PALLIATIVE AND END OF LIFE CARE FOR HOMELESS PEOPLE IN LONDON – CHALLENGES AND RECOMMENDATIONS

Initial findings from a qualitative study

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Palliative care for homeless or vulnerably housed people in London

a) Summary

In response to the challenges surrounding end of life care (EoLC) for homeless people, this qualitative research seeks to explore current provision of support and services for homeless and vulnerably housed people who may be approaching the end of their lives.

Through this research we aim to identify some of the gaps in services, explore what works well and develop recommendations as to what would make a difference. This is a collaborative project, funded by The Oak Foundation conducted by the UK charity Pathway, St Mungo’s, Coordinate my care and the Marie Curie Palliative Care Research Department at University College London.

These initial findings, which draw together the voices of both homeless people and those working to support them demonstrate the complexities and challenges of providing high quality palliative and EoLC to homeless people in London. Many gaps and inadequacies in service provision were identified and changes are needed to improve the care of homeless and vulnerably housed people with advanced ill health.

Figure 1 summarises the key challenges we have observed and our recommendations for future practice and policy which are elaborated on in Table 3.

NB. This research is not yet complete. This report outlines some of the initial findings that have emerged from the group discussions and individual interviews conducted as of June 21st 2016.

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Key challenges and recommendations

Challenges to palliative care

Uncertainty/complexity
- **Prognosis** - is often difficult to determine – particularly with conditions such as advanced liver disease
- **End of life conversations and planning** - what, how and when: complex due to real or perceived fragility of group, denial, use of substances to blank out reality, uncertainty regarding disease trajectories, fear of people losing hope and aspiration to change, fear of people thinking you’ve given up on them.
- **Lack of options** - hostel staff feel they have no, or limited options to offer homeless people with advanced ill health

The hostel environment
- **The hostel system** - the focus of the hostel system is recovery and "move on" to less supported accommodation. This is not appropriate for people who are approaching the end of their lives.
- **The role of a hostel** - hostels were not designed to be a "home", nor were they designed to provide care at the end of life. As a result, hostels don't have the resources, and staff don't have the training to provide the level of care people with advanced ill health require.

Inflexibility and gaps in services
- **Inflexibility** - homeless people don't fit into the boxes prescribed for them by mainstream services. Communication between services is challenging.
- **Gaps** - current systems and services (eg most hospices and care homes) cannot accommodate the specific requirements of homeless people with advanced ill health meaning there is often no provision for this group as their health deteriorates

Recommendations
- **Multidisciplinary working** - Multidisciplinary working is essential in coordinating bespoke, appropriate care for homeless patients with advanced ill health. Extension of St Mungo's palliative care coordinator role.
- **In reach** - care needs to be delivered where it can be accessed. Call for greater in-reach into hostels and strengthening relationships and collaboration between professionals.
- **Individualised care** - strong therapeutic relationships are vital in providing person centered, individualised care. Parallel planning could be a tool for focusing treatment plans on the wishes of the patient – not just starting towards the end of life.
- **High support facilities** - a high support facility which understands the challenges of homeless health care and which could act as a step up from a hostel and a step down from hospital to provide respite care for individuals with advanced ill health, which can also provide a place in which they can die.

Increased collaboration

Pan London funding

A pan London approach to services that considered the individual, rather than their local connection would be hugely beneficial to homeless people with advanced ill health.

*Figure 1 Key challenges and recommendations for palliative care provision for homeless people*
b) Introduction

Homeless and vulnerably housed people are a marginalized group who often experience high rates of morbidity and die young as a result of complex problems (1-3). In the UK the number of A&E visits and hospital admissions are reported to be four times higher for homeless people (4), while primary care services are underused (5). Challenges to homeless people’s access to health care are varied and multifaceted. They include mistrust of health care professionals (6, 7), perceived stigma and discrimination (8), competing priorities (7), difficulties registering with GPs (due to a lack of fixed address or photo ID) (4) and keeping appointments (8). For homeless persons with a terminal illness, these issues may be confounded by decreased health and mobility associated with advanced illness.

The reported mean age at death for homeless people ranges from 34 to 47 years, with age-adjusted death rates up to four times higher than the housed population in North American and European cities (1, 9, 10). In the US and elsewhere, the prevalence of alcohol or drug dependency, psychosis and personality disorder is substantially higher in the homeless than the housed populations (11) with dual diagnoses (severe mental illness together with substance misuse) and tri-morbidities (combinations of physical health, mental health and addiction issues) common (12). Drug and alcohol abuse account for a significant proportion of homeless people’s deaths in many countries, for instance almost a third of homeless deaths in the UK (13). Chronic progressive illnesses such as cancer, liver or respiratory disease, where palliative care would be appropriate are also experienced earlier by the homeless population compared with the housed population. Cognitive impairment at a young age, often as a result of high alcohol intake, is also very common.

