

Exploring the acceptability of and implementation of SUGEST: Diverse caregivers' perspectives on a machine learning-supported prognostic tool for earlier identification of palliative care needs

Emma Louise Gale

eg243@st-andrews.ac.uk

University of St Andrews

Sarah P Bowers

University of St Andrews

Joanna Bowden

University of St Andrews

Kristian Pollock

University of Nottingham

Luciana R Pedro

University of St Andrews

Lynsey R Brown

University of St Andrews

Colin McCowan

University of St Andrews

Sarah E.E. Mills

University of St Andrews

Research Article

Keywords: qualitative, interviews, NHS, artificial intelligence, healthcare, health systems, end-of-life care, health equity, shared decision-making, advanced care planning

Posted Date: October 9th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-10895385/v1>

License:   This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Additional Declarations: No competing interests reported.

Abstract

Background

Earlier identification of people who may benefit from palliative care creates opportunities for timely conversations and future care planning yet frequently occurs late in the illness trajectory. Machine learning-supported approaches using routinely collected healthcare data may support earlier identification, but little is known about their acceptability to family caregivers, particularly those from communities experiencing health inequalities. The Scottish Unscheduled Geriatric End-of-Life Screening Tool (SUGEST) is being developed to identify patterns of unscheduled healthcare use that may indicate unmet palliative care needs. This paper reports caregiver perspectives on the acceptability, perceived benefits, communication and future implementation of SUGEST.

Methods

Semi-structured interviews were conducted with family caregivers across Scotland. Purposive sampling included participants from diverse backgrounds and communities experiencing health inequalities. The interview guide, developed with a Patient and Public Involvement group, explored experiences of palliative care and perspectives on SUGEST. Interviews were transcribed verbatim and analysed using reflexive thematic analysis.

Results

Fifteen bereaved family caregivers participated. Five themes were generated: (1) the lived experience of fragmented and crisis-driven care; (2) trust and acceptability of SUGEST; (3) the perceived benefits of earlier identification of palliative care needs; (4) communication and preferences for the use of SUGEST; and (5) implementing SUGEST in practice. Caregivers described care pathways as reactive and fragmented, with repeated crises and perceptions that palliative care was introduced too late. Participants were largely positive about SUGEST's potential to prompt earlier recognition of unmet need, enabling timely conversations, future care planning and support. Acceptability was conditional upon transparent and representative data, clinician oversight, compassionate and appropriate communication, and clinical pathways capable of responding to identified need.

Conclusions

Caregivers perceived the value of SUGEST to lie not in identifying risk itself, but in what earlier identification could enable. Machine learning-supported identification should prompt clinical review, creating opportunities to assess palliative care needs and initiate sensitive conversations, future care planning and support. Realising this potential requires trustworthy, equitable and adequately resourced

systems with clear pathways from identification to clinical action. These findings will inform the development and implementation of SUGEST and wider machine learning-supported approaches to earlier identification of palliative care needs.

1. Introduction

The global need for palliative care continues to increase as populations age, multimorbidity becomes more common and more people live for longer with advanced progressive illness [1]. Timely access to palliative care improves quality of life, symptom management, advance care planning and a range of patient and caregiver outcomes, whilst reducing unnecessary out-of-hours or emergency healthcare utilisation [2–5]. Despite these well-established benefits, under-identification of people who may benefit from palliative care, and resultant substantial unmet need, remains. Preventable serious health-related suffering at the end of life is projected to increase globally from 26 million people annually to 48 million by 2060 [6], with recent evidence indicating that 45.6% of decedents in England and 43.0% in Wales experienced insufficient primary palliative care provision during their final three months of life [7]. Many people also continue to be identified late in the course of illness, limiting opportunities for proactive planning and coordinated support [8]. Earlier identification of palliative care needs therefore remains one of the major challenges facing healthcare systems internationally.

Current approaches to identifying patients who may benefit from palliative care rely largely on clinician judgement or the use of structured screening tools [9], such as the Supportive and Palliative Care Indicators Tool (SPICT) [10], the Gold Standards Framework [11] and the Palliative Needs World Health Organization Collaborating Centre–Catalan Institute of Oncology (NECPAL) tool [12]. These can be used across a range of primary, community and secondary care settings. Although these approaches can improve recognition of potential palliative care needs, they depend upon clinicians' unprompted identification of patients who may have unmet palliative care needs and relies on clinicians having an awareness of the tool, the time and ability to make use of it in a clinical context and making consistent and informed decision-making. These factors combine to make implementation of existing tools, and identification of people with unmet palliative care needs, challenging within busy clinical environments [9]. This is particularly relevant in unscheduled care settings, where many patients experience repeated emergency department attendances or out-of-hours contacts during the final months of life, often representing missed opportunities for earlier identification and future care planning [13–16].

Consequently, palliative care pathways frequently remain reactive, with support introduced only after repeated crises or significant clinical deterioration [17].

Recent advances in routinely collected electronic health records and machine learning have created new opportunities to more reliably and proactively identify patients who may benefit from palliative care [9, 18]. Machine learning-supported prognostic models have demonstrated encouraging predictive performance across a range of healthcare settings, suggesting that they may complement existing approaches by identifying patients who might otherwise be overlooked [9]. In the United States, the Geriatric End-of-Life Screening Tool (GEST) was developed using routinely collected electronic health

record data to identify older adults attending emergency departments who were at high risk of six-month mortality, with the aim of creating opportunities for advance care planning and palliative care assessment [18]. The GEST therefore provides an example of how automated screening of routinely collected healthcare data can identify individuals who may benefit from further clinical assessment [18]. Importantly, such approaches are intended to support and supplement clinical judgement rather than to replace it. However, despite emerging work exploring their translation into clinical practice, considerably less attention has been paid to the acceptability and practical implementation of prognostic models within routine care.

Successful implementation of machine learning in healthcare depends on more than technical performance. Increasing attention has been directed towards issues of transparency, explainability, fairness, data quality and algorithmic bias, alongside wider questions concerning trust, communication, organisational readiness and health inequalities [19–22]. These considerations are reflected in the Scottish policy context, which emphasises the development and adoption of trustworthy, ethical and inclusive AI and recognises challenges relating to safety, explainability, generalisability, bias and local implementation within healthcare [23]. Without careful consideration of these factors, technologies intended to improve care risk reinforcing existing inequities or failing to translate into meaningful improvements in practice. Understanding stakeholder perspectives is therefore essential to ensure that machine learning-supported tools are implemented in ways that are acceptable, equitable and responsive to the needs of patients and families.

Family caregivers occupy a unique position within palliative care, frequently coordinating care, navigating complex healthcare systems and participating in decisions throughout the illness trajectory [24]. Their experiences provide valuable insights into barriers to timely identification, communication and service delivery [25], yet their perspectives on machine learning-supported tools for earlier identification remain largely unexplored. This evidence gap is particularly evident for caregivers from underserved communities and those whose experiences are shaped by wider contextual factors associated with health inequalities [26, 27]. Understanding these perspectives is essential to ensure that future implementation reflects the priorities of those most closely involved in care.

The Marie-Curie funded *Scottish Unscheduled Geriatric End-of-Life Screening Tool (SUGEST)* programme uses a mixed-methods applied health research approach to develop and validate a machine learning-supported tool to facilitate earlier identification of people who may benefit from assessment of palliative and end-of-life care needs within NHS Scotland. Building on the principles demonstrated by GEST, SUGEST is being developed to use routinely collected healthcare data to examine patterns of unscheduled and escalating healthcare use preceding death and to identify patterns that may indicate emerging or unmet palliative care needs. Building on the GEST approach, SUGEST is intended to flag individuals whose patterns of healthcare use suggest that further clinical assessment may be warranted to identify unmet care needs and risk of near-term mortality, thereby creating opportunities for earlier recognition, future care planning and appropriate support. The SUGEST approach is therefore intended to

supplement rather than replace clinical judgement and to identify people whose needs might otherwise remain unrecognised until much later in their illness course.

The aim of this study was to explore caregivers' perspectives on the acceptability, perceived potential benefits, communication and implementation of SUGEST [28]. By examining the experiences of caregivers from diverse backgrounds, this study sought to identify the conditions under which machine learning-supported tools could be integrated into routine palliative care practice in ways that are acceptable, equitable and person-centred.

2. Methods

2.1. Study design

This qualitative interview study formed part of the wider SUGEST research programme, which comprises four interconnected work packages (Fig. 1) [28]. Work Packages 1–3 focus on developing, comparing and externally validating SUGEST using routinely collected healthcare data, including consideration of how differences in healthcare access and patterns of service use among people with protected characteristics and other underserved groups may influence identification and care pathways and outcomes. Work Package 4 uses qualitative research with patients, unpaid caregivers and healthcare professionals to inform the development, communication and future implementation of SUGEST, with particular attention to acceptability, ethics, equity and experiences associated with health inequalities.

Within Work Package 4, patients and caregivers participated in the first phase of qualitative interviews, followed by healthcare professionals in the second phase. Patient, caregiver and healthcare professional data were analysed separately to reflect their distinct roles, experiences and perspectives of palliative care and will be reported separately. This manuscript reports findings from the caregiver interviews. By exploring caregivers' perspectives while SUGEST is still under development, the study sought not simply to evaluate the acceptability of a predetermined tool, but to inform how SUGEST should be developed and implemented in practice, including its communication, use in clinical decision-making and implications for equitable palliative care.

An interpretivist qualitative approach was adopted to explore how caregivers understood and made sense of the potential use of a machine learning-supported prognostic tool [29]. Semi-structured interviews were selected to allow participants to describe their experiences and perspectives in their own words while providing flexibility to explore emerging issues in greater depth. Data were analysed using Braun and Clarke's reflexive thematic analysis, allowing themes to be developed inductively from participants' accounts [30].

Ethical approval

was obtained from the University of St Andrews Teaching and Research Ethics Committee (MD-0698-832-2025), and all participants provided written informed consent prior to participation. The protocol

was published prior to recruitment via the Open Science Framework to aid in methodology transparency [28].

2.2. Patient and public involvement

Patient and public involvement informed the design, ethical development and conduct of the study. Contributors were recruited through the Fife Centre for Equalities and through community support groups engaged by the research team. The group included individuals with lived experience of palliative and end-of-life care, alongside representatives from underserved and marginalised communities.

The PPI group feedback informed the study design, participant-facing materials, recruitment strategy and semi-structured interview guide to enhance the acceptability, accessibility and inclusivity of the study. Through a series of structured workshops, contributors reviewed the participant information sheet, consent form, recruitment materials and interview guide, refining its wording, structure and content. The revised interview guide was then piloted with the group prior to participant recruitment, with minor amendments made to improve its clarity and relevance.

