Scottish Health and Homelessness Conference 2018

# End of life care for people who are homeless
## research, resources & next steps


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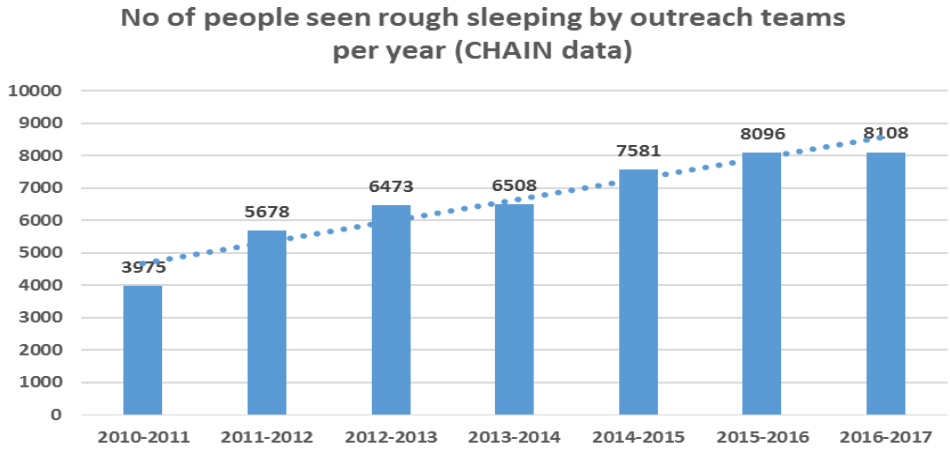
# Homelessness in London

## Rough sleeping

There was an increase of 104% in the number of people seen rough sleeping on the streets of London between 2010-2011 and
2016 – 2017




## Homeless hostels

9,186 bed spaces for single people who are homeless pan London in 2015-2016 (a 26% decrease from 2011-2012)

## Temporary accommodation e.g. B&Bs

54,280 households in temporary accommodation in London in 2016-2017

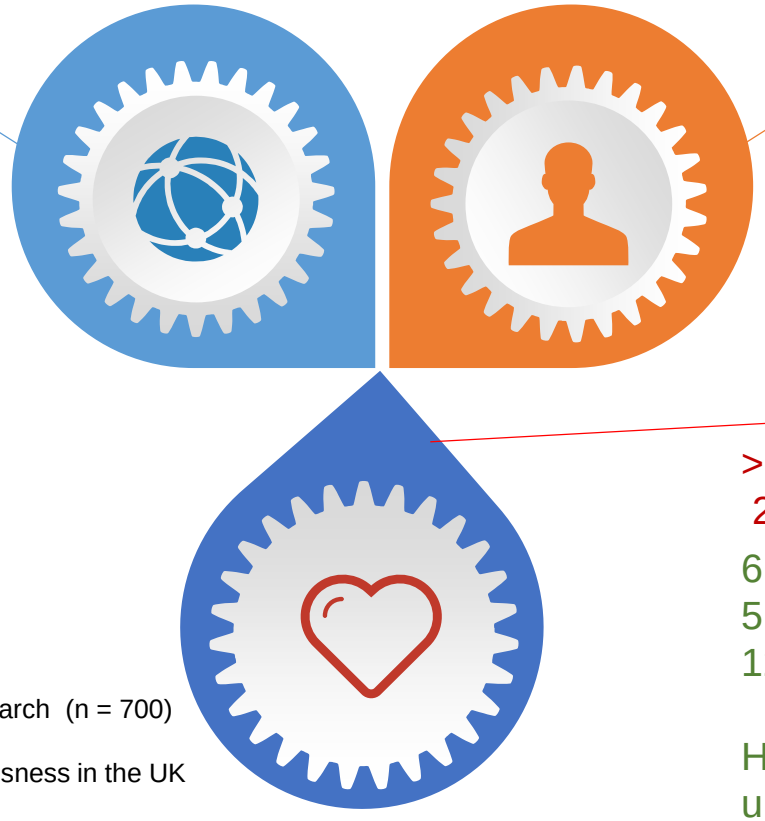
## Hidden homelessness

?

# Homelessness and Health
# Complex needs & Tri-morbidity

## Substance Misuse

> 60% history of substance misuse



## Mental Health

70% reach criteria for personality disorder

## Physical Health

>80% at least 1 health problem,
20% have more than 3 health problems

6 x more likely to have heart disease
5 x more likely to have a stroke
12 x more likely to have epilepsy

High prevalence of infectious diseases yet unequal access to treatment
**Onset of related functional impairment 10-15 years early**


Homeless Link (2014) The unhealthy State of Homelessness, (n= >2,500)

St Mungo's (2010), Homelessness, it makes you sick, Homeless Link Research (n = 700)

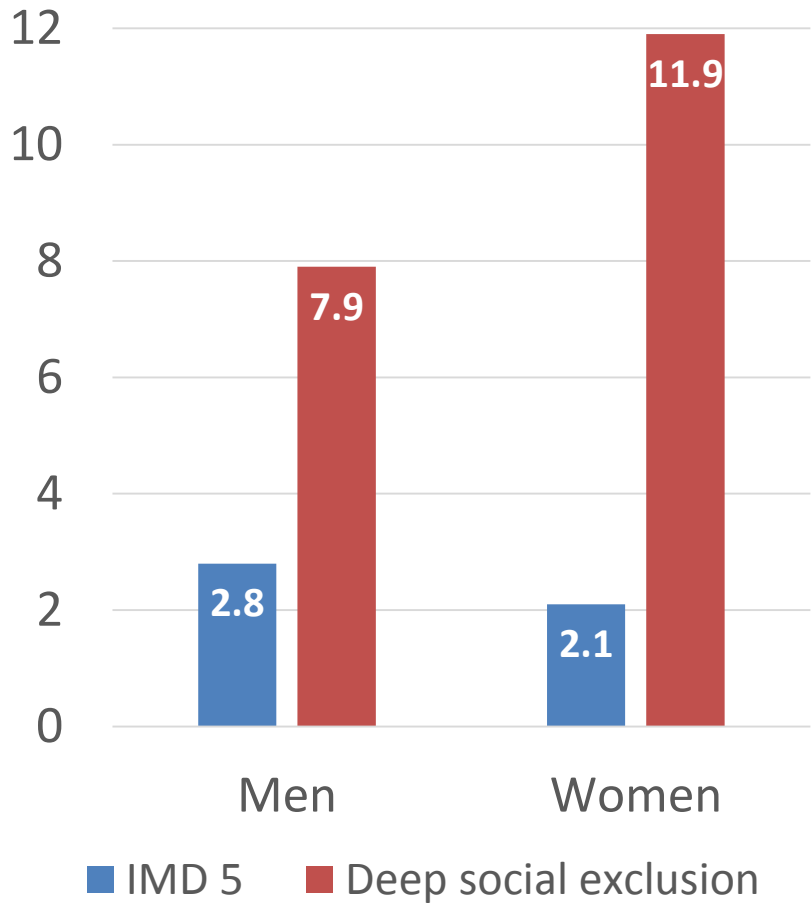
Suzanne Fitzpatrick et al (2010) Census survey multiple exclusion homelessness in the UK (n= 1268)

