



Development and preliminary usability testing of an electronic conversation guide incorporating patient values and prognostic information in preparation for older people's decision-making near the end of life

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ABSTRACT

Initiating end-of-life conversations can be daunting for clinicians and overwhelming for patients and families. This leads to delays in communicating prognosis and preparing for the inevitable in old age, often generating potentially harmful overtreatment and poor-quality deaths. We aimed to develop an electronic resource, called Communicating Health Alternatives Tool (CHAT) that was compatible with hospital medical records software to facilitate preparation for shared decision-making across health settings with older adults deemed to be in the last year of life.

The project used mixed methods including: literature review, user-directed specifications, web-based interface development with authentication and authorization; clinician and consumer co-design, iterative consultation for user testing; and ongoing developer integration of user feedback. An internet-based conversation guide to facilitate clinician-led advance care planning was co-developed covering screening for short-term risk of death, patient values and preferences, and treatment choices for chronic kidney disease and dementia. Printed summary of such discussion could be used to begin the process in hospital or community health services. Clinicians, patients, and caregivers agreed with its ease of use and were generally accepting of its contents and format. CHAT is available to health services for implementation in effectiveness trials to determine whether the interaction and documentation leads to formal decision-making, goal-concordant care, and subsequent reduction of unwanted treatments at the end of life.

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1. Introduction

De-escalating medical procedures, prescriptions (Scott et al., 2014), and avoiding hospital transfers (Kada et al., 2017) near the end of life (EOL) in old age is relevant for multimorbid patients but complex for clinicians (Hillman and Cardona-Morrell, 2015). This is particularly true when patients or substitute decision-makers have poor understanding of disease prognosis and experience conflict between personal values and treatment preferences (Heyland et al., 2015). Decision aids are valuable to improve consumer-clinician communication in the face of uncertainty and when there is no clear single management option (Hoffmann et al., 2014). Patient decision aids are the tools used by healthcare providers to facilitate that information exchange (“An introduction to patient decision aids”, 2013). There is moderate evidence that presenting patients with prognostic probabilities improves their understanding of risk of overtreatment, and low-level evidence that patient decision aids align choices with patient values (Stacey et al., 2014). Recent reviews of patient decision aids for EOL (Cardona-Morrell et al., 2017; Phillips et al., 2019), however, revealed either a scarcity of tools for this context and/or a lack of numeric prognostic information to assist patients and families in genuinely informed treatment decisions. More importantly, patients' personal values and preferences for non-medical aspects of end-of-life care were not generally incorporated (Cardona-Morrell et al., 2017; Phillips et al., 2019).

Shared medical decision-making is the process of identifying health conditions to assess and communicate evidence-based prognostic odds, and incorporate patient values and preferences into alternative management options (Bae, 2017). It involves multiple discussions combining objective information, intuition, and personal biases from patient and clinicians before a recommendation that respects patient autonomy is agreed on the best possible health outcome for the patient and social implications for their family (Ofstad et al., 2016). Studies on decision-making in chronic conditions highlight the need for clinicians to explore personalised values that go beyond medical treatment options and take into account patients' priorities, cultural context and life outlook (Lee et al., 2013). Previous research on prognostic tools and preferences for disclosure (Cardona et al., 2019a; Lewis et al., 2021), have identified several aspects illustrating the complexity of decision-making near the EOL: full or partial prognostic disclosure may be a clinician's duty but is not welcome by all patients and may best be delivered gradually over several encounters (Cardona et al., 2018a). Many clinicians withhold bad news from families assuming lack of readiness (Cardona et al., 2019a), and patient willingness to engage in decision-making with clinicians varies with age, education and type of health conditions under examination (Robinson and Thomson, 2001). The way choices are presented as generating gains or losses may unduly influence the direction of patient preferences (Moxey et al., 2003). Patient's and family preferences for prognostic information also change as disease progresses and death approaches (Munday et al., 2007), but higher stability of decisions is observed among patients with severe progressive illness and those who have completed advance care directives (Auriemma et al., 2014).

Decision-making to administer, withhold or withdraw life-saving treatment needs to be a step-by-step consultation process. Hence conversation guides for clinicians can play a role in setting the scene on illness stage and assessing patient readiness for the preliminary discussion on goals of care; that is, they are a conversation starter (Balaban, 2000). Recent calls for taking advantage of the benefits of digital information exchange to support elicitation of patient preference (de Vries et al., 2019), supplement systematic evidence that current decision aids for end-of-life are still inadequate to meet patients' needs both in terms of information shared and individual engagement (Phillips et al., 2019). Hence, our aim was to design and test a resource that would assist clinician's (nurses or doctors) routine engagement in preliminary discussions with their patient and/or surrogate before formal advance care planning. This engagement is anticipated to overcome the delays in

exploring patient preferences and values before a health crisis, emotionally prepare families to consider management options, and can form the basis for the formal health directive at a future consumer-health provider discussion. In a nutshell, The Communicating Health Alternatives Tool (CHAT app) is intended to fill the gap of holding preliminary discussions to 'break the ice' and get patients and surrogate decision-makers in a reflective frame of mind. It does this by assisting clinicians in enhancing patient's/surrogate's understanding of the stage of illness, the risks and benefits of alternative treatments, knowledge of consequences of treatment limitations or withdrawal, and align goals of care with preferences and values as a first step in ongoing discussions leading to a treatment decision. The ultimate purpose is the normalisation of the early end-of-life care planning (Chu, 2019; Masters et al., 2021) consultation with families of people with selected conditions (chronic kidney disease, chronic pulmonary obstructive disease, and dementia/cognitive impairment) to prevent potentially unwarranted or unwanted treatments.

1.1. Objectives

1. To develop an electronic, flexible resource compatible with hospital electronic medical records, that is applicable across several settings and chronic conditions to facilitate preparation for shared decision-making with older adults deemed to be in the last year of life.
2. To offer an acceptable combination of modules that incorporates quantitative prognosis and patient values as a conversation guide during the clinical encounter across settings.
3. To field test usability and acceptability of the developed tool in a subgroup of the intended target population.

2. Methods

2.1. The process

We used mixed methods including literature reviews, co-design (Sanz et al., 2021), user-directed specifications, web-based interface development with authentication, authorization, and secure cloud services, clinician and consumer co-design, iterative consultation for user testing, and developer integration of user feedback.