2.3. Participants and recruitment

Unpaid caregivers were recruited to explore perspectives on the acceptability and feasibility of SUGEST. Caregivers were defined as adults (≥ 18 years) who were currently providing, or had previously provided, unpaid care and support to an individual receiving palliative or end-of-life care. Participants were required to have the capacity to provide informed consent and be able to participate in an interview conducted in English. Individuals who were unable to provide informed consent were excluded.

Purposive sampling [31, 32] was used to recruit caregivers with diverse demographic, socioeconomic and geographical characteristics from across Scotland. Recruitment specifically sought to include participants from underserved communities and protected characteristic groups, recognising the importance of ensuring that the future implementation of SUGEST is informed by a broad range of lived experiences.

Participants were recruited through community, voluntary-sector and healthcare organisations, including Marie Curie and the Fife Centre for Equalities, using study advertisements, participant information sheets, QR codes linking to study information and social media. Participants were not recruited directly through NHS services. This was an intentional recruitment strategy, recognising that people from underserved communities and those with protected characteristics may access and engage with healthcare services differently, and that recruitment solely through established healthcare pathways could therefore exclude or underrepresent some groups. To broaden access to participation, the lead researcher (ELG) attended caregiver support groups both online and in person to introduce the study and answer questions. Snowball sampling was also used, whereby participants shared study information within their own networks.

Recruitment and data collection occurred concurrently, allowing participant characteristics to be reviewed throughout the recruitment period. Recruitment ceased when the planned sample had been recruited and the dataset was considered sufficient to address the study aims.

2.4. Procedure and materials

2.4.1. Study materials

A semi-structured interview guide was developed and piloted by the research team in collaboration with a patient and public involvement (PPI) group to improve its clarity, relevance and acceptability (Section 2.4). The interview guide explored caregivers' experiences of palliative and end-of-life care before introducing the SUGEST tool and discussing its perceived acceptability and feasibility (Supplementary file 1). Open-ended questions and prompts were incorporated throughout to facilitate discussion while allowing participants to raise issues they considered important.

2.4.2. Data collection

Individuals expressing an interest in participating contacted the research team after receiving study information through participating organisations or study advertisements. Following initial contact, potential participants completed a screening questionnaire to confirm their eligibility. Screening responses and subsequent correspondence were reviewed for consistency and authenticity, with additional eligibility checks undertaken where required to minimise the inclusion of fraudulent or automated responses. Eligible individuals were then provided with a participant information sheet and given the opportunity to discuss the study and ask questions before providing written informed consent.

Following consent, participants completed a demographic questionnaire before an interview was arranged. All interviews were conducted (by ELG) using a semi-structured format and took place either face-to-face in a private research room at the University of St Andrews, via Microsoft Teams or by telephone, according to participant preference. At the beginning of each interview, participants were reminded that participation was voluntary and that they could decline to answer any question, pause the interview or withdraw at any time without providing a reason.

The interview guide provided a consistent framework across interviews while allowing flexibility to explore participants' experiences in greater depth. Interviews began by exploring caregivers' experiences of palliative and end-of-life care before introducing the SUGEST tool and discussing its perceived acceptability, feasibility and implementation. Prompts and follow-up questions were used where appropriate to clarify responses and explore emerging topics. Interviews were audio-recorded with participants' consent, using Microsoft Teams for online interviews and a digital audio recorder for face-to-face and telephone interviews. Following each interview, participants received a £20 voucher in recognition of their time and contribution and were provided with a debrief sheet containing relevant sources of support and information about the subsequent handling of their data. The lead researcher also completed a reflexive log documenting methodological observations, emerging interpretations and reflections on the interview process to support the ongoing analytical process.

2.4.3. Data management

Audio recordings were transcribed verbatim (by ELG) and checked against the original recordings to ensure accuracy and completeness. Transcripts were pseudonymised through the removal of identifiable information and the allocation of unique participant identification numbers prior to analysis. Audio recordings, transcripts and study documentation were stored securely, and access was limited to members of the research team as per University standard policy on retention and management of research data.

2.5. Data analysis

Data were analysed using Braun and Clarke's reflexive thematic analysis [30]. An inductive approach was adopted, allowing codes and themes to be developed from participants' accounts rather than informed by pre-existing theoretical frameworks [33]. Analysis commenced alongside data collection to support familiarisation with the dataset and exploration of emerging concepts. Anonymised transcripts were imported into Quirkos 3 (Quirkos Ltd., Edinburgh, UK) for analysis.

Initial semantic coding was undertaken systematically across all transcripts and refined iteratively as analysis progressed. Through repeated engagement with the data, codes were organised into broader patterns of shared meaning, supporting the development and refinement of latent themes. Reflexivity was embedded throughout the analytical process through the maintenance of a reflexive journal documenting methodological decisions, emerging interpretations and researcher reflections. To enhance analytical rigour, a randomly selected 20% of transcripts were independently examined by a second researcher (SPB), with developing interpretations discussed regularly within the multidisciplinary research team and the SUGEST Patient and Public Involvement group to challenge assumptions, explore alternative interpretations and refine the final themes.

3. Results

3.1. Participant characteristics

Recruitment took place between August 2025 and January 2026. Twenty-one individuals expressed interest in participating, of whom 4 did not proceed after receiving the study information and 2 did not meet the eligibility criteria applied during recruitment. The remaining 15 individuals participated in the study.

All 15 participants were bereaved family caregivers (mean age = 44.2 ± 17.3 years; range = 20–70 years) of whom 9 (60.0%) were female. Most participants were first-degree relatives of the individual they had cared for (12; 80.0%), while 3 (20.0%) were second-degree relatives. Most interviews were conducted via Microsoft Teams (12; 80.0%), with the remainder undertaken face-to-face (3; 20.0%). Mean interview duration was 35.0 minutes (SD = 5.8; range = 28–48 minutes).

Purposive sampling achieved a diverse sample. Nine participants (60.0%) identified as belonging to an ethnic minority group, with representation from African, East Asian, Middle Eastern, South Asian and Eastern European backgrounds, including first- and second-generation migrants, refugees and individuals with lived experience of seeking asylum. Eight (53.3%) were recruited from areas of high socioeconomic disadvantage, 4 (26.7%) had experience as young carers and 3 (20.0%) resided in rural communities. Five participants (33.3%) reported neurodivergence or mental health conditions, while a further 2 (13.3%) identified as living with a disability. Six (40.0%) identified with a practising faith, including Buddhism, Christianity, Hinduism and Islam.

3.2. Thematic findings

Reflexive thematic analysis identified five overarching themes that captured caregivers' perspectives on the acceptability and future implementation of SUGEST (Fig. 2). Together, these themes describe caregivers' views on the opportunities, challenges and practical considerations associated with integrating a machine learning-supported prognostic tool into routine palliative care.

Note

Protected characteristics (as defined by the Equality Act 2010; e.g. age, gender, ethnicity, disability, faith, socioeconomic status, migrant/refugee or asylum seeker background) and other contextual factors (rurality and caring experience) influence and intersect with all themes

3.2.1. Theme 1: Lived Experience of Care Use

Theme 1 comprised five subthemes reflecting caregivers' experiences of navigating unscheduled and palliative care while caring for a relative with a life-limiting illness (Table 1). Participants described repeated cycles of crisis, fragmented care pathways, delayed access to palliative care and the emotional burden of caregiving, alongside the influence of protected characteristics and wider contextual factors on experiences of accessing and navigating healthcare services.

Table 1
Analytical structure of Theme 1: Lived Experience of Care Use

Subtheme	Sub-subthemes	Description
1.1 Living in repeat crisis routine	1.1.1 Regular out-of-hours use 1.1.2 Excessive waiting times 1.1.3 Repeated escalation 1.1.4 Crisis ambiguity (not clear what counts as urgent) 1.1.5 Crisis as ongoing, not episodic	Caregivers described repeated cycles of crisis characterised by frequent reliance on unscheduled care, prolonged waiting times, escalating healthcare needs and uncertainty surrounding when urgent care should be sought.
1.2 Systems respond late and in fragments	1.2.1 Services not joining the dots 1.2.2 Passed between departments excessively 1.2.3 Not set up across health boards 1.2.4 Mortality before help 1.2.5 Extended suffering from delayed systems 1.2.6 Loss of continuity of care 1.2.7 System delay through 'waiting and seeing'	Participants described fragmented healthcare systems characterised by poor coordination, delayed recognition of deterioration, lack of continuity and prolonged delays in accessing appropriate palliative care.
1.3 Emotional distress from unscheduled care use	1.3.1 Core burden 1.3.2 Ongoing vigilance and pressure 1.3.3 Distress from interaction with service 1.3.4 Distress from health care environment	Caregivers described considerable emotional burden associated with caring, including continual vigilance, pressure to make decisions and distress arising from both interactions with healthcare services and the healthcare environment itself.

Subtheme	Sub-subthemes	Description
1.4 Palliative relief as both relief and threat	1.4.1 Palliative care came too late 1.4.2 Palliative care needs reframing 1.4.3 Palliative care as relief 1.4.4 Palliative care as threat 1.4.5 Timing conflict within families 1.4.6 Transition from treatment to comfort 1.4.7 Role of individuals in making palliative care transition 1.4.8 Palliative care as structured support vs system absence	Participants viewed palliative care as both a valuable source of support and a challenging transition, with experiences shaped by the timing of referral, perceptions of palliative care and differing family readiness for its introduction.
1.5 Difference and inequity shape whether people feel seen and heard	1.5.1 Cultural and religious frameworks shape care use 1.5.2 Language barriers and translation burden 1.5.3 Socioeconomic constraints shaping care decisions 1.5.4 Neurodivergence and mental health affecting care interaction 1.5.5 Migrant and minority experiences of mistrust 1.5.6 Being perceived and treated as “difficult” or “less deserving” 1.5.7 Structural invisibility of complex patients	Participants described how protected characteristics and wider contextual factors influenced experiences of accessing, navigating and receiving care, contributing to inequitable experiences and feelings of not being seen, heard or understood within the healthcare system.

Repeated cycles of crisis featured prominently in caregivers' accounts. Participants described episodes of deterioration being managed through repeated attendances at Emergency Departments (EDs), urgent General Practitioner (GP) appointments and emergency hospital admissions. Rather than being isolated events, these episodes formed an ongoing pattern characterised by uncertainty about when symptoms required urgent intervention and repeated escalation of care before support was received. Prolonged waiting times during episodes of acute deterioration further contributed to feelings of helplessness.

