



**Inpatient Hospice Admissions in Lothian
Who is Admitted and Why?
A Mixed Method Prospective Study**

**Collaboration between Marie Curie Hospice Edinburgh and St
Columba's Hospice Care**

Report December 2020

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Executive Summary

Context

Over the past four years both hospices in Lothian, St Columba's Hospice Care and Marie Curie Hospice, noted a rising trend for patients to die during their admission to a hospice inpatient unit (from 63% in 2015/16 to 76% in 2018/19). It is unclear why this is and a mixed method prospective study of admission into both hospices was commissioned to increase the understanding of the use of hospice beds.

Methods

The study explores the patient characteristics of those admitted and considers the reason for the admission alongside the experience of the patient and those close to them. A mixed method approach (convergent design) was employed, with data collected prospectively over a four month period. Data extraction sheet was designed for quantitative data collection including demographics, clinical characteristics and outcome for each patients admitted (e.g. death or discharge). In addition, Phase of Illness, Adapted Karnofsky Performance Scale, Integrated Palliative Care Outcome scale and the OACC suite measures (Outcome Assessment and Complexity Collaborative). Qualitative data collection included 40 interviews with 22 patients or a relative proxy, 11 health care professionals, 7 pro-forma interviews- from referring professionals. Quantitative data was analysed descriptively using SPSS 24 and thematic analysis was undertaken for the qualitative data.

Results

276 patients were admitted to the two hospice inpatient units in Lothian; 70% from a community setting and 30% from hospital. All admissions were "urgent" and the median length of stay was 12 days. The patients were mainly white (95%), mainly with cancer (95%), and more likely to be from middle/upper socio-economic groups (68%), in keeping with the demographics of the locality.

26% of patients admitted were identified as "stable" (as defined by Phase of Illness descriptor). Patients categorised as "unstable" were more likely to be admitted from a community setting than hospital 36% (59/164) vs 27% (20/74). 47% of patients admitted had low physical function, assessed using Adapted Karnofsky score (AKPS), with only 7% scoring >70% (high function).

Review of complexity as defined using the patient reported IPOS score demonstrated a wide range (12 to 57; mean 33), indicating that a number of patients had very low IPOS scores on admission, with little reported physical/emotional distress or concerns. The most prevalent issue reported was concern for family, then a range of symptoms linked to advanced illness (weakness, poor mobility, poor appetite, drowsiness). Many patients reported significant impact of multiple domains. 28% were assessed as having delirium on admission.

Admissions from a community setting were more likely to be for symptom management whereas admissions from hospital were more likely to be for end of life care. In 24% of cases it was unclear at the time of admission if the admission would be for end of life care or if the patient had a reversible condition. Patients also reported that a key factor in bringing them to admission was anxiety and fear, with the admission bringing a significant degree of

comfort. Social isolation was also a factor, with those living alone struggling to feel supported there at end of life. Patients also spoke about admission being the last thing they would go for or “the last resort”.

Alternatives to admission were explored, considering also what resources were in place prior to admission. 21% of admissions had no community resources in place and of those 142 patients admitted for end of life care /possible end of life care, 80% had no support in terms of direct hands on physical care. And for some of those who did have support in the form of direct care, the packages were not always tailor made and person centred and therefore not always seen as being appropriate to support the patient to continue to be at home. 40% of patients admitted to the hospice from a community setting were NOT known to the District Nursing team (77/ 193), including 20 patients admitted for end of life care.

68% of patients being admitted during this four month period died during their admission. These included 90% of patients who were recognised as dying on admission. The median length of stay for those who died was 9 days, ranging from death on the same day, to 90 days after admission. Most patients admitted from hospital died during the admission (86%), with a median length of stay of 7 days (range from death on the day of admission to the same day and up to 63 days).

Conclusion

Hospices admit people for two key reasons, symptom management and end of life care. It is not always possible to be clear about which of the two categories are applicable at the time of admission and the reason for admission is often multi-faceted in nature and may not fall so strictly within these 2 key reasons. For some patients it may be related to complex symptoms but there was a variety of different needs across those patients admitted, including declining physical function, social isolation, and need for emotional support. These needs may be met with less medically focused care but with well-coordinated nursing and social care. Patients reported feeling well supported by the hospice, but for some of them it was not their preferred place of care or death. There were significant gaps in provision of community resources.

Recommendations

Hospice inpatient care remains an essential part of the provision of specialist palliative care and for many admissions there were no alternatives identified. However there is potential to offer greater support to those at home, including access to skilled and appropriate hands on physical care alongside emotional support. There is scope for service development to maximise the “home first” approach, with some hospice inpatient resource being redirected to community services. There is also a need to offer an alternative to admission to a medical in-patient palliative care unit, which focuses on complex symptoms, for those whose needs are less complex but for whom home is unsustainable due to existential, psychological or social issues.

Partnership working across the system is necessary to achieve such change.

1. Background

Healthcare services are changing and there is a need to help more people to remain independent for longer at home, or in a community setting [1]. In adopting the ‘Three Conversations model’[2] NHS Lothian is taking a consistent approach across health and social care to support patients to be supported to live well in their community setting as far as possible, with “Home First” a key driver for the Edinburgh Integration Joint Board[3]. Such an approach resonates with the established practice of specialist palliative care services.

Over the last 3 years, hospice services in Lothian have been redesigned to provide additional support for patients in the community, via the introduction of the 7-day Clinical Nurse Specialist (CNS) service and the creation of a multi-disciplinary community service. This has enabled more people to be supported in the community, with fewer hospice admissions.

Improvements in the provision of care in the community are expected to impact upon the delivery of other specialist palliative care services, in particular inpatient services. However of those patients admitted to the hospices’ inpatient beds in Lothian, we have seen a change in the proportion who will die during the admission (Table 1). It is unclear why this is and the impact on the demand for hospice beds in the future.

Table 1: Inpatient deaths in Lothian Hospices

	Marie Curie Hospice Edinburgh			St Columba’s Hospice			Combined Hospices Total		
	Number of admissions/year	Number of deaths in IPU	% who die during admission	Number of admissions/year	Number of deaths in IPU	% who die during admission	Number of admissions/year	Number of deaths in IPU	% who die during admission
2015/16	479	302	63%	471	301	64%	950	603	63%
2016/17	405	249	62%	453	335	74%	858	584	68%
2017/18	407	334	82%	444	320	72%	851	654	77%
2018/19	354	285	81%	426	304	71%	780	589	76%

Both Marie Curie Hospice and St Columba’s Hospice Care agreed that there was a need to better understand why patients are admitted into the inpatient units, the different factors which contribute to the decision to admit and what the patients’ needs and wishes were in

this process. Better understanding of this will provide insight into of the overall use of hospice beds and how resources are most effectively allocated to meet patient and family needs and preferences.

We undertook a rigorous service evaluation which will inform future hospice service development and innovation for the increasing numbers of people in Lothian who would benefit from palliative care, including specialist palliative care. The findings from this study will underpin the development of the services of the two Edinburgh based hospices but also has wider potential for hospices in Scotland and across the UK who may be experiencing similar trends.

2. Context – Specialist Palliative Care in Hospices in Lothian

There are two specialist palliative care inpatient units in Lothian.

At the time of the study, St Columba's Hospice had 30 inpatient care beds for patients from North Edinburgh and East Lothian. St Columba's Hospice has a specialist community service in North Edinburgh. In East Lothian, the specialist palliative care community service is provided by the NHS, with specialist support from St Columba's Hospice, including access to inpatient beds.

Total population supported 370,000 people.

At the time of the study, the Marie Curie Hospice in Edinburgh had 20 inpatient care beds for patients from South Edinburgh, Midlothian and West Lothian. Marie Curie Hospice has two specialist community services, one serving the population of South Edinburgh and Midlothian, and a second providing a service for the population of West Lothian, based in St John's hospital in Livingston.

Total population supported 500,000 people.

3. Aims and Objectives of the study:

Aims

This study will provide an in depth understanding of:

1. Who is admitted to inpatient hospice units in Lothian
2. The reasons for patients being admitted to the inpatient units and their outcomes
3. The experiences and wishes of patients and their families regarding the inpatient admission and preferred place of death

Objectives

1. Provide a description of patients admitted to the in-patient unit in terms of:
 - a. Demographics
Age; gender; marital status; SIMD; cohabitation status,
 - b. Characteristics
Primary diagnosis;
Phase of illness, physical function and complexity of care needs
Delirium status on referral
Planned/unplanned admission; source of referral
2. Explore the reasons why patients are admitted to the inpatient units.
 - a. Reason for admission (symptom control/ EOL) and issues identified at first assessment.
 - b. Assess the appropriateness of admission into either of the IPU's based on patients', families', staff' perception.
 - c. Identify what community-based resource was in place prior to admission, including health and social care services and specialist palliative care services and identify any obvious gaps in service delivery which may have contributed to the admission.
 - d. Preferred place of death
 - e. Outcomes of the admissions (length of stay, discharge or death)
3. Explore the experiences and wishes of patients and their families regarding the inpatient admission and about preferred place of death

4. Methodology

Design

A mixed method approach – convergent design was adopted using both quantitative and qualitative data [4]. A convergent design allows more complete understanding of an issue, whereby both types of data can be compared and combined. A research nurse, who was a senior hospice nurse working across both sites, collected all the data.

Data were collected prospectively over a period of four months between July and November 2019. All patients admitted to the IPU at either hospice during the data collection period were included in the analysis

All patients were considered for inclusion in the qualitative study, and a convenience sample of 20 patients was sought. Carers were included as a proxy if the patient was too unwell to participate.

For those patients interviewed, we also sought to recruit both the admitting and referring clinician to offer their perspective.

4.1. Quantitative data collection and analysis

A data extraction sheet was designed for the quantitative data collection, to capture demographics, clinical characteristics and outcomes for each patient admitted to the inpatient units, from patient notes. Quantitative data was analysed descriptively using SPSS 24.

