RESEARCH ARTICLE

Development of Social Determinants of Health Screening Tool (SDoHST): qualitative validation with stakeholders and patients in South Australia

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ABSTRACT

Background: It is well-established that social determinants of health contribute to health and well-being. Among the social determinants of health, health-related social needs (HRSNs) are unmet needs that can be identified by the health care system and addressed through referral to community services. Despite the importance of identifying patients with HRSNs, none of the few screening tools for HRSNs available internationally have received a comprehensive psychometric validation. This study aims to conduct a qualitative validation of the Social Determinants of Health Screening Tool (SDoHST).

Methods: This study took place at Lyell McEwin Hospital, a major tertiary hospital located in Adelaide, South Australia. Patient (n = 5) and stakeholder (n = 9) focus groups were conducted face to face, audio recorded, and transcribed verbatim. Inductive content analysis of focus group transcripts was performed to inform tool modifications (e.g. item rewording).

Results: The patient focus group recommended the addition of an explanatory paragraph to improve face validity, and highlighted the importance of reliable transport and internet access. The stakeholder focus group recommended using language that carries less stigma to this particular community and incorporating questions surrounding cultural, linguistic, and spiritual needs. The final version of the SDoHST included 12 items (four original items were removed and seven new items were added during the validation process).

Conclusion: The SDoHST is the first validated tool to measure social determinants of health (and specifically HRSNs) in Australia, receiving a comprehensive qualitative validation. The instrument is readily available and future studies will further investigate its psychometric properties with quantitative methods.

PLAIN LANGUAGE SUMMARY

A brief guide to screening tools for social determinants of health and their validation

The importance of social context in contributing to overall health is well-established. Social determinants of health (SDoH) are social and environmental factors such as employment, housing security, financial stability, social isolation, and personal safety, which contribute up to 60% of overall health. In recent years, there has been a paradigm shift in how healthcare systems view health and wellbeing. There is a growing call to intervene in adverse SDoH from within the healthcare system. One such intervention involves screening patients for unmet needs, such as housing or food insecurity, and providing appropriate connections to organizations in the community to assist with their needs.

The screening tools implemented in this context are multiple and diverse. Some target only one or two factors while others assess multiple SDoH. However, little is reported about the development of these tools. If a screening tool is not thoroughly developed and validated, it is impossible to know whether the data collected with the tool are appropriate or relevant. This study details the development and validation of a screening tool for unmet social needs by community members and healthcare providers at a major metropolitan hospital in South Australia.

Social determinants of health in South Australia

It is well-established that social determinants of health (e.g. socio-economic, neighbourhood and physical environment, food environment, health care, and sociocultural factors) contribute substantially to health and wellbeing. Health outcomes in Australia follow the ‘social gradient’: people with more socioeconomic disadvantage experience poorer health and live shorter lives than those who are more advantaged.

In South Australia, disadvantage is highly concentrated in the northern suburbs of Adelaide. There is a considerable gap in life expectancy between the most and least advantaged suburbs; those in the north live on average 10 years...
Screening for social determinants of health in South Australia

In South Australia, the 25-item Flinders University Social Health Screening Tool (FUST) was the first unique screening tool developed to measure patients’ social determinants of health across different clinical settings. The pilot study indicated that patients perceived the FUST as relevant and useful. However, the researchers also identified limitations regarding the use of the FUST. The four main limitations were that the FUST: (1) included items measuring clinical and quality of life domains (e.g., items measuring stress and anxiety) in addition to the items measuring HRSNs; (2) did not provide comprehensive coverage of all social determinants of health domains (e.g., items only evaluated transportation to medical appointments but not transportation to access non-medical resources, such as transportation to go to the supermarket and buy food or other essential items); (3) had items with distinct response categories (ranging from two to six response categories) and open-ended questions (“Where were you born?”); and (4) its psychometric properties have not been comprehensively evaluated. A comprehensive psychometric validation is required to ensure that the screeners are accurately measuring social determinants of health in the South Australian context. Henrikson et al. discussed how in the absence of rigorously developed screening tools, any estimates of the prevalence of social risk or the effectiveness of identifying and intervening on these risks will be limited.

