Ministry of Housing, Communities & Local Government

St Mungo's
Ending homelessness
Rebuilding lives

hospice UK

Healthy London Partnership

NHS
London
Clinical Networks

London EOLC and Homelessness Event
19 October 2018

#EOLCLDN

Welcome

Ministry of Housing, Communities & Local Government

NHS London Clinical Networks

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Rebuilding lives

hospice UK

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Agenda

Time	Topic	Lead
12.30	Registration	
13.00	Welcome and introductions	Dr Caroline Stirling – Clinical Director, London End of Life Care Clinical Network
13.05	Personal view - The reality of EOLC for homeless Londoners	Martin Murphy – Project Manager, Homeless Health Peer Advocacy Service, Groundswell
13.15	System view – The reality of EOLC for homeless Londoners	Jane Cook – Health and Homelessness Adviser, Ministry of Housing, Communities and Local Government
13.30	What the evidence tell us about EOLC for homeless people	Dr Caroline Shulman – GP in Homeless and Inclusion Health, Kings Health Partnership, Pathway Homeless Team and Honorary Senior Lecturer, UCL
14.15	St Mungo's: Sharing best practice and taking a multiagency approach	Niamh Brophy – Palliative Care Coordinator, St Mungo's
14.45	Trinity Hospice - Improving access to EOLC for homeless people	Dr Barbara Sheehy-Skeffington – Consultant in Palliative Medicine, Royal Trinity Hospice
15.15	Introduction to a resource on emerging practice – Hospice UK	Melanie Hodson – Information Specialist, Hospice UK
15.30	Tea break	
15.50	Table discussions to think about local initiatives and next steps	
16.30	Table Feedback and final remarks	Dr Caroline Stirling – Clinical Director, London End of Life Care Clinical Network
17.00	Close	

Personal view - The reality of EOLC for homeless Londoners

Martin Murphy – Project Manager, Homeless Health Peer Advocacy Service, Groundswell

Twitter: @itsGroundswell

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Groundswell

Out of homelessness

Who are Groundswell?

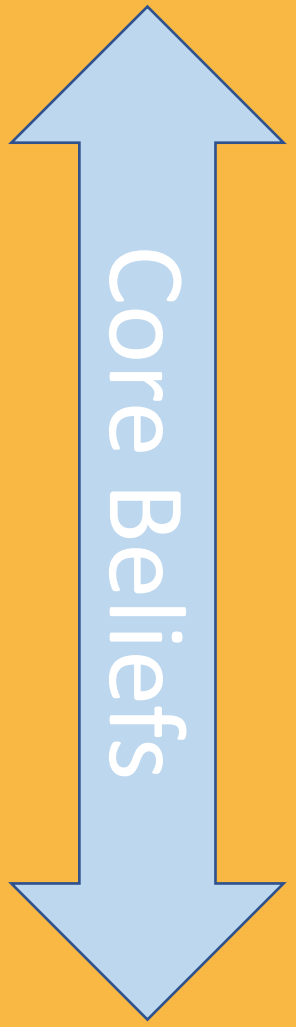
We enable homeless and vulnerable people to take more control of their lives, have a greater influence on services and play a fuller role in the community.

Speaking up & speaking out about homelessness

- Homeless Health Peer Advocacy
- Peer Research & Peer Journalism
- Service User Participation
- Information for Self-Advocacy

Groundswell's Journey

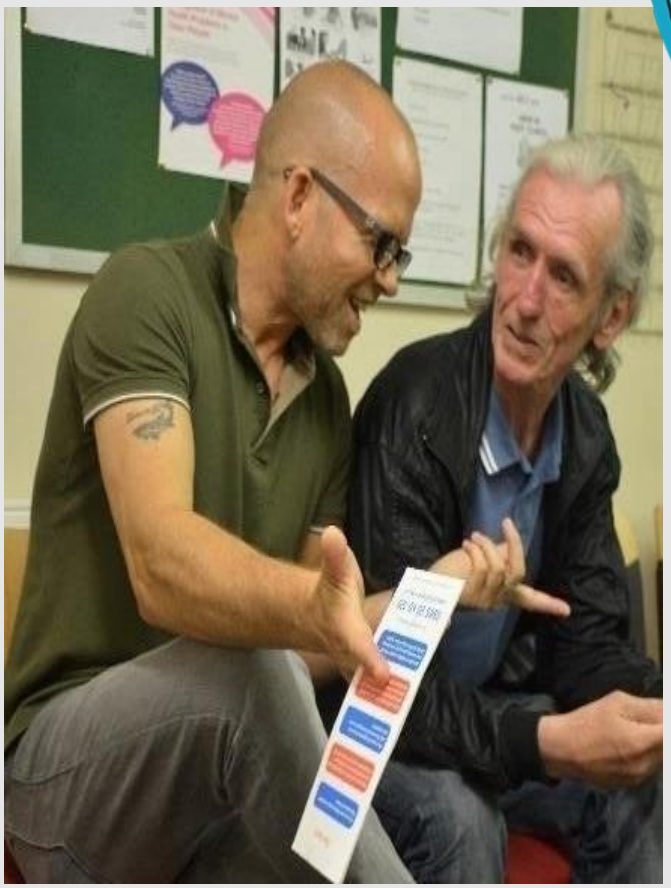
1. **Era 1: Campaigning**
2. **Era 2: Peer Research & 'Client Involvement'**
3. **Era 3: Health Advocacy**
4. **Era 3.1: HHPA National, Insight & Action**



One-to-One Support

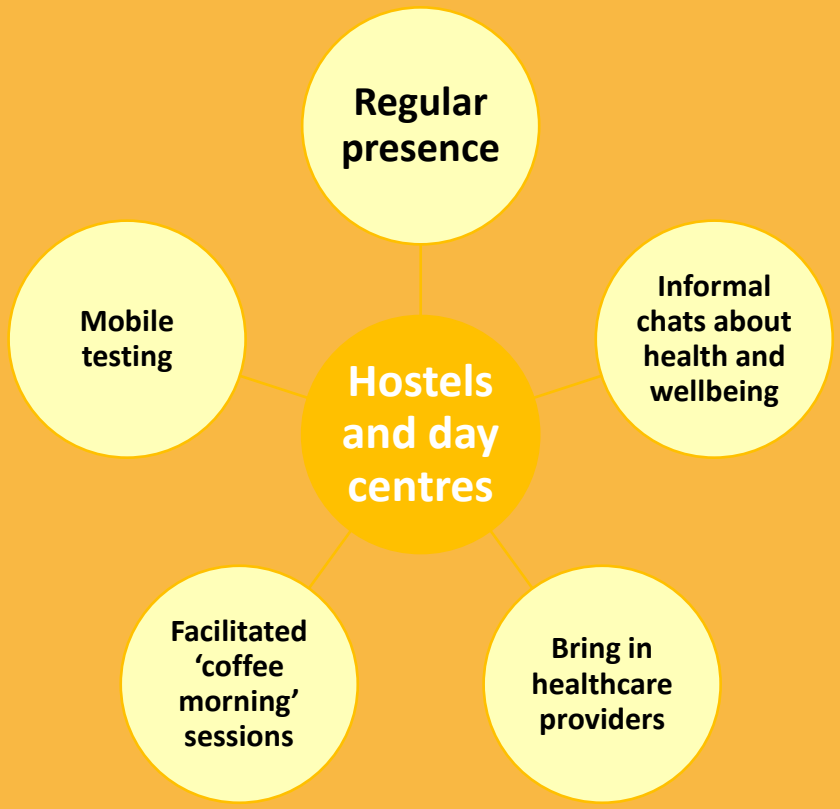
Peer Advocates will help you get your health problems sorted by:

1. Helping you make health appointments
2. Going with you to health appointments
3. Paying for your travel fares if needed
4. Staying in touch with you while you sort things out
5. Supporting you to have your say about the type of health care you get
6. Supporting you before, during and after appointments to understand your options



"As a Peer you can share your experience and show there is a solution, then clients can find their own confidence and begin advocating for themselves."

Health In-Reach

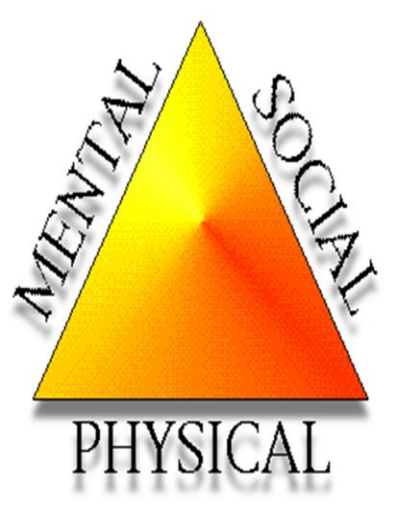


"We create a safe non-judgemental environment where people feel safe to discuss anything that is on their mind."

What is Good Health?

Health is achieved through a combination of:

- **Physical well-being**
- **Mental well-being**
- **Social well-being**



"a state of complete physical, mental, and social well-being… not merely the absence of disease or infirmity“
World Health Organization (WHO) 1948

"Social status and respect matter beyond anything, and the psychological damage done by being at the bottom is crippling"
Richard G Wilkinson: The Spirit Level

Quotes and Questions

John Driscoll
Groundswell Project Worker and Advocate

A Thought

Reading previous material on the subject we seem to know how to improve EOLC for people experiencing homelessness so is it simply a lack of money/time/resources?

Case Study

Quote

“It was a privilege to be with Peter, to see what he had to go through and I was with him until the end.”

Question

Can working with people at the end of their life be rewarding?

Case Study

Quote

“Luckily he had a good manager at the hostel and me to fight for what he wanted.”

Question

How important is it to have the right staff with the right skills?

Case Study

Quote

“The hospital staff and nurses were really helpful. That’s not always the way, sometimes staff look at you and see that you are going through addiction and you’re your own worst enemy and think why should I care for you, why should I bother. If there are ten people in the ward and one of them had caused a lot of the issues by himself, who should I help first?”

Question

Is there a bias here that needs to be tackled and if so how do we tackle it? This person is dying but it's their own fault?

Case Study

Quote

“On his last trip to the hospital it was to accident and emergency and the nurses explained to him that he only had around five days to live and all he wanted to do was go back to the hostel and be with people that he knew. It was nice to see that he got his wish, even though the Macmillan nurses had to come to him in the hostel”

Question

How important is choice and how do we ensure everyone has choice at end of life?

Case Study

Quote

“They don’t want to die knowing that they’ve got no one around they know, you want to die knowing you have people you know there. That’s the memory you will pass with. He was able to be with the people that he wanted to be with and that was fine”

Question

How can we help people find peace at the end of their life?

Case Study

Quote

“I know that sometimes hostels don’t want to deal with cancer, things are a downward spiral and staff are affected by that and they see the residents get affected by that too. Because obviously someone close to them is dying. But Peter, If you put him in a hospice he would not have been happy he would have died miserable.“

Question

Do hostel staff get an appropriate level of support?