The OACC suite of measures was in use in both hospices, and so clinical data was also collected regarding Phase of Illness, Adapted Karnofsky Performance Status (AKPS)[5] and Integrated Palliative Outcome Score (IPOS)[6] on admission.

Phase of illness on admission

Phase of Illness describes whether the plan of care needs to change or not, based on changes to the patient's condition.

- "Unstable" indicates that the current plan of care needs to be radically and urgently developed,
- "Deteriorating" indicates the plan of care needs to be adapted to reflect that the person's condition is changing,
- "Dying" notes that the plan of care needs to ensure all end of life measures are in place.
- "Stable" indicates that the current plan of care does not need to be altered, although clearly being admitted to the hospice is in itself a change in the plan of care.

Adapted Karnofsky Performance Scale

This describe the patient's functional status, with 100% being absolutely independent in all areas, and 10% being completely bedfast and unable to care for themselves.

Integrated Palliative Outcome Scale (IPOS)

The IPOS describes the patient's own assessment of their issues and symptom burden. If the patient is unable to manage a staff member can complete the scale on their behalf. This is a self-reported 5 point assessment scale where a patient rates their symptoms over 10 physical domains, and 7 psychological/spiritual/social domains leading to a maximum possible score of 68.

Demographic data was also collected, including deprivation, ethnicity, age, gender and cohabiting status.

Postcode analysis allowed the deprivation of patients to be categorised using Scottish Index of Multiple Deprivation (SIMD)[7], with SIMD 1 being the most deprived and SIMD 5 being the least deprived.

4.2 Qualitative data collection and analysis

Face to face interviews with a patient or family member were carried out with a subset of those admitted.

The admitting clinician was also invited for interview.

The referring clinician was invited to complete a proforma stating reason for referral either face to face or via telephone. This also asked if the person would have preferred to stay at home, and if so, what would have facilitated this.

The research nurse ensured the invitation to the patient/family to take part in the study was done sensitively, seeking support from the ward-based staff before making any approach. This was done on day one or two of the patient's admission. Patients who were actively dying, or where the staff judged there was extreme distress, were excluded. Written information about the study was shared with the patient if they had 'capacity', or with their family, with informed, written consent required prior to inclusion.

Interviews were transcribed verbatim with anonymity ensured by removing identifiable places and allocating anonymous identifiers in place of names in the transcripts.

Data were analysed using thematic analysis[8]. Themes were developed and refined inductively, through re-reading the transcripts. Initial coding was carried out using NVivo12.

5. Ethical approval

The study proposal was reviewed by the research steering groups in each hospice. The study did not require National Health Service ethical approval as it was evaluation work carried out at the two hospices. Confirmation that ethical approval was not required was provided by the South East Scotland Research Ethics Committee (SES REC). Caldicott approval was also given by both hospices.

6. Results

6.1 Description of patients admitted to the inpatient units in Lothian.

There were 276 admissions to the two inpatient units in Lothian during the study period. 126 admissions were to Marie Curie Hospice, Edinburgh and 150 admissions to St Columba's Hospice Care. Of these, there were 259 unique patients admitted in the study period.

This analysis was undertaken on number of admissions (n=276), except when analysing patient characteristics, where the number of individual patients was used (n=259).

A total of 40 interviews were carried out. (22 patients or a relative proxy, 11 health care professionals, 7 pro-forma interviews-source of referrals).

6.1.1 Demographics

The gender of patients was distributed fairly even with 53% of admissions being female and 47% male.

Figure 1 shows 72% of patients lived with another person, while 28% lived alone.

Figure 1 : Cohabitation

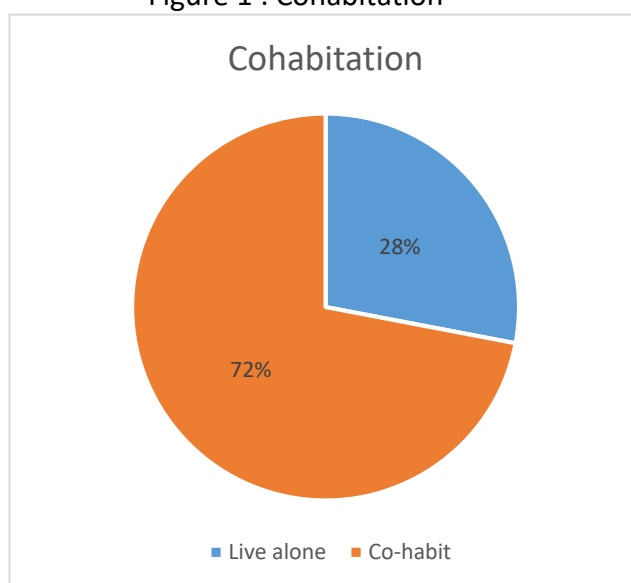
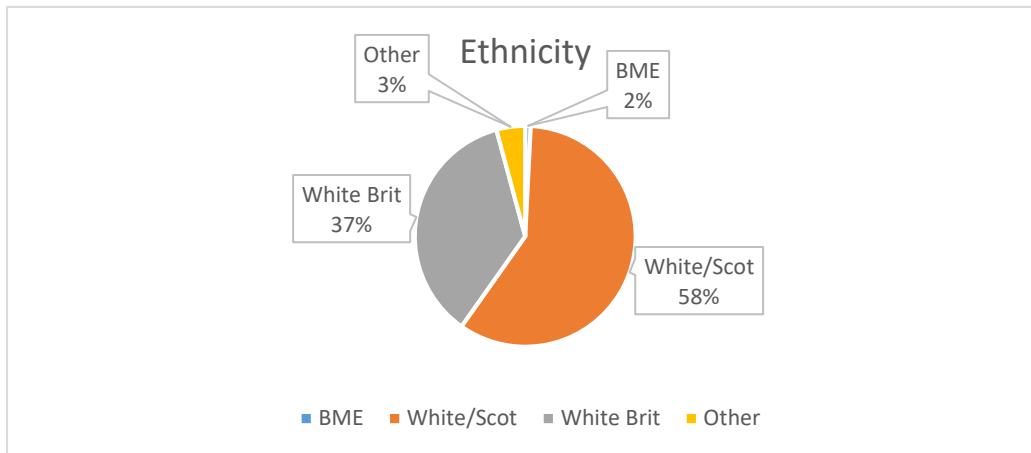


Figure 2 indicates that the majority of patients admitted (58%) considered themselves to be White Scottish, 37% to be white British, around 3% from other white backgrounds such as Polish or Irish, and 2% from Black or Minority Ethnic backgrounds.

Figure 2 : Ethnicity



The age of patients admitted ranged from 26 to 95 years of age with a mean of 69.6. years (median = 71 years).

Figure 3 : Age of admissions

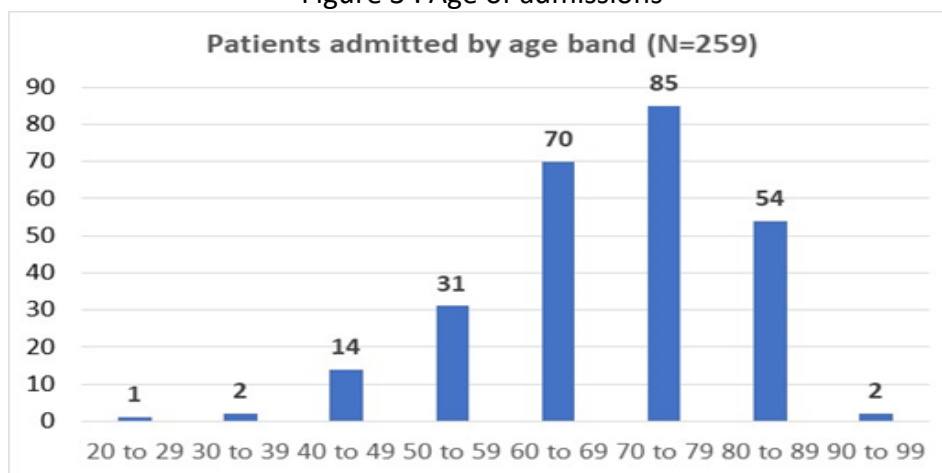
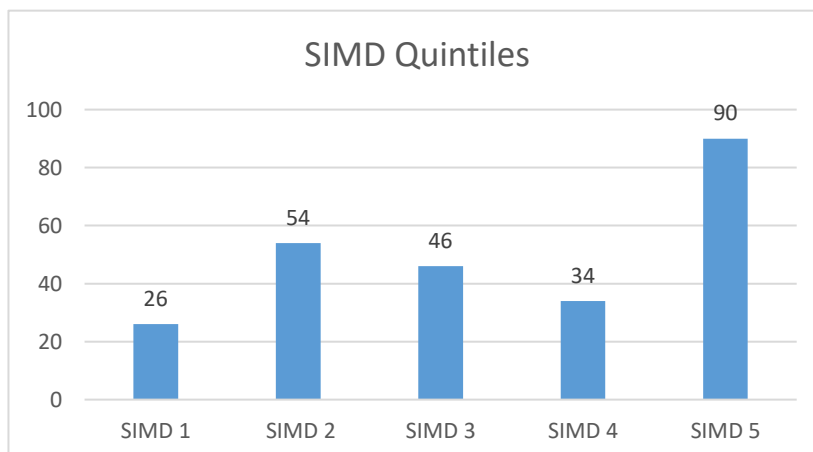


Figure 4 : Deprivation detailed by SIMD quintiles



Patients from across all deprivation categories were admitted although only 10% of patients admitted were from the most deprived areas compared to 36% from the least deprived areas of the region.

6.1.2 Type of Admission and Source of Referral

The hospices both operate on a system where admissions are almost always requested for the first available bed “urgent/unplanned” as opposed to being planned in advance.

Reflecting this 99 % of admissions were identified as urgent/emergency (to first available bed) with only 1% being planned.