In summary, despite the development of the FUST as the first instrument to measure social determinants of health in South Australia, there is a need for a brief screening tool that: (1) focuses specifically on measuring HRSNs; (2) provides in-depth measurement of key HRSNs domains (e.g., housing instability, food insecurity, transportation difficulties, utility assistance needs, interpersonal safety); (3) is brief and easy to administer and score, providing standardized measurement of HRSNs; and (4) undergoes a comprehensive psychometric validation, following gold standard practices. These requirements prompted the development of a new tool, the Social Determinants of Health Screening Tool (SDoHST). To provide a comprehensive psychometric validation of the SDoHST, this study focused on qualitative validation as the initial stage of instrument development (before the quantitative validation). The stages for instrument development in health sciences and the importance of qualitative validation are discussed below.

Qualitative validation of psychological instruments

The development and validation of questionnaires in health sciences, including health literacy questionnaires, patient-reported outcome measures, patient-reported experience measures, and quality of life instruments, should follow a specific sequence of stages to guarantee instrument construct validity. These development stages include: (1) defining the construct and target population; (2) construction of an item list; (3) pre-testing; and (4) field-testing. The definition of the construct and target population refers to identifying what the instrument aims to measure (e.g., social determinants of health) and which is the target population the instrument will be applied to (e.g., hospital patients). The construction of an item list refers to the development and/or adaptation of items to measure the construct among the target population (e.g., development of items to measure social determinants of health among hospital patients). The pretesting stage refers to piloting the instrument in a small sample of respondents to gather initial insights about instrument functioning. From the pilot sample, researchers gather information about content and face validity, acceptability, and perceived relevance, among other psychometric properties.
leading to early instrument modifications, such as rewording or exclusion of problematic items and changes in response categories and scoring. The final stage of instrument development is field-testing, in which the developed instrument is applied to a large sample of respondents and quantitative psychometric evaluation is conducted to further evaluate the instrument’s psychometric properties, such as dimensionality (structural validity), internal consistency, and test–retest reliability, and criterion validity (concurrent, discriminant, predictive validity)17.

Despite these well-established stages required for sound questionnaire development, most research in health sciences tends to focus solely on the final stage, the assessment of validity through quantitative psychometric methods after the instrument was field-tested and responses from a large sample of respondents have been collected. The focus on quantitative psychometric methods over (and sometimes at the expense of) the initial phases of health questionnaire construction and qualitative validation led prominent researchers in the field such as Fayers and Machin17 to discuss how “the importance of the initial qualitative stages cannot be overemphasised. If an important issue has been overlooked and therefore omitted from the instrument, later quantitative validation will be unable to detect this. Thus, no amount of subsequent quantitative validation can compensate for a poorly designed questionnaire”. The authors further highlighted that “unfortunately, many forms of so-called validation will leave the investigator completely unaware that the foundations are unsound” and that “it is rare to see major changes needed to an instrument that has been designed using careful application of qualitative methods”17.

Aims and objectives

This study aimed to conduct a comprehensive development and qualitative validation of the SDoHST, encompassing the development stages of defining the construct and target population, construction of an item list, and pre-testing. Following state-of-the-art recommendations for qualitative validation17, this study employed three methodological steps: (1) development of an initial item pool; (2) piloting the instrument in a patient group, content analysis, and cognitive debriefing of the focus group recommendations to inform questionnaire modifications; and (3) piloting the instrument in a group of stakeholders, content analysis, and cognitive debriefing of the focus group recommendations to further inform questionnaire modifications. The output of this study will be a questionnaire to measure social determinants of health (e.g. SDoHST) developed and validated through qualitative methods that are ready to be field-tested among a large sample of hospital patients in SA and will undergo a future quantitative psychometric evaluation to further examine its psychometric properties.

