Early findings from a project to improve access to healthcare by twinning community palliative care teams with hostels

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Today's Talk

- Background: research findings on challenges around support received by people experiencing homelessness who have advanced ill health
- Recommendations from this research
- Training for hostel staff: evaluation and resources
- Pilot intervention
- Other ongoing projects
- Conclusion and implications

Homeless deaths rose by a record 22% last year, says ONS report

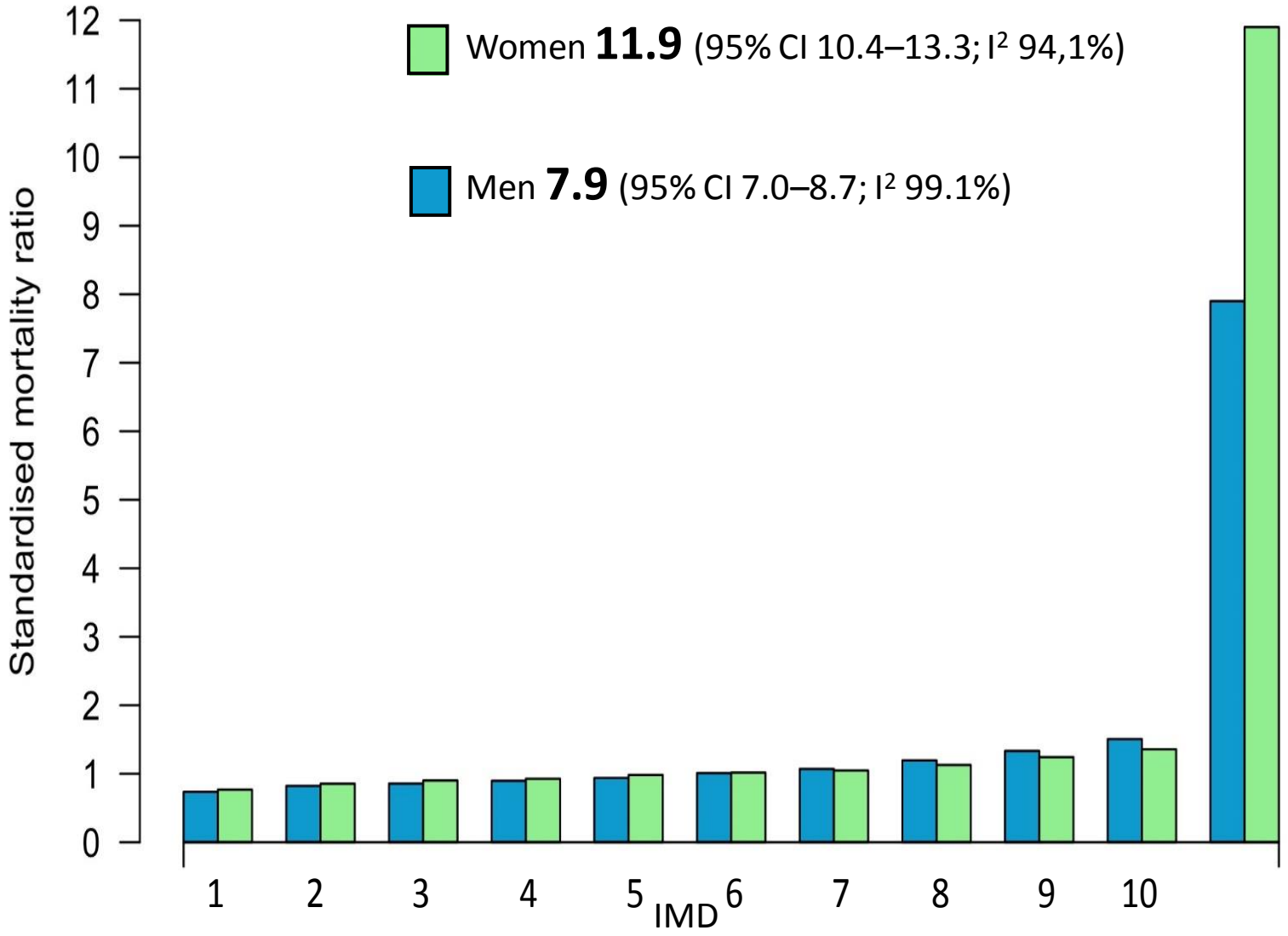
Charities demand action after estimated 726 homeless people die in England and Wales

▲ Jon Sparkes from Crisis said homeless people 'should not be dying unnoticed and unaccounted for'. Photograph: Yui Mok/PA

Homeless people are dying young

Average age of death in the UK (ONS):

45 for men (88%)
43 for women (12%)



Morbidity and mortality in homeless individuals, prisoners, sex workers, and individuals with substance use disorders in high-income countries: systematic review and meta-analysis. R Aldridge, A Story, S Hwang et al, The Lancet Nov 2017

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsofhomelesspeopleinenglandandwales/2018
Office of National Statistics 723 deaths in 2018.

Dying as a homeless person

Deaths are often sudden, untimely and undignified, with access to palliative care being very unusual
(Crisis report 2012)

Gemma

How can we improve palliative care for people who are homeless?

What is Palliative Care?

Palliative care

- is a holistic multidisciplinary approach in the care and support of people with a life limiting condition and advanced ill health
- aims to help people have a good quality of life
- can occur alongside active treatment

What are the challenges to palliative care access for people experiencing homelessness and what can be done to improve care?