Quotes and Questions

Dennis Rogers
Groundswell Case Worker and Advocate

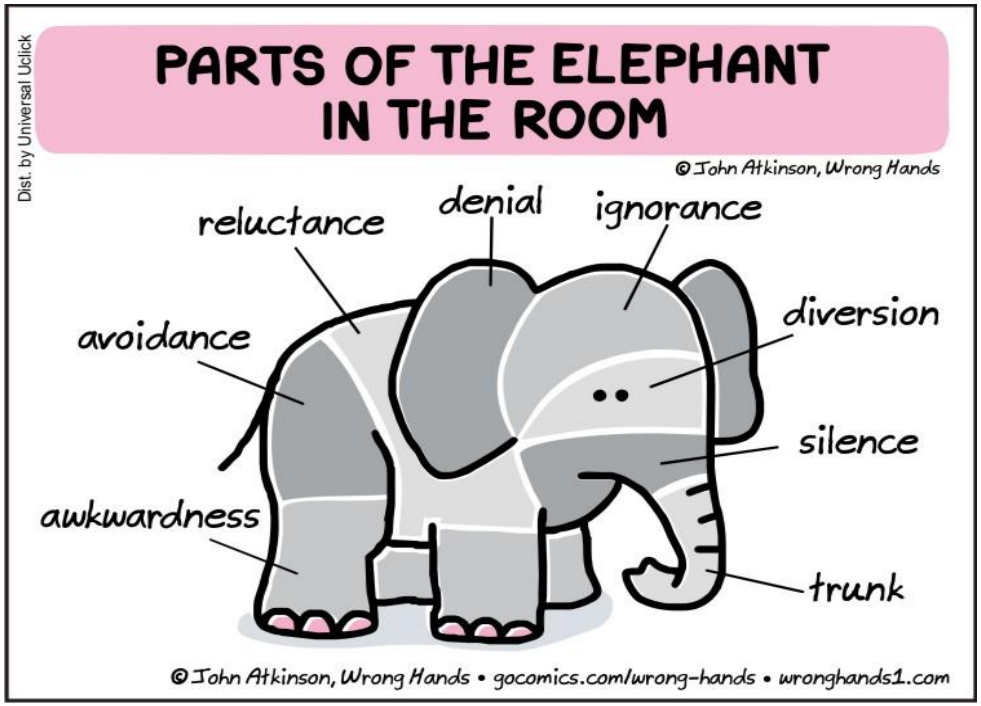
Case Study

Quote

“My last appointment with her was to go to UCH hospital for her cancer treatment. They’d agreed for her to have the procedure but they wanted her in at 8 o’clock in the morning. I had to persuade them to keep her in from the night before, because she’s a chronic alcoholic and there’s no guarantee that I could get her there for 8 in the morning without her having a drink. She’d be too stressed. So I persuaded them to admit her Sunday so that she could have the procedure Monday morning. That took a lot of work because the nurse said “do you expect us to admit every alcoholic the night before”. I asked her to look into her records about her mental health and other issues which were going on and she eventually agreed to admit her.”

Question

Another question of bias? How important is the role of the advocate/companion/family member/befriender? Can everyone have someone?



People With No Recourse to Public Funds

Things to think about

- Record and monitor DNA rates 37/41
- Investigate reason for and patterns in high DNA rates - Notes
- Improved communication between health and homelessness professionals
- More nurses in hostels
- Multi disciplinary EOLC working group
- Raise awareness and campaign for specialist hospice
- Communication around deaths in hostels
- Better Endings – Ripples

Better Endings – Ripples

Better Endings aims to radically improve people's experiences at end of life. Through 2017 we have been working with a diverse group of people in Southwark and Lambeth to develop new approaches. Led by Innovation Unit and supported by Guy's and St Thomas' Charity, Better Endings has created a much-needed space for clinical and care professionals, individuals and families, voluntary and community organisations, private businesses to work creatively together.
https://www.innovationunit.org/projects/better-endings/

www.groundswell.org.uk

System view – The reality of EOLC for homeless Londoners

Jane Cook – Health and Homelessness Adviser, Ministry of Housing, Communities and Local Government

Twitter: @janeyecook

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Jane Cook

Health and Homelessness Adviser
Rough Sleepers Initiative

Ministry of Housing, Communities & Local Government

Ambition and wider context

Rough sleeping strategy:

Halve rough sleeping by 2022

End rough sleeping by 2027

Homelessness Reduction Act 2017

Prevention of homelessness

Develop wider homelessness strategy

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Rough sleeping – the London picture

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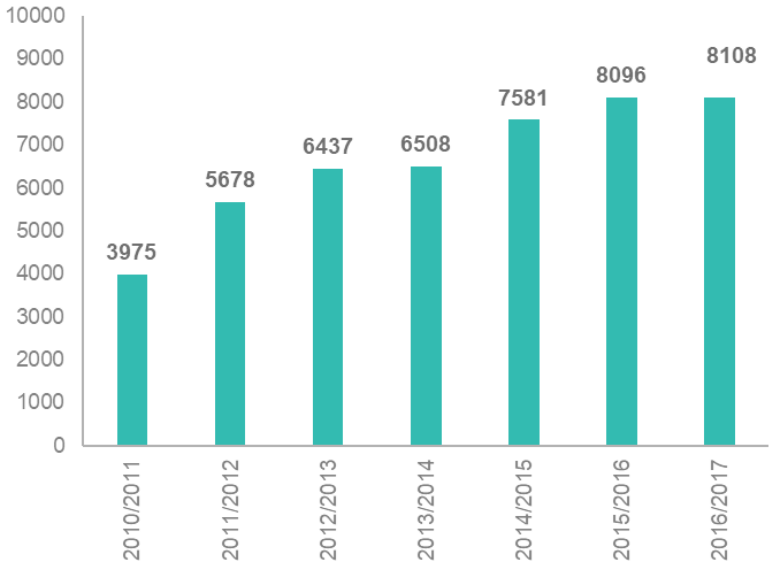
Numbers of rough sleepers - London

This graph shows the number of people seen sleeping rough by outreach teams in London each year, recorded on the Combined Homelessness and Information Network (CHAIN)

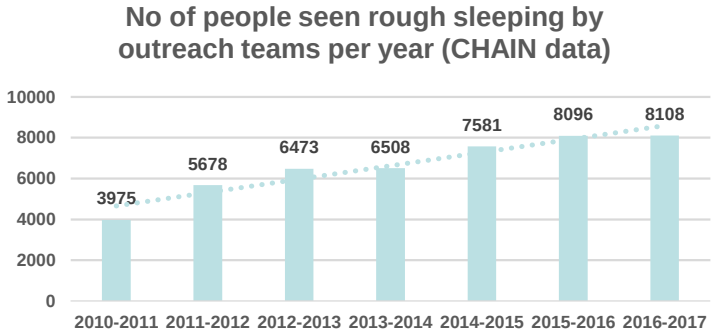


The number of people seen sleeping rough on the streets of London had more than **doubled** between 2010/11 and 2016/17

Homelessness is increasing

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

Unknown numbers

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Impact on health

- High levels of mortality and morbidity among people who are homeless
- Mortality rates are eight to twelve-fold higher than the general population
- Average age of death is 47 years for men and 43 for females who are homeless compared to 77 years for the general population

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Homelessness Reduction Act (April 2017)

If Homeless or threatened with homelessness and eligible:

Local authority legally obliged to assess and provide meaningful assistance to prevent or alleviate homelessness

Relief duty lasts for 56 days

Duty to refer by hospitals (October 2018)

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Hospices in London

In London there are:

- 22 hospices in London (4 are for children)
- 49 palliative care leads

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Model of care

‘How we care for the dying is an indicator of how we care for all sick and vulnerable’

National End of Life Strategy 2008

Equity and choice are key for those who are homeless and are dying.

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7. Contacts

Jane Cook jane.cook@communities.gsi.gov.uk
T. 07766 516371

What the evidence tell us about EOLC for homeless people

Dr Caroline Shulman – GP in Homeless and Inclusion Health, Kings Health Partnership, Pathway Homeless Team and Honorary Senior Lecturer, UCL

Twitter: @carolineshulman

#EOLCLDN

London Clinical network2018

What the evidence tells us about end of life care for homeless people?

Dr Caroline Shulman

Caroline.Shulman1@nhs.net
@carolineshulman; @PathwayUK

Understanding the complexity of need of people experiencing homelessness

Homelessness background

- Definition
- Causes
- Health impact

Palliative care research

- Complexities and Gaps in provision
- Recommendations

Moving forward:

- Support people experiencing homelessness who have advanced ill health

Who is homeless?

People staying in hostels

People living in squats

People who are insecurely housed

People who are sofa surfing

Rough sleepers

What do we mean by "homelessness"

People in temporary accommodation

Underlying causes of homelessness

Many routes to homelessness – Structural and Individual

Adverse childhood events / complex trauma
A child's exposure to multiple traumatic events have wide ranging and long term implications for how they think, feel and behave

Impact on adults

- Low self esteem
- Feeling unsafe
- Self-harm
- Substance misuse
- Impulsive behaviour
- Anti-social or aggressive behaviour
- Chaotic lifestyle
- Increased risk of additional mental health issues & suicide
- hypersensitive & hypervigilant behaviour

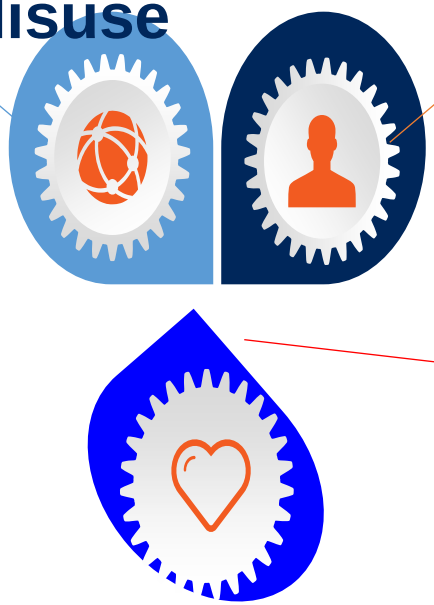
Herman, D. B., Susser, E. S., Struening, E. L., & Link, B. L.,1997: Adverse childhood experiences: Are they risk factors for adult homelessness? American Journal of Public Health, 87(2), 249-255.

Maguire, N.J., et al. 2009: Homelessness and complex trauma: a review of the literature. Southampton, UK, University of Southampton, accessed at: http://eprints.soton.ac.uk/69749/

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

St Mungos (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)

Complex needs & access to healthcare:
inverse care law

- **Barriers to accessing primary care**
- GP registration
- Chaotic behaviour
- Health not seen as a priority
- Fear / distrust
- Inflexibility / appointment system

Welcoming or alien?