There is a small body of research exploring the views and experiences of advanced care planning, palliative or end of life care (EoLC) for homeless people. The effectiveness of current advance care planning strategies appear uncertain (14, 15). It has been suggested that as homeless people may be less likely to have family members to act as surrogate decision-makers, this population may value advance care directives (16). Currently, homeless persons rarely have the opportunity to discuss EoLC or complete advance directives. The appropriateness of advanced care planning for this population has been questioned due to often high levels of anxiety around issues of death and dying (6). In a recent Canadian study, the majority of homeless men completing the directive (50% of all participants) reported feeling at peace upon completion of the directive (74.5%), while 16.3% reported anxiety or discomfort (17). Those who completed the directive were more likely to know their EoLC wishes, but never have told anyone, to think about death daily and to view friends and/or family as important.

Given the complexities of providing health care and more specifically specialist palliative care (palliative care teams and hospices) for the homeless population, qualitative research that seeks to understand the experiences and views of homeless people and care providers could be especially useful in exploring underlying reasons for the difficulties in provision of care for this group.
c) The current research

This collaborative project, funded by The Oak Foundation, gathered the views and experiences of homeless people, formerly homeless people, hostel and outreach staff and health and social care professionals with regards to palliative and EoLC for homeless people in London.

Aims
To explore the perspectives of service users and professionals regarding:

- The services and supports that are currently available for homeless people with advanced ill health that may be at risk of dying.
- What, if anything is stopping people from accessing these services?
- What would good care for this population at the end of life look like?
- What is needed, in terms of services and supports to enable high quality palliative and EoLC to be provided for and received by this population?

Methods
To achieve these aims, focus groups and individual interviews were held with the following groups, recruited from three London Boroughs (Lambeth, Hackney and Westminster):

- Currently homeless or vulnerably housed people
- Formerly homeless people – experts by experience
- Hostel Staff (key workers and managers)
- Out-reach staff
- Day centre staff
- A range of health care professionals (see table 2)

Ethical approval for the research was obtained from the ethics committee of University College London. Written consent was obtained from formerly homeless people, hostel, outreach and health and social care professionals. Verbal consent was obtained from homeless and vulnerably housed participants, as approved by the research ethics committee. All participants completed a demographic form. All focus groups and interviews were audio recorded and transcribed.

Data collection ran from October 2015 – July 2016. Groups ranged in size from 2-7 participants, groups held with health and social care professionals and formerly homeless people lasted for around three hours. Focus groups and interviews with homeless people lasted approximately one hour.

Data analysis
Summaries and field notes were completed following each interview and focus group. Themes identified in the summaries were used as an initial framework for coding verbatim transcripts. The findings outlined in this report are based on this initial coding.
d) Results

Participants
As of June 2016, 105 people shared their views on palliative and EoLC for homeless people. Table 1 and Table 2 outline the demographic characteristics and experiences of each group of participants.

Table 1 Demographic characteristics of participants

<table>
<thead>
<tr>
<th></th>
<th>Health/social care professionals</th>
<th>Hostel/outreach staff</th>
<th>Formerly homeless people</th>
<th>Currently homeless or vulnerably housed people</th>
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</thead>
<tbody>
<tr>
<td><strong>Borough</strong></td>
<td>N=35</td>
<td>N=32</td>
<td>N=10</td>
<td>N=28</td>
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<td>Hackney</td>
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<td>7</td>
<td>1</td>
<td>6</td>
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<td>Westminster</td>
<td>6</td>
<td>12</td>
<td>4</td>
<td>13</td>
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<tr>
<td>Lambeth</td>
<td>21</td>
<td>12</td>
<td>-</td>
<td>9</td>
</tr>
<tr>
<td>Pan London</td>
<td>-</td>
<td>1 (outreach)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>not reported</td>
<td>-</td>
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<td>5</td>
<td>-</td>
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<td><strong>Gender</strong></td>
<td></td>
<td></td>
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<td>11</td>
<td>13</td>
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<tr>
<td>Female</td>
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Table 2 Participant experiences