Methods

Study design

As qualitative research is the most appropriate way to guide the initial stages of questionnaire development, including the investigation of instrument content and face validity18, this study used a qualitative research design to develop and validate the SDoHST incorporating both stakeholder and patient opinion. This approach, based on Brod et al.s’ best practices for qualitative validation of questionnaires17, employed adapted grounded theory19 that permits the utilization and incorporation of clinical knowledge, stakeholder opinion, and scientific literature. The qualitative analysis was conducted according to two subsequent phases. Phase one focused on obtaining patient opinions to inform the respondents’ understanding of questionnaire items. For instance, whether patients accessing hospital services understood each item of the questionnaire, what they understood the questionnaire was measuring, if the language was accessible, if the questionnaire induced response burden (was too long or short), among others. Phase two focused on obtaining stakeholder opinion to investigate whether items were designed according to the current theoretical understanding of social determinants of health internationally and what were potential specificities to the South Australian context. For example, investigating whether crucial information about patients’ social determinants of health, such as financial challenges experienced by hospital patients during treatment and follow-up were adequately addressed by the questionnaire and whether item content would encompass the majority of unmet needs experienced by the hospital patients (e.g. patients without stable housing, living temporarily on shelters on caravans, etc.). Following the content analysis of each focus group, the recommendations by stakeholders and patients were discussed amongst the research team during a cognitive debriefing session18. Cognitive debriefing sessions took place among the research team due to several members of the research team having experience relating to social determinants of health subject matter and/or questionnaire development. The role of the cognitive debriefing sessions was to use the information gathered in each focus group and analysed through content analysis to reach consensus on format, instructions, clarity, understandability, and relevance of the SDoHST, informing questionnaire items refinement and modifications20. Any modifications made to the SDoHST required consensus among all participants both within the focus groups as well as during the cognitive debriefing sessions.

Setting and participants

This study took place at Lyell McEwin Hospital and received ethical approval from the Central Adelaide Local Health Network Human Research Ethics Committee (approval number #14092). Written informed consent was obtained from all participants. Participants were purposively sampled21 for both phases of this study, based on personal experiences and knowledge of social determinants of health. Purposive
sampling (also called judgement sampling) is a form of convenience sampling in which participants are chosen deliberately due to characteristics they possess (e.g. clinical stakeholders)\(^{22}\). For phase one, current adult patients accessing cancer services at Lyell McEwin Hospital were invited to participate in a focus group to explore the patient understanding, comprehension, and acceptability of the scale. For phase two, stakeholders with experience in the area of social determinants of health influence on patient experiences and wellbeing and those likely to be using the screening tool as part of their service provision were invited to participate in a focus group. Stakeholders that met to discuss the content validity and scientific merit of the tool included social workers, nurses, physiotherapists, and researchers from Lyell McEwin Hospital and other parts of Adelaide.

**Data collection**

Two researchers (P.H.R.S & K.E.N) collaboratively facilitated both focus groups to ensure consistency across the data collection period. To gather information on both stakeholder and patient focus groups, we developed a focus group interview schedule that included a 22 question semi-structured interview to evaluate face validity (e.g. “What do you think this questionnaire is trying to measure?”), content validity (e.g. “Do you believe these sections cover the social problems people may be experiencing?” or “Do you think there are any other social factors that should be included?”), item clarity (e.g. “Do you believe patients will understand all the items in the questionnaire?”), item comprehension (e.g. “Do you understand all the items in the questionnaire?”), questionnaire length (e.g. “Is the questionnaire too long? Is the questionnaire too brief?”), among others. The 22-question semi-structured interview questions were tailored for stakeholders (e.g. “Do you believe patients will understand all the items in the questionnaire?”) and patients (e.g. “Do you understand all the items in the questionnaire?”). Although many of the questions included in the interview guide are not open-ended, the facilitators encouraged lengthy discussion amongst participants before reaching a yes/no consensus. The 22-question semi-structured interview is displayed in Supplementary File 1.

Focus groups were conducted in alignment with qualitative validation recommendations of sample size “between three to a dozen individuals”\(^{23}\) and session length “between half an hour to two-and-a-half hours per focus group, with sections from one to two hours being preferred”\(^{24}\). Any suggestions or concerns that were not comprehensively answered during the patient focus group and first cognitive debriefing session were added to the second focus group guide to gauge stakeholder perspectives. The focus groups were conducted face to face, audio recorded, and transcribed verbatim.