- **Real or perceived**
- Discriminated against / stigmatised
- Not treated with respect
- Not listened to
- Unwelcome

Complex needs & access to healthcare

- **Results in**

- Seeking treatment only when problems reach advanced stage
- High A&E attendance
- High rate of self discharge from hospital
- Unsafe discharge destination

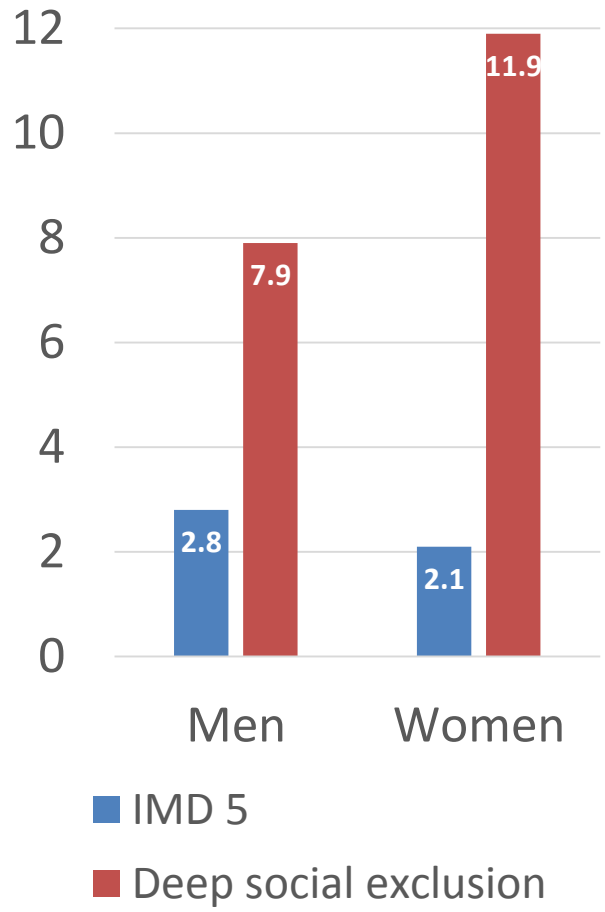
Revolving Door

Homeless people die young

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

47 for men 90%

43 for women 10%

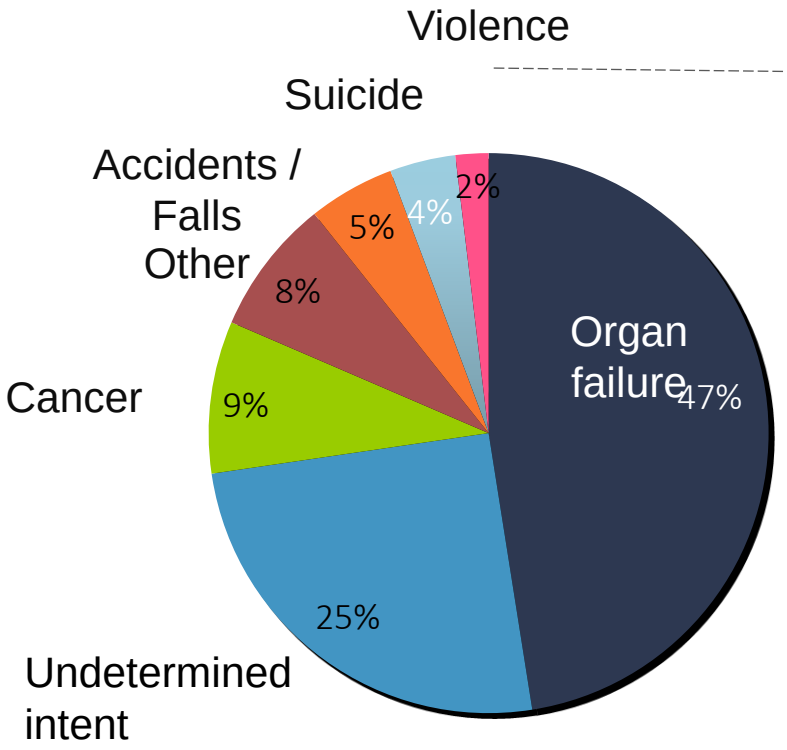


Thomas B. Homelessness Kills: An analysis of the mortality of homeless people in early twenty-first century England. London Crisis; 2012.

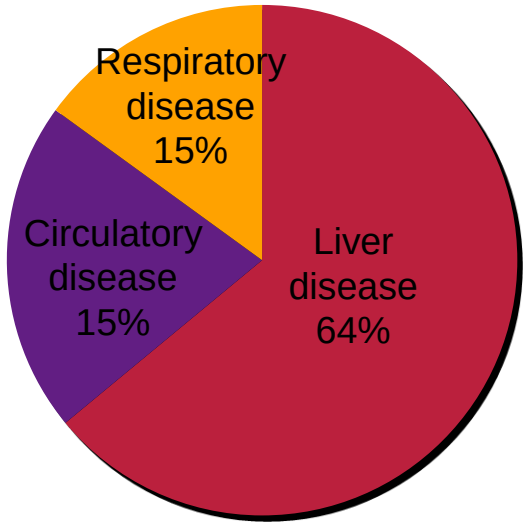
Morbidity and mortality in homeless individuals, prisoners, sex workers, and individuals with substance use disorders in high-income countries: systematic review and meta-analysis. R Aldridge, A Story, S Hwang et al, The Lancet Nov 2017

Causes of death
data from St Mungo's

Primary cause of death



Multiple organ failure



Dying as a homeless person

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

How do we improve palliative care for homeless people

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

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?

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

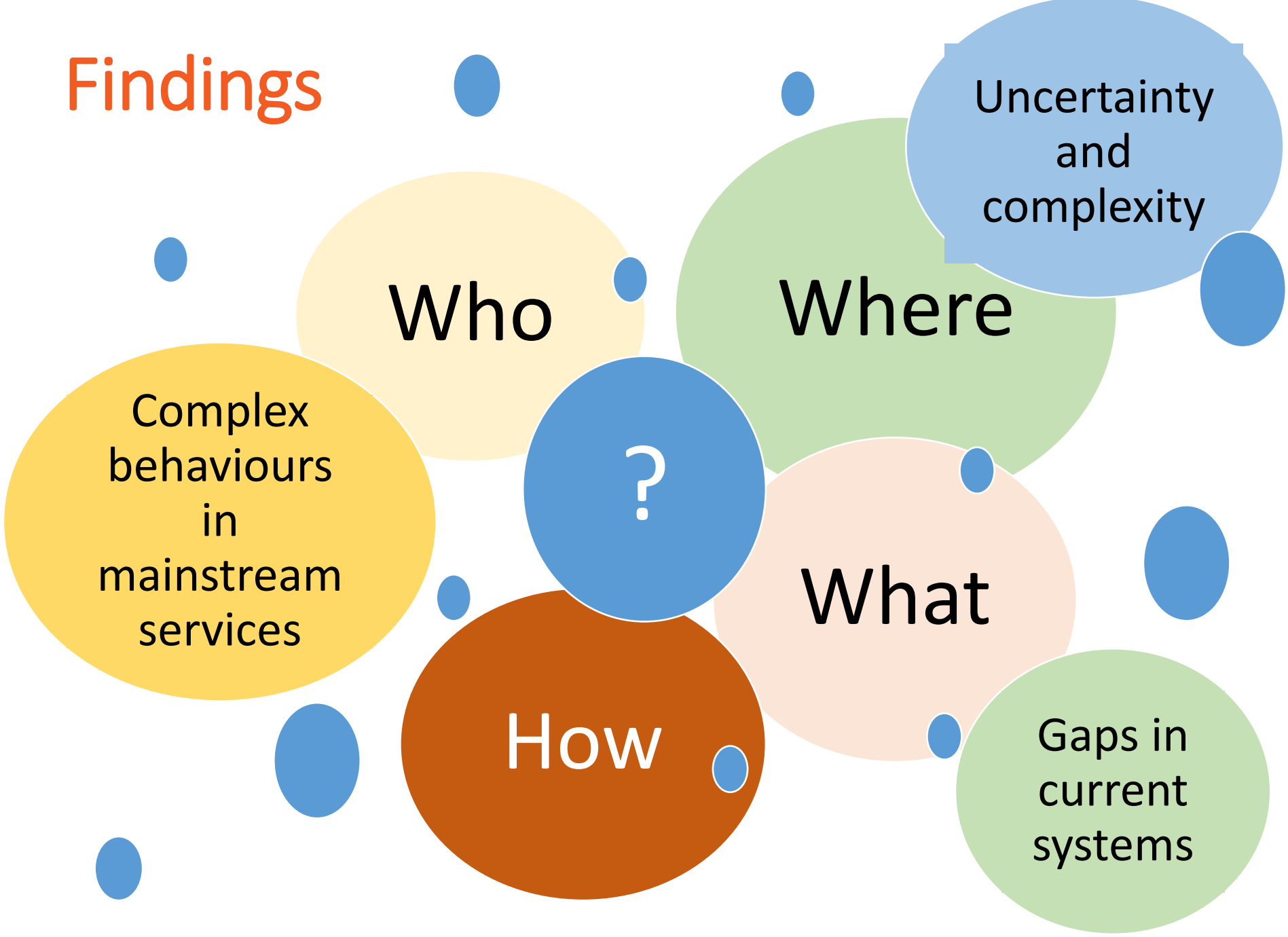
Shulman C, Hudson B F, Low J, Hewett N et al (2018) End-of-life care for homeless people: a qualitative analysis exploring the challenges to access and provision of palliative care. Palliative Medicine 32(1): 36-45 https://doi.org/10.1177/0269216317717101

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

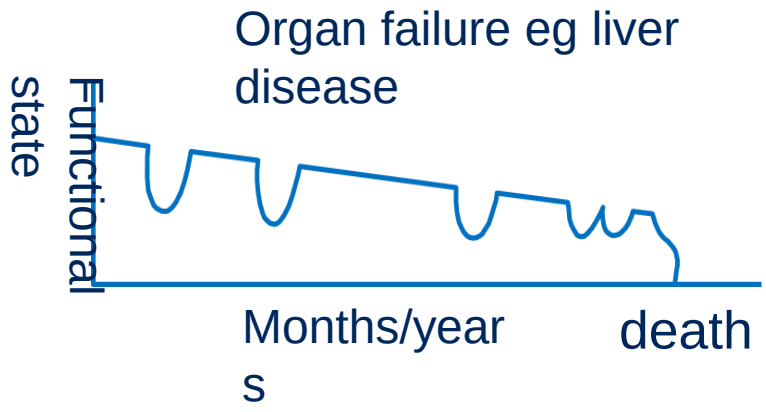

Uncertainty and complexity
Who
Where
Complex behaviours in mainstream services
?
What
How
Gaps in current systems

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



"I think everyone knew she was very, very sick. But… I sort of have an informal list of people…a **"this isn't good list".** But actually, then a third of them probably move up to my "**this is really bad" list**. But….how do you know out of those….?"

In-reach nurse

Some of these patients, I'd fast track them every time they come in. But the reality is that they go on and pick up again. And obviously you can only do that so many times…

Hospital palliative care specialist

Where is Palliative Care being delivered?

Lack of options

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

What hostels do and don’t provide

Hostels provide:

- Usually shared facilities
- Key work support
- Support to attend appointments
- Meals sometimes
- Concierge access out of hours in some of the ‘high’ support hostels

Hostels don't provide:

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

Challenges for hostels as a place of care

"…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**

"…it was really hard to get that [social services] support. It was really really hard, and to begin with they only wanted to give us two hours a week" ***Hostel worker***

Lack of options for place 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"

"…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**

When I was in hostels …I felt very lonely, I needed more, support… more people to listen to me. And I know.. it's hard, whoever's working with you has to put up with a lot, but… maybe they're short-staffed, or… they're stretched, but…many times I felt... Isolated and lonely - **Expert by experience**

Challenges for hostels as a place of care

- Hostels are designed to provide temporary accommodation
- Hostels have been left to support people with increasing complexity at a young age, with limited resources
- Difficulty accessing social services & adequate medical support including palliative care
- Practical difficulties (methadone pick up / storage of medication)

But 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….

