

Liverpool Homelessness and Palliative Care Coordinator Project

Evaluation report

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Executive Summary

Background

This report presents the findings of a qualitative evaluation of the Homelessness & Palliative Care Coordinator (HPCC) project in Liverpool. The project was first funded in October 2020 by the Masonic Charitable Foundation for one year. It was then extended to a total of three years.

The project brings together professionals from different organisations who could have a role in supporting people experiencing homelessness at end of life. This includes professionals from Marie Curie, Brownlow Group Practice and hostel staff. By increasing service provider collaboration, the project aims to improve multi-agency communication and the identification of people experiencing homelessness who could benefit from end-of-life care and support.

Brownlow Health have completed two quantitative outcome and quality audits based on the population within their caseload who are experiencing homelessness. The audit findings demonstrate a marked and welcome increase in key outcome and quality metrics over the time period of the HPCC project.

As the project is a new initiative, it was felt to be important to understand in more detail about the *how* and *why* behind these positive changes. With this in mind, it was agreed that a qualitative evaluation of the project to date would generate useful insight for both the local teams and wider stakeholders with an interest in improving end of life care provision for people experiencing homelessness.

Methodology

This evaluation used qualitative methods. Nine semi-structured interviews were conducted with professionals who have worked within the HPCC project. Participants included consultants and ward sisters at Marie Curie, homeless and palliative care co-ordinators, GPs and hostel staff. One interview was conducted with a patient who had received care through the project. Interviews were transcribed and thematically analysed. Additionally, one focus group was completed with five participants who worked at a hostel, who were supported by the project to look after residents at end of life.

Results

Seven key themes were identified through the thematic analysis.

Outcome themes:

1. **More person centred support for people experiencing homelessness**

The findings of the evaluation suggest that the HPCC project has had a positive impact on the support for people who are homeless with a palliative care need. An important element of palliative care for the homeless population is **receiving the medication needed to control their symptoms**. Participants felt that the HPCC

project has shown to professionals and to people experiencing homelessness that it is possible to provide symptom control in a hostel setting.

The impact of the HPCC project has extended beyond the homeless population who currently have a terminal illness to others who are homeless and experience the death of someone residing in the same hostel. The HPCC co-ordinator spends times talking to other residents when someone is unwell and after they die. This has **helped residents to understand what is happening, to prepare for the death and to receive support while they grieve.**

2. **Improved multi-agency working through better communication**

A key component of the HPCC project is multi-agency working. Participants explained that prior to the project, support was available, but they felt that it lacked a joined-up approach involving all appropriate services. The enhanced multi-agency working that has developed since the project was initiated has been driven by improved communication between professionals. The **Care Coordinator plays a pivotal role in the multi-agency workings of the project**, connecting agencies and providing support where needed. This ranges from supporting health professionals to holding space for hostel residents to grieve and understand what is happening when another resident is dying.

3. **Increased understanding and awareness**

As a result of this project, **a national ECHO network** has been set up to provide education and best practice on supporting people who are homeless at end of life. Whilst the project has had some impact in changing attitudes around homeless people within the workforce, this area is still ongoing. Through continued education and role-modelling it is possible that the HPCC project can be a catalyst in a culture shift in supporting people who are homeless at end of life.

More locally, work has also been done to **increase awareness of trauma informed care**. Some participants also discussed a culture shift within the workforce, both at Marie Curie and the NHS, towards people who are experiencing homelessness. Within Marie Curie, this was mentioned particularly about those who are using substances while receiving support from the hospice. As a result, interviewees reported there is now more understanding of the patients' situation.

4. **Increased support for hostel staff**

A key part of the project has been supporting hostels to deliver care and support for their residents who are living with a terminal illness. Participants acknowledged that hostel support staff are not medically trained and often have a close relationship with their residents. Due to this close relationship, hostel staff have an important role to play in terms of **emotional support for residents**.

A key element of the support provided to the hostels by the project was **helping hostel staff understand what they should expect when someone required care for a terminal illness**. Hostel staff also discussed what they should expect to

happen to an individual as their illness progressed. This was seen as important to give them **confidence to know when they might need to contact someone for medical assistance** for a resident or when they might need to go to hospital.

Process evaluation themes:

5. **What works well – a proactive and flexible service, delivered through partnership working, respecting and maximising collective experience and expertise**

Participants identified several factors that worked well about how the project operates, including:

- having a nurse in the HPCC coordinator role
- partnership working
- working in a proactive and flexible way
- supporting palliative care support for people experiencing homelessness to become more mainstream

6. **Improvements**

In terms of areas for improvement in the future, the following was identified:

- the availability of care packages in hostels is a limiting factor in terms of supporting people. While it is outside the gift of this project to introduce care packages through the project, there may be an opportunity for the project team to advocate for changes.
- there can still be challenges in supporting some people in environments such as hospices
- need to work through resource provision, particularly as there is just one care coordinator

7. **Sustainability**

Participants felt that there was a need to keep the HPCC post for the work to be sustainable, to keep services connected and provide outreach support.

Some participants felt that **the HPCC project was not only sustainable but also something which could grow**. They discussed how there will always be a need to support the homeless population at end of life and that this wasn't restricted to the project's current geographical area.

Conclusion

This evaluation has found that the HPCC project has been meeting its aims to improve access to palliative care services for people who are homeless and to educate the professionals who support them. The evaluation indicates that the HPCC project has

contributed to improved pathways and access to local services for people experiencing homelessness. In turn, this has enabled **better end of life experiences for people experiencing homelessness**, reflecting what's most important to the person.

Professionals involved in the project report having improved knowledge and understanding of how they can support people experiencing homelessness. They also acknowledge the professional satisfaction that comes from working in a well-functioning, multidisciplinary and multiagency team that is working towards a common goal.

The results of this evaluation provide evidence to support the continuation of the service. Participants identified that the project could easily become more integrated within the Integrated Mersey Palliative Care Team (IMPACT). The coordinator role is seen as a crucial component of the HPCC project, and this would require funding on an ongoing basis. However, as highlighted by one interviewee, the work delivered through this project does not represent a huge stretch to be delivered.