While CHAT is not technically a decision aid but a preparatory conversation guide, our process was informed by internationally recognised quality criteria (Elwyn et al., 2006; Witteman et al., 2021) where we searched the medical literature to identify evidence for treatment options, harms and benefits to provide qualitative information to clinicians. We limited the search for evidence of harms and benefits to randomised trials or controlled cohorts for treatment effectiveness of the three conditions as far as possible. In our effort to understand users' context and decision-making process, we searched for qualitative studies or patient surveys to select items or questions that informed the patient values clarification module development. We incorporated the findings from literature reviews in the conversation guide design, and the users' suggestions into the final version of the conversation guide prototype and examined the users' interaction with the prototype (Witteman et al., 2021). Questions were based on modified versions of other instruments as specified below in the results, in addition to newly developed questions based on the clinicians' experience.

The core development took place over 24 months (2018–2019) through ongoing interaction within the co-authors: a geriatric nurse, a clinical GP researcher and software engineers. Co-design (Harrison et al., 2022) entailed participatory consultations with a purposive sample of 12 clinicians in our affiliated institutions (seven nurses in renal, geriatrics, intensive care, internal medicine specialties), a social worker, three general practitioners a respiratory physician, an academic pharmacist, attending a one-on-one demonstration to give their opinion on the construction of different modules. Further, 13 older members of

the public were recruited for usability testing from the membership of an end-of-life Consumer Advisory Group established for other research projects after responding to our newspaper advertisement, senior citizens posters and online expression of interest. Inclusion criteria for the consumers were: aged 60+ years who had either of our target chronic diseases themselves, or personal or family experience in the dying process, played a role discussing treatment options, or were considering advance care planning for themselves or an older person they cared for. Their role in co-design (Harrison et al., 2022) consisted of assisting as receivers of the draft questionnaire administered by nurse researchers, and providing experience-based feedback on question clarity, literacy appropriateness and burden of administration, using a standard form based on the System Usability Scale (Sauro, 2011) with narrative interpretation rather than attempt to score. Feedback from both clinicians and members of the public was incorporated in subsequent versions of the modules. Fig. 1 illustrates the process.

3. Results

The CHAT app uses language appropriate for a participant with an 8th grade reading level to facilitate understanding. A set of demographic questions for both the patient and their surrogate (if appropriate) opens the e-documentation clinicians complete before the 3 modules of the interview (Fig. 2 also shows partial questions on the risk screening tool). The components and features are illustrated below.

3.1. Screening for risk of death

This is an online version of the CriSTAL checklist, an acronym for **C**riteria for **S**creening and **T**riaging to **A**ppropriate **a**lternative care (Cardona-Morrell and Hillman, 2015). The set of clinical factors flags patients with chronic illness who may be vulnerable to deterioration in the short term (Appendix A, Supplementary file 1). The print version of the CriSTAL checklist was adapted into the online CHAT application to facilitate the use for clinicians selecting those most likely to benefit from an end-of-life discussion. CHAT automatically calculates the risk score as clinicians click on the relevant risk factors, by adding one point per risk factor. Patients with a CriSTAL risk score of 6 or higher (out of a maximum 19 points) are considered at high risk of death based on the previously described validation for medical and surgical patient populations (Cardona et al., 2018b; Cardona et al., 2019b; Eguaras Córdoba et al., 2021).

3.2. Personal values and preferences

A newly developed generic module was built using modified versions of questions from other studies (Clifford et al., 2017; Cox et al., 2015; Mold et al., 1994; Sinclair et al., 2017; Wang, 2017) and is applied to all people with advanced comorbidities. Decisions on which questions were more relevant and efficient for this module of the conversation guide were discussed among the core investigators (MC, EL, GI, MT, LB) based on their expertise. This screenshot (Fig. 3) displays the layout of selected questions asked during the 'Personal Values' questionnaire and the importance rating for each. No scoring is calculated, as the answers are to inform subjective perceptions and can change from one visit to another. The side bar displays the patient summary and a quick navigation. Supplementary file 2 shows the full values questionnaire.

3.3. Chronic conditions

Disease-specific questions on preference for management options or decision-making were also modified from previously used themes or questions by others on chronic kidney disease (CKD) (Davison and Jassal, 2016; FINDERUP et al., 2018; Kidney Health Australia; Ontario Renal Network) and dementia/cognitive impairment (Elliott et al., 2009; Jornet et al., 2017). For dementia, some items were based on

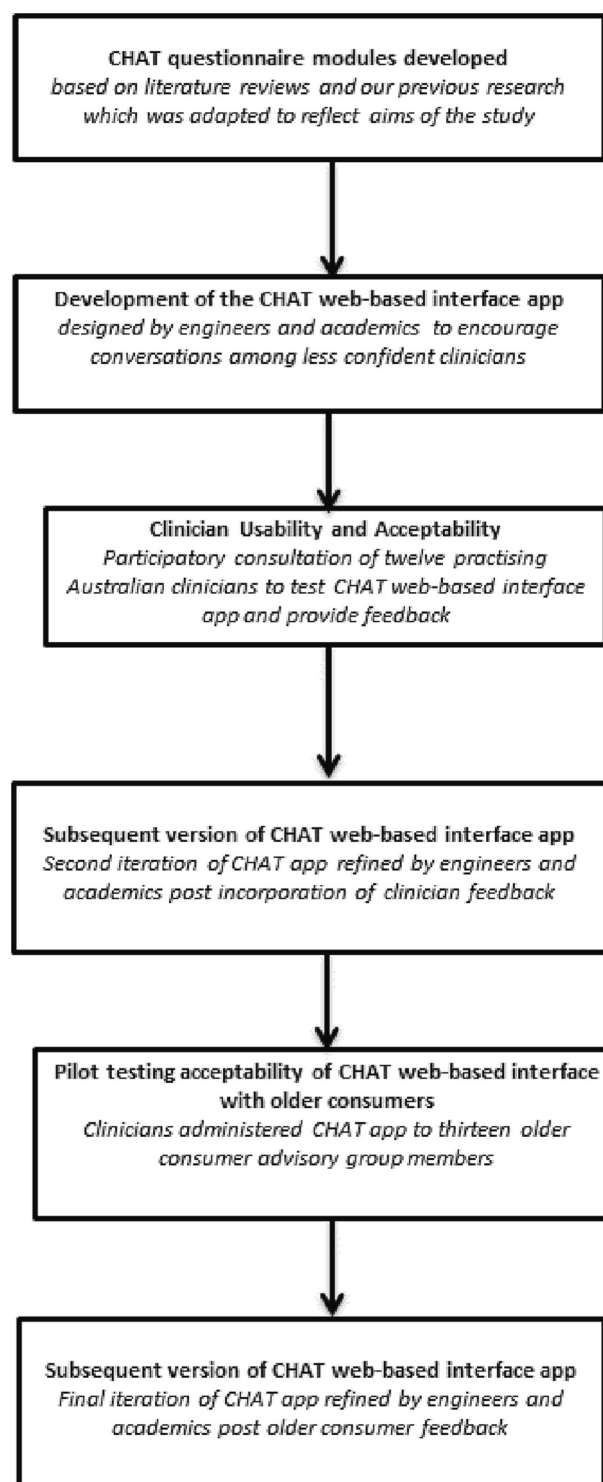


Fig. 1. Development and pilot testing process.