"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 worker

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

Challenges for conversations around deteriorating health and future wishes

A lot of people are frightened to think about it. Most people won't talk about it, they won't entertain talking about it. They see it as so far away, you know? Why bother now, let's wait until it's a bit nearer the time **– Hostel resident**

"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

Case study: Paul (age 52)

- Liver disease and severe COPD
- Heavy drinker
- Frequent hospital admissions from Temporary Accommodation (TA)
- Unable to cope in TA
- Admitted to hospital very ill and frail
- Said he wanted to be looked after
- Improved while in hospital
- While an inpatient social services deemed him not to have any care and support needs
- Cycle recurring
- Finally moved from TA into a hostel
- Died in his hostel within a week following being discharged from hospital

Case study: John (age 48)

- Had been in semi-independent living
- Long history of homelessness and addiction - On methadone
- Late presentation – lung cancer with bony metastases
- Vulnerable to exploitation – financial and opiates
- Needed more support that could be offered in his accommodation
- Not accepted for sheltered accommodation due to heroin use.
- Deemed to have needs too high for a hostel -nowhere to store opiates
- His wishes were that he wanted to reconnect with daughter and to die in a place he could call home, with support.
- Admitted to hospice while awaiting an appropriate place of care.

Overcoming the challenges

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1. A shift in focus

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 we 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

3. In-reach into hostels and day centres

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
- Training
- Bereavement support

Examples of Projects from around the country and globe

- St Lukes Plymouth: Train people working with homeless people to be End of life ambassadors
- St Lukes, Basildon: link with hospital liver team to work with people with advanced liver disease
- St Lukes, Chester: homeless lead and counsellors support homeless people in hostels and in the hospice
- Bradford respite and intermediate care support services for homeless people
- Ottowa: Diane Morrison hospice – within a hostel
- Toronto: Palliative Education And Care for the Homeless PEACH) mobile end of life care

*4. In an ideal world there should be **choices** including:*

- A home – (not just temporary accommodation) ..

- A hostel based hospice:

A facility that

Understands the needs of people who are homeless

Acts as a step up from hostel or the street

Acts as a step down from hospital

Could provide adequate 24 hour support

Offers respite AND/OR an acceptable, comfortable place to live until the end of their life

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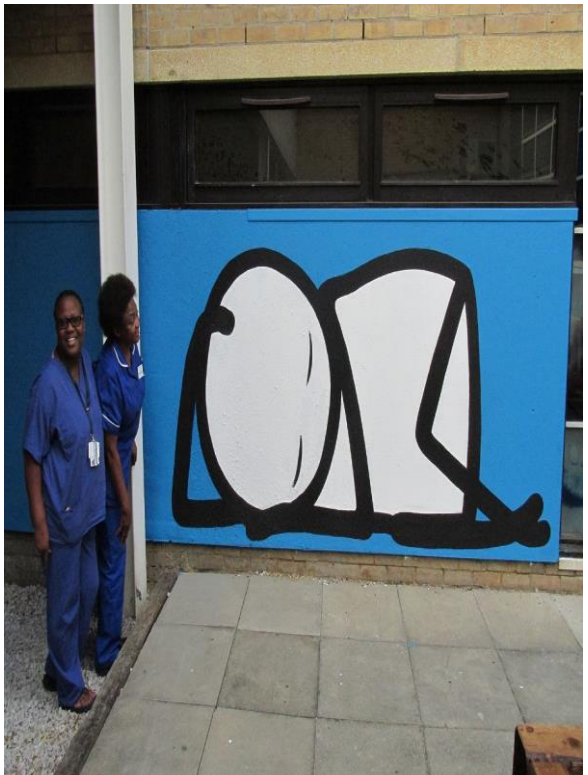
..In the Meantime

Due to lack of alternatives, hostels may be best placed to provide support and care at end of life – **but need additional multidisciplinary support**



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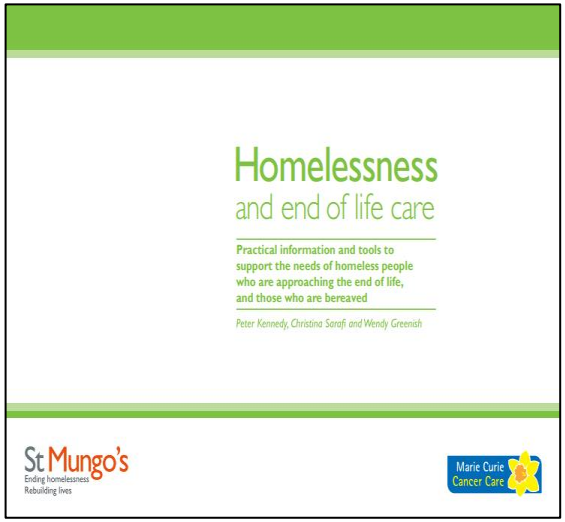
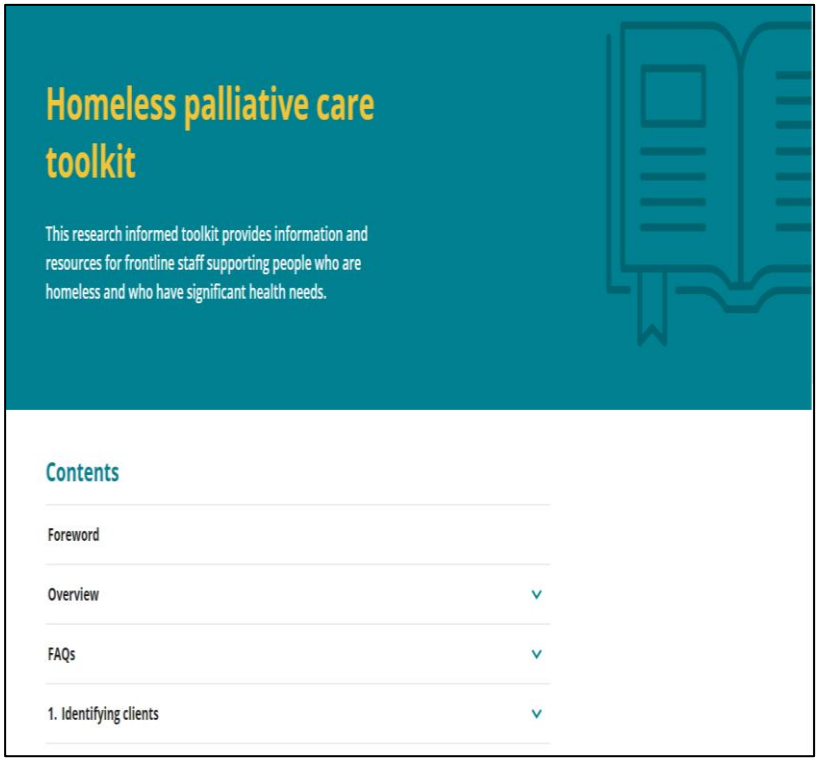
New Online toolkit – launched today!

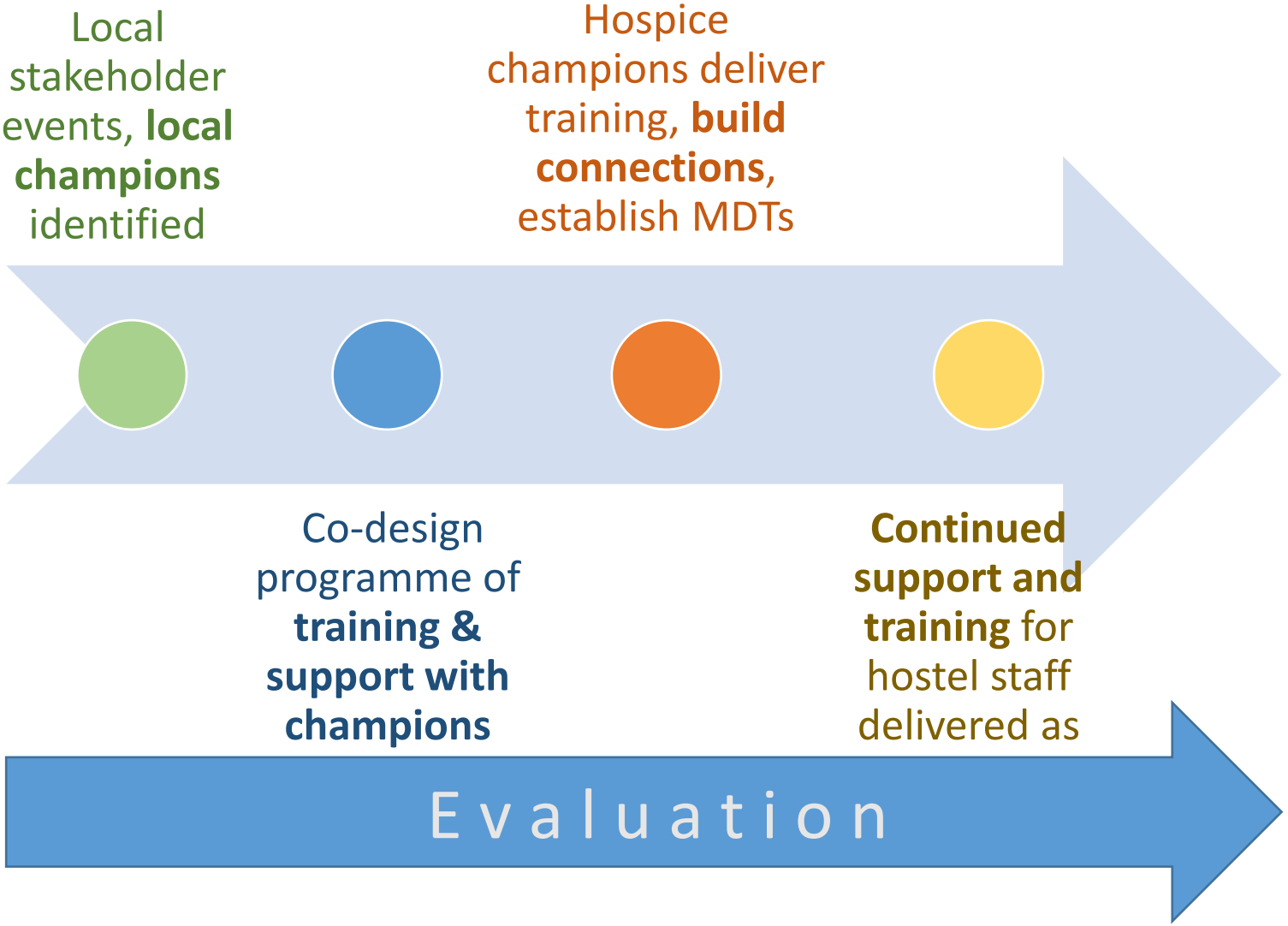


www.mungos.org/endoflifecare



www.homelesspalliativecare.com

Next steps – embedding training & support in hostels



In Summary: Working together to improve palliative care

- 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.
- **Training of staff** from both palliative care and homelessness sector: **homelesspalliativecare.com**
- **Develop specialized services** for homeless people with high support needs