**Measures**

The Social Determinants of Health Screening Tool (SDoHST): Before the development of the SDoHST, a review of social determinants of health literature published between 2000 and 2018 was conducted to identify existing social determinants of health (including HRSNs) screening tools in Australia and internationally and examine their psychometric properties\(^{3}\). The review identified seven key HRSNs dimensions (housing, food, household bills, transport, safety, support, and employment) that should be measured by screening tools. Among the reviewed tools, two prominent tools identified were the FUST\(^{16}\) and the Accountable Health Communities HRSN screening tool\(^{13}\). Based on this theoretical information from the review, in the first version of the SDoHST, nine items were developed to measure the seven key HRSNs dimensions (housing, food, household bills, transport, safety, support, and employment). For example, the review identified that available screening tools mostly did not measure non-medical related transportation needs. Given the importance of non-medical related transportation needs for hospital patients\(^{11}\), the item “In the past 6 months have you been unable to do your day to day activities such as, shopping, going to appointments or work because you did not have transport?” was developed for the SDoHST and included in the Transport domain. As another example, available tools mostly evaluated support received from family and friends but did not include support received from community services. Given the importance of support from community services to mitigate the impacts of disadvantages on health\(^ {25}\), the item “In the past 6 months, did you feel that you had support from family, friends or community services?” was developed for the SDoHST and included in the Support domain. The nine items developed for the SDoHST were newly developed (including new item wording and timeframe) and they were only conceptually related to existing items from the FUST\(^ {16}\), the Accountable Health Communities HRSN screening tool\(^ {11}\) or other instruments. The SDoHST items were asked in the context of the past six months and had a two-point response scale (“Yes,” or “No.”). The SDoHST items are displayed in Table 1.

**Data analysis**

Inductive content analysis of focus group transcripts was conducted with NVivo 12 software (QSR International Pty Ltd. version 12.6.1)\(^ {26}\). The goal of this analysis was to ascertain the consensus reached during focus groups through pattern recognition and inductive reasoning\(^ {18}\). To limit the introduction of researcher bias in focus group discussions, the analyst was not involved in the initial development of the tool (BP)\(^ {27}\). A structured codebook was made for each focus group based on the interview guide prior to commencing analysis and then inductive codes and themes were placed within the respective question that prompted participant response (Supplementary File 2). After completion of data analysis, the analyst made corresponding changes to the tool; these changes were discussed during a cognitive debriefing session for each focus group before finalizing items. Where consensus was not met during the focus group, opinion was obtained during the cognitive debriefing to resolve outstanding items.
### Table 1. Modification of the SDoHST questionnaire items according to patients (phase one) and stakeholder (phase two) opinions.

| Original items (version 1) | Phase 1 modifications (version 2) | Phase 2 modifications (version 3) |
|----------------------------|----------------------------------|----------------------------------|
| Response categories: yes, no | Response categories: yes, no | Response categories: yes, no |
| Introduction: “We are using this questionnaire to help us better understand your current social situation. Your answers will help us assist you with any social needs you have. You do not have to answer any questions if you do not want to. When answering these questions, please think back to how these issues have affected you over the past 6 months.” | Introduction: “This questionnaire helps identify any unmet needs that you or your family might have that could affect your health. Your answers will help staff understand the bigger picture of you and your family’s health. You do not have to answer any questions if you do not want to. Thank you for your answers!” |
| Housing | Housing | Housing |
| In the past 6 months were you worried that you did not have enough money to pay your rent or mortgage? | Were you worried that you did not have enough money to pay your rent or mortgage? | Did you and your family have a stable place to live? |
| At any time in the last six months, were you and your family homeless or living in a shelter? | Were you and your family homeless or living in a shelter? | Did you and your family have a stable place to live? |
| Food | Food | Food |
| In the past 6 months were you worried that you did not have enough money for food for your family? | Were you worried that you did not have enough money for food for your family? | Did you and everyone you live with have enough to eat? (New item) |
| Household bills | Household bills | Finances (New title) |
| In the past 6 months were you unable to pay your electricity, gas, or water bills? | Were you unable to pay your electricity, gas or water bills? | Did you and your family have enough money for the things you need (food, rent, medicines, bills)? |
| Transport | Transport | Did you and your family have stable access to internet or mobile data? |
| In the past 6 months have you been unable to do your day-to-day activities, such as shopping, going to appointments, or work because you did not have transport? | Have you had access to reliable transport to do your day-to-day activities? | Did you and your family have a stable income? (New item) |
| Safety | Safety | Safety |
| In the past 6 months did you feel that you or your family were not safe in your home environment? | Did you feel that you or your family was not safe in your home environment? | Did you and everyone in your family feel safe and unafraid at home? |
| In the past 6 months did you feel that you or your family were not safe in your neighbourhood? | Did you feel that you or your family was not safe in your neighbourhood? | Item removed |
| Support | Support | Support |
| In the past 6 months, did you feel that you had support from family, friends, or community services? | Did you feel that you had support from family, friends or community services? | Did you have enough support from family, friends or partner? |
| Employment | Employment | Employment |
| Did you or anyone in your household undertake paid work in the last 6 months? | Did you or anyone you live with do paid work? | Did you have enough opportunities to take part in your culture, religion or language? (New item) |
| Item removed | Item removed | Did you have enough support from community or health services? (New item) |