Story, A. (2013) Slopes and cliffs: comparative morbidity of housed and homeless people. The Lancet. Nov 29. Volume 382. Special issue. S1-S105

# Homeless people die young

Average age of death in the UK for single homeless people:

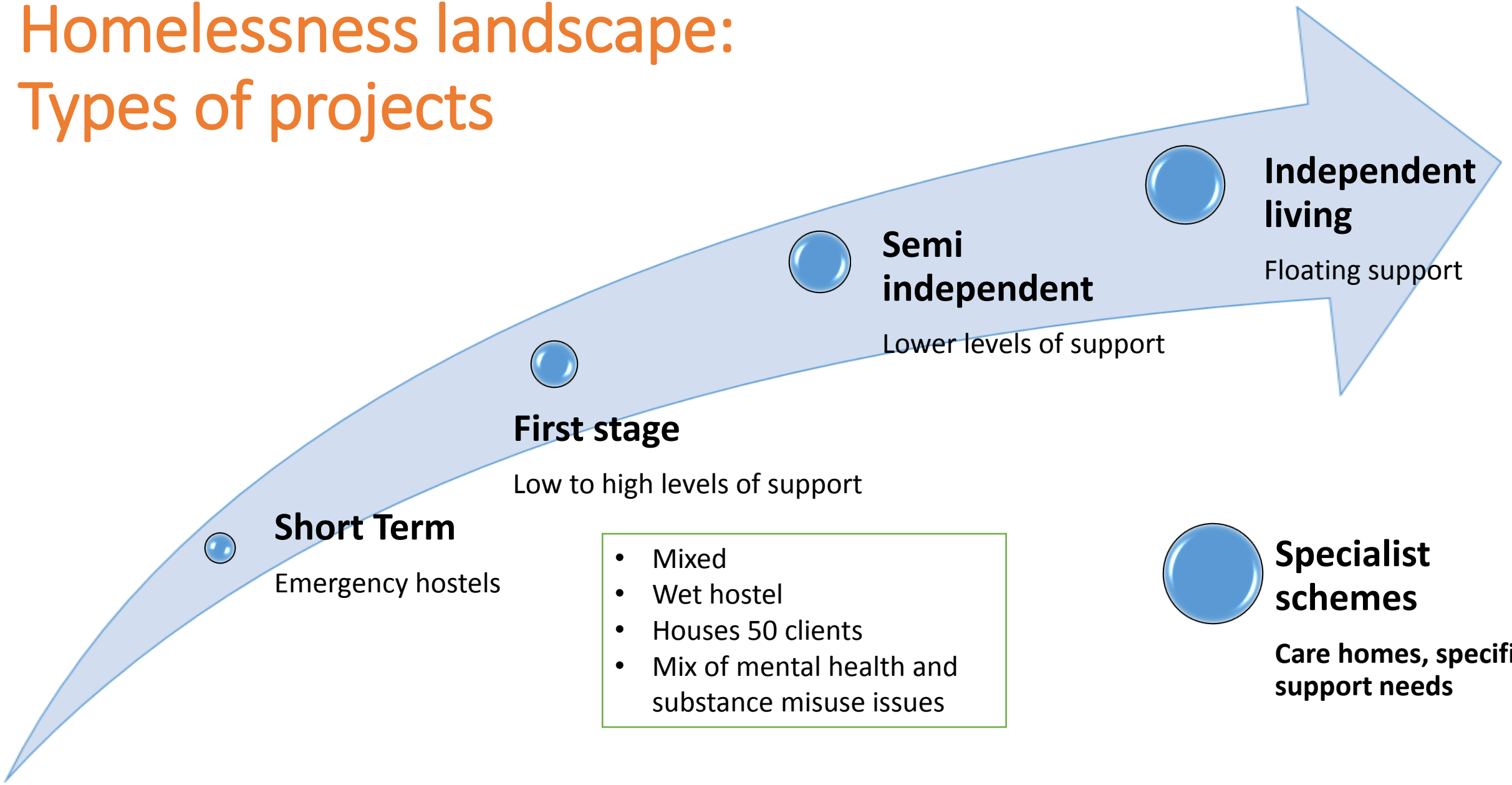
47 for men 90%
43 for women 10%




Thomas B. Homelessness Kills: An analysis of the mortality of homeless people in early twenty-first century England. London Crisis; 2012.

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

# Homelessness landscape: Types of projects



**Short Term**

Emergency hostels

**First stage**

Low to high levels of support

- Mixed
- Wet hostel
- Houses 50 clients
- Mix of mental health and substance misuse issues

**Semi independent**

Lower levels of support

**Independent living**

Floating support

**Specialist schemes**

**Care homes, specific support needs**

# What hostels do and don’t provide

## Hostels do provide:

- Bedroom
- Shared kitchen/ toilet/ laundry facilities
- Key work support
- Support to attend appointments
- One meal a day
- Concierge access out of hours
- (high support hostels only)

## Hostels don't provide:

- Long term accommodation (6-18 months)
- Medical or nursing care
- Domestic or personal care
- Administration of medication
- Storage of medication
- 24 hour support


# Gemma

**How can we improve palliative care for homeless people?**

28 years old

Street homeless for many years, now living in hostel

Decompensated liver disease

Multiple hospital attendances & admissions

Frequently self discharging

Died in hostel one weekend following collapse

# Our research

*What are the challenges to palliative care for people who are homeless in London, and what could be done to improve care for this group?*