"It was just... cycles. Emergency admission, discharge, 'keep an eye on him.' Over and over. Nothing planned. Nobody joining the dots." (C04)

"We were there nearly nine hours before a doctor even saw her. She was gasping... I remember one nurse saying, 'We've no beds, love.'" (C03)

Participants consistently described fragmented healthcare pathways. Poor communication between healthcare professionals, repeated referrals between services and a lack of continuity meant that caregivers frequently became the central coordinators of care, repeatedly needing to explain medical histories, organising appointments and transferring information between services. Delayed recognition of deterioration and repeated "wait and see" approaches reinforced perceptions that opportunities for earlier referral to palliative care had been missed.

"Every appointment felt like another delay. 'Let's try this.' 'Let's wait and see.'" (C01)

These experiences placed a considerable emotional burden on caregivers, who described living in a continual state of heightened vigilance, monitoring subtle changes in health, anticipating deterioration and deciding when emergency care should be sought. Participants also described uncertainty surrounding illness progression, distress associated with repeated healthcare encounters and the weight of the responsibility of advocating for relatives.

"That limbo is incredibly draining. You're always braced for the next crisis, but never quite allowed to plan." (C02)

Although palliative care was generally viewed positively once introduced, many participants felt that it was introduced too late. Participants described palliative care as providing reassurance, holistic support and improved symptom management, yet the term itself was frequently understood as signifying dying or the withdrawal of active treatment. Participants described mixed emotions surrounding its introduction, with some families welcoming additional support while others initially viewing referral with apprehension.

"That came late, far too late, if you ask me... By the time the word 'palliative' was even mentioned, she was already barely eating." (C03)

Finally, participants described how aspects of their identities and wider contextual factors shaped experiences of care. Cultural and religious beliefs influenced caregivers' perceptions of illness, hospital

attendance and discussions surrounding death, while language barriers often required family members to interpret information during healthcare encounters. Socioeconomic disadvantage, migration experiences, neurodivergence, disability, previous caring responsibilities and rurality further adversely influenced access to services, communication with healthcare professionals and navigation of the healthcare system.

"Where we come from, you don't rush to hospital. You wait. You pray. You see if it passes. But here... waiting sometimes made things worse." (C05)

Participants also reflected that the individuals who they cared for with complex or intersecting needs were sometimes perceived as "difficult" or "less deserving", resulting in their concerns being minimised or overlooked by clinicians. They described how multiple intersecting needs could render some patients structurally invisible within healthcare systems, with services often failing to recognise or respond to the full context of their circumstances.

3.2.2. Theme 2: Negotiating Trust and Acceptability of SUGEST

Theme 2 comprised four subthemes reflecting caregivers' views on trust and acceptability of SUGEST (Table 2). Participants described trust as fundamental to the tool's acceptability, with their level of confidence in the tool depending on transparent data use, the quality and interpretation of healthcare records, appropriate safeguards and meaningful human oversight. They also identified ethical, practical and implementation considerations that would influence trust in its future use.

Table 2
, Analytical structure of Theme 2: Negotiating trust and acceptability of SUGEST

Subtheme	Sub-subthemes	Description
2.1 Data usage in designing and delivering SUGEST	2.1.1 Consent, control and transparency 2.1.2 Data accuracy and completeness concerns 2.1.3 Data representing real lives 2.1.4 Interpretation of data versus reality 2.1.5. Moral acceptability of using data in this way 2.1.6 Data inequity and representation risks	Participants discussed how healthcare data should be used within SUGEST, emphasising the importance of consent, transparency, data quality, accurate representation of patients' lived experiences and equitable use of routinely collected information.
2.2 Distrust in SUGEST design	2.2.1 Distrust in systems versus individuals 2.2.2 Distrust in data systems and record keeping 2.2.3 Distrust in objectivity and neutrality 2.2.4 Distrust in algorithmic decision making	Participants distinguished between trust in individual healthcare professionals and trust in healthcare systems, expressing concerns regarding data quality, algorithmic decision-making, objectivity and the reliability of healthcare records used to inform SUGEST.
2.3 Concerns and consequences of SUGEST	2.3.1 Inequality and bias amplification 2.3.2 Emotional and psychological consequences 2.3.3 Labelling and identity risks 2.3.4 Clinical and ethical boundaries	Participants described potential ethical, emotional and practical consequences of SUGEST, including risks of bias, inequity, labelling, psychological distress, cultural conflict, unreliable predictions and unintended impacts on groups with protected characteristics.

Subtheme	Sub-subthemes	Description
	2.3.5 Cultural and religious conflict 2.3.6 Scope and reliability concerns 2.3.7 Moral and ethical discomfort with the tool 2.3.8 Protected characteristic-specific risks	
2.4 Considerations for designing SUGEST	2.4.1 Co-design and real-world testing 2.4.2 Inclusivity and fairness 2.4.3 Action after identification 2.4.4 Transparency and safeguards	Participants identified key considerations for the future design and implementation of SUGEST, emphasising co-design, inclusivity, transparency, appropriate safeguards and ensuring that identification through the tool is followed by meaningful clinical action and support.

In addition to trust, participants described transparency as fundamental to the acceptability of SUGEST. Many wanted to understand what information of theirs would be used, how predictions would be generated and who would have access to their healthcare data. Participants emphasised the importance of consent, maintaining control over personal information and being able to question or correct inaccurate records. They also questioned whether routinely collected healthcare data adequately reflected the complexity of people's lives, expressing concerns that incomplete or fragmented records could result in decisions based on an incomplete understanding of patients' circumstances.

"I'd want transparency. What data. How it's used. Who sees it. And the ability to challenge it if it's wrong."
(C01)

"I'd be furious, unless they showed me what it was based on and let me correct it. Because otherwise you're planning care based on fiction." (C11)

Participants distinguished between trusting individual healthcare professionals and trusting healthcare systems. While confidence in clinicians was generally high, trust in healthcare records, organisational systems and algorithmic decision-making was considerably lower. Previous experiences of incomplete records, poor communication between services shaped how participants perceived institutional trust.

"I trust individual nurses. I trust some doctors. I don't trust systems. Things fall through gaps constantly."
(C01)

"Bias isn't something algorithms fix... If the data reflects fragmented care... then the output will too." (C02)

Participants also identified potential risks associated with SUGEST, including the amplification of existing inequalities where healthcare records failed to capture patients' circumstances. Concerns were raised relating to the emotional impact of prognostic predictions, the risk of labelling individuals, the reliability of predictions based on incomplete data and the ethics of using AI to support end-of-life care.

"It will be used to categorise people. And people like my husband, with alcoholism, will be categorised as 'less worthy'. I've seen it already. A tool won't remove that. It'll make it quicker." (C11)

"Honestly? It makes me uncomfortable. I don't like the idea of a computer predicting death." (C07)

Despite these concerns, participants identified practical ways to improve trust in SUGEST. They emphasised involving patients, caregivers and healthcare professionals throughout development and implementation, ensuring the tool reflects their diverse situations and experiences, incorporates appropriate safeguards and supports, rather than replaces, clinical judgement. Participants also stressed that earlier identification should be accompanied by meaningful support rather than prognostic information alone.

"Keep people involved, real families, carers, patients. Let us test it, give feedback." (C03)

"Planning is important. But only if there is support alongside it... only if it comes with real help, not just words." (C13)

"Explain what the tool does, what it doesn't do, and make it clear it doesn't replace human judgement." (C08)

3.2.3. Theme 3: Perceived Benefits of SUGEST

Theme 3 comprised two subthemes reflecting caregivers' perspectives on the potential benefits of implementing SUGEST (Table 3). Participants described how earlier identification of palliative care needs could improve planning, emotional preparedness, support for patients and families, quality of care and healthcare delivery. They also viewed SUGEST as enabling more proactive and equitable care while reducing reliance on crisis-driven, unscheduled care.

Table 3
Analytical structure of Theme 3: Perceived benefits of SUGEST

Subtheme	Sub-subthemes	Description
3.1 Benefits for patients and families	3.1.1 Earlier identification and planning	Participants described how SUGEST could benefit patients and families through earlier identification of palliative care needs, improved planning, greater emotional preparedness, increased support and enhanced quality of care.
	3.1.2 Emotional benefits for families	
	3.1.3 Increased support and engagement	
	3.1.4 Dignity and quality of care	
3.2 Benefits for healthcare systems	3.2.1 Financial improvements in the NHS	Participants described how SUGEST could improve healthcare delivery by supporting earlier intervention, reducing avoidable crisis care, improving efficiency, addressing inequalities and increasing confidence in clinical decision-making.
	3.2.2 Reducing inequalities	
	3.2.3 Improved care quality	
	3.2.4 Improved system efficiency	
	3.2.5 System confidence and trust building	

Participants consistently described earlier identification as the principal benefit of SUGEST. Many believed recognising deterioration sooner would provide patients and families with more time to prepare for future care, discuss preferences and make practical decisions. Earlier planning was viewed as reducing uncertainty, facilitating timely conversations about palliative care, improving symptom management and increasing access to support services.

"If identifying risk means earlier referrals to get earlier appointments, better symptom management, fewer emergency trips, then yes, that's a good thing." (C15)

"I'd plan better, definitely. Maybe set up power-of-attorney, get my papers sorted, even talk to [redacted] about what I want. It takes the fear away when you've got a plan." (C03)

Participants also described important emotional benefits for patients and families. Earlier identification was viewed as reducing uncertainty, improving preparedness and helping families feel better supported throughout the illness trajectory. Several participants believed it could reduce feelings of abandonment

and promote more compassionate, dignified care by enabling conversations before deterioration reached crisis point.

"It could reduce the limbo." (C02)

"It would help people feel less abandoned." (C03)

"Knowing earlier would've been... empowering, actually." (C06)

Participants also identified potential benefits for healthcare systems. Earlier identification was viewed as reducing avoidable emergency admissions, improving care planning and supporting more efficient use of healthcare resources through greater access to community-based care.

"It could save the NHS money too, fewer ambulances, fewer admissions." (C03)

"Instead of constant crisis mode, we could have slowed things down. We could've planned care at home properly, rather than reacting every time something went wrong." (C04)

Several participants further suggested that SUGEST could improve equity and consistency by identifying individuals who might otherwise remain overlooked, particularly those less likely to seek support. Earlier recognition was also perceived as increasing clinicians' confidence to initiate palliative care conversations and reducing the moral distress associated with recognising deterioration only after repeated crises.