**Note.** The original nine items (i.e. version 1) were developed based on a review of studies investigating the psychometric properties of instruments designed to measure social determinants of health literature published between 2000 and 2018. The nine items, created to measure the most relevant HRSN domains, were newly developed and only conceptually related to existing items from the FUST16, the Accountable Health Communities HRSN screening tool11 or other instruments. The cells highlighted with light shading on the second (phase one – patient focus group) and third (phase two – stakeholder focus group) columns indicate that the original item (first column) was modified, removed or a new item was included during the qualitative validation. See Supplementary File 3 for each version of the questionnaire.
Results

Overall modifications and dimensions

Five patients participated in the focus group for phase one and nine stakeholders participated in the focus group for phase two. Both focus groups lasted between 1 and 2 h. The recommendations received from both phase one and phase two led to substantive changes to the item content and wording of the original nine-item pool. After the instrument modifications throughout phases one and two, the final version of the SDoHST included 12 items (four original items were removed and seven new items were added during the validation process). Table 1 provides an in-depth explanation of the instrument modifications at each phase, including which items were excluded and which items were developed during the validation process. For example, Table 1 indicates that in the section “Finances” the item “Were you unable to pay your internet bill?” was added during phase one (due to recommendations from the patient focus group) but it was modified to “Did you and your family have stable access to internet or mobile data?” during phase two.

Across both patient and stakeholder focus groups, the original seven dimensions (“Housing,” “Food,” “Transport,” “Household bills,” “Employment,” “Safety,” and “Support”) were considered comprehensive and exhaustive to cover the patients’ unmet needs. However, due to changes in items within the “Household bills” section to include broader financial responsibilities, this dimension was re-named “Finances.”

Patient focus group (phase one)

The patient focus group provided recommendations regarding response categories and time frame, along with the suggestion of new items. Any new items that were suggested during focus groups, particularly during the patient focus group in which patients suggested items measuring the frequency or intensity of cancer symptoms, were discussed during the cognitive debriefing sessions and were not included in the SDoHST if they were not relevant to the measurement of HRSNs.

Response categories and time frame

Patients provided feedback on several components of the SDoHST, such as adequacy of response categories and terminology. The patients argued that the 2-point response scale (“Yes”, and “No”) was adequate for the items measuring their unmet needs. Patients also indicated that “In the past 6 months” could be removed from each of the questions and stated only once at the beginning of the instrument, making the items shorter and easier to read (Table 1). For example, in the “Food” section, the item “Were you worried that you did not have enough money for food for your family?” was considered more readable than “In the past 6 months, were you worried that you did not have enough money for food for your family?”

Face validity

One main finding from the patient focus group was that patients were not entirely clear regarding what the SDoHST was measuring (e.g. lack of face validity), prompting the development and inclusion of an introductory text at the beginning of the tool (Table 1). Based on patients’ recommendations, an introductory text was developed: “We are using this questionnaire to help us better understand your current social situation. Your answers will help us assist you with any social needs you have. You do not have to answer any questions if you do not want to. When answering these questions, please think back to how these issues have affected you over the past 6 months.”

