43	22	26	14	11	8	163
3	17	18	14	4	3	0	2	58
4	4	5	3	6	4	2	3	27

Appendix 7 shows the change in IPOS scores in graphs.

Died before being seen by heart failure team

21 patients died before being seen by the heart failure team. We reviewed the data and looked at the patient journey to highlight some key themes emerging.

For 7 patients the community SPCT were key working and supporting the patients well at the end of their life with no indication for specialist HF input. They were supported to remain at home or were admitted to the hospice for end of life care.

4 patients had late referrals and or a sudden cardiac event. 1 patient was seen at home for their initial home visit following LAS doing CPR due to cardiac arrest and died at home. 2 patients were

key worked by St Christopher's Rehab team where a sudden deterioration occurred and no ACP was in place.

If GPs reviewed patients following initial PC review after referral they were then subsequently referred to hospital where they died in hospital (4 patients).

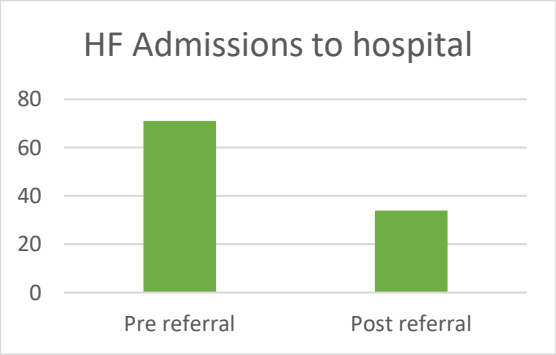
There were late referrals in at least 3 cases with death within 1-2 days following referral.

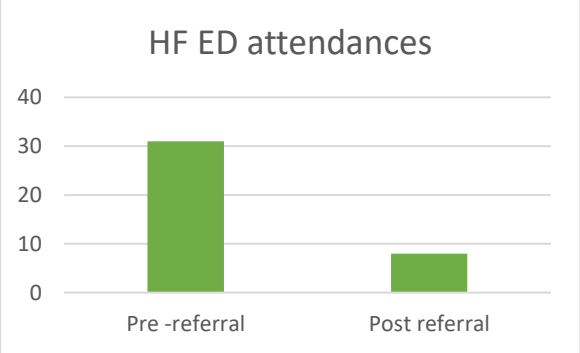
IN at 3 instances family members had not alerted to a change in patient condition, hospital admission or LAS presence and therefore we found out late that there had been a change and/ or death.

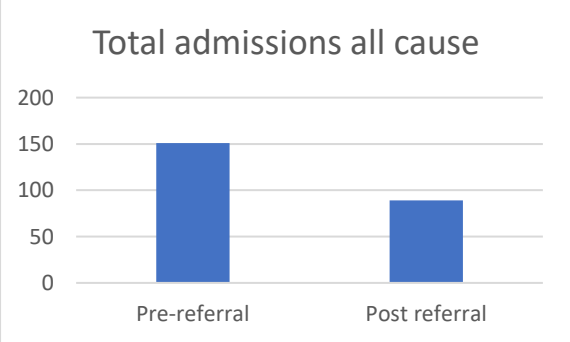
Hospital Avoidance

We analysed data for Croydon only – as the effect on Bromley is already well established from the pilot project.

We looked back at 1 year pre-referral to palliative care for all patients referred to the palliative heart failure service – looking at number of admissions, HF versus non-HF admissions, sole ED attendance HF versus non-HF and total length of stay for all cause, comparing pre-referral (1 year prior) and post-referral.







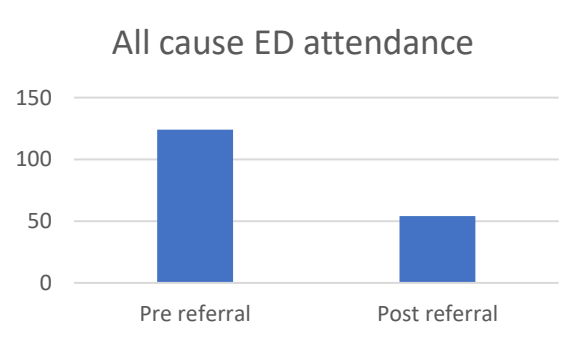


Table 12: Summary of hospital attendances pre/post referral to the service

	Pre-referral	Post-referral	% change
HF admission	**71**	**34**	**˅ 52%**
HF ED attendances	**31**	**8**	**˅ 74%**
All cause admission	**151**	**89**	**˅41%**
All cause ED attendances	**124**	**54**	**˅56%**
Total bed days	**2084**	**1011**	**˅51%**

Case studies:

We have provided some case studies of specific patients who have accessed the palliative heart failure service both in Bromley and in Croydon to help give some context to the numbers and the individual journeys that people living with and dying from heart failure have and how the service has contributed to their care.

Bromley:

Case 1

*- **89-year-old gentleman***

- LVSD, EF 30-35%, dementia, T2DM, osteoarthritis, AF and IHD

Ethnicity: White British

On referral: CFS 6. EGFR 82

ACP: DNACPR with treatment of reversible conditions at home/hospice. PPD - Home

Social: Lives at home with his wife with family support. He enjoyed playing bowls and gardening. D used to work for the BBC in the props department, following time in the army

D had several hospital admissions in quick succession for decompensated HF. D was often offloaded in hospital with IV furosemide and discharged home, with a reduced baseline and increased frailty each time. D was referred to the community matron on discharge from one hospital admission, who referred to STC following their assessment.

The palliative HF service visited D and diagnosed fluid overload, decreased mobility, increased fatigue, reduced appetite, increased breathlessness and pressure damage to his sacrum. The following steps were taken:

- *Oral diuretics up titrated*
- *Other meds rationalised*
- *Equipment ordered to ensure a safe living environment*
- *ACP broached and a detailed conversation was had with the patient and family. D's UCP was updated accordingly.*

D had no response to up titration of oral diuretics, with symptoms worsening.

D did not want to return to hospital – he was very clear on this. D was still under the PRUH HF CNS who had referred to H@H (hospice at home). H@H commenced IV furosemide, however this was not tolerated as his blood pressure dropped below 80 systolic and was subsequently discontinued.

STC HF service commenced S/C furosemide with close monitoring. D had a very minimal response 5 days later and appeared to be deteriorating.

There was then a MDT discussion between the STC consultant, STC HF nurse and PRUH cardiology consultant. Metolazone 2.5mg three times a week was commenced. Very good results were seen from commencement of Metolazone. D's fluid status improved quickly and subsequently symptoms improved.

D deteriorated despite a vast improvement in symptoms. D passed away comfortably at home a few days later. However, without the intervention to offload at home, his symptom burden would have been greater at the time of death, likely causing a more symptomatic death.

Case 2

*- **70-year-old gentleman***

- LVSD, EF 20-25%, COPD, AF and liver cirrhosis

Ethnicity: White British

On referral: CFS 6. EGFR 51

Referrals made during spell of care: Care navigator and rehab

ACP: DNACPR with treatment of reversible conditions at home/hospice. PPD – Home

Social: Lives with his wife, with support from his daughters. He used to enjoy playing golf when able. B also enjoyed reading and watching television

B was referred by the PRUH HF team for support with symptom management and ACP after several hospital admissions with decompensated heart failure.

HF CNS visited B on the hospital ward with the PRUH HF team prior to discharge. The CNS initiated ACP discussions, particularly around ICD deactivation as per B's wish. Following this consultation, B agreed to have his ICD deactivated in hospital prior to discharge home. This showed the importance of open ACP discussions, working alongside the acute sector with good cross-organisational coordination of care, to improve patient outcomes.

We continued his care at home where he achieved his PPC and PPD (home). He decompensated whilst at home and we avoided further hospital admissions by using oral metolazone (prescribed by the PRUH HF consultants), sub cut furosemide and the IPU for ascitic drainage. This approach allowed B to die at home, with his family around him in familiar surroundings.

B's symptoms were complex and required a MDT approach. However, with specific heart failure input and coordination, B was able to die at home with a significantly reduced symptom burden.

Case 3

- ***64-year-old gentleman***

- Hereditary ATTR amyloidosis, autonomic neuropathy, pulmonary emboli

Ethnicity: White British

On referral: EGFR 51

Referrals made during spell of care: Rehab for BMS and Gym, Singing for Breathlessness and Complementary therapy

ACP: Full active treatment, including CPR. PPD – undecided

Social: Lives with his wife, in their own home. P has grown up children and young grandchildren. P is a retired BT manager

P was referred by the PRUH HF team for symptom management, psychological support and ACP.

P lives with his wife and is largely independent with all ADLs, with support from his wife with heavy housework. P had experienced multiple hospital admissions for decompensated heart failure and hypokalaemia. P frequently became fluid overloaded at home and as a result of diuresis would become hypokalaemic.

P had a long hospital stay at the beginning of 2024 with joint acute/STC working. I saw P whilst on the ward and plans were made for more robust support in the community to try and prevent further hospital admissions, as per his wish. He was successfully offloaded and once his potassium was within range he was discharged home. His diuretic management plan was overseen by his cardiology consultant – Bumetanide 2mg+1mg, Spironolactone 100mg OD and Amiloride 100mg OD.

Once home, P has been monitored as appropriate and has been seen in outpatients (to maintain his independence) and also at home when he has felt less well. He has engaged well with the rehab team for BMS and gym sessions. He has also benefited from the Singing for Breathlessness group. We have titrated his diuretics and other heart failure medication in line with symptoms, thus far avoiding further decompensating. His bloods are monitored as appropriate and he has had no further hospital admissions, to date. He remains on the HF caseload.

By seeing P on the ward whilst he was still an inpatient, we were able to realistically plan for his discharge and this gave P some reassurance and confidence to come home knowing how he will be looked after and by whom.

Case 4

- ***88-year-old gentleman***

- Heart failure on background of cardiac amyloidosis with moderate LVSD, AF and CKD 3

Ethnicity: White British

On referral: CFS 6. EGFR 48

ACP: DNACPR, full active treatment including acute hospital setting, but not CPR, PPD – undecided

Social: Lives with his wife, in their own home. R was a keen sportsman, and enjoyed windsurfing until age 81. His daughter died 20 yrs ago from breast cancer

R was referred via Hospital@Home for support with symptom management after a recent hospital admission for decompensated heart failure with severe fluid overload. He lives with his wife and had been independent with all ADLs prior to hospital admission. His level of function reduced significantly pre- and during hospital admission due to decompensation and he became much more dependent on others (largely due to reduced mobility secondary to fluid overload and increased breathlessness). IV furosemide was tried in hospital, but this was not tolerated due to BP and deranged electrolytes. He was discharged with a very poor prognosis.

R was referred to the H@H palliative pathway on discharge and handed over to STC HF team shortly afterwards. R remained grossly overloaded and spent most of his time in bed. H@H had commenced sub cut furosemide once he was home as a trial. R seemed to respond well and his weight was decreasing daily. Unfortunately, his potassium levels dropped which were subsequently replaced with Sando-K.

R reported to feeling better each day and his weight continued to decrease. His mobility increased and he was able to move around his home more freely. He started to spend his days downstairs again, instead of upstairs in bed. Following 12 days of subcutaneous furosemide (200mg/24hrs) R lost 5kg and his level of function improved significantly. I reverted him back to oral diuretics and switched him to Bumetanide 3mg+2mg and increased his Eplerenone to 25mg in an attempt to savour his potassium. He is now on a reduced dose of Bumetanide 2mg+1mg as he has maintained his weight. His bloods remain stable.

Croydon

Case 5

- 84-year-old lady

- Heart failure with preserved ejection fraction (EF>55%) with severe TR, mild to moderate MR.

Ethnicity: White British

PMH: COPD, Alzheimer's, Crohns

On referral CFS 8, CKD 2

Referrals made during her spell of care: Rehab, Welfare, DN, OT, CHC

ACP: DNACPR, ceiling of care - to remain at home, PPD – Home

Social: Married, with 4 children (2 sons 2 daughters). C has multiple grandchildren/great grandchildren

Patient C was referred for help with symptom management and advance care planning to aid hospital avoidance. She had preserved heart failure and dementia, and was referred by the community rapid response service who brought her to our attention at the heart failure MDM. She did not have any access to heart failure services due to her Ejection Fraction being >50% but had been accessing rapid response for hospital avoidance. She was supported by her husband at home but both were in their 80s. At the start of her time under St Christopher's' care she was given sub-cutaneous furosemide with the aim of managing her fluid overload and supporting her to remain at home where she wanted to be. This was managed successfully with her losing the excess fluid and getting back to spending good times with her family, sitting in her kitchen helping with preparing meals and enjoying a good glass of gin or an Irish coffee. Over time her fluid levels crept back up and she struggled with leg ulcers secondary to oedema. Her renal function deteriorated and her response to medication became less and less effective. Her overall function was deteriorating requiring more and more help to meet her needs, and there was more stress placed on her husband to do more for her and manage her expectations around things such as fluid restrictions and how to have a good night's sleep.

We spoke openly about her wishes for the future, what she wanted to achieve and what mattered most to her. Being at home with her family visiting was the most important thing for her.

She deteriorated quite quickly towards the end of her life, requiring another intervention with sub-cutaneous furosemide but this time with the aim of managing symptoms and preventing significant fluid overload and pulmonary oedema. The focus shifted towards symptom control and not focusing on renal function – a hard decision for her husband to come to terms with as part of his role and identity as her carer, which was centred around managing her fluid levels and her medications. Equipment was put in place, funding for her care was arranged and help with night sits sorted out. Discussions were had with her family to help them prepare and to know what to expect next. We encouraged them to move their wedding anniversary celebrations forward and they enjoyed a good time with their 4 children, numerous grandchildren and extended family with them to celebrate their long and happy marriage before she died peacefully at home with her husband by her side about a week later.

Her husband attended our focus groups and supported other carers going through similar journeys with advice and reassurance and has contributed to our community of practice talking about advance care planning and the benefit of palliative care as well as being interviewed about the lived experience which was presented at our conference.

By collaborating with others and building relationships we were able to encourage referral, work together to support and help reach out to people such as patient C who would not otherwise have had any dedicated heart failure input and may have led to numerous hospital admissions when she would have preferred to remain at home. We also had the ability to manage and co-ordinate her treatment with sub-cutaneous furosemide: a new intervention for the borough which needed palliative care involvement to facilitate.

Case 6

- 87-year-old lady

- Heart Failure with preserved Ejection Fraction (EF 53%) Mild MR and TR with pulmonary hypertension

Ethnicity: White British

PMH: CKD, AF, Myelodysplasia, macular degeneration

On referral: CFS 7, eGFR 39

Referrals made during spell of care: IPU, SLT, Psychological/ spiritual care

ACP: DNACPR, escalation plan to stay at home, PPD Home or Hospice

Social: Married (husband has dementia), with live-in care. C has 2 daughters who are not local (1 in Australia)

Patient C was referred by the acute care of the elderly consultant direct. Her GP had referred her to the ACE clinic where she attended and was reviewed by the consultant. From that she was referred both to St Christopher's heart failure service and also the complex care team. She lived with her husband who has advanced dementia and they had live-in care paid for privately – mostly to support her husband. She also had additional care from the life team following her last hospital admission. She has two daughters: one who lives in Australia and one who lives in Devon. She was an ex-head teacher of an infant school and an artist. Her daughter came over from Australia to visit and they managed to spend time together and had a birthday party.

She had numerous problems including:

- *Worsening heart failure (preserved)*
- *Worsening renal function – likely cardiorenal syndrome*
- *Bruising and bleeding secondary to anti-coagulation, bone marrow suppression and thrombocytopaenia*
- *AF*
- *Chest x-ray showed pulmonary oedema*
- *She was declining hospital admission and was very pragmatic about her prognosis and the possibility she was at the end of her life. She wanted to avoid investigations and trips to the hospital. Her DOAC was stopped due to bleeding and she was counselled on the risks due to her AF*

She was seen by the heart failure service and based on the degree of oedema (with signs of ascites, pulmonary oedema and extreme peripheral oedema) and a plan to trial sub-cut furosemide at home was discussed and agreed, with the aim of offloading and providing some comfort. Advance care planning was discussed and her wishes documented and shared accordingly. She acknowledged that due to the complexity of having her husband at home with advanced dementia, she would prefer to be in the hospice setting for end of life care when the time came.

