

Proposed SUGEST Interview Schedule - Caregivers

Introduction

Thank you for agreeing to take part in this interview. My name is Emma, and I'm a Researcher at the University of St Andrews. I'm part of a team exploring how the NHS might use a new tool called SUGEST.

SUGEST is being developed to help doctors and nurses identify when someone may be in need of palliative care, for example, in the next six months, especially when they come into emergency or out-of-hours care.

The tool works by using anonymous information from a person's existing health records, such as hospital visits, medications, and long-term conditions, to calculate a risk score. This score gives doctors an idea of whether someone might need palliative care, which could help them offer earlier support or start important conversations about care needs.

It's important to know this isn't a diagnosis or a definite prediction. It's just one tool to support care planning. What we want to understand is how people feel about this, especially those who have cared for, or are currently caring for, someone receiving palliative care, and what would make this approach feel acceptable, respectful, and helpful.

Because of that, this interview includes some questions about experiences of serious illness, dying, and decision-making whilst receiving palliative care. We know these topics can be sensitive. You are always in control, you don't have to answer anything you don't want to, and you can pause, take a break, or stop the interview entirely at any point without needing to give a reason.

The interview will last around 45 minutes and will be audio recorded so I can listen carefully to what you share and analyse it afterwards. Everything you say will be kept confidential, and your name won't appear in anything we write up or publish.

Does that all sound okay to you? Do you have any questions before we begin?

You'll also have a chance to ask questions again at the end of the interview.

Section 1: Experience of Unscheduled and Palliative Care (Context)

To start, I'd like to hear a bit about your experiences with healthcare — especially times when you or someone you cared for had contact with emergency or out-of-hours services, or received palliative care. These questions help us understand the background to your views."

Please remember you can share only what you're comfortable with and skip anything that doesn't feel right to talk about.

1. Have you had experiences of A&E or out-of-hours?

2. Have you or someone you cared for received palliative or palliative care?
3. What, if anything, helped you feel supported during that time?
4. Were there any missed opportunities for planning or communication that stood out?
5. How do you feel about the idea of palliative care and potential end of life — is it something you feel at peace with, or do you find it difficult to think about?

Section 2: Understanding and First Reactions to SUGEST

Next, we'll talk about the SUGEST tool. Just a reminder, this is a new NHS tool designed to help clinicians recognise when someone may require palliative care, so that support can be offered earlier. We're really interested in your honest reactions to this idea — what feels helpful, what feels worrying, and anything in between.

Some of the questions mention dying directly. Please feel free to take a break, skip a question, or stop at any time.

5. How do you feel about the idea of using medical data to help identify people who may be at risk of requiring palliative care in the next 6 months?
6. How would you feel if a doctor told you they had used a tool like this to help plan your care?
7. Do you think incorporating a tool like SUGEST into care planning is a good idea? Why or why not?
8. What do you think would make learning about a potential requirement for palliative care more helpful or acceptable to you?

Section 3: Personal Preferences – Communication and Consent

This part is about how people might want to be told if a tool like SUGEST suggests they could require palliative care. We know there's no one-size-fits-all answer, so we'd really like to hear what you think respectful and supportive communication would look like — either for you or for someone you care for.

9. If you were identified as high risk, would you want to know?
10. At what point would you wish to be told – for example, if you were low risk, medium or high risk? Or would you prefer a percentage or risk indicator eg. 60% or 1.5 times more likely.
11. Who else should be told? (e.g. family, GP, carer)
12. When would be the right time to tell someone they are high risk?
13. How would you like to be told — face-to-face, phone call, letter?
14. Who should tell you? A GP, hospital doctor, nurse, someone else?
15. What would make that conversation feel respectful, supportive, or safe?

Section 4: Trust, Ethics, and Cultural Considerations

Now we'd like to ask about issues of trust, fairness, and personal beliefs. Tools like SUGEST rely on data and prediction, and we know different people may feel differently about that — especially depending on their background or community.

15. Do you have any concerns about how this kind of method could be used in care planning?
16. What might make it harder for people in your community to trust or accept this?
17. Are there particular cultural, religious, or personal beliefs that might affect how people react to learning about their risk of requiring palliative care?
18. How can we make learning about the risk of requiring palliative care inclusive, fair and helpful for everyone?

Section 5: Impact on Care and Decision-Making

This section explores how knowing someone may require palliative care, through a tool like SUGEST, might affect the way care is planned or decisions are made. We'd like to hear your thoughts on how this kind of information could be used in a helpful and meaningful way.

19. How could knowing your risk affect the way you make decisions about your care?
20. Would you want this to lead to conversations about planning or support?
21. Could learning about the risk of requiring palliative care improve how care is planned or offered to people?

Section 6: Feasibility and Integration into NHS Practice

Finally, we'd like your thoughts on where and how SUGEST could work in the real world, in NHS settings like A&E, GP surgeries, or hospitals. What would make it work well? What could get in the way? And how can we make sure it feels safe and respectful for everyone involved?

22. Where in the NHS journey do you think this tool could be used best? (e.g. ambulance, A&E, GP, follow-up)
23. What support would professionals need to use it effectively and sensitively?
24. What could stop this type of method for identifying those at risk of palliative care from working well in real life?
25. What advice would you give us to make this useful, kind, and safe for patients and families?

Finish

That's the last of the main questions. Just before we finish...

26. Is there anything else you think we should have asked?