Table 2 : Source of referral : planned or emergency

Planned or unplanned admission	MCHE	St Columba's	Total	Total (%)
Urgent (first available bed)	125	149	274	99%
Planned	1	1	2	1%
Total	126	150	276	100%

The majority of admissions (70%, n=193) were from the community, with 30% from the hospital (n=83). Over half of all referrals were from the Hospices' Community Palliative Care teams (56%) with 55% being referred by the CNS team and 1% by Day Therapies. 12% of admissions were referred to the hospice by the primary care team, of whom 5% (n=13) had no previous specialist palliative care involvement.

Table 3 : Source of referral

Source of referral	MCHE	St Columba's	Total	Total (%)
Admitted from community				
Community palliative care team CNS	66	87	153	55%
Day therapies	0	2	2	1%
Primary care (previous palliative care team involvement)	13	7	20	7%
Primary care (no previous palliative care team involvement)	7	6	13	5%
Other/unknown	1	4	5	2%

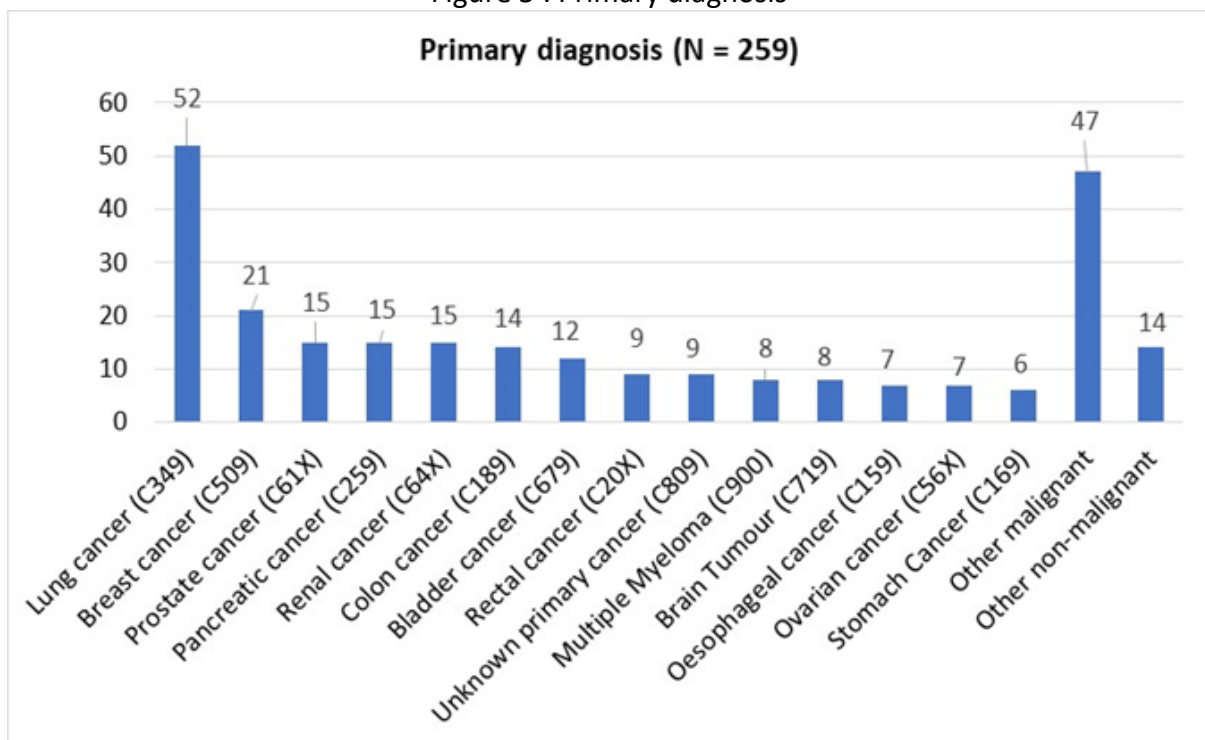
Admitted from hospital				
Hospital (hospital palliative care involvement)	14	11	25	9%
Hospital (previous community palliative care involvement and hospital palliative care involvement)	8	8	16	6%
Hospital (previous community palliative care involvement)	5	9	14	5%
Hospital (no previous palliative care involvement)	12	16	28	10%
Grand Total	126	150	276	100%

6.1.3 Clinical characteristics

Primary Diagnosis

The vast majority of patients (95%) had malignant conditions with only 5% of patients admitted with a non-malignant condition as their primary diagnosis. The most common diagnosis was lung cancer (52/259 patients; 20%) followed by breast cancer (21/259; 8%) whilst the most frequently seen non-malignant conditions were pulmonary fibrosis (4 patients; 1.5%) and cardiac failure (4 patients; 1.5%).

Figure 5 : Primary diagnosis



Phase of illness and source of referral

238 patients (86%) had phase of illness noted at time of admission.

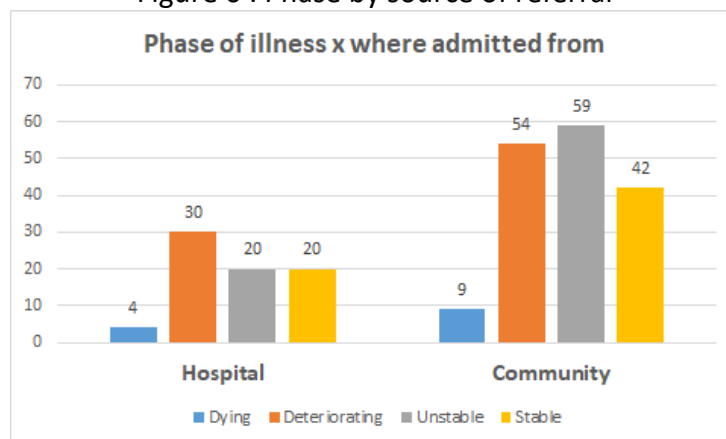
The most common status noted was “deteriorating” (35%) followed by “unstable” (33%). 5% of patients admitted during this time were assessed as “dying” on admission (all of whom did die).

62 patients (26%) were assessed to be “stable” on admission, of whom 39 were admitted from a community setting and 23 from hospital. This would indicate that the current plan of care was working, but the location of care (perhaps related to care needs) needed to change.

Of the 13 patients referred from primary care with no previous palliative care involvement, two-thirds were assessed to be “deteriorating” or “dying” on admission, where a change in place of care was the intervention rather than the overall plan needing to be changed (unstable).

Unstable patients were mainly admitted from home. By definition, these are patients where the overall plan of care urgently and radically needs to be changed.

Figure 6 : Phase by source of referral



Functional Level using Adapted Karnofsky Performance Scale (AKPS)

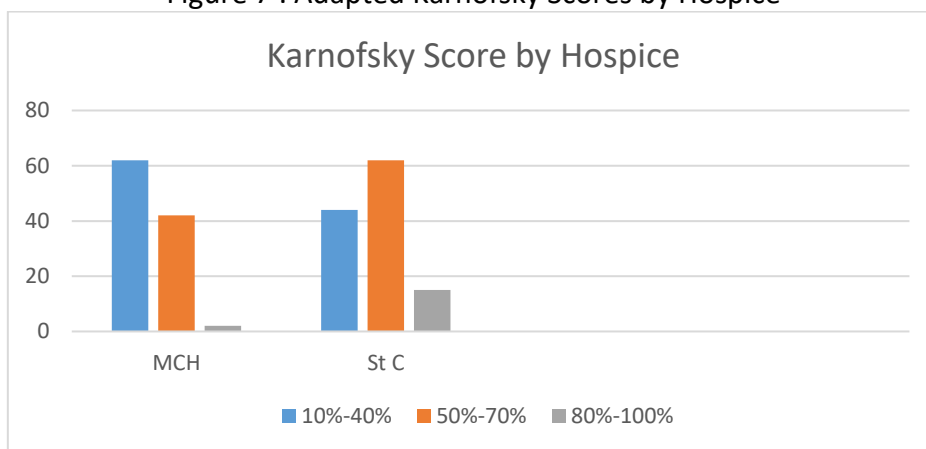
Nearly half of those admitted (47%) had a very low AKPS score indicating low function and high dependency (score of 10% to 40%). However, 46% of those admitted had a medium AKPS (50% to 70%) indicating reasonably good function.

Only 2% of admissions to Marie Curie had an AKPS of 80% or higher; this compares to 12% of admissions to St Columba’s Hospice Care.

Table 4 : Adapted Karnofsky Scores

Adapted Karnofsky performance status	Description - group	MCHE	MCHE%	St Columbas	St Columbas (%)	Total	Total %
10%	Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly	62	58%	44	36%	106	47%
20%							
30%							
40%							
50%	Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	42	40%	62	51%	104	46%
60%							
70%							
80%	Able to carry on normal activity and to work; no special care needed	2	2%	15	12%	17	7%
90%							
100%							
		106	100%	121	100%	227	100%

Figure 7 : Adapted Karnofsky Scores by Hospice

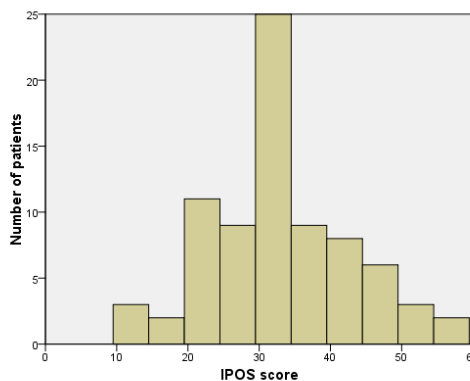


Complexity of symptoms

Completion rates for this score on admission was considerably lower than the other measures, with data available for only 78 out of the 259 patients.

