



# **Integrated health and social care for people experiencing homelessness: additional consultation with experts by experience on draft NICE guideline**

## **Who are Groundswell?**

[Groundswell](#) began in 1996. Our focus was to enable people experiencing homelessness to have a direct voice in influencing services and policy. Groundswell's vision is of an equal and inclusive society, where the solutions to homelessness come from the experiences of people who are homeless. We believe that lived experience of homelessness and using support services brings unique insight that creates change. Everyone on our volunteer team has been homeless, over half our staff too.

[#HealthNow](#) is a national partnership led by Groundswell with the aim of reducing health inequalities for people experiencing homelessness using peer-led approaches. Through the #HealthNow campaign we have established a network of peers who are volunteering at organisations across the UK and Ireland to tackle homeless health inequality, all with personal experience of homelessness. The purpose of the network is to: share experiences; learn from one another; and promote opportunities to have their voices heard and participate in activities that promote positive change for people experiencing homelessness.

## **Our involvement in the NICE consultation**

Groundswell previously facilitated a workshop with the #HealthNow Peer Network to ensure they were able to contribute to the initial scoping document for the NICE guideline which at the time was titled 'Integrated health and care for people who are homeless through being roofless'. Feedback from the peers about their involvement in this process was very positive, they were particularly pleased that their recommendation to change the title of the guideline to 'Integrated health and social care for people experiencing homelessness' was accepted.

The #HealthNow peer network were delighted to be invited by the advisory committee for the NICE guideline on Integrated health and social care for people experiencing homelessness, who provide advice and recommendations to NICE, to have the opportunity to review the draft guideline and provide a unique perspective through their lived experience of homelessness

Groundswell's Peer Coordinator arranged a 2 hour workshop which was promoted through the #HealthNow network and took place on the 21<sup>st</sup> October 2021. Prior to the workshop the draft guideline was circulated through the network and anyone planning to attend was

advised to review this before the workshop. In total 14 participants attended the workshop representing the East of England, South East, North West, North East, and Ireland. Participants were volunteering in a range of roles including Peer Researchers, Citizen Journalists, Experts by Experience and Peer Advocates. Through a focus group discussion, the peers were presented with the questions provided by the NICE committee. Attendees and the wider peer network were also invited to provide additional feedback to the questions and consultation via email.

## What we had to say:

### 1. What do you think about the section “General principles”?

Overall, the peers did agree with the general principles section however, they did find the section very “wordy” and not concise with one of the peers suggesting that the entire section could be summarised as:

*“be nice to people and do your job”*

The group did acknowledge that while some of the guidance in this section may seem obvious to them this may not be the case for all services. With reference to that it was also felt that the way some of the recommendations were suggested could influence how highly they would be prioritised for implementation. For example:

*“consider using psychologically informed environments or trauma-informed care”*  
(Page 6, lines 15-16)

Peers felt strongly that trauma-informed care is essential to delivering health and social care effectively to people experiencing homelessness and would link into a number of the other recommendations in the guideline. The use of the term ‘consider’ suggests that this is optional and does not convey the importance of the approach. The peers suggest using the term ‘should’ rather than ‘consider’.

### 2. Are there any particular issues around communication that are important but have not been covered in the section “Communication and information”?

The group agreed with the recommendations within this section, and the recommendations sound very good although they were unsure exactly how these may

be implemented in practice. Peers were pleased to see the inclusion of non-verbal communication:

*It's good in a way, having encountered a lot of passive aggressive people in healthcare services they say one thing but their body language and demeanour say "why are you bothering me?"*

They also wanted to make additional suggestions for the consideration of the committee on the following points:

#### 1.1.9 health and social care working with people experiencing should

- Add the importance of sending reminders about appointments and following up if someone doesn't attend rather than assume disengagement.
- Add 'empathy' to line 3 so sentence should read 'Be emphatic, non-judgemental and use recovery-oriented language that avoids jargon'.
- Confusion regarding the choice of the term 'recovery-oriented language'. Contradiction in the sentence 'use recovery-oriented language that avoids jargon' as seems like recovery-oriented language is a jargon.
- Add no acronyms should be used, unless they are explained.