With thanks to

The Oak Foundation

Pathway: Dr Briony Hudson, Dr Nigel Hewett & Julian Daley

St Mungo's: Niamh Brophy & Peter Kennedy

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

Coordinate My Care: Diana Howard

Publications

Faculty of Homeless and inclusion health: Join for free – publications, network, local meetings
http://www.pathway.org.uk/faculty/

- 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
- Shulman, C., Hudson, B.F, Brophy, N., Kennedy, N., & Stone, P (2018). *Evaluation of training on palliative care for staff working within a homeless. Nurse Education Today. Available online from October 2nd 2018*
- *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
- Homelesspalliativecare.com website

St Mungo's: Sharing best practice and taking a multiagency approach

Niamh Brophy – Palliative Care Coordinator, St Mungo's

Twitter: @NiamhBrophyLDN, @StMungos

#EOLCLDN

St Mungo's
Ending homelessness
Rebuilding lives

Sharing best practice and taking a multiagency approach

Niamh Brophy
Niamh.Brophy@mungos.org
@NiamhBrophyLDN

Home

“A home provides roots, identity, a sense of belonging and a place of emotional well-being. Homelessness is about the loss of all these things”

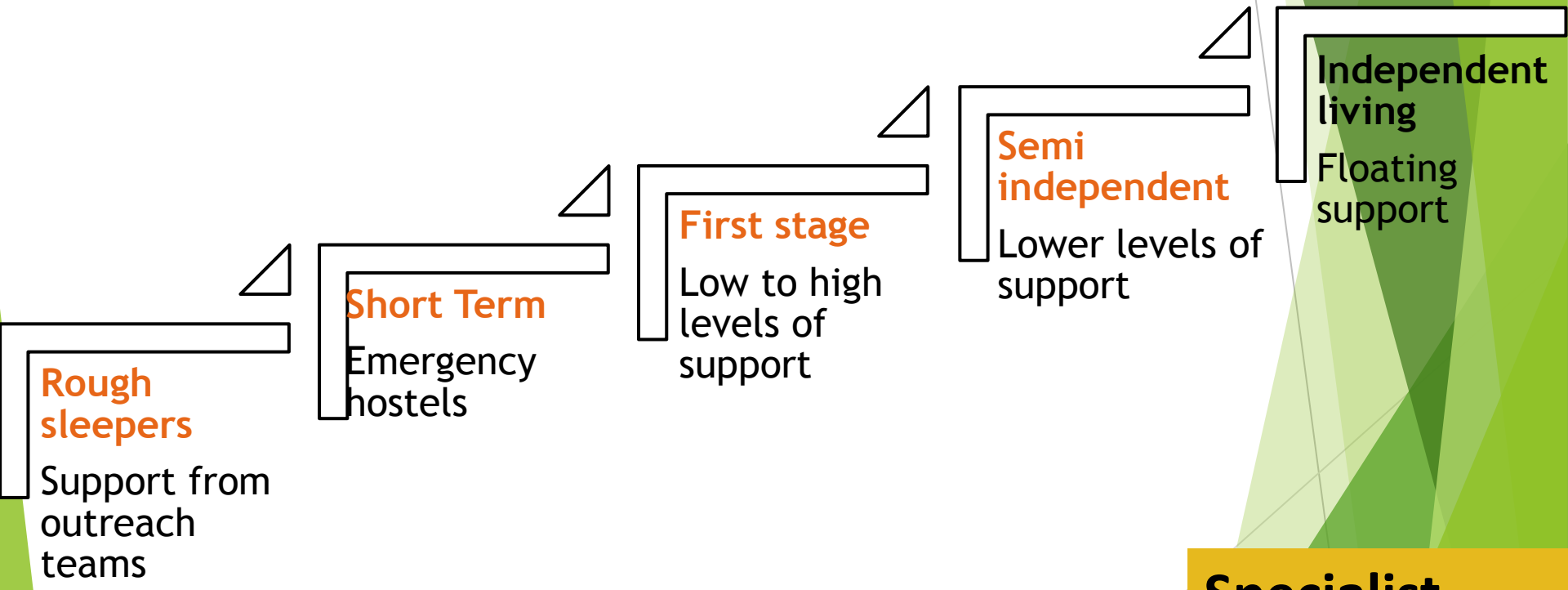
Crisis (2010)

Isolation and loss of support networks

- Many had few and limited contact with family members
- 28% consider themselves to have no close friends
- More than half spent most of their time alone (with only 25% finding this unacceptable)

Bonner & Luscombe, 2008. The seeds of exclusion. (N=438)

Homelessness landscape: The Recovery pathway



Specialist schemes

Care homes, specific support

Challenges for recovery pathway and traditional models of care

AGE: Care home / shelter accommodation often have age criteria :

- Many homeless people are “young olds” – evidence of accelerated aging with conditions usually experienced by people who are much older
- Cognitive impairment at a young age – from head injuries and sustained alcohol abuse

MENTAL HEALTH DIFFICULTIES, COMPLEX BEHAVIOUR AND SUBSTANCE MISUSE:

- Often deemed inappropriate for care homes, sheltered accommodation or hospice

Results in difficulty accommodating choice

St Mungo's
Palliative Care Coordinator Role

Case management

Education and training

Befriending volunteer service

Co-Ordinate a **flexible and responsive care pathway** for clients with a terminal prognosis or acute/fatal health conditions

Advocate for clients entitlements, challenging inequalities and exclusions

Increase **knowledge and confidence** of hostel staff supporting end of life client

Build **trusting relationships** in order to identify wishes

Case Studies

Challenges and solutions

JOHN, 43

- Long history of homelessness and addiction
- No family; only Dog who is closest companion
- Late presentation: terminal cancer
- Discharged from hospital to the street
  - No address for medical care, no community assessment completed, no methadone script arranged

•Presented to council as homeless; Placed in inappropriate temporary accommodation without his dog

•Hostels refused referral because he was not for ‘recovery’

• One wish to be reunited with his dog, intended to return to the streets to achieve this

Outcome for John

Source his own script

Waited weeks for OT assessment

Commissioners reviewed referral criteria for hostel

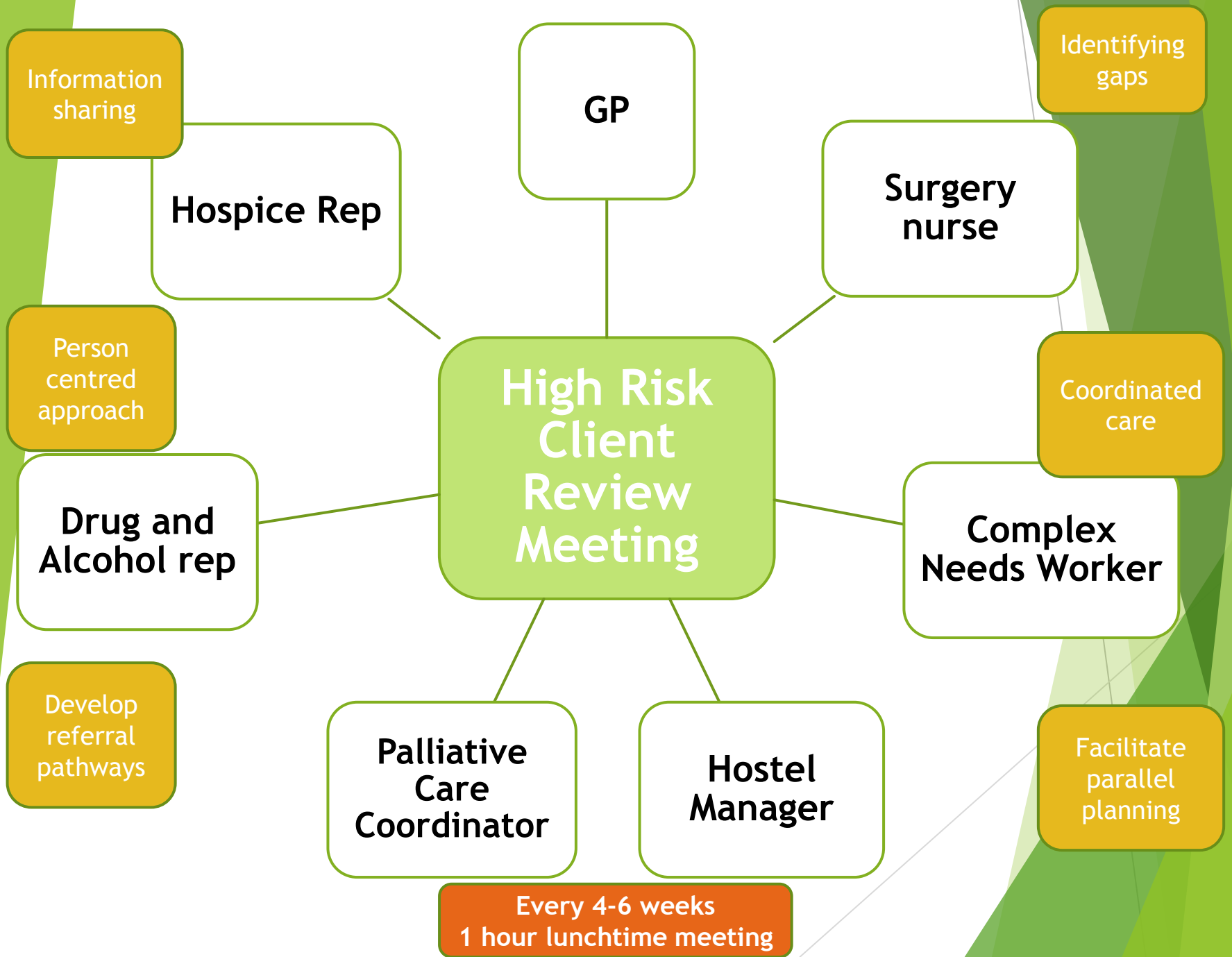
Placed in hostel and reunited with dog

Regular multiagency meetings

Staff feel supported and more confident in situation

"Commissioning needs to be flexible and think about the outcomes we want to achieve but sometimes we also need to remind ourselves that individuals lie at the heart of our decisions and when we can we should be flexible and work with providers and the wider system to make sure the individual in the last few weeks and days of their lives have their wishes met and are treated with dignity, compassion and respect, whatever background they come from"

Commissioning Manager


Information sharing
Hospice Rep
GP
Identifying gaps
Surgery nurse
Person centred approach
High Risk Client Review Meeting
Coordinated care
Drug and Alcohol rep
Complex Needs Worker
Develop referral pathways
Palliative Care Coordinator
Hostel Manager
Facilitate parallel planning
Every 4-6 weeks
1 hour lunchtime meeting

Scott, 47

Scott, 47

- Grew up in an abusive family home
- Placed in care at age 12 where he was also abused
- Left care at 18 and became street homeless
- Began drinking — developed pancreatitis before aged 20
- Dependant on drugs by aged 22
- In and out of hostels and sleeping rough for the next 25 years