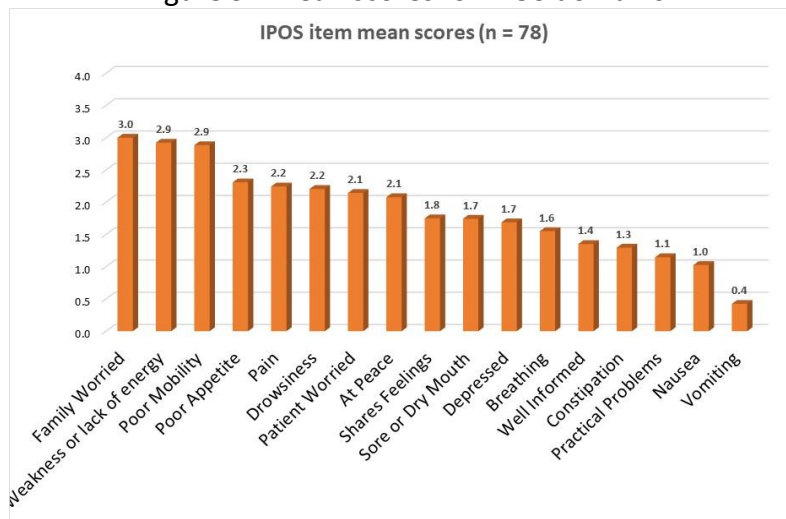
IPOS scores ranged from 12 to 57, with a mean overall IPOS score of 33 (median score was 32). The higher the score, the higher the patient is reporting the issues and symptoms have affected them over the past three days.

Figure 8 : IPOS Scores



The issues that patients identified as the most concerning for them covered a wide range. However, the most prevalent was their belief that their family were worried about them, closely followed by feelings of weakness/lack of energy and poor mobility (max possible score for each domain is 4). Pain was also a commonly expressed issue as was distress and lack of peace.

Figure 9 : Mean scores for IPOS domains



Delirium

78% of admissions were assessed for delirium (216/276), with 28% of these screened positively for delirium (61/216).

Table 5 : 4AT Delirium Scores

4AT score	4AT score description	MCHE	MCHE %	St Columbas	St Columbas (%)	Total	Total %
0	delirium or severe cognitive impairment unlikely (but delirium still possible if [4] information incomplete)	53	55%	72	60%	125	58%
1 to 3	possible cognitive impairment	17	18%	13	11%	30	14%
4 or more	possible delirium +/- cognitive impairment	26	27%	35	29%	61	28%
		96	100%	120	100%	216	100%

6.2 Understanding why patients were admitted to in patient units.

6.2.1 Reasons for admission

The quantitative data collection highlighted the clinical picture for those patients admitted to the hospice. 27% of admissions were identified as being for end of life care, and 46% for symptom control. However, in 24% of admissions it was unclear at the time of admission if the patient's deterioration was reversible with symptom management or if the patient was dying.

Table 6 : Reasons for admission

Reason for admission	MCHE	MCHE %	St Columbas	St Columbas %	Total	Total (%)
Symptom control	44	35%	84	56%	128	46%
End of Life care	43	34%	32	21%	75	27%
symptom control/ possible EOLC	35	28%	32	21%	67	24%
Blood transfusion/ symptom control	1	1%	2	1%	3	1%
Assessment of complex needs	2	2%	0	0%	2	1%
Other	1	1%	0	0%	1	0%
	126	100%	150	100%	276	100%

Admissions from home were more likely to be for symptom management whereas admissions from hospital were more likely to be for end of life care.

Table 7 : Reason for admission, by source of referral

Reason for admission		CNS referral	Hospital referral	Primary care referral	Other referral	Total (%)
Reason for admission	Symptom control	87	22	15	4	128 (46%)
	End of Life care	28	36	10	1	75 (27%)
	symptom control/ possible EOLC	34	25	8	0	67 (24%)
	Blood transfusion/ symptom control	3	0	0	0	3 (1%)
	Assessment of complex needs	2	0	0	0	2 (1%)
	Other	1	0	0	0	1 (1%)
Total		155	83	33	5	276 (100%)

The qualitative data analysis provided further insight into the reasons for the patient admission, based on interviews with the patients and with those who admitted them. Thematic analysis identified this as symptom control, anxiety or fear, social isolation, end of life care, either through the wish of the patient or because the family were struggling to cope.

- *Symptom control such as pain control*

Management of physical symptoms were a frequent reason for admission. These included pain, shortness of breath, nausea. The following quotes detail patient views of these admission reasons, which were echoed by admitting staff members.

(MC = Marie Curie; SC=St Columba's)

MC2 patient *'just constantly hiccupping all the time, and throwing up, severe stomach pains' 'I just physically deteriorated' 'They ahhh doubled up that medicine but even that didn't work.'* *'I wasnae gonna say no [to coming into the hospice] cos there's no better place to be like for like pain relief an that, ken, press a wee button, and get pain relief if you're feeling sick, ken press a button, cos I was having tae phone up the nurses on the emergency, ken on the after house line for them to come out and give me anti-nausea.'*

SC6 patient *'I was put on medication for nausea and dizziness and I've still had problems so that's the reasons I've ended up in here. It was to sort it out regarding the dizziness, breathlessness and just general fatigue.'*

- *Anxiety and fear.*

Anxiety and fear also played a prominent role in the decision to go to the hospice. Patients and family members articulated fears of struggling to control symptoms however these could become more general anxiety and fear, perhaps to the point of existential anxiety. Staff members were able to recognise this readily. (Text shown in **block** highlights the words of the interviewer)

SC3 patient *If I'm just here at home – I can't cope with things. I um get a bit anxious in terms of being on my own and something happening*

SC3 staff *'I think he's very frightened. He lives alone and the symptoms that he's experiencing now; though they don't appear to be very severe at present; he felt that things couldn't get any worse for him and that he is dying.'* *'He was frightened and didn't appear to be managing anymore.'*

SC11 wife *'AS soon as the breathing thing happened, that was the change in him. And he was like-I can't breathe. But some of it I think was mental'* *'But he started to go into almost like a panic mode'*

SC11 Staff *'So for somebody like him I think it's an anxiety type thing and it's comforting for him to be in this situation rather than the hospital.'*

MC7 patient *'I think it was getting a bit serious for that one night, I've had some serious nights but never to the extent where it's been doubled over in pain, severe pain. When it's up at about an 8, 9 or a 10 on a pain scale yeah. **Do you feel unsafe, because you said safe, do you feel unsafe when you are in that much pain at home?** Not suicidal but my safety zone is a bath, I jump in a bath, just for the heat because the pains in my chest, I fill it up so much, because these things are usually jangling, well not today, but usually hanging out my arm, so I need to, bum facing the taps so that arms out that side like that, so I can get my chest underneath the water, dangle that way and just get as much heat in the chest as possible. I know it's an absolute nightmare **No you do what you need to do to make it work.** It needs to be done, gingerly get in and out of the bath cos you're soaking wet and you're like 'if I slip here, then that's me nobody to help, I've no got a wee buzzer or anything like that, Aye I'm scared, I'm petrified'*

'Are you hoping to get back home again? Eh, suddenly no – I'm not really that fussed to be honest with you, I'm quite happy here as I am at home, I think if anybody's giving me better care it will be here rather than my house'

MC7 staff *'Yeah so this is a youngish man who is in his mid 40's who was diagnosed a few months ago with quite advanced disease – incurable and admitted because of*

complex pain, I think due to his locally advanced disease, but lots of, lots of psychological distress as well and low mood and anxiety.'

These latter quotes illustrate the level of existential comfort that could be found by being at the hospice.

Social isolation

Social isolation was an issue that compounded other issues including anxiety and physical symptoms. These issues are best illustrated by patient stories which offer the broader context. The story of MC9 illustrates the interaction between psychological aspect and practical elements of social isolation. Living alone made it more difficult to cope with unexpected problems and also, perhaps amplified fears of symptoms that may come with dying. For this lady, having people care for her in her home was something that she could not accept.

Story of MC9

This patient was living with pancreatic cancer. She had two sons who visited her and one who was helping to look after her but, as she became more unwell, she did not want her sons to see her in what she referred to as a 'disgraceful situation'. Nor did she wish to have nurses caring for her in the home. *'So I did tell the Marie Curie nurse I did want to come in – cos I didnae want, didn't want people coming in to the house looking after me or my sons finding me in a disgraceful situation you know what I mean? So that was the reason for [admission to the hospice]'*. When asked about her decision to come to the hospice *'Well I'm on my own and then I think well you are getting the right care [at the hospice] you know you're not worrying during the night. You know, I don't want people coming in overnight and sleeping in my house. I thought I'd just rather go right in, I said this from the very beginning'*. When asked further she admitted that she had been fearful at home alone in case something went wrong. This followed from an incidence where she had been unable to get off the toilet and having to *'kind of slam myself down on my knees'* and then struggling to get herself to a phone, having to wait on the floor until her son could come to help her. Once in the hospice these fears were spoken of as in the past tense. *'I feel like I'm a lot happier now I'm here, and quite settled on going, you know what I mean'*. In discussing being in the hospice she was able to allude to other fears that being admitted must have alleviated as she discussed her wishes for medication *'I don't want to be screaming out in pain, you know what I mean, so I'm ready to go now.'* *'I said I'll just drift then one day you'll no be able to get me round, and that will be that. Another dose of morphine.'*

This next story of MC2 further highlights how social isolation appears to have impacted upon the patient's capacity to stay at home and on their capacity to cope with symptoms.