"Design it for the quiet ones. The ones who don't complain. The ones who feel grateful even when they're struggling. If your tool helps them be seen, then it is doing something right." (C05)

"Anything that helps flag patterns earlier... repeated admissions, escalating needs... could reduce moral distress for staff. That feeling of, we should have seen this sooner." (C12)

3.2.4. Theme 4: Communication and Use Preferences of SUGEST

Theme 4 comprised six subthemes reflecting caregivers' preferences for communicating information generated by SUGEST (Table 4). Participants described communication as extending beyond the delivery of prognostic information to encompass who should be involved, how and when conversations should occur, and the need for compassionate communication, ongoing support and individual choice.

Table 4
Analytical structure of Theme 4: Communication and use preferences of SUGEST

Subtheme	Sub-subthemes	Description
4.1 Who should be involved in conversations	4.1.1 Patient, carer and family involvement 4.1.2 Professional roles and trusted relationships 4.1.3 Cultural, relational and decision-making control	Participants described conversations about SUGEST as requiring involvement of the patient and those they wished to include, facilitated by trusted healthcare professionals who understood individual, cultural and family contexts.
4.2 What information should be communicated	4.2.1 Amount and pacing of information 4.2.2 Type and framing of information 4.2.3 Clarity and accessibility of information 4.2.4 Personal relevance and meaning of information	Participants described information about SUGEST as needing to be personalised, clearly explained and paced according to individual preferences, with an emphasis on practical meaning, accessibility and future planning rather than prediction alone.
4.3 How should conversations be delivered	4.3.1 Mode and format of communication 4.3.2 Interpersonal approach and communication style 4.3.3 Time, pace and flexibility of conversations 4.3.4 Enabling understanding and interaction 4.3.5 Language, translation and accessibility in delivery	Participants described conversations as being most effective when delivered using compassionate, person-centred communication, appropriate formats, accessible language and sufficient time to support understanding, dialogue and shared decision-making.
4.4 Ongoing support and follow-up	4.4.1 Immediate support following identification 4.4.2 Continuity and consistency of support 4.4.3 Ongoing and adaptive support over time	Participants described communication as an ongoing process that should be accompanied by timely, consistent and holistic emotional, practical and clinical support responsive to changing needs over time.

Subtheme	Sub-subthemes	Description
	4.4.4 Holistic and practical support needs 4.4.5 Accessibility and inclusivity of follow-up support	
4.5 Timing and setting of conversations	4.5.1 Timing conversations before escalation 4.5.2 Avoiding A&E and acute distress 4.5.3 Private, calm and familiar settings	Participants described conversations as being most appropriate before crisis occurred and in private, calm and familiar environments that supported sensitive discussion, reflection and future care planning.
4.6 Choice, autonomy and control in communication	4.6.1 Choice over engagement with the tool 4.6.2 Control over information and involvement 4.6.3 Respecting individual preferences and readiness	Participants emphasised the importance of preserving individual choice regarding engagement with SUGEST, the amount and format of information received, who should be involved in discussions and the pace at which conversations occurred.

Participants consistently emphasised that patients should retain control over whether they received information about SUGEST and who they wished to involve in conversations. Where patients wished to receive information, participants felt that conversations should involve the patient alongside those they chose to include, rather than assuming family or caregiver involvement. Preferences varied according to individual circumstances, including situations where patients chose not to receive information themselves, but caregivers required information to prepare for future care. Trusted healthcare professionals with established relationships with the caregiver and patient in familiar settings were consistently preferred, alongside communication that recognised cultural beliefs, family dynamics and different approaches to shared decision-making.

"Only who the patient chooses." (C07)

"Me first. I was the carer. I was the one there all the time. If my wife wanted others involved, then of course. But it shouldn't be assumed." (C08)

"Someone who knows us. Not someone reading notes for the first time." (C05)

Participants preferred information that was personalised, practical and delivered progressively over time, rather than in a one-off conversation. Rather than numerical predictions or life expectancy estimates,

they wanted clear information about what earlier identification meant for future care, available support and practical next steps. Information was expected to be delivered in plain language, repeated where necessary and tailored to individual preferences.

"Slowly. Repeated. In plain language. Written down as well as spoken." (C01)

"I wouldn't want numbers. No percentages, no 'six months', none of that." (C01)

"Tell me what it means practically. Is he deteriorating? What should I watch for? Who do I phone? What support can we get?" (C11)

Participants emphasised that how conversations were delivered was as important as the information itself. Face-to-face discussions were consistently preferred, supported by written information where appropriate. Compassionate communication, active listening, sufficient time and opportunities to ask questions were viewed as essential, alongside professional interpretation services where required.

"Face-to-face, every time. None o' this phone call nonsense." (C03)

"Listening, first of all. Let the person talk. Ask what they already understand." (C03)

"Proper interpreters, not family. Translating for your own parent is awful." (C04)

Participants emphasised that earlier identification should be accompanied by immediate emotional support, clear guidance about available services and practical next steps, regular follow-up with built-in continuity and support that reflected changing needs and social circumstances.

"Information without support is cruel. It raises anxiety and then leaves you alone with it." (C03)

"Not just information. If you're going to tell someone, you better have a plan for what happens next." (C11)

"I didn't need prediction, I needed practical support... respite, transport, someone to explain things." (C07)

Participants preferred conversations to occur proactively, before deterioration resulted in crisis, allowing sufficient time to prepare, ask questions and consider future care. Emergency departments and other acute healthcare settings were widely viewed as inappropriate environments for these conversations because of time pressures, distress and lack of privacy, with calm, familiar settings preferred.

"Maybe when it first shows up, not too early, but before you're in crisis." (C03)

"A&E is too frantic. That's not where you introduce conversations about the end of someone's life." (C10)

"In a wee quiet room, with someone who's got time." (C03)

Maintaining individual choice and autonomy was fundamental throughout participants' accounts. Although participants discussed choice in relation to SUGEST, their emphasis was primarily on what

followed identification: individuals should retain control over whether they received information, how much they received, who was involved and how communication was delivered. Participants also recognised that preferences could change over time and that decisions to decline information should be respected without judgement.

"It has to be a choice... maybe doctors could say, 'There's a tool that can help us plan ahead, would you like to use it?' That way you're not forcing it on people." (C03)

"Real choice. Not the kind where technically you can say no, but you feel like if you do, you'll be seen as difficult." (C09)

"Understand that refusing information is not ignorance... for some of us, hope is not denial, it is faith." (C07)

3.2.5. Theme 5: Enabling implementation of SUGEST in practice

Theme 5 comprised two subthemes reflecting caregivers' perspectives on implementing SUGEST in routine clinical practice (Table 5). Participants identified practical considerations for implementation, including integration within existing healthcare systems, organisational capacity to respond following earlier identification and ensuring healthcare professionals had the knowledge, skills and confidence to use SUGEST safely.

Table 5
, Analytical structure of Theme 5: Enabling implementation of SUGEST in practice

Subtheme	Sub-subthemes	Description
5.1 System integration and operational delivery	5.1.1 Embedding the tool into existing systems	Participants described successful implementation of SUGEST as dependent upon integration with existing healthcare systems, adequate organisational capacity and ensuring that identification through the tool resulted in meaningful clinical action and continuity of care.
	5.1.2 Capacity, resources and follow-through	
5.2 Workforce preparedness and training	5.2.1 Interpersonal, cultural and patient-centred skills	Participants described implementation as requiring a workforce equipped with the interpersonal, cultural and technical competencies needed to use SUGEST safely, communicate its outputs effectively and integrate algorithmic information with clinical judgement.
	5.2.2 Competence and safe use of the tool	

Participants consistently emphasised that SUGEST should be integrated into existing clinical systems rather than functioning as a standalone technology. Many questioned whether current healthcare infrastructure, including fragmented electronic health records and variation between health boards, could adequately support implementation. Participants also highlighted the challenges of delivering equitable implementation across diverse settings, particularly rural areas with more limited digital infrastructure and healthcare services. Organisational capacity was viewed as equally important, with participants

emphasising that earlier identification would only be beneficial if healthcare services had sufficient resources to respond. Identification without timely action, conversations or continuity of care was perceived as likely to increase frustration for patients and families.

"Algorithms don't work on reality. They work on representations of reality. And the NHS record is a very fragmented, inconsistent representation... Until transferring between boards like [redacted - two NHS boards] is genuinely fixed, any system built on top of that infrastructure will inherit its flaws." (C02)

"I think it could [improve care], if the system can keep up with it... But if people are identified and then nothing changes, that would feel quite cruel." (C15)

"A flag on a screen doesn't help unless it triggers resources, conversations, and continuity. Otherwise it's just information floating in the system." (C02)

Participants also emphasised the importance of workforce preparedness. Beyond understanding how SUGEST functioned, healthcare professionals were expected to possess strong interpersonal, cultural and patient-centred communication skills alongside the confidence to discuss uncertainty and palliative care sensitively. Participants stressed that data outputs from SUGEST should be recognised as probabilistic rather than definitive, interpreted alongside clinical judgement and individual circumstances, and challenged where they conflicted with clinical assessment. They also highlighted the importance of being able to correct inaccurate healthcare records to improve future decision-making.

"Clinicians need the permission to challenge the tool and to say, 'This doesn't match what I'm seeing.'" (C02)

"Staff need training not just on how the tool works, but how to talk about what it means." (C14)

"Training in humility." (C07)

4. Discussion

4.1. Principal findings

To our knowledge, this study is among the first qualitative studies to explore caregivers' perspectives on the acceptability, communication and implementation of a machine learning-supported prognostic tool designed to facilitate earlier identification of palliative care needs. Although increasing attention has focused on developing artificial intelligence (AI) and machine learning models for palliative care and refining existing screening tools, research has largely prioritised predictive performance, with comparatively little attention to caregiver acceptability or the social, ethical and organisational conditions required for successful implementation in routine clinical practice [5, 9, 18, 19, 21].

Caregivers' support for SUGEST was driven not by a desire for more accurate prognostic prediction, but by dissatisfaction with current models of identification for palliative care and its subsequent delivery. Participants described current care pathways as reactive, fragmented and characterised by repeated

cycles of crisis, emergency healthcare use and delayed access to supportive care, reflecting wider evidence that many people continue to be identified too late for palliative care approaches to their care despite the well-established benefits of earlier integration [3, 4, 34]. Within this context, earlier identification was seen as valuable because it could facilitate timely discussions, proactive care planning and earlier access to support, rather than because it could predict deterioration more accurately.

However, acceptability of SUGEST was consistently described as conditional. Four interdependent conditions underpinned caregivers' acceptance: **(1)** earlier identification had to trigger meaningful clinical action rather than simply generate additional information; **(2)** the technology needed to be trustworthy, transparent and informed by accurate, representative data; **(3)** earlier identification needed to be accompanied by compassionate, person-centred communication delivered by trusted healthcare professionals; and **(4)** successful implementation depended upon healthcare systems having sufficient capacity, continuity and resources to respond appropriately. Collectively, these findings demonstrate that technical readiness alone is unlikely to translate into successful clinical implementation.