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<th>Information from health care professionals, hostel and outreach staff</th>
<th>Information from homeless and vulnerably housed participants</th>
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</thead>
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<td><strong>Place of work</strong></td>
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<td>Outreach service</td>
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<tr>
<td>Hospital</td>
<td></td>
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<td>GP surgery</td>
<td></td>
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<td>Hospice</td>
<td></td>
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<td>Hostel</td>
<td></td>
</tr>
<tr>
<td>Day centre</td>
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<td>Supported housing</td>
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</tr>
<tr>
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</tr>
<tr>
<td>GP</td>
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</tr>
<tr>
<td>Nurse practitioner</td>
<td></td>
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<tr>
<td>Nurse specialist</td>
<td></td>
</tr>
<tr>
<td>Drug and alcohol worker</td>
<td></td>
</tr>
<tr>
<td>Addiction psychiatrist</td>
<td></td>
</tr>
<tr>
<td>Palliative care consultant</td>
<td></td>
</tr>
<tr>
<td>Mental health nurse</td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td></td>
</tr>
<tr>
<td>Service manager</td>
<td></td>
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<tr>
<td>Housing worker</td>
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<tr>
<td>Outreach worker</td>
<td></td>
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<tr>
<td>Hostel worker</td>
<td></td>
</tr>
<tr>
<td>Complex needs hostel worker</td>
<td></td>
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<tr>
<td>How long have you been (or were you) homeless?</td>
<td></td>
</tr>
<tr>
<td>Less than 1 year</td>
<td>6</td>
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<tr>
<td>1-5 years</td>
<td>9</td>
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<tr>
<td>5-10 years</td>
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<tr>
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<tr>
<td>15 years +</td>
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</tr>
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<td>Not reported</td>
<td>5</td>
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<tr>
<td>Have you ever slept rough?</td>
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<td>24</td>
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<tr>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Not reported</td>
<td>3</td>
</tr>
<tr>
<td>How would you describe your health overall?</td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>8</td>
</tr>
<tr>
<td>Fair</td>
<td>12</td>
</tr>
<tr>
<td>Good</td>
<td>4</td>
</tr>
<tr>
<td>Very good</td>
<td>1</td>
</tr>
<tr>
<td>Not reported</td>
<td>3</td>
</tr>
<tr>
<td>Do you use drugs?</td>
<td></td>
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<tr>
<td>Yes</td>
<td>7</td>
</tr>
<tr>
<td>No</td>
<td>16</td>
</tr>
<tr>
<td>Not reported</td>
<td>5</td>
</tr>
<tr>
<td>Methadone/subutex</td>
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<tr>
<td>Yes</td>
<td>3</td>
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<tr>
<td>Health and social care professionals N=35</td>
<td>Hostel/outreach staff N=32</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>----------------------------</td>
</tr>
<tr>
<td>Hostel manager</td>
<td>-</td>
</tr>
<tr>
<td>Day centre manager</td>
<td>-</td>
</tr>
<tr>
<td>Palliative care coordinator</td>
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</tr>
<tr>
<td>Expert by experience</td>
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<td>Less than 1 year</td>
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<tr>
<td>1-5 years</td>
<td>3</td>
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<tr>
<td>5-10 years</td>
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<td>10-15 years</td>
<td>3</td>
</tr>
<tr>
<td>15 years +</td>
<td>2</td>
</tr>
<tr>
<td>Not reported</td>
<td>-</td>
</tr>
<tr>
<td><strong>Personal experience of homelessness?</strong></td>
<td></td>
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<tr>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
</tr>
<tr>
<td>Not reported</td>
<td>-</td>
</tr>
</tbody>
</table>

Do you drink alcohol?

- No: 20
- Not reported: 5

Have you been to A&E in the last year?

- Yes: 21
- No: 2
- Not reported: 5

Personal experience of homelessness?

- Yes: 8
- No: 27
- Not reported: 1
Challenges to the provision of palliative care to homeless people in London

Participants described many issues relating to accessing and providing high quality palliative and EoLC for homeless people in London. The issues raised have been grouped into challenges and also recommendations for improvements in the care and support of homeless people with advanced ill health (Figure 1).

Uncertainty and complexity in planning

Individuals from all professional groups recruited to this research (hostel staff, outreach staff, health and social care staff) commented on the complexity concerning the planning of care and support for homeless individuals with advanced ill health. These complexities centred around three main areas of uncertainty;

1) Prognosis
2) Raising and discussing issues around EoLC with homeless people
3) Uncertainty of the options available to homeless people with advanced ill health.

Prognosis

“The number of people that have come with 6 months to live and we've still got them two and a half years later...because what these doctors don’t seem to understand is that our clients tend to be made of quite stern stuff and they don’t give in easily” – Hostel staff

Identifying which homeless individuals may be approaching the end of their lives was described as challenging by a large number of participants in this research, from those working in hostels, outreach and medical services.

Hostel managers who participated in focus groups were asked to estimate the percentage of their residents for whom the answer to the surprise question (“would I be surprised if this person were to die in the next 6 months”) would be no. Most indicated that a large number of their residents would fall into this category, some estimating up to half. The health of homeless people is often poor and it was suggested by one specialist nurse practitioner that, given the complex and often multiple morbidities of homeless people, the majority of the work that they do in supporting this population could be considered palliative care. For many homeless people, health care interventions have the aim of improving quality of life, rather than working towards a “cure”.