common complications that lead to hospital transfers (Bail et al., 2013) or intensive care admission (Ferrante et al., 2015); a surrogate version of the questions was made available given the role families have in decision-making on place of care (Denning et al., 2013). Both CKD and cognitive impairment were selected as the pilot health states due to frequency of cases in older age and convenience of testing in hospitals. No scoring system applies, only informative responses to guide clinicians. The CKD and dementia questionnaires are shown in Supplementary files 3 and 4 respectively.

Fig. 2. Demographics module and risk of death.

3.4. The CKD module

It was designed with a table of prognostic factors derived from the literature review (EK, EL) for different management options and questions on satisfaction with current management which led to skips or activation of further questionnaire sections. It was later redesigned, as feedback from renal nurses on the generic and evidence-based tables on treatment alternatives suggested the inclusion of routine symptom checklist, images, and infographics already in use in routine dialysis care. These were added as an “additional information” button where nurses can refresh knowledge on evidence for alternatives and read scripted information on what treatment not to offer older patients in end-stage CKD (e.g. transplant) if asked (Supplementary file 3).

3.5. The cognitive impairment/dementia module

This module applies to patients with cognitive impairment who have mental capacity, or their surrogates of people with dementia. It focuses on preferred place of treatment, and the level of intervention intensity in the case of future critical illness, such as hospital or ICU admission, intravenous medications or life support. There were several favourable comments on what participants liked about the dementia questionnaire with participants stating it was ‘extremely satisfying’, ‘normalised dementia diagnosis’, ‘reiterated what and how I felt with regard to dementia’ and one participant commenting ‘This is the first time I’ve ever spoken in depth about my dad’s dementia. It’s taken a lot of pressure off my chest’. One participant suggested families should receive more information about dementia if the CHAT app were to be developed into a decision tool. No participants had further comments on how a dementia module could be improved (Supplementary file 4).

The “Conditions” section is supplemented with a self-reported question “Today’s Health”: a slider scale from 0 to 100 where the patient can describe their perceived state of health (Fig. 4). As seen in this screenshot the ‘Today’s Health’ self-assessment uses only part of the screen, so clinicians can easily navigate back to the ‘Hospital’ view or the ‘Patient’ view or to other features of the conversation guide as indicated by the arrows. The green bar at the top displays the progress of the questionnaire so the clinician can see how many questions are left

and adjust the speed of the consultation if required. The final purple button on the top right corner (grey navigation bar) is a link to the clinician’s profile, which is used by the system to track modifications on patient preferences including date stamps for auditing purposes.

If patients are fatigued or the interview needs to be suspended for the patient to undergo procedures, there are provisions to resume later, either the same day or at a subsequent appointment. This screenshot displaying the patient overview (Fig. 5) includes the patient identifiers, their latest CrISTAL score, their values as assessed by the Patient Values Questionnaire, and their chronic conditions.

3.6. The My Choices summary

This reproduces all patient/surrogate responses into a printable PDF file. Once the interview is completed, the clinician can cross-check, edit and save all changes before printing a copy for the patient or surrogate to take home or to share with their local general practitioner or specialist so a follow-up discussion and advance directive can be progressed.

3.7. The original COPD module

A module on chronic obstructive pulmonary disease (COPD) with detailed treatment choices was originally developed (Supplementary file 5 shows selected screenshots). However, feedback obtained from clinicians led to the exclusion of this module from CHAT.

It included a button with bullet point script on alternatives, and a pop-up image of a table (Supplementary file 5) containing comprehensive evidence-based details of prognostic factors, harms and benefits of the various treatments derived from our literature review (by BMR, EL and MC). The first round of feedback on this module strongly indicated doctors rejected that level of information density during a patient encounter. While there were no negative reactions from participating patients and nurses perceived this module as complex but useful, objection from the respiratory physician was clear to the appropriateness of generalising treatment options for a condition that -in their experience- required a personalised plan where every patient was different, and some options would not be offered in certain settings. As a result, the treatment options and prognostic details were removed altogether.