4.2. Earlier identification of palliative care needs

One of the central findings of this study was that caregivers valued SUGEST because of its potential to facilitate earlier identification of people who may benefit from assessment of palliative care needs and future care planning, rather than for prediction alone. Participants described experiences of care as reactive and fragmented, with repeated emergency healthcare use and perceptions that supportive and palliative care were introduced too late. This reflects evidence that unscheduled care becomes increasingly concentrated towards the end of life. In a retrospective cohort of 56,407 decedents in Scotland, Mason et al. (2020) found that 94.9% had accessed at least one unscheduled NHS service during their final year, with contacts increasing substantially in the final month [14]. Extending this work, Bowers et al. (2026) examined 299,361 decedents in Scotland and found that people living with multiple long-term conditions had a 51% higher likelihood of using unscheduled care, with more frequent contacts beginning earlier in their final year than among those with fewer than two chronic conditions [16]. Similarly, Mills et al. (2019) found that among 2,443 Scottish patients with cancer, 60.4% of final-year unscheduled care attendances occurred during the final 12 weeks of life and 19.7% in the final week alone [15].

Comparable patterns are evident elsewhere in the UK. In a population linkage study in Wales, Chohan et al. (2025) found that 89% of patients with a likely palliative condition accessed emergency ambulance services during their final year, including 32% during their final seven days, with 58% of presentations resulting in acute hospital admission [35]. Similarly, McFerran et al. (2023) found that 48.9% of 3,134 patients with cancer in Northern Ireland experienced at least one unscheduled emergency admission during their final 28 days and required an average of 19.5 days of unscheduled emergency care during their final year [36]. Such published evidence of the scale and increasing frequency of unscheduled care usage towards the end of life closely mirrors our caregiver participants' accounts of repeated crises and reactive care in the present study. Patterns of escalating unscheduled care may therefore provide

important opportunities for earlier identification of palliative care needs, enabling meaningful future care planning and coordinated support before further deterioration while potentially reducing subsequent reliance on emergency services.

The potential value of earlier identification is supported by evidence that earlier integration of palliative care can improve outcomes for patients and families. A systematic review of 41 randomised controlled trials (RCTs) by Creangă-Murariu et al. (2025) found that early palliative care, typically initiated within eight weeks of an advanced cancer diagnosis, improved quality of life and reduced physical and emotional symptom burden in 32 trials (78%), with several also reporting reduced emergency department and intensive care use [4]. A meta-analysis of 39 RCTs by Johnson et al. (2024) demonstrated moderate-to-substantial improvements in health-related quality of life and emotional wellbeing from three months following specialist palliative care intervention, regardless of underlying condition [34]. The authors advocated needs-based referral at least three to six months before death, contrasting sharply with a global median duration of specialist palliative care of only 18.9 days before death and six days for non-cancer conditions [34]. Similarly, Shih et al. (2022), in a meta-analysis of 12 RCTs involving 2,980 patients, found significant improvements in quality of life both within three months and beyond three months, alongside reduced physical symptom severity [37]. Together, this evidence reinforces caregivers' views that earlier identification is valuable not simply because deterioration can be recognised sooner, but because it creates opportunities for earlier conversations, planning and support before crisis.

Against this backdrop, automated approaches using routinely collected healthcare data offer one potential means of supporting earlier and more systematic identification of palliative care needs. Emerging evidence suggests that automated identification can influence subsequent care. In a pragmatic cluster-randomised trial of 3,183 hospitalised patients, Wilson et al. (2023) found that machine learning-supported clinical decision making increased the frequency of palliative care consultations and reduced 60-day and 90-day readmissions [38]. Although machine learning models using routinely collected electronic health record data have also demonstrated predictive capability across advanced cancer and emergency care populations [5, 18], caregivers in our study emphasised that predictive performance alone was insufficient: earlier identification was valuable only if it resulted in timely clinical review, coordinated care and meaningful support.

Rather than asking whether algorithms can identify people approaching the end of life more accurately, caregivers' accounts redirected attention towards a more fundamental question: does earlier identification lead to earlier discussions, better planning and better care experiences? This shifts the focus from predictive performance to clinical utility: the value of SUGEST lies not in prediction itself, but in what prediction enables. Realising this potential, however, depends upon patients and families trusting the technologies, data and clinical systems through which earlier identification is achieved.

4.3. Trust and acceptability

An equally important finding concerned the conditions under which caregivers were willing to trust SUGEST. Participants rarely discussed predictive accuracy, instead framing acceptability around transparent data use, accurate and representative healthcare records, explainable outputs and meaningful human oversight. This suggests that successful implementation depends not only on technical performance, but on whether machine learning can be trusted within existing clinical practice.

The rapid expansion of machine learning-supported models in healthcare has been accompanied by increasing recognition that technical performance alone is insufficient to ensure safe, ethical and equitable implementation. Contemporary frameworks for trustworthy machine learning-supported models emphasise transparency, explainability, accountability, fairness and human oversight as fundamental to clinical adoption [19, 20, 39]. Firstly, our findings reinforce these principles while demonstrating the importance caregivers placed on the relational context surrounding the technology. In qualitative interviews with 22 patients, care partners, clinicians and bioethicists, Rhee et al. (2026) identified the primacy of the doctor–patient relationship over artificial intelligence (AI) performance as a central ethical theme [39]. Participants preferred a clinician they trusted over a highly accurate AI model operating independently and expressed concern that autonomous prognostic algorithms could reduce patients to actionable data, overlooking the relational, religious and psychosocial contexts in which serious illness decisions are made [39]. Similarly, an integrative review of AI in end-of-life care by Abejas et al. (2025) identified a tension between system-level efficiencies offered by automated screening and resource optimisation and preserving dignity, relational connection and patient autonomy, warning that prioritising efficiency could contribute to depersonalisation of care [19]. These findings closely reflect caregivers' views in our study that SUGEST should support, rather than replace, clinical judgement and that its outputs should be interpreted within patients' individual and family circumstances.

Secondly, participants questioned whether routinely collected healthcare data adequately represented patients' characteristics and lived experiences, particularly among those experiencing fragmented healthcare, language barriers, socioeconomic disadvantage and other forms of marginalisation. This concern is supported by evidence regarding representation within existing palliative care AI research. In a scoping mapping study, Silva-Ferreira et al. (2025) found that machine learning models in palliative care were predominantly developed using relatively homogeneous datasets from high-income countries, with ethnic minority communities, socioeconomically disadvantaged populations and people with non-cancer diagnoses underrepresented [22]. As models learn from the data on which they are developed, such underrepresentation creates a risk that predictive performance and subsequent clinical utility may not be equitable across populations.

Caregivers' concerns extended beyond who was represented in development datasets to whether routinely collected electronic health records could adequately capture patients' circumstances. Electronic health records reflect interactions with healthcare systems rather than complete representations of clinical or social need, meaning that people experiencing barriers to healthcare may also be less visible within the data used for prediction. This concern is particularly relevant to SUGEST given its use of routinely collected healthcare data. Haimovich et al. (2023), for example, developed the

Geriatric End-of-Life Screening Tool using electronic health record data from 123,128 older emergency department patients, which demonstrated good ability to distinguish between patients who did and did not die within six months (area under the receiver operating characteristic curve = 0.82) [18]. Despite this predictive performance, the authors acknowledged that structural racism in healthcare utilisation and laboratory testing could introduce latent bias into electronic health record-based models, while incomplete historical records among people with limited healthcare access could constrain prediction. This directly reflects caregivers' concerns that fragmented or incomplete records could result in predictions based on an incomplete representation of patients' lives and potentially reproduce existing healthcare inequities.

These concerns may be particularly important for populations already underserved by palliative care. Sítima et al. (2024), drawing on research with socially disadvantaged populations, highlighted how competing priorities such as housing, food and immediate safety can take precedence over chronic disease management and routine healthcare engagement [40]. Consequently, lower or fragmented routine healthcare utilisation should not necessarily be interpreted as lower clinical need. This provides an important context for caregivers' concerns that individuals who interact less frequently or differently with healthcare systems may become less visible to algorithms trained predominantly on recorded healthcare activity. For SUGEST, equitable implementation therefore requires consideration not only of representation within training data, but of whose needs are visible within routinely collected data in the first place.

Importantly, caregivers did not reject machine learning itself. Rather, they rejected the notion that SUGEST data outputs should be accepted uncritically as universally definitive or objective truths. Participants emphasised that clinicians should retain responsibility for interpreting outputs alongside their knowledge of the patient and should be able to question them where they conflicted with clinical judgement or individual circumstances. The SUGEST approach was therefore considered acceptable as a clinical decision-support tool but not as a stand-alone judgement. This is particularly salient within palliative care, where decisions incorporate not only clinical status but relationships, values, cultural and religious beliefs and psychosocial circumstances. Rhee et al. (2026) similarly found that patients and clinicians valued face-to-face discussion and human relational judgement when making serious illness and goals-of-care decisions [39]. Thus, human oversight was valued not merely as a safeguard against algorithmic error, but because clinicians can incorporate dimensions of patients' lives that may not be captured within the data informing a prediction.

Caregivers' accounts therefore suggest that trust in SUGEST is relational rather than purely technological, shaped by both the safeguards surrounding the technology and the clinical relationships through which it is used. How SUGEST is communicated to patients and families is therefore central to establishing and maintaining this trust in practice.

4.4. Communication, shared decision-making and implementation

If trust determined whether SUGEST was acceptable, communication determined how that trust could be established and maintained in practice. Caregivers in this study consistently reframed the purpose of SUGEST from technical mortality prediction to a catalyst for clinically-led, sensitive conversations. Rather than valuing an algorithm-generated estimate of deterioration or mortality in isolation, they viewed earlier identification as an opportunity to initiate timely, compassionate and person-centred discussions about future care, individual priorities and available support. The perceived value of SUGEST therefore lay not in the statistical prediction itself, but in its ability to create clinical "windows of opportunity" for conversations that participants felt were currently too often delayed until periods of acute, distressful deterioration.