#### 1.1.10 Take into account each person's communication and information needs and preferences, and their circumstances

- Also need to ensure information signs in services are in multiple languages.
- People shouldn't have to ask for information in different forms, they should be asked and offered.
- Responsibility of health and social care workers to check people's understanding and shouldn't assume understanding.

#### 1.1.11 Consider involving an advocate to support communication even when this is not a statutory requirement

- The word 'consider' is a light term – doesn't seem to stress the importance of advocates.
- Discussion around advocates not being able to support clients presenting with mental health issues in hospitals and if this is related to another policy or guideline?

### 3. What do you think about recommendation 1.2.4 and recording of homelessness status in patient/client records?

The hope is that declaring homeless status should improve care in some way however for our peers it feels like declaring homelessness can work against you in the system:

*The reality is, if it assisted and if it engaged across a variety of services so that declaration of homelessness immediately put you into a different tier and people treated you differently, I don't think most people would have a problem with it. The problem is, experience tells us that if you actually declare it, it becomes a problem and you are denied services.*

There was a lot of discussion around how and when people are asked to disclose their status, how it is recorded on a person's medical record and how long it remains there. There is a lot of stigma and discrimination towards people experiencing homelessness and homeless status being recorded as a 'problem' on medical records contributes to the negative association with the term 'homelessness'. The peers wondered if it could be recorded in a different way, perhaps using 'additional needs' to record homeless status and any other issues that may need to be considered when supporting someone with their health and social care needs. There should be transparency about recording this information, it should also be someone's choice if it is recorded on their medical record.

### 4. Have we captured the role of peers appropriately and adequately in section "The role of peers"?

As a group of peers who are all actively volunteering in roles that contribute to improving health and social care for people experiencing homelessness, and an organisation that promotes peer-led approaches, we are extremely pleased to see that peers play such a prominent role in this guideline. However, the guidance suggests a distinction between health and social care professionals and people with lived experience. Roles for people with lived experience of homelessness in the health and social care sector do not need to be defined peer roles. In order for services to effectively involve people with lived experience of homelessness they may need to review their volunteer and recruitment policies to ensure any barriers to participation are identified and addressed.



Additional suggestions to the points in the recommendation have been made below.

#### 1.4.1 Offer Peer support to people experiencing homelessness

- Add supporting attendance at A&E, going back to the previous point about people presenting in mental health crisis not being able to have the support of anyone including an advocate.

#### 1.4.2 Involve Peers (Experts by Experience) in delivering and designing services

- In the second bullet point there should be an addition that rather than just consult with peers through seeking the user perspective, where possible peers should be given the opportunity to coproduce design of services along with other key stakeholders.
- The term 'data collection' in the third bullet point doesn't seem the right choice of word. Peer Researchers present in the meeting specified that data collection only forms part of their involvement with research, they also contribute to designing research tools, supporting with data analysis, providing feedback on research findings, coproducing recommendations, and disseminating research. Peers felt the term 'participatory research' was more appropriate.
- Peers felt that a few key roles were missing from this list including peer trainers, who provide peer-led training to health and social care staff. Also, the role peers play in challenging care providers through platforms such as the #HealthNow alliances, where stakeholders from health, homelessness, and housing work together with peers to address inequality.

#### 1.4.3 Support peers to deliver services effectively and maintain their own wellbeing and development

- Add making inclusive recruitment practises within services. Ensuring recruitment processes have no barriers i.e. minimum education requirements or clear criminal records.
- The term 'psychosocial' was deemed to be jargon and the term caused some confusion.
- Comment around ensuring peers are protected from being given tasks outside their remit/role.
- Ensure peers are provided with self-care workshops and training to support wellbeing i.e. through supervision, reflective practice. Participants felt this is key to supporting the wellbeing of peers and to ensure they are not triggered through the activities involved in undertaking their role.
- If peers are contributing through a voluntary role, it should be clear what they are receiving in return i.e. progression support, incentives, expenses, qualifications, training etc.

- The section is missing the importance that support for peers will vary depending on the person. The support needs to be carefully tailored to the individual -not one size fits all.
- Provide a menu or framework of support for peers to be able to select the support that they need and create their own support plan.
- Make the recommendation more person centred by changing 'training, supervision and governance structures appropriate to the role but add 'and tailored to the person's needs'.