Systematic review

- Synthesis of previous research
- 2005-2016
- 13 studies: one from UK (7 hostel staff)
- Mainly from north America

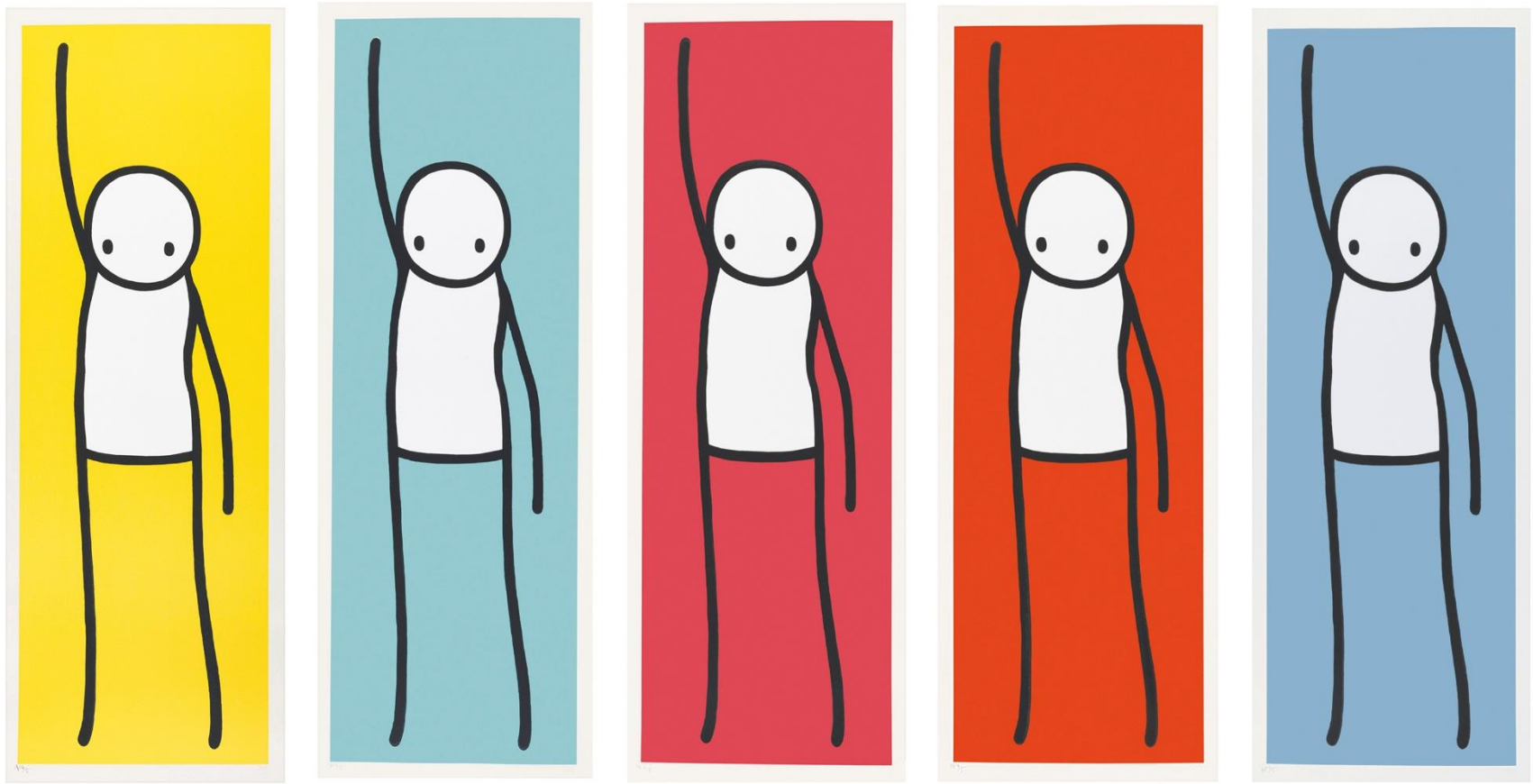
Qualitative study

- 3 London Boroughs
- Focus group and interviews 2015--2016
- 127 participants:
  - 28 PEH
  - 10 EBE's
  - 49 health and social care providers
  - 40 hostel and outreach staff

Tenancy sustainment team

OAK FOUNDATION · St Mungo's Ending homelessness Rebuilding lives · pathway Healthcare for homeless people · coordinate my care Personalised Care Plan · Marie Curie Care and support through terminal illness · UCL

Findings



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Main Findings: Uncertainty and Complexity

…around who is palliative due to:

Disease trajectory & Young age

Substance misuse & complex behaviour

Lack of access to and utilisation of mainstream services

Many deaths are sudden,
but not unexpected

"I think that people are just resistant to the concept of them [people who are homeless] being palliative patients. You are dealing with people who are still relatively young…it's difficult".
Specialist GP

They sort of…could be classed as palliative but they are also reversibly palliative. So if you don't stop drinking, if you don't stop doing these things, then you are probably going to die in 6 months. And it's a little bit difficult sometimes to class them as palliative, when you have a reversible cause to it. **Healthcare professional**

This uncertainty results in people not being considered for referral to palliative care services

Main Findings: Gaps in Current systems & Lack of Options in Place of Care

Many people with very complex needs, at risk of dying, are in hostels or temporary accommodation with inadequate support & care.

Gaps in current systems: challenges with traditional models of care

"At least three times a shift we check she's okay. It's hard… particularly on weekends and nights when we only have two staff… it's a big hostel [60 residents]… this isn't an appropriate environment, but it's the best we have" **Hostel staff**

"…We're social workers, cleaners, advisors, we're just everything… We either do it or there's no one else to do it" **TST staff**

- Homelessness services role is to support people into recovery
- Hostels are designed to provide temporary accommodation
- Staff left to support people with increasing complexity, with limited resources
- Staff go way over and above their role
- Often have difficulty accessing social services & adequate medical support

Main Findings: Gaps in Current systems – lack of options in place of care

Most care homes are for people with dementia who are older; it's just, it's our patients just don't fit any of these like rigid things....the care homes themselves are like 'what?! 'We don't want this 29 year old"… you know? **Specialist nurse**

- Hostels taking burden of supporting people who are very unwell / "young olds" / people with cognitive impairment
- Lack of alternative places of care due to:
  - Young age
  - Mental health difficulties
  - Substance misuse

Main Findings: Barriers to Advance Care Planning

Lack of confidence

Denial - from all sides

Concern about fragility & removing hope

Uncertainty of prognosis

Lack of options to offer

"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…no one feels qualified…" **Health care professional**