These findings align with wider evidence supporting earlier serious illness conversations, advance care planning and shared decision-making. In a systematic review of early identification screening instruments, Xie et al. (2024) argued that such tools are most valuable for identifying unmet palliative care needs and prompting holistic clinical review, rather than functioning as precise survival calculators [9]. Hui et al. (2022) similarly highlighted the importance of initiating serious illness conversations before the terminal phase, allowing patients and families time to process prognostic information and consider care preferences [3]. However, timing requires careful judgement. Downar et al. (2017) described a 'Goldilocks' challenge in advance care planning, whereby conversations initiated too early may cause unnecessary anxiety or place premature demands on services, while those initiated too late leave patients and families making decisions during crisis [41]. Caregivers' accounts suggest that SUGEST could help navigate this challenge by prompting clinical review of whether an individual may have current or emerging palliative care needs, whether a palliative approach may be appropriate and whether future care planning could be beneficial, rather than using data outputs as a definitive trigger for prognostic disclosure.

Importantly, participants described communication as an ethical and relational process rather than simply the transfer of clinical information. Discussions needed to be delivered by trusted healthcare professionals, in an appropriate care setting, using accessible language, respecting cultural and religious beliefs, and recognising that individuals differed in how much information they wished to receive and when. Nikoloudi and Mystakidou (2026) similarly concluded that, within emotionally complex settings such as serious illness care, clinicians should remain central to communication, integrating statistical risk predictions within individualised, narrative-based discussions to preserve patient dignity and clinical safety [20]. Rather than diminishing the clinician's role, caregivers in our study suggested that compassionate communication, active listening and relationship-based continuity become even more important when data-driven tools are introduced into clinical pathways.

Our findings further demonstrate that communication preferences cannot be assumed to be uniform, with contextual factors including protected characteristics and shaping how prognostic information was understood, communicated and trusted. Ethnicity, language, faith, disability and neurodivergence influenced preferences regarding direct disclosure, family involvement, communication format and accessibility of information. This reflects Alanazi et al. (2024), who highlighted cultural variation in end-

of-life communication and decision-making, including preferences for family involvement and concerns that direct discussion of death may be distressing or culturally inappropriate [42]. Sítima et al. (2024) similarly identified language barriers, cultural beliefs and limited cultural competency among healthcare professionals as barriers to equitable palliative care [40]. Language was particularly salient in the present study, with caregivers describing the burden placed on family members when interpreting sensitive clinical information and emphasising the need for professional interpretation. These findings suggest that communication following identification through SUGEST must be culturally responsive and accessible rather than delivered through a standardised 'one size fits all' approach.

The need for tailored communication may be particularly important where existing knowledge or trust in palliative care differs across communities. In a national UK survey, Peeler et al. (2025) found that 24% of adults reported limited knowledge of palliative care, while 18% of ethnic minority respondents, compared with 4% of White respondents, believed that palliative care shortened life [43]. In this context, algorithmically generated identification of palliative care need could be misunderstood or reinforce existing mistrust if introduced without appropriate explanation and sensitive clinical contextualisation. Participants also highlighted the need to adapt communication for people with neurodivergence, disability or differing communication needs, reinforcing the importance of flexible modes and formats rather than a single approach to disclosure.

Participants described communication as an ongoing process requiring time, continuity, support and opportunities to revisit discussions as circumstances and individual readiness evolved. This need remains poorly met in practice. In the Better End of Life national survey of 1,179 decedents in England and Wales, 29.6% had never discussed dying or death with a healthcare professional; bereaved respondents also reported better communication from community nursing and specialist palliative care teams than hospital staff and valued a consistent point of contact and opportunities for unhurried discussion [44]. Alanazi et al. (2024), in a systematic review of ethical decision-making in end-of-life nursing, similarly highlighted the value of ongoing, trust-based communication for shared deliberation, negotiation of values and recognition of psychosocial and spiritual needs [42]. Swan et al. (2021) found that rapid and unpredictable deterioration without proactive, coordinated planning could intensify caregiver exhaustion and isolation [45]. Together, this evidence reflects caregivers' views in our study that communication following identification through SUGEST should not end with disclosure, but should enable ongoing preparation, shared decision-making and practical, emotional and informational support as needs change. Its value therefore depends upon healthcare systems having the capacity to translate earlier conversations into sustained and meaningful support.

Translating these communication preferences into practice requires both system integration and workforce preparedness. Participants emphasised that SUGEST should be embedded within existing clinical systems and linked to clear pathways for review, referral and follow-up, rather than functioning as a standalone alert. This reflects wider evidence that implementation of machine learning in palliative care is constrained by fragmented digital infrastructure, workflow integration and organisational readiness [22, 46]. Scottish research similarly demonstrates that people approaching the end of life

frequently move between primary, emergency, acute and community care, making continuity and effective information sharing across services particularly important [13, 47]. Earlier identification therefore requires clear clinical ownership of who reviews a SUGEST output, who initiates subsequent conversations and what pathway of care follows.

Participants also emphasised that successful implementation would require healthcare professionals to be prepared not only to understand how SUGEST operates, but to interpret its outputs alongside clinical judgement and communicate their implications sensitively and appropriately. From caregivers' perspectives, workforce preparedness was therefore an important component of implementation, particularly within acute and unscheduled care settings where opportunities for individualised communication may be constrained. Further exploration of healthcare professionals' perspectives will be important in determining the specific training and support required for implementation.

4.5. Implications

The findings of this study identify several implications for the future translation of SUGEST into routine palliative care. At a clinical level, implementation will require SUGEST outputs to be interpreted alongside clinical judgement and connected to appropriate conversations, care planning and support. At a system and policy level, this will depend on high-quality and representative data, appropriate governance and sufficient service capacity to respond to identified need. Further research should evaluate SUGEST prospectively in routine practice, including its acceptability, effectiveness, equity and resource implications, while continuing to incorporate the perspectives of patients, caregivers and healthcare professionals. Key implications for clinical practice, policy and future research are summarised in Fig. 3.

4.6. Strengths and Limitations

This study has several important strengths. To our knowledge, it is among the first qualitative studies to explore caregivers' perspectives on the acceptability, communication and implementation of a machine learning-supported prognostic tool for palliative care. Purposive recruitment of caregivers with diverse protected characteristics and lived experiences, including individuals from ethnic minority and migrant communities, those experiencing socioeconomic disadvantage, neurodivergence, disability, young carers and those living in rural areas, enabled perspectives that are often underrepresented in palliative care research to be captured.

The original intention had been that the SUGEST would be developed first, with qualitative interviews exploring views on the tool following on from this. However, delays in access to healthcare data required to develop SUGEST meant that this qualitative work was undertaken both before and during the development of the SUGEST tool. An unintended benefit of this situation has been that rather than retrospectively evaluating the acceptability of an existing tool, caregivers' perspectives and views can directly inform its development and future implementation. The richness of the interviews generated nuanced insights into the social, ethical and practical considerations surrounding both the focus of the tool itself, as well as its implementation.

Methodological rigour was strengthened through reflexive thematic analysis, transparent documentation of the analytical process, independent review of 20% of transcripts, multidisciplinary discussion of developing interpretations and ongoing involvement of the SUGEST Patient and Public Involvement group. Collectively, these approaches enabled the study to move beyond exploring whether caregivers considered SUGEST acceptable to identifying the conditions under which they believed it should be designed, communicated and implemented.

Several limitations should also be considered. Participants were recruited from across Scotland and their accounts predominantly reflected experiences within the Scottish health and care context; therefore, the findings may not be directly transferable to systems with different models of palliative care delivery, service organisation or digital infrastructure. As SUGEST had not yet been developed or implemented, discussions were necessarily hypothetical, and views regarding acceptability and implementation represent anticipated rather than observed experiences. Although the sample reflected substantial diversity, its size precluded exploration of differences between demographic groups. All participants were bereaved caregivers, and the perspectives of people currently providing care may differ, particularly among individuals who do not identify themselves as caregivers despite providing unpaid care and support. Future research should therefore explore acceptability among active caregivers, including those who do and do not self-identify as caregivers. As with all qualitative research, the findings provide depth of understanding rather than statistical generalisability. Finally, this study reports caregivers' perspectives only; patient and healthcare professional perspectives are being examined separately within the wider SUGEST programme, alongside future prospective evaluation of the tool in routine clinical practice. Despite these limitations, this study provides novel and rich insights into the conditions under which caregivers believe machine learning-supported prognostic tools should be designed, communicated and implemented to support earlier, more equitable and person-centred palliative care.

5. Conclusion

Caregivers described their experiences of current palliative care pathways as reactive, fragmented and characterised by repeated cycles of crisis, highlighting the need for earlier identification of palliative care needs. Within this context, SUGEST was viewed as having the potential to facilitate valuable earlier conversations, proactive care planning and improved support for patients and families. However, acceptability was consistently described as conditional rather than universal. Caregivers emphasised that successful implementation depended upon trustworthy and representative data, transparent and equitable use of machine learning, compassionate communication with skilled clinicians, respect for individual choice and healthcare systems capable of translating earlier identification into meaningful clinical action.

These findings provide an important foundation for the future development and implementation of machine learning-supported tools designed to support earlier identification of palliative care needs. Rather than replacing clinical judgement, SUGEST was consistently viewed as a tool to support clinicians

in recognising potential unmet palliative care needs and initiating timely, person-centred conversations and resultant care planning. Ultimately, the greatest caregiver-perceived benefit of SUGEST lies not in generating an estimate of mortality risk within a specified timeframe, but in its potential to facilitate proactive conversations and more timely, person-centred palliative care and support, with the potential to reduce reliance on crisis-driven unscheduled care.

Abbreviations

AI

Artificial intelligence

A&E

Accident and Emergency

ED

Emergency Department

GEST

Geriatric End-of-Life Screening Tool

GP

General Practitioner

NECPAL

Palliative Needs World Health Organization Collaborating Centre–Catalan Institute of Oncology

NHS

National Health Service

PPI

Patient and Public Involvement

RCT

Randomised Controlled Trial

SD

Standard deviation

SPICT

Supportive and Palliative Care Indicators Tool

SUGEST

Scottish Unscheduled Geriatric End-of-Life Screening Tool

Declarations

Ethics approval and consent to participate

Ethical approval for this study was granted by the School of Medicine Ethics Committee, acting on behalf of the University Teaching and Research Ethics Committee (UTREC) at the University of St Andrews (Approval Code: MD-0698-832-2025; approved July 2025). The study was conducted in accordance with

the Declaration of Helsinki and relevant institutional ethical guidelines. All participants provided written informed consent prior to participation.

Availability of data materials

The full interview transcripts generated during the current study are not publicly available or available on request, as participants provided consent for the publication of anonymised quotations but not for the sharing of interview transcripts in their entirety. Anonymised quotations supporting the findings are included within this article. Queries regarding data access and availability may be directed to the corresponding author, Dr Emma Louise Gale.

Consent for publications

Not applicable

Competing interests

The authors declare that they have no competing interests.