Scott

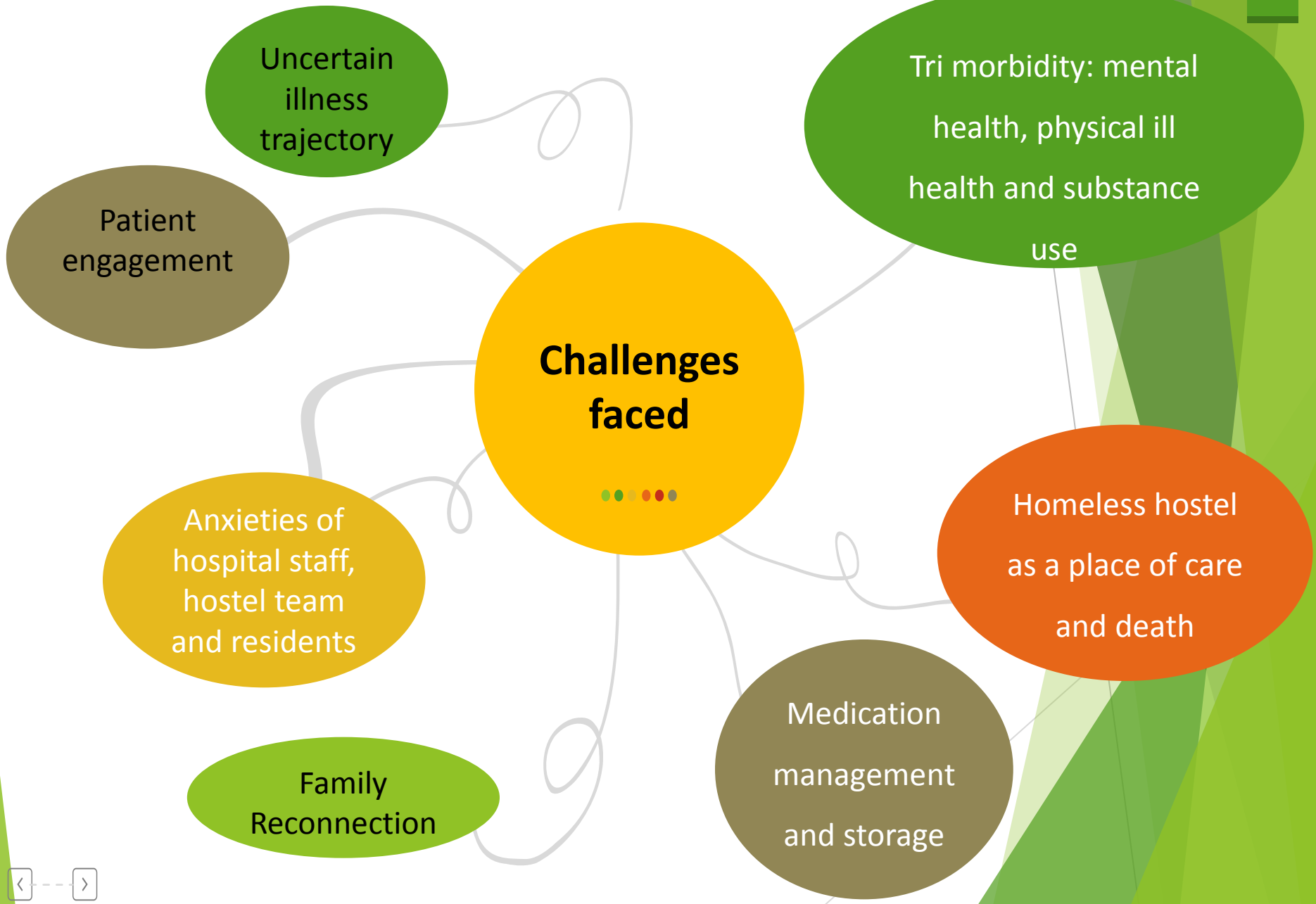
•Regular crisis led admissions for alcohol related issues

•Prone to disruptive behaviors and angry outbursts, making it difficult at times for others to engage openly with him

• Self discharges were high, planning and after-care minimal

•Rejected detox and rehab

•Staff concerned that he might die


Challenges faced
Uncertain illness trajectory
Patient engagement
Tri morbidity: mental health, physical ill health and substance use
Anxieties of hospital staff, hostel team and residents
Homeless hostel as a place of care and death
Family Reconnection
Medication management and storage

Challenges: Communication about prognosis

- Warning shots vs exploration of insight in to illness
- Mistrust of health care professionals a barrier to communication
- Use of jargon prevents understanding
- Checking understanding and involving advocates seen as helpful.

"Life is not worth living without alcohol"

"I'm not yellow yet…I was given months to live years ago. I'm not interested in someone telling me what to do!"

Questions to consider

PHYSICAL

- What do you understand about your current health situation?
- What are your main concerns … *about seeing the doctor?*
- How are you feeling about *…your recent hospital admission?*
- Tell me about what you would like to see happen next?
- This may not be your worry or concern right now, just *mine*, and it's important I share it with you

SUBSTANCE USE

- What are your thoughts around reducing your drinking/substance use?
- Say you struggled to stop drinking, what do you think might happen in the next 3/6/9 months?
- What are the likely benefits of going 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?

RELATIONSHIPS

- Tell me about 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 at some stage?
- How can we support your *…partner, friend, mother?*

TREATMENT AND CARE

- What extra support do you think would be helpful to you *and us (e.g. nursing or personal care)*?
- If you became very ill, where would you wish 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?
- What would be helpful for others to know about you when … *talking about your care?*

EMOTIONAL

- How are you feeling about your recent … *diagnosis/hospital admission/poor health?*
- It may be just me, but I've noticed you seem a bit withdrawn lately, what can I help with?
- Tell me more about what is worrying you?
- What do you feel would help right now?

HOPES FOR FUTURE

- What is most important to you at the moment?
- What are the things you most want to do?
- Would you like support to reconnect with family?
- Tell me the ways *I/we* can best support your goals and aspirations *(short, medium, long term)*

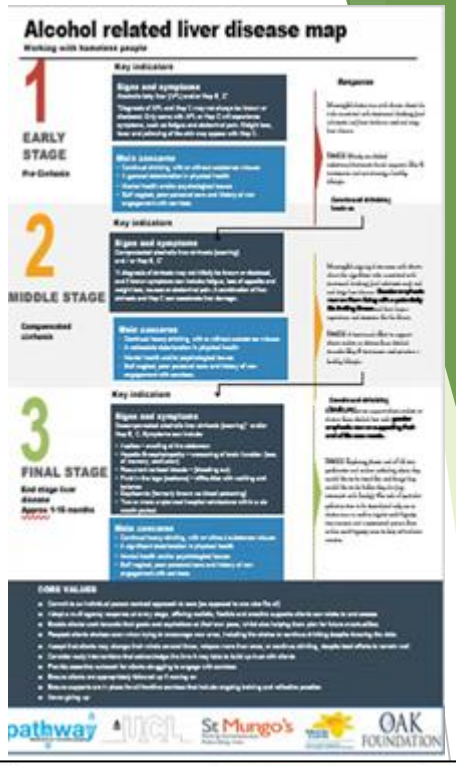
SOCIAL / PRACTICAL ISSUES

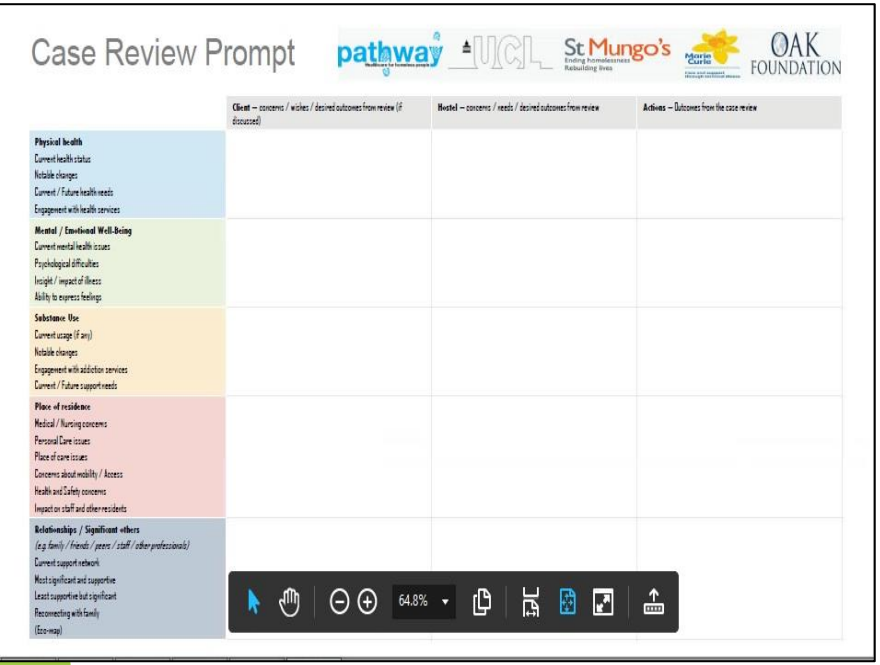
- How can we make things more comfortable for you?
- We notice you are having trouble attending appointments, what can we do to help?
- Have you thought about making a will or letter of wishes?
- Have you ever thought about how you'd like to be remembered?

Outcome for Scott

Tools and Resources

- ✓Case Review Prompt
- ✓End of life hostel checklist
- ✓Liver Disease Map
- ✓Conversation Mapping Tool & Question Prompt





Recommendations

Relationships

It can be hard to develop relationships.

