

# End of life care for people who are homeless

## *Exploration of change through training and support*

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# Gemma

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

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



# Our research – challenges to palliative care access

## Complexity

Who?

When?

How?

Where?

## Uncertainty

- Disease trajectory
- Substance misuse
- Access to health care services

## Lack of options

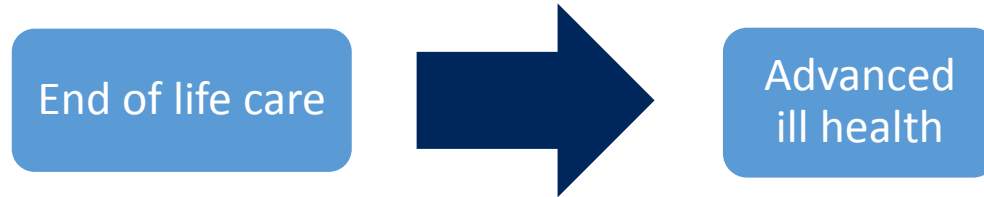
- Gaps in services for people with high care & support needs and addictions
- Many remain in hostels

## Barriers to planning

- Denial
- Lack of confidence
- Concern about fragility

# Our research – recommendations

## 1. A Shift in Focus:



## 2. Appropriate places of care :

*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

## 3. More support for hostels:

*In the meantime....*

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

# Developing training for hostel staff



[www.mungos.org/endoflifecare](http://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

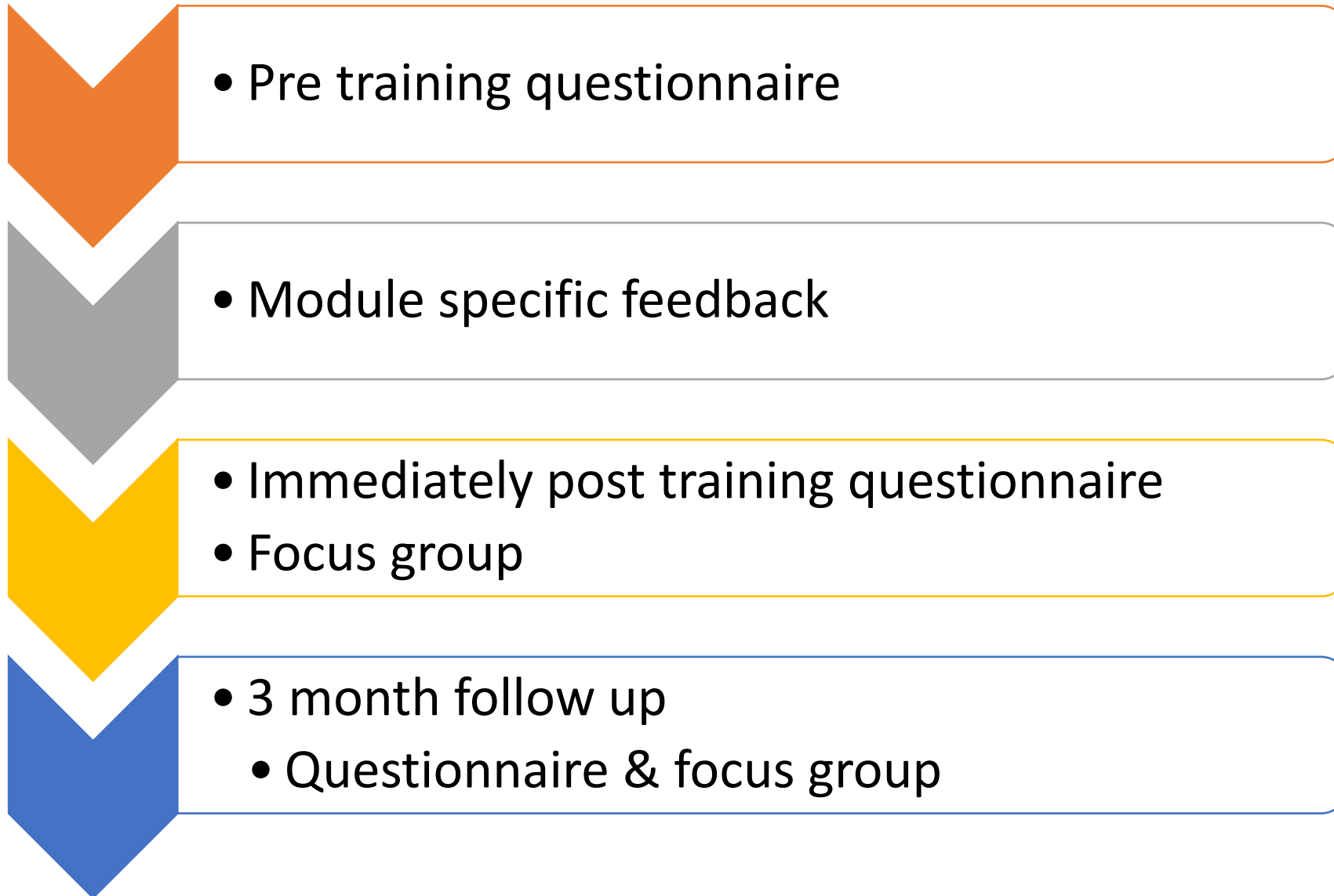
Engaging clients

Bereavement

End of life care



# Mixed methods evaluation



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

*Kidney failure*

*won't address physical health needs*

mental health

**Limited access to healthcare due to exclusions re behaviour**

mid 30s

issues

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.*



# 3 month follow up – qualitative findings

## Impact

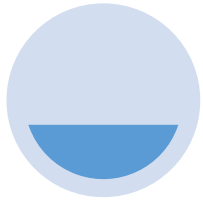
- More discussion about end of life care within hostel
- Some conversation tools being used
- Memorials being used as a trigger for conversations
- A letter of wishes added to the checking in process
- A section has been added to the agenda of team meetings to discuss clients of concern
- GP planning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