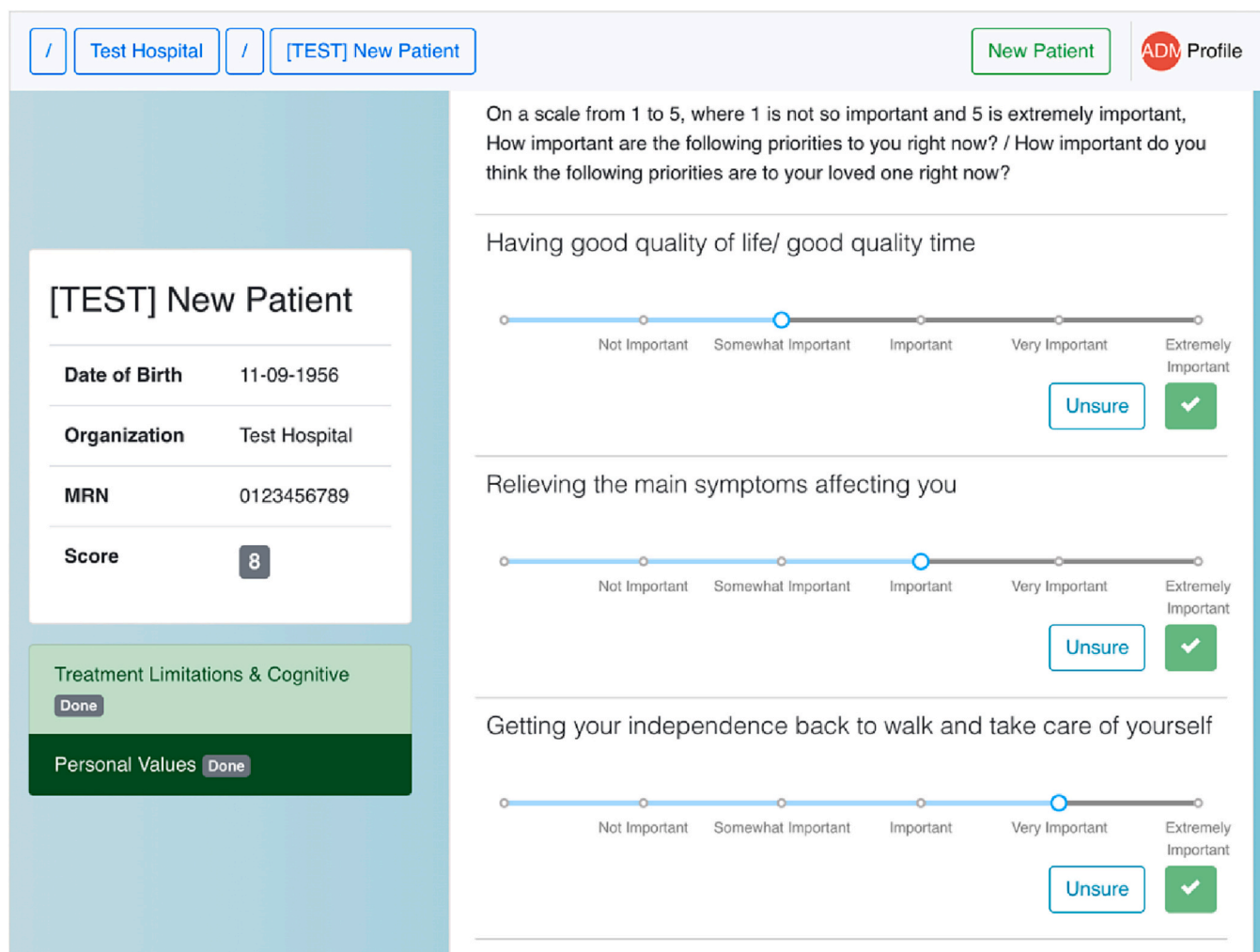


Fig. 3. Selected questions of the Personal Values module.

CHAT interviews for COPD patients in future will include the risk of death and patient values module only.

3.8. Technical information

This covers authentication, authorization, back-end and front-end and are detailed below.

3.8.1. Authentication

We secured the data entry function on the application with a password protected entry. Users of the app could only gain access if they were given a username and password by the research team. Secure access to the CHAT systems is achieved by implementation of the OpenID Connect (Fett et al., 2017), an interoperable authentication protocol. OpenID Connect allows for integrating third party identity providers to manage logins and identity in a privacy preserving secure manner. User provisioning and access is managed by Azure Active Directory (AAD), an enterprise grade identity service provider that allows single sign-on (SSO) and multi-factor authentication capabilities. This approach allows for external identity providers, such as the New South Wales Health SSO service to be the authentication provider for the CHAT service.

3.8.2. Authorization

The authorization procedure is implemented using role-based access control (RBAC), which is governed by the roles exposed by the identity provider to the CHAT service, and the roles assigned to the user in the

FHIR PractitionerRole object. The identity provider role is to discover whether a user is allowed to authenticate with the service, and the PractitionerRole authorizes the user's visibility to clinical records, and product features. The PractitionerRole is an assigned relationship between the health service and the petitioner, allowing a clinician to have different levels of access per health service.

User provisioning is handled by the research team, first by inviting the user to the configured Identity Provider, then assigning the user the correct role that allows them to authenticate with the CHAT Service, clinician, or administrator. The second step in provisioning a user is to create a Practitioner and PractitionerRole in the CHAT service, this is achieved by using the CHAT Portal's user interface and has the option of assigning a PractitionerRole of Researcher or Nurse to the new user backend.

3.8.3. CHAT back-end/FHIR server

The CHAT backend service is built upon the HL7 Fast Healthcare Interoperability Resources (FHIR) specification (Saripalle, 2019), to achieve interoperability and data mobility with existing health care services. We used an open source FHIR project developed by Microsoft to ensure compliance with the specification. The back-end leverages Azure cloud services to achieve government regulation compliance and strong data security for maintaining and storing personal health information which is rated as highly sensitive by the Australian Signal Directorate and relevant government bodies (Supplementary file 6).