Advanced liver disease is common amongst homeless people, often following prolonged and extensive alcohol use and/or as a complication of hepatitis C contracted through IV drug use. Even with decompensated liver disease predicting when someone is considered ‘palliative’ can be challenging as it can have an uncertain trajectory, as outlined in the 2011 Marie Curie and St Mungo’s report (18). Behavioural factors such as whether or not there is continued alcohol use also has a marked impact on prognosis. For patients with liver disease, the additive impact of cocaine use in drinkers with impaired liver function and the formation of cocaethylene in the liver, also considerably increases the risk of sudden death.
Hostel, outreach, medical and social care professionals described witnessing homeless people living for years after their life expectancy had been estimated to be 6 months at best. However, they also described others with a similar diagnosis who died relatively swiftly. A common observation was that for most patients with liver disease, their health was marked by periods of acute deterioration, requiring hospital treatment, often followed by periods of significant recovery. The fluctuating nature of the symptoms presented by these patients made identifying when and how to initiate conversations about EoLC preferences and planning difficult. People with advanced liver disease were very rarely, if ever, classified as palliative and as such access to specialist palliative care services was rare.

In contrast for illnesses such as cancer, with a more predictable trajectory, participants (particularly hostel staff) reported a greater degree of success in accessing services for patients, including access to hospice support and beds. Although gaining access to these services could not be described as easy or straightforward, it seemed more achievable for hostel residents with cancer than with other diagnoses. Even for cancer patients, hostel staff were required to advocate strongly for their residents to access these services. Hospices were usually not an option if there was ongoing illicit drug use or excessive alcohol use.

**Uncertainty around end of life conversations**

“For people who aren’t engaging... Self-discharging, in and out of hostels .....nobody feels they completely know that person...and having those... very difficult conversations, well ...sometimes people feel that someone else should be doing it... no one feels qualified... So...if someone comes into hospital ....and we only have a 5 minute chat – should I have had that conversation with them...?” – Health care professional

In addition to uncertainties regarding prognosis, a lack of confidence was expressed by all professional groups regarding how, when and if to discuss end of life issues with homeless people.

Some of the reasons for this apparent lack of confidence in talking with homeless people about their future health and preferences for care were related to concerns about fragility. Staff expressed concerns that discussions about deteriorating health and potential EoLC would have a negative impact on the wellbeing of homeless people and would represent the removal of hope for the future. They feared that these conversations may make the homeless person think they had been given up on. Furthermore, accepting that a homeless person might be dying contradicted the recovery-focused models employed by the majority of hostels.

In our research, homeless people found it difficult to talk about EoLC and a lack of understanding and denial was expressed about the implications of continued heavy alcohol use. The denial from homeless people and also, to a lesser degree from hostel staff, represented a barrier to end of life conversations, planning and support for those with an anticipated reduced life expectancy.

Furthermore, differing views were expressed about who would be best placed to have conversations about EoLC. Medical staff often cited the fragility of homeless people and their lack of a sufficiently developed relationship with patients as barriers to these conversations. Hostel staff reported a lack of medical knowledge or qualification was adding to their discomfort in discussing these issues. It was reported that medical staff often issue warnings to patients with advanced liver disease (ie “if you do not stop drinking, you could be dead in 6 months”) but these statements are rarely followed up with a frank discussion about planning for this eventuality if they are unable to stop drinking.
During our research we have also encountered examples of truly inspirational work being done by both hostel and medical staff with regards to end of life conversations and planning but it seems that generally end of life conversations with homeless people are not occurring regularly, so an individual’s preferences for the care they would receive at end of life are not known.

Lack of options for homeless people with advanced ill health

“There’s no pathway for them, a lot of clients ... come back [to the hostel from detox] and... you may as well... stand at the door with a bottle of beer and say “here you go” – Hostel staff

Another factor underlying the uncertainty and apparent reluctance to have conversations with homeless people about the end of their lives and future care preferences, concerns a lack of options to present homeless people with. It was felt that conversations about future choices would be marred by the very limited range of options available. Hostel staff felt that if they had concrete, acceptable and viable options to offer people, then conversations about next steps might be easier.

Perhaps in response, or at least linked to the lack of options for homeless people with advanced ill health, challenges in engaging homeless people in health services and conversations about continued care preferences were described. Again, if a greater variety of options, to account for individual preferences and choices were available, people may be more inclined to engage with them.

The hostel environment

Several factors were explored by all participant groups regarding delivering palliative and EoLC to individuals who are living in a hostel. These fell into two key areas:

1) Challenges relating to the hostel system
2) Conceptualisation of what a hostel is, and what it is not.

The hostel system

“Our staff ... go on training courses or whatever but... you don’t necessarily come in to work with homeless people to watch clients die, you know... like, help them in the final few days and stuff. And that takes a very, a kind of set kind of person with a set kind of resilience. You know... not everybody that trains as a nurse can be an intensive care nurse, I imagine” – Hostel manager

Traditionally, the hostel system has focused on recovery and on helping people transition to less supported accommodation. The ultimate goal of the hostel system would be to support a currently homeless individual into private rented accommodation. For some people this is appropriate and they are well served by the hostel system with regards to helping them to move forward with their lives. For people who are long term homeless, or who have advanced health issues, this may be less so. Hostel managers working in the more complex needs hostels, described how they were having to take much younger people than in the past, due to the younger age of people presenting with complex problems.