She initially responded well with reported improvement in her level of oedema. She continued to sit out of bed but was confined essentially to her upstairs room apart from when they had the family party. She was grateful to be having treatment at home and although she knew it would in all likelihood not resolve her fluid overload she was glad to be having care at home and that we would help facilitate her wishes and try to optimise her symptoms as much as possible.

She deteriorated very suddenly. Her mobility reduced over a couple of days and she became bed-bound, unable to lay comfortably due to her ascites, oedema and breathlessness, having periods of ongoing bleeding secondary to liver failure. She was admitted urgently to the IPU for end of life care and managed symptomatically dying 5 days later. Her daughter managed to make it over from Australia and was able to spend some more time with her and support her sister.

Again, by linking in with the complex care team and showcasing to them what palliative care can offer we were able to build relationships and confidence in clinicians to know who to refer, when to refer and how, allowing easier access for those people who may otherwise not have linked in with palliative care.

Case 7

- 87-year-old lady

- Heart Failure with reduced ejection fraction (EF 35-40%). Moderate MR & TR CRT-D in situ

Ethnicity: Black British Caribbean

PMH: Osteoarthritis, multiple level spinal canal stenosis previous laminectomy

On referral: CFS 5, eGFR 59

Referrals made during spell of care: Wellbeing (create and chat), Complimentary therapy for acupuncture, care navigation

ACP: DNACPR but declined to deactivate Defib, PPD Home, treatment escalation still for hospital for reversible causes

Social: Ex nurse and midwife and reverend, who moved in with son and daughter in law. C has a strong Christian faith, and is very sociable.

Patient C was referred by her heart failure CNS for help with symptom control of pain, advance care planning and discussion about deactivation of her internal defibrillator.

She is well supported by her son and daughter in law and being a very active member of her church, she also has good social links. Getting out of the house to attend church meetings and services, and any other opportunities for social engagement are important to her. She was referred to our hospice biographer to help facilitate documenting her memories of her varied life and experience as a nurse and midwife especially.

The main concerns for her being chronic pain secondary to spinal canal stenosis, she is awaiting decisions about potential further decompression surgery but she feels due to her level of frailty and overall health she would likely decline any offer of surgery.

We discussed her wishes for the future and potential end of life care: she was clear about not wanting resuscitation but felt her quality of life was good enough that she would not want to consider deactivation of her internal device just yet. She has very good understanding of her health issues and the likely trajectory (being an ex-nurse).

Her electrophysiology team would at times flag that she was triggering for fluid build-up. We were able to respond quite quickly and adjust her diuretics at home with very good response and she was very alert to any changes and knew when to flag issues.

She is able to engage with our create and chat group and comes regularly, meeting up with the group, and values the time to talk and share stories with other people living with life-limiting conditions.

She was referred for symptom control of her chronic pain. We discussed how this was difficult to manage and she was also reluctant to make any adjustments to her analgesia regime but engaged with attending the hospice for some acupuncture which she finds helpful.

Joined up working has enabled good cross-organisational coordination of care and allowed her to engage with supportive services and gain access to patient support groups, alongside her active heart failure management.

Co-Design summary

As part of the project we ran a series of workshops and groups with people who had an experience of heart failure or supporting people who live with it. This was with the aim of understanding more about how people living with heart failure, or those supporting people with it, would want services and support to look like. We focused in particular on developing community support. By community support we mean either that from a community, non-medical setting or service, or peer-to-peer support (peer in this setting means someone you are equal with through experience, scenario characteristic, profession or identity, for example).

This user involvement is an important feature of any project, as it allows for people with a lived experience of an area to be part of its development and to share feedback on it. This often means that a service is more likely to succeed or be relevant, as people who have the most to gain from it are inputting into its design, and making it work well for them. Co-production is considered to be an essential part of service development across most healthcare providers and settings.

It is important that with a co-production session we are able to speak to all aspects of a person's experience. As a result, our work focused mainly on understanding the issues people with heart failure face, and what would improve their experiences. We also looked at what works well for them and any strengths or assets they have. As we were working with a broad community we also ran these sessions as a session for multiple stakeholders. These multiple stakeholders included patients living in Bromley and Croydon, family and household unpaid carers living in both boroughs, and also healthcare providers in healthcare services with a role to provide support and care in both boroughs.

Our approach

Our approach with heart failure was to consider an unpaid carer's experience and voice as important as someone we are directly providing care to who is experiencing heart failure. Unpaid carers are a major provider of care, and our previous work suggests that they are overlooked in terms of service provision and in need of specific support as well.

We also considered that a household or family carer could act as a proxy or an advocate for patients or the household experience, due to the partial difficulty of being able to enable some people living with heart failure to visit a group out of the house, or any energy or fatigue that might affect them and their ability to take part. We also understood that due to the nature of heart failure and the unpredictability of need or the impact of healthcare, we would be less able to work with a consistent group of people or bring a larger group of people, and so would have to work separately with some to enable them to take part.

We trialled:

- Group settings with wellbeing offers
- Group settings in community, rather than clinical, locations
- Mixed and single experience groups

- Online focus groups
- One to one conversations in the household with patients.

We began our approach with a co-design session which focused on finding out what people might want and what would work well for them. This was based in Bromley. For this we trialled a two-part session, with patients and carers and members of our St Christopher's wellbeing team, as well as the heart failure team. The session was run by a member of the community action team, which is responsible for co-production at the hospice. The session involved providing lunch and also complementary therapies for attendees, including hand massage and nail painting. It had several parts, changing in emphasis, so that people attending would not become too tired and there would be a quasi-therapeutic outcome and perceived benefit. Although people were not invited on the basis of the therapy, most of the participants actually chose to take part in it.

From this session we were able to derive that people had several concerns about information, and gave feedback on communications to them and information they needed about heart failure. Specific to the experience of heart failure, we were able to understand fairly early on that although sometimes it is advisable to run some lived experience sessions without the clinical team responsible, so that people are able to say more without concern about reprisal or impact on services, having the heart failure project lead (a clinical lead) available in the groups was a very useful piece of health promotion, as areas could be translated and health advice or check-ins could be offered. In this way the session was helpful and supportive to participants and clarified areas they wanted more information on, as well as gathering information for the project. This also guided how we developed the sessions and the project. We'll explain below how heart failure in particular seemed to be a condition that impacted people's knowledge, certainty and ability to plan, so having a clinical lead at the sessions was additionally helpful.

We heard more about people's experiences and even challenges they might have attending the session. We saw that people attending the group could identify with and recognise what other people were saying, and so there was a helpful quality to taking part for them.

As a result, in our next sessions we decided to focus on the peer-to-peer quality of the groups, to run more groups but in a way that allowed for participants to share their experiences with each other and support each other. Peer groups can be vehicles for people with a similar experience or living with a similar scenario to support one another, and to learn about their experience, as well as to normalise it. They are particularly effective for health promotion and health advocacy.

For our next session, we began to offer a focus group based around peer support, taking place over 90 minutes, facilitated by a non-clinical community engagement lead, with the clinical lead for the project present and listening or clarifying when required. We offered this session to carers and to patients. This group was offered in a comfortable, warm and informal community space, which was confidential, with access to refreshments and good parking and bus routes. This made it easier for people to attend.

While useful we found that both groups found it difficult to speak openly in front of each other – for example carers wanted to be able to speak more openly and realistically about their concerns and experiences of caring, without worrying about how this made patients feel. So, after this we re-structured the group to be for unpaid carers and decided to visit patients at home. Following this, at regular periods we offered the groups to carers, for 90 minutes, with some semi-structured questions, but largely encouragement of free-flowing conversations around the topic area. A typical question might involve something like 'what is the most helpful thing anyone has done for you and why?', then encouraging people to share. A group activity can be useful in this way as people can be

helpful memory aides for others or discuss shared or differing experiences, being able to identify what contexts or scenarios also make them differ. We agreed group rules around listening and confidentiality and encouraged people to support one another or share something that they did. Much of the time people shared that the groups allowed for people to speak openly in a way that they said didn't feel possible at home or with family or friends.

The majority of these groups were attended by women. Ages ranged from mid-50s to mid-80s. We usually saw quite small numbers, as people's situations changed even during the week, making them unavailable. The majority of the participants were drawn from BAME groups or what we refer to as global majority populations, and the majority lived in Croydon. Each group reviewed a different topic with different recommendations for what might help. Over the time the group ran, people's circumstances changed as did availability. One man, in his 80s, experienced the death of his wife, and so did not come again to the group, although he later made a film about his life and experience to contribute to the project. As a result, rather than working with one consistent group we worked with a range of people.

To provide the most accessible way of gaining patient feedback and recommendations, as the majority of patients were provided care at home, we also designed a series of questions that could be asked of patients on home visits, with their consent, to ensure that patients were able to take part.

We also ran a focus group with HCPs outside palliative care settings on their recommendations for how to improve access and accessibility for heart failure support and care from palliative care. These HCPs were drawn from specialist units in Croydon and Bromley, and represented different organisations and teams.

Overall, we had 33 attendees over the course of the months we ran this part of the project:

- 9 patients
- 14 carers
- 10 HCPs

Key themes shared with us – patients and carers –

"I'm fighting with myself to be who I was, still trying to be me and who we were"

- Uncertainty and sometimes unpredictable changes in condition around heart failure made it very difficult to plan and to know what was next. Uncertainty was felt to have multiple social, emotional and psychological impacts, as well as logistical and practical.

- Some people had faced the idea of very imminent death for themselves or someone they cared for several times, then lived far longer than expected. Others were assumed to be doing well, but had then had a sudden change in condition. People shared a concern about going to bed and not waking up, or for carers being asleep if something suddenly happened. There was a shared sense of anxiety here, with this term and state being referred to fairly frequently, and in ways that people reported interfered with normal life.

- People reported that transitions between hospital/ healthcare provider to hospice are inconsistent and not always well-managed, with poor communication and understanding of hospices leaving people assuming that they are imminently dying. There is a lack of

information provided to people about why they are referred which worsens this feeling, and sometimes meant people did not immediately accept the referral.

- People felt that they had a lack of knowledge or information about heart failure – they cited a lack of public knowledge about it and in early referrals from GPs. Some people had not had this specific term used with them. One person new to St Christopher's found out in the peer group that there were stages, although her partner had been living with heart failure for a long time. Another had only been told the week before by our clinical lead, which she appreciated. They talked about the difference between cancer care and provision, and that for heart failure.

- There was a voiced desire to know more about the future and what it would look like, aligned with the perception that HCPs had this information but were not sharing it. The concern was shared in one session that HCPs 'sugar coat' things which is not helpful.

- Dealing with comorbidities and multiple conditions could be very confusing for carers as they found it hard to know what was related to heart failure and what was related to other conditions. This made it hard to address it or to know if they should alert HCPs to issues or how to treat them themselves.

- The phrase 'heart failure' itself has an impact on how people feel about it. There is a strong emotional and psychosocial meaning around hearts and failure. The heart has a central and unavoidable iconography in our society – both as a symbol of love or distress, and also as an engine or source of life. To have a heart fail one patient said, is to feel like a total failure. Heart failure also makes people think about the absolute end of life, not a stage.

- The burden of care in older age, particularly for female partners of men, who had been caregivers most of their lives and therefore had no outlet or felt no escape from the care burden – again here we heard refrains about people being able to live their own life.

- The impact of the specific family relationship on the caring experience, for example if someone was a daughter, wife, husband, they would have a different relationship to the caring itself, and the difficulties of caring if there was a troubling family dynamic.

- The physical burden of caring for much older people with heart failure. One carer had put off an important operation because she could not then care for her husband. This was impacting her own health and physical symptoms.

- The pressure and mental health impact of ongoing and constant anxiety for carers about the wellbeing and status of the person they are caring for. Disrupted sleep and pressure of needing to explain to social network and professional caregivers in a way that best represents the person they care for needs given the uncertain progression.

- The isolation carers and patients both face as their social networks and support fall away because they have less mobility to meet others, or when they do, they are considered to be inappropriate for speaking about illness or causing discomfort to others. For women, an idea it was their duty to care was discussed.

- The impact on people's mental health and feelings about death when the word hospice is mentioned: "the first time we came to the word hospice it was like an arrow in the heart to her (patient). From there on she would only say: 'I'm going to die'."

- The theme of constantly having to re-negotiate acceptance and hope or lack of either (whether being unable to find them and their importance) in order to cope, balanced with the uncertainty heart failure represented.

- The importance of future planning conversations, advance care planning and especially Do Not Resuscitate conversations held with HCPs. Carers especially thought it 'wise' to have had these conversations facilitated for them, because it removed a burden, and so welcomed them. They also spoke openly and with interest about the topics of assisted dying and advance care planning. Carers felt that patients were more anxious about the topics and suggested there was continuing prep work to bring the conversation to patients 'give me time'.

Key themes - healthcare professionals –

"we look after them because nobody will"

- For specialists in this area diagnosis issues and lack of formal support pathways or teams means that people fall through the cracks with heart failure and at times there is no obvious team to support them – "it feels like we are back where we were with cancer ten years ago". This is particularly true for HFpEfs who were referred to as a 'forgotten group'.

- There was shared uncertainty about when to refer people to hospice care: some said they often end up referring people when they only have a couple more weeks of life left to live. In general, because of the project they are able to refer people earlier and more consistently, and they feel that they now have more confidence in referring people earlier when this would make more difference.

- They welcome the additional interventions through this project which have ensured far smoother transitions. HCPs described the situation previously like a merry-go-round where people would come in and out of services.

- They felt uncertain at times about how to speak about the hospice or describe it and used different methods. They welcomed the support provided through the project about how to communicate and asked for continuing support and training with this area.

- The importance of holding ongoing conversations with people about what the end of life might look like, and continually asking people to think about planning for all eventualities, was also confirmed by HCPs.

- However, views differed on telling people 'the truth' about heart failure. Some said that they didn't have a crystal ball because of the uncertain trajectory of heart failure. Others agreed that in reality, people would not want to know what would ultimately end their life so it was best not to know. They also suggested that the term heart failure scares people and

confuses them. Related to heart failure, people have an idea that hospitals can fix them. Some hospital teams may exacerbate this idea of a fix when the reality is people need to know more about what will happen.

- Community hubs would improve accessibility to hospices as patients often feedback that the hospice is too far away. But this is also part of their pushback – at times patients feel that hospitals are giving up on them because they don't understand hospice care.

Recommendations that people made to improve these situations:

Joining up and working across systems, organisations working together:

- Organisations working together to improve referrals and knowledge of the system is important. The project worked across healthcare organisations to ensure excellent transitions in care and that people access end of life care. Our team engaged proactively with HCPs in other institutions in order to support access to hospice services and good transitions. HCPs commented on how different and helpful the approach of the heart failure project was. It had helped them better refer to hospices, understand hospice services and describe them. They wanted to encourage practices like this to continue.

- The importance of the hospice also being able to recognise when it should refer to other healthcare providers and specialists e.g. gerontologists was also recommended. MDMs that involve people from organisations work very well and should continue.

HCPs can support referrals and health promotion in every conversation:

- Health promotion supported by HCPs, with the hospice supporting HCPs to talk about what a hospice offers in order to encourage people to take up referrals and accept them; to train HCPs to talk about palliative and end of life care provision in order to support this process and to keep establishing good lines of communication across places and institutions.

- Information being provided to patients and carers early on, more public education about heart failure being provided and in different formats, not just digital or paper-based.

- Health promotion directly from patient to patient, in the shape of films for example, or peer groups and educators, about hospices and about heart failure.

- For community support, peer groups where people could talk about their experiences and learn from each other about heart failure, and also other topics about living with ill health, advance care planning and coping would be welcome.

- Equally, hospices and healthcare providers can work together to consider the language of referrals, as they have done this many times.

Added outputs of the groups

As well as providing feedback and recommendations, as part of the process of the project we began to trial approaches and evaluate them during the project. The two key areas we worked on were the peer support groups and films, both of which are still developing as a legacy of the project.

1. Carers peer support groups -

In the act of taking part in the first focus groups people recognised multiple benefits to exploring a situation with other people experiencing something similar. They discussed their experiences of being patients, or carers, and important topics related to staying well and the end of life, including areas such as assisted dying, future planning, recognising symptoms of heart failure and managing multiple conditions, as well as carer fatigue, and goal setting.

As a result, they asked for them to continue and we transitioned them into a peer support model which will run until April 2025. The groups will continue to be facilitated by a staff member in a community location which is more local and accessible than the hospice with a review of the groups, their outcomes and whether to continue them specifically for heart failure carers.