Recommendations

- **Seek long-term funding for the project and coordinator post**
Research has identified that reliability is a crucial factor in delivering services for people experiencing homelessness.¹ Given that the evidence that project has delivered impact, Marie Curie should seek long-term funding for the project.
- **Influencing care package options for hostels and in the community**
The current success relies somewhat on the willingness of hostel staff to provide care to their residents when more formalised care is unavailable. This limits the success of the project because it is partly dependent on hostel staff turnover and willingness to provide this support. To maximise impact, care packages are needed within the community to support residents to stay in their preferred place. The HPCC could consider using the evidence from the project so far to advocate to social care providers about the need for increased provision.
- **Share learning so far on administration of medication within hostels**
The project has innovated to enable the safe, risk-assessed, and person-centred administration of medication within hostels. This is not common practice in other areas. There is therefore the opportunity to share this knowledge with others to influence practice further.
- **Increase education sessions on homelessness and trauma informed care**
The HPCC project has increased awareness and education about the complexities of supporting people who are homeless at end of life. It has also highlighted the importance of trauma informed care. Although there has been progress in this area, educating the workforce is still ongoing. Continued education and awareness raising can help with the ongoing attitudes and culture shifts needed to provide the best care at end of life for people who are homeless.

¹ Klop, H.T., De Veer, A.J., Van Dongen, S.I., Francke, A.L., Rietjens, J.A. and Onwuteaka-Philipsen, B.D., 2018. Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. *BMC palliative care*, 17(1), pp.1-16.

- **Explore ways to make hospices more accessible to people experiencing homelessness**

Participants discussed how the project has helped to improve attitudes and access to hospices to a degree. However, there was acknowledgement that there can be difficulties around balancing the environment for other patients and those close to them within the hospice setting. More exploration is needed to understand how best to support homeless people within a hospice, and educate staff working at the hospice.

1. Background

Rationale for the Homelessness and Palliative Care Project

The Homelessness and Palliative Care (HPCC) project aims to bring together professionals who could have a role in supporting people who are homeless at end of life. By increasing service provider collaboration, the project aims to improve multi-agency communication and the identification of people who are homeless and suitable for end-of-life care. The project was first funded by the Masonic Charitable Foundation for one year from October 2020 and was then extended to a total of three years.

The project was initiated in recognition of the evidence base that indicates substantial inequalities in end of life care provision for people experiencing homelessness. In particular, the project is informed by the following recommendation by Shulman et al²:

“Given the unique and complex needs of homeless people with advanced ill health, specialised, flexible services are key in promoting compassionate, coordinated care. This will require a joint response from health, housing and social services. At the minimum, this should include increased collaboration between services, the promotion of in-reach into hostels and greater training and support for all professional groups”

Aims of the project

The project aims to:

- improve pathways and access to local services
- improve knowledge of palliative care for people working in homelessness services
- improve end-of-life experiences for people who are homeless, including support to die in their preferred place of death

A key component of the project was the creation of a new clinical Homelessness & Palliative Care Coordinator role. The HPCC coordinator is based at the Marie Curie Hospice in Liverpool. The role was created to improve access to end-of-life care for those who are homeless by working to identify patients sooner and improve communication across services. To do this, the HPCC supports members of the homeless population with a palliative care need. The HPCC also supports other professionals providing care and support to those who are homeless at end of life. The project commenced in October 2020. Due to COVID-19 infection control precautions during this first year, face to face support for people experiencing homelessness and hostels was limited. Instead, the first

² Shulman C, Hudson B, Low J, Hewett N, Daley J, Kennedy P et al. End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care. *Palliative Medicine*. 2017;32(1):36-45.

year focussed on building relationships with professionals in the Liverpool City Region. Since then, the HPCC project has expanded and now has several parts:

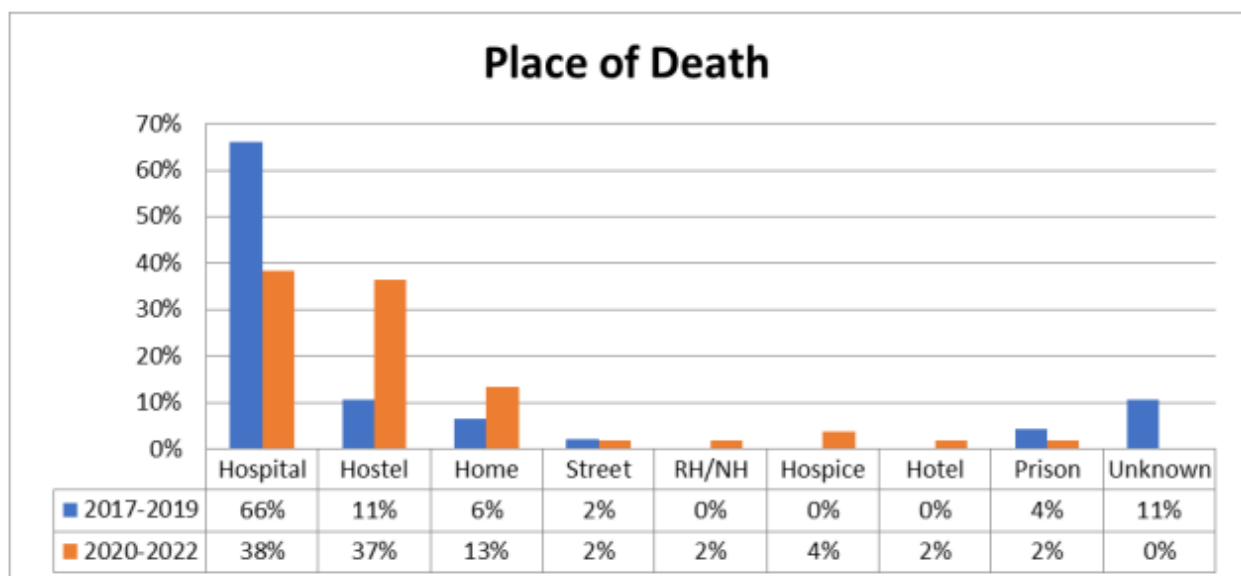
- The creation of the Homeless Palliative Care Multidisciplinary Team. This consists of GPs, Palliative Care Consultants, Palliative Care Nurses and other members of the palliative care multi-disciplinary team.
- Homeless Gold Standards Framework Meetings
- Outreach visits to the Royal Liverpool Hospital
- Support for two hostels
- A national homelessness ECHO

Audit findings

The HPCC project was commissioned following a 2019 audit conducted by Brownlow Health General Practice. The audit focused on people experiencing homelessness under their care who had died between 2017 and 2019. The audit was then repeated for 2020-2022. In the period 2017 to 2019 audit there were 47 recorded deaths. This rose slightly to 52 recorded deaths in 2020 to 2022.

Research has shown that being somewhere comfortable where people know them is a priority area for people experiencing homelessness. For many, this will mean dying in a hostel they are familiar with rather than another place such as a hospital. Figure 1 shows Place of Death for the two time periods. In 2017-2019, 66% of those who died did so in hospital, compared to 38% in 2020-2022. In 2017-2019, 11% died in hospital compared to 37% in 2020-2022. In 2017-2019, 11% died in hospital compared to 37% in 2020-2022.