Overcoming the challenges

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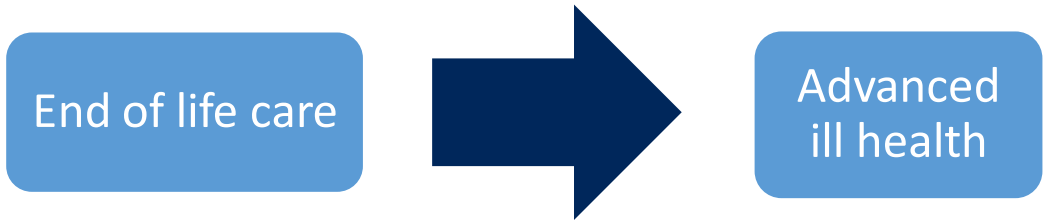
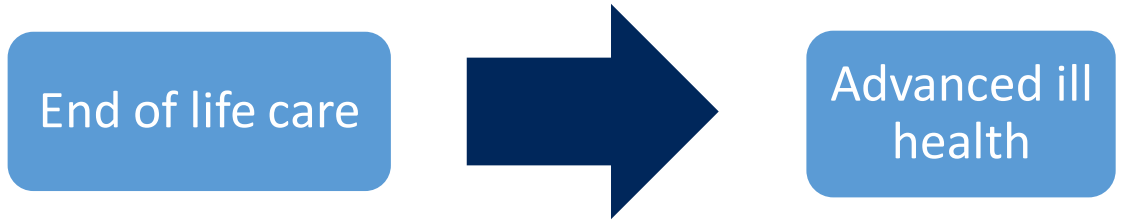
Recommendations around palliative care

1. A Shift in Focus: (parallel planning)



Recommendations around palliative care

1. A Shift in Focus: (parallel planning)



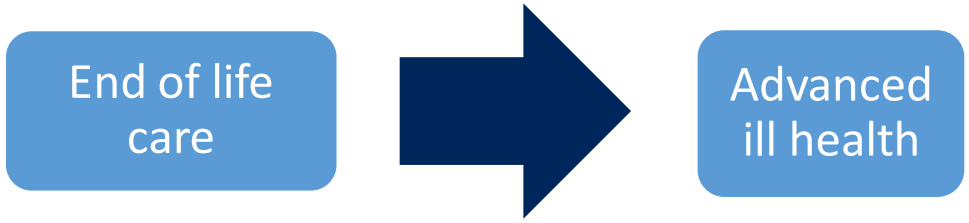
…as a way of working with Uncertainty

Supporting decisions, while keeping options open

- Identify people whose health is a concern
- Person-centred exploration of insights into illness, wishes and choices, not just giving warnings– but how to live well
- Respecting choices even if we feel they are unwise
- Early & repeated conversations
- Not just issues for the very end of life, but about living well.

Recommendations around palliative care

1. A Shift in Focus:
(parallel planning)



2. *Choice* in Place of Care and *Care* in Place of Choice:

a) Care in own home – eg Housing First

- History of rough sleeping associated with high risks of long term health issues
- Housing first / floating support models need to include comprehensive long-term wrap around support

Recommendations around palliative care

1. A Shift in Focus:
(parallel planning)

End of life care → Advanced ill health

2. Choice in Place of Care and Care in Place of Choice:

a) Care in own home – eg Housing First

b) High support need facility that

- Understands the needs of people who are homeless
- Acts as a step up from hostel/street & a step down from hospital
- Could provide adequate 24 hour support
- Offers respite AND/OR a comfortable place to live until the end of life

Example in Ottowa and Toronto

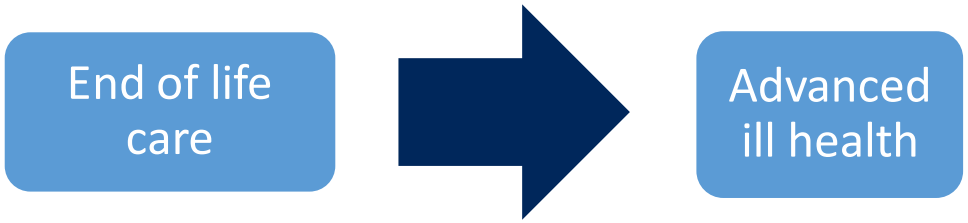
What if the hostel is seen as their home?

It was his desire to remain here, he wanted to remain here, and …for me personally…I don't think we should go against that…. ***Hostel staff***

There's been a few guys that were in hospital, told they were dying … they didn't want to go to any hospice, they didn't want to … stay in hospital, they wanted to die in the homeless hostel…. ***Expert by Experience***

Recommendations around palliative care

1. A Shift in Focus: (parallel planning)



2. Choice in Place of Care and Care in Place of Choice:

a) Care in own home – eg Housing First

b) High support need facility

c) More in-reach (into hostels / day centres)

- Greater multi agency working - regular meetings to discuss clients of concern
- More training and support for all groups

Training and Support

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Homeless palliative care toolkit

- Identifying Clients
- Assessing Needs
- Sharing Care
- Communication
- Bereavement
- Practicalities after a death
- Self Care