2. Films made to help people understand experiences –

Two films about experience have been made and will be used to support patients, carers and also the training of HCPs. One of the films has already been shown at the conference along with a presentation of the themes reported on here.

- A film of a patient sharing their experience to help people referred to hospice understand what the experience could be like
- A film made by a carer describing his experience to help other people understand it and the care and dedication he put into care; also the anticipatory loss he had dealt with.

Feedback from HF team

We asked for feedback from the Croydon Heart failure (as this was a new service for them), on how confident they felt before and after having the integrated service, discussing or referring patients and how working together has shaped their service and the impact on their work.

Table 10: feedback from Croydon HF team

	Before the service		During/ after the service	
How familiar are you with palliative care and what it offers?	50%		87%	
How often would you refer your patients to palliative care?	Once or twice a yr	66% (4)	Once or twice a yr	
	Once or twice a month	17% (1)	Once or twice a month	83% (5)
	Once or twice a week		Once or twice a week	17% (1)
	Other	17% (1)	Other	
How confident do you feel talking about palliative care?	Not so confident	34% (2)	Not so confident	
	Somewhat confident	50% (3)	Somewhat confident	
	Very confident	16%(1)	Very confident	67% (5)
	Extremely confident		Extremely confident	33% (1)

Individual impact on practice/ care:

The team report a better understanding of how palliative care can support their patients with more awareness of what services are available, that it is not just about end of life care but helping people to live with their HF. They feel more confident and proactive in making referrals at an earlier stage, recognising there is benefit in terms of symptom management and quality of life. They also noted feeling more confident in approaching sensitive conversations and talking to people about what matters to them. They felt an improvement in their symptom control skills. They felt lucky to have the service, reporting it was well-managed and feel they are in a better place now to support their heart failure patients, they felt it really helped having a single person as their contact and someone to discuss their patients with rather than just making a referral, and they want representation to carry on. They felt by working collaboratively patient care was more streamlined and their patients were supported much better, and they were also able to alleviate fears around referral to St Christopher's because they were referring to a specialist within palliative care who would understand the journey they have been on and their specific needs.

Joint working was also mentioned as having helped them to increase their confidence and competence in having challenging conversations.

Conference and communities of practice

Community of practice (CoP):

We ran 6 online sessions (1 a month)

Table 11: summary of community of practice topics and attendees

VCOP	Date 2024	Time	Topic	Speaker	Number of attendees
Session 1	Wednesday 24th January	3.00 – 4.30pm	Likely trajectory	Isobel Jackson- STC palliative heart failure ANP	80
Session 2	Tuesday 13th February	12.30 – 2.00pm	Meaningful conversations	Dr Joy Ross STC Consultant & Isobel Jackson	35
Session 3	Wednesday 6th March	3.00 – 4.30pm	Symptom management in heart failure	Dr Sidhu – Croydon Lead Heart Failure Consultant	**55**
Session 4	Wednesday 10th April	3.00 – 4.30pm	Symptom management EOL in heart failure	Dr Ross and Fiona Hodson Nurse Consultant	43
Session 5	Wednesday 8th May	3.00 – 4.30pm	ICD's	Dr Mohammad Albarjas – Bromley Lead Heart Failure Consultant	28
Session 6	Tuesday 11th June	12.30 – 2.00pm	Changing focus of rehabilitation	Gail Preston STC rehab	35

We had 201 delegates sign up in total with 69% of those being external to St Christopher's and 74 organisations in total with the most being in primary care.

We developed a learn site where the recordings and any additional resources were stored for people to access at a later date should they not be able to attend, however the majority acknowledged they registered but did not access the learn site.

Attendees seemed to value the case studies and opportunities for break out rooms and discussion, to learn together.

Appendix 8 shows the professional learning event review and summary of other teaching given.

We had a family member of a patient come and speak with us about their experience of living alongside heart failure and the challenges around advance care planning. This also led to us producing a video of an interview with him which was utilised at the conference.

We also carried out a survey monkey to establish what the barriers were to people accessing the learn site, their thoughts on the future of the community: We received 18 responses:

67% said they had accessed the learn site and 100% of those felt it met their needs

For those that didn't access it the majority was due to time constraints.

89% of delegates felt they wanted the community to continue with 6% saying no and 6% unsure.

Future areas they wanted us to focus on included:

- Heart failure symptoms
- Fluid management
- New services and evidence

81% of responders wanted the shape of the community to be a mix of peer learning, case-based discussion or webinar format.

People felt the community was a good network with valuable information and resources.

Conference

We ran a one-day hybrid conference – "Improving Palliative Care for People with Advancing heart Failure" with 77 total delegates (external) with 39 virtual and 38 in person and 12 (St Christopher's staff 8 virtual and 4 in person).

8% delegates were international 32% national 30% from the home counties and 30% local i.e. St Christopher's catchment area.

The majority of attendees were from the hospice sector.

Overall rating for the conference was average 4.59 / 5, with 47% stating that the conference answered their gaps in knowledge and 44% stating to some degree.

78% of people felt the conference motivated them to think about the future of end of life care and the elements of the programme that they felt had the greatest value for them were:

Nobody told me I had heart failure- the voice of the lived experience

Innovative efforts in practice- 2 case studies from the other hospices providing a collaborative approach, and collaboration opportunities.

Appendix 9 shows the Professional Learning summary from the conference.

The feedback from the conference was overwhelmingly positive, especially regarding the virtual experience. Many found the content inspiring and practical, with particular praise for the opportunity to hear about collaborative projects and challenges. Some delegates felt the conference lacked information about symptom control and patient care, however they would have been signposted to join our community of practice which is more relevant for this area.

Other literature produced

HUK poster- our abstract for this year's hospice UK conference was accepted as a poster presentation. As such a poster has been produced showcasing the projects merit for one years' worth of data.

Sub cut furosemide brochure-the decision support tool has been converted into a handy A5 sized brochure for health care professionals to sue when out and about reviewing patients**.**

Patient literature- we utilised the literature from the initial pilot project making some small adjustments and these have been used by ourselves as well as the heart failure teams to promote the service and give information to patients/ carers of what to expect from the service.

Nursing Times article- this is currently in progress, hoping to be completed and sent off soon. This aims to show case this service as an innovation piece, highlighting the benefits of collaborative working across organisational boundaries as well as highlighting the benefit that palliative care brings to those people living with and dying from heart failure.

Key Learning

Clinical

- Collaborative working increases referrals, improves Hf teams confidence in talking to their patients about palliative care .
- Improves access to SPC for those who don't have HFrEF
- Improves patient outcomes
- More likely to die where they want to and avoid hospital
- Reduces deaths in hospital

Education

- HCPs value the community of practice and want it to continue
- HCPs want more focus on symptom control
- HCPs value case study discussion and shared learning forum

- Experiences from across organisations, geographies and speciality brings a wealth of resource to utilise

Co-design

- HCPs value the community of practice and want it to continue
- HCPs want more focus on symptom control
- HCPs value case study discussion and shared learning forum
- Experiences from across organisations, geographies and speciality brings a wealth of resource to utilise

Infusion service

- Well received by patients
- People happy to come to the hospice
- Improves level of fatigue and enables people to live well
- Could be delivered by an Outpatient nurse rather than HF specialist
- Challenges around utilising for IV furosemide when SC is offered and limited HCP resource availability

Recommendations for ongoing service development

- Continued collaborative working- single point of contact at hospice or in palliative care for HCPs externally is important
- Continued learning together in the form of a community of practice or series of webinars is valued and wanted
- Utilise Outpatient teams at the hospice to deliver infusions which would free up specialist nurses to assess and plan care safely and effectively and value their expertise
- Heart failure peer support groups should continue to enable shared support and learning of experiences for this specific demographic.
- Hospice should consider linking in more with external MDMs to enable education, support and improve transitions for patients between organisations.

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Appendices

Appendix 1: Timeline of project and activities

Timeline of project and allied activity

Date	Project activity	Allied activity
3/4/23	Start date	
05/04/23		ACNS teaching
12/04/23		ACNS teaching
17/04/23	Interview for Bromley HF ANP 1st meeting with community action lead	
18/04/23	PRUH teaching- what palliative care has to offer	
19/04/23	1st Meeting with education lead Meeting with SystmOne lead regarding data management	ACNS teaching
25/04/23	Meeting with Karen Barkway- Croydon transformational lead	Meeting about Sub cut furosemide template on SystmOne Meeting about writing up sub cut furosemide
28/04/23	1st steering group	
04/05/23	Meet with Bromley GP Meet with Comms about patient information leaflets	
05/05/23	1st meeting about IPU(outpatient infusions service) plans	
09/05/23	1st meeting with Croydon community HF team	
16/05/23	2nd meeting with comms, Met with Mark Essop regarding Bromley GP referral pathway Meeting with EoL steering group lead Croydon- regarding Croydon GP referral pathway	
17/05/23	RGS conference	
19/05/23	Met with Jenny Welstand	
30/05/23	1st CUH HF MDM cancelled Teaching at the PRUH- sub cut furosemide	
2/6/23	Met with spoc ctl- re referral flow 1st frailty/ complex care MDT- introductions	
01/06/23	Meeting with AM Care director	
02/06/23	2nd spoc meeting regarding patient flow CCT MDT	
05/06/23	Working group starts Gemma in post	
07/06/23	Meeting with Croydon lead pharmacist – identify issues with sub cut furosemide in Croydon	
12/06/23		Support for Gemma at first Bromley HF mdm

13/06/23	1st Croydon HF MDM Data protection Impact assessment meeting	
21/06/23	2nd meeting- Croydon ICB leads and pharmacy regarding moving sub cut furosemide forward in Croydon	
22/06/23	2nd meeting with Croydon STC team Met with Jan Noble re project management	
26/06/23	Steering group 2	
03/07/23	Present at care cabinet to present infusions service	
04/07/23		Presented on HCUK conference- NMP in cardiology
05/07/23		Presented at St Georges- for ESC faculty MSc programme- on integrating palliative care and palliative interventions Presented on HCUK conference NMP in EOL care
06/07/23	Presented HF service to Croydon EoL steering group	
20/07/23	Day with HF CNS in clinic	
11/07/23	Meet with rehab tram regarding linking in CT and rehab for the infusion service	Global palliative care meeting
18/07/23	Teaching with Croydon HF team on palliative care	
19/07/23	One croydon Alliance meeting- present HF service	
25/07/23	Clinical leadership group- presenting HF service	
27/07/23	Shared learning meeting with Hull	
01/08/23	Joint visit with consultant geriatrician Croydon	
02/08/23	Croydon GP meeting- presenting service including referral criteria	
15/08/23	Meeting with Karen Barkway and Deba Hussein regarding referral stream	
16/08/23	Meeting with Thomas Fischer Bromley regarding refreshing GPs about the service	
23/08/23	Meeting with community action lead	
30/08/23	1st Community action focus group- 6 attendees Caritas	
01/09/23	Meeting with James Harrison- re 6 month report	
06/09/23	Burdett Symposium	
07/09/23	Day with rapid response	
28/09/23	Teaching with CCT and Community nursing Croydon Meeting with Mark Essop finalised Bromley GP referral process on emis.	

11/10/23		Present on HCUK conference- EOL care for HF patient
23/10/23	Budget meeting	
24/10/2023	Steering group meeting 3- Extension approved	
30/10/23	Prep for COP and conference began	
28/11/2023	Infusions service presented at MOG- SOP approved	
30/11/23- 01/12/2023		British Society for heart failure annual conference
06/12/2023		Meetings with 2 Pal HF services- London and Dorothy House- sharing experiences and learning
07/12/2023	Croydon EOL steering group	
12/12/2023		Present at NMP in EOL care HCUK conferences- presenting HF service
08/1/2024	Planning for conference kick off 1 Meeting to plan/ support with community action workstream	
10/01/2023	2nd focus group- Croydon	
22/01/24	**Steering group 4**	
24/01/2024	**1st COP**	
07/02/2024	**3rd Focus Group - Carers**	
08/02/2024	Croydon EOL steering group	
13/02/2024	**2nd COP**	
15/02/2024	Medications in Croydon meeting	
27/02/2024		Teaching on KCL symptom control module
06/03/2024	Interview for comms 3rd COP	
07/03/2024	Croydon EOL steering group Conference meeting 2	
04/03/2024	Conference meeting 3	
15/03/2024		Gemma presented at HCUK conference – improving EOLC for ppl with CVD and HF
10/04/2024	4th COP	
16/04/24	4th Focus Group – carers	
23/04/2024	HCP focus group	
24/04/2024	Steering group 5	
08/05/24	5th Focus group- carers 5th COP	
09/05/2024		Teaching on GP COP
21/05/2024	Teaching to HF team Croydon- outcomes of the project so far Conference meeting	
23/05/2024		Bromley Cardiovascular group meeting
29/05/2024		Wednesday learning forum- DAPA update
11/06/2024	Conference meeting 6th COP	
19/06/2024	Conference	
20/05/2024		Presenting to Bromley CVD group

04/07/2024		Teaching to doctors ST Christopher's
11/06/2024		Geriatric registrar shadowing for the day
23/07/24	Steering group 6	
20/08/2024		Teaching to rapid response Croydon- what is palliative care

Ongoing meetings:

Complex Care Team MDT Croydon- 1-2 per week 1 hour

Croydon Comm HF team MDT 4 hours a week

Bromley HF MDT once a week 2 hours

Bromley palliative heart failure MDM once a month

Working groups:

5/6/23, 19/06/23, 25/07/23, 01/08/23,15/08/23, 29/08/23, 26/09/23, 10/10/24, 24/10/24, 07/11/24, 19/12/24, 13/02/24, 26/03/24, 09/04/24, 07/05/2024, 16/07/2024

Other activity / personal development opportunities:

ACP course- monthly study days (2-3 days at a time)

Clinical supervision and coaching

Management course- 4 afternoons

Masters module started in January- 6 days at Uni

Appendix 2: Summary themes from steering group meetings

Key themes from the steering groups:

SG1- Relationship building, linking in with external services; data protection and scoping out patient touch points to enable reach.

SG2- Referrals starting to come through from Croydon, patient and GP literature completed and being distributed, new HF ANP in post, links with EOL steering group in Croydon, starting to move forward with education and co-design, issues flagged with access to injectable furosemide in Croydon due to limited formulary.

SG3- Increasing referrals coming through, positive feedback from the HF teams around impact, starting to move forward with infusion service- laying the foundations, agreed to request an extension from Burdett as over referral target and to enable effective attention at the allied elements of the project. Infusion service plans submitted to Medicines Optimisation Group for governance sign off, 6month data reviewed.

SG4 - Focus groups started as part of co-design, plans started for the conference, infusion service ready to go, first community of practice planned with over 100 delegates signed up so far, changes made to community team now seeing patients first and referring on and some patients to be considered for advice only, admin support considered.

SG5- Continued issues around provision of furosemide in Croydon, discussion around conference presentation and abstracts/ sharing learning from the project, conference shaping up and focus groups continuing, we reviewed the telemonitoring aspect as this had not been started yet, thinking about the benefit this may or may not offer and to look at scope of our service as opposed to other services already set up with this, thoughts voiced about succession planning, recognition noted about the benefit of this specialism, and thoughts were voiced about mapping future educational opportunities.

SG6- Continued challenges with sub cut furosemide, 1 yr. data reported on with positive outcomes for PPD achievement, number of referrals and time on caseload. Conference had been completed with positive feedback, 5-6 focus groups already carried out, noted St Christopher's CPCT reporting improved competence in supporting people living with/ dying from heart failure and feedback from the HF team positive about the integration, thoughts voiced about the use of webinars to share learning moving forward.

Appendix 3: Case History - Advance Care Planning

AB - 54yr Male with HF (reduced EF 10-15% and moderate mitral and tricuspid valve regurgitation)

Ethinicity: Asian, British, Pakistan

Past Medical History: Type 2 Diabetes on insulin, Renal failure (eGFR 13), Hypercholesterolaemia

Referrals: Social work, District Nurses

ACP: DNACPR, treatment escalation – ceiling of treatment home, PPD Home

Social: Married, 1 daughter, 4 sons, Muslim faith

Patient AB was initially referred from rapid response for help managing fluid overload. He had struggled with an extensive hospital stay due to complications from diabetes, an amputation, renal failure and fluid overload secondary to his heart failure.

On discharge from hospital he was seen by one of the St Christopher's Community CNSs who recognised the complexity of his situation and requested specialist heart failure input. The geriatric registrar who supports rapid response also requested support and we arranged a joint home visit.