Figure 1. Place of Death, 2017-2019 compared to 2020-2022 Brownlow Health General Practice Audit Findings



The audit also looked at markers of quality end of life care. This included if those with expected deaths were recorded on the Gold Standards Framework at the GP practice, if a Preferred Place of Care and Death had been recorded and if an end of life discussion had taken place with patient.

In 2017-2019, there were 16 deaths that were recorded as expected or partially expected. In 2020-2022, there were 20 expected or partially expected deaths. Analysis across the two time periods show substantial improvement on these quality measures:

- In 2017-2019, five individuals (31%) whose deaths were expected were on the Gold Standards Framework. This compares to 18 (90%) of those with expected deaths in 2020-22.
- In 2017-2019, 3 individuals (19%) whose deaths were expected had a recorded Place of Care and Place of Death. This compares to 14 (70%) in 2020-2022.
- In 2017-2019, 3 individuals (19%) had a record of an end of life care discussion having taken place. This compares to 17 (85%) in 2020-2022.

Rationale for this evaluation

The audit findings clearly show a marked and welcome increase in key outcome and quality metrics over the time period of the HPCC project. As the project is a new initiative, it was felt to be important to understand in more detail about the *how* and *why* behind these positive changes. With this in mind, it was agreed that a qualitative evaluation of the project to date would be beneficial to both the local teams and to other stakeholders with an interest in improving end of life care provision for people experiencing homelessness.

2. Methodology

This evaluation used focus group and semi-structured in-depth interview methods. Nine semi-structured interviews were conducted with professionals who have worked within the HPCC project. Participants included consultants and ward sisters at Marie Cure, homeless and palliative care co-ordinators, GPs and hostel staff. One focus group was conducted with five hostel staff. Due to the population being small, only one interview was conducted with a patient who had received care through the project. The population supported by the project is small and at the time of data collection, no other individuals with lived experience were identified to take part.

All professional staff interviews were conducted over the telephone and lasted between 16.46 and 45.29 minutes. The interview with the individual with lived experience and the focus group both took place in person. Interviews and the focus group were audio recorded and transcribed. Interviews were thematically analysed using Braun and Clarke's framework³ in NVivo.

Interviews explored:

- The aims and expectations of the project
- The needs of the population
- Multi-agency working
- The difference that the project made to the interviewees professionally
- The impact on the those who are homeless and at end of life and on the hostels supported by the project
- What worked well and what could be improved

³ Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology.' *Qualitative Research in Psychology*, 3(2) pp. 77-101.

3. Results

In this section, the main findings from the thematic analysis are presented. Seven key themes were identified through the thematic analysis. In this section, each of the following themes will be discussed in turn.

Outcome themes:

- 8. More person centred support for people experiencing homelessness
- 9. Improved multi-agency working through better communication
- 10. Increased understanding and awareness
- 11. Increased support for hostel staff

Process evaluation themes:

- 12. What works well – a proactive and flexible service, delivered through partnership working, respecting and maximising collective experience and expertise
- 13. Improvements
- 14. Sustainability

Outcome Theme 1. More person centred support for people experiencing homelessness

Better support and reducing isolation

The participant with lived experience spoke about the difference the project has made to him. He explained that prior to the project he had been trying to get support and felt let down.

“I think I’ve got good support...I feel like I haven’t had it in the past, I’ve felt let down so I think it’s taken all what I done to get the help so I’m in a better place here.”
(Person with lived experience)

Receiving support as part of the HPCC project allowed the participant to feel less alone.

“What three words would I use [to describe how the project makes me feel] ...grateful would be one... Just to know that there’s someone there that is looking after me instead of me thinking that I was all on my own.” (Person with lived experience)

Preferred Place of Death

Participants who were professionals discussed the difference the HPCC contributed to for people who are homeless. Hostel staff discussed this in relation to residents being able to die at the hostel. This was seen as important, as residents often used alcohol and other substances which can make it difficult to access care in other locations. The staff also reflected on how many people experiencing homelessness feel they have limited options, so it was important that they could be given some choice.

“It gives them a choice, doesn’t it? It gives them that dignity... As much as it’s a harm-reduction hostel, it’s their home, or they see it as their home...it’s just a sad time, and a scary time and that, to be around people that they know...we’re all here and we build a rapport with the residents and we get to know them and they get to know other residents....” (Hostel 5)

Ensuring that people experiencing homelessness have the option to die in their preferred place requires professionals to know where that place is. As illustrated by the 2017-2019 audit, prior to the project there were very few conversations with this population about their preferred place of death (PPD). There was therefore no way of knowing if and when PPD had been achieved. Since the start of the project, there has been an **increase in PPD being recorded** as the result of professionals having more advanced care planning discussions with patients.

“So I think it’s made a huge, huge difference. We did the audit and saw a huge increase in ...end of life discussions so... I think we’ve been able to get people to die where they want to in hostels, which isn’t happening anywhere else as far as I understand.” (Brownlow 1)

More appropriate hospital admissions

Participants felt that the more joined up approach has led to **more appropriate hospital admissions**. Hostel staff noted that when a resident at a hostel became unwell, often the only option available would be to call an ambulance. The HPCC project has helped to connect services together, so that now if hostel staff have a concern, they can ring other professionals to discuss the best course of action. This might be one of the health professionals going to visit the resident at the hostel, or advice being given over the phone.

"Because before the project, people would just get scared and ring an ambulance or ring an out of hours call doctor...they have the patients notes but don't really know the patient, and the majority will just end up in an ambulance in the hospital." (Marie Curie 6)

Participants also felt that the work of the project has also **helped people experiencing homelessness who do need to go to hospital to feel able to do so**. Interviewees reported that previously, when a hostel resident attended hospital and was given a terminal diagnosis where they would need care, they would not be able to return to the hostel because of this. Now, with health professionals working together to care for hostel residents and the residents seeing others go to hospital and return, they are more likely to go to the hospital when needed.

"... when they've gone [to hospital] in the past...people will say, 'You can't come back here because you're too complex for us now, so you're gone.' That doesn't happen for them here because we can facilitate that now, so they know if we're telling them to go to hospital, we really mean it, and we mean that they can come back, but right now they need the care of the hospital." (Hostel 2)

Increasing access to palliative services

The joint agency approach to providing care to the homeless population was also discussed by participants **as increasing access to palliative care services**. The HPCC project has changed the way services work together to support people experiencing homelessness people with a terminal illness, particularly through joint outreach visits. This has meant that people experiencing homelessness who may be unable to attend regular appointments have now received the care and support they need through professionals going out to see them.