Story of MC2

This man lived alone, was known to the CNS team and was admitted to the hospice for control of a range of symptoms including nausea, pain and persistent hiccupping. This was the explanation that gave when asked what were the reasons for his admission *'Er well the doctors and [CNS team] couldnae put their finger on where the hiccups were coming fae, just constantly hiccupping all the time, and throwing up and stomach pains' 'I think I just physically deteriorated'*. The staff member that admitted him explained the background giving greater emphasis to social circumstances *'[he] has phoned the DNS a couple of times, they were coming out but has not got anybody, I'm not sure he was eating that well, he's not got anybody to pop in frequently to check on him'*. The patient alluded to his social circumstances in practical terms citing carers that came in to prepare meals that he had no appetite for. He hoped that being in the hospice would sort out his pain *'I wisanae gonna say no cos there is no better place to be for pain relief an that ken'*. He also hoped the stay would enable him to get stronger to return home. *'To try to build my strength up really, and that's a personal goal to try to build the strength up, Get back to day therapies.'*

The admitting staff member recounted how difficult it was to unpick the social situation from disease progression and physical symptoms *'[his] situation as well, isolation, just yeah, I think [he's] deteriorated a bit and a bit more fatigued I think [CNS] were worried that is [the patient] tipping or [is he] deteriorating but not clear, so just needing a little bit of assessment and a little bit of time here to see where [he] is at, how much of it is social circumstances versus cancer progression' 'so rather than trying to struggle at home, and getting syringe drivers and things at home actually coming in is the preference'*

- *End-of-life care*

Patients were also admitted to the hospice explicitly for end of life care; for some this was the clearly expressed choice of the patient.

SC3 patient ***'So coming to the hospice – was that something you wanted to happen? I've known about this now for a long time. I've known this was terminal for a long time. So it's allowed me to have conversations and make plans and all that kind of thing. And particularly my son and daughter, and I said to them ages ago: when I die I'd far rather die at the hospice than alone so yes.'***

At other times the family/carers simply were not able to cope with the level of end of life care needs.

MC6 carer *'she was becoming iller and iller and we were having to give her morphine and having to administer morphine and we hadn't anticipated that, we didn't, we thought naively I think, I never realised naively we thought we'd get a lot of support at home from DN teams and to be fair to the district nurses when you call, they do come*

but it can take an hour or two so it's not immediate and eventually we were not able to control her pain.' 'She was getting less and less able to move, to walk' 'she started to have a reaction to the morphine which she was given and she started to become paranoid and quite agitated.' 'the Tuesday and the Wednesday she started to be really sick, so she was projectile vomiting and she was bringing up bile so that was quite alarming and upsetting for her, then they had to put a line up her nose to deal with the bile' 'She wanted to come, her daughter, my wife's sister died here. She wanted to come here because of that'

6.2.2 Appropriateness of admission

The qualitative data provided insights into the appropriateness of the admission based on the perception of the patients and those who admitted the patient.

In all the cases of the patients who were interviewed, admissions were considered appropriate by patients and by the clinicians interviewed. It was evident that that when asked about why the admission happened that anxiety and fear appeared to be issues that were the 'final straw' making it unavoidable. For these people admission was reactive and the last possible option.

SC3 Referrer 'I felt due to the levels of distress from the patient and from his daughter that it was reasonable to bring him in' 'the level of distress in the house was high'

SC3 Patient 'If I'm just here at home – I can't cope with things. I um get a bit anxious in terms of being on my own and something happening'

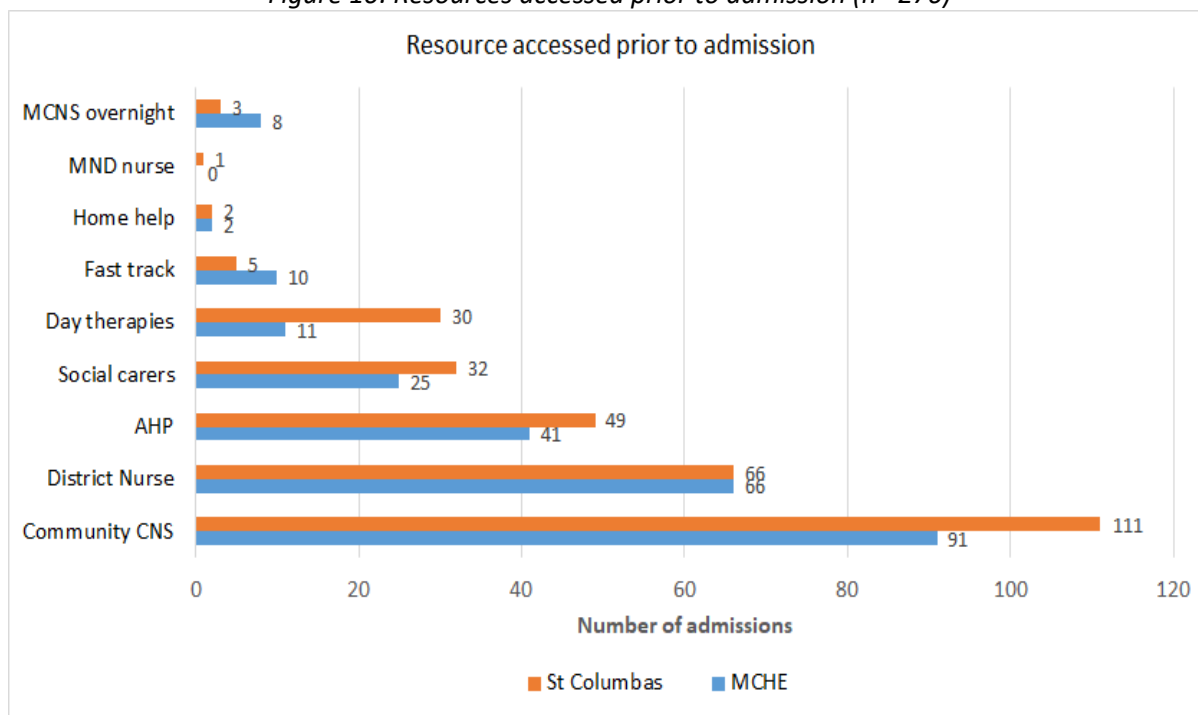
SC11 Wife 'As soon as the breathing thing happened, that was the change in him. And he was like-I can't breathe. But some of it I think was mental' 'But he started to go into almost like a panic mode'

This is not to say that all admissions were unavoidable and that different resources could perhaps have enabled people to stay at home. To further explore this the quantitative data collection identified what community-based support was recorded as being in place prior to admission.

6.2.3 Community resource in place prior to admission

Community CNS input was the most common resource identified (73% of patients had CNS input) followed by district nursing (48%) and allied health professional input (33%). About one fifth had social care support.

Figure 10: Resources accessed prior to admission (n =276)



Of note, only a small number of admissions had “hands on” practical care from social carers or the Marie Curie Nursing Service (Managed Care or Fast Track).

Of the patients who had the district nurse service (n = 132), the main reason for admission was symptom control (42%) or symptom control/possible EOLC (30%) (Table 17).

Table 8: Reason for admission of referred patients with District Nurse resource (n=132)

Reason for admission	Frequency	Percent
Symptom control	56	42.4
symptom control/ possible EOLC	40	30.3
End of Life care	31	23.5
Other	1	0.8
Assessment of complex needs	2	1.5
Blood transfusion/ symptom control	2	1.5
Total	132	100

Table 9: Source of referral of community-based patients with District nurse resource (n=116)

Source of referral of community-based patients with District Nurse input	Frequency	Percent
Admitted via community palliative care team CNS	101	87%
Primary care (previous palliative care team involvement)	9	8%
Primary care (no previous palliative care team involvement)	6	5%
Total admissions from the community with district nurse resource	116	100%

Of the 193 patients admitted to the hospices from a community setting only 116 (60%) were noted to have been under the care of the DN team whilst 40% had no known involvement with this service.

Table 10: Prior resource for admissions from the community with and without DN support (n=116)

Resource	With District Nurse (Number of admissions)	With District Nurse %	Without District Nurse (Number of admissions)	Without District Nurse (%)	Total
Community CNS	108	63%	63	37%	171
AHP	57	75%	19	25%	76
Social carers	34	67%	17	33%	51
Day therapies	19	56%	15	44%	34
Fast track	14	93%	1	7%	15
Home help	2	50%	2	50%	4
MND nurse	0	0%	1	100%	1
MCNS overnight	9	82%	2	18%	11

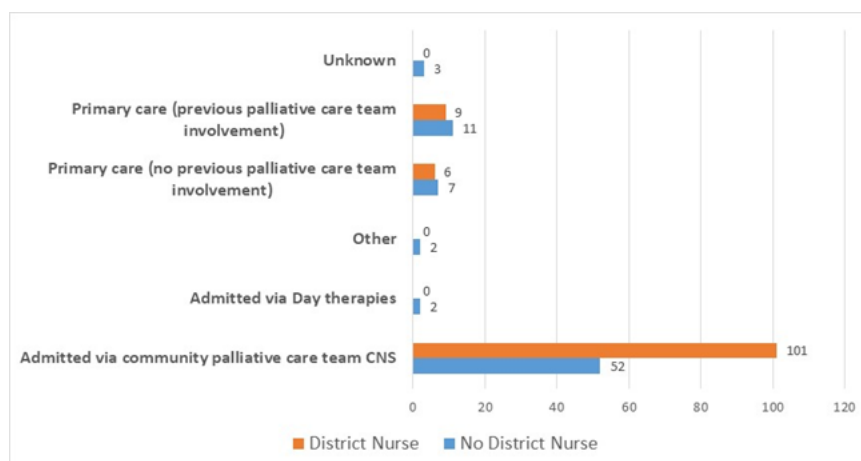
Patients admitted from the community with no DN input were more likely to be admitted for symptom control (73%) compared with 43% if the patient was known to the DN. 13 patients were admitted for end of life care who were not known to the DN team.

Table 11: Reason for admission from the community with and without DN support (n=193)

	Without district nurse (number admissions)	Without district nurse (% admissions)	With district nurse (number admissions)	With district nurse (% admissions)
Assessment of complex needs	0	0%	2	2%
Blood transfusion/ symptom control	1	1%	2	2%
End of Life care	13	17%	26	22%
Other	0	0%	1	1%
Symptom control	66	73%	50	43%
symptom control/ possible EOLC	7	9%	35	30%
	77	100%	116	100%

Most patients admitted from the community who had a DN, were referred via their community palliative care CNS (n=101) (Figure 11).