Consider involving staff from the homelessness sector to support you eg

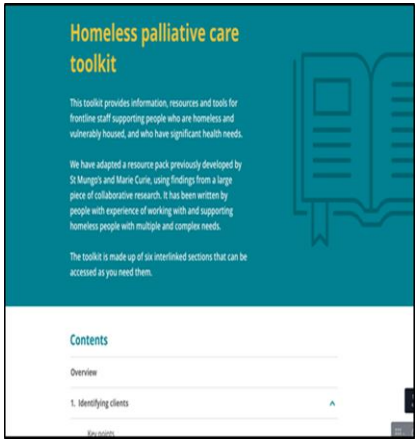
- Hostel staff
- Peer mentors
- Hospital homelessness teams
- Outreach workers

National Mental Health Development Unit, Mental Health Good Guide Practice (2010)

Multiagency working

- Consider early referrals to palliative care
- Involve other agencies in discharge planning & care planning
- Training front line homelessness staff
- Optimizing symptom control
- Increasing access to social services package of care and NHS Continuing health care funding, OT referrals

Thank you for listening



Niamh Brophy
Niamh.Brophy@mungos.org

Trinity Hospice - Improving access to EOLC for homeless people

Dr Barbara Sheehy-Skeffington – Consultant in Palliative Medicine,
Royal Trinity Hospice

#EOLCLDN

Royal Trinity Hospice
Living every moment

Improving access to End of Life Care for homeless people

Dr Barbara Sheehy-Skeffington
Consultant in Palliative Medicine
Royal Trinity Hospice
bskeffington@royaltrinityhospice.london

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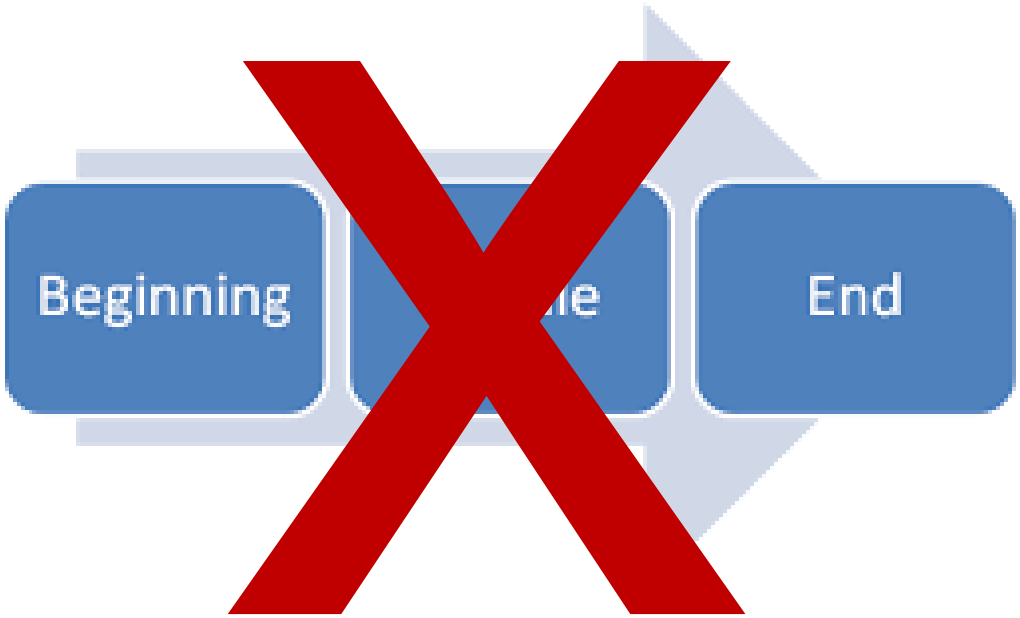
Our story…



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Outline

- Why
- What we did
- What we hope to do
- What we learned
- What you should do

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Why?

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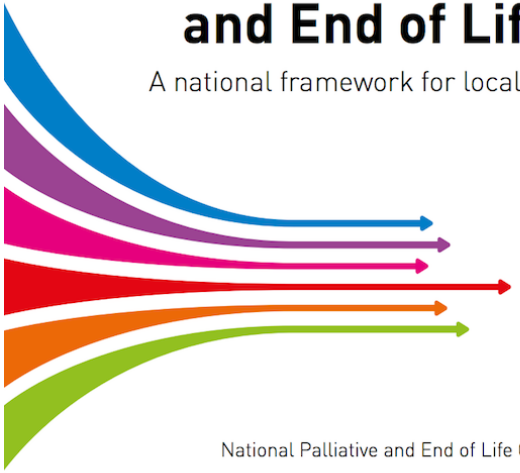
Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020



National Palliative and End of Life Care Partnership

01 Each person is seen as an individual
02 Each person gets fair access to care
03 Maximising comfort and wellbeing
04 Care is coordinated
05 All staff are prepared to care
06 Each community is prepared to help

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April 2016:

- 1st meeting of EOLC and Homelessness Group
- also attended by Niamh Brophy and Jane Cook

- Relationship building between palliative care and homeless services – making connections with local hostels
- Education/training in palliative care to homelessness professionals and vice versa
- Host open day +/- study day at the hospice for professionals working in homelessness
- Service mapping of SPC services for the information of homelessness services and vice versa

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October 2016:

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More than **30 representatives** from more than **15 different organisations**

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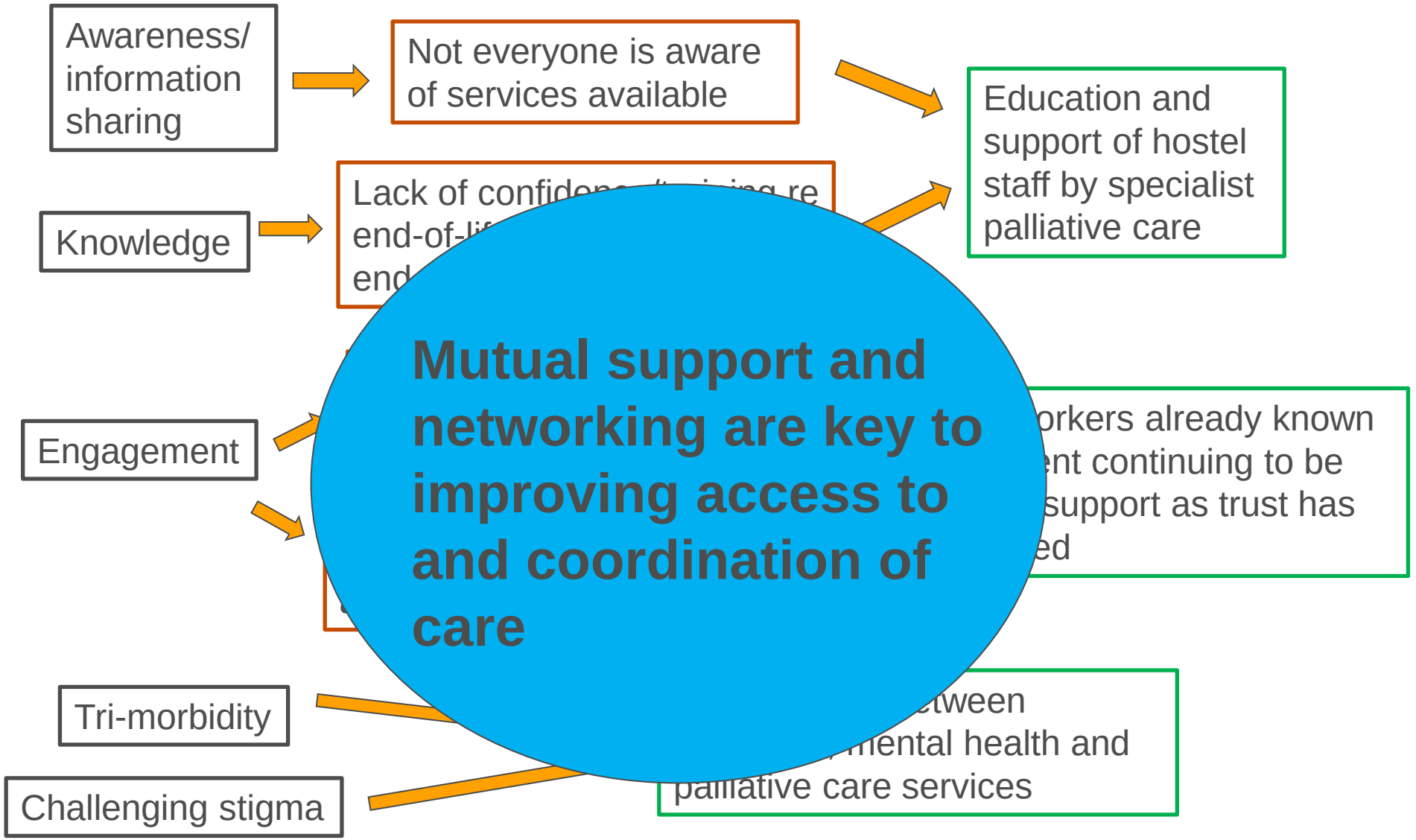
Awareness/ information sharing
Not everyone is aware of services available
Education and support of hostel staff by specialist palliative care
Knowledge
Lack of confidence/training re end-of-life
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Mutual support and networking are key to improving access to and coordination of care
Engagement
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Tri-morbidity
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mental health and
palliative care services
Challenging stigma
Health and safety in certain environments
Early referral to palliative care services
Flexible approach by palliative care services

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2018:

- Hostel visits – 5 hostels, Compass team
- Linked with Homeless Health Service in Westminster – presented at one of their bi-monthly Health Action Group meetings
- Met with specialist GP surgery for homeless in Westminster

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Homelessness Awareness Week

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All welcome!
Please email Helen King to book into the Cardboard Citizens workshop, or email homelessnessworkingparty@royaltrinityhospice.london for more information.

Monday 1 October	Tuesday 2 October	Wednesday 3 October	Thursday 4 October	Friday 5 October
12:30, Old Chapel Presentation: Victoria Aseervatham, Homeless Health Commissioner for Westminster 'What does Homeless-ness look like?'	**10-11am, Old Chapel** Virtual Reality Session: Letizia Forrest and Leon Ancliffe (Flix Films) Drop in	**1.30** Journal Club: Dr Barbara Sheehy-Skeffington	**8.30-9.30am, Old Chapel** Breakfast club: Niamh Brophy, Palliative Care Coordinator at St Mungo's Niamh will talk about her role and the ways they have found to support the homeless population and staff involved in their care	**3.00, Old Chapel** Reflective tea party 'The Way Forward' We will talk about the Homeless Project at Trinity and have an open discussion reflecting on the challenges and possible ways forward
2-4pm, Old Chapel Immersive workshop: Cardboard Citizens (20 places) 'What does homeless-ness feel like?'	**2.00** Presentation: Dr Caroline Shulman, General Practitioner in Homeless and Inclusion Health, Gerry Rolfe, Groundswell Caroline will talk about her work + research about palliative care needs of the homeless population. Gerry will talk about her lived experience of being homeless	**3.30-4.30pm** Presentation: Niamh Brophy, Palliative Care Coor-dinator, St Mungo's Niamh will talk about her unique role and the ways they have found to support the homeless population and staff involved in their care	**3.30pm, Old Chapel** Schwartz Round: Specially themed around homelessness	
	6pm, Old Chapel Film night			**9.30pm Glass Door 'Sleep Out'** A few of us are taking on this charity event by sleeping on the streets for one night. Get in touch to join us!