Symptom management

An important element of palliative care for the homeless population is **receiving the medication needed to control their symptoms**. Previously, people experiencing homelessness who use substances might think that they would not be given medication due to this. Services might have been hesitant to administer medication in a hostel setting where other residents use substances. Participants felt that the HPCC project has shown to professionals and to people who are homeless that it is possible to provide risk-assessed symptom control to patients who use substances and that this can also be done in a hostel setting.

"They shouldn't feel fearful that they're not gonna get the painkillers that they need to because I think. We've set some really good examples of how you know we

haven't. Haven't been. What's the right word overly cautious about that? You know..., we've done what's kind of right for the patient and I think w. We set some really good examples of how we've used controlled drugs in like hostels ...and things we are, you know, people might have concerns about that, so I think they've got symptom control." (Marie Curie 4)

"To die where they want to in hostels, which isn't happening anywhere else as far as I understand.... And so you having syringe drivers in hostels and been done anywhere else. That using kind of really strong opiates so. We had somebody, so in the end on a really high fentanyl patch dose, but was getting oral up to a point before that. So I think all these things haven't really been achieved anywhere else in the country and so by all of this working together here in Liverpool, we've managed to do that. And I think kind of set good practise." (Brownlow 1)

Supporting the wider community

The impact of the HPCC project has extended beyond the homeless population who currently have a terminal illness to others who are homeless and experience the death of someone residing in the same hostel. The HPCC co-ordinator spends times talking to other residents when someone is unwell and after they die. This has **helped residents to understand what is happening, to prepare for the death and to receive support while they grieve**. Participants felt this helped other residents access support if and when they want it, to discuss how they are feeling about a resident dying, in an informal way and in the place they feel comfortable.

"Yes. I think just talking things through as [to] why we weren't taking this gentleman to hospital, why was he asleep for 15, 20 hours a day...I think they almost thought the patient could keep up with the lifestyle that he led, and when he wasn't, it wasn't that he was...just tired or sleepy...." (Marie Curie 6)

"And I think what [HPCC] has done [was] to be there to offer conversations with people if they want to and often it's for other residents..., knowing that it was a peaceful death that there wasn't any kind of suffering. We expected this. We planned for this. This is what he wanted and knowing that I think helps as part that grieving process and we started some conversations early before them dying...And I think that was really kind of useful that we were preparing people for it which we hadn't necessarily done [previously]..and I think it it's obvious for us because we see a bright yellow person who looks really unwell and but isn't necessarily obvious to them.it still comes as a shock to them that that this person died, although everybody else involved knew...That's important." (Brownlow 1)

Some participants reflected how improving access to palliative services is beneficial to the wider community, explaining that it has shown others experiencing homelessness that when they need care, services are available to support them:

"...it's definitely helped to link more of those residents in with palliative care services...whether that be outreach visits...people coming up to wellbeing, who wouldn't have access to wellbeing before...people ending up on the inpatient unit because they need to be in somewhere and hospital isn't the right place for them.

So since we've started doing this, there's definitely been more people linking in with different services.” (Marie Curie 3)

Outcome Theme 2: Improved multi-agency working through better communication

A key component of the HPCC project is multi-agency working. Participants explained that prior to the project, support was available but they felt that it lacked a joined-up approach involving all appropriate services. The enhanced multi-agency working that has developed since the project was initiated has been driven by improved communication between professionals. This multi-agency working and strong communication was highlighted by the interviewee with lived experience and in interviews with professionals:

“So they work together, she [consultant] tells him [GP] how I am and how I'm feeling. It makes me feel like I've got no worries because they're taking the worries away... If they see I'm not well, they spot it before I do.” (Person with lived experience)

“The communication is absolute key, down from our consultant who works with us to let us know prior to the patient coming in...what's expected of us...the GP letting us know about the patients, the support worker...the patient passed away and...I contacted the support worker and she was literally at the door as I rang her.” (Marie Curie 1)

Multidisciplinary Team Gold Standard Framework Meetings

The introduction of monthly Multidisciplinary Team (MDT) Gold Standard Framework meetings has been an important facilitator for improved communication and multi-agency working. At the monthly meetings, the team discuss patients on their caseload and identify any opportunities for joint-agency visits to support a particular individual. Where a patient has died, the multi-agency team consider what worked well and what could have been done better, to inform their ways of working and support for future patients.

The MDT was originally an informal meeting, which has since become a formal and recorded event. Having them on a regular basis provides a scheduled focal point for the team:

“I think there's an ongoing dialogue. So, there's a monthly homelessness GSF meeting..., just for anybody whose health is causing concern for them. So, there's that formal point every month where we discuss key patients that we're worried about, and that will often prompt...maybe a joint visit. (Marie Curie 2)

The monthly meetings provide an opportunity to learn more about each other's expertise. This in turn facilitates better communication and joint working, as professionals are better placed to highlight to others when an individual might require more or different support.

“...even though it [GSF]...was a virtual meeting, it really helped to build up those relationships. And I feel like we've got really good working relationships with the Brownlow, GPs...and the key workers there now and that has just come from literally seeing everyone on screen once a month and chatting about things and then getting to know how people work and even that meeting,.. developed throughout the time that we've been doing it.” (Marie Curie 3)

Building a “one-team” culture

By developing good working relationships through good communication, participants felt that the multi-agency aspect of the project worked well and was one of its strengths. There was a sense of all organisations being one, mutually supportive team. This was facilitated by the MDT meetings described above, as well as an increase in healthcare professionals working in hostels themselves providing advice, practical help and advocacy support for hostel staff. Over time, the combination of increased formal and informal communication has built up a sense of mutual respect for different agencies own expertise and skills:

“...I think before, personally, there was a lot of dread because of what I’m going to have to face today, alone...But that’s significantly reduced now, because it’s not just a “me,” it’s “we” with everyone involved. Even when the doctors say, “We,” they mean us as well. It feels like, for me personally, a lot less dread and a lot less fear, definitely.” (Hostel 2)

Enhancing existing working relationships

Multi-agency working within the HPCC project also helped to improve working relationships that were already in place. Several participants discussed how the support provided by district nurses within the hostels had improved.

One explained that Marie Curie being involved “gave a bit more weight to district nurses going in [to the hostel]” (Marie Curie 2). Prior to the project, hostels sometimes found it difficult to get support for their residents from district nursing. There was a sense that district nurses had felt unsure about the support needed in the hostels and what their role should be within that. Some participants also mentioned that at times the district nurses might have felt uncomfortable going into the hostel.