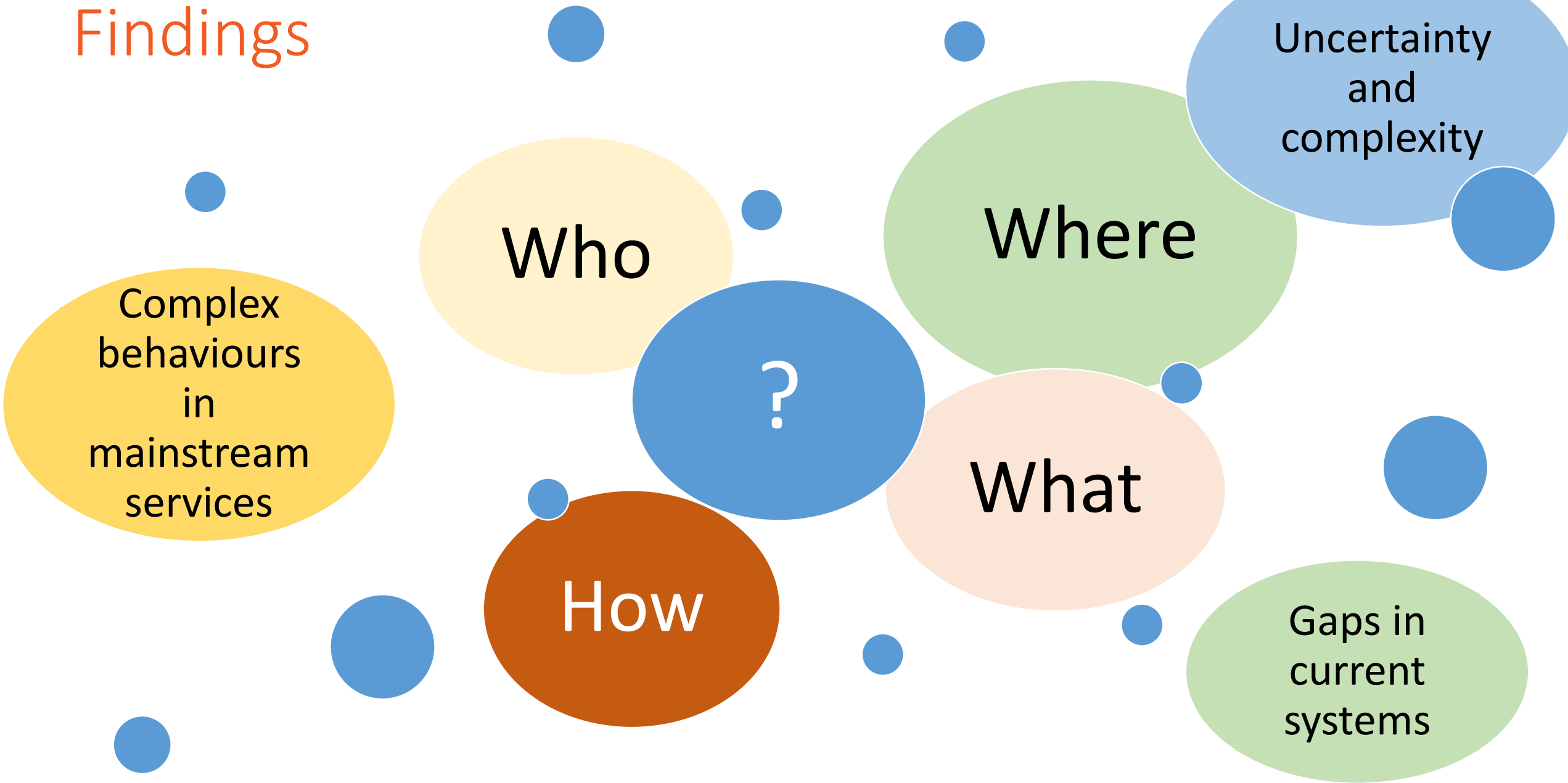

Shulman C, Hudson B F, Low J, Hewett N et al (2018) End-of-life care for homeless people: a qualitative analysis exploring the challenges to access and provision of palliative care. Palliative Medicine 32(1): 36-45 https://doi.org/10.1177/0269216317717101

Hudson BF, Shulman C, Low J, et al. Challenges to discussing palliative care with people experiencing homelessness: a qualitative study. BMJ Open 2017;7:e017502. doi:10.1136/ bmjopen-2017-017502

# Palliative care & homelessness

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

# Findings

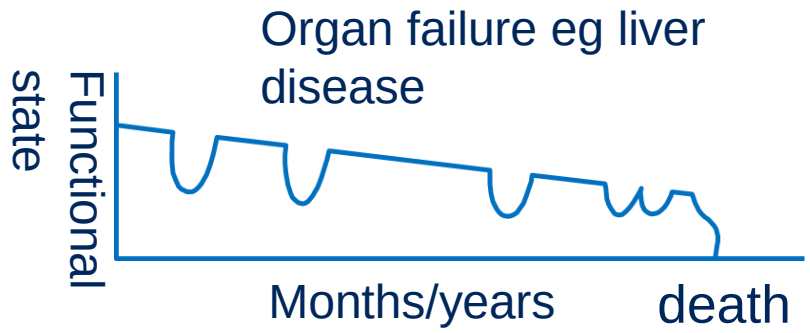

Uncertainty and complexity
Who
Where
Complex behaviours in mainstream services
?
What
How
Gaps in current systems

# Uncertainty & complexity

## …around who is palliative due to:

- **disease trajectory**
- **substance misuse / complex behaviour**
- **access to and utilisation of health care**