The key issues for him were:

- *Significant fluid overload with oedema to mid abdomen and ascites. He could not sleep or lay comfortably in bed due to severe orthopnoea and would become agitated getting from bed to chair and back again frequently.*
- *High symptom burden with agitation, intermittent confusion, ongoing infection from a UTI and from an infected amputation injury with a vacuum dressing insitu, frequency of passing urine, and poor sleep, reducing mobility and increasing care needs.*
- *Carer stress with a young daughter taking centre stage for decision making and translating for her father in the context of a strong Muslim family. He also developed fluctuating capacity and decisions were being considered in his best interest at times when he lacked capacity.*
- *Families expectations around treatment escalation plans wanting to source more intensive care in the acute sector versus him wishing to remain at home on a background of limited improvement during his recent 5 months in hospital.*

Discussions around appropriate treatment options for managing his symptoms were challenging in the context of a family who disagreed at times with his decision making and wish to remain at home. We weighed up options in terms of sub-cutaneous furosemide versus alfentanil to aid breathlessness and fluid levels, starting with an alfentanil pump which allowed the first good night's sleep he had had in weeks with improved breathlessness. This was followed by a furosemide pump due to escalating oedema causing distress. Conversations were had about balancing his end stage renal function with symptom control and how we can support him and the family to allow him to stay at home. The family, especially his wife, were not fully in agreement with a decision around resuscitation. His daughter, although she agreed in principal, had resuscitated her father at home once before and although she knew it was not the right treatment for him, would particularly struggle to not try this again.

A DNACPR decision was put in place based on medical grounds due to the rapidly deteriorating clinical picture and clear patient wish to not go back to hospital, and the family were supported to see why this was actioned and important to his care. The daughter was supported and equipped to know what to do in the event of his death, and that it was ok not to do anything but call us for help.

Case History contd:

Night sits were arranged, fast track funding put in place and medications arranged. He died peacefully at home with his family around him. All this was possible because of joined-up working with the rapid response team who shared his experiences from before referral and gave background information, staying alongside to help facilitate things like blood tests, urine tests and joint working.

Some additional complexities were to do with father-daughter boundaries and a young daughter holding the burden of decision making. The intersectionality of ethnicity and language along with gender may have contributed to late access to palliative care and non-existent conversations in the acute sector about the end of life and planning ahead

Appendix 4 – subcutaneous furosemide decision tool and SOP

Sub Cutaneous Furosemide in the management of Heart Failure Policy (2024)

Outline the details of the organisation's position on a specified subject

Document Control Information		
Responsible Committee:	**Medicines Optimisation Group**	
Lead Author(s):	**Isobel Jackson**	
Supporting Author(s):		
Approved by: **(Job title)**		**Date: September 2024**
Date of Next Review:		
Document Objectives:	**To support colleagues in the community and inpatient teams to assess, prescribe, administer Subcutaneous furosemide alongside monitoring and coordination of care.** **This is aimed at those patients with Heart Failure presenting with fluid overload who wish to avoid hospital admission and their oral diuretics are now ineffective at managing their symptoms.**	
Policy Summary:		
Other related internal documentation		
Key words (to aid Discovery on The Vine)	**Sub Cutaneous Furosemide, Heart Failure, End of life, symptom control**	

1. Introduction

Heart failure is a chronic condition affecting over 500000 people in the UK accounting for 1 million bed days in the acute sector per year and 5% of all emergency admissions and is a growing concern, with many services focused on acute care and up-titration of heart failure therapies.

Due to the nature of heart failure, towards the end of life, people living with heart failure will have frequent episodes of acute decompensation leading to increased symptom burden including severe breathlessness, fatigue and oedema- the culmination of which will lead to frequent unplanned hospital attendances to obtain IV off loading at a time when remaining at home would usually be their preference.

There are services currently available offering intravenous diuretic therapy in patients' homes which is supported by a number of national organisations. The use of both IV and SC diuretics has been piloted in a number of areas around the UK and has been found to be effective in the management of fluid overload and associated symptoms leading to reduced hospital admissions. That said, it is not always appropriate to offer IV therapy to patients at the end of their life, especially those with low BP, poor renal function and / or are frail.

By offering sub-cutaneous furosemide in the home setting we are enabling people to remain in their preferred place of care with limited complications. The outcomes from our previous audit of practice showed that SC furosemide was both effective and safe for administering at home for people at the end stage of their heart failure with better outcomes on renal function, blood pressure and patient tolerance.

The main outcomes from offering this service include:

- Reduced hospital admissions
- Improved patient experience and management of symptoms
- Improved outcomes in terms of achieving PPD/PPC- enabling better choice at the end of life

St Christopher's provides direct care to people living with and dying from heart failure across all boroughs. Since the commencement of the relevant heart failure services we are now reaching and supporting more people living with and dying from heart failure and aim to provide support to enable this demographic to remain in their preferred place of care.

Clinicians at St Christopher's should be empowered to make a clinical assessment of need for this treatment and be confident in initiating therapy where appropriate, on the inpatient unit or in the community- be it in patients' homes or care homes.

Advantages to the patient include:

- The option to remain at home
- Avoids intermittent IV furosemide and the siting of a cannula
- Allows mobility and continued independence
- Allows community staff to plan care around timing of the infusion

2. Purpose

This policy seeks to empower our clinicians to assess individual situations, make prescribing decisions, enact treatment and safely monitor and co-ordinate care for those people receiving sub-cutaneous furosemide as part of their care.

Although the guidance refers to individuals with heart failure- there will be patients who may also benefit and who may be prone to fluid overload such as those living with severe valvular heart disease or pulmonary hypertension.

Allied community services may limit their treatment options for SC / IV diuresis based on renal function or BP- under the guidance of palliative care when the focus shifts towards symptom

management and end of life care- these parameters may become less relevant, however discussion with the individual about this will be needed to enable informed consent.

Eligible Patients:

- End stage heart failure patients (preserved or reduced EF), who are unresponsive to high dose oral diuretics with poor venous access
- End stage heart failure patients (preserved or reduced EF), who wish to avoid hospital admission or attendance as day case and IV diuretics cannot be offered in the community
- End stage heart failure patients (preserved or reduced EF), who cannot tolerate or may decline IV diuretic therapy
- End stage heart failure patients (preserved or reduced EF), in the last days of life who require high dose diuretics to manage symptoms
- Consider for use in end stage renal failure with fluid overload but discuss with consultant/ renal team first- not suitable for patients who are anuric.

Inclusion criteria:

- Patients who have a confirmed diagnosis of heart failure on echo (preserved or reduced)
- Able to consent to treatment or decision made in best interest in collaboration with their next of kin or LPOA
- Suitable for SC administration/ not appropriate for IV therapy
- Able to access toilet facilities safely
- Evidence of fluid overload or severe fluid retention which has failed to be relieved by other means- utilise decision support tool, and a cardiac assessment has been carried out
- Weight gain > 3kg above dry weight **+** signs and symptoms of fluid overload

Exclusion criteria:

- Patient or NOK/LPOA in best interest does not consent
- Severe postural and symptomatic hypotension (review antihypertensive medications first)
- Hypotension with a systolic BP < 80mmHg
- Patients in acute mental health crisis or state of delirium.
- Concerns about risk in terms of home set up- falls risk, lacking social support (see decision support tool)
- Previous reactions to IV furosemide including site reactions to SC therapy.

3. Scope

This policy covers all patients with heart failure or associated diagnosis, receiving direct patient care from St Christopher's in all boroughs.

There will be variability in how medications are sourced and administered depending on the borough in which they reside. For example, GP's in Bromley can prescribe furosemide according to the SEL formulary, however in Croydon, GP's are unlikely to be able to prescribe

due to the SWL formulary marking it as hospital only- as a result the local community pharmacy are unlikely to stock this and we may have to dispense from our stores.

For those residents of Croydon, there will be times when the treatment of fluid overload is managed via close coordination with Croydon Rapid response service who also provide this service. Parts of this policy will have roots in their policy to enable a more joined up service.

Symptomatic management of dyspnoea should be initiated concordantly alongside the use of diuretics using opioids and/or benzodiazepines.

4. Definitions

Heart Failure:

Heart failure is where functional or structural abnormalities in the heart lead to insufficient blood being delivered at a rate commensurate with the bodies requirements. Leading to symptoms of breathlessness, fatigue and fluid build-up/ oedema.

Fluid Overload:

When there is more fluid in the circulating system than the heart can manage. This occurs when the circulating volume is excessive resulting in pulmonary oedema, peripheral (legs/ arms/hands) oedema, sacral, and abdominal oedema, usually resulting in reduced efficacy of oral diuretics due to gut oedema. (Tidy 2024)

Cardiac Assessment:

This will include the following assessments-

- Blood pressure- lying or sitting and standing (if possible)
- Manual pulse rate
- O2 saturations
- Heart sounds (where trained to do so)
- Chest auscultation (where trained to do so)
- Assessment of peripheral oedema
- Weight history- preferably with a known dry weight if available and appropriate to monitor

Pulmonary Oedema:

An excess of fluid in the lungs- usually heard as fine crackles on chest auscultation. This can occur gradually over time or acutely resulting in sudden acute breathlessness and can trigger urgent admission to hospital. This is usually managed with IV diuretics and O2 in the acute phase. Usually acute pulmonary oedema would be managed in the acute sector, however at the end of life this may not be appropriate and consideration for symptom control in terms of opioids +/- midazolam may be more appropriate in the home or hospice setting.

Symptomatic hypotension:

Symptoms of dizziness or syncope on standing- measured as drop of 20mmHg systolic BP or 10mmHg diastolic drop.

5. Roles & Responsibilities

There will be occasions where the prescriber is not the individual (lead clinician / decision maker) making the assessment and starting treatment.

It is the responsibility of the prescriber- non-medical or Doctor – to ensure that SC furosemide is prescribed in accordance with hospice policy and approved medicines guidelines and within their scope of practice. This should only be prescribed once other diuretic therapy/ options have been exhausted.

The prescriber should ensure that the lead clinical/ decision maker has discussed the nature of unlicensed medication administration with the patient and /or NOK and that consent has been obtained for the treatment.

It is the responsibility of the lead clinician / decision maker to ensure appropriate follow up is arranged both in terms of district nursing and GP input, St Christopher's follow up as well as appropriate monitoring of renal function and blood pressure.

The lead clinician / decision maker should ensure that the treatment is correctly documented on SystmOne- ensuring the sub cutaneous furosemide tab on the medications section has been completed, sending a task to the heart failure team to alert them that a patient has been commenced on sub cut furosemide. This will enable more support to be accessed should the need arise and ensure collection of appropriate data for evidencing practice.

Dosage changes should be documented clearly on the patients record with reasoning by the decision maker at the time.

Depending on who is administering the treatment- as collaboration across organisational boundaries is needed to ensure service provision- the administering practitioner will follow own local guidance on the safe use of syringe pumps and will follow own local infection control policy.

6. DECISION SUPPORT TOOL

The following decision support is to be used to help guide decision making for those less familiar with the use of subcutaneous furosemide. It does not replace individual clinical reasoning and decision making and is intended as a guide only. There will be occasions where individual patients do not meet the exacting criteria. In these circumstances if the clinician is uncertain about their decision-making process they must discuss the clinical scenario with a senior clinician, consultant or heart failure team. It may at times be necessary to discuss with a cardiology consultant- in these circumstances please liaise with the relevant heart failure clinician/ team to support this.

Step 1- identify patient who would be eligible as per the eligibility criteria above

Step 2- follow the decision support flow chart:

*Alternative options that may be available prior to considering-

1) Lifestyle measures (fluid restriction, compliance with medications)
2) Consider switch from furosemide to bumetanide
3) Consider thiazide diuretic +/- MRA

4) If symptomatic hypotension consider non-HF antihypertensives e.g. doxazosin/ amlodipine
5) Consider temporary reduction/ withdrawal of ACEi/ARB/SacVal/MRA if needed hypotension- discuss with cardiology

Decision flowchart

Trial of sub-cutaneous furosemide- follow Process/procedure

7. CONTRAINDICATIONS / CAUTIONS

In the final days of life these precautions may not necessarily be a deterrent to use, dose will need to be carefully titrated and discussion with senior clinician considered if uncertain:

Contra-indications	Cautions
Hypersensitivity to loop diuretics	BP < 90mmHg
Hypovolaemia	Impaired micturition (ensure patient is able to safely pass urine- rule out risk of retention)
Dehydration	Gout (may worsen or cause flare)
Severe hypokalaemia (K+ < 3.3mmol/l)	
Severe hyponatraemia (Na+ < 130mmol/l)	
Anuria	
CrCl< 30ml/min per 1.73m²	
Hypersensitivity to sulphonamides	
Comatose or pre-comatose states associated with hepatic cirrhosis	

8. PROCESS / PROCEDURE

- **Aim:**

To reduce symptoms of fluid overload by the shortest time and lowest dose of diuretic possible to achieve the desired outcome.

Key points to consider

- Dose should not be altered within 72 hours of commencement to enable safe adjustment according to response
- Dose should be reviewed every 48- 72 hours in the community / 24 hours in IPU, aiming for weight loss 0.5 – 1kg daily
- The patient/ NOK must be counselled on side effects- including discussion around safe toileting and what to do out of hours should any issues arise.
- Ensure baseline observations and renal function are documented and baseline weight (if appropriate to weigh)
- Provide guidance to patient/ NOK around fluid restriction
- Check medication adherence and that an up to date medication list is documented- ensure subcutaneous furosemide template is completed on initiation and discontinuation.
- Ensure UCP is up to date for those patients in the community
- Furosemide should be used as a solitary agent in a syringe pump and not mixed with other agents.

Prescribing and administration:

➢ Use previous 24-hour dose of oral Furosemide (or equivalent if using Bumetanide) as the starting dose for continuous infusion i.e. 1:1 oral to SC ratio for Furosemide and titrate up/

down according to response and titrate up/ down according to response. 1mg Bumetanide is the equivalent to 40mg Furosemide.

➢ STOP oral loop diuretics (Furosemide and Bumetanide) whilst on the infusion

➢ Furosemide should be diluted with normal saline or water for injection- or can be administered undiluted if not enough capacity to dilute. Maximum dose in 24 hours via McKinley T34 pump would be 230mg in a 30ml syringe, but check own local policy on syringe driver guidelines

➢ Please follow local procedures and guidelines about the use of syringe pumps

➢ Furosemide ampoules are supplied as 10mg/ml and are available in 2ml, 5ml or 25ml ampoules

➢ Check baseline BP on commencement of Furosemide syringe driver

➢ A District Nurse referral should be completed for them to re-prime the pump and check BP at each syringe change and report any symptoms of concern such as site reactions and low BP. ***Highlight to DNs' the importance of target BP > 80mmHG systolic.***

➢ GP should be notified as soon as possible and asked to URGENTLY prescribe Furosemide ampoules (if they are able to do so)

➢ If starting close to a weekend please ensure we provide enough initial supply to cover.

➢ Patient should be reviewed regularly to ensure effectiveness of regime but also to monitor for signs of over diuresis and that patient is tolerating therapy.

➢ Renal function should be checked 3-7 days after commencing or as close to this as possible- this may be less relevant if administering for symptom control at the end of life

Appendix 5 – SOP outpatient infusion service

Infusion Service

Outline the details of the organisation's position on a specified subject

Document Control Information		
Responsible Committee:	**Medical Optimisation Group (MOG)**	
Lead Author(s):	**Isobel Jackson**	
Supporting Author(s):	**Joy Ross, Amanda Mayo, Fiona Hodson**	
Approved by: **(Job title)**	**MOG**	**Date: 28/11/2023**
Date of Next Review:		
Document Objectives:	**To outline the processes in place for referral into the infusions service including the eligibility criteria, steps needed to ensure a safe and effective service and the processes for referral, setting up appointments and arranging appropriate treatment and follow up**	
Policy Summary:	**The Palliative heart failure service is aiming to reach more people living with heart failure, who would frequently attend acute services for interventions to manage their symptoms such as IV iron and IV furosemide. By provision of an outpatient infusions service within the hospice setting we aim to reduce inappropriate and lengthy hospital admissions and help to reduce burden of care on acute services., alongside building awareness of this demographic of the benefits of hospice involvement in their care.** **The heart failure outpatient infusions service is a new service aimed at providing an alternative place of treatment for heart failure patients when they require IV intervention for symptom management.**	
Other related internal documentation		
Key words (to aid Discovery on The Vine)	**Heart failure, infusions, outpatients, iron, furosemide**	

This policy applies in the following areas of St Christopher's:

All teams and departments	☒

1. Introduction

We know that our service is now reaching more patients with end-stage heart failure, many of whom no longer wish to receive treatment in the hospital setting and/ or others who struggle with the transition to hospice/ home based care. There is a gap in service provision, where patients could receive active palliative interventions to improve symptom control whilst also introducing them to the wider offer of hospice setting. The aim of this is to explore the feasibility of provision of a day case service to meet the needs of this group of people living with heart failure.