Availability of internet and reliable transportation

The patients also provided insight into details that had not been given full consideration during the original development of the tool but that were particularly relevant in their lives, so these suggestions resulted in the addition of two items. These were the items “Were you unable to pay your internet bill?” added under the “Household bills” dimension and the item “Did you have enough money for fuel for transport?” added under the “Transport” dimension.

Discussions around transportation issues highlighted the importance of reliable transportation, because as patients pointed out, there could be a working vehicle at their home but there may not be money for fuel, they may not be able to operate the car because of current illnesses or a family member may be using the vehicle each day. As such, the original item under the “Transport,” which read “In the past 6 months have you been unable to do your day to day activities such as, shopping, going to appointments or work because you did not have transport?” was modified to “Have you had access to reliable transport to do your day to day activities?”

Limitations regarding instrument development

Despite best efforts to create questions that considered most scenarios, patients highlighted that it is impossible to ensure that items cover all possible unmet needs since “no one person is going to have the exact same [situation to another] person. Everyone’s got a different story. Everyone’s got a different background. Everyone’s got a different, you know, set of bills or whatever else.”

Stakeholder focus group (phase two)

The modifications based on the stakeholder focus group were largely related to the inclusivity of the items included in the SDoHST, and the appropriate use of terminology. The stakeholder focus group resulted in significant modifications to the tool, as evidenced by the removal of four items and the addition of six new items (Table 1). Once all changes discussed in the focus group had been addressed, the updated tool was circulated to stakeholders for final input and to ensure suggestions were not misinterpreted.
Response categories and time frame
Stakeholders agreed with patients that the 2-point response scale (“Yes”, and “No”) was the best option for the tool. The stakeholders also argued that the phrase stating the time frame of six months (“In the past 6 months…”) should be added back underneath each dimension heading to make it easier for respondents to remember the intended time frame, compared to reading it only once at the beginning of the questionnaire. The stakeholders discussed how reminding patients about the six-month time frame is important since patients might not be experiencing an unmet need at the moment, but could have experienced it over the past months, indicating a situation of disadvantage.

Use of the term “social”
The stakeholders provided suggestions to improve the wording of several questionnaire items. The stakeholders highlighted potential issues with the use of the term “social” due to its connotation and associations with social services and child protection, “[is] what I see when I see the word ‘social’… the same as somebody who is very vulnerable, who sees that and sees that as a child protection officer in terms of looking at the word ‘social’. So I think I think the wording is really, really, really important.” Since the word “social” also appears in the original instrument title SDoHST and “social determinants of health” is an academic term the meaning of which might not be immediately clear to respondents, the stakeholder focus group proposed the title “Unmet Needs Screening Tool” to be used when the instrument is applied to patients. Similarly, the term “social” was also removed from the introduction of the tool, which was rewritten as “This questionnaire helps identify any unmet needs that you or your family might have that could affect your health. Your answers will help staff understand the bigger picture of you and your family’s health. You do not have to answer any questions if you do not want to. Thank you for your answers!”

One item to address all “money” needs
Before the stakeholder focus group, there were a few questions that asked whether patients had enough money for specific things, such as rent, food or transport (e.g. “Were you worried that you did not have enough money to pay your rent or mortgage?”). However, the stakeholders argued that these questions should be combined into a single question, mentioning that “As a suggestion sometimes we use the language around money last or running out before payday… You get a sense of whether people can actually get through a fortnight on the income they have, which is both food and household bills related.” Therefore, under the “Finances” dimension, the question (e.g. “Were you unable to pay your electricity, gas or water bills?”) was then modified to include information regarding rent, food or transport, resulting in the item “Did you and your family have enough money for the things you need (food, rent, medicines, bills)?”