In light of the increasingly complex needs of hostel residents and the cuts to other services, the role of hostel staff appears to be changing. The presence of hostel residents with advanced ill health demands a deviation from traditional roles and the adoption of new goals – putting life into people’s days, rather than days into people’s lives. While the majority of hostel staff describe going above and
beyond the remit of their traditional roles and taking on the challenges and tasks associated with caring for people with high support needs, this role evolution has not been welcomed by all.

The “move on” culture of hostels was identified as a concern for hostel residents. The potential of being moved on meant that hostel residents did not feel secure in their accommodation and were aware that they could be moved on to another hostel at what felt like any time. Hostel residents expressed concern about what would happen with regards to their accommodation if their health were to deteriorate further. The requirement to move residents on from hostels, usually within 2 years of arrival meant that residents experienced a lot of sideways moves when they were not deemed to have made sufficient progress to warrant a move on to less supportive accommodation, but couldn’t remain where they were. This was particularly pertinent for homeless people with health issues for whom a move to less supported accommodation would be unlikely. The ever present threat of move on prevented residents feeling that they could establish a home within a hostel and led to worries about what would happen to them should their health deteriorate to the point where they would be unable to look after themselves.

The current hostel system is not set up to cater for residents with advanced ill health and the systems and structures simply are not there. Hostel staff describe doing the best they can to support residents with high care needs, often at a high emotional cost.

There are very limited care homes that cater for homeless people whose health is deteriorating, which are difficult to access as they are funded through panel and places are scare.

The role of hostels - conceptualization of what a hostel is, and what it is not

“It’s hit and miss, depending mostly on the member of staff, and the client’s situation as well. So... you will have certain staff who are quite happy to throw themselves in and actually do as much as they can for that individual, and then you have other staff who are actually, you know, ‘this is not my remit ...it’s not my bag ...if I wanted to go into nursing, I would have been a nurse’... and I can see their point”- Hostel manager

There is often insufficient, if not absent medical support for residents within a hostel. Different views emerged from our participants regarding whether or not a planned hostel death was, or could ever be appropriate. What was clear was that there is a shocking lack of acceptable alternatives for homeless people with advanced ill health when it comes to place of care and death.

When thinking about planned hostel deaths for residents with advanced ill health, some current hostel residents felt that a hostel was not an appropriate place of care for someone with high care needs. Many hostel and medical staff agreed for reasons including the chaotic and noisy environments of hostels and concerns around vulnerability and safeguarding of unwell residents. Furthermore participants agreed that hostels did not have sufficient resources to provide the level of care and support that people require at the end of life. Many felt that for your life to end in a hostel would be a lonely and isolated experience.

Other participants felt that for some, the hostel was the closest they would come to being in a place called home. As such, some felt that residents should be allowed to choose whether they wanted to spend the rest of their days in this familiar environment, surrounded by peers, despite the lack of medical support.

It seems that the role of the hostel in the care of residents with advanced ill health is changing. As the demands on hostels grow, in terms of caring for residents with advanced ill health, many accounts
were given of hostel staff exceeding the remit of their roles in order to try and facilitate residents remaining in the hostel for as long as possible, either due to a lack of alternatives apart from hospital admission, or due to residents wishes.

Medical in-reach into hostels was greatly valued by hostel staff and examples of excellent in-reach services from nurses and GPs were described by hostel and medical staff, particularly in Lambeth.

Despite some examples of excellent practice, hostel staff still described difficulties in accessing adequate medical and social services support for residents. Suggestions of employing permanent carers or medical staff within hostels were raised but were countered by concerns about what this would mean for the understanding or labelling of hostels as care providers for residents.

**Inflexibility and gaps in systems**

“For someone to come out of our hostel to do a detox for me is utterly pointless. If there’s no positive move from detox, it’s...you’re dancing with the devil. Don’t let people come back to the hostel...but often they do and, you know, 95% of people just end up drinking again” – Hostel resident

“It always strikes me as.... patients who are so much younger... most care homes are for people with dementia who are older. It’s just... our patients just don’t fit any of these like rigid things...So the care homes are like ‘what?’ we don’t want this 29 year old”, you know?” - Health care professional

Repeatedly participants told us that homeless people do not fit into the boxes prescribed for them by mainstream health services and that the homeless people under their care had been let down time and again by services.

Many participants in this research expressed frustration with the inflexibility of current services with regards to the care and treatment of homeless people, particularly those with advanced ill health. Current services seem unable to accommodate the unique requirements of the homeless population in terms of behaviour and substance use. There was also a particular challenge with homeless people experiencing severe cognitive impairment at a young age. Participants described a lack of dry facilities that could support people with complex health issues. This meant that people with advanced liver disease, who wanted to stay dry, ended up back in wet hostels.