Historically heart failure (HF) patients would routinely be admitted to hospital due to decompensation for off-loading or attend planned infusions services in the acute sector each of which at the end of someone's life are more burdensome and are focused on acute clinical care. This service aims to provide an alternative location and as such increased choice for their treatment as well as providing more insight into the benefits of hospice care for individuals quality of life.

This Standard Operating Procedure (SOP) applies to the St Christopher's heart failure Service; including the heart failure ANP's, Medical support and nurse consultant support who sit within the wider care directorate teams; to deliver best possible outcomes for people living with and dying from heart failure. It will involve close working alongside allied professionals within the hospice setting to ensure the smooth and safe provision of an outpatient infusion service.

2. Aims & objectives

The core elements of the Heart Failure service are to:

- Enable those living with and dying from HF to live as well as they can through a full holistic assessment of need and optimised symptom control
- This includes providing a timely and responsive service to those in need of urgent control of heart failure symptoms including the management of decompensated heart failure and fluid overload.
- Support to carers and important others who support the patient to ensure their information needs are met and their needs are explored.
- Cementing relationships with acute colleagues and streamlining patients to ensure they receive the right care in the right place in a timely way
- Breaking down inequalities in treatment provision between differing Heart Failure diagnoses.
- Provide an alternative to acute hospital setting for an urgent intervention such as:
    - IV Furosemide
    - IV Iron
    - One stop review (including medication review)
- Thereby allowing better choice at end of life for those living with end stage heart failure who may otherwise have limited options about their location of care and level of community support.

3. Definitions

IV Furosemide is offered as a means of off-loading fluid during a period of decompensation of heart failure when the oral route is no longer suitable. Some people living with heart failure receiving support from palliative care may still be appropriate to consider for more intense diuresis using the

IV route, therefore offering this service allows more choice in treatment options for this demographic.

IV Iron is used as a treatment option for iron deficiency associated with heart failure, leading to poor quality of life, poor prognosis and increased hospital admissions. Historically this has only been offered to those patients with reduced systolic function, limiting treatment options for those living with preserved heart failure.

4. Procedures

This outlines the steps needed to safely administer IV infusions in the hospice setting for outpatient palliative heart failure patients.

Consideration would have been given to the option of sub-cutaneous furosemide in the community setting according to patient condition and wishes and IV therapy has been identified as the preferred option.

The patient will have been seen and assessed by one of the Heart failure ANP's or Nurse consultant prior to arranging attendance at the Outpatient Infusion Service and they will have identified that the patient meets the below eligibility criteria:

For IV Iron- this is only for the treatment of non-anaemic heart failure patients- anaemia should have been investigated by the treating cardiology team and/or GP prior to consideration for IV iron treatment (1). If unclear the patient should be discussed with the MDT prior to considering IV iron replacement.

Eligibility criteria:

Furosemide/ One stop assessment	**Iron/ One stop assessment**
Heart failure diagnosis – any aetiology	Heart failure diagnosis – any aetiology
Signs of fluid overload- increased weight > 2kgs of dry weight if known, &/or oedema no longer confined to legs; &/or signs of poor absorption of medications Would benefit from offloading but not in the acute sector Able to be cannulated Well enough to attend hospice for the day- Prognosis > 2 weeks Bloods done in the community within the week before to check renal function/ electrolytes Baseline observations done in the community as per guidelines below and stable. ***Mobility***- Should be able to transfer into/ out of car and able to toilet themselves independently	Ferritin < 100 ug/L **OR** Ferritin 100-299ug/L when TSAT < 20% No clinical signs of infection identified (CRP/ WBC in normal range and no symptoms of infection) Not anaemic- if so, reversible causes considered prior to infusion. Bloods checked for the above including FBC no more than one week prior Symptoms of significant fatigue/ weakness Well enough to attend hospice- Prognosis > 1 month Able to be cannulated Observations stable as per guidelines below and weight documented ***Mobility*** - Should be able to transfer into/ out of car and able to toilet themselves independently

Baseline observations should be available from the patients last clinical assessment (within the last week) and repeated on the day of planned treatment when the patient arrives into clinic.

Should the patient not meet this criteria, alternative plan of care should be drawn up to meet their needs and discussed as a multi-disciplinary team.

Lead ANP will triage and book in all referrals to the service.

To be deemed Stable:

Systolic BP within 20mmHg of baseline and above 90mmHg. No fever. Oxygen saturations within normal range for the patient i.e. > 94% or 88-92% for COPD. Heart rate > 50 and < 100 bpm.

Clinical instability:

Systolic BP < 90mmHg or more than 20mmgHg less than baseline BP; or Heart rate outside normal parameters as above, the patient should be re-assessed and consider discussing with the MDT prior to commencing any treatment. Clinical picture, patient goals and MDM discussion will inform a clearly documented risk/benefit assessment to guide plan of care.

If the patient presents with a fever (> 37.5 degrees C) treatment should be delayed and the patient be assessed for infection. The HF nurse should liaise with St Christopher's medics and/or the patient's own GP or acute services as needed to ensure correct treatment is received.

Implementation:

1- Patient assessed at home by community HF Nurse (Bromley and Croydon boroughs only- during pilot phase Jan- June 2024) and considered appropriate (meets criteria) for day care service with patient consent
    a. Community bloods and observations done prior to referral in to the service and reviewed by HF nurse- patient stable and meets criteria
2- Mode of transport identified by HF nurse who assessed patient at home- patient is encouraged to attend by own means where possible.
3- HF nurses communicate need for intervention with each other either verbally or via tasks on SystmOne.
4- Lead HF Nurse coordinates timing of booking into clinic (to be booked onto HF outpatient infusion service System 1 calendar) which involves the following:
    a. Liaising with pharmacy around drug supply.
    b. Liaising with patient / family around timings
    c. Liaising with admin team for transport booking if needed
    d. Highlights to housekeeping that patients are due to attend
    e. Highlights to medical team (via Dr Ross) to ensure support in place
    f. Liaise with IPU nursing (01 bleep holder) regarding support for cannulation
    g. Liaising with allied services if appropriate – comp therapy / rehab – if available
5- Patient arrives and is shown to clinic room, met by Lead HF nurse or volunteer
6- Patient clerked including, observations, weight, check of blood results, discuss plan with patient and get consent to continue.
7- Medication prescribed on paper drug chart by Lead HF nurse
8- Trained clinician identified to cannulate. During which time- medication drawn up and ready to administer.
9- Medication administered according to policy (see Medusa)
10- Patient monitored including observations and check of IV site.

11- On completion of medication administration- repeat observations and removal of IV cannula (if returning next day for further furosemide risk assessment to be done to deem whether cannula safe to be left in situ or whether daily re-siting is preferable).
12- Once patient has completed all interventions (including rehab/ comp therapy etc) – repeat bloods done as appropriate and patient is discharged from the outpatient infusion service with clear plans for next steps- post treatment information provided including patient literature.
13- At end of all day-care provision, patient is discharged from HF outpatient infusions service and handed back to community HF service and community nursing team and follow up booked in.
14- GP letter sent to inform of service provided and any relevant follow up needed – update sent to GP on day of discharge from the infusions service.

Pharmacy requirements

Pharmacy will be liaised with regarding provision of all injectable medications for the infusions service.

A baseline stock will be kept available for urgent treatment

For all other infusions- the medication will be requested via pharmacy for the individual patient.

5. Roles & Responsibilities

The Heart Failure team encompasses

1- Lead HF ANP providing palliative Heart Failure services to the London Borough of Croydon and facilitating the infusions service
    - The Lead HF ANP will oversee the running of the infusions service and work closely with the Bromley HF nurse to ensure appropriate referrals, coordinate care delivery and discharge back to the care of the Bromley HF nurse on completion of treatment. The Lead HF ANP will also ensure any Croydon patients requiring treatment are reviewed prior to referral as per the implementation process and ensure any post discharge actions are followed up.
2- HF ANP covering Bromley
    - The Bromley HF ANP will review any Bromley HF patients prior to referral into the service and work alongside the Lead HF nurse to ensure appropriate care is delivered and take hand over once the intervention is complete ensuring any post discharge actions are followed up
3- Nurse consultant support
    - The Nurse consultant will act as a support to provide multidisciplinary input and support clinical decision making and in the event of unplanned sickness may act to support to the service
4- Lead Medical Consultant support
    - The Lead Medical Consultant will work closely with the HF ANP's to support clinical decision making and help coordinate medical support for the deliverance of the service.
5- The Pharmacy team will ensure a baseline stock of medication is in place to ensure the service can meet the needs of the patients in the event of urgent treatment being required.

6- The 101 bleep holder will be made aware of patients being treated in the outpatient infusion service – to help coordinate and facilitate treatment in the event of emergency care being needed.

In cases of emergency including anaphylaxis

2222 system will be used to obtain urgent medical assistance.

Anaphylaxis kit will be available in the clinic room.

Extra fluids will be available in case of hypotension.

Medical support will be in place during first transfusion of iron.

Information regarding treatment during emergency will be provided to the patient prior to them consenting for treatment.

6. Training

The Heart failure nurse should be trained and competent in the use of infusion pumps within the hospice setting.

7. Monitoring Compliance & Effectiveness

The service will be evaluated and patients will be asked to complete an evaluation questionnaire – see appendices

8. Updating & Review

9. Appendices

Appendix A

Use of SystmOne

SystmOne will be used to send tasks between the Heart Failure clinicians to aid coordination of the service and highlight patients for referral alongside any actions needed to ensure efficient coordinated care is delivered.

SystmOne will be used to book patients into the diary under the “Heart Failure Outpatients Infusion Service” on the appropriate day and time.

SystmOne could be used to enable data analysis for service evaluation.

Appendix B

Hazards with mitigating factors:

Implementation stage	Hazards	Mitigating factors

1-3	***Referral process-*** patient doesn't meet criteria; error in referral process; Issues with obtaining transport where necessary	• Patient referral rejected if not meeting criteria • Preference for patients to find own way to the hospice, hospice transport only if absolutely necessary • Verbal handover between HF colleagues to ensure team is aware of incoming referral
4	***Coordination of service***- Unable to obtain drugs on time; patient condition changes between assessment at home and booking of HF infusions service; allied services unable to provide intervention due to capacity of service; patient DNA's	• Basic stock levels of furosemide in place to enable reactive service, iron infusions can be more planned as not urgent. • HF team to reassess at home and day-care cancelled until clarity obtained about patient's condition and/ or referral closed.
5-7	***Pre-medication administration*** – On repeat assessment patient not stable enough to go ahead/ change in clinical picture which deems them no longer suitable, staff sickness- service not able to operate	• Patient/ family to be made aware that final assessment will be done on arrival and if signs of clinical instability treatment will either be delayed or cancelled and the patients care plan reassessed. Information regarding this to be in patient literature. • Patient should meet criteria prior to referral • In the event of staff sickness- the patient care plan will be reviewed by senior clinician to amend plan of care.
8-10	***Medication administration***- patient unable to be cannulated, allergic reaction or clinical instability during treatment, patient fall during treatment/ when mobilising to toilet.	• Consider sub cut furosemide instead of IV and discuss option with patient/ family • Anaphylaxis kit available and in the clinic room • Phone access in place to utilise 2222 response • Medical support available- Dr to remain present when first giving IV iron • Consider location of clinic room so more staff around for support if needed- closer to spoc office • Pre, peri and post treatment observations carried out • Patient should meet criteria and have reasonable mobility / be able to self-toilet.

		• 2222 process will be followed in event of drug reaction or severe side effects and senior medical support sought urgently
11-12	***Post medication administration***- patient becomes unstable – needing medical review +/- need for admission or transfer to hospital; transport unavailable or delays to get patient home which may impact on HF service provision for that day and impact on patient experience	• Treatment escalation plan discussed with patient/ family prior to referral- clear plan in notes of whether patient is for hospital transfer or not. Patient / family made aware that if unwell in department ambulance will be called. • Consider volunteer support or HCA to stay with patient while waiting for transport / to be collected by family.
13-14	***Follow up-*** Community follow up delays, failure in process to refer back, errors in communicating with the GP/ community teams.	• Part of SOP will be to communicate with GP about actions taken and outcomes and clear plan for review. • HF nurses to communicate directly with each relevant community team once treatment complete • Consider MDM discussion for each patient referred after completion of treatment.
Overall hazards-	Patient fails to or is delayed arriving; patient instability before during or after treatment; communication breakdown or inability of services to coordinate; medication not being available; drug error.	• Patient/ family clear about expected arrival time/ admin booked transport in advance if needed. • Clear TEP in place, patient/ family made aware that treatment will only go ahead if deemed stable and meets criteria on day of treatment/ emergency equipment and medical support available; • Minimum stocks of furosemide in place; • Second person checking for IV drugs – second person to draw up/ prepare medication to break chain of prescribing/ supply and administration. • Incident reporting will be used

Appendix C

Evaluation of the Outpatient infusion service- nurse to complete part 1; give part 2 to patient

Data collection- PART 1

Name of patient:……

Date of treatment starting ……..

Treatment offered:

Furosemide infusion □ Dose given……

Iron infusion □ Dose given……

Number of days attending for……

Borough:

Bromley □

Croydon □

How did they get to the hospice today?

Own transport □ Brought in by family □ Public transport □

Taxi □ Hospice transport □

Reason for referral

Fluid overload/ unresponsive to oral diuretics □

Hospital avoidance □

Management of fatigue in line with ferritin level □

	Day 1	Day 2	Day 3	Day 4	Day 5
Weights (Kg)					
BP pre tx					
BP post tx					
Bloods					
Creatinine					
eGFR					
urea					
Potassium					
Sodium					

If ongoing- final weight……..

Part 2- Evaluation of the St Christopher's Heart Failure Outpatient infusions service

Many thanks for taking the time to complete this questionnaire. This information will be used to help shape our services moving forward so they meet the needs of our community. All information is anonymous and confidential.

Do you have regular community heart failure nurse follow up (either at home or in clinic) from the NHS? Bromley health care services or Croydon community services.

Yes □

No □

In the last year have you attended hospital for either IV furosemide or IV iron treatment?

Furosemide:		**Iron:**	
Yes, as a day case	□	Yes, as a day case	□
Yes, when an inpatient in hospital	□	No	□
No	□		

Do you feel you had enough information provided to you about the service that was being offered:

Prior to attending?		**&**	**During your time at the hospice?**	
Yes	□		Yes	□
No	□		No	□

If no -what information would you have found helpful?

……
……
…….

Do you feel you had enough information about post discharge support and the ongoing plan for your care?

Yes □

No □

If No- what information would you have found helpful?

……
……
…….

Did you find the services available met your requirements such as the location and set up of the clinic room, toilet facilities, refreshments?

Yes

No

If no, do you have any suggestions?

……
……
……..

How did you feel about attending the hospice prior to coming? Tick all that apply

I was familiar with the hospice and had no concerns about attending □

I was familiar with the hospice but felt unsure about visiting □

I was pleased I could come somewhere for this treatment other than the hospital □

I was anxious about coming □

I was reluctant to attend but I didn't want to go to hospital □

Having attended the hospice for this treatment- how do you feel now about coming? Tick all that apply

I feel the same as before I attended □

I still feel anxious about coming □

I don't want to attend again □

I am pleased to have had this treatment somewhere other than the hospital □

I feel comfortable attending □

I was pleased with the service and have no concerns about coming again □

Do you feel the treatment has helped?

Yes □

No □

Unsure yet- difficult to tell □

Do you have any other feedback you wish to share?

……
……

Remove watermark once policy has been ratified

Appendix 6 – Case History deactivation of cardiac device

AB - 54yr Male with HF (reduced EF 10-15% and moderate mitral and tricuspid valve regurgitation)

Ethinicity: Asian, British, Pakistan

Past Medical History: Type 2 Diabetes on insulin, Renal failure (eGFR 13), Hypercholesterolaemia

Referrals: Social work, District Nurses

ACP: DNACPR, treatment escalation – ceiling of treatment home, PPD Home

Social: Married, 1 daughter, 4 sons, Muslim faith

Patient AB was initially referred from rapid response for help managing fluid overload. He had struggled with an extensive hospital stay due to complications from diabetes, an amputation, renal failure and fluid overload secondary to his heart failure.