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- Talks
- Victoria Aseervatham
- Caroline Shulman
- Niamh Brophy
- Gerry Rolfe

- Cardboard Citizens
- Virtual Reality
- Schwartz Round

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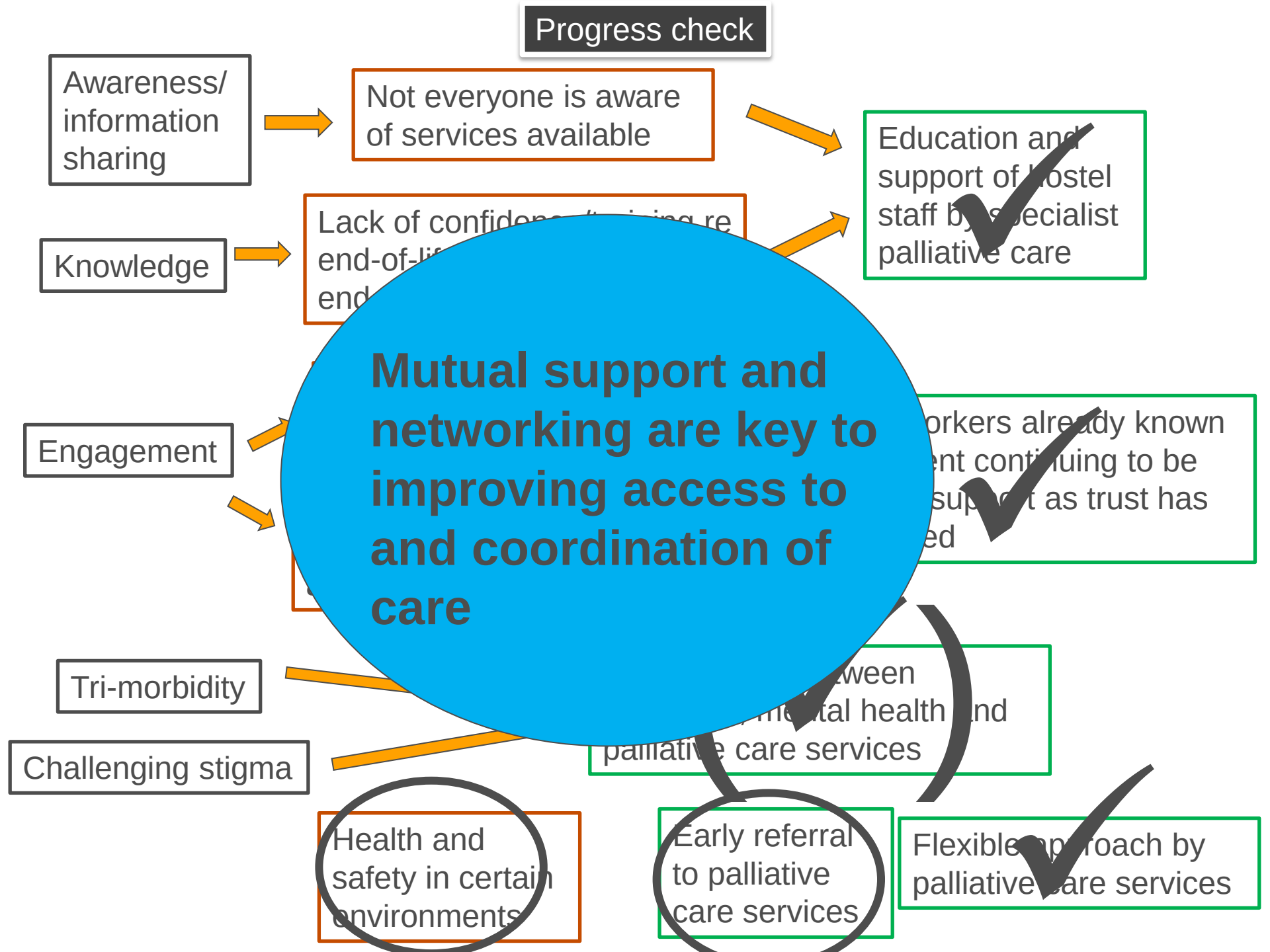
Sleep Out


END
HOMELESSNESS
SLEEPOUT
... because no one should have to sleep on the streets of London.


Progress check
Awareness/ information sharing
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Knowledge
Lack of confidence/training re end-of-life end
Mutual support and networking are key to improving access to and coordination of care
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Tri-morbidity
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Challenging stigma
Health and safety in certain environments
Early referral to palliative care services
Flexible approach by palliative care services

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Ongoing work and what we hope to do next:

- Hostel visits
- Advance care planning training
- EOLC workshops
- Leaflets
- Breakfast Club

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Lessons learned

- Time
- Don’t be overwhelmed by the task
- Don’t wait for the master plan
- Do work with national bodies to share good practice

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What you should do

- Please accept referrals
- Actively seek referrals!
- Be flexible
- Find out about the homeless services in your area and make connections – you will be welcomed with open arms!

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Thank you for listening!

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Homelessness Stakeholder Event

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Palliative care and the homeless community: How can we help?

Come along to inform the development of palliative care services for the homeless. Are their needs being met, what is being done well and are there gaps in support?

Programme

2pm	**Registration and Coffee**
2.15pm	**Welcome** Dr Barbara Sheehy-Skeffington, Consultant in Palliative Medicine, Royal Trinity Hospice
2.30pm	**Introduction to Royal Trinity Hospice and Specialist Palliative Care Services: what we do and how to access our services** – Dr Barbara Sheehy-Skeffington, Consultant in Palliative Medicine, Royal Trinity Hospice **Caring for homeless people; the challenges and opportunities** – Kendra Schneller, Homeless Nurse Practitioner
3.15pm	**Small group workshops based on case studies, followed by feed back to larger group and discussion**
4pm	**Current status of engagement of homeless services with palliative care services; challenges and opportunities** – Niamh Brophy, Palliative Care Coordinator, St Mungo's Broadway **Caring for homeless people as a GP** – speaker TBC (representative from Dr Hickey Practice, Westminster) **Advance care planning in homeless people with multi-morbidity: A qualitative study – presentation of initial findings** – Dr Caroline Shulman GP in Homeless and Inclusion Health, KHP Pathway Team
5-7pm	**Reception and Networking;** tours of the hospice will be available

RSVP
to Rebecca at
r.blatchford@nhs.net

When?	Time?	Where?
Thursday 13th October	2-5pm (with wine & nibbles after)	Old Chapel Room, Royal Trinity Hospice, 30 Clapham Common North Side

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Summary of feedback for Homelessness Awareness Week

Victoria Aseervatham

17 attended

Mostly 8-10; some 6/7

Cardboard Citizens Workshop

17 attended

Mostly 8-10; two forms with 3/4, one didn't elaborate at all, the other suggested giving scenarios rather than improvisation

"was a great eye-opener to understanding homelessness"

VR

19 attended

Mostly 9/10; one 6

Caroline/Gerry

23 attended

Mostly 10s

"Thank you for this opportunity to challenge pre-conception and prejudice"

Niamh Brophy 1

26 attended

8-10 (mostly 10)

"Informative, interesting, relevant"

"Excellent session, good learning from case studies"

Niamh Brophy 2

12 attended

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Ministry of Housing, Communities & Local Government

St Mungo's
Ending homelessness
Rebuilding lives

hospice UK

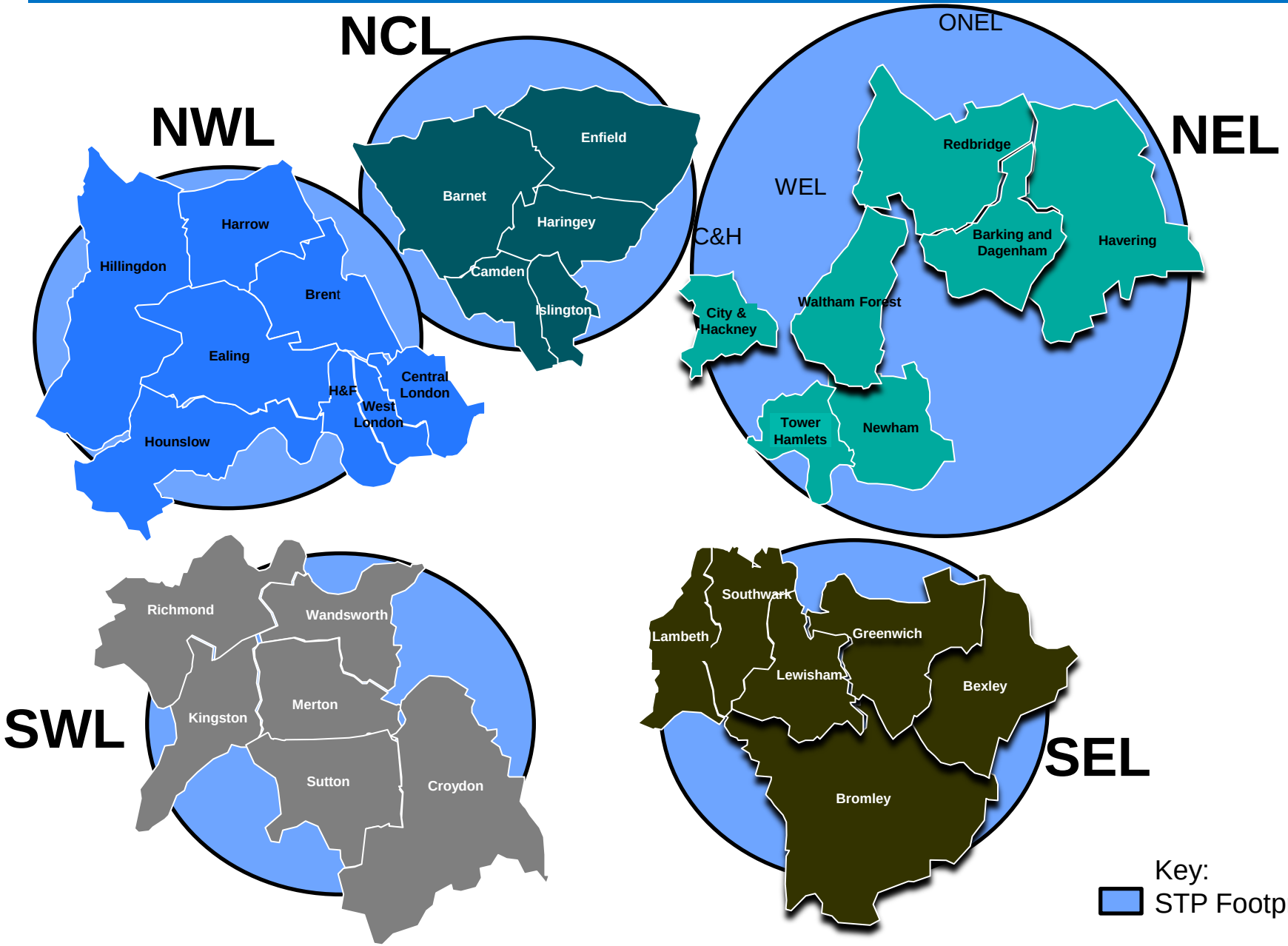
Healthy London Partnership

NHS
London
Clinical Networks

Table Discussions

#EOLCLDN

STP Areas


NCL
Enfield
Barnet
Haringey
Camden
Islington
NWL
Harrow
Hillingdon
Brent
Ealing
H&F
Central London
West London
Hounslow
ONEL
NEL
Redbridge
WEL
C&H
Barking and Dagenham
Havering
Waltham Forest
City & Hackney
Tower Hamlets
Newham
SWL
Richmond
Wandsworth
Kingston
Merton
Sutton
Croydon
SEL
Southwark
Lambeth
Greenwich
Lewisham
Bexley
Bromley
Key:
STP Footprint

iCommit

TO PROGRESS EOLC AND HOMELESSNESS

My name is

……..

I work as

……..

Representing

……

I commit to …

Evaluation Form

Open a browser on any laptop, tablet or smartphone

Go to slido.com

Enter the event code #7557

#EOLCLDN

Ministry of Housing, Communities & Local Government

St Mungo's
Ending homelessness
Rebuilding lives

hospice UK

Healthy London Partnership

NHS
London
Clinical Networks

Thank you for coming

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