The importance of stable income and housing
The stakeholders also highlighted that some items were too restrictive and provided suggestions to create more inclusive and empathetic language. For example, the item “Did you or anyone you live with do paid work?” from the “Employment” dimension was discussed at length because of its inability to capture welfare payments. The stakeholders discussed how, instead of receiving paid work (or living with someone who does), many patients receive government or welfare payments that help them meet their needs and prevent situations of disadvantage. For these reasons, it was considered more important to ensure that patients had a stable income (from paid work or benefits) than income necessarily from paid work, so a new item “Did you and your family have a stable income?” was added in the “Finances” section. Similarly, the item “Were you and your family homeless or living in a shelter?” was modified to “Did you and your family have a stable place to live?” because stakeholders discussed that perceptions of homelessness are not equivalent across patients and stability of housing is more important to measure: “Like, ‘I’m not homeless because I’ve currently got a roof over head, (it’s) just my best friend’s friend’s cousin.” That is, certain patients would not define themselves as “homelessness”, but their housing situation was unstable and would constitute an unmet need.

Food security and nutrition
Stakeholders highlighted the importance of gathering information about food security concerns and nutrition rather than money for buying food as was specified in the original item (e.g. “Were you worried that you did not have enough money for food for your family?”). The stakeholders discussed that: “Did you or your household, or did you or anyone in your household go without food? And then you have that instead of the money, and then you have a question that’s more about your money lasting and that means that food is about food, and you could also possibly make it a second layer that’s got the nutrition element which makes sense.” As such, the original item in the “Food” section was removed and two items were added, “Did you and everyone you live with have enough to eat?” and “Did you and your family eat fresh foods (fruit, vegetables, meat)?”

Support from cultural and religious practices
The stakeholders recommended that one source of support for patients was the opportunity to engage in cultural and religious practices, especially for Culturally and Linguistically Diverse groups and Aboriginal and/or Torres Strait Islanders. Due to this recommendation, the item “Did you have enough opportunities to take part in your culture, religion or language?” was included. The stakeholders also questioned the use of the term “community services” in the item “Did you feel that you had support from family, friends or community services?” The stakeholders argued that: “Seems like community services isn’t quite right, because that to me is getting some Meals on Wheels or cleaning support or something like that, and someone may have adequate community
services but still be extremely socially isolated because they don’t have that connection or cultural connection. I wonder if that’s the right thing to have with that in that question.” The term “community services” was removed from the item and a new separate item regarding community or health services was included in the Support dimension, “Did you have enough support from community or health services?”

Holistic approach in healthcare
Stakeholders echoed the research team’s intention in developing the SDoHST, highlighting the importance of considering the whole person in healthcare, “I think this is the most important thing in healthcare. Like, you know, if we don’t see the person in the context of who they are and how they’re living, how can we possibly help their wellness? And so I think this is just so important to give us that context.” Importantly, stakeholders similarly reflected that the SDOHST will never perfectly fit each patient but that through this validation process, progress towards an inclusive tool has been achieved, “I think we can never have the specificity to make it right for everybody. And so and I think if we want, like my dream for this tool is that it’s the new norm and that we all find a way to adapt it, to integrate it and to respond to it. Um, and so if that’s the case, then we will have to, you know, adapt it for a particular audience that we’re talking to, but that it gives us the language whereby we can broaden it out or bring it back in.”

Discussion
This study aimed to conduct a comprehensive development and qualitative validation of the SDoHST, encompassing the development stages of defining the construct and target population, construction of an item list and pre-testing. Nine items were originally developed to measure HSRNs of patients accessing hospital services across seven dimensions (housing, food, household bills, transport, safety, support, and employment). A qualitative validation was conducted and patients and stakeholders provided recommendations regarding the instrument response categories, time frame, problematic terms (e.g. the term “social”), and the inclusion of new items (to measure reliable transportation), among many others. After incorporating these recommendations, the final version of the SDoHST included 12 items (four original items were removed and seven new items were included). To the best of our knowledge, this is the first validated tool to measure social determinants of health (and specifically HRSNs) in Australia. While web-based screening and referral systems have been qualitatively evaluated (regarding their perceived relevance, easiness of use, etc.)29, to the best of our knowledge, this is also the first social SDoHST (in Australia or internationally) to undergo a psychometric qualitative validation (in which the input from patients and stakeholders were used to remove, rewrite, and improve the questionnaire items). The SDoHST is available for use in Australia and future research will conduct a quantitative validation to further investigate its psychometric properties.

