NU-GEST

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Participant Information Sheet

Dear Participant,

We are researchers from the School of Medicine at the University of St Andrews, conducting a study on how people feel about a new NHS tool called **NU-GEST**, which is being designed to help healthcare staff identify when someone might need palliative care.

Your insights as someone who is currently experiencing, or supporting someone through, palliative care will help us understand how this type of tool should (or should not) be used in practice. The findings will be used to guide how healthcare professionals communicate risk, plan care, and offer support in a way that is respectful, person-centred, and appropriate.

Please read the information below carefully before deciding whether to take part. Participation is entirely voluntary, and you may withdraw at any time up to one week after your interview.

What is the study about?

The **NU-GEST** study explores how people feel about the idea of doctors using existing health data (such as hospital visits or medication records) to estimate when someone might need palliative care — for example, within the next six months. The tool would produce a risk score to help support earlier conversations about care planning and available support.

We are particularly interested in the views of people who are currently receiving palliative care, or those closely involved in that process.

Am I eligible to take part?

You may be eligible if you:

- Are aged 18 or over
- Live in Scotland
- Can provide informed consent and take part in an interview in English
- Are currently receiving palliative care, or are supporting a close family member or loved one who is receiving palliative care

What would I be required to do and what data are you collecting?

f you choose to take part, you will be invited to a one-to-one interview lasting approximately 45–60 minutes, conducted either in person, online (via Microsoft Teams), or by telephone, depending on your preference.

The interview will explore your experiences of palliative care, your reactions to the idea of the NU-GEST tool, and your thoughts on how it could be used in a respectful and supportive way. You may skip any question or pause at any time.

Topics will include:

- Experiences of unscheduled or out-of-hours care
- Your views on being told about potential risk of needing palliative care
- Preferences around communication and decision-making
- Ethical or cultural considerations
- What would make a tool like NU-GEST feel helpful or harmful
- Your advice for how such tools should (or shouldn't) be used in the NHS

With your permission, the interview will be audio recorded and transcribed**.** You will also be asked to complete a brief demographic form (age, gender, ethnicity, location, etc.). All data will be anonymised and securely stored. All data will be anonymised and securely stored in accordance with University policy.

Do I have to take part?

No. Taking part is completely voluntary. You are free to withdraw at any time up to one week after your interview, without giving a reason.

You can also skip any question or stop the interview at any time.

Will my participation be confidential?

Yes. This study is fully anonymous, and your responses cannot be linked back to you.

Informed consent

It is important that you are able to give your informed consent before taking part in this study.

What are the risks and benefits of taking part?

There are no known risks to taking part, but we understand that talking about palliative care can be emotionally difficult. You will not be asked to share anything you don't feel comfortable discussing.

You will receive a £20 voucher to thank you for your time. You will also receive a Debrief Sheet after the interview with details of support services, such as Marie Curie, NHS 24, and Cruse Bereavement Support.

Although there is no direct personal benefit, your insights will play a vital role in helping the NHS understand how to communicate better and plan support around palliative care.

How will my data be used and stored?

Your data will be treated in accordance with UK GDPR and University of St Andrews data protection policies. The University of St Andrews (the 'Data Controller') is bound by the UK 2018 Data Protection Act and the General Data Protection Regulation (GDPR), which require a lawful basis for all processing of personal data (in this case it is the 'performance of a task carried out in the public interest' – namely, for research purposes) and an additional lawful basis for processing personal data containing special characteristics (in this case it is 'public interest research').You have a range of rights under data protection legislation. For more information on data protection legislation and your rights visit https://www.st-andrews.ac.uk/terms/data-protection/rights/. For any queries, email dataprot@st-andrews.ac.uk.

Your data (including the eligibility screening, consent, demographic questions and interview data) will be initially stores pseudonymously (using an ID code and a key), until the interview has been transcribed, at which point the key is deleted and the data is anonymous. Only the research team will have access to identifiable data and key during the data collection. Your anonymised responses may be quoted in academic publications, reports, and presentations, but you will not be identifiable in any materials shared. You will be able to withdraw your data up to one week post interview, after which the anonymised data cannot be recognised as yours to be withdrawn.

How will our data be used, and in what form will it be shared further?

Your anonymised data will be used only for research, academic publications, public engagement, and policy discussions. The anonymised dataset will be securely stored on the University's OneDrive system, with access to the research team only.

When will our data be destroyed?

Locally stored copies of the data will be deleted once the dataset has been archived in the St Andrews Research Repository. Anonymised data will be retained in the repository for up to 10 years, in accordance with research data management policies.

Who is organising and funding the study?

This research is being conducted by Dr Emma Louise Gale**,** a Research Fellow at the University of St Andrews. It is part of a larger project exploring how digital tools might be ethically and practically used in NHS palliative care. This study has received full ethical approval from the University Teaching and Research Ethics Committee (UTREC) MD-0698-832-2025.

What should we do if we have concerns about this study?

In the first instance, you are encouraged to raise your concerns with the researcher. However, if you do not feel comfortable doing so, then you should contact the School Ethics Contact (contact details below). A full outline of the procedures governed by the University Teaching and Research Ethics Committee is available at https://www.st-andrews.ac.uk/research/integrity-ethics/humans/ethical-guidance/complaints/

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