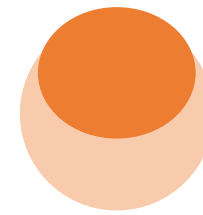
## However

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



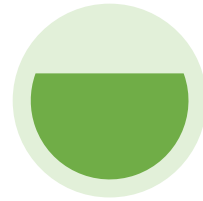
## Content & structure

- ❑ 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



## 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



## Evaluation

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

# Lessons learnt from pilot

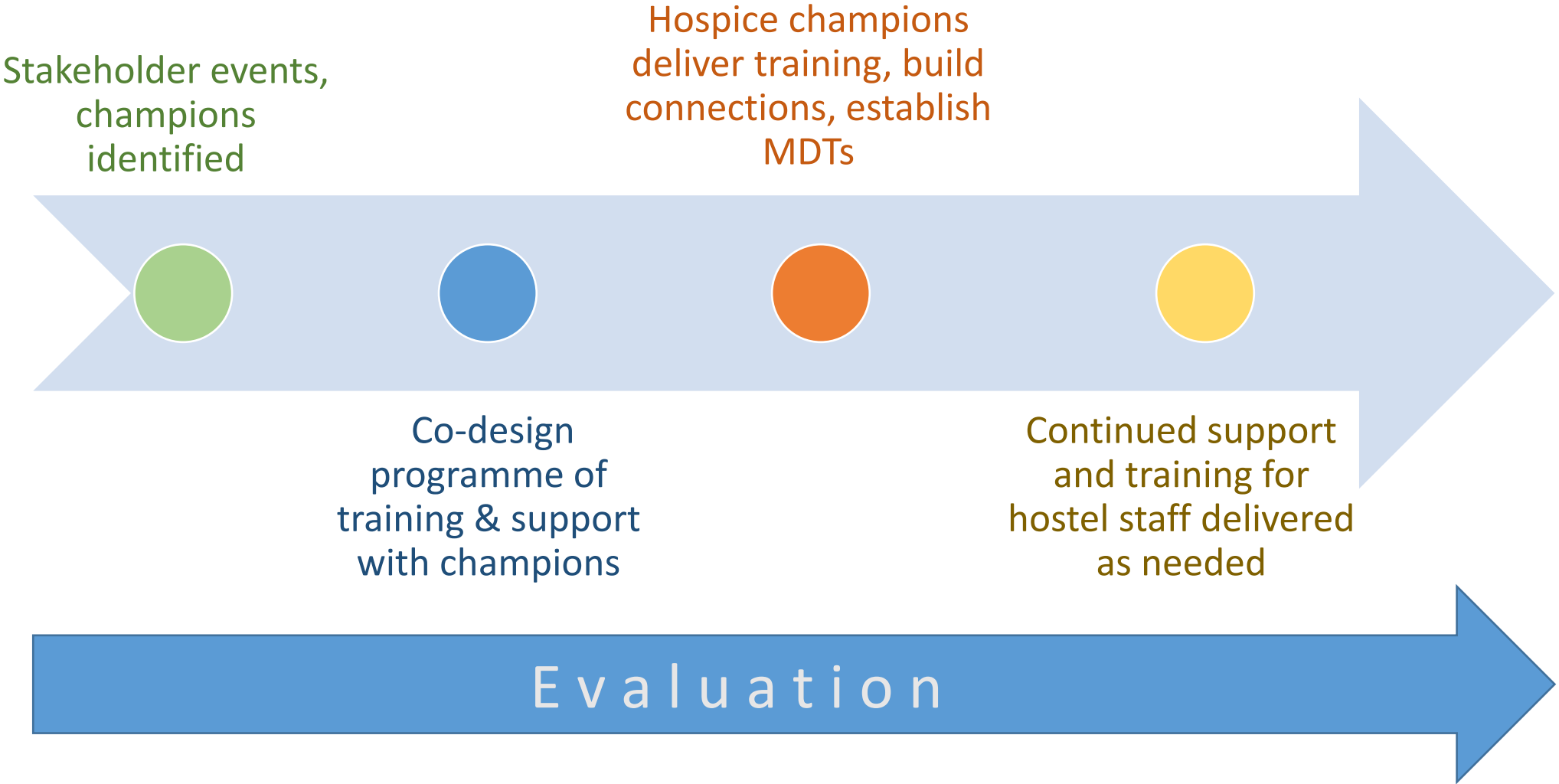
# Training alone is not enough

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

# Next steps – embedding training & support in hostels



# *With thanks to*

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# 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):0269216317717101.
- 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