On discharge from hospital he was seen by one of the St Christopher's Community CNSs who recognised the complexity of his situation and requested specialist heart failure input. The geriatric registrar who supports rapid response also requested support and we arranged a joint home visit.

The key issues for him were:

- *Significant fluid overload with oedema to mid abdomen and ascites. He could not sleep or lay comfortably in bed due to severe orthopnoea and would become agitated getting from bed to chair and back again frequently.*
- *High symptom burden with agitation, intermittent confusion, ongoing infection from a UTI and from an infected amputation injury with a vacuum dressing insitu, frequency of passing urine, and poor sleep, reducing mobility and increasing care needs.*
- *Carer stress with a young daughter taking centre stage for decision making and translating for her father in the context of a strong Muslim family. He also developed fluctuating capacity and decisions were being considered in his best interest at times when he lacked capacity.*
- *Families expectations around treatment escalation plans wanting to source more intensive care in the acute sector versus him wishing to remain at home on a background of limited improvement during his recent 5 months in hospital.*

Discussions around appropriate treatment options for managing his symptoms were challenging in the context of a family who disagreed at times with his decision making and wish to remain at home. We weighed up options in terms of sub-cutaneous furosemide versus alfentanil to aid breathlessness and fluid levels, starting with an alfentanil pump which allowed the first good night's sleep he had had in weeks with improved breathlessness. This was followed by a furosemide pump due to escalating oedema causing distress. Conversations were had about balancing his end stage renal function with symptom control and how we can support him and the family to allow him to stay at home. The family, especially his wife, were not fully in agreement with a decision around resuscitation. His daughter, although she agreed in principal, had resuscitated her father at home once before and although she knew it was not the right treatment for him, would particularly struggle to not try this again.

A DNACPR decision was put in place based on medical grounds due to the rapidly deteriorating clinical picture and clear patient wish to not go back to hospital, and the family were supported to see why this was actioned and important to his care. The daughter was supported and equipped to know what to do in the event of his death, and that it was ok not to do anything but call us for help.

Case 1 – Bromley

- 89-year-old male

- Severe LV impairment with an EF of 15%, CRT-D in situ and Alzheimer's disease

Ethnicity: White British

On referral: CFS 7. EGFR 30

ACP: DNACPR, CRT-D deactivated under STC. Treatment of reversible conditions at home only. PPD (preferred place of death) – home.

Social: Lives with his wife, in their own home. Family support, mainly from his Son. Had been married to his wife for over 60 years.

D was referred by the PRUH HF team for support with ACP discussions, particularly around ICD deactivation. He was on the maximum tolerated heart failure medications and his PPC (preferred place of care)/PPD was at home.

D had a low symptom burden, however was deteriorating rapidly and his family were keen to ensure he was looked after at home, as per his wishes.

The first step was a home visit to meet D and his family. Due to the patient's Alzheimer's diagnosis, he was unable to fully engage in conversation, therefore his wife and children were engaging on his behalf. An in-depth conversation re. why and how an ICD is deactivated and why this was relevant to D was had. D's family agreed that an ICD deactivation would be in D's best interest and literature was given to the family to read about it before signing the consent form. Conversations were had with a palliative care consultant and cardiology consultant and an MDT decision was made to deactivate his ICD.

D was able to have his ICD deactivated at home due to the place of implantation. I liaised with the cardiac physiology team at the hospital and they arranged to come to D's home in the coming days.

The specific heart failure approach and the link/communication with external heart failure professionals allowed D to die peacefully at home, without any unnecessary intervention/therapies from his device. His family were informed that his "ICD could be switched off" whilst he was in hospital, however were not aware of the details/benefits of it and this caused some apprehension.

<u>Case 2 – Croydon</u>

- 73-year-old male

- Heart Failure with Reduced Ejection Fraction (EF 17%). Severe MR CRT-D in situ

Ethnicity: Black British Caribbean

PMH: Hypertensive cardiomyopathy, Hypertension, CVA, CKD< Anxiety and Depression

On referral: CFS 8, eGFR 29

Referrals made during spell of care: Choose Home, Rehab

ACP: DNACPR, CRT-D deactivated, Treatment escalation plan: stay at home, PPD Home

Social: Lives alone, divorced, 1 son, strong Christian faith

Patient J was referred following a hospital admission for symptom control, advance care planning (with an active ICD) and social support. He was well known to the community heart failure team.

He lived alone but following the aforementioned hospital admission his son had moved in to support him. He was initially from the Caribbean; an ex-computer programmer having travelled the world with this. He had a strong Christian faith which guided his decision making. He was a very proud man and had not been open with his son about the extent of his heart failure, as a result his son was coming to terms with the diagnosis knowing that time was already short. He spoke about feeling that time with his father had been robbed from him, and that he would have done things differently had he known sooner. His son recognised the challenges of supporting a parent, especially when their relationship was strained and although there was family around he found it hard to speak openly with them.

J had expressed his wish to remain at home and he recognised that the medications he used to be on for his heart failure were no longer appropriate for him due to severe hypotension. He was becoming increasingly frail. He agreed that should his heart stop he would not want attempts to restart it, however he had an active defibrillator in situ. Conversation about deactivating this took time; he needed space to acknowledge that turning this off was not the same as suicide. We also gave him time to recover from some post-hospital delirium and allow a capacious decision to be made. Given time and information he agreed to deactivate and this was facilitated for him with help from the heart failure team at home. As he had had his device implanted under Croydon, they were able to facilitate this being deactivated at home.

He deteriorated quite gradually: hypotension continued to limit his heart failure therapies and his diuretics were also gradually reduced. He was frail and mostly staying in bed, so equipment was arranged to support this. He voiced a desire to try to improve his function and be able to do a little bit for himself so he was referred to our living well at home team.

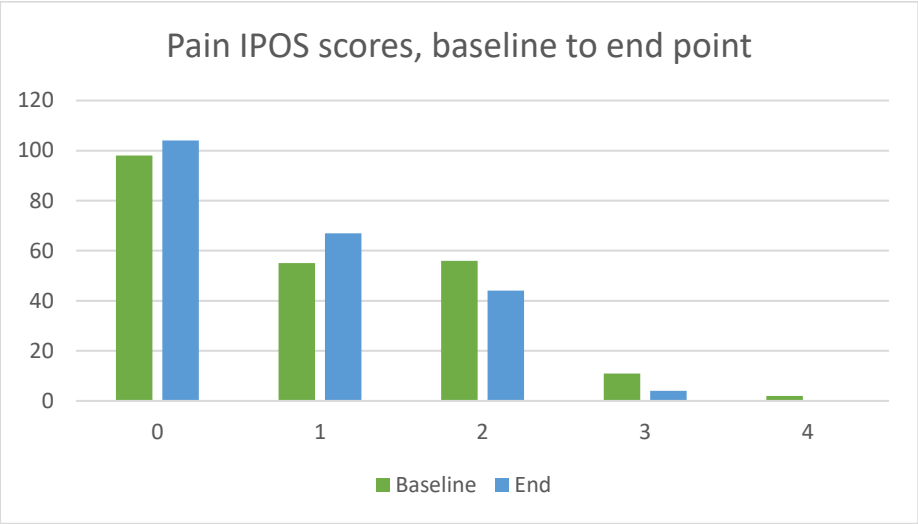
He carried on for a short period and then deteriorated quite suddenly. He was supported at home with an end of life syringe pump to manage symptoms of breathlessness and agitation and had care put in place. He died peacefully at home.

The ability to coordinate between services – acute trusts, community heart failure services and St Christopher's – allowed for a smooth and efficient service which enabled quick and easy access to deactivate his ICD at home in a timely manner, and appropriate symptom management and support at the end of his life without having to go back to hospital.

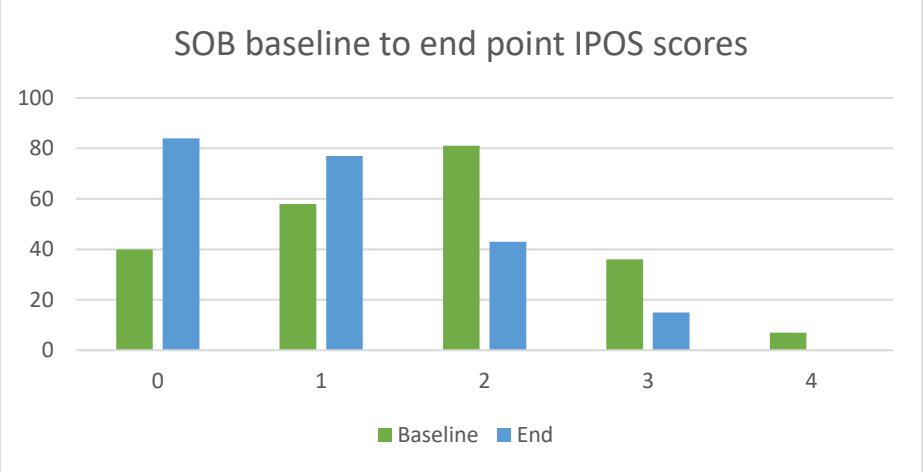
Appendix 7 – Graphs of change in overall IPOS scores by symptom

Physical IPOS results:

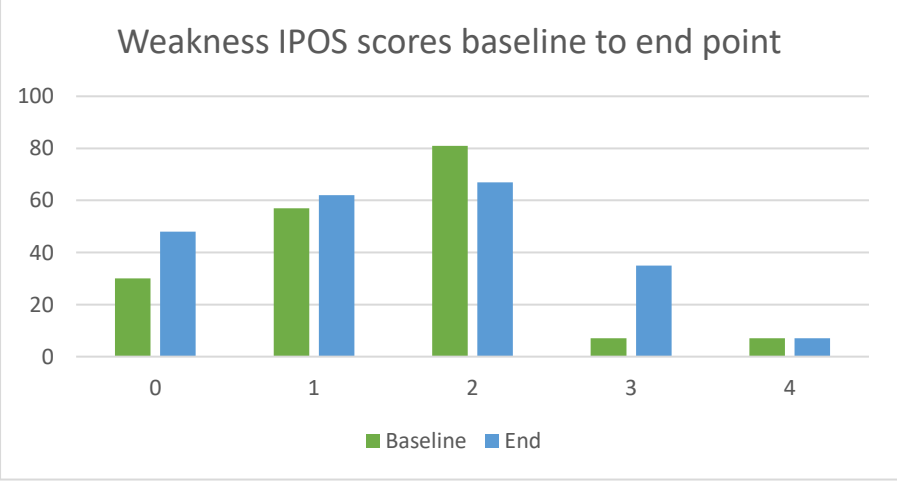
PAIN:



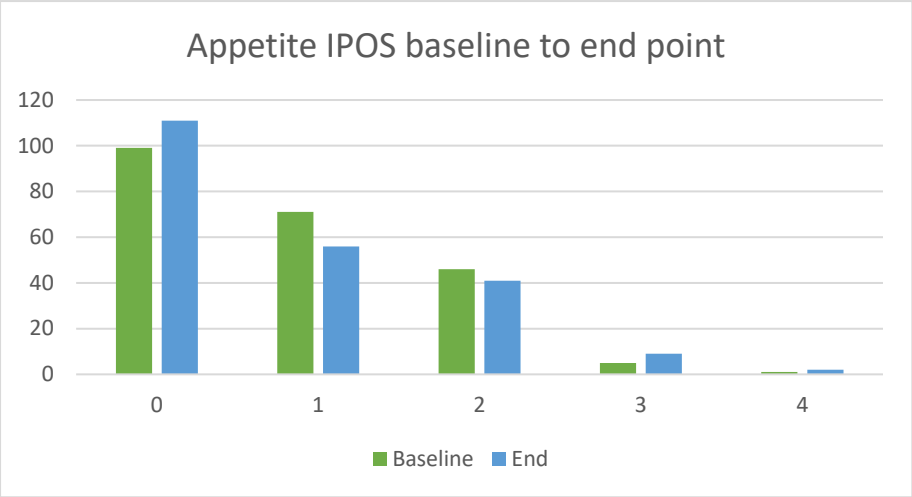
SOB:



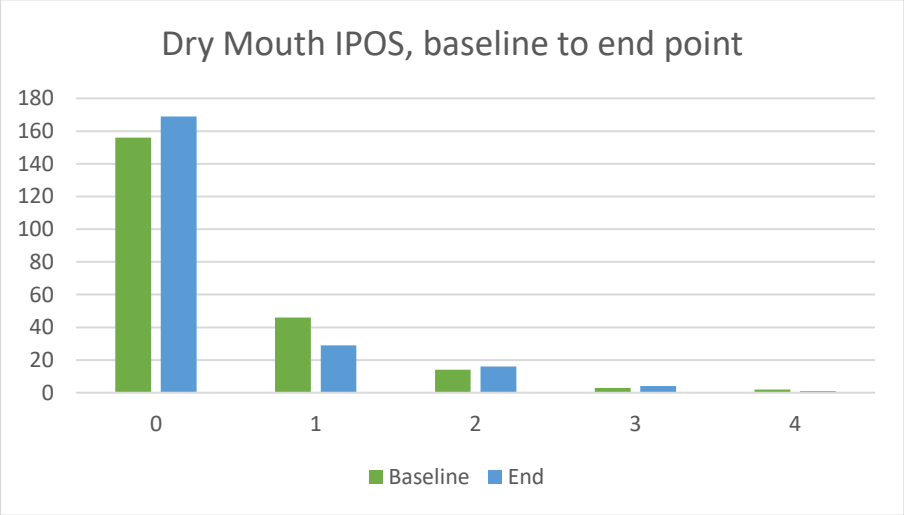
Weakness:



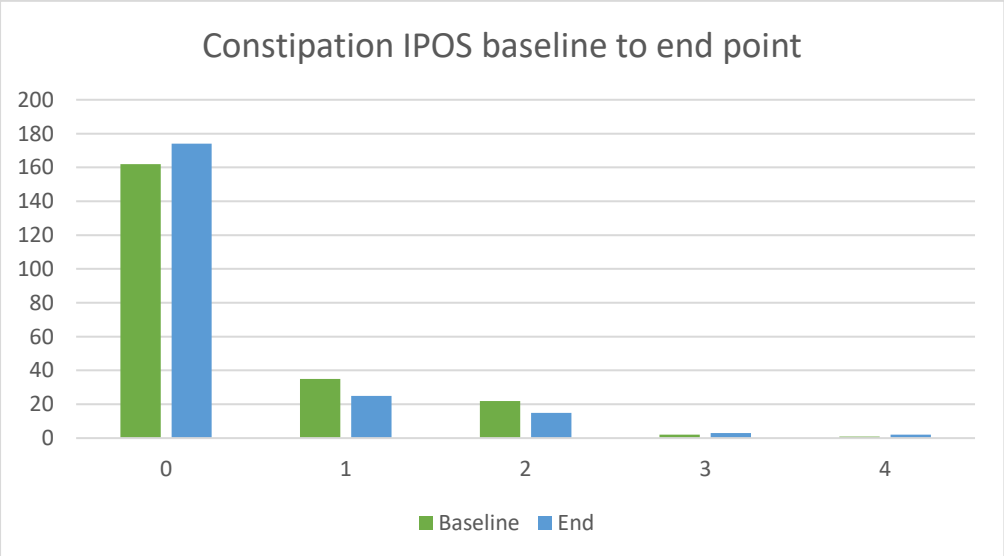
Appetite:



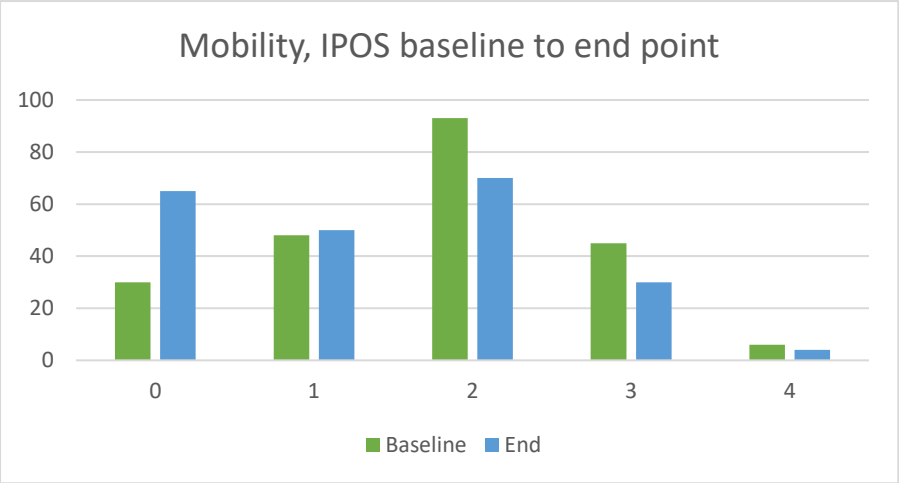
Dry Mouth:



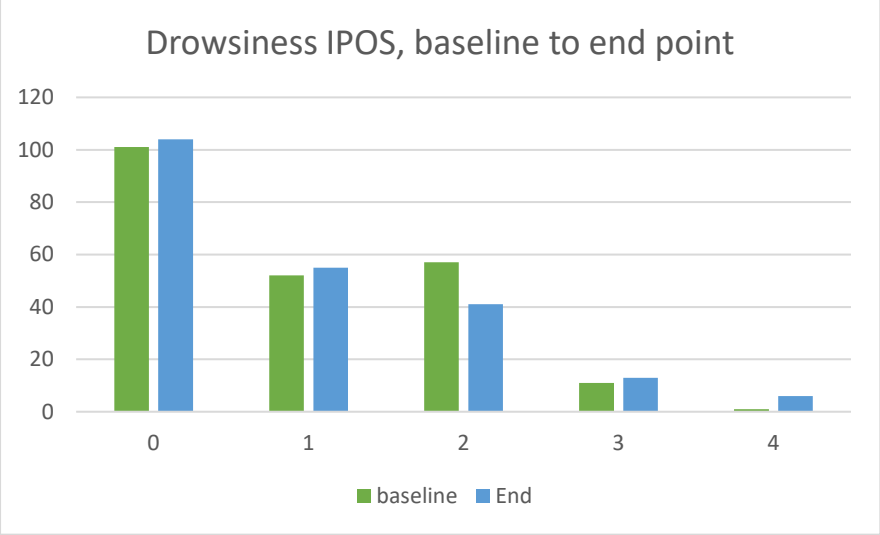
Constipation:



Mobility:

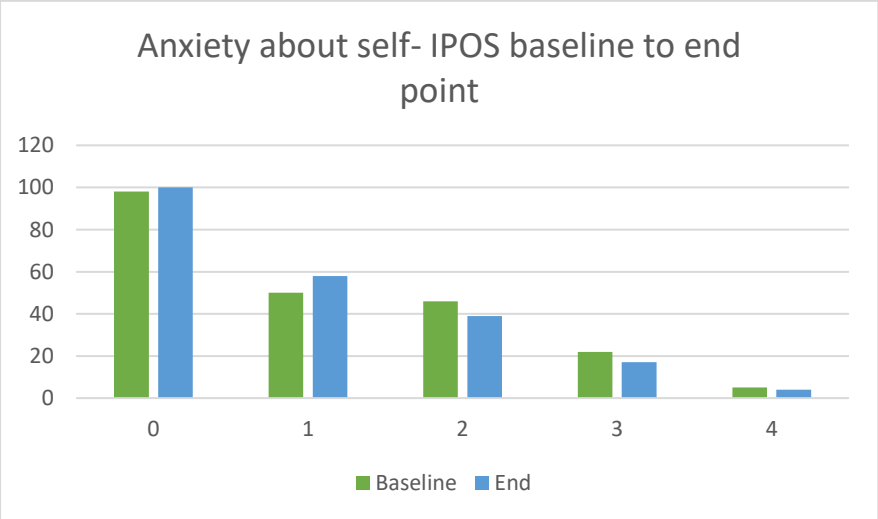


Drowsiness:

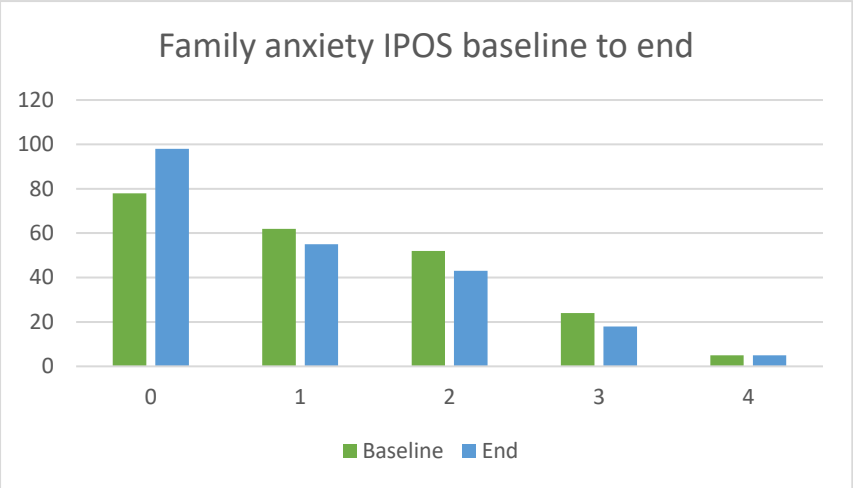


Psychological IPOS results:

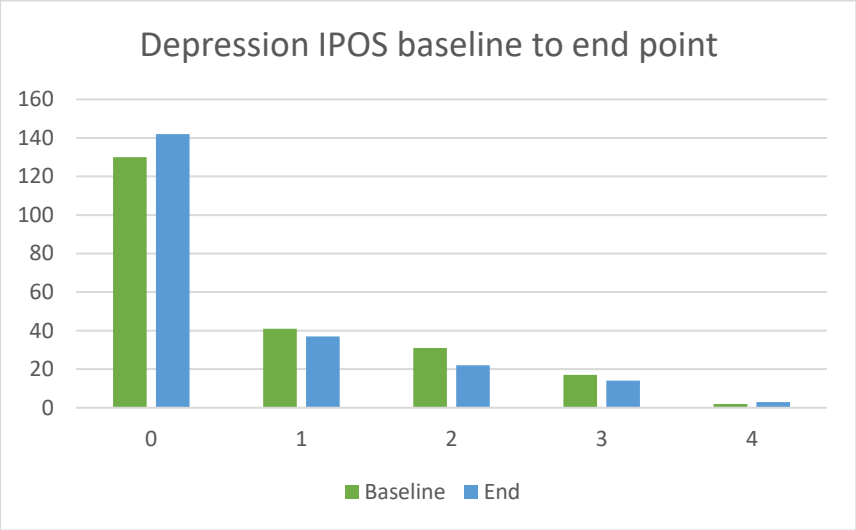
Anxiety about self:



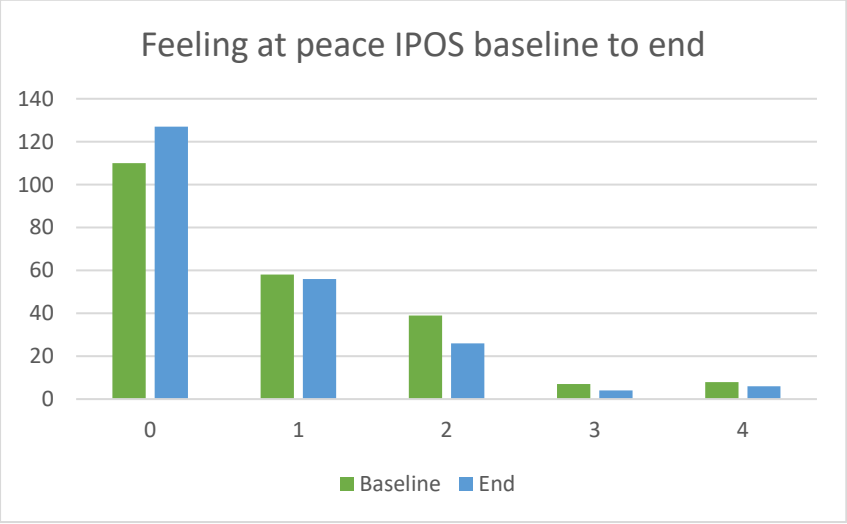
Anxiety from friends/ family:



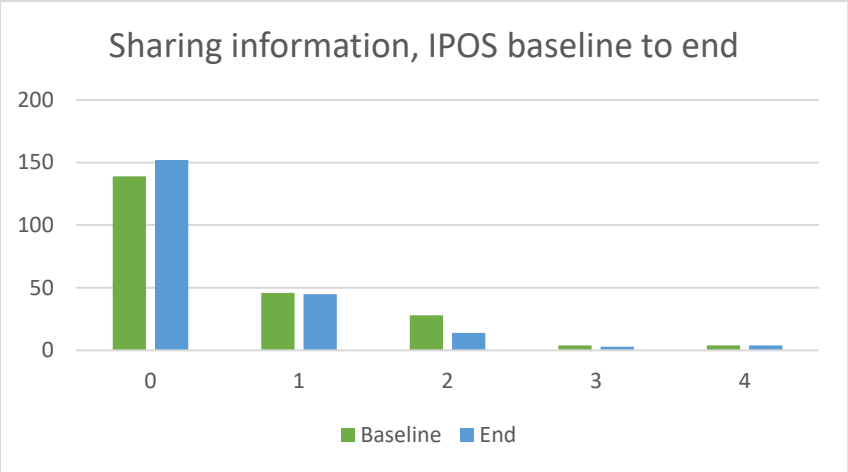
Depression:



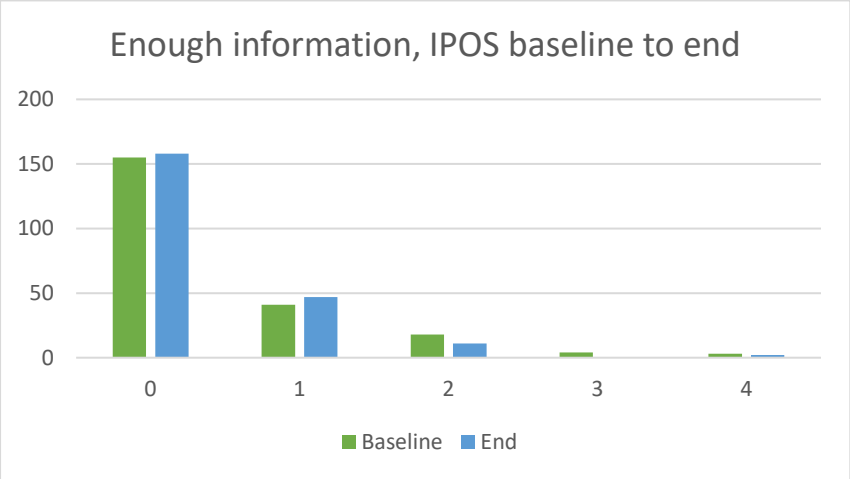
Feeling at peace:



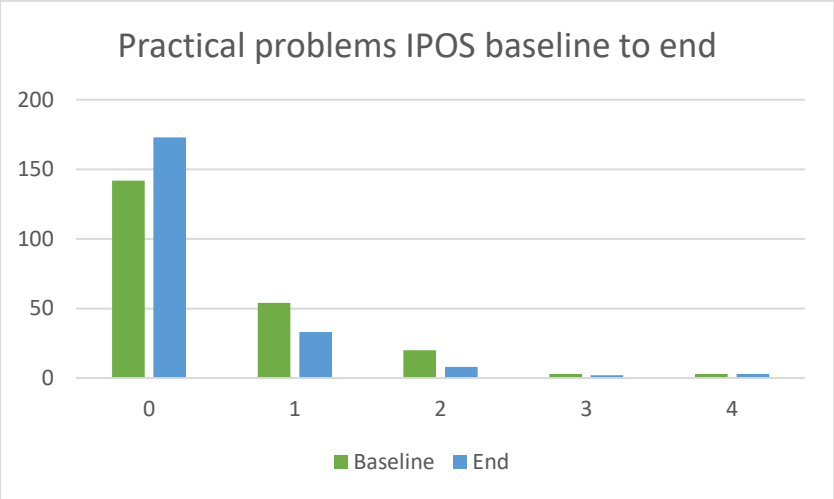
Sharing information with family:



Having enough information:



Practical problems:



Appendix 8- Professional learning event review / community of practice

Professional Learning Event Review

Event Title: Heart Failure Community of Practice 2024

Attendance

201 delegates signed up

31% STCH

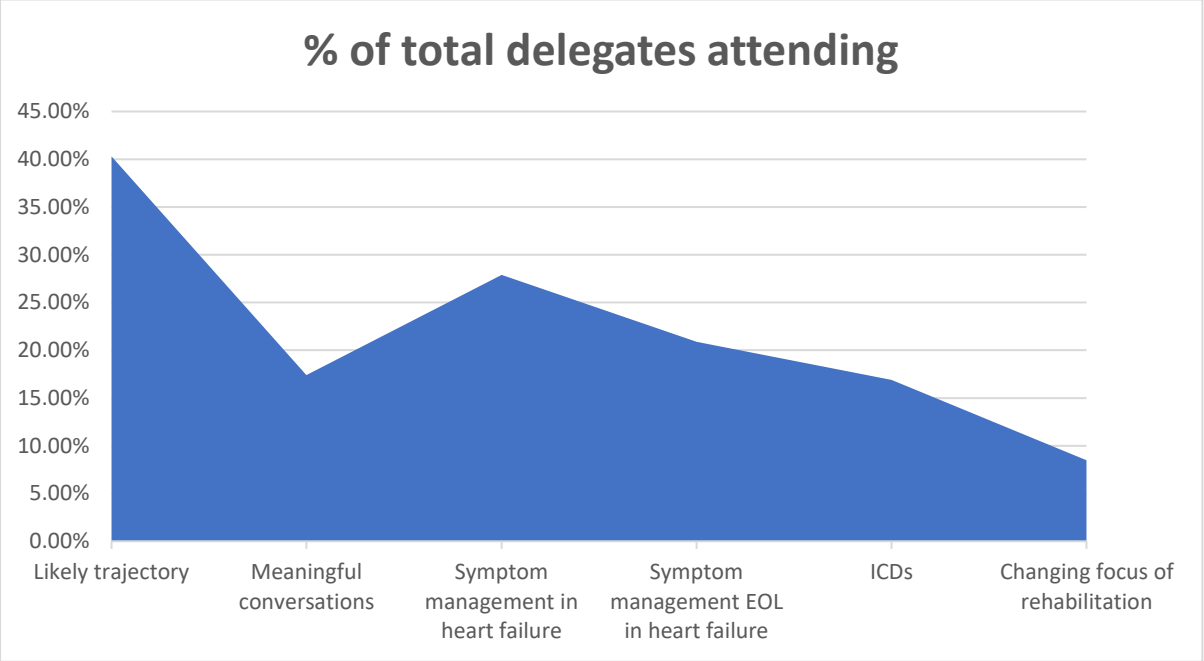
Attendance trend:

The percentage of total 'signed up' attendees declines over the course of the sessions

Total 201 attendees over the 6 sessions.

The first session had the best turn out but then declined for future sessions.

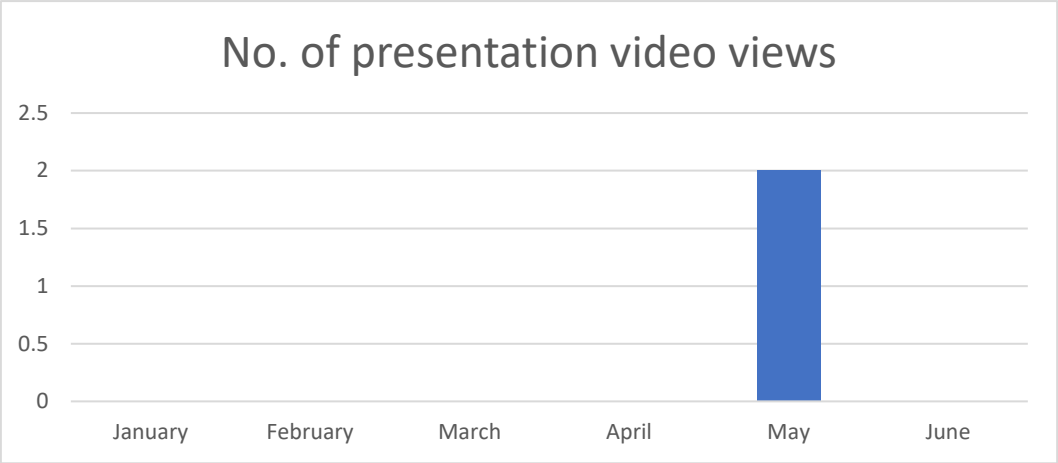
We noticed there was a spike in attendee numbers for 'Symptom Management in Heart Failure' (session 3). The speaker for this session was external and we were able to put their bio and further information on the webpage which may have attracted more attendees.