To achieve some of the design goals of the CHAT project it was

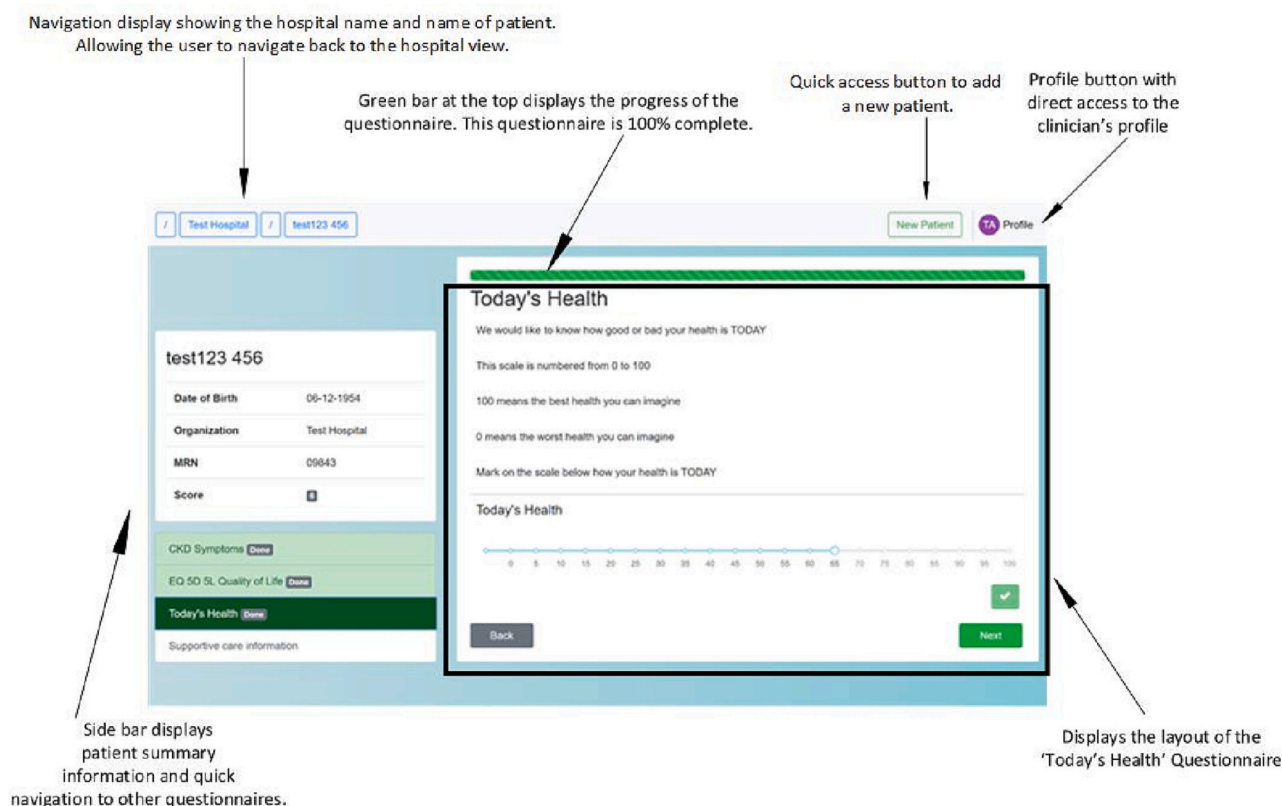


Fig. 4. Features of the Chronic Conditions module.

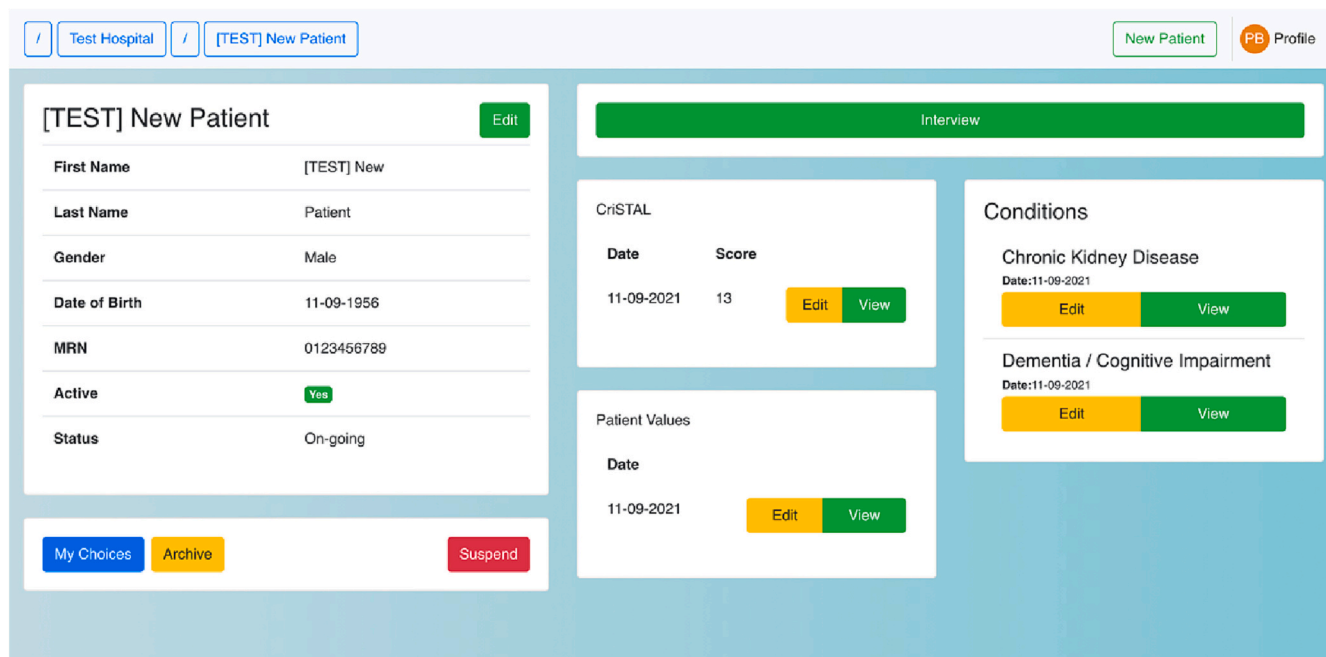


Fig. 5. Overview of all CHAT modules.

necessary to modify the standard FHIR specification. The FHIR specification has a mechanism for modifications, called extensions, allowing the ability to modify resources and elements, without breaking adherence to the specification.

For the CriSTAL questionnaire, a new extension was developed to tag questions with scoring rules and values. The new extension allowed for

dynamic changes to the scoring calculation without having to modify code in the service.

A standard questionnaire extension was used called questionnaire-item-control, this extension allows for modifying the standard format of a question to be displayed differently depending on the value specified in the extension, such as, displaying a slider for a single choice

question. Other extensions were used to express exclusivity on multi-choice questions, display a supporting link and hiding computed values.

3.8.4. CHAT front-end

CHAT is designed as a web-based interface to be used from computers. A future extension is planned for a mobile phone app version. The CHAT front-end is single page application developed and implemented using React JS, Redux for state management, and Redux Final Form for form development. It allows the practitioner to register patients, fill out various questionnaires where certain selections activate other modules (e.g. CKD or cognitive impairment/dementia) and when all necessary questionnaires are completed, export the questionnaires as a printable PDF format. This may now be kept on record, with a printed copy given to the patient/surrogate. Fig. 6 shows the relationship between the different components indicating the clinician's ability to move between screens to edit various sections during the clinical encounter and the final printable *My Choices* PDF.

A demonstration video summarising the basic features can be accessed in OSF (<https://osf.io/6v7nb/>).

3.9. Overall usability testing

3.9.1. Healthcare provider views

Clinicians asked for usability and acceptability feedback at the end of

the interview proposed refinements to question wording and flow through a series of iterative internal consultations (Supplementary files 7 and 8). No questionnaire validation was attempted in this stage of the research, and one clinician gave qualitative feedback without using the standard form. Feedback was incorporated in subsequent versions of the conversation guide prototype (2020–2021).

Our participants' inclusion criteria were a) doctors or nurses from relevant specialties –geriatric medicine, respiratory medicine, internal medicine, intensive care, social work, b) older people aged 60+ years with multiple comorbidities, and c) informal caregivers. After obtaining written consent from patients and family members who assisted in piloting CHAT app, nurses administered the CHAT to 13 older volunteer participants from our Consumer Advisory group and older patients either in the community, at a local hospital, or at the university premises. The pilot testing was endorsed by the University of New South Wales Health, Medical, Community and Social Ethical Review Panel (approval HC16159).

