Institution: University College London

Unit of Assessment: 4 – Psychology, Psychiatry and Neuroscience

Title of case study: Improving the quality and co-ordination of palliative care for people experiencing homelessness

Period when the underpinning research was undertaken: 2015 - 2020

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Dr Briony Hudson	Honorary Senior Research Associate	2015 - Present
Dr Caroline Shulman	GP in Homeless Health and Honorary Senior Lecturer	2015 - Present
Dr Megan Armstrong	Senior Research Fellow	2018 – Present
Prof Paddy Stone	Head of Marie Curie Palliative Care Research Department	2014 – Present

Period when the claimed impact occurred: 2016 - 2020

Is this case study continued from a case study submitted in 2014? No

1. Summary of the impact

Research at UCL has been seminal in demonstrating the UK's failure to provide care and dignity in dying to the homeless community. Research conducted by Stone, Hudson, Shulman and colleagues at UCL proposed a roadmap for addressing this that has been adopted into policy and practice by practitioners, government, national healthcare bodies and homeless and palliative care charities nationally. As a result of these changes, frontline workers feel more confident and less traumatised in dealing with such patients, ensuring that they receive a compassionate and comfortable end. The UCL research-derived roadmap also informed London's response to caring for some 7000 people experiencing homelessness during the COVID-19 pandemic.

2. Underpinning research

Research undertaken at the Marie Curie Centre for Palliative Care Research at UCL was the first major project in the UK to highlight the unmet needs of people approaching the end of their lives while experiencing homelessness, and the lack of support for the frontline homelessness staff who are often left to support them. Stone, Shulman and Hudson began an extensive research project in 2015 that involved both a large qualitative study exploring palliative care access for people who are homeless or vulnerably housed in London **[R1]** and a systematic review of international qualitative literature **[R2].** The project sought to establish an accurate understanding of the situation and identify the specific factors that made the provision of palliative care particularly challenging in the context of homelessness. Findings from this study included:

- **Complex needs:** Many people experiencing homelessness have multiple needs, often including a combination of physical health, mental health and addiction issues. Many utilise health services in a different manner to people who are housed. Previous negative experiences with health care providers and services may lead to mistrust of health care settings and mainstream services.
- **Uncertainty in illness**: The trajectories of many of the illnesses faced by people experiencing homelessness are hard to predict, making it difficult to know when, how and where they might benefit from palliative care. This means the majority of those people who may benefit are not accessing the services they need.

- **Place of care:** Most people experiencing homelessness remain in hostels or temporary accommodation due to a lack of an alternative place of care. Barriers to mainstream services include ongoing addictions, mental health difficulties and the comparatively young age of many of those in need of palliative support. Most palliative care providers are inexperienced in supporting people with complex needs in temporary accommodation or hostels, and hospices may struggle to support people with addiction or mental health issues on an inpatient basis. A lack of in-reach from health and social care providers means that hostel staff are often left to support extremely vulnerable and sick people with inadequate support.

Research outcome recommendations

The research identified: the need for training and support for hostel staff; a reframing of how palliative care is thought of in this population to ensure that more people are referred into services; more in-reach support and multidisciplinary support in the place where people are living; and advocacy for more choice around place of care and options for end of life.

In response to these recommendations, the UCL team developed and evaluated a training programme for hostel staff **[R3]** and an online toolkit to support frontline homelessness staff **[R4]** and conducted a further study of the specific challenges of discussing deteriorating health, insights and choices with people experiencing homelessness **[R5]**. The team received additional funding from the Oak Foundation (£330,000) to conduct a second phase of active research (2018-present) to develop a sustainable model linking community palliative care teams with homeless hostels. They collaborated with Dr Rogans-Watson, a clinician specialising in Elderly Care, to study the aging of a population in a homeless hostel in London **[R6].** The research revealed massive early ageing and frailty (average age of residents = 55, with frailty scores equivalent to late 80s) and excessive multimorbidity, with an average of seven conditions per person, higher than any other sector of the UK population.

3. References to the research

[R1] Shulman, C., Hudson, B. F., Low, J., Hewett, N., Daley, J., Kennedy, P., Davis, S., Brophy, N., Howard, D., Vivat, B., & Stone, P. (2018). End-of-life care for homeless people: a qualitative analysis exploring the challenges to access and provision of palliative care. *Palliative Medicine*, *32(1)*, 36–45. doi: 10.1177/0269216317717101

[R2] Hudson, B F., Flemming, K., Shulman, C., Candy, B. (2016). Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. *BMC Palliative Care, 15(96)*. doi: 10.1186/s12904-016-0168-6

[R3] Shulman, C., Hudson, B. F., Kennedy, P., Brophy, N., & Stone, P. (2018). Evaluation of training on palliative care for staff working within a homeless hostel. *Nurse Education Today*, *71*, 135–144. doi: 10.1016/j.nedt.2018.09.022