Many deaths are sudden,
but not unexpected

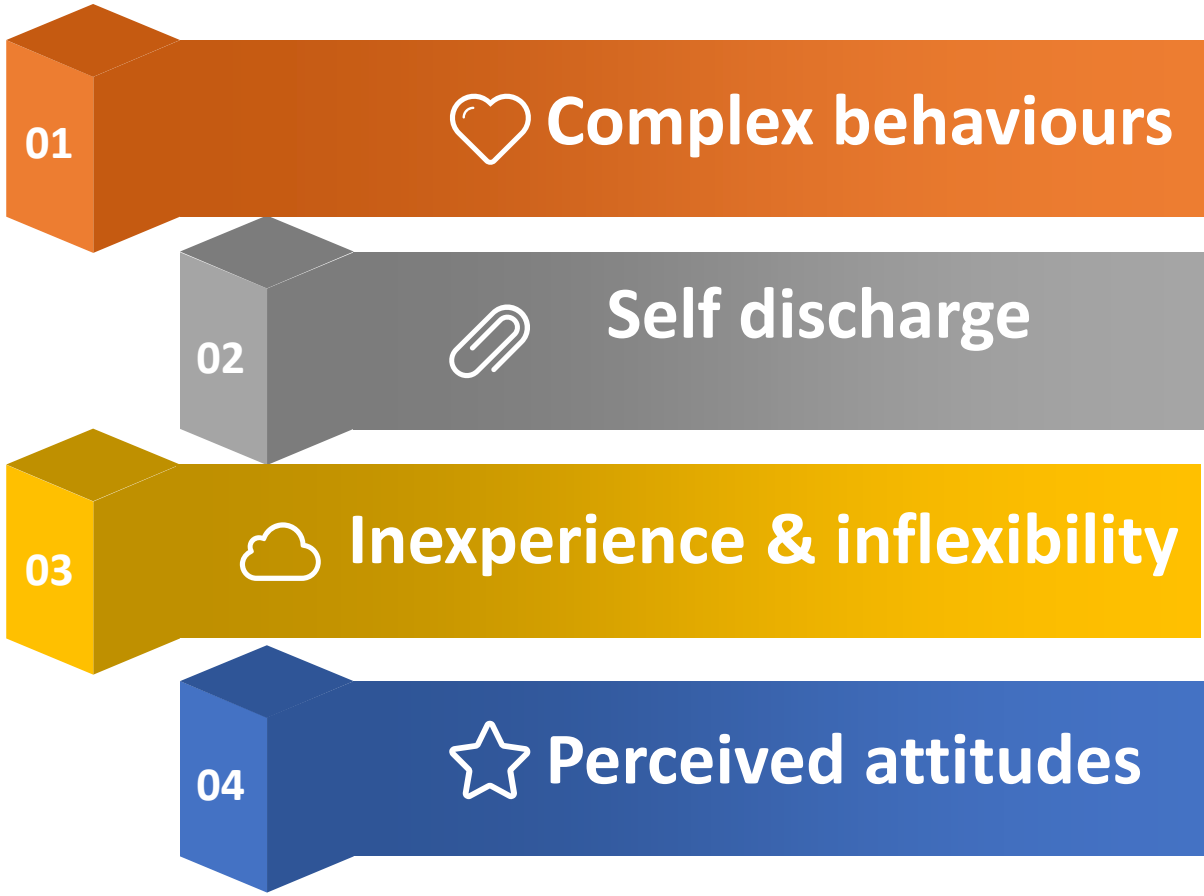


# Mainstream services

## Difficulties accessing and delivering care

*"...one problem is that hospitals are so busy... if someone is repeatedly coming back in...popping off the ward for a couple of cans, they just discharge them.... But.... if that's going to be the pattern for the last 6 months of someone's life, you want to try and actually use it"*

*– General Practitioner*

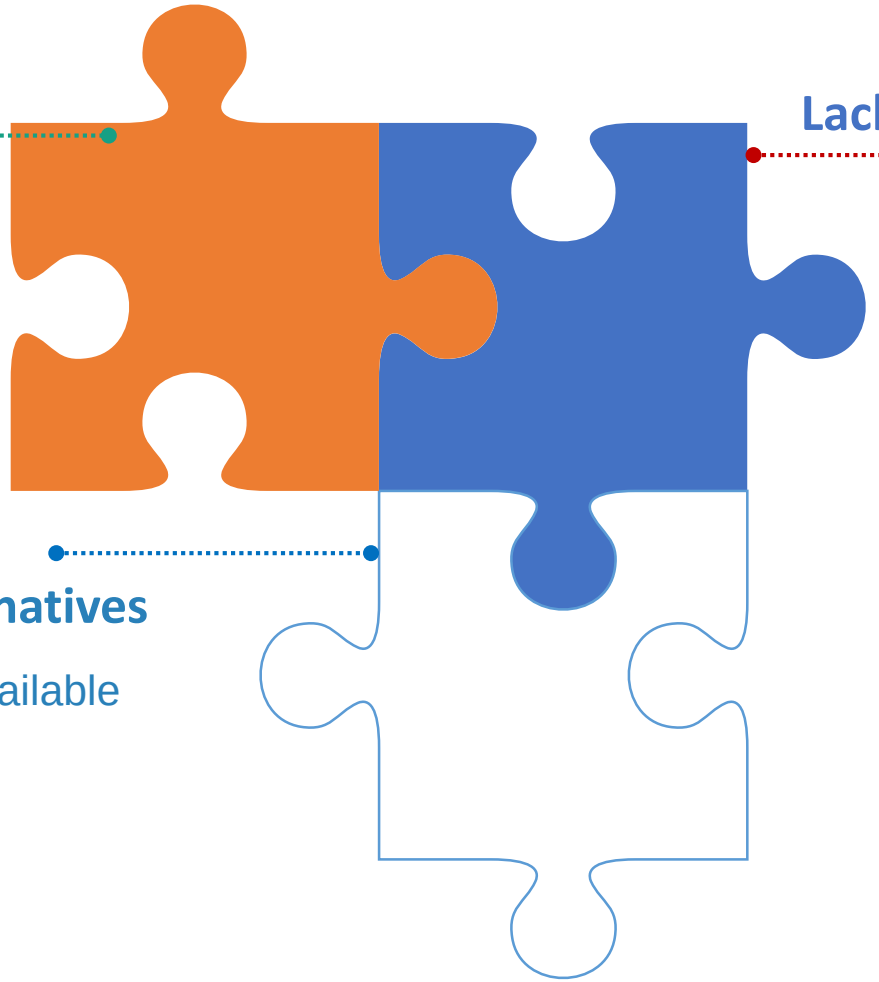


# Gaps in current services

Place of care for people who are homeless with advanced ill health

**Fragmentation**

- Lack of tailored services
- Who is responsible for care? Health or social services



**Lack of flexibility**

- Discharged if don't attend
- Location of care not flexible
- Often lack of joined up working between addiction and mental health services
- Zero tolerance

**Lack of acceptable alternatives**

- Staff not sure what is available
- Young age

# Lack of options for place of care

*"…In the past we have tried to put people into hospice … one person [in his 40's] we did get in there. And he was asked to leave because of his behaviour when drunk. And in the end he died in the hostel, he had cancer"* **Hostel staff**

*"…so he's young & he's got HIV. He lives in a hostel….he hates it…it's got 28 beds & 2 staff. He's incontinent in there... lives in complete squalor… the hostel are saying "this is the best we can do!"… there is no more suitable place, there is no alternative. So the big question is 'where should he go?"* **Specialist GP**

# Many people with deteriorating health remain in hostels

- Small staff numbers and limited training
- Limited access to support
- Limited experience of palliative care
- Environment
- Practical issues (storage of medication, facilities)
- Safeguarding concerns

*"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]… you really can only do so much … this isn't an appropriate environment, but it's the best we have"*

*Hostel staff*

# But what if the hostel is seen as their home?

- Many participants emphasised that hostels are not, and perhaps should not become care homes.
- Choice and compassion?
- Hospitals may better serve the physical needs of dying homeless people, some felt hostels were best placed to meet their emotional needs.

"I mean, we can make people as comfortable as possible but…when we have 42 residents, if there's only 2 of us on shift, we might have someone chaotic next door, or someone's screaming upstairs, the person is alone. We are not going to be able to manage that".

