

Involving people experiencing homelessness in guideline development

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Background

NICE is committed to involving people who use services, carers and the public in the development of guidance to ensure they are focused on the people most directly affected by the recommendations.

During the development of the NICE guideline 'Integrated health and social care for people experiencing homelessness'¹ the advisory committee identified the need for a targeted engagement exercise with people experiencing homelessness additional to the routine stakeholder consultation.

What we did and why

Additional consultation is a targeted engagement exercise to obtain a range of views, experiences, and expertise, independent from the committee.

A targeted engagement with people with lived experience of homelessness was conducted to actively engage people affected by the guideline and address significant barriers that they may have in taking part in a guideline consultation process.

This targeted consultation enabled the committee to test the relevance, feasibility, and acceptability of the draft guideline and selected recommendations at the stakeholder consultation stage.

To achieve this, Groundswell, a homelessness charity in England, was commissioned to use a group-based method in the form as a focus group.

They engaged with their established #HealthNow peer-network of people with lived experience of homelessness to generate feedback on the draft guideline.

To support the engagement, the advisory committee provided ten questions relating to the draft guidance to ask about the relevance and acceptability of the proposed recommendations.

Results

Fourteen people with lived experience of homelessness participated in the focus group during the consultation period.

The advisory committee received a report² summarising the focus group's response to the ten questions, which addressed the following issues:

- If they agreed with the general principles of the guideline

- If there were any missed issues around communication
- If patient records should include their homelessness status
- If the language in the guideline was person centred, respectful, and non-judgmental
- If the terms used in the guideline were defined for a lay audience

The report was presented to the advisory committee and considered alongside other stakeholder comments that had been received during the consultation period.

The advisory committee considered each point and provided a written response³ to each of the comments, outlining if any changes had been made to the guideline based on their feedback.

The committee also provided a rationale for each of the comments that had not changed the guideline.

The report and responses to the feedback formed part of the guideline documentation and were published on the NICE website.

Impact

The committee received clear feedback to validate the guidance and revise the recommendations as appropriate.

Most of the feedback was acted upon, making changes to the recommendations. This included changes to the language and terminology used and the provision of services and their delivery.

Language and terminology: Key phrases were changed following the feedback to ensure the guideline was appropriate and sensitive. For example, the feedback highlighted the term 'complex needs' had negative connotations and reinforced the perception that a person is problematic, which can lead to them being treated negatively.

The language was changed to 'severe and multiple disadvantage', to recognise a life course approach and cover the various different needs, such as mental health needs.

Service delivery: Multiple recommendations were updated to reflect the feedback. For example, a recommendation was amended to explicitly state that acronyms should be avoided and to include sending reminders about appointments and following up if people do not attend.

The committee also included a recommendation for future research into psychologically informed environments, in the hope that with more evidence, any future updates would have the basis to make stronger recommendations.

Next Steps

The guideline was published in March 2022. NICE developed information for the public⁴ as part of the guideline publication to highlight the key areas for the public.

Alongside this, six charities were identified, and their contact details published, to provide more advice and support for the public.

"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."

Groundswell

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1. National Institute for Health and Care Excellence (2022) Integrated health and social care for people experiencing homelessness. Available from <https://www.nice.org.uk/guidance/ng214>

2. National Institute for Health and Care Excellence (2022) Supporting documentation - Groundswell Consultation Report. Available from <https://www.nice.org.uk/guidance/ng214/documents/supporting-documentation-5>

3. National Institute for Health and Care Excellence (2022) Supporting documentation - Groundswell Consultation Comments and Responses. Available from <https://www.nice.org.uk/guidance/ng214/documents/supporting-documentation-7>

4. National Institute for Health and Care Excellence (2022) Integrated health and social care for people experiencing homelessness: information for the public. Available from <https://www.nice.org.uk/guidance/ng214/informationforpublic>