Figure 11: Source of referral of community admissions with and without DN



21% of patients admitted to the hospices had no previous community resources in place. Most of these admissions were people who had been transferred from hospital. However nearly a quarter (24%) of those admitted from the community had zero or only one community resource in place. 40 patients (15%) had no previous specialist palliative care involvement (27 of these patients were admitted from hospital and 13 from primary care).

There is also evidence that a proportion of admissions had no previous social care involvement, as described below. This table details 114 admissions for end of life care / possible end of life care and whether there was a social care package was in place prior to admission.

Table 12 : Social care involvement

	No social care involvement prior to admission	Social care involvement prior to admission	Total
Assessment of complex needs	1	1	2
Blood transfusion/ symptom control	3		3
Symptom control	100	28	128
End of Life care	55	20	75
Symptom control/ possible EOLC	59	8	67
Other	1		1
Grand Total	219	57	276

The qualitative analysis provided more in-depth data on the support which was in place at home when patients were admitted to the hospices. These were wide ranging and generally appropriate although not always effective in terms of actually meeting patient needs. These could be standard ‘packages of care’ that were not working well either in terms of medication schedules or what was being done. The issues are illustrated in the following quotes and the story of MC1.

SC8 brother *‘I was explaining that the carers weren’t coming in. He’s got tablets he’s on every 6 hours and it’s they’re coming in at 11 then at 4 then 8 which is no 6 hour gap.’*

MC5 patient *‘lots and lots of different people and I didn’t know the people, I met so many people and I was tired all the time and it was becoming problematic because I needed just a few people to do it’*

‘So you had some people that were kinda coming in, your carers, were they quite regular at coming in? Yeah they would always do, they were supposed to have 4, but

they always were quickly before they wanted you to go, really quickly, they didn't want to do things problematic things like that' 'they were always asking what you've got to do and what and I was tired'

Story of MC1.

This person was admitted to the hospice for help with pain and constipation related to rectal cancer. There was input at home from a GP, district nurses, MC nurses, a care package was being arranged to assist with house work and food preparation and there was also some input from McMillan. However, there was a variety of district nurses attending to change the wound cleaning each day and the patient was very self-conscious about this due to the site of the wound. The patient was not able to build up the degree of trust with the rotating staff that would have begun to counter the embarrassment. Pain during wound cleaning was also extremely difficult to manage and control. In addition, due to the difficulties with getting constipation under control she feared leaving the home in case of public soiling. This led to ever increasing social isolation.

This patient had many 'services' in place to try to support staying at home as was the patient's wish. However, the services came from different areas for different specific tasks where all the difficulties could be approached, once in the hospice, by the same team. There did not seem to be any further services that could have been added yet the shape of care at home was not the most appropriate for this person's circumstances, as what was needed was input from a small number of consistent people, rather than group of people, which could have enabled her to her build trust and overcome her embarrassment during wound care.

With the current set up of support at home as described in this section it appeared to be difficult to provide the emotional safety/existential comfort, symptom management and security that the hospice provides.

6.3 Outcome: discharge or death and length of stay.

Over the four months of this study 68% of patients died during their IPU admission (St Columba's = 62% (93/150); Marie Curie = 75% (95/126). 87 patients (31.5%) were discharged and one was still in the IPU at the end of data collection.

Of those patients who were referred from the hospital, 86% died compared to 61% of those admitted from the community. A large majority of patients who were assessed as being "dying" or "deteriorating" on admission, died during the admission (90%). Only 65/155 (58%) of those admitted by the Community CNS team died during the admission.

The length of time the patients stayed in the inpatient unit across the whole sample was a median of 12 days.

Table 13 : Length of stay

Marie Curie Hospice Edinburgh			
	Died	Discharged	Total
Mean	11.5	19.2	13.4
SD	12.6	15.4	13.7
Median	7	17	9
Min	0	1	0.0
Max	70	67	70.0
St Columba's Hospice			
	Died	Discharged	Total*
Mean	14.2	24.9	19.4
SD	13.4	20.5	22.1
Median	11	18	14
Min	0	0	0.0
Max	70	97	189
Total			
	Died	Discharged	Total*
Mean	12.9	22.8	16.6
SD	13.0	18.9	18.9
Median	9	17	12
Min	0	0	0.0
Max	70	97	189

Length of stay was shorter for Marie Curie patients (Median = 9 days) compared with St Columba's patients (Median = 14 days). Length of stay was shorter for those who died during their admission (Median = 9 days) (7 days Marie Curie and 11 days St Columba's) and longer for those who were discharged (Median = 17 days). The majority (80%) of those discharged were discharged to their home (70 of 87 patients). The other discharges were to care home (n=3), hospital (n=7) and community hospital (n=7).

Table 14: Length of stay x where admitted from x outcome (n=276)

Admitted from community	Died (n=115)	Discharged (n=75)	Total (n=190)
Mean LOS	13.4	22.1	16.8
SD	13.8	19.7	16.9
Median LOS	10	16	13
Range : Min - Max	0 -70	0 -97	0 - 97

Admitted from hospital	Died (n=73)	Discharged (n=12)	Total* (n=86)
Mean	12.1	27.3	16.2
SD	11.7	13.5	22.9
Median	7	27	10
Range : Min- Max	0-63	9 -48	0-189*

*The total figure also includes on patient who was still in the IPU after 189 days.

The vast majority of patients admitted from hospital (71/83; 86%) died during their admission, and these patients had a median length of stay of 7 days.

7. Experiences and wishes of patients and their families regarding the inpatient admission and about preferred place of death

7.1 Expectations and experiences of being in the hospice

The qualitative data provided insight into the expectations and experiences of the patients being admitted to the hospice. Whilst there remains a great deal of stigma about the terms hospice and palliative care, as was evident from some of those admitted, this abated once patients were admitted.

MC1 patient *'when you hear a hospice – It's full of people that's dying that is what I thought'*

'[nurses] told me what a nice place it was and how the nurses were great and I wasnae coming in to die I was coming in to get help'

'I had to get it in my head that I wasn't coming in here to die'

'I'm quite confident now and not half as scared as I was'

SC6 patient ***'It wasn't something that you wanted to happen to come into the hospice? I was scared. You were scared. Yeah. Can I ask why exactly? Because of my perception of a hospice. Sure, and what was your perception? That you never get out. And that***

they're cold places but I found that to be entirely the opposite situation. I find it – I mean I'm on a nice wee ward here; it's very quiet'

*'[hospice] is such a horrible word I think that. And it's just from childhood even. **And it's not shifted that idea?** It's not, no. **The word that hospice associates with.....** When you go in you never come out. **Correct, I don't know that that's a reassurance to you that you're not the only person that thinks that.'***

*'I told the CNS about [my daughter's] baby and she says well if she does have the baby while you're in, you can go. **Absolutely.** Which I didn't know. **Yeah, yeah. You're free to come and go.** Yes so that was encouraging'*

Prior fear could be explicitly stated by patients as they reflected on how they felt about hospices, and the emotions surrounding their decisions to be admitted.

Any level of familiarity with the setting was helpful for this. If a patient had been in a hospice before or had experience of visiting someone in the hospice then they were more disposed to coming in. Familiarity reduced fear and anxiety.

MC2 staff *'He was admitted two years ago but he talks about "oh yeah I got fixed, I felt better for a while, it kind of psychologically helps'*

SC10 patient *'a friend of mine who had Motor Neurone Disease was in here a couple of years [ago] for respite – well maybe three years ago. For respite care and it was lovely you know.'* *'[aunt] was so well looked after here that she felt safe.'*

7.2 Experiences of being admitted to the hospice

Experiences of being in the hospice and of hospice care were overall very positive once patients were admitted.

MC1 patient *'I'd just be sitting at home right now in pain and knowing that nobody could get on top of it. Where I'm here I've got to take because they are trying to get my bowels to move, but I'm not in pain, I'm quite comfortable lying here.'*

MC 4 patient *'It's not something wanted but it's been an ideal choice so far, good choice, no one wants to be anywhere where you are sick and [not] getting better, but eh, yeah, the hospice has been good.'*

Positive experiences were also evident when the patient had planned to come to the hospice at the end of life

MC9 patient *'well I feel like a lot happier now I'm here and I'm quite settled on going, you know what I mean. I'm not thinking 'oh my god' I don't know how other people feel. And I just said to them as long as it's kind of painless **yup you're ready** I don't want to be screaming out in pain, you know what I mean, so I'm ready to go now. I mean it's not life, my sons would say that as well.'*

In order to assess if patients had been cared for and died according to their stated preferences, data was collected on 'preferred place of death'. Of the 276 admissions to the hospice, 81% had had a documented discussion about where they wanted to die, or had a reason documented as to why a discussion did not occur.

Most of the patients admitted wished to die in the hospice (52%) and 14% wished to die at home.

Table 16 : Preferred place of death

Preferred place of death	MCHE	MCHE %	St Columbas	St Columbas %	Total	Total %
Discussion not appropriate	7	6%	14	9%	21	8%
Home	24	19%	16	11%	40	14%
Hospice	73	58%	71	47%	144	52%
Patient declined discussion	7	6%	2	1%	2	1%
Patient unable to express preference	0	0%	1	1%	8	3%
Patient undecided	5	4%	3	2%	8	3%
Not discussed	10	8%	43	29%	53	19%
Grand Total	126	100%	150	100%	276	100%

Of the patients who died in a hospice (188 deaths) 56% had stated the hospice as their preferred place of death. Home was documented as the preferred place for 15% of those who died in the hospice. This proportion was similar in each hospice.

Preferred place of death was not discussed with 29% of patients who died in the inpatient units, and in 16% of all patients, there was no documentation around any discussion about preferred place of death.