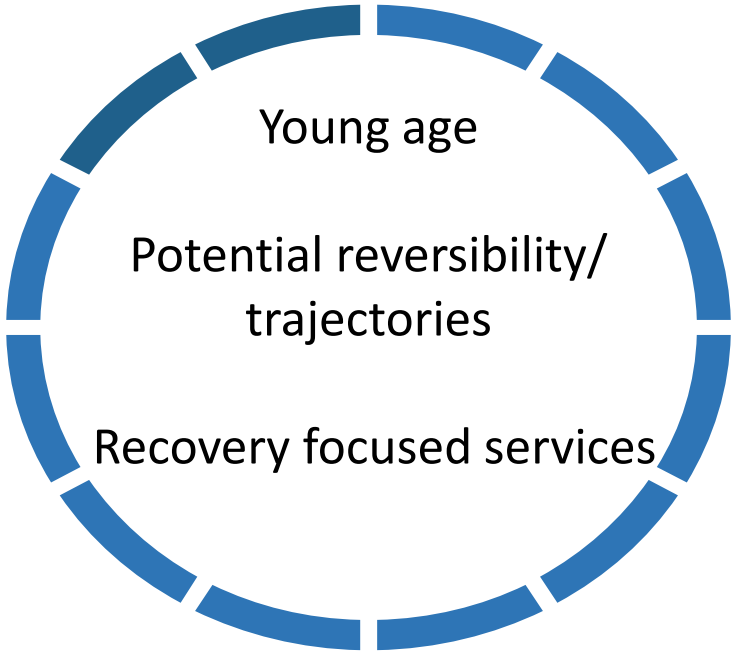
*Hostel staff*

"People just need to be themselves, that's quite comforting at the end of life I think, that everything is normal, like Stewart; bargain hunt on the telly, K in one hand, cigarette in the other. He was happy. And people shouting? Not a problem, because its like " *I feel like I can be myself, right up to my last breath here, in this situation*".

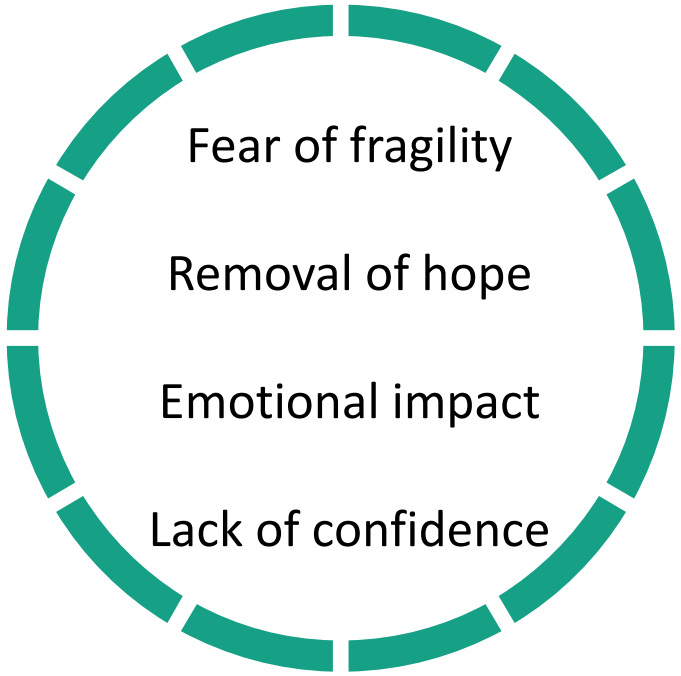
*Hostel staff*

# Why might it be difficult to engage clients about deteriorating health?

## Culture focus & recovery




## Fear of impact on person




## Uncertainty & lack of options

# Challenges for conversations around deteriorating health and future wishes

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… 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

"It's really hard to have that conversation… we're trained to do recovery…. our hostel is commissioned to engage people with support and recovery…. getting better, moving into jobs, whatever… and then… it's really hard to come out of that mind set and go into another… which is… death."

Hostel staff

Hudson BF, Shulman C, Low J, et al. Challenges to discussing palliative care with people experiencing homelessness: a qualitative study. BMJ Open 2017;7:e017502. doi:10.1136/ bmjopen-2017-017502

# Our recommendations

## 1. A Shift in Focus:

- End of life care → advanced deteriorating ill health

## 2. More support for hostels:

- Greater multi agency working (regular meetings discussing clients of concern)
- More in-reach into hostels
- More training and support for all groups

## 3. Appropriate places of care :

- 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

# 1. A shift in focus

End of life care → deteriorating health

If you can't predict, how do you plan?

**Parallel planning** **Supporting decisions, while keeping options open**

- Exploration of insights into illness, wishes and choices, not just giving warnings– how to live well
- Early & repeated conversations
- Not just issues for the very end of life, but about living well.
- Person centered - respecting choices even if we feel they are unwise.

# 2. Multiagency meetings to support care planning

It's making sure we are sharing the load where applicable. I think we are a very effective team and sometimes we…individuals…might take on more than they need to.

I think that palliative care, end of life care is something which is so multidisciplinary.

We are incredibly good at what we do but we cannot solve all of the problems for end of life care on our own

– specialist nurse practitioner

# In-reach into hostels and day centres

**Palliative care in-reach can help with:**

- Identifying people whose health is a concern
- Having conversations – not just end of life, but living well
- Supporting the development of care plans
- Optimizing pain relief and other symptom control
- Facilitating access to social services package of care/ CHC
- Training
- Bereavement support

# *In an ideal world……*

©STIK

## 3. A facility that

Understands the needs of people who are homeless

Acts as a step up from hostel/street

& a step down from hospital

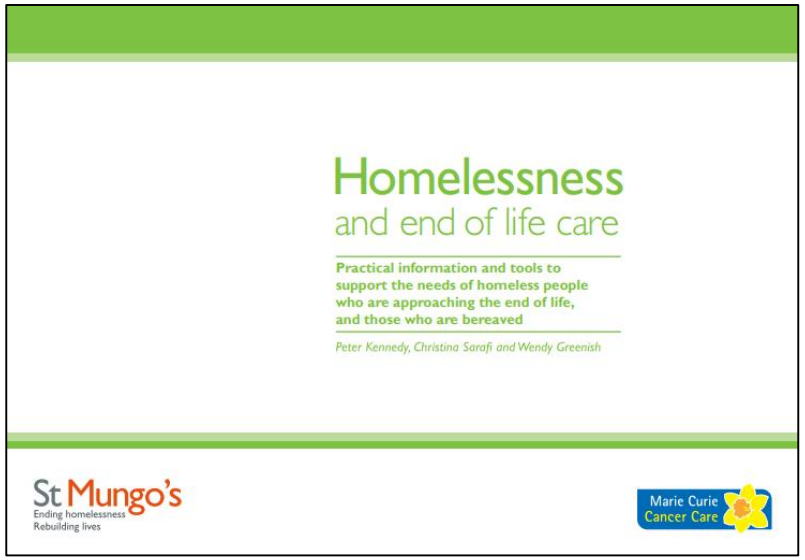
Could provide adequate 24 hour support

Offers respite AND/OR a comfortable place to live until the end of life

## ..In the meantime…

Hostels **need additional multidisciplinary support,** due to a lack of alternatives

# Developing training for hostel staff




www.mungos.org/endoflifecare


- Run twice in two hostels in London, aiming for all staff to attend.