www.homelesspalliativecare.com

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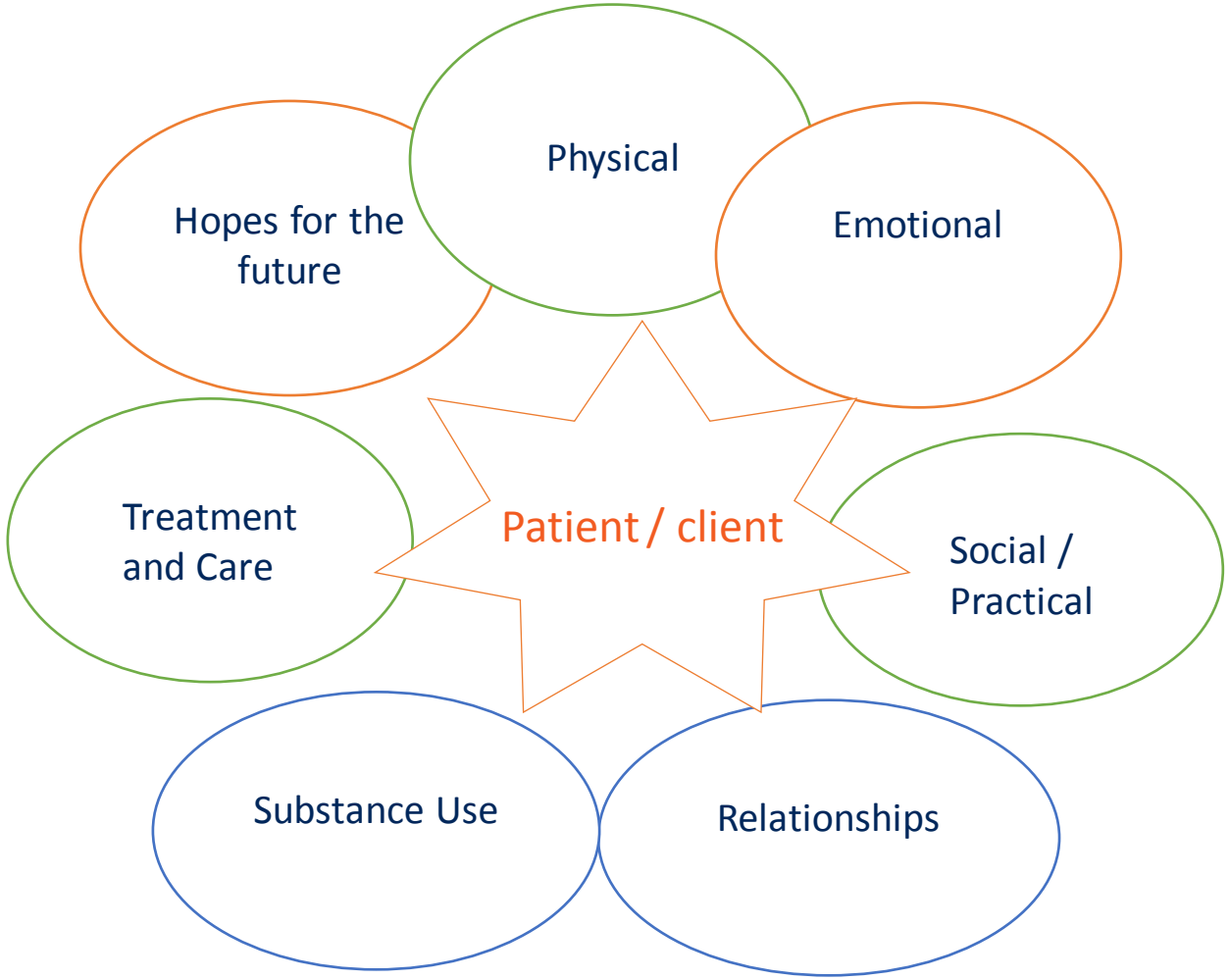
Marie Curie Care and support through terminal illness
OAK FOUNDATION

Person centred care - support and concerns mapping

start from where client is and work alongside them

- Place patient in centre
- Locate important issues to address
- Colour lines according to priority



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Questions to consider

PHYSICAL

- Do you have thoughts about where things are going with your illness?
- What do you understand about your current health situation?
- What are your main concerns?
- What would you like to see happen next?

SUBSTANCE USE

- Do you wish to reduce your drinking/substance use?
- Say you struggled to stop drinking, what do you think might happen in the next 3/6/9 months?
- Would you like to go to detox/rehab?
- Can we make a plan to meet again in a few days/weeks/months, and see where you're at with everything then?

TREATMENT AND CARE

- Do you feel you need any extra support with your care (nursing or personal care)?
- Are you having any difficulties getting around?
- If you became very ill, where would you want to be cared for? Here at the hostel, in a hospital or a hospice?
- Would you like to talk to your GP/doctor about what treatments you want/do not want?

EMOTIONAL

- How are you feeling about your recent diagnosis/hospital admission/poor health?
- I've noticed you seem a bit withdrawn lately, can I help with anything?
- Would you like to tell me about your concerns/worries?
- What do you feel would help right now?

HOPES FOR FUTURE

- What is most important to you at the moment?
- Are there things you have always wanted to do?
- Would you like support to reconnect with family?

SOCIAL / PRACTICAL ISSUES

- Have you been having trouble attending appointments, could we help with this?
- Have you thought about making a will or letter of wishes?
- What do you want to see happen with your possessions/pets after you die?
- Have you ever thought about how you'd like to be remembered?

RELATIONSHIPS

- Who are the people you trust the most?
- Who would you like to be there if you got ill (again)?
- Who would you NOT want to be there if you got ill?
- Would you like to get in touch with family?

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Two day training in two hostels

Qualitative findings – post training

8 years of training… today was the first time any trainers have bothered about us. Its always been focused on client's needs. Never about us, and if we are less stressed …the clients are going to get the best of us.

Keep everything in but spread it out more…

When just you do training, it can be very difficult to implement… because you're just one of many. Whereas if it's all of us… the voices of many that's going to push changes through.

3 month follow up – qualitative findings

Impact

- More discussion about end of life care within hostel
- Some conversation tools being used
- Deaths and memorials being used as a trigger for conversations
- A section has been added to the agenda of team meetings to discuss clients of concern

However

High staff turnover meant that many staff who were working 3 months later had not accessed the training