Communication between hospitals and hostels was challenged by a lack of information sharing around planned (or unplanned) hospital discharges and difficulties for hostels in accessing information about their residents’, including information about hospital appointments. This limited information complicates the advocacy role hostel staff play for clients and makes attendance at appointments difficult. Where hospital Pathway teams were in place, some of these problems were mitigated (see later).

This research suggests that individualized care for homeless people at the end of life is badly lacking. Examples were given of hostels being unable to accept seriously ill residents back into the hostel following hospital admissions. Hostels felt unable to meet the care needs of seriously ill patients and were concerned about the impact of the patient’s presence on other residents. Hostel managers were aware of the dangers of setting a precedent of accepting ill patients back from hospital and the message this might send to hospitals about the hostel’s role in the care of people with advanced illness. Further challenges for hostels in caring for residents with advanced ill health, which have not been expanded here included issues around the storage and administration of medication.
Suggestions for improving palliative care for homeless people in London

Increased collaboration

“What was very beneficial is having a coordinator... the hospice was involved early... so that relationship started to build a year before... So that resident would go to [the hospice], like getting massages... a bit of counselling. They kind of knew the place, and the only way that... happened was because we had a coordinator within the organisation that set that up” – Hostel staff

Our participants identified several suggestions for increasing collaboration between services to improve access to palliative and EoLC for homeless people, centring on the following areas;

1) Multidisciplinary working and Information sharing
2) In-reach

Multidisciplinary working and information sharing

“I mean normally what happens is that they are sent home with a discharge or they take self-discharge in which case they get nothing, or they are sent home with a discharge summary and they lose it or it’s mislaid. So by the time they come to me, they haven’t got it. So those are the sort of scenarios” – Hostel staff

Our research demonstrates the importance of multidisciplinary and multiagency team working in order to provide compassionate, planned EoLC that takes individuals preferences into account and avoids crises. Multidisciplinary working enables relationships to be developed between all professionals working to support homeless people, which then increases awareness of services and the roles they could play in supporting other individuals.

Palliative care coordinator

The role of the palliative care coordinator within St Mungo’s hostels was seen as a model that should be expanded. The palliative care coordinator is an invaluable link between health professionals and hostel staff and can offer support to the homeless person and those working to support them.

Emergency care plans

Another example of information sharing, within the hostel was the use of emergency care plans for all residents. These are not universal but an example was provided from a hostel in which emergency care plans were drawn up for clients on an individualised basis (with and sometimes without the involvement of hostel residents). These plans listed what hostel staff should do in a number of emergency situations. This sharing of information about the residents’ health status and potential crises empowered staff (who have no medical training) and enabled them to feel more confident that crises could be handled effectively. In addition to the increase in staff confidence, these plans served to increase the likelihood of the resident receiving appropriate care and support in the case of a health crises, tailored to their needs and preferences. The electronic sharing of information was also discussed as a possibility by participants in this research.
Hospital Pathway teams

A number of hostel and day centre staff commented on the positive impact of hospital Pathway teams. Pathway teams have been set up in a number of hospitals to provide multidisciplinary support to patients when admitted, and facilitate safe discharge planning and communication between hospitals, hostels and other community teams.

In reach

“He doesn’t fit our criteria, he doesn’t drink, he’s got mental health, he doesn’t drink, doesn’t take drugs, he’s 75...is this how we treat our elderly people?” – Hostel staff

Another aspect of compassionate and flexible care should involve the delivery of care in settings that are familiar to the audience they intend to serve. Participants, both those that are currently homeless, formerly homeless and professional staff emphasized the need for in-reach into hostels.

A number of hostels, such as those in Lambeth in which the health inclusion teams work, have good support from nurses and in-reach GPs. This was greatly valued by hostel staff, however evenings, night times and weekends were still left without medical support.

Extending services and supports to hostels would remove a number of the barriers identified in this research as hindering access to services, such as difficulties in getting to appointments and concerns about the stigma they may encounter if they do make it there.

In reach is especially relevant for homeless people with advanced ill health for whom the challenges of accessing services may be magnified by decreased mobility or fear about the changes in health they are experiencing. Continuing to foster the relationships that are beginning to blossom between hostels and hospices will be an important step in the improvement of care and support for homeless people who may be reaching the end of their lives. Fantastic examples of collaboration between hospices and hostels have been demonstrated in this research and are promising for the future of palliative care services for the homeless population.

Specialised services for homeless people

“We need a specialist environment that focused on people, of that level of need and support. As much as I love hostels, I’ve always worked in big hostels, I kind of feel that sometimes the environment is too big and too diverse to help people. Not everyone, because it does a lot for a lot of people, and I’ve got proof that it does. But sometimes you know you have people who are more vulnerable and need more intensive support, errm, but in a less intensive environment. And we just don’t have that”– Hostel staff

The need for specialised services for homeless people, particularly those with advanced ill health was a common theme throughout discussions with all groups of participants.