# Core modules of the training for hostel staff

Identifying clients

Person centred care

Shared care

Self care

Engaging clients

Bereavement

End of life care

# Engaging clients & exploring insights

## Engaging clients whose health is deteriorating

**Hopes/concerns about the future**

**Treatment/ Support options**

**Motivation for change**

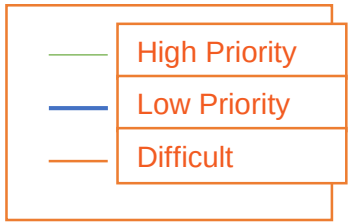
**Important relationships**

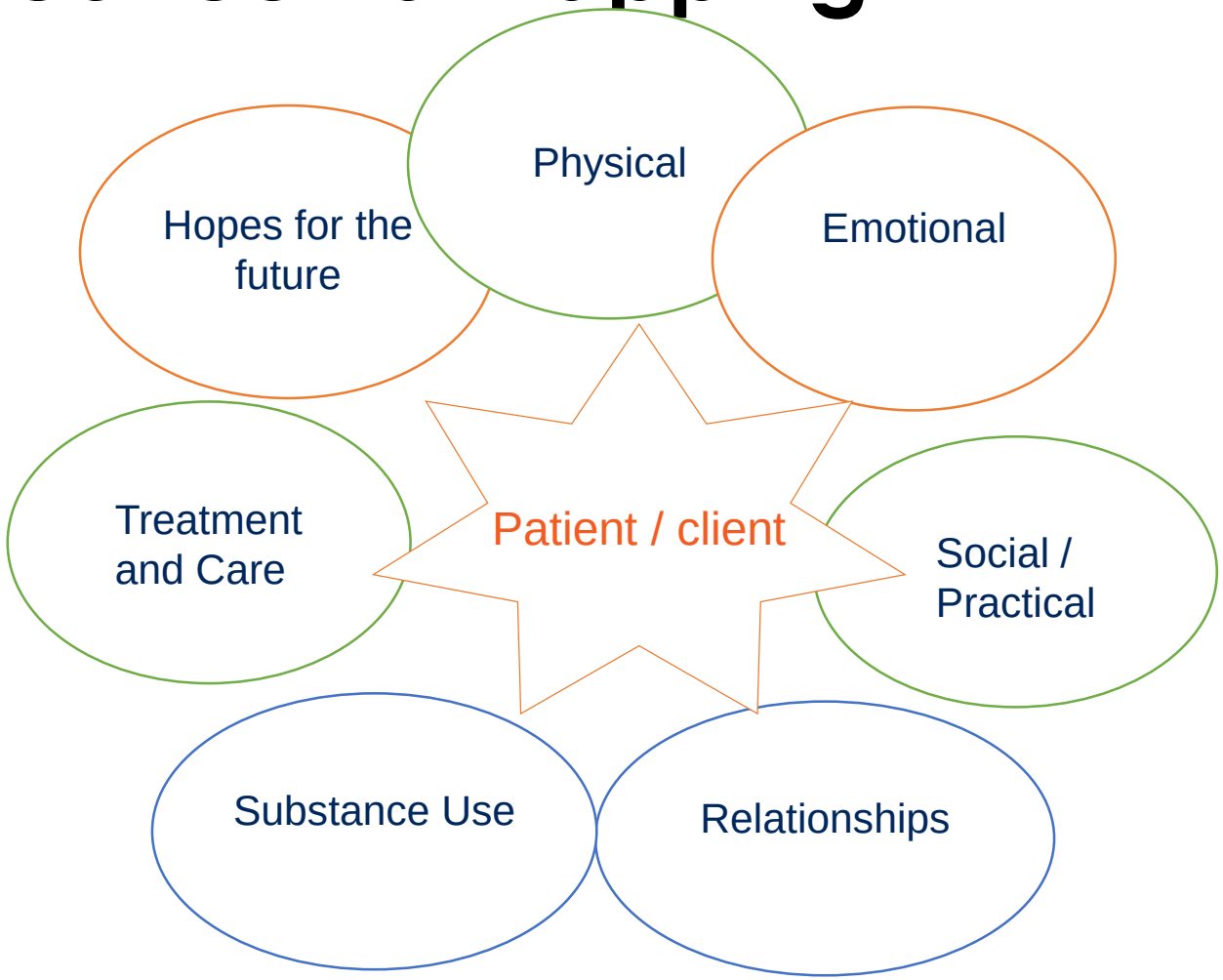
**Insight into illness**

**Advance planning**

# Person centred care - Support and concerns mapping

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




*Supporting front line staff to start from where their client is – work alongside them*