Overall clinician feedback indicated user-friendliness (Fig. 7) and nurses trialling the CHAT on different patients and informal caregivers concluded that the duration (between 30 and 45 min) of the testing consultation was long but acceptable given the topic for a non-emergency service.

The conversation guide components and additional information gave nurses confidence to answer patient questions during the session.

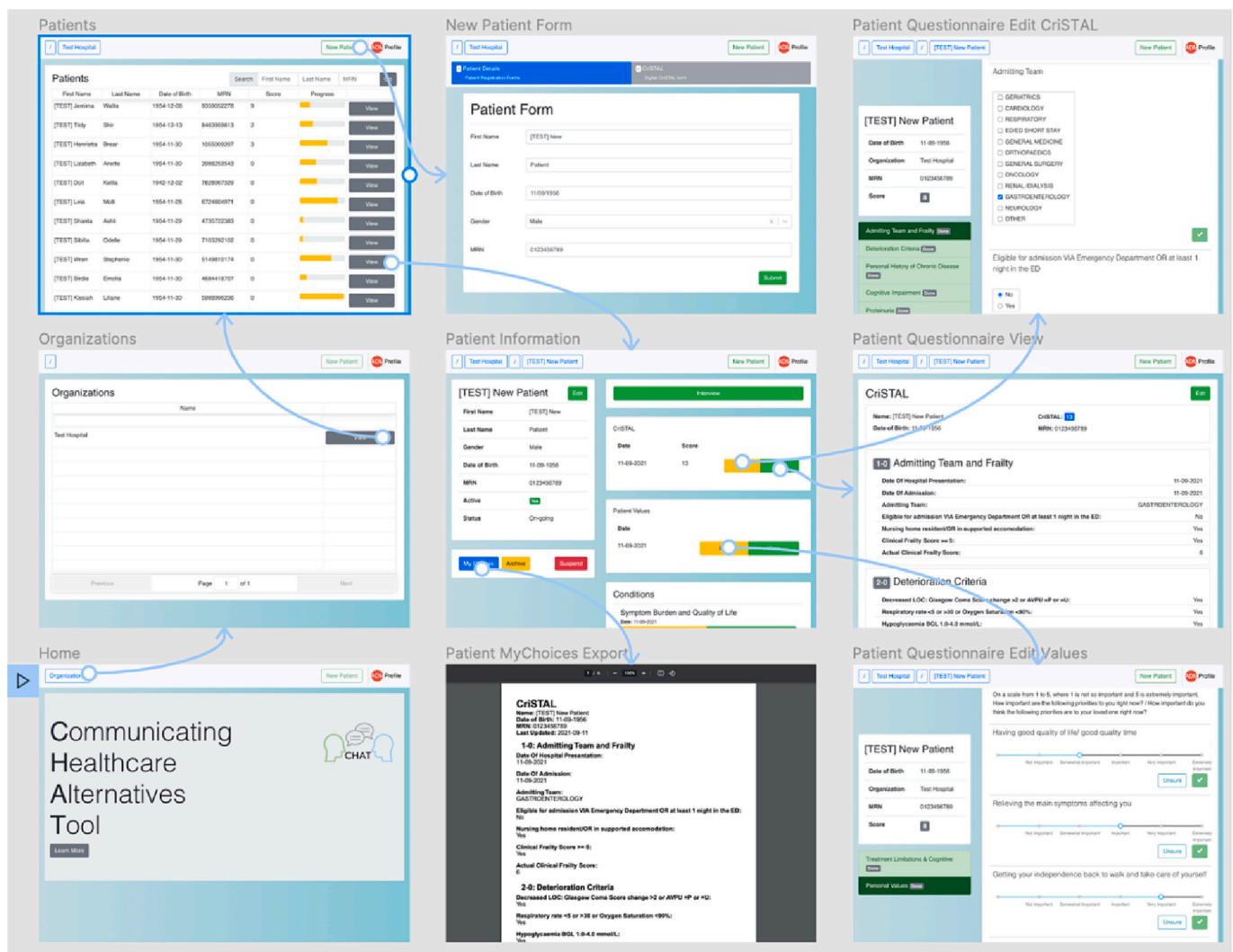


Fig. 6. CHAT app front-end and screen sequence.

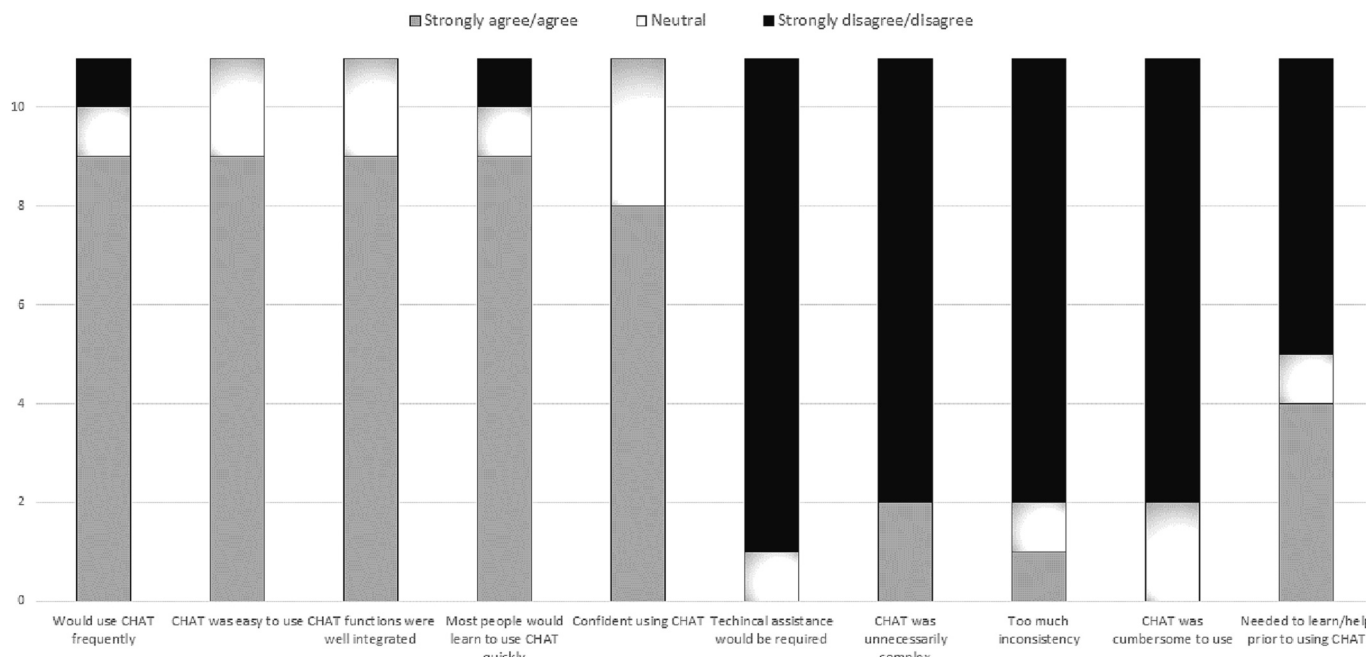


Fig. 7. Clinician's reactions to CHAT prototype.