Links and relationship with hospice and regular MDT's not yet established

Therefore: Training alone is not enough

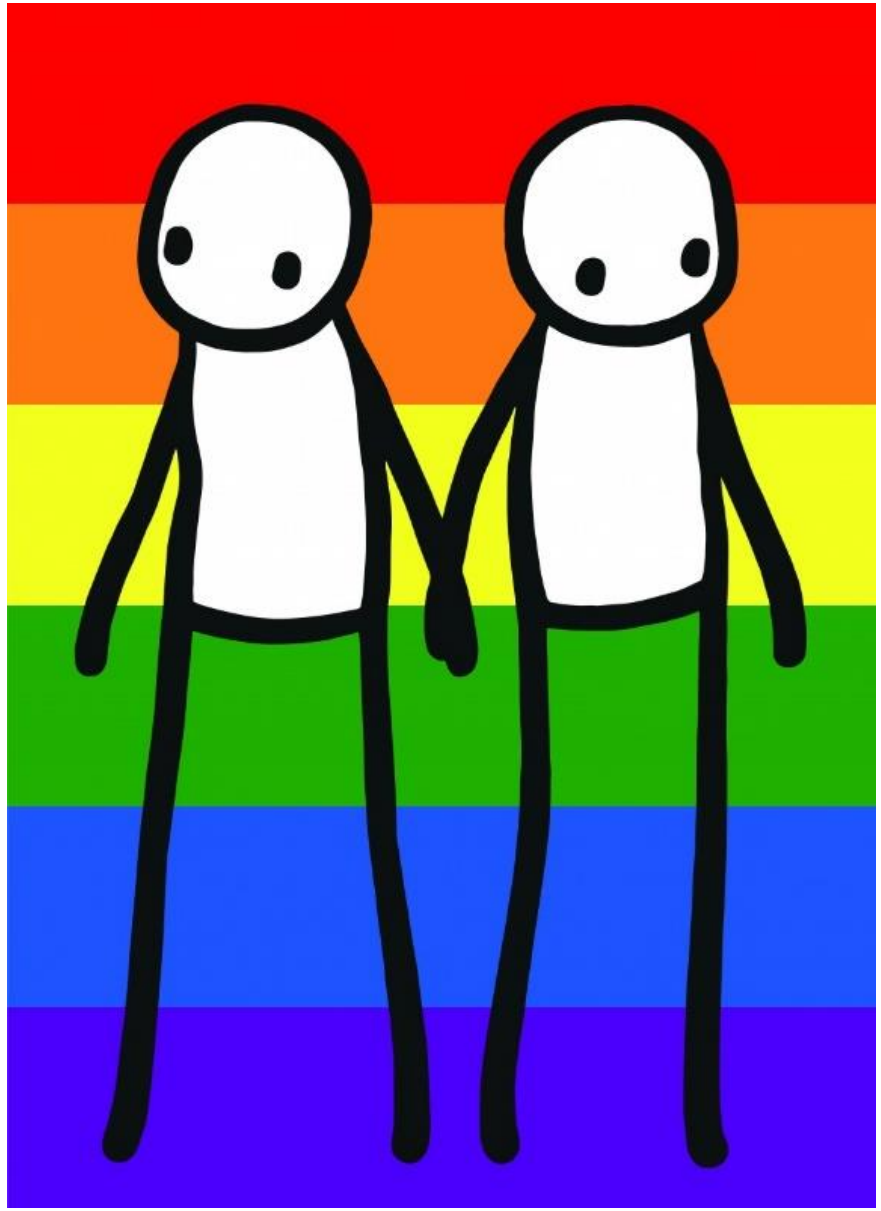
Current Project:
twinning hospices and hostels

Aims:

1. Improve access to high quality care and support for people experiencing homelessness with advanced ill health

2. Reduce burden on frontline staff

by embedding training, support and a MDT approach into hostels



Aiming for in-reach and multiagency working to discuss clients of concern

Homelessness champions

2-4 palliative care specialists identified from hospice

Work with 1-2 hostels

2 half days per month each (part pf job plan)

Provide training and support on:

Identifying residents of concern & red flags

Advocate for support from external services

Bereavement and self care support

Supporting (advance) care planning

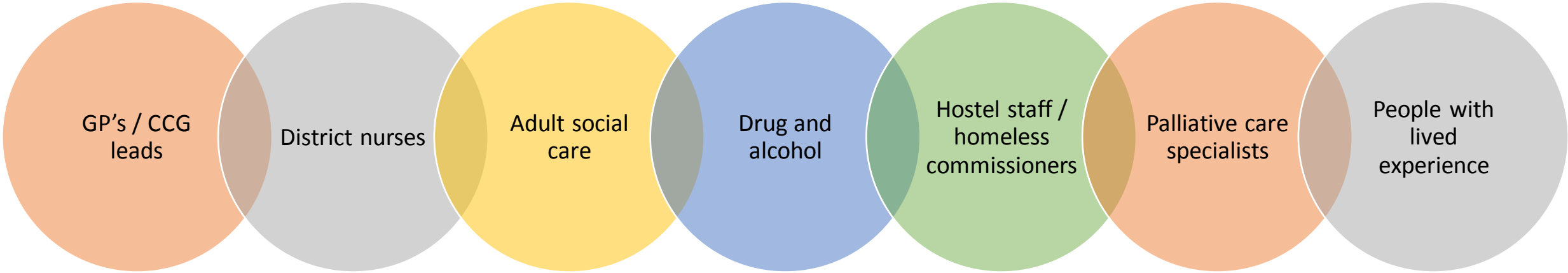

Integrating palliative care in homelessness
Complexity of Need
Their role as a champion
Hostel / homelessness landscape
Using resources and toolkit
Training for champions
Background to homelessness
Case examples

Stakeholder event – launched in each area

Aims:

- Inform about findings of previous project
- Share and co-design proposed project
- Develop links going forward to support multi-agency support
- Plan next steps

Invitees:



Stakeholder event – un-foreseen outputs a potential intervention on their own?

"Great to hear frontline staff at the hostels are getting the recognition for the work they do. One of the outcomes of the project is to see whether things improve for the frontline staff which may simply be improved just by this recognition". **Overall manager of housing provider**

"I will become more open to having more dialog about why they have overstayed and get more involved and behind this. However, if people are staying longer in the hostel and they are unwell, need to look at who is going to care for them." **Commissioner for hostel provision – Monitors overstays.**

The stakeholder meeting.. was invaluable for them to understand that we were not trying to trick them or implicate them in any way ..but to just support them".
Champion from hospice

Project evaluation – mixed methods

Questionnaires for hostel staff at baseline & 6 months

- Confidence about:
  - Identifying and securing support
  - Supporting a resident with advanced health needs
- Attitudes regarding a planned hostel death
- Support received from managers
- Collaboration with external services