Funding

This research was funded by Marie Curie (MC-23-002) through a research call focused on addressing health inequalities in palliative and end-of-life care. The funder had no role in the study design, data collection, analysis or interpretation of the data, or preparation of the manuscript.

Author contributions

ELG: conceptualisation, methodology, investigation, data curation, formal analysis, visualisation and writing – original draft. SPB: methodology, formal analysis and writing – review and editing. All other authors contributed to interpretation of the findings, critically reviewed the manuscript and approved the final version.

Acknowledgements

The authors would like to thank the SUGEST Patient and Public Involvement group and all study participants for their contributions to the research. The authors also acknowledge the support of the University of St Andrews, NHS Fife and the Fife Centre for Equalities.

References

1. Fantoni ER, Wynne N, Finucane AM. Estimates of population-level palliative care need in the UK: a descriptive analysis of mortality data before and during the COVID-19 pandemic. *BMC Palliat care*. 2024;23(1):271.
2. Hui D, et al. Improving patient and caregiver outcomes in oncology: Team-based, timely, and targeted palliative care. *Cancer J Clin*. 2018;68(5):356–76.
3. Hui D, Heung Y, Bruera E. Timely palliative care: personalizing the process of referral. *Cancers*. 2022;14(4):1047.
4. Creangă-Murariu I, et al. Timing matters: A systematic review of early versus delayed palliative care in advanced cancer. *Cancers*. 2025;17(15):2598.
5. Zaborowski N, et al. Early palliative care consults reduce patients' length of stay and overall hospital costs. *Am J Hospice Palliat Medicine®*. 2022;39(11):1268–73.
6. Knaul FM, et al. The evolution of serious health-related suffering from 1990 to 2021: an update to The Lancet Commission on global access to palliative care and pain relief. *Lancet Global Health*. 2025;13(3):e422–36.
7. Johansson T et al. *Unmet palliative care needs in England and Wales: population-based estimates and future projections (2025–2050)*. medRxiv, 2026: p. 2026.02. 16.26345914.
8. Mah SJ, et al. Timing of palliative care, end-of-life quality indicators, and health resource utilization. *JAMA Netw open*. 2024;7(10):e2440977.
9. Xie Z, et al. Screening instruments for early identification of unmet palliative care needs: a systematic review and meta-analysis. *BMJ supportive Palliat care*. 2024;14(3):256–68.
10. Highet G, et al. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. *BMJ supportive Palliat care*. 2014;4(3):285–90.
11. Shaw KL, et al. Improving end-of-life care: a critical review of the Gold Standards Framework in primary care. *Palliat Med*. 2010;24(3):317–29.
12. Gomez-Batiste X, et al. Utility of the NECPAL CCOMS-ICO© tool and the Surprise Question as screening tools for early palliative care and to predict mortality in patients with advanced chronic conditions: A cohort study. *Palliat Med*. 2017;31(8):754–63.
13. Mills SE, et al. Urgent need for system reform in future care planning, access to palliative care and care coordination. *British Medical Journal Publishing Group*; 2026.
14. Mason B, et al. Unscheduled and out-of-hours care for people in their last year of life: a retrospective cohort analysis of national datasets. *BMJ open*. 2020;10(11):e041888.
15. Mills S, et al. Factors affecting use of unscheduled care for people with advanced cancer: a retrospective cohort study in Scotland. *British Journal of General Practice*; 2019.
16. Bowers SP et al. *Use of unscheduled care in the last year of life for people with multiple long-term health conditions: a retrospective cohort study of 299 361 decedents*. *BJGP open*, 2026. 10(1): p. BJGPO. 2025.0049.

17. Bowers SP, et al. We do what needs to be done: caregivers' experiences of healthcare and support for people with multiple long-term conditions in the last year of life. *BMC palliative care*; 2026.
18. Haimovich AD, et al. Automatable end-of-life screening for older adults in the emergency department using electronic health records. *J Am Geriatr Soc.* 2023;71(6):1829–39.
19. Abejas AG, et al. Ethical challenges and opportunities of AI in end-of-life palliative care: integrative review. *Interact J Med Res.* 2025;14(1):e73517.
20. Nikoloudi M, Mystakidou K. Artificial intelligence in palliative care: a scoping review of current applications, challenges, and future directions. *Am J Hospice Palliat Medicine®.* 2026;43(9):1007–15.
21. Polineni TNS, et al. AI-Driven Insights Into End-Of-Life Decision-Making: Ethical, Legal, And Clinical Perspectives On Leveraging Machine Learning To Improve Patient Autonomy And Palliative Care Outcomes. *Migration Lett.* 2022;19(6):1159–72.
22. Silva-Ferreira M, et al. Mapping study on AI-based technologies in palliative care—a scoping study. *BMC Palliat Care.* 2025;24(1):274.
23. Heikkinen K. *Artificial Intelligence and Healthcare in Scotland*, S. Parliament, Editor. 2024.
24. Severino MC, De Rosis S. The experience of family caregivers along the palliative care pathway: a qualitative case study. *Qualitative Res Organ Management: Int J*, 2026: pp. 1–22.
25. Goodrich J, et al. Priorities for 'out-of-hours' home-based palliative care for professionals, patients, and family caregivers: A qualitative interview study. *Int J Nurs Stud.* 2025;171:105193.
26. Giesbrecht M, et al. Critically examining diversity in end-of-life family caregiving: implications for equitable caregiver support and Canada's Compassionate Care Benefit. *Int J Equity Health.* 2012;11(1):65.
27. Stajduhar KI, et al. Caregiving at the margins: an ethnographic exploration of family caregivers experiences providing care for structurally vulnerable populations at the end-of-life. *Palliat Med.* 2020;34(7):946–53.
28. Gale EL, Pedro LR, Brown LR, McCowan C, Mills SEE. Exploring the Acceptability and Implementation of a Prognostic Tool in Palliative Care amongst Individuals with Protected Characteristics: A Qualitative Study Protocol. *Open Science Framework*; 2026.
29. Willis J. *Foundations of qualitative research: Interpretive and critical approaches.* sage; 2007.
30. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Res Psychol.* 2006;3(2):77–101.
31. Ritchie J, Lewis J, Elam RG. *Selecting samples.* Qualitative research practice: A guide for social science students and researchers. Thousand Oaks, CA: Sage; 2013. p. 111.
32. Webber-Ritchey KJ, et al. Recruitment strategies to optimize participation by diverse populations. *Nurs Sci Q.* 2021;34(3):235–43.
33. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. *Am J evaluation.* 2006;27(2):237–46.

34. Johnson MJ, et al. Benefits of specialist palliative care by identifying active ingredients of service composition, structure, and delivery model: a systematic review with meta-analysis and meta-regression. *PLoS Med.* 2024;21(8):e1004436.
35. Chohan A, et al. How many end-of-life care patients access unscheduled care via 999? *J Paramedic Pract.* 2025;17(6):248–56.
36. McFerran E, et al. Cost consequences of unscheduled emergency admissions in cancer patients in the last year of life. *Support Care Cancer.* 2023;31(3):201.
37. Shih H-H, Chang H-J, Huang T-W. Effects of early palliative care in advanced cancer patients: a meta-analysis. *Am J Hospice Palliat Medicine®.* 2022;39(11):1350–7.
38. Wilson PM, et al. Effect of an artificial intelligence decision support tool on palliative care referral in hospitalized patients: a randomized clinical trial. *J Pain Symptom Manag.* 2023;66(1):24–32.
39. Rhee JY, et al. A qualitative study with patients, care-partners, clinicians, and bioethicists to identify ethical considerations of artificial intelligence tools in palliative care. *Palliat Med.* 2026;40(5):667–77.
40. Sítima G, Galhardo-Branco C, Reis-Pina P. Equity of access to palliative care: a scoping review. *Int J Equity Health.* 2024;23(1):248.
41. Downar J, et al. The surprise question for predicting death in seriously ill patients: a systematic review and meta-analysis. *Can Med Assoc J.* 2017;189(13):E484–93.
42. Alanazi MA, et al. Navigating end-of-life decision-making in nursing: a systematic review of ethical challenges and palliative care practices. *BMC Nurs.* 2024;23(1):467.
43. Peeler A, et al. Confronting global inequities in palliative care. *BMJ global health.* 2025;10(5):e017624.
44. Johansson T, Pask S, Goodrich J. *Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales.* 2024. Available from: [experiences-at-the-end-of-life-in-england-and-wales](#)
45. Swan S, et al. Factors influencing adult carer support planning for unpaid caregiving at the end of life in Scotland: Qualitative insights from triangulated interviews and focus groups. Volume 30. *Health & Social Care in the Community*; 2022. pp. 1422–32. 4.
46. Vu E, et al. Applications of machine learning in palliative care: a systematic review. *Cancers.* 2023;15(5):1596.
47. Mason B, et al. Integrating lived experiences of out-of-hours health services for people with palliative and end-of-life care needs with national datasets for people dying in Scotland in 2016: A mixed methods, multi-stage design. *Palliat Med.* 2022;36(3):478–88.