# 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

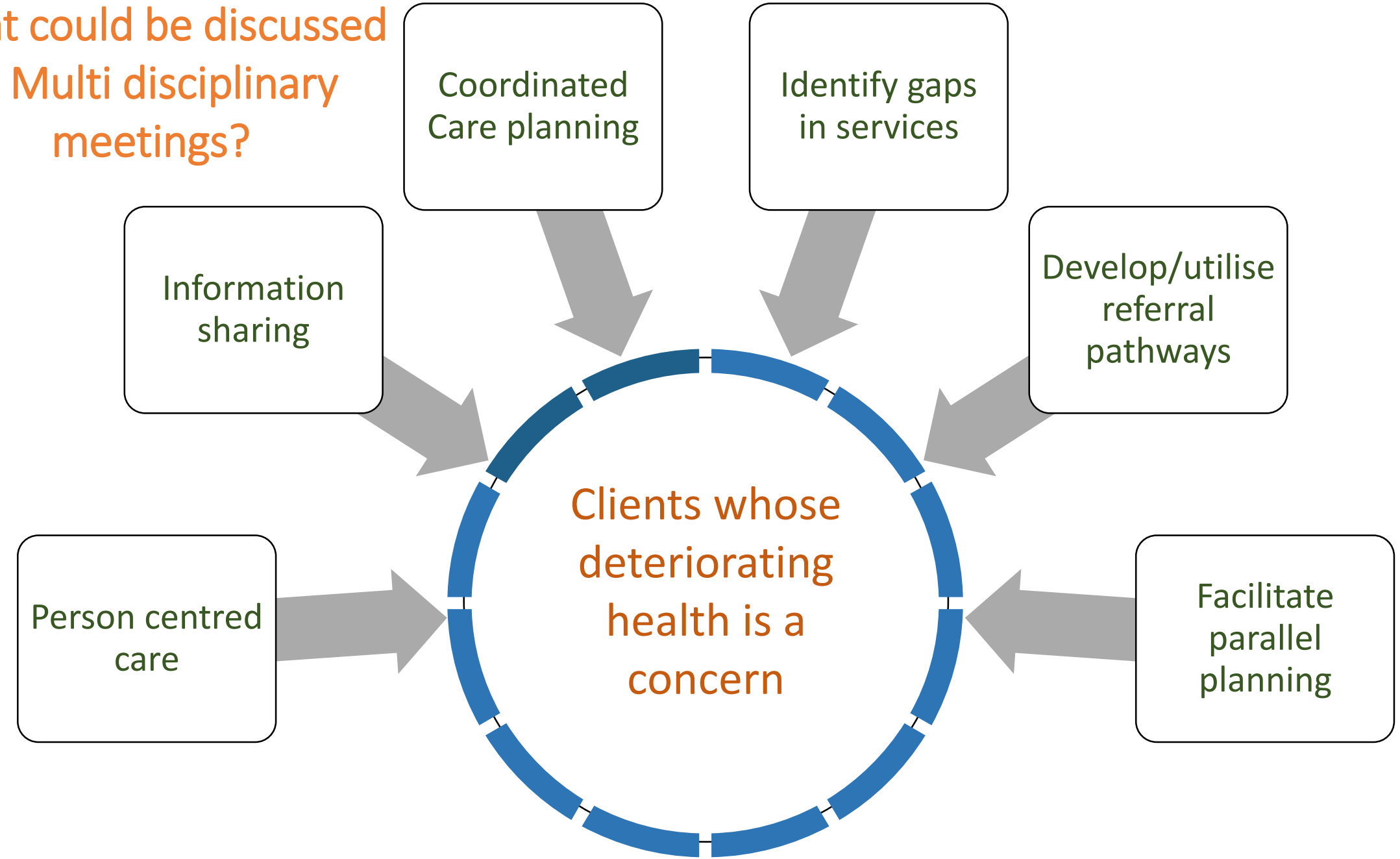
- Who are the people you trust the most?
- Who would you like to be there if you got ill (again)?
- Who would you NOT want to be there if you got ill?
- Would you like to get in touch with family?

# Shared care - Multiagency working

- Every 4 weeks
- Lunchtime, 1 hour meeting
- Discussing all clients whose deteriorating health is a concern

## Who could attend?

# What could be discussed in Multi disciplinary meetings?



# Case Review Prompt



| | **Client** – concerns / wishes / desired outcomes from review (if discussed) | **Hostel** – concerns / needs / desired outcomes from review | **Actions** – Outcomes from the case review |
|---|---|---|---|
| **Physical health**<br>Current health status<br>Notable changes<br>Current / Future health needs<br>Engagement with health services | | | |
| **Mental / Emotional Well-Being**<br>Current mental health issues<br>Psychological difficulties<br>Insight / impact of illness<br>Ability to express feelings | | | |
| **Substance Use**<br>Current usage (if any)<br>Notable changes<br>Engagement with addiction services<br>Current / Future support needs | | | |

# End of Life Care – hostel checklist

## Professionals involved in care

| Name | D.O.B | Project |
|---|---|---|
| **GP details** | Next of Kin | Diagnosis/NHS number |

| Professionals involved in care (Name / role) | Contact details |
|---|---|
| | |
| | |
| | |

| To do | Comments / Action points |
|---|---|
| Obtain consent from the resident to discuss their care with others | |
| GP/healthcare professional involvement | |
| Communication with resident about what's happening (using mapping tool) | |
| Resident's capacity assessed (if in doubt) | |
| Case review meeting arranged | |
| Identify all professionals involved in resident's care | |
| Identify other professionals that may be required in future | |
| Conversation with resident about their wishes | |
| Place of care assessment considered by team (if in hostel) | |
| Preferred place of death discussed and considered by team | |
| Next of kin notified/Family reconnection discussed | |
| Important relationships identified **(using Eco map)** and other residents briefed (with client's consent) | |
| Action plan identified and regularly reviewed | |
| Emergency care plan developed | |
| Is resident entitled to additional benefits i.e. DS 1500 payment | |

# Mixed methods evaluation

- Pre training questionnaire
- Module specific feedback
- Immediately post training questionnaire
- Focus group
- 3 month follow up
  - Questionnaire & focus group

# “Please tell us a little about a client whose health you are concerned about…”

Kidney failure

won’t address physical health needs

mental health issues

Limited access to healthcare due to exclusions re behaviour

mid 30s

Lethargic

Liver disease

heroin and crack

persistent oral thrush

refusing care - self neglect

Double incontinence

*lack of understanding*

*HIV positive*

engages sporadically with services

Refusing GP interventions / to go to hospital

Confining self to bed

**Heavy alcohol use** – drinking a bottle of vodka a day

Low motivation to change lifestyle

alcoholic hepatitis

# Qualitative findings – post training

Keep everything in but spread it out more. It's a lot of information if you have never done it before. at the end of the day your brain is bursting actually.

*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.*

*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.*

- 2 days too long, but all info important
- Need more interactive learning opportunities
- Participants felt they came away with new knowledge
- Appreciated focus on hostel staff, self care section helpful
- Training was well attended – potential for system change

# 3 month follow up – qualitative findings

## Impact

- More discussion about end of life care within hostel
- Some conversation tools being used
- Memorials being used as a trigger for conversations
- A section has been added to the agenda of team meetings to discuss clients of concern
- GP planning to participate in multidisciplinary meetings at hostel

## Yet to be established

- Regular MDTs discussing clients of concern
- Relationships with hospices for advice and support
- Development of hostel policy around end of life care

## However

- Some hostel staff concerned their service would become a “hospice”, others felt more confident in supporting people with advanced ill health

# Lessons learnt from pilot

## Content & structure

- **Recognition of challenges** and roles of hostel staff was appreciated
- **Time commitment** needs to be addressed- some resistance to follow up evaluation
- Needs to be **embedded**, and not burdensome to have lasting impact

## Evaluation

- In pilot, more value from **qualitative** than quantitative data
- **Outcomes** relating to change in practice will be important when training rolled out

## Context

- High staff **turnover**
- **Managers** released staff but didn't attend the training
- This gave participants freedom, but potentially insufficient high level "buy-in" at 3 months
- More is needed for whole **system change**