Multiple requests for wording simplification, question flow, font size/colour changes, clarification on the use of Likert scales, and layout improvements were recommended and trialled at the various rounds.

3.9.2. Patients and caregivers perspective

All patients with chronic conditions and/or informal caregivers (of patients with dementia) reported that the duration of the consultation was just right, and no participant reported the information to be upsetting. For people over the age of 80 our interviewers noticed the interview length led to some respondent fatigue despite their interest in the testing. All reported that CHAT was completely balanced (i.e. not trying to persuade them to one treatment choice or another). Caregivers were satisfied and some relieved with the questionnaire content. Only two patients reported wanting more information during the consultation and all-but-one patient found the information presented as unclear. More than half of the participants reported that CHAT was very helpful in deciding about treatments for their (or their surrogates') health condition.

Performance of the CriSTAL scoring and questionnaire sections to be skipped were repeatedly tested for error checks, autofill and other questions relocated for logical conversation flow. User feedback was communicated to the software engineers on a periodic basis and changes in logic and language incorporated following several rounds of feedback on the different modules between 2019 and 2021.

4. Discussion

At the time of CHAT planning, the literature did not offer comprehensive electronic resources for the purpose of end-of-life decision preparation. The CHAT development including consumer co-design and internal capacity building of engineering students has resulted in a simple guide to encourage clinicians to document patient end-of-life preferences early, and to motivate patients and families to commence the stepwise decision-making process. The guide is expected to improve conversations through facilitating the discussion with ready-made questions and sequence that covers risk, values and treatment preferences. The findings of more recently released studies on considerations about dementia care are consistent with the importance of preventing decisional conflict, and covering feeding options, general wellbeing,

medications, place of care and goals of care, and as in our CHAT tool (Davies et al., 2021; Davies et al., 2019; Pei et al., 2022).

Increasing evidence suggests that discussions on terminal care preferences are delayed or omitted by clinicians (Daren K. Heyland et al., 2013). End-of life conversations including those nurse-led discussions, can enhance patient autonomy (Walczak et al., 2017) or engagement in their own health management (FINDERUP et al., 2021), and that patient subgroups using decision aids are less inclined to request aggressive treatments towards the EOL (Green et al., 2020). To address this gap, our goal was to enable an early and standard conversation flow by a range of clinicians including non-doctors in preparation for the difficult decision time. A mixed methods approach was taken with literature reviews to build the evidence, qualitative consultation with older members of the public, and field testing with clinician end-users. Engineers, clinicians, and researchers translated the needs into a web-based interface that enabled the production of a statement of wishes at the end of conversations.

The CHAT app was designed as a combination of an informative risk of death tool for clinicians, a patient values clarification statement alongside evidence summaries and prognostic knowledge awareness, question prompt list, and evidence-based description of the options, with associated benefits and harms of treatment options presented for specific health conditions if patients or surrogates wanted to know more (Trevena et al., 2013). Following clinician feedback, neutral question language was chosen to prevent biasing response choices regardless of interviewer uncertainty (Kacew and Strohbehn, 2020) and complex numeric information removed. Our process incorporated pragmatic aspects proposed in a recent conceptual framework for ageing and decision making (Löckenhoff, 2018): involving aged patients recognising their cognitive decline and the complexity of their health experience; aiming for joint decisions with clinicians and informal caregivers; and targeting special outcomes for this stage in their lives. Our approach also follows recent recommendations to promote personal health choices using digital support for values clarification (de Vries et al., 2019). While we could not find usability testing of other end-of-life conversation guides, our usability testing outcomes are encouraging, consistently with findings from navigation of two other web-based tools for mechanical ventilation decision targeting patients, clinicians or surrogate decision makers (Cox et al., 2015; Dauber-Decker et al., 2021). Timing

of the discussions is paramount. Achieving a balance between receiving information about likely timing of death and enhancing understanding of personalised options without losing hope for supportive care would be challenging if these discussions are held too late in the dying trajectory (Brighton and Bristowe, 2016).

Despite the knowledge that decision aids contribute evidence to prevent variation in practice (Hoffmann et al., 2014), minimise family conflict (Cardona-Morrell et al., 2017), and avoid clinicians biases in treatment recommendations during goals of care discussions (Callaghan and Fanning, 2018), doctors consulted during our pilot test were disinclined to use the comprehensive numeric prognostic information in routine care, while nurses found the quantitative prognostic information useful only if they could access by it before the interview with patients. Doctors were confident in being up-to-date on clinical practice that did not require that level of detailed quantitative explanation for them or to patients. It might not be feasible in practice for CHAT to be updated yearly for all emerging treatments in plain English for older patients, so it is reassuring that clinicians feel confident about their continuing education. Doctors perceived that the tables were too complex and could confuse patients and lead to cognitive overload. In the past this has been flagged by others as a risk for provider-introduced bias and care disparities among the less educated minority groups (Burgess, 2010). Others have proposed a generic Reframe-Emotion-Map-Align-Plan (REMAP) framework, which prescribes physician statements for progressive goals of care discussion (Childers et al., 2017).

The argument of prognostic certainty being irrelevant and non-disclosure being recommended to enable meaningful dying (Han, 2016) was not found in our pilot. Doctors and nurses involved in our pilot testing were more motivated to use the CriSTAL risk of death tool and values clarifications modules. Patients and surrogates also welcomed the values clarification module as an ice-breaker in preparation for future discussions and decisions, but an effectiveness trial (Fagerlin et al., 2013) will be needed to determine its impact on and consistency with the final decision. Across other health systems there is still resistance to using prognostic tools due to perceived inaccuracy that may negatively affect referral and judgment in treatment changes (Petrova et al., 2021).