In particular, suggestions for the improvement of services often focused on providing;

1) Individualised care
2) High support facilities for those with advanced ill health, including those with severe cognitive impairment
3) The need for training and support for all professionals working with this group
4) Pan London commissioning to provide these very specialised services to those that need them.
Individualized care

“The main thing for me is that the client is in the driving seat. And I can talk about myself in a way that makes them feel comfortable to talk about what they really want. So they may say, “I never want to go into a care home”; where some people will say “actually that would be alright”. And even if it’s not a perfect option, we look at a few things that wouldn’t be too bad... And at least we know what we are looking at... it gives them time to self-prepare” – Hostel staff

Suggestions for the changes needed to afford a greater degree of flexibility were numerous, but the majority shared a core element; individualized, person centred care, rather than the one size fits all approach evident in many current mainstream services. Delivering care that meets the specific needs of an individual, rather than a patient group was seen as a way of moving the care and treatment of homeless people with advanced ill health forward.

One way of introducing and incorporating truly person centred care to this population could be through the use of parallel planning. This approach places the individual at the centre of discussions and tries to ascertain, for them, what is important in the care that they receive now and in the future.

As this approach doesn’t need to consider whether someone is approaching end of life or not, many of the complexities and challenges around uncertainty become less relevant. By establishing an individual’s priorities, steps can then be taken to work towards their goals and to help to plan for other eventualities along the way. This approach involves hoping and planning for the best, but also planning for the worst. Deciding in partnership with the individual what to do now and in the future, for a range of opportunities could empower them to think about the future and the direction that their life is likely to take. This incorporates the possibility that they cannot stop drinking, for example, and what the likely trajectory would be, while not removing the possibility of change.

Delivering and planning individualized care would require the development of strong therapeutic relationships between homeless people and professionals. The development of such trusting relationships will take time and may be hard to develop in the current context of cuts and limited resources, but are essential in improving care and support for this population.

Individualized care needs to extend beyond planning and discussions. This approach needs to be supported with a range of services and supports that genuinely incorporate a space for individual needs and choice. For the homeless population this could involve choice over whether they stay in a hostel that allows alcohol in communal areas, a hostel that does not allow any alcohol on the premises or one that allows alcohol in resident’s rooms only. Rehabilitation and detox is another area that would benefit from a greater variety of options to reflect individual preferences and choices.

Individualized, person centred care will only be meaningful if people are actually able to access services that respect their choices.

High support facilities

“The care homes can’t manage their behaviour, the hospitals... you know they are out with their drip stand to the off licence” – Hostel staff

All participants recognized the lack of appropriate accommodation and support for homeless people who are approaching the end of their lives. We asked participants to think about what good care would look like for homeless people whose needs are too great for mainstream hostels. Participants agreed that a high support facility which understands the challenges of homelessness and homeless health
care is urgently needed. The facility could act as a step up from a hostel and a step down from hospital to provide respite care for individuals with advanced ill health or be a place where someone could peacefully end their life. This would reflect the uncertain trajectory and recurrent health crises associated with advanced liver disease. By allowing people to access the facility earlier in their illness, they would have a chance to develop relationships with facility staff, which could make their final transition to the facility easier.

Participants were unsure about what exactly this facility should look like, whether it should be part of a hostel or separate, but nearby. What was agreed was that the facility should be acceptable to homeless people, with staff that are trained in homeless health care and where they will feel safe and accepted. Previous research around respite care for homeless people in London has been conducted by Pathway (19) and internationally by Podymow et al at the Inner city health project in Ottawa, Canada (20), which explore these options in detail.

Training and support

“Our staff could get training that allows them to be more comfortable to be able to do that... but then that takes time, you never have time in this environment, not in the ratio we’ve got with staff to clients here, we don’t have time to do that. But that’s what we need, that’s the sort of support you need”- Hostel manager

Throughout this research it has been abundantly clear that professionals are doing all that they can with the resources they have to try and promote dignity and quality of life for homeless people with advanced ill health. Hostel staff carry a huge practical and emotional burden in caring for seriously ill residents and the potential impact this may have on their own wellbeing cannot be overlooked.

Greater training and support is needed for all professionals working with homeless people with advanced ill health. This should incorporate practical elements, such as multidisciplinary team training to raise awareness of other professionals working with this client group and to promote collaboration, through to psychological support and resilience training skills. Increased bereavement support for both staff and homeless people is also needed.

Pan London commissioning for palliative and end of life care

“There is a group of people who have chronic ongoing needs .... there isn’t enough provision pan London. It is a pan London problem because you only have 2 or 3 of those per borough.... there are places that take these kind of clients but they are probably isn’t enough” – Health care professional

A source of great frustration was the fragmented approach to services across London. For a group with such specific needs, allocating resources by borough was seen as a real barrier to high quality palliative and EoLC for the homeless population. A pan London approach to services that considered the individual, rather than their local connection would be hugely beneficial to homeless people with advanced ill health.