Figures

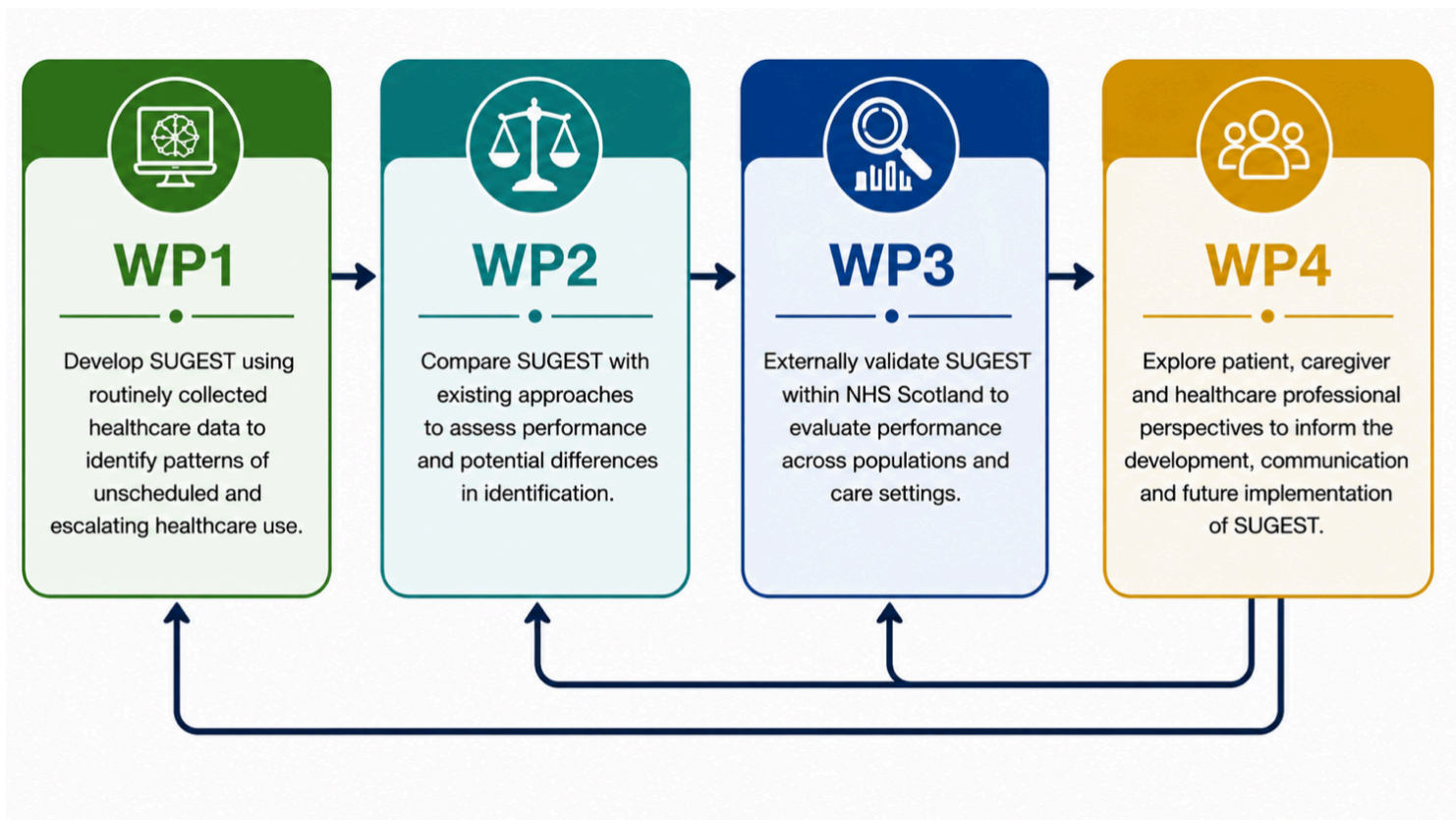


Figure 1

Overview of the four interconnected work packages within the Scottish Unscheduled Geriatric End-of-Life Screening Tool (SUGEST) programme.

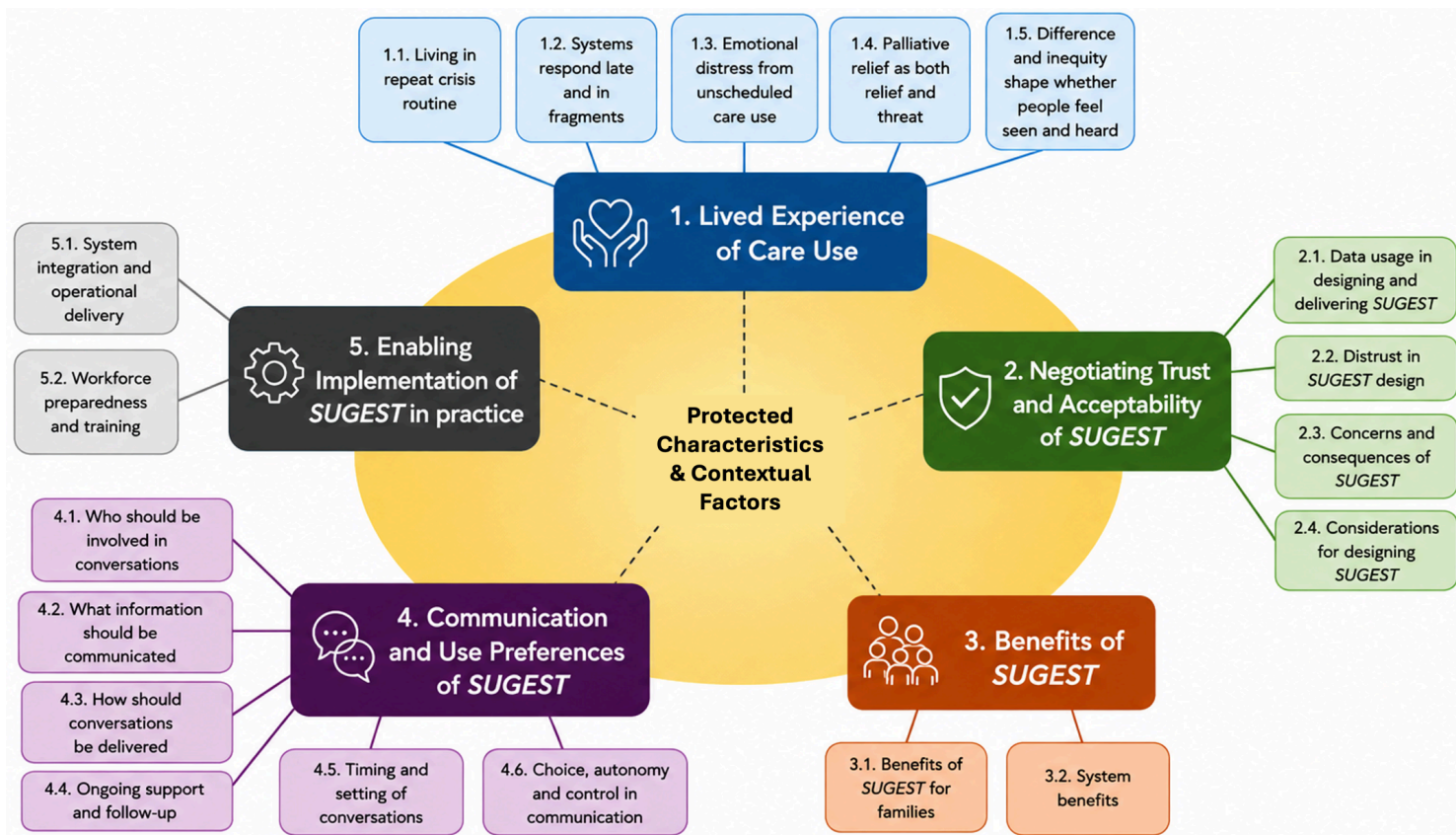


Figure 2

Thematic map of caregivers' perspective on the acceptability and future implementation of SUGEST

Note: Protected characteristics (as defined by the Equality Act 2010; e.g. age, gender, ethnicity, disability, faith, socioeconomic status, migrant/refugee or asylum seeker background) and other contextual factors (rurality and caring experience) influence and intersect with all themes

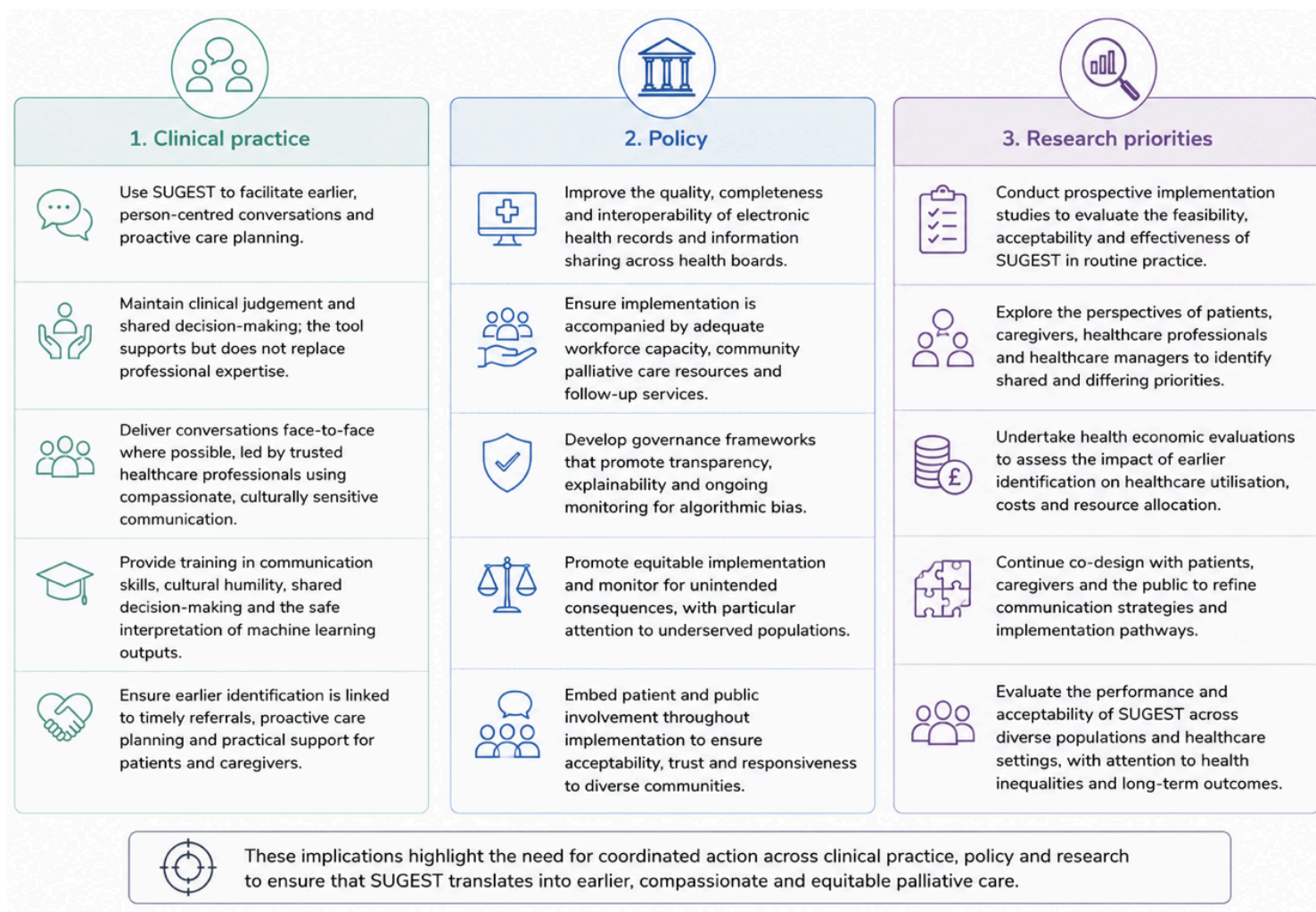


Figure 3

Implications of the study findings for the future implementation of SUGEST

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [SUGESTSupplementaryMaterial1.pdf](#)