With Marie Curie as a link between the hostel and district nurses, it was felt that district nurses had a better understanding of the support needed within the hostel.

“It’s so much better now ... the communication was not good ... it seemed like we were battling with the GP ... against other agencies, like district nurses for example. But then since we’ve had... Marie Curie in, because they’re on both sides, they know the medical side of the nurses and they know our side, and they know what we want. They’re sort of the middle ground.” (Hostel 2)

“... this is probably one of the things I’m most proud of actually with the same hostel... The district nurses, for example, weren’t really keen on going into the hostel and I get it because I was a bit weary of going into the hostel myself at first, but there was a bit of kind of resistance there, but we managed to... kind of get them [the district nurses] on board and then when we were looking after the next patient, there was just no resistance from the same district nursing team [them]. They were all fully engaged with it. And so I think that team working was really you have really ...valued... that and quite proud of it I suppose.” (Marie Curie 4)

“Of who to ring...if they’re not sure about things...one of the hostel managers...emailed [the GP] and me together and...said she was worried. So you know, we’ve obviously built those links...I felt like they valued the fact we were advocating for them, particularly when...other agencies...weren’t keen to go in.

We...did it in a nice way, but we're quite firm that this is what needed to happen...I think they valued the debrief as well afterwards.” (Marie Curie 4)

As part of the wider team, participants could talk to other professionals about patients who might not be identified through the GSF meetings but whose needs might overlap with another professional's expertise. This has led to the working relationships developed within the HPCC project expanding out into other areas of work, resulting in a more general joined up and collaborative approach.

“...the other aspect that I found really good...is that overlap with some of the other work that we do and being able to pull those services together as well. So some of the...patients have overlapped with the people that we do...work with the liver teams and actually being able to get (GP) to come to some of those liver meetings and discuss those patients... collaboratively just shows how nicely it all fits together and that's kind of something I'm quite proud of” (Marie Curie 3)

Outcome Theme 3: Improved understanding, knowledge and awareness for healthcare professionals

Project ECHO

The HPCC project brings professionals together to provide information around end of life care for people who are homeless. Early in the project, HPCC team members felt that it could have a bigger impact if this information could be shared more widely. They therefore began to work on the ECHO network with a Marie Curie researcher who had developed a homelessness toolkit for care and hostel staff. The need for a sharing platform for information around end of life care for people who are homeless is evident from the number of people from around the country who have attended the ECHO network:

“I think we had over 90 people attend which was amazing.” (Marie Curie 5).

Increased understanding of trauma informed care

More locally, work has also been done to **increase awareness of trauma informed care**. There has been acknowledgement that people experiencing homelessness may have experienced trauma throughout their life. The HPCC team members reflected on this in relation to individuals attending the hospice, where certain parts of the environment could be unknowingly triggering for them:

“But what I do know now is the effect of trauma on people on how they behave, how they react and respond. Whether coming into our environment is gonna make them feel safe... we've we had a gentleman in the community who was vulnerably housed and coming towards the end of his life. And he was terrified of going into a bed. Because going into a bed with a trigger to his childhood trauma... When people come into the hospice, we wanna make them comfortable, make get them in the bed... for this man in particular, putting him in a bed was the worst thing that we could have done...” (Marie Curie 5)

The HPCC felt that all staff within the hospice should be trauma informed and this was something they wanted to take forward. They explained that although they had delivered some educational sessions, it was hard to reach every hospice worker:

“...when I say everybody, it needs to be domestics, kitchen staff, porters...everybody needs have that understanding because we all come into contact with patients, don't we?” (Marie Curie 5)

Changing attitudes

Participants were asked what impact, if any, the project had on them and their colleagues as working professionals. Some discussed a culture shift within the workforce, both at Marie Curie and the NHS, towards people who are experiencing homelessness. Within Marie Curie, this was mentioned particularly about those who are using substances while receiving support from the hospice. As a result, interviewees reported there is now more understanding of the patients' situation.

“Yes. I think just because that contact with the homeless population has increased in frequency, so it's becoming more of the norm for people, and...certainly my own observation is that I've heard fewer negative comments.” (Marie Curie 2)

“I think it's [the project] given me a greater understanding of homeless people and I think I think right or wrongly, you have a preconceived idea of what homeless people are like.” (Marie Curie 1)

Understanding and knowledge informing practice

Participants also discussed how they felt their knowledge and skills for supporting people who are homeless at end of life had improved because of their involvement in the project. For some, this was due to working with others who had more specialist knowledge. This meant that when faced with situations where previously they would have been unsure what to do, they are now able to think more laterally about potential options of care.

“And just in terms of sort of clinical practice...You have to think quite laterally and kind of come up with some different solutions and maybe [be] a bit braver in what you do.... Yeah, it's definitely developed me as a clinician, I think.” (Marie Curie 4)

Upskilling was particularly helpful where multiple professionals from different services were working together. By drawing on each other's specialist knowledge, they were able to explore more options, whilst also learning more about the other's specialism and upskilling each other in the process.

“We've been a good combination. [The GP] knows all the substance misuse stuff and we know the palliative care stuff and so I think [the GP] could probably manage these patients without us. I don't think we could manage them without him. So I think it's that the combination [has] upskilled both of us to be honest. So yeah, that's been a good sharing of knowledge and expertise I think.” (Marie Curie 4)

By being able to think laterally and draw on the knowledge that they gain from working with the other professionals, some participants felt that they are **able to provide more informed options** to people experiencing homelessness with a terminal illness.

“... it's given me an option...I'm able to have those discussions with patients, with solutions to offer which made a huge difference. So it's not just that we tell somebody that they've got a poor prognosis, to be able to say that...we can look after you as part of this team... We can rely on...resources from Marie Curie, physio, OT, consultants, we can get specialist reviews, everything. So that's been

brilliant and I think it's built so much trust with hospices, with staff, with patients as well...and so I think that's the big change that we've then been able to have those conversations...and take seriously the...wishes of people.” (Brownlow 1)

The increased understanding gained by participants through multi-agency working also led to an **increase in their confidence**, both in terms of their ability to manage symptoms and problem solve and also about who they could contact and where to access the information that they needed.

“Just confidence in recognizing when there's an issue. Confidence in asking for help and confidence in managing scenarios. Using medication, thinking about problems. Looking for solutions before the problems arise and calling on the appropriate resources.” (Brownlow 2)

When discussing the impact of the project on them, several participants expressed a **sense of pride** in being involved in it and the difference that it had made to them. For most participants, being able to give people who are homeless the best possible death in their preferred place was an achievement and something in which they were proud to play a part.