As highlighted in this research and also outlined in Dorney-Smith and Hewett’s report on options for respite care for homeless people with advanced ill health (19), provision for homeless people with significant care needs (who would benefit from care home provision) is a London wide challenge. Recognising this and taking into account the very specific care needs of this group as their health deteriorates, pan London commissioning of high support services seems like a sensible option.
e) Conclusions and recommendations

This research has highlighted many challenges to the provision of and access to palliative and EoLC for homeless people in London. The challenges described to us by participants were complex and multifaceted. There are no simple solutions to addressing these challenges, however the recommendations put forward in this report, alongside the continued tireless work of professionals of all types, could add dignity and quality to the final weeks, months and days of some of London’s most vulnerable people.

It is our responsibility as health care professionals and providers to ensure that the systems in place are fit for purpose, and are able to meet and excel the demands of each sector of our society.

By increasing collaboration between, flexibility within and easier access to a wider range of services, and by providing staff with the training, support and tools necessary to carry out their roles effectively, we have an opportunity to elicit real change in the quality of life of homeless people in London and beyond.

Table 3 summary of recommendations

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<th>RECOMMENDATIONS</th>
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<tr>
<td>Consider London wide commissioning for palliative care services - including high support facilities that can offer respite and support people until they die.</td>
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<td>Increase input from palliative care specialists to assist in the identification of homeless people that may benefit from palliative care support, and in the delivery of this support.</td>
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<td>Extend the St Mungo’s palliative care co-ordinator role.</td>
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<td>Extend the use of early parallel planning for homeless people to maximise quality of life</td>
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<td>Assess the training needs of all professional groups and deliver bespoke, responsive training.</td>
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<td>Regular multidisciplinary meetings eg in hostels to discuss complex patients and foster relationships between professionals and improve information sharing, understanding and planning.</td>
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<td>Develop and extend links between hospices and hostels.</td>
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<td>Increase in-reach into hostels, from a variety of services</td>
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f) Case study example

From this research we have collected many examples, from all participant groups that demonstrate the challenges to palliative and end of life care for homeless people, which we would be happy to share. For this initial report, we have chosen one particular case which we feel highlights many of the challenges and issues faced in the provision of high quality care for the homeless population as their health deteriorates.

I’ve got loads of experiences, I think the two that had most impact on me... were a couple. And they both had end stage renal failure... So this lady was a frequent flyer to ITU, so she just kept on going into ITU and then just as soon as she was well enough basically self-discharging herself and, and going back to [the hostel]. So what was happening was basically she was being referred to social services in the hospital but by the time the social services and the hospital had responded, she’d... self-discharged and gone home. And then they were insisting on a referral to the community social services and by the time that had happened the fifth time,... I’d stamped my feet and, and raised a complaint.

When the social worker finally came... she really didn’t know how to engage with [the client] at all. And she deteriorated over a period of about 5 weeks and the, the poor hostel...I mean ... by the time she died, she wasn’t able to get out of bed and ... you know the hostel were really in no fit state to be managing that.

I think .....to her... she was sort of desperately trying to carry on, you know? The pain thing was also a major issue...she was an... intravenous drug user and a drinker. She got back in contact with her family, she had children. And the family ... wanted her home. We’d identified a hospice that would have her. And all that needed to happen was she needed to be stabilised; so she was already on fentanyl patches, and then they could transfer her home. And this was... and it’s an unbelievable story really... it was all in place and then [the hospice] at the last minute...pulled out saying, that actually she’d been deemed not to be palliative, because it was felt that it was behavioural. If she wasn’t behaving like that, it wouldn’t be an EoL care situation. And that there was no guarantee that she was going to die. So they pulled out... and then she overdosed about two or three weeks later.

And then 6 weeks later her partner, who also had end stage renal failure I think he just gave up at that point. She was 34, he was 47. He... I know it’s tragic... they got a dog, we.... we nearly took the dog, but that’s also another story. He was... he became really unwell, septic and...in the renal unit again ... he kept on self-discharging... I’d gone to the hostel at like 11 o’clock at night because they [the hostel] were beside themselves with somebody who was really unwell, who’s got a temperature of whatever and they didn’t know what to do. We persuaded him to go back [to hospital], he stabilised. And he was just talking about getting back in contact with the daughter again...and he died.

And it was really affecting because it was just... there were so many things in that situation that kind of just seemed... and indeed he wasn’t taken on by palliative care either. Despite the fact it was quite clear that he was deteriorating at a rapid.... at a rapid rate but he, his renal failure was not deemed to be palliative, so... God knows.
g) Acknowledgements

With thanks to the staff and services users of health care facilities, hostels and day centres across Lambeth, Westminster and Hackney.

h) References

5. Critical Condition: Homeless people’s access to GPs Crisis, 2002.