Table 17: Place of death for patients who died in the hospice inpatient unit

Last recorded preferred place of death for those who died in the hospice	MCHE	MCHE %	St Columbas	St Columbas %	Total	Total %
Hospice	61	64%	44	47%	105	56%
Home	14	15%	15	16%	29	15%
Not discussed	7	7%	24	26%	31	16%
Discussion not appropriate	4	4%	6	6%	10	5%
Patient declined discussion	0	0%	1	1%	1	1%
Patient unable to express preference	6	6%	1	1%	7	4%
Patient undecided	3	3%	2	2%	5	3%
Total	95	100%	93	100%	188	100%

8. Discussion

8.1 Who are the patients admitted to inpatient hospice units in Lothian?

Over a four-month period there were 276 admissions to the inpatient units in the Lothian Hospices, representing 259 patients.

There were more patients admitted to both hospices from the highest socioeconomic area than from the lowest. This is consistent with the socioeconomic profile of the population of the area and offers some reassurance around equity of access across the population, but does not demonstrate any bias towards those from poorer backgrounds.

Most of those admitted identified as being white, and British or Scottish. Only one percent of patients were from black or minority ethnic backgrounds with the remaining four percent identifying as being from other countries than UK. This is more “white” than the wider population in Edinburgh IJB, which from the 2011 census had a non-white population of 8%^[9]; however, the hospice population, being older, is not representative, so it is not possible to see any significance in this finding.

The vast majority (95%) of patients had a cancer diagnosis with lung cancer being the most frequently seen. Those with non-malignant conditions (5%) are underrepresented in the inpatient units. We know from other hospice activity analysis that hospice community services are more fully utilised by patients with conditions other than cancer. The fact that these patients are not admitted to the IPU may reflect greater uncertainty of prognosis in non-malignant conditions or that hospice inpatient services are associated with cancer in the minds of both referrers and patients.

8.2 Why are patients admitted to inpatient hospice units in Lothian

The majority of patients were admitted to the inpatient units from the community setting (70%); just under one-third (30%) were referred from hospital. Both hospices describe admissions as “urgent” or “unplanned”, in other words, a request for the first available bed, rather than being planned in advance. This reflects the hospice’s role in crisis management. Many patients interviewed commented they would rather not have been admitted – for some hospice admission may be viewed as a “last resort”.

While it is possible that for some people the deterioration is very rapid, and admission is unavoidable, it may be that further support in advance of the crises, or at the time of referral would prevent or delay inpatient use. It may be possible to be more sophisticated in our pre-admission assessment and support, including ensuring primary care is fully and appropriately involved.

Admissions from hospital

Those who were admitted from hospital were primarily referred for end-of-life care, and died during the admission (86%), often within a few days (median LOS 7 days), including a small number on the day of admission.

There are often compelling reasons to admit such patients, not least in terms of holistic care and support for loved ones. Very few referrals were viewed as being inappropriate. However, some patients transferred from hospital had relatively straightforward palliative care needs, perhaps on the less complex end of the range; others were clearly highly complex with unstable needs where a hospice admission is essential. It is not clear how many possibly appropriate referrals are not offered hospice care; often the challenge for the referrer is around prognostication, which is not always easy.

The small number of patients admitted from hospital who are eventually discharged home (n=12/86, 14%), after a significant period of support, may reflect those patients whose discharge planning needs are complex, and require the multidisciplinary approach of the hospice team, or whose condition stabilises or even improves following their need for acute care.

Unsurprisingly, admissions from hospital were more likely to be assessed as having a “Stable” or “Deteriorating” phase of illness than community admissions.

Many hospital referrals come via the Hospital Palliative Care teams and it is recognised that there is a great deal of scrutiny in their decision as to whether a referral to the hospice is the best option. There is no tool currently in use to support this, or to aid prioritisation of admission, and this is perhaps an area for development. Alternatives to hospice admission from hospital include discharge home or transfer to another inpatient unit.

In response to the current pandemic both hospices have reduced beds so it is more critical than ever that these are used to their best effect.

Admissions from community

At the time of admission, 54% of patients admitted from the community were thought to be admitted for symptom control, however 61% of admissions from the community die on the inpatient unit.

This would suggest that determining reversibility is not always easy, and the admission is in part about exploring both the possibility of reversibility. Staff spoke about the need to “see what happens” where an outcome is less clear or predictable. A hospice admission allows the issue of reversibility to be explored and tested, and then if it is not possible, to support the patient and family in the transition into end of life care.

Based on our analysis, 40% of those admitted from community were not under the care of the DN at the time of admission (n=77). This is an area that merits further exploring to ensure services are appropriately connected and working in partnership.

The number of patients who had no “hands on” care prior to admission was also surprisingly high (79%). While some of these will be patients whose condition changed rapidly meriting a crisis admission for symptom management, some were admitted for end of life care, and for

whom more timely, and appropriate support at home may have delayed, or avoided an admission, or reduced the distress experienced in advance of admission.

Involvement of palliative care prior to IPU admission

10% (n=28) of all admissions came via the hospital and had no previous specialist palliative care input either at the hospital prior to referral, or within the community prior to referral. Similarly, 5% (n=13) of admissions via the community had no prior involvement from specialist palliative care services. Therefore, 15% of all hospice IPU admissions (n=41) had neither been previously supported, or assessed by a specialist prior to admission.

Analysis of this group shows that they were more likely to be assessed as being “deteriorating” or “dying” : this may be a sudden change leading to a crisis admission, but perhaps the hospice community service being accessed as an alternative to admission may allow such patients to access the support to be at or to remain at home. This would certainly indicate that an increase in community hospice support may have avoided an admission.

Of note, this group of patients was under represented in the qualitative study as the level of distress made recruitment difficult.

Outcome prediction

For around one quarter of those admitted, the person making the referral was unsure if the patient’s condition could be considered end-of-life or whether their deterioration could be reversed with symptom control. From the qualitative data we see a range of reasons for admission reflected in how patients, their carers and hospice staff described anxiety and fear, social isolation and simply the inability of the patient or their family to carry on coping at home as contributory factors. It was evident that for a group of patients and their families that the hospice could provide a degree of ‘emotional safety/existential comfort’. Perhaps it is these factors that are intuitively understood by staff making referrals who then may not be able to classify patient need according to the categories of either symptom control or end-of-life care. The use of these categories is long standing and may be less than helpful, and perhaps considering what the admission hopes to achieve might be more useful. More detailed classifications may identify if patients could be cared for at home, if that is their wish, with a different form or structure of community-based support or, in the event of admission, whether hospice specialist palliative care, or nursing led care (whether in the hospice or elsewhere) would be most appropriate for their needs.

The majority of patients who were discharged (87 patients) were discharged home (80%, n=70) with only a small number (20%, n=17) moving to hospital or long-term care.

Place of death

It is part of the hospice approach to explore with patients where they would like to be cared for, and where they would like to be at end of life. Following admission to a hospice 52% of

patients stated they wished to die in the hospice, while 14% wished to die at home. As previously discussed, not all admissions to a hospice are for end of life care, so it is not surprising that some patients would express this preference.

There was a gap in documentation around this important discussion, so it is not possible to say whether people's preference in place of death was achieved. 29% of patients in St Columba's and 8% at Marie Curie had no documented preference. This is an area for improvement.

Differences between the two hospices

The proportion of patients who die on the in-patient units was somewhat similar in both hospices (St Columba's Hospice Care 62% and Marie Curie Hospice 75%), however the length of time a patient stayed was shorter in the Marie Curie Hospice, median 9 days, compared with St Columba's Hospice Care with a median of 14 days.

It is not clear why this is and there are a number of hypotheses. It may be simply related to the number of overall beds, with St Columba's Hospice Care having 30 compared to Marie Curie's 20 at the time of the study. The additional pressure on beds in the Marie Curie Hospice catchment area may impact decision making around both admission and discharge.

This is supported by analysis of the data around patient dependency and symptom complexity on admission between the two hospices which does show some variations.

Differences were seen in Karnofsky scores on admission, with more dependent patients (ie closer to death) admitted to Marie Curie Hospice than to St Columba's Hospice Care (61% scored <40% in Marie Curie, compared to 41% in St Columba's). No difference was seen in prevalence of delirium between the two hospices, but proportionately more patients were admitted to St Columba's Hospice Care for symptom management (56% in St Columba's compared to 35% in Marie Curie) rather than end of life care (21% in St Columba's compared to 34% in Marie Curie). This may be down to the way staff have categorised the admission, but there does seem to be an indication of variation in practice between the two hospices, more than merely the number of hospice beds.

Greater clarity around the intentional use of beds would therefore be helpful.

8.3 Patients' perception on being admitted to the hospice

Patient expectations and experiences of being admitted to the hospices were broadly positive. It was regarded as the right place for them to be in either because they wished to die in the hospice or they were suffering due to ongoing inadequately managed symptoms, social isolation and/or anxiety and fear. A level of familiarity with hospices either based on stories from friends or prior experience could facilitate a more positive picture prior to admission. There were some patients who described a fear of hospices in general, considering them to be 'cold' or scary places where people would only go to die, yet following admission that their views had changed. Their perceptions became much more

positive and they understood that people could stay in a hospice for a period of time before being discharged back home and this enabled a sense of comfort.

8.4 Alternatives to admission to the hospice inpatient unit

Our findings reveal that, prior to admission, the majority of patients had palliative care input from the hospice community nurse specialist (73%), but less than half had district nursing involvement (48%) and only one fifth were receiving social care support. Furthermore, it was evident that 21% of the patients had no previous community resources in place. This would suggest that hospice admission may not always be necessary if there were an increase in rapidly accessible, appropriate support at home, and services were in place to avoid a crises rather than waiting for the crises.

While the IPOS scores indicate that physical symptomatology of hospice admissions is often complex, the clear message from this review is that the psychological and social needs of the patients admitted to the inpatient units in this study were significant.