Video views:

Recordings of the sessions are made available to all 'signed up' delegates after the session. The chart below shows the number of times the presentations have been played.

Total 2 video views across the 6 recordings



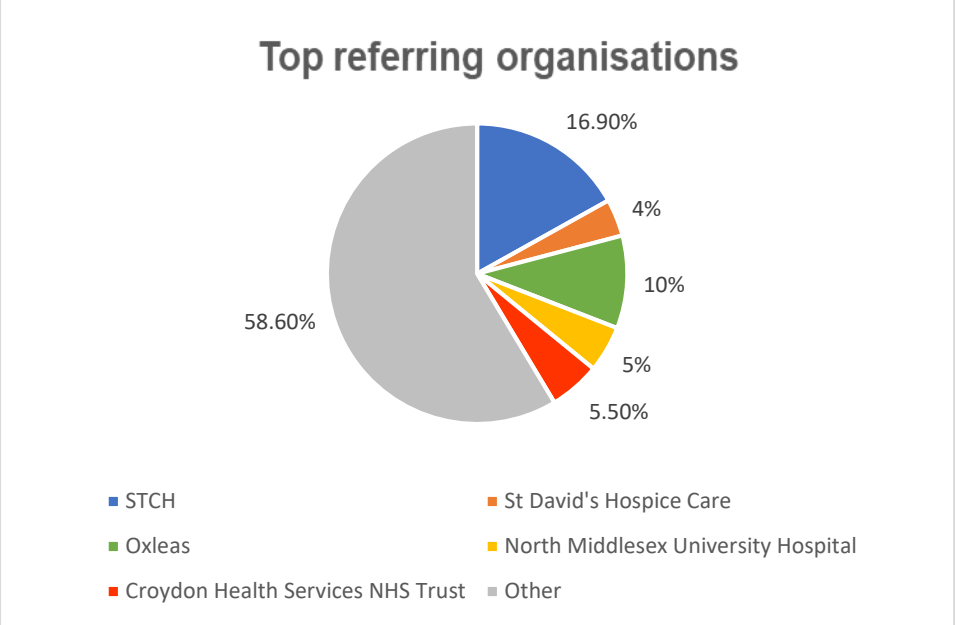
Learning resources web page:

(The learn site is where presentations and recordings are shared)

47 delegates registered to the learn site. When surveyed on its use, the majority said 'I have registered but not returned'.

Referring organisations:

The 201 attendees were from a total of 74 different organisations. The biggest proportion being primary care, when not including St Christopher's.

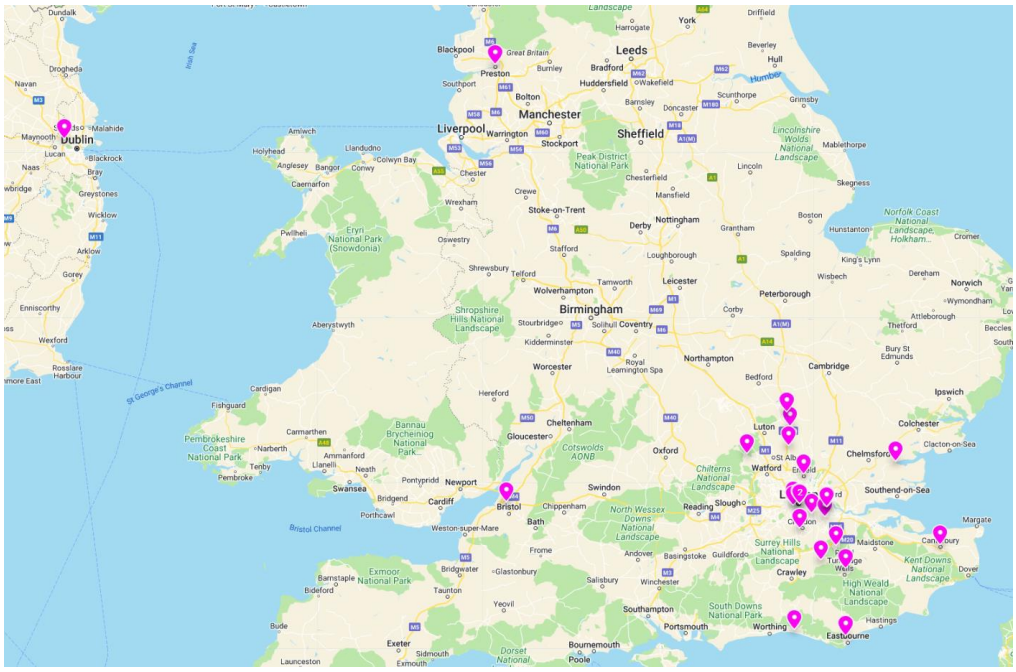


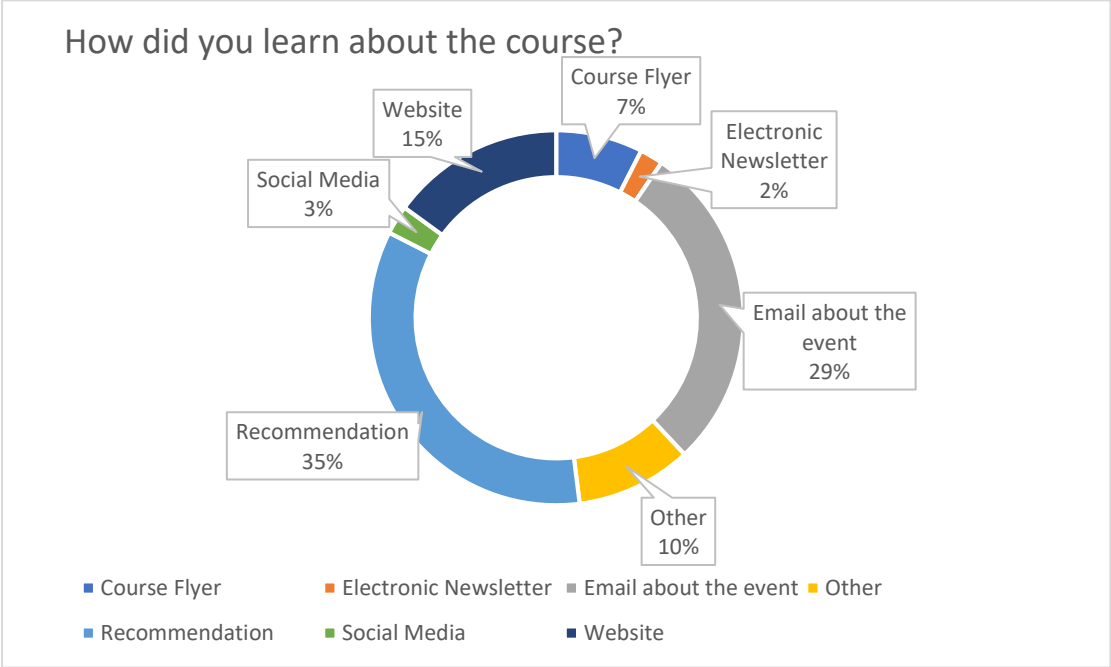
Demographic

The vast majority of delegates were nurses with a large amount specialising in Heart Failure.

58% work in a borough in London with the other 42% nationally.

We asked them to put their location on a Padlet, results below from 27 attendees.





Evaluations

'Changing focus of rehabilitation' was rated the highest with the most 5 stars – although the number of attendees and survey response number was low. The sessions on 'Symptom Management' was well received with the best overall/average rating of the sessions.

'Likely Trajectory' was rated as the most important topic.

Topic	Speaker	% 5 star	% 4 star	% 3 star	How important was this topic to you? (rated 5/5)	Number of evaluations submitted
Likely trajectory	Isobel Jackson	44.7%	44.7%	7.9%	73.7%	38
Meaningful conversations	Dr Joy Ross & Isobel Jackson	30.4%	47.8%	21.7%	65.2%	23
Symptom management in heart failure	Dr Sidhu	46.4%	39.2%	7.1%	64.2%	28
Symptom management EOL in heart failure	Dr Ross and Fiona Hodson	47%	29.4%	17.7%	58.8%	17
ICDs	Dr Mohammad Albarjas	N/A	N/A	N/A	N/A	19
Changing focus of rehabilitation	Gail Preston	66.6%	16.6%	16.6%	50%	6

Learner feedback:

Please see a few comments and feedback below:

- Well-presented session. Lovely to have input for a patient.
- Breakout groups are a useful addition.
- Very interesting session. Definitely helpful in knowing and understanding best practice for management of heart failure in EOL. Thank you so much!
- Great talk. Even as a Heart Failure Nurse it's so lovely to discuss complex cases. Cases really related to my own practice so really good to have some things openly discussed
- It's really good to have the opportunity to learn from others in similar situations
- Very medicalised please review medical jargon
- It would be good to have more discussions from a MDT holistic point of view in the groups
- Ran out of time for the case studies at the end which was a shame as case studies are always very good learning

The case studies were really beneficial and this is portrayed in many comments within the feedback.

Although we did not receive a lot of verbatim feedback, more than half include a thank you message to the speakers.

Additional Teaching and presenting during the project by project lead.

05/04/2023	Associate Clinical Nurse Specialist (ACNS) teaching
12/04/2023	ACNS teaching
18/04/2023	PRUH Heart Failure team- what does palliative care have to offer
19/04/2023	ACNS teaching
30/05/2023	PRUH- sub cut furosemide teaching
04/07/2023	Presented to Health Care UK conference- Non Medical Prescribing in cardiology
05/07/2023	• Presented at St Georges- European Society of Cardiology faculty MSC programme on integrating palliative care and palliative interventions for HF • Presented at Health Care UK conference on NMP in EOL care
06/07/2023	Presented to Croydon End of Life steering group
18/07/2023	Teaching to Croydon HF team on what palliative care has to offer
28/09/2023	Teaching to complex care team Croydon- what palliative care has to offer- integrating our services
11/10/2023	Presented to Health Care UK conference- EOL care for people with HF
12/12/2023	Presented at Health Care UK conference- NMP in EOL care HF case study
27/02/2024	Teaching on KCL symptom control module- heart failure
15/03/2024	Gemma (HF ANP Bromley) presented at HCUK conference – improving EOLC for ppl with CVD and HF
09/05/2024	GP community of practice-Palliative care in HF/ Sub cut furosemide/ ICD's/ symptom control
21/05/2024	Teaching to Croydon HF team- outcomes on the project so far
29/05/2024	Wednesday Learning Forum - all about DAPA
19/05/2024	Presented on the Heart Failure conference
20/05/2024	Presented to Bromley Cardiovascular group- the project so far
04/07/2024	Teaching to St Christopher's doctors- palliative management for Heart Failure
20/08/2024	Palliative care teaching to rapid response Croydon
04/09, 11/09, 25/09	Associate Clinical Nurse Specialist teaching on heart failure STC

Appendix 9- Summary of Conference

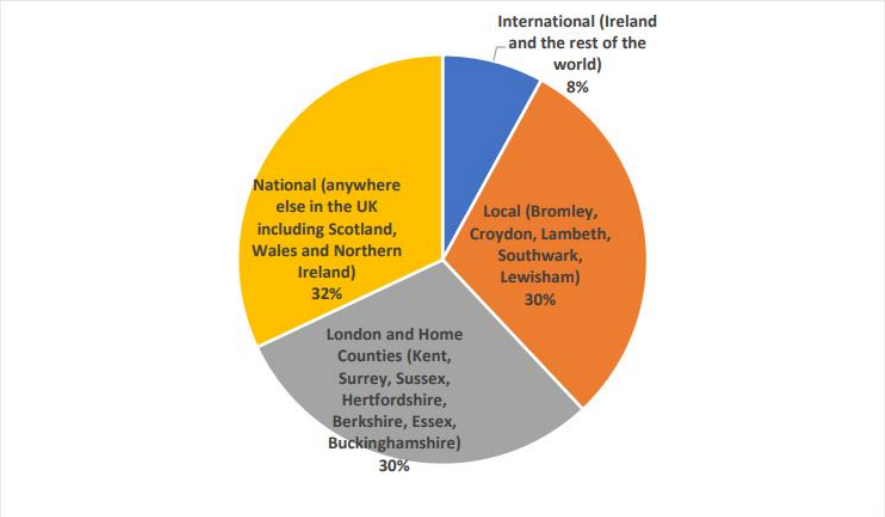
Attendance

Attendance vs target:
Attended: 89 virtual & in-person vs 90
No Shows: 5 (2 staff)

Attendence breakdown:

Category	Number of attendees	
Delegate	77	39 Virtual & 38 in-person
Speaker	15	3 virtual & 12 in-person
St Christopher's Staff	12	8 virtual & 4 in-person
Support Staff	3	In-person

Locations:
The biggest percentage (32%) of attendees were National

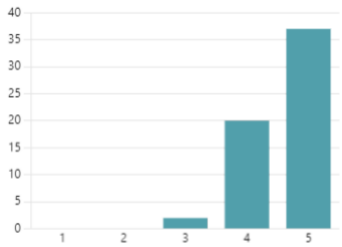


Evaluations

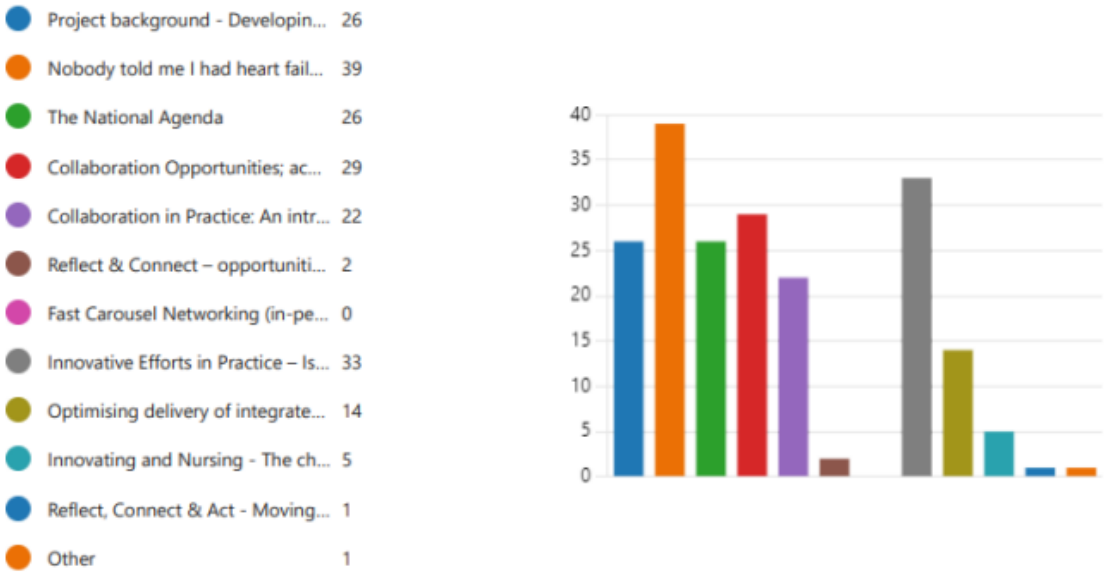
Learner satisfaction
Total evaluations received: 42 In-person & 17 virtual

3. How would you rate this conference overall?

4.59
Average Rating



8. Which elements of the event programme would you consider to have had the greatest value?



Learner Quotes:

great to hear all the collaborative projects ongoing and learning from the challenges of these
a well organised and informative day. venue and catering were excellent
well organised and balanced day
Very varied and interesting presentations lots of resources to follow up
Very well run, organised and enjoyable day
Very well organised, interesting and speakers very informative. Interesting and helpful to see what other colleagues are doing across the UK/ Really enjoyed the dat. Staff really friendly. Good timekeeping and lovely food
excellent day, inspiring talks, lots of practical advice for setting up services
Disappointed that the day did not involve symptom control and care of the patient
the innovating and nursing session did not feel like it fitted with the content of the day