“I'm proud, not only of myself, I'm proud of every single person that I've worked with... now it can be taken forward and we've shown that if it's done right, it can work. And to be part of that, yes, for me, it's a massive sense of achievement, of pride.” (Hostel 5)

Outcome Theme 4. Improved support for hostel staff

HPCC project team providing emotional and bereavement support for hostel staff

For many people experiencing homelessness, the hostel is their home and where they feel most comfortable. The hostel can often be their preferred place of death. A key part of the project has been supporting hostels to deliver care and support for their residents who are living with a terminal illness. Participants acknowledged that hostel support staff are not medically trained and often have a close relationship with their residents. They therefore felt that it was important to provide **emotional support**.

Emotional support extended beyond a resident's death to include after care, with Marie Curie consultants and the co-ordinator facilitating reflective practices. These exercises allowed hostel staff to reflect on how the process of supporting a resident at end of life went. Doing so allowed them to consider what worked well and what could be better. As a result, one hostel made changes to its approach, which made supporting a second resident at end of life easier and was something that the hostel staff found useful.

The coordinator also provides **bereavement support** to hostel staff, delivered flexibly to support their needs and circumstances. These sessions were seen as important as it was recognised that the hostel staff may not have previously experienced death before.

“But what I sometimes do, along with the district nurses, is to just have meetings with them [hostel staff], not formal meetings, but just dropping in and seeing how they are, see how they're coping. As well as you're looking after the patient, you're looking after the staff as well, because they feel like the patient's family. They've

lived in the hostel for maybe a little while, and they need support just as if we were Marie Curie supporting the patient and family.” (Marie Curie 6)

“You expect to see death, you know and you expect it if you're a doctor or nurse...you're kind of expected to be able to cope with seeing people die and dealing with that afterwards. But it's just that recognition hostel staff aren't medically trained...they've not necessarily seen death happen. (Marie Curie 3)

Hostel staff discussed how they had **grown in confidence in advocating for and supporting their residents** with care for their terminal illness. They explained that conversations with Marie Curie consultants and the coordinator enabled them to challenge other professionals on decisions made about a resident's care. One aspect of this was learning key phrases that consultants and the HPCC used when discussing resident care.

“And just giving us the power to have conversations with people on the phone to say, “No, this can be done,” [or] with you saying no it can't or you don't want to discharge them or you want them to go into a nursing home or something, we've got the power now. We've got the...buzz phrases you can say to people on the phone to people for them to think that we might know exactly what we're talking about... we can get what the clients want.” (Hostel 2)

A key element of the support provided to the hostels by the project was **helping hostel staff understand what they should expect when someone required care for a terminal illness**. This was seen as particularly helpful regarding medication. One of the hostels supported by the project was a harm reduction facility where residents were still able to use alcohol and other substances. This meant that there could be complexities and hesitations about providing the medication needed for a resident's terminal illness.

“So when Marie Curie have come in it's been about expectations, what we can expect, what might happen, what might not happen, ...what medication people could be on, and there's been a lot of communication around end-of-life medication for our clients...and giving people that power at the end of their life, meaning that they don't necessarily have to stop using substances or drinking, and that it can be done around their addiction rather than having to cut them off from things that they've known and been used to and have done all of their life basically.” (Hostel 2)

Hostel staff also discussed what they should expect to happen to an individual as their illness progressed. This was seen as important to give them **confidence to know when they might need to contact someone for medical assistance** for a resident or when they might need to go to hospital.

“What they [hostel staff] don't want is somebody dying...unexpectedly in a way that's not right on the premises... And I think talking about death, talking about what we expect... and we're expecting like somebody turns yellow like that's what's gonna happen with they don't need to go to hospital. So I think really managing that is. Um, this resulted in people's staying where they should be. And I think...probably in the past maybe pain relief was not adequate and there were hesitations around that. We've managed to modify that.”(Brownlow 1)

Process evaluation theme 1: What works well – a proactive and flexible service, delivered through partnership working through respecting and maximising collective experience and expertise

Appointing someone with clinical experience to HPCC role

Participants discussed how the HPCC role helped to bring professionals and the project together. One participant also explained that **having a nurse in the role of the HPCC** worked well, as it allowed them to pass on skills and knowledge to more junior members of the team.

“I think... having a dedicated person to work on this is really good and having an established member of the nursing team working on it, because... they're, again, you get that element of role-modelling for the more junior nurses... So I think, and obviously the nurses are our biggest workforce here, so I think that's worked really well.” (Marie Curie 2)

Partnership working

Partnership working was also an aspect that participants identified as working well. They explained that by bringing together professionals from across the city the project has highlighted the breadth of expertise outside their organisation, from which they could benefit. Participants felt that by working on the project they had been able to develop strong working relationships not only with the HPCC but also with others within the wider project team.

“So I think it's still it's working well...there's massive difference with having links to the consultants... So although the project is around the coordinator role, actually those relationships that have developed over time with the consultants and with other members of the of the palliative team [are] really helpful.” (Brownlow 1)

“I can ask any question without feeling stupid, because they understand we're not medical professionals, and sometimes the way you get spoke to by others, it's like you should know things. So it's kind of just the whole attitude of Marie Curie that supports us and encourage - You feel comfortable asking them questions.” (Hostel team member)

Proactive and Flexible Service

By having a team of multi-agency professionals working together, it was felt that the project enabled a more **proactive and flexible service**.

“I have tried to be really responsive, I think because patients don't wait until your next available [appointment]...similarly, [GPs] were really flexible as well” (Marie Curie 4)

Some participants felt that the project had worked well in **helping palliative care support for the homeless population become more mainstream**. The project has shown that it is possible to support people who are homeless in a hostel and has brought the professionals needed to carry out this work onside.

“I think it's really good that it's highlighting this area of work...Enabling this work to become more mainstream and so it's having a kind of knock on effect. So for example, I think there's still lots of work to do, but in terms of normalising this as a role for the...district nurses involved...I think it's had a really positive impact.” (Brownlow 2)

Improvements

Although participants felt that overall, the project worked well, there were some areas for improvement. Some commented that to be able to provide the level of care needed by hostel residents, there was **a need for more care packages in hostels and in the community**. Currently, part of the project's success has been the willingness of hostel staff to provide care for their residents.

“One of the big concerns which we haven't...really dealt with is around personal care...about people being left in...unsanitary ways until kind of visits of a package of care. Maybe four times a day, but what we've found is that support workers in hostels, although it's not their role stepped up to do that...to facilitate the wishes of their residents” (Brownlow 1)

There was also acknowledgement that some requirements were difficult to meet in the hostel. This concerned the facilities that a resident might need when terminally ill, such as a ramp into the building. The participants felt that although these things would be useful, there was no budget for them.