Qualitative interviews at 6 months with champions and hostel staff

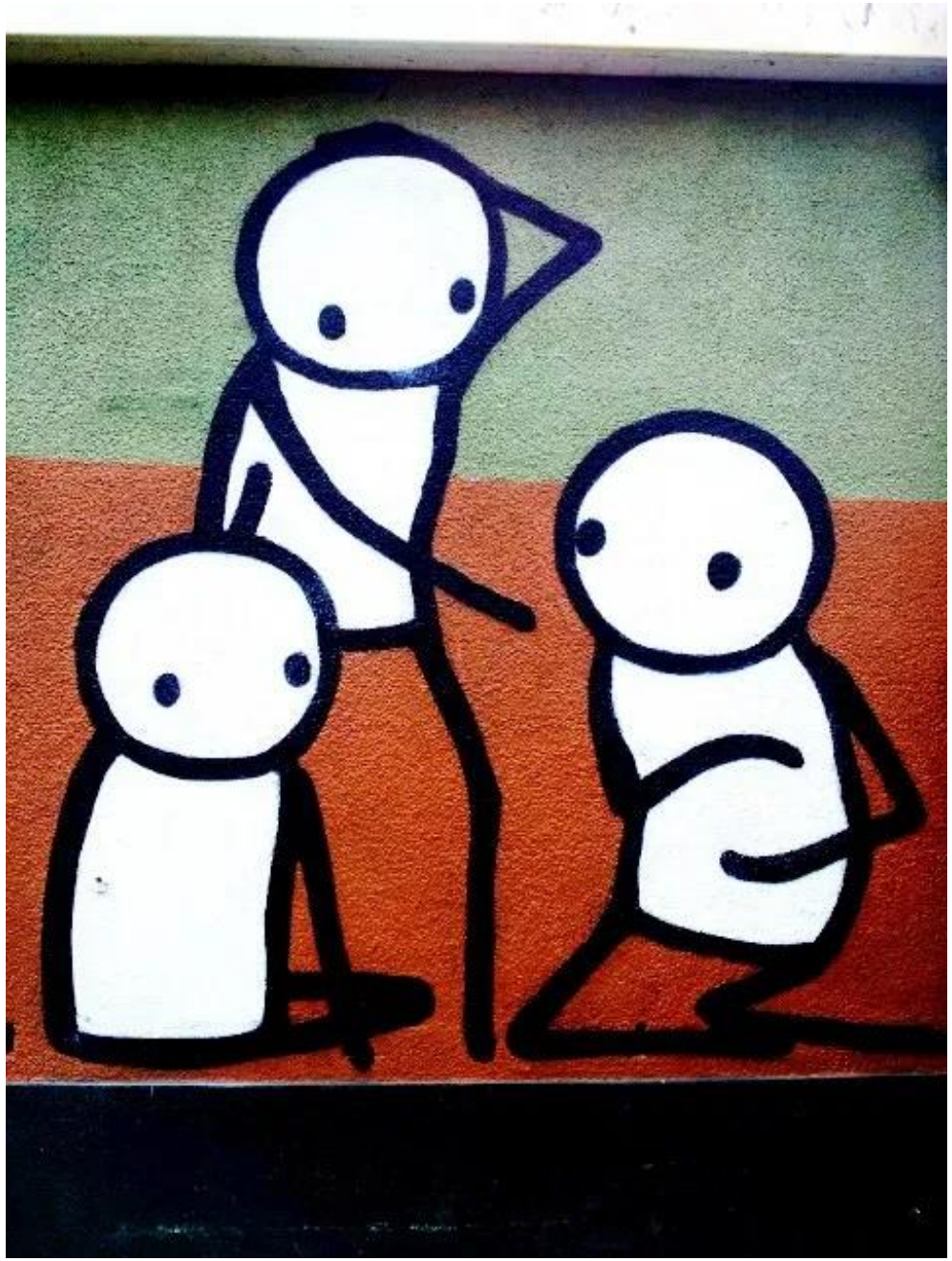
- Achievements & challenges of the project
- Impact on stress & staff morale
- Impact on quality of support for residents
- Perspectives on sustainability / going forward
- Illustrative case examples

Monthly data collection from champions

- Number of clients discussed
- Referrals made to:
  - Social services
  - Palliative care
- Ambulance call outs
- Unplanned hospital attendances
- Advice & training given
- Progress & challenges

…to date

- 8 hostels currently linked with 6 hospices in London, Kent and Birmingham
  - Hull and Manchester sites to launch in
- Evaluation near to completion in London
- Preliminary analysis from 3 hostels – with 3 hostel managers, 5 hostel staff and 6 champions (one evaluated early due to maternity leave)



Baseline barriers

Different boroughs starting from different places (eg GP support)