# Training alone is not enough

For lasting change, training needs to be accompanied by

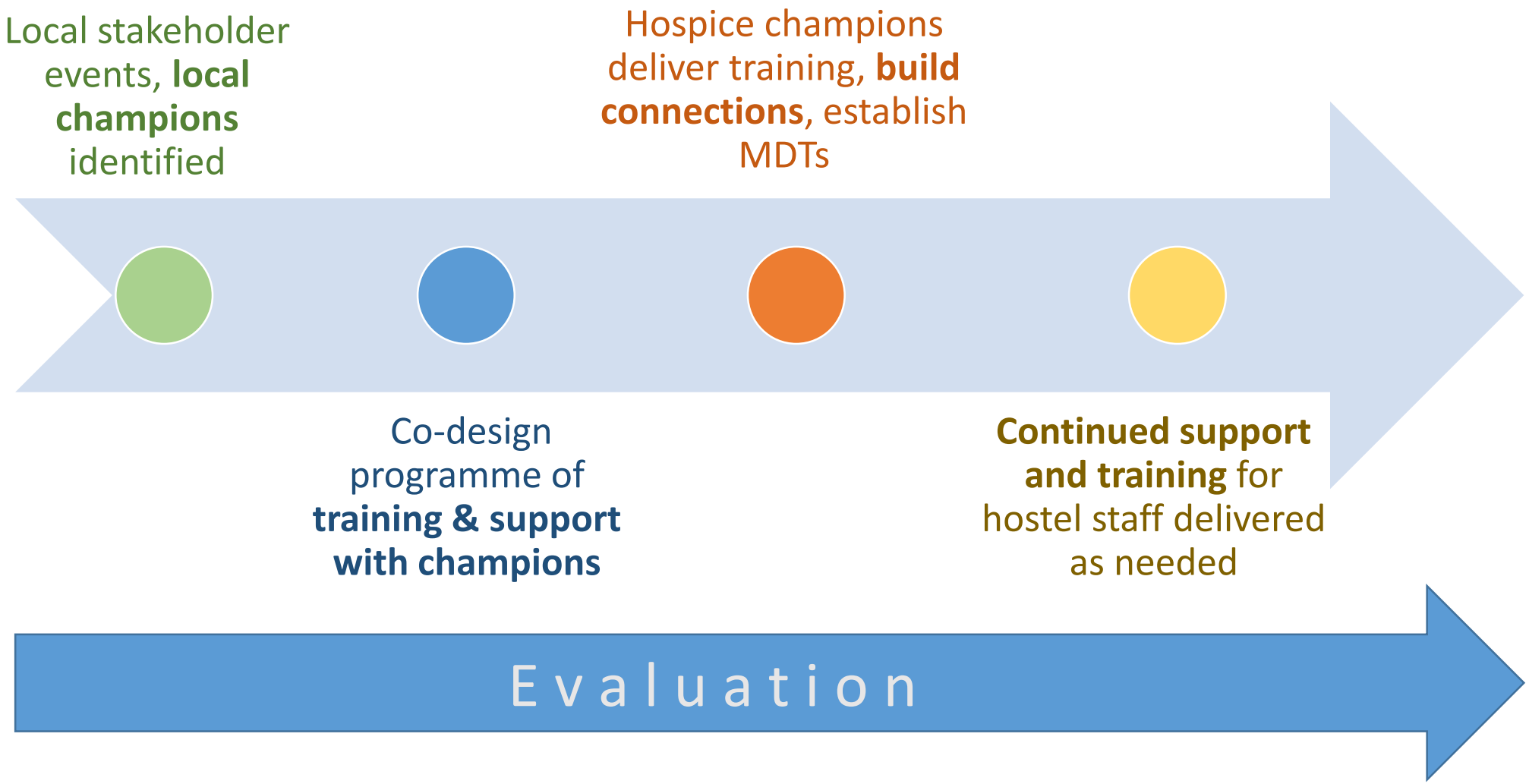
multi disciplinary, multi agency support

Training can help with understanding, approach and tools but may also need "**champions"** within teams to facilitate and sustain change by

- developing relationships
- connecting services
- coordinating client focused meetings and actions

….very few people know what our lives are like in the hostel. We need someone who could support us… I think it could only come from a hospice.
If we had somebody that stepped up to come and give us the benefit of their experience. Or even on the end of the phone and we could call them, and say "*so and so passed away this morning and its just so upsetting*" or *"I don't know what to do about this*". that would be fantastic.

# Next steps – embedding training & support in hostels



# In Summary: Palliative care for homeless people is everyone's job

- Need for greater **collaboration & shared understanding** between health, palliative care, drug & alcohol, social, housing & voluntary sectors to achieve support within hostels (Training / In-reach / MDT's)

- **Change of focus**: identify people with deteriorating health and support with palliative care while keeping options open

- Regular **multiagency meetings** to discuss clients of concern & provide person centered care

- **Increased in-reach** into homeless hostels and day centers.

- **Develop specialized services** for homeless people with high support needs

# *With thanks* to


**The Oak Foundation**

**Pathway:** Dr Caroline Shulman, Dr Nigel Hewett & Julian Daley

**St Mungo's**: Niamh Brophy & Peter Kennedy

**Marie Curie Palliative Care Research Department, UCL**: Dr Joseph Low, Sarah Davis, Dr Bella Vivat & Professor Patrick Stone

**Coordinate My Care**: Diana Howard

# Useful resources

- Reporting a rough sleeper:

http://www.streetlink.org.uk or **0300 500 0914 or download the app**

- Information including Borough specific info regarding homelessness services:

http://www.homeless.org.uk (search on “find homelessness services in England”)
http://www.homeless.org.uk/search-homelessness-services

- NHS Cards: https://www.healthylondon.org/wp-content/uploads/2018/01/Groundswell-RTHC-2017_PRINT-READY.pdf

- Faculty of Homeless and inclusion health: Join for free – publications, network, local meetings

http://www.pathway.org.uk/faculty/

- Shelter helpline

**0808 800 4444 Web: www.shelter.org.uk**

- Research and publications

http://www.crisis.org.uk

# Publications


- Hudson BF, Flemming K, Shulman C, Candy B. Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. *BMC Palliative Care*. 2016;15(1):96.
- Shulman C, Hudson BF, Low J, Hewett N, Daley J, Kennedy P, et al. End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care. *Palliative Medicine*. 2017;0(0):026921631771710 1.
- Hudson BF, Shulman C, Low J, Hewett N, Daley J, Kennedy P, et al. (2017) Challenges to discussing palliative care with people experiencing homelessness: a qualitative study. *BMJ Open* 2017;7:e017502. doi: 10.1136/bmjopen-2017-017502
- *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


- For full publication list from this project see: http://www.pathway.org.uk/services/end-life-care-homelessness/