“...what didn't work is stuff we're never going to be able to change anyway. It's going to be like the building layout, for example. The fact that we don't have a ramp. We could do 24/7 care, but there's just no money in the budget for that...there's nothing really that we can action this time, that we can actually change.” (Hostel 2)

Some participants discussed the difficulties experienced by some people experiencing homelessness receiving care in a hospice, due to their substance use. They discussed how it is difficult to balance their sometimes challenging behaviour with the needs of others within the hospice.

“...when you've got families whose loved ones are dying next to somebody who's behaviour is challenging or unusual, that's unacceptable. And I and I get that. But it's how maybe if wishes are around more Hospice care if somebody is still kind of wishing to do things that they thought. It just doesn't marry up does it and but I'm not sure how to do that really.” (Brownlow 1)

Participants also discussed **resource provision** as something that needed to be improved. Some mentioned that having only one person in a specific role meant that there could sometimes be delays, both in terms of identifying patients who could benefit from the project support and supporting multiple hostels with different needs.

“I think if anything, we just need a bit more resource to be able to do that. So I think that kind of homeless palliative care coordinator role that [HPCC] currently is quite key to upskill in the hostels...getting out there, finding out what they're worried about, finding out different ways about which they practice and ways which we can...support them. But I guess even at the moment that time that dedicated time

from [HPCC] is quite limited and actually if you've got people in different hostels, it's kind of how much you can support that." (Marie Curie 3)

Sustainability

Participants felt that there was a need to keep the HPCC post for the work to be sustainable, to keep services connected and provide outreach support.

"I think that the Care Coordinator role is really is really pivotal to keeping that going...so I'm hoping it will be the norm." (Brownlow 2)

The HPCC project is currently a standalone project, but some felt that it would be able to become a part of the Integrated Mersey Palliative Care Team (IMPACT). This would provide a central point where people with a terminal illness and those supporting them, such as those working in hostels, would be able to call to get appropriate support. From discussions with the hostel staff, it was evident that they were already aware of the IMPACT line and had used it when they had needed support for a resident.

"That's the vision. And I think it was necessary...to focus on this as an individual project in order to bring about that change, and I think it requires a bit of culture change within the hospice, within the palliative care community. It's just a different way of approaching that specific patient cohort. And the idea would be that that would then become our business as usual...specifically as part of our IMPACT service, which aims to be very flexible and respond to patient need, I think it would be absorbed into that. So that's the vision at the moment." (Marie Curie 2)

"I think it is sustainable. I think it would be a real shame if we lost it because I don't think the need's gonna go away and I think in terms of just our medical input, I think that's sustainable. I don't think it's been a massive reach to do this." (Marie Curie 4)

Some participants felt that **the HPCC project was not only sustainable but also something which could grow**. They discussed how there will always be a need to support the homeless population at end of life and that this wasn't restricted to the project's current geographical area.

"I think it can only go from strength to strength. I really do. And I think it's making a difference. It is making a difference." (Marie Curie 1)

However, one participant explained that whilst they felt that it was a project which could grow, it was too early to know if the HPCC role was sustainable.

"I think the bit that's quite a bit difficult to answer at the moment..., but I think in terms of the actual that kind of homeless support worker role and kind of the regular contacts with the hostels and the kind of (HPCC) out there, I think that's only really just started to ramp up over the last couple of months. So I think we kind of need to see the effect of that before we can say whether...we need to do anything else there. I think it could grow and grow if I'm honest. I think it could get bigger, bigger and bigger." (Marie Curie 3)

Although the key members of the HPCC project felt that they had gained skills and knowledge from being involved, some participants mentioned that for the HPCC project to be sustainable, it was important for **more staff to increase their skills and knowledge**. Some participants suggested that it would be useful to have formal education and training

around the topic. It was suggested that this would also help with the culture shift towards those who work in palliative care having more understanding of the homeless population.

“...I attended a teaching session which was actually given by one of the GPs at Brownlow Group Practice, and he spoke very eloquently about that when he sees a homeless person with significant medical problems, and maybe they’re difficult and they’re not doing what you want them to do, and he always tries to see the child that’s been damaged at some point in the past. So I think that’s what we want our staff to be able to do and to be able to see and just sort of change their reaction to the homeless people.” (Marie Curie 2)

4. Discussion

This qualitative evaluation explores the impact of the HPCC for people experiencing homeless and the professionals who work with them. Quantitative audit findings have shown marked improvement in outcome and quality metrics since the project's inception. This evaluation sought to understand the story behind these numbers through the use of semi-structured interviews and focus group methods with people with lived experience, health professionals and hostel staff. By identifying what worked well and what could be better, this evaluation aims to inform practice and learning more broadly.

A 2018 systematic review on people experiencing homelessness's views on palliative care consolidated the recommendations for practice themes from the 27 studies that met their inclusion criteria (Table 1). The recommendations fell into three categories: Delivering Care, Overall Organisation and Training, Education and Knowledge. This evaluation has gathered evidence to support that the programme has delivered against all three of the key recommendation domains.

Table 1. Themes regarding recommendations for Practice (Klop et al, 2018)⁴

Delivering Care	Overall organisation	Training, education and knowledge
Patient-centred approach	Availability of accommodation	Training regarding providing palliative care for (older) homeless people and their specific needs
Trustful and respectful relationships	People involved and coordination	Education about addressing preferences, advance directives, after death wishes and surrogate decision-makers
Reliability, experience, sensitivity and commitment of healthcare professionals	Hospital discharge policies	
Attention to various areas of concern of homeless people	Policies and guidelines	
Flexible programmes and availability	Partnering and exchange of knowledge between organizations	
Support after death		

⁴ Klop, H.T., De Veer, A.J., Van Dongen, S.I., Francke, A.L., Rietjens, J.A. and Onwuteaka-Philipsen, B.D., 2018. Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. *BMC palliative care*, 17(1), pp.1-16.

For people experiencing homelessness, there is evidence the HPCC project facilitates improved symptom management options and an increase in people being cared for and dying in their preferred place. It has enabled more appropriate use of other health services, such as acute hospitals. This has been achieved by joint professional visits to hostels, excellent communication amongst the multidisciplinary team and a mutual respect of the expertise and experience all parties bring to the project. Participants also described being able to “rely” on Marie Curie and how that helps to build and foster trust between all parties. For support after death, the HPCC team have offered conversations to residents.