Difficulty accessing adequate social services

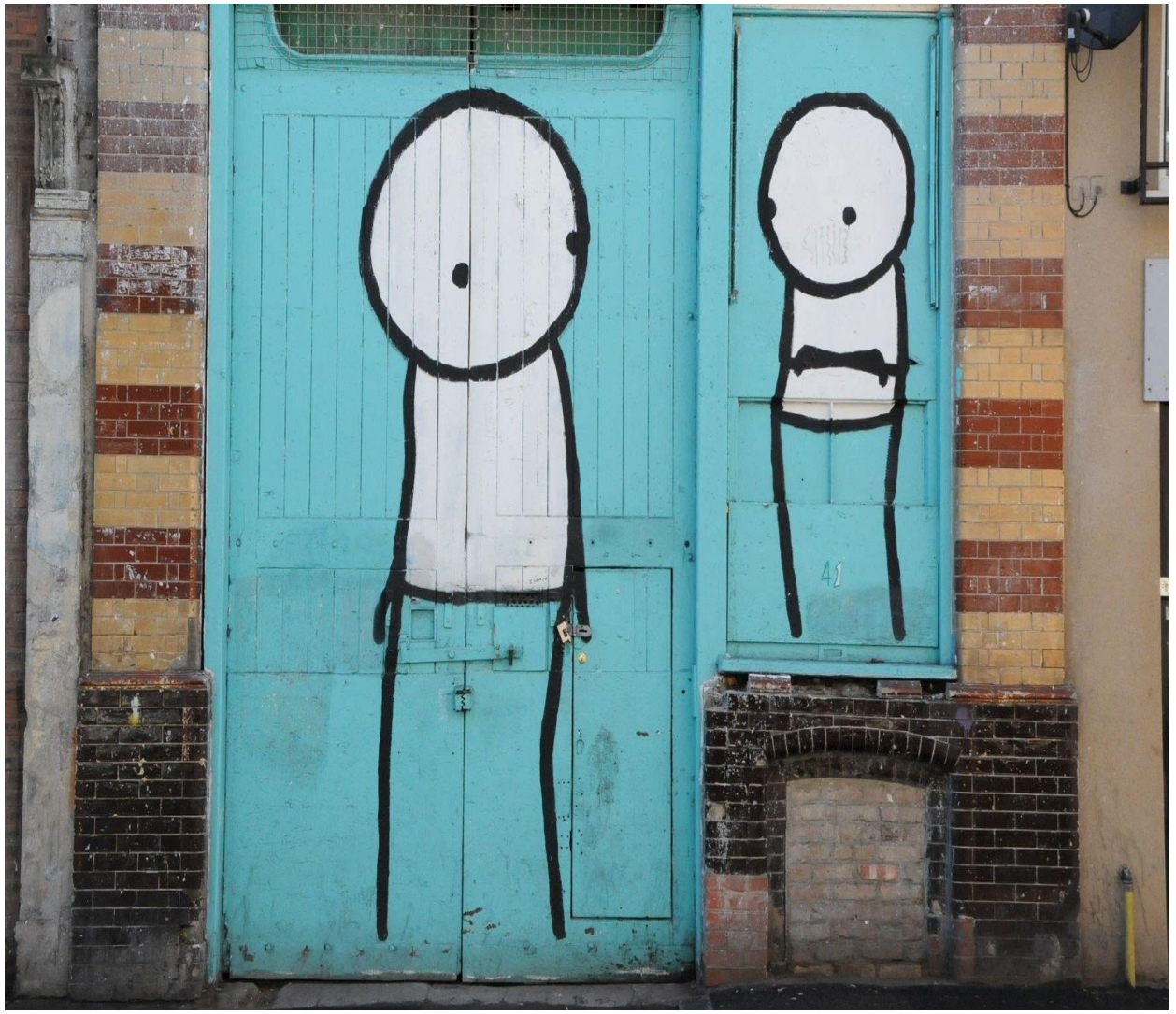
Many very sick people in the hostels

Recovery focus – planned death ‘not a palatable option’

Hostel staff unsupported and not listened to by external agencies

Focus on ‘move on’ targets

Preliminary findings



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Abbie (age 42)

Overview

- Abbie was very unwell and refusing medical assistance.
- In and out of hospital with decompensated liver disease, untreated Hep C, chest infections, incontinence, episodes of unresponsiveness, rectal bleeding, underweight
- Alcohol and drug dependent
- No engagement with key worker or services
- Hostel staff had little knowledge of her life prior to being in hostel
- Hostel staff placed Abbie in a room with large glass windows in reception so they could keep an eye on her
- Her partner was banned from visiting her as they thought he was a bad influence on her


In and out of care
Had an absent daughter
Previously lived on the streets
Had a partner of many years
Previous suicide attempts
Parents both deceased
Brother recently died

Abbie (age 42)

Wishes and insights

- Adamant she did not want to return to hospital (many friends had died in hospital)
- Did want to cut down from alcohol. Struggles to cut down due to isolation and being surrounded by other ‘addicts’
- Felt GP had given up on her but wanted assistance with managing Hep C
- Wanted to maintain relationship with partner despite understanding he could be a bad influence on her
- Hated being in glass room as wanted her privacy

Abbie (age 42)

Actions

- Contacted the GP for a referral to the hospice
  - GP declined saying she was too young and needed to stop drinking – and that the priority was for her to engage with alcohol service. He refused to come to see Abbie
- Champions directly referred Abbie into the hospice
- Discussed with hostel staff *care vs control*
- Moved Abbie back to her room

Abbie (age 42)

Outcomes

- Abbie engaged with the hospice and recovered some of her independence, and physical and emotional wellbeing
- Abbie felt listened to and a plan was made in line with her priorities
- Basic teaching provided to hostel staff around Abbie's health needs and how to monitor for a deterioration
- Hostel staff felt more supported and started working in a more 'person–centred' way
- Champions felt they better understood the difficulties hostel staff face regularly and learnt better how to communicate with homelessness population
- Much improved engagement with her key worker and other hostel staff
- Abbie made a comment to key worker – *'you must really care to be going to this much effort'.*

Six month follow up - Hostel staff

Increased staff's knowledge, confidence and empowerment

"I have learnt a colossal amount, to the extent that I have been promoted here. I started updating my CV, and it was like wow everything was related to the palliative care project."

"I think everyone is just a little bit braver now, to step forward and [to outside agencies] be like, actually, this is how it is supposed to be. You're not supposed to be telling us that."

Six month follow up - Hostel staff

Support with grief and bereavement

"We still don't know the cause of death….But that had a really detrimental effect, especially on E because she had been working so closely with him. And she found him, with his carer who had come in to clean the room. So she has been able to sit down with MK [champion] and ..have a debrief around it, just to talk to someone about it, about the death and how that made her feel on a personal level…"

Change in culture around planned death

"..initially when we think that someone is going to die, we would have said "no,no,no, we need to move them on quickly, we don't want them dying within the hostel" ..but then we started to change our way of thinking because of this..we did start saying, well yes this is his home".

Six month follow up - Hostel staff

Overview of the project

"Beneficial doesn't really sum it up…invaluable. Because we have been working in isolation for such a long time and people don't really know how hard it is to work here. It just a shame that this hasn't always been in place." Manager

"….I've worked in homelessness for such a long time and this is the first time that I have ever come across anybody doing anything like this… And I've seen so many people die ..so much of it over the last 19 years…And its invaluable having that second pair of eyes looking at it with you and going, have you thought about it this way? How can we change that? It should have been done years ago". Palliative champion