Older members of the public rated the questions as clear and important, albeit some who had not considered the issues before found them a little confronting. None of the users found the contents upsetting but this could have been due to the type of volunteers we recruited, who were generally keen to discuss terminal illness issues, the role of clinicians, and assist in improving end-of-life care. Momentum is building with others in Canada successfully introducing hypothetical scenarios for older frail patients in non-trial conditions using the Clinical Frailty Scale and discussions on future care in the face of multimorbidity and deteriorating health (Moorhouse and Mallery, 2012). In the past year one trial has also proposed a preparation support for future critical illness (D. K. Heyland et al., 2020) but their usability testing was not available in the literature. In some residential aged care settings, there is already either a policy encouraging end-of-life discussions within a month of admission, or support for goals of care discussions to inform advance care plans (Martin et al., 2022; Williams et al., 2020). There are still gaps on place of death and documentation of non-medical preferences, but this awareness may facilitate future implementation of CHAT and normalisation of the topic in residential aged care.

While the question is not *if* but *when* to hold preparation for death discussions, debate persists on how to approach these conversations with terminal patients. Some propose to “just ask” hospitalised patients directly in case of acute illness (You et al., 2014), while others favour a stepwise approach (Baile et al., 2000; Balaban, 2000) with a road map before crisis time (Heyland, 2020). The *where* is also a critical question since the pressures of the Emergency Department — our initial target setting, is not the most suitable environment for a long private conversation. GPs may be willing to start the conversation but are time-poor (Lewis et al., 2020) and may not feel fully equipped to communicate

the answers for complex cases (Marcus and Mott, 2014). Future iterations of the CHAT app can investigate whether nurses are the best placed to use the app in the initial stages, and whether the app can bridge this knowledge gap by allowing better collaboration with the GP and the specialist in the patient care trajectory.

4.1. Strengths and limitations

This development process was designed as a capacity building initiative with the contributions of biomedical engineering Master's and post-doctoral students. While this translated in delays, it also aimed to keep the skills in-house for future adaptations to other chronic conditions relevant to patients in our affiliated health settings and to avoid the costs of external consultants. The intermittent contributions of patient members of the target group and the inclusion of patient values and preferences effectively meant that co-design ensured a relevant and appropriate set of questions and interview duration. The CHAT app was planned in a simple language to facilitate patient understanding and designed to be used not only by doctors but also other clinicians, who often play the valuable role of informants and mediators in decision-making (Bern-Klug et al., 2001).

Among the limitations of this development, while our literature review in the initial stages found and incorporated prognostic probabilities in the first prototype, the usability testing yielded clinician objections to the added complexity and in the end our conversation guide did not include these probabilities. The questionnaire's effectiveness has not been validated as testing to assess discordance between patient values and actual treatment administered, fidelity of administration in routine care, and quality of documentation (Comer et al., 2020; Ma et al., 2020), are part of our subsequent research program. CHAT did not include video (El-Jawahri et al., 2010) or other visual aids as our concurrent investigation on visual preferences for prognostic information on a separate group of older people revealed that the preferred format was the traditional verbal delivery by the clinician with a written summary, rather than pictures, video, infographics or statistical tables (Lewis et al., 2021). Other limitations that could be addressed in the future include language barriers and future refinements to ensure the cultural appropriateness of conversation guides for diverse populations, who may approach the topic of death in different ways, just as they differ in their preferences for other healthcare delivery (Lavery et al., 2017). The combination of capacity building affected by rapid student turnover and the intermittent disruption by COVID-19 lockdowns considerably delayed the completion of field testing with patients and clinicians.

4.2. Practice implications

The use of this conversation guide to enhance clinician confidence should not be treated as a box ticking exercise. CHAT is designed as an open and honest discussion to empower patients or their surrogates to start considering options and reflection on how personal values may or may not conflict with those management options. We intend to conduct an effectiveness randomised controlled trial of the impact of the CHAT structured, clinician-guided end-of-life discussion on both the likelihood of opting for non-invasive management among older people and/or their substitute decision-makers, and satisfaction with the process. Beneficiaries in hospital wards, residential aged care and general practice will be a broad, multimorbid older frail group rather than a disease-specific target group with only chronic kidney disease or dementia, as recently recommended in the validation of a values clarification tool for people with serious illness (You et al., 2019). We believe that patients managed by other specialties will also benefit from this conversation on preparation for future critical illness and death. In recent times oncologists have still been reported to inadequately address the information needs on prognosis, goals of care, or treatment cessation of their terminal patients in the last month of life (Knutzen et al., 2021).

In conclusion, a range of initiatives have attempted to address the delayed discussion on the sensitive plan for end-of-life care in routine practice. Our proposed CHAT app version 1.0 aims to fill this gap of incorporating risk of death screening, patient values, increasing awareness of irreversible disease trajectories among patients, treatment options, and gradually preparing patients and families for a normalisation of the prognostic conversation and future formalisation of care directives. The easy accessibility to CHAT through a secure web-interface, its compatibility with the electronic medical record, and simplicity of information on two common chronic conditions are a first step in the right direction to enhance awareness among clinicians of the potential for unnecessary treatments when difficult conversations are not initiated. We offer technical support for this web-based product and hope to introduce it free of charge to health services interested in undertaking wide testing of its feasibility and effectiveness in a randomised controlled trial.

Abbreviations

CHAT	Communicating Health Alternatives Tool
CKD	Chronic kidney disease
CriSTAL	Criteria for Screening and Triaging to Appropriate Alternative care
COPD	Chronic obstructive pulmonary disease
EOL	End of life
FHIR	Fast Healthcare Interoperability Resources
RBAC	Role-based access control
SSO	Single sign-on

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Ethics approval and consent to participate

Data collection and contact with patients and clinicians was approved by the University of New South Wales Health, Medical, Community and Social Ethics Review Panel [approval HC16159]. Written informed consent to participate was obtained from all participants and contributors to the field testing. All methods were performed in accordance with the relevant institutional guidelines and regulations.

Consent for publication

Not applicable.

CRedit authorship contribution statement

Conceptualisation: MC, EL, JH, AB, CF, HA; funding acquisition: MC, EL, HA, NL; contextual literature search: EK, JT, GI, BMR, AM, EL, MC; Development: JH, JLL, MC, EL, ABB, GI, CF, AM, PGB; Supervision: NL, MC, JH; pilot testing: EL, MC, SR, LB, MT; feedback: JH, NL, EL, GI, SR, LB, ABB, HA, AM, MT, PGB; manuscript production: MC, ABB, EL, PB; manuscript revision: all authors.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Availability of data and materials

The dataset(s) supporting the conclusions of this article is(are) included within the main text of this article and its additional files in Appendix A.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.invent.2023.100643>.

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