More broadly, the approach that was both implicitly and explicitly described by professionals in the interviews and focus groups brings to mind the four principles of person centred care outlined by the Health Foundation.⁵ These principles are:

1. Affording people dignity, compassion and respect.
2. Offering coordinated care, support or treatment.
3. Offering personalised care, support or treatment.
4. Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life

Figure X. Health Foundation’s Four Principles of Person Centred Care



For example, providing people with options for their care was explicitly described as being directly linked to dignity. Through the project, agencies come together to coordinate care in a way that reflects the person rather than reflecting organisational boundaries. For many people experiencing homelessness, a hostel that they know and where they are known is a strength in their lives. In interviews for this evaluation, health professionals recognised this as an asset for some of their patients and worked with them to be able to be cared for in this setting, without compromising the ability to access significant symptom management or social support.

The 2018 systematic review found that the attitudes and behaviours of health professionals is reported by people experiencing homelessness as an important facilitator or a damaging barrier in accessing the care and support they need at end of life.⁶

This theme about shifting professional attitudes was a recurring theme in interviews. This was both in terms of challenging preconceived views about people experiencing homelessness and preconceived views of what care and support is possible. For example, teams have provided reassurance to residents that they can return to the hostel if they attend hospital. The HPCC team have also successfully managed to safely administer pain medication in less familiar environments, such as hostels. While participants recognised there is still more to do to shift culture, the work the health and hostel professionals have done so far to challenge perceptions provides an example of what can be achieved through taking a person centred approach.

There is both quantitative and qualitative evidence to support the continuation of the service. Participants identified that the project could easily become more integrated within the Integrated Mersey Palliative Care Team (IMPACT). The coordinator role is seen as a crucial component of the HPCC project, and this would require funding on an ongoing basis.

⁶ Klop, H.T., De Veer, A.J., Van Dongen, S.I., Francke, A.L., Rietjens, J.A. and Onwuteaka-Philipsen, B.D., 2018. Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. *BMC palliative care*, 17(1), pp.1-16.

5. Conclusions

The HPCC project was set up with the following aims:

1. To improve pathways and access to local services
2. To improve end-of-life experiences for people experiencing homelessness, including support to die in their preferred place of death
3. To improve knowledge of palliative care for people working in homelessness services

Triangulated with audit findings, this evaluation indicates that the HPCC project has **contributed to improved pathways and access to local services** for people experiencing homelessness. In turn, this has enabled **better end of life experiences for people experiencing homelessness**, reflecting what's most important to the person.

Professionals involved in the project report having improved knowledge and understanding of how they can support people experiencing homelessness. They also acknowledge the professional satisfaction that comes from working in a well-functioning, multidisciplinary and multiagency team that is working towards a common goal.

The project brought together professionals from different organisations to work together. The introduction of the GSF meeting has led to professionals discussing individuals with a palliative care need to identify appropriate courses of action. These meetings have led to more people experiencing homelessness being identified as needing support, with joint visits from Marie Curie and GPs.

Participants discussed experiences of people who are homeless attending the hospice for care both before and after the start of the HPCC project. They discussed how prior to the project, not many people experiencing homelessness received care within a hostel environment and when they did, there were difficulties.

Through better multi-agency working, professionals are now able to provide people who are homeless with more options at the end of their lives. The project has aided the increase in advanced care planning conversations with people who are homeless, including recording their preferred place of death. By having these conversations, it has become evident that many people who are homeless want to die in the hostels where they reside. The HPCC project has allowed professionals to come together to make this happen.

Education and role modelling to other members of the workforce, has contributed to the beginning of a culture shift within the hospice to make it more accessible to those who are homeless. However, it was suggested by a number of participants that this is an area that still needs to be explored to make it improve accessibility. This includes educating professionals to encourage a positive culture shift to supporting people who are homeless within a hospice.

At a local level, the aim of improving knowledge of palliative care for people working in homeless services has happened through Marie Curie supporting hostels to understand their residents' needs at end of life. Marie Curie have also worked with GPs who specialise in supporting people experiencing homelessness, to upskill them. The evaluation found that hostel staff and GPs felt more confident in supporting people experiencing homelessness at end of life and also had more knowledge about what to expect. This has also helped GPs feel more confident in providing symptom relief and identifying options for patients at end of life. The project has also increased the knowledge of Marie Curie consultants and HPCCs. By working closely with GPs and exploring the topic, Marie Curie staff have also learnt more about the homeless population and trauma informed working, which has led to presentations to highlight the issue within the hospice. At a national level, this project has been a key contributor to the development of an ECHO network, bringing professionals together from across the country to learn more and share best practice on the topic of homelessness and palliative care.

Whilst participants were positive for the most part, some felt that there were areas of improvement to provide people who are homeless with the best possible death and also to ensure that the work of the project was sustainable. There are therefore a number of recommendations to help improve the service to ensure the support provided is appropriate and sustainable.

6. Recommendations

- **Seek long-term funding for the project and coordinator post**
Research has identified that reliability is a crucial factor in delivering services for people experiencing homelessness.⁷ Given that the evidence that project has delivered impact, Marie Curie should seek long-term funding for the project.
- **Explore care package options for hostels and in the community**
The current success relies somewhat on the willingness of hostel staff to provide care to their residents when more formalised care is unavailable. This limits the success of the project because it is partly dependent on hostel staff turnover and willingness to provide this support. To maximise impact, care packages are needed within the community to support residents to stay in their preferred place.
- **Increase medication support for the homeless in community and hostel accommodation**
There is currently hesitation around administering medication in hostels. To ensure that all patients receive the same level of care within the community more needs to be done to provide guidelines for what is and isn't appropriate. This should be based on risk assessments.
- **Increase education sessions on homelessness and trauma informed care**
The HPCC project has increased awareness and education about the complexities of supporting people who are homeless at end of life. It has also highlighted the importance of trauma informed care. Although there has been progress in this area, educating the workforce is still ongoing. Continued education and awareness raising can help with the ongoing attitudes and culture shifts needed to provide the best care at end of life for people who are homeless.
- **Explore ways to make hospices more accessible to people experiencing homelessness**
Participants discussed how the project has helped to improve attitudes and access to hospices to a degree. However, there was acknowledgement that there can be difficulties around balancing the environment for other patients and those close to them within the hospice setting. More exploration is needed to understand how best to support people within a hospice and educate staff working at the hospice.

⁷ Klop, H.T., De Veer, A.J., Van Dongen, S.I., Francke, A.L., Rietjens, J.A. and Onwuteaka-Philipsen, B.D., 2018. Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. *BMC palliative care*, 17(1), pp.1-16.