Champions tasks and achievements

Provided support to staff and residents to develop (advanced) care plans

Set up complex case meetings at the hostel

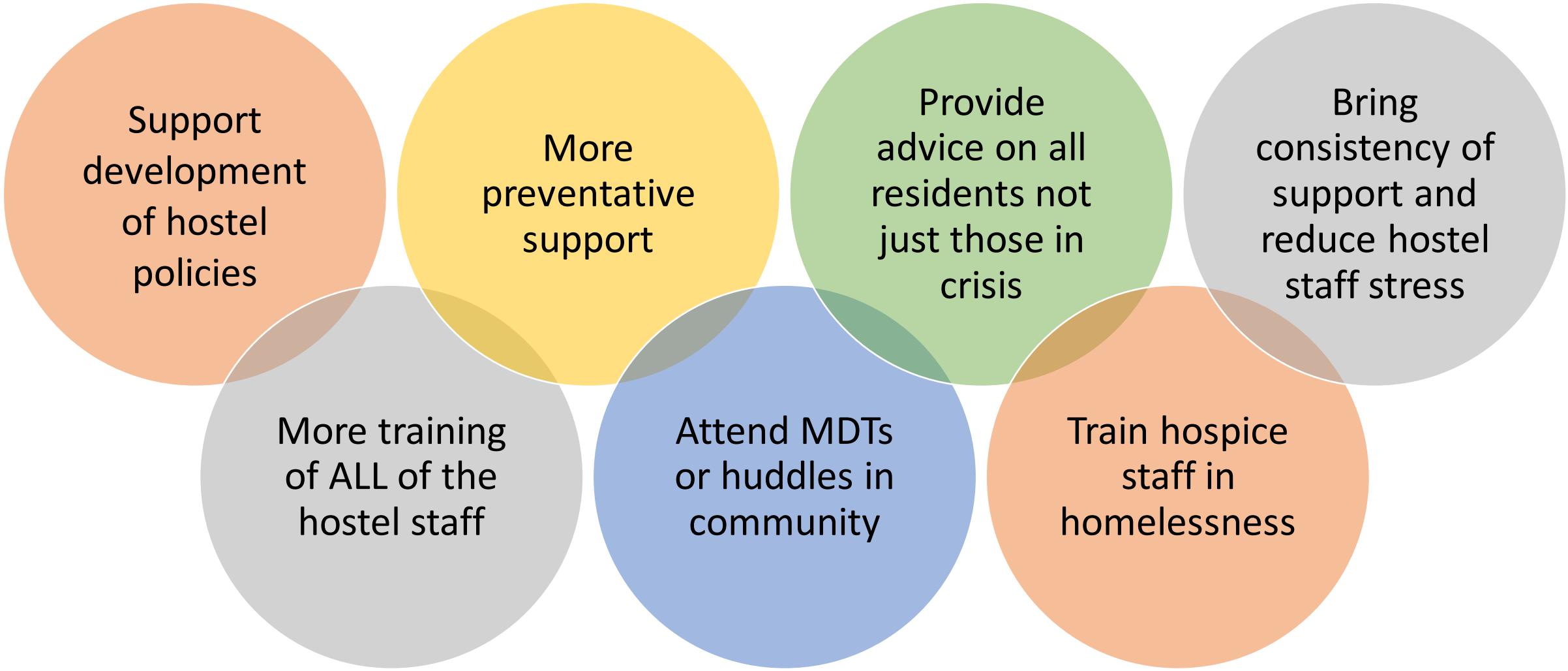
Got more external services involved e.g., social services packages of care

Held a death café

Individuals helped with getting into care home / OT assessments / hospital bed

Some individuals referred into palliative services

If the Champions could have more time…



Lots of other examples around the country including

Homelessness led

- Palliative care coordinator role, St Mungo's

Primary Healthcare led

- Bradford: specialist primary care & hospital Pathway team with intermediate care beds

Palliative care led

- Range of innovative projects providing training and additional support including: St Luke's Cheshire; St Luke's Basildon (with liver outpatients); St Ann's Manchester; Mary's Hospice & Mary Stevens Hospice Birmingham; St Columba's Hospice Edinburgh (ECHO)….
- Much of this work has been done with little funding or by applying for funding from charitable sector

All have relied on someone championing for the need to support this excluded group.

PEOPLE WITH NO RECOURSE TO PUBLIC FUNDS

http://guidance.nrpfnetwork.org.uk/reader/practice-guidance-adults/

Conclusions

- People experiencing homelessness are dying unsupported in unacceptable situations – with the burden of support lying with frontline hostel and outreach staff who have no training
- Identifying who would benefit from palliative care referral is complex
- For lasting change, training alone of hostel staff is not enough
- Preliminary findings of our project twinning hostels with palliative care teams confirms the needs and the value of holistic in-reach support
- There remains a need for alternative places of care for people with high support needs
- The early research findings have been widely disseminated to policy makers, commissioners and providers of care at national and local level

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Implications - Listen to and involve people with lived experience

Practice

- Palliative care in PEH is complex, but needs a shift in focus / parallel planning
- For high quality care we need collaboration between health, social care, housing and addiction services
- The palliative care community are well placed to provide holistic in-reach support and facilitate multidisciplinary approach in hostels
- GP support (ideally in-reach) is also vital in large hostels

Research

- Explore other ways of disseminating / rolling out training and support
    - developing and evaluating videos for health care providers and frontline staff
- Explore other models of supporting a multidisciplinary approach for PEH in a range of settings
- Quantify problem: Develop tools to support identification of 'people of concern' & identify numbers of people dying with inadequate support

Advocacy and policy

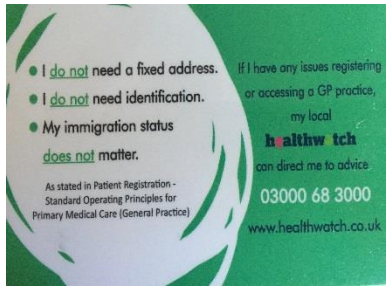
- Need for a cross departmental homelessness strategy – including addressing needs of people with NRPF
- Continue to advocate for *choice* in place of care and *care* in place of choice including high support need facility

Useful Resources

Homeless Link to find out about homeless hostels and day centers in your area
http://www.homeless.org.uk

London Housing Foundation Atlas to identify homeless services https://lhf.org.uk/atlas/

Advocating for homeless people around GP registration
https://www.healthylondon.org/homeless/healthcare-cards



Reporting a rough sleeper:
http://www.streetlink.org.uk

With thanks to…

The Oak Foundation

Pathway: Nigel Hewett & Julian Daley

St Mungo's: Niamh Brophy & Peter Kennedy

Marie Curie Palliative Care Research Department, UCL: Briony Hudson, Patrick Stone

Publications

- Faculty of Homeless and inclusion health: Join for free – Standards for providers and commissioners, publications, network, local meetings: http://www.pathway.org.uk/faculty/
- Training toolkit: www.homelesspalliativecare.com
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- NHS England podcast https://healthsector.webex.com/healthsector/ldr.php?RCID=437fdf890e93e01d09d09b45bec93975
- NHS England End of life care Webinar:
- Palliative care toolkit for people experiencing homelessness
- *CQC & Faculty of Homeless and Inclusion Health* (2017). A Second Class Ending. Exploring the barriers and championing outstanding end of life care for people who are homeless