Even complex symptom management can be delivered in a community setting, but to avoid hospice admission the other aspects highlighted by our patients would need to be addressed. In particular, review of IPOS scores on admission identified that the most common issues expressed by patients was around support for their family.

Analysis of Phase of Illness on admission indicates that 26% of all admissions were assessed as “stable”- the place of care needed to change, but the plan of care did not. These may well be patients whose care needs, or family support needs, were unable to be met in their current setting. This would suggest that there are variations in complexity within hospice admissions, and while high quality nursing inpatient care may be what is needed, these patients could perhaps be cared for in a different model, or in a different place. There is potential for primary care, palliative care and social care services to tailor home based services to meet such needs and thus could avoid, or delay, admission to the hospices.

Most patients were screened for delirium[10] on admission; and 28% were assessed as likely to have delirium. This proportion is in line with the findings reported in the wider research literature. For some patients, delirium may have contributed to the reason for admission. Better prevention, identification, and management of delirium in the community setting, along with a greater understanding of the support needs of community staff, may enable patients to remain in their home for longer.

9. Recommendations

9.1 Service development

Our study has shown that inpatient hospice care provides a safe and effective place of care for patients with complex physical and emotional needs, with no alternative able to support these needs.

There is also, however, a recognition that, for some patients, an alternative to admission may be preferable. We therefore recommend that

- 9.1.1. some inpatient hospice resources are reconfigured to improve and develop alternative interventions that are responsive and flexible to allow urgent complex palliative care to be delivered at home, either as an alternative to admission, or to support discharge from hospital
- 9.1.2. criteria are developed to support decision making for patients who are referred to the inpatient units from the acute hospital setting, to consider alternatives, including discharge home with additional resource and access to hospice services, or transfer to an alternative place of care. This is particularly important for those patients who have not had the support of the Hospital Palliative Care Team.
- 9.1.3. Consideration is given to exploring new modalities of inpatient care, either in the hospice or in an alternative inpatient setting, where needs are less complex, but high quality care and support gives the physical and emotional safety net described by patients in a person centred way. This is particularly relevant within the urban area, reflecting the absence of GP led community hospital beds.

We have also identified that some patients who access a hospice bed have had no (or very little) community support other than from the hospice, prior to admission. Hospice and primary and social care services remain disjointed (or missing) with the teams working in parallel rather than fully integrated.

In order to enable people to be cared for effectively and safely at home we, therefore, recommend that:

- 9.1.4. Hospice and primary and social care services work to become more integrated, from the time that the patient is identified as having palliative care needs. This would ensure that patients who have advanced illness are known to the right team at the right time within the overall provision of palliative care services, avoid duplication but also avoid gaps in service provision. This requires an all systems approach working together to agree the best approach, and in particular creating opportunities to access services rapidly when a patient moves into crises. This is also critical as we look ahead to the increasing numbers of people who will require palliative and end of life care in the future.

Currently patients are admitted to a hospice inpatient bed either for end of life care or for complex symptom management. We recommend that:

- 9.1.5. More consideration is given to the wider psychological needs and existential distress for some patients for whom home does not currently provide emotional security. Such patients may benefit from an increase in access to a multi-disciplinary holistic support in all settings, offering a team of staff and volunteers who are trained to understand and support emotional safety. It is important too to recognise that complex emotional and psychological needs, with extreme existential angst, may merit a hospice admission.

In addition, we recommend that

- 9.1.6. Hospices increase realistic discussion around preferred place of care with patients and family and ensure that the reasons for not having the discussion are documented.
- 9.1.7. To ensure that the patient's voice is clearly heard, and to demonstrate the impact of hospice services we should ensure Patient Reported Outcome Measures are completed with all patients including AKPS; IPOS; phase of illness. This must be underpinned by training and support for staff.
- 9.1.8. The percentage of patients with a non-cancer diagnosis being admitted to the hospice inpatient units is very low. Hospices need to understand what support is most useful to those suffering from and dying with organ failure, frailty or neurological conditions in the appropriate setting for the person and should engage with the wider team of non-malignant specialists to consider this within NHS Lothian, including approaches to referral to hospice services by these teams.
- 9.1.9. Delirium is a common symptom at time of admission. Should people wish to stay at home, it would be helpful to offer further training on delirium management and prevention in the home setting to the Community Hospice teams and Primary care teams and that interventions to assist carers in supporting patients with delirium in the home setting are developed, evaluated and implemented.

9.2 Further investigation/research

- Whilst the demographics of the patients admitted to the hospices reflects the population living in the areas the hospices services, it would be useful to understand how the wider hospice services are used by our population. Further exploration of indication of bias and needs for care and support will widen access, including an increase in understanding of any barriers to accessing hospice services.
- Further work into understanding and responding to the emotional and existential distress which may require an admission

10. Strengths and limitations of the study

The key strength of this study was its aim in gathering local data for local services and this has resulted in key recommendation for both the hospices in Lothian as their services are being developed to meet the need in the future and ensuring inpatient hospice beds are used in the most appropriate way. The weakness of the study lies in the fact that those who were interviewed tended to be less ill and therefore agreed to participate in the study. Therefore, the qualitative data may not reflect the whole sample in relation to clinical picture.

There was also some missing data from the OACC suite measures on both sites. In part this was due to the relatively recent implementation of these measures, and a degree of non-completion.

References

1. Calderwood, C. *Realistic Medicine*. 2014; Available from: <https://www2.gov.scot/resource/0049/00492520.pdf>.
2. Partners4change. *The key to the door of a new way of working*. [cited 2020; Available from: <http://partners4change.co.uk/the-three-conversations/>].
3. Edinburgh Integration Joint Board. *Edinburgh Integration Joint Board Strategic Plan*. 2019; Available from: <https://www.edinburghhsc.scot/wp-content/uploads/2020/01/Strategic-Plan-2019-2022-1.pdf>
4. Creswell, J.W. and V.L.P. Clark, *Designing and conducting mixed methods research*. 2017: Sage publications.
5. Abernethy, A.P., et al., *The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]*. BMC palliative care, 2005. **4**(1): p. 7.
6. Witt J, M.F., de Wolf-Linder S, Higginson IJ, Daveson BA. *Introducing the Outcome Assessment and Complexity Collaborative (OACC) Suite of Measures 2013* [cited 2020; Available from: <https://www.kcl.ac.uk/cicelysaunders/attachments/studies-oacc-brief-introduction-booklet.pdf>].
7. Scottish Government, *Scottish Index of Multiple Deprivation 2020v2 data zones*. 2020.
8. Braun, V. and V. Clarke, *Using thematic analysis in psychology*. Qualitative research in psychology, 2006. **3**(2): p. 77-101.
9. Edinburgh City Council, *2011 Census Report*. 2013.
10. Watt, C.L., et al., *The incidence and prevalence of delirium across palliative care settings: a systematic review*. Palliative medicine, 2019. **33**(8): p. 865-877.

Appendix I: Basic demographics of those interviewed

	Age	Sex	Marital status	Diagnosis	Staff interviewed	Referrer interviewed	Phase	AKPS	IPOS	LOS days	Outcome	SIMD quintile	Admitted from	Services in place
MC1	75	F	Wid	Mal	Yes	No	Unstable	50	N/A	18	Discharged	2	Home	DN CNS
MC2	57	M	Sing	Mal	Yes	No	Unstable	50	N/A	8	Discharged	1	Home	DN CNS AHP SC DT
MC3	64	F	Mar	Mal	No	No	Unstable	80	N/A	24	Discharged	2	Home	CNS AHP
MC4	75	M	Mar	Mal	Yes	No	N/A	N/A	23	9	Died	N/A	Hosp	0
MC5	36	F	Sing	Mal	No	No	Unstable	N/A	30	16	Died	1	Home	DN CNS AHP SC MCNS
MC6	88	F	Sing	Mal	Yes	Yes	Deteriorating	20	N/A	5	Died	4	Hosp	DN
MC7	46	M	Sing	Mal	Yes	Yes	Unstable	N/A	N/A	17	Discharged	1	Home	CNS DN DT
MC8	76	F	Mar	Non Mal	Yes	Yes	N/A	N/A	N/A	1	Died	5	Home	CNS DN SC
MC9	70	F	Wid	Mal	no	yes	Deteriorating	60	34	6	Died	2	Home	CNS
MC10	64	M	Sing	Mal	Yes	No	Stable	60	/	49	died	2	Home	DN, CNS, GP
MC11	65	F	Mar	Mal	Yes	Yes	unstable	60	29	5	discharged	4	home	DN, CNS, OT
SC1	82	M	Mar	Mal	No	No	N/A	N/A	N/A	14	Discharged	3	Home	DN CNS
SC2	59	M	Mar	Mal	Yes	No	Stable	50	32	13	Discharged	1	Home	DN CNS AHP
SC3	71	M	Sing	Mal	Yes	No	N/A	N/A	N/A	13	Died	5	Home	DN AHP
SC4	64	F	Sing	Mal	Yes	No	Stable	80	N/A	16	Discharged	4	Home	0
SC5	60	F	Sing	Mal	No	Yes	Stable	80	N/A	22	Discharged	5	Home	CNS

SC6	61	F	Div	Mal	No	Yes	N/A	N/A	N/A	10	Discharged	2	Home	CNS DN
SC7	71	M	Mar	Mal	No	Yes	N/A	N/A	N/A	5	Discharged	2	Home	CNS
SC8	67	M	Sing	Mal	No	No	Unstable	40	N/A	43	Discharged	4	Home	DN CNS AHP SC
SC9	80	M	Wid		No	No	Stable	N/A	N/A	14	Died	5	Home	CNS
SC10	68	F	Sing	Mal	No	No	Unstable	50	N/A	30	Died	5	Home	DN
SC11	68	M	Mar	Mal	No	No	Stable	50	N/A	27	Discharged	3	Home	DN CNS AHP