[R4] www.homelesspalliativecare.com

[R5] Hudson, B. F., Shulman, C., Low, J., Hewett, N., Daley, J., Davis, S., Brophy, N., Howard, D., Vivat, B., Kennedy, P., & Stone, P. (2017). Challenges to discussing palliative care with people experiencing homelessness: a qualitative study. *BMJ Open*, *7(11)*, e017502. doi: 10.1136/bmjopen-2017-017502

[R6] Rogans-Watson, R., Shulman, C., Lewer, D., Armstrong, M. and Hudson, B. (2020). Premature frailty, geriatric conditions and multimorbidity among people experiencing homelessness: a cross-sectional observational study in a London hostel. *Housing, Care and Support*, *32(3/4)*, 77-91. doi: 10.1108/HCS-05-2020-0007

4. Details of the impact

The impact of this seminal body of work in bringing the previously neglected but urgent human issue of palliative care for people experiencing homelessness to the attention of policy makers and service providers is widely recognised by key stakeholders from the public and third sector **[S1, S2].**

Influencing the national health policy agenda for homelessness

The National Clinical Director for Palliative Care at NHS England states, "*At national strategic level the [UCL] research provided evidence of gaps in provision and we are continuing to pursue options for improving the access to, and quality of, palliative and end of life care for people who are homeless. Without the team at UCL, this issue would have remained relatively unnoticed at national strategic levels so their work will have had a significant impact for this incredibly vulnerable group*" **[S1].**

The team co-authored the Care Quality Commission's (CQC) November 2017 report on end-of-life care for homeless people **[S2]**. The CQC published a report on inequalities in end-of-life care in 2016 but realised the need for a separate document to address the specific issue of end-of-life care for those experiencing homelessness. This decision was inspired and heavily influenced by the UCL study **[R1],** as demonstrated by the choice of co-authors and as highlighted in the introduction, which singles out the 2018 paper as a key source informing the report's content. The report's purpose is to *"stimulate cross-sector and multidisciplinary conversations and ideas, encourage innovation, and ultimately drive improvement to address the inequalities faced by this vulnerable and excluded group"* **[S2].**

Hudson and Shulman contributed to the 3rd edition of homeless health charity Pathway's *Homeless and Inclusion Health Standards for Commissioners and Healthcare Providers* **[S3].** The document sets clear minimum standards for planning, commissioning and providing healthcare for homeless people and other multiply excluded groups and "*challenges all parties to work to these standards and to work with [Pathway] to revise and improve them*". Despite a stated commitment to "*meeting the health needs of excluded groups with respect, dignity, and compassion*", the previous editions focussed on access to treatment and did not address palliative care at all. This 3rd edition (February 2018) contains a two-page section on standards for palliative care contributed by Shulman and Hudson that follows the recommendations of the UCL research **[R1].**

For NHS Improvement the research has "*highlighted an urgent, unmet need and has raised this issue higher up our policy agenda. The work on frailty* **[R6]** *has also added to this picture of complexity and need, making it hard to continue to ignore the challenges faced by this population. The evidence-based recommendations for how the provision of care could be improved are being adopted extensively into our strategy and policy going forward".* The NHS England End of Life Care group funded Shulman to develop training and mentoring within communities of practice to implement the recommendations from the research **[S1]**.

Sir Ed Davey MP **[S4]** was inspired by the research to table an Early Day Motion on homelessness and end of life care in October 2017. Significant support for the motion led him to propose a Private Member's Bill (Homelessness: End of Life Care) containing measures to improve care and services for homeless people approaching the end of life. The UCL team collaborated with the charity Shelter to draft the bill, which passed first reading in the House of Commons in February 2018. Brexit and then Covid-19 pushed the bill from the legislative timetable, but the issue was moved much higher up the policy agenda, leading directly to discussions with the under-secretary of state for mental health and inequalities and representatives from the Ministry of Housing, Communities and Local Government (MHCLG) **[S4].** As a direct consequence, MHCLG changed their homelessness code of guidance for local authorities in November 2018 to improve choice and access to appropriate housing and support for people experiencing homelessness who have a terminal illness **[S5]**.

Marie Curie (the UK's leading end-of-life charity) have retained Hudson on a permanent basis and used their platform to amplify the UCL research findings to policy makers (inviting the UCL team to present in the Houses of Parliament as part of the Marie Curie Lecture Series) and to practitioners (Hudson presented at the Marie Curie Palliative Care Virtual 2020 Research Conference) **[S6]**. Marie Curie's CEO concludes that "*the research from UCL has widened our discussions around equity in support at the end of life and as such has influenced our strategic thinking and planning. We are happy to support Drs Hudson and Shulman in developing and*

disseminating the training, tools and discussions the research has sparked to support us in moving towards our goal of improving the end of life experience for everyone" **[S6]**.