**5. Are there some specific training requirements for peers that would be beneficial to mention?**

Although the group felt that training should very much depend on the individual and the role they did want to recommend training they have received that they have found to be beneficial:

- Safeguarding
- First aid
- Mental Health First Aid
- Trauma Informed Care
- Advocacy
- Professional Boundaries
- Risk Management
- Facilitation
- Personal Development

**6. We have tried to use language in the guideline that is 'recovery oriented', meaning language that is person centred, respectful, non-judgmental and strengths based, conveying a sense of hope and commitment to the potential of every person and their recovery journey. Have we got the language right? Any comments/suggestions?**

Generally it was felt that you have got the language right, although the peers also reflected that the document is very long and they didn't feel that within the workshop there was sufficient time to review it comprehensively. They did wish to highlight some examples that they felt did not fit the definition of 'recovery oriented':

- Problem substance use
- Perhaps the definition of sofa surfing as staying with family and friends is too hopeful and doesn't effectively describe the reality for many people who are sofa surfing.
- 'Unwilling to engage' in the definition of assertive outreach. Implies a problem with the person rather than the service or system.



- The term 'influence their habits' in the definition of low-threshold services.
- The definition of complex needs includes the word 'problematic' which has negative connotations. Also, the term 'repeated homelessness' within this definition puts the responsibility on the person rather than a system driven issue. Suggested alternatives to complex needs could be multiple disadvantage or multiple unmet needs – highlights that the system is not designed to meet the needs of the individual.

**7. We have included definitions of some of the terms used in the guideline so that readers know what we mean by them. What do you think about them, are they understandable/useful? Are any definitions missing that a 'lay person' reading the guideline would find helpful?**

The majority of the peers are currently involved in working within the health and social care sector so while they understood the language they did feel the language was targeted towards professionals rather than a 'lay person'. Therefore, the definitions provided were essential to support understanding of the recommendations. They did make some suggested amendments to the definitions:

- Low-threshold services: definition is quite complex, could it be simplified.
- Multi-disciplinary team: change from 'working together' to 'working with'.
- Confusion among the group regarding who was included in modern slavery – perhaps a definition of 'modern slavery' would be useful.
- Change victims of modern slavery to include 'victims of modern slavery and trafficking'.
- Change 'safehouse for victims of modern slavery to just 'victims of modern slavery'.
- Reflective practice: definition should include 'to help staff and volunteers' rather than just to help staff.
- Safeguarding adult review: the sentence needs more clarity if all the bullets are applicable.
- The group disagreed with the term 'service user' within trauma informed care definition.
- Wrap around health and social care support: the phrase 'in addition to housing need' this should not just be an addition but a priority.

**8. Should we include a definition of peers in the section 'Terms used in this guideline', and if so what definition should we use?**

Yes, the group felt that given the emphasis on the role of the peer within the guideline a definition should be included as the word 'peer' can mean different things to different



people. For example, a peer review for academic research or use of the word peer by MPs. The definition could be:

‘A person with lived experience of homelessness who is using their experience to benefit others through different means such as direct support, research, coproduction and media.’

9. **In some places in the guideline, we have used the term “complex needs” to describe when a person has “persistent, problematic and interrelated health and social care needs that affect the person's life and may include repeat homelessness, mental, psychological and physical health needs, drug or alcohol problems and criminal justice involvement. People with complex needs may have underlying adverse childhood experiences or experiences of trauma. They may have had sporadic and inconsistent contact with services or been serially excluded from services.” What do you think about using the term “complex needs”? Is there a better term we should use instead?**

As noted above, the group felt that the term complex needs has negative connotations. People feel labelled with this term and it reinforces that the person is problematic and can lead to people being treated negatively as a result. Multiple disadvantage or multiple unmet needs were suggested as alternative terms.

10. **Do you have any other comments on the guideline?**

It is incredible positive that NICE is producing guidance relating to people experiencing homelessness, feels that this is acknowledgement of the inequalities people have faced when accessing health and social care and a commitment to reducing them. The integration of health and social care provision is essential but there are a lot of system barriers that will prevent this and it's not clear how this guidance is going to ensure action. We also hope that the final published guideline is presented in a more accessible way as in its current format it is too long and too difficult to process.

Thank you for ensuring people who have personal experience of homelessness have had the opportunity to contribute in a meaningful way to the development of this guideline.