Three of Shulman and Hudson's key papers **[R1, R2, R6]** were central to the homelessness sections of Hospice UK's seminal report 'Care Committed to Me' (December 2018), a resource for commissioners, service providers and health, care and support staff **[S6].**

Influencing practice in service providers working with homeless people
Frontline organisations have been keen to integrate the research recommendations into their practice. The UCL team have delivered workshops at events organised by partner organisations (Hospice UK, National palliative care associations, Marie Curie, Pathway, various NHS entities and clinical networks, St Mungo's, individual hospices and homeless charities, local authorities) **[S7].** These include:

- **3 webinars for NHS England**: The last national live webinar in May 2020 was attended by 132 frontline clinicians and care professionals, providers, commissioners, voluntary sector leaders and policy makers. The slide set is accessible on NHS England's End of Life Practitioners Network which now has over 600 members**.**
- **33 National Conferences and 4 international conferences:** reaching over 2220 attendees working in: social work, mainstream health, liver disease and cancer care, palliative care, homeless services, homeless charities, nursing, housing, digital health, addiction.
- **16 local meetings, seminars and conferences**: over 500 attendees, organised by charities, hospices and local networks of GPs, nurses and clinicians.
- **2 webinars and a webex prior to Covid-19, and 4 webinars during the Covid-19 pandemic**: 660 attendees from primary and end of life care, multidisciplinary teams and health needs assessment.
- **17 teaching sessions**: over 580 GPs, medical students, and junior doctors, nurses and consultants working in hospices, A&E, acute medicine, addiction and palliative care.

In total, more than 4000 frontline and policy staff and commissioners of services have received training live. At least 5000 more professionals are accessing the learning through the online homeless palliative care toolkit **[R4]** which has been disseminated widely through conferences, homeless charities, health networks such as the London Network of Nurses and Midwives and through NHS England webinars. The toolkit currently has 5356 unique users, 16526 page-views, and has had 9625 new and 1279 repeat visitors **[S8].**

Covid-19 Pandemic
During the COVID-19 pandemic, the UK Government announced that homeless shelters with communal facilities should close and all homeless people on the streets should be brought inside. Shulman has supported the Healthy London Partnership's pan-London response (involving some 7000 homeless people), contributing her expertise on the specific health needs and challenges of this population in a number of roles, including:

- Chair of the Clinical Leads Group, a forum for clinical leaders across London to escalate and resolve key issues, barriers and challenges
- Support line for specialist homeless health practitioners, flagging issues of risk, safety, and clinical governance
- Steering and advising key governing groups – London's Homeless Health Integrated Systems Partnership and the Rough Sleeping Strategy Group
- Supporting the development of clinical protocols and referral pathways.

In the words of the Healthy London Partnership Homeless Health Lead: *"Your clinical leadership was absolutely vital in what we have achieved pan-London. We would not have done it without you. At every step highlighting the frontline realities and risks to the population we have been trying to support, helping us develop solutions and providing encouragement and support to the specialist homeless health clinical leads across London. The incredible outcome of numbers of lives saved is in no small part due to what you have contributed"* **[S1]**.

Impact on wellbeing of staff and volunteers working with terminally ill homeless people
Ultimately the changes in policy and practice guided, inspired and evidenced by the research have improved the health and wellbeing of terminally ill people experiencing homelessness, along with the wellbeing of frontline staff who are better supported and empowered to work holistically with this population. Hostel staff who are being supported by in-reach palliative care teams have reported improved confidence and wellbeing, better relationships with healthcare services and hostel residents and an increased ability to support their customers **[S9]**.

A training suite based on UCL research has been delivered to 250 staff across St Mungo's services. The findings and recommendations from the UCL team's research have led to "*completely new ways of working [at St Mungo's], establishing relationships with key healthcare organisations and professionals allowing our staff to connect service users with the quality care they need. This has led to lower stress and churn among hostel staff, as well as greatly improved care for critically ill residents*" **[S5]**. As a result of the UCL research, Hospice UK put out a competitive call for grants inviting hospices to submit proposals to develop services for people who are homeless and require palliative care. Seventeen proposals were selected from over 30 submissions and are currently 'live' (total award value GBP319,200) developing and enhancing palliative care provision for those who are homeless **[S6].**

5. Sources to corroborate the impact

[S1]   Supporting statements from public sector bodies (NHS England, NHS Improvement, Health London Partnership).
[S2]   *A Second Class Ending: Exploring the barriers and championing outstanding end of life care for people who are homeless*. Care Quality Commission. 2017. (pp2 and 21). https://www.cqc.org.uk/sites/default/files/20171031_a_second_class_ending.pdf
[S3]   Homeless and Inclusion Health Standards for Commissioners. Pathway. 2018. (pp2, 44-46, 52). https://www.pathway.org.uk/wp-content/uploads/Inclusion-Health-Standards-for-Commissioners-and-Service-Providers.pdf
[S4]   Letter from Sir Ed Davey MP.
[S5]   Homelessness Code of Guidance. Ministry for Housing, Communities and Local Government. Feb 2018. (Version Control Sheet and Paras 8.40 and 17.10). https://assets.publishing.service.gov.uk/media/5a969da940f0b67aa5087b93/Homelessness_code_of_guidance.pdf
[S6]   Supporting statements from third sector organisations (Marie Curie, St Mungo's, Hospice UK).
[S7]   List of training sessions and practitioner conference appearances with approximate participant numbers.
[S8]   Google analytics for the online toolkit.
[S9]   Feedback from evaluation report for pilot of in-reach palliative care teams.