The findings of this study showed that the original nine items developed by the research team, composed of health professionals with clinical and scholarly expertise in social determinants of health, were subjected to substantial changes after input from stakeholder and patient focus groups. The findings emphasized the importance of consulting with patients in a focus group, the target population of the questionnaire. For instance, the patients indicated that several of their needs were not being addressed in the original version of the questionnaire, such as their need to be able to pay for internet to receive information related to hospital appointments and follow-ups, leading to the creation of the item “Were you unable to pay your internet bill?”

The findings demonstrated that the content validity and construct representation of the original items evolved considerably based on the opinion of stakeholders who will be using the tool in their service provision during the second focus group. To give one example, stakeholders recommended the inclusion of the item “Did you and your family eat fresh foods (fruit, vegetables, meat)?”29 to ensure not only that patients had access to food, but that the food they regularly eat would meet their nutritional needs. They also suggested the inclusion of items to evaluate whether patients could participate in opportunities involving their culture, religion or language.

The entire process of validation of the SDoHST questionnaire highlights the importance of early phases of questionnaire development in health sciences, such as clearly defining the construct and target population, construction of an item list, and qualitative validation with stakeholders (patients and stakeholders) to ensure the questionnaire construct validity (specifically content validity, face validity, and construct representation) prior to application to a large sample and subsequent quantitative psychometric validation. As pointed out by Fayers and Machin17, in case the items are poorly written and/or do not comprehensively and exhaustively cover the construct of interest, no amount of quantitative validation can compensate for developmental shortcomings.

The fundamental role of qualitative validation in the initial (and, subsequently, successful) development of health instruments observed in this study is consistent with findings from the medical research literature. For instance, qualitative validation based on patients’ and experts’ opinions was used to develop the Early Psychosis Screener (EPS), a screening tool that identifies patients at clinically high risk of psychotic spectrum disorder30. Qualitative validation has also been employed to identify the key domains underlying continuity of care in mental health services (i.e. knowledge, flexibility, availability, coordination, and transitions), subsequently leading to the development of the 72-item CONNECT instrument31. Initially developed based on qualitative validation, the CONNECT instrument later displayed excellent psychometric properties when its psychometric properties were quantitatively evaluated32. Qualitative validation was also essential to identify domains (such as the domain of Kurunpa, i.e. spirit) that are central to the social and emotional well-being of Aboriginal Australians, leading to the development of the “Men, hearts and minds” questionnaire.
The “Men, hearts and minds” questionnaire provides a culturally appropriate alternative to Western-developed mental health questionnaires to investigate the social and emotional well-being of Aboriginal peoples in Australia.13

More than just providing a solid theoretical foundation for item development, qualitative validation has also been used to evaluate the validity of established mainstream instruments and to inform major adaptations to instruments (such as the modifications to the SDoHST reported in our study suggested by patients and stakeholders). For instance, qualitative validation was used to elucidate interpretative differences between patients regarding mainstream instruments such as the Short-Form 36 Health Status Questionnaire34 and the Edinburgh Postnatal Depression Scale.35 As another example, Kosinski et al.36 reported that patients with systemic lupus erythematosus had interpretative differences regarding four items of the Functional Assessment of Chronic Illness Therapy – Fatigue (FACIT-Fatigue) scale. Kosinski et al.36 reported how certain patients questioned the usefulness of one FACIT-Fatigue item “I have energy” since part of their lived experience with systemic lupus erythematosus is that they “constantly felt tired”.

In other cases, the findings from the qualitative validation provided robust evidence against the instrument construct validity. For example, qualitative validation of the Minnesota Living with Heart Failure questionnaire among patients with severe heart failure indicated that the “introduction to the questionnaire, which contains essential instructions, was almost never read”, that “patients did not interpret items as intended” and that other items were “considered not applicable to the respondents’ circumstances”. The researchers concluded that the Minnesota Living with Heart Failure “does not measure the concept that it is intended to measure” but “problems regarding individual items and response categories can be remedied”.

Overall, in accordance with our study, findings from the medical literature further establish the fundamental role of qualitative validation in questionnaire development. The findings also indicate the problems that occur when researchers skip the stage of qualitative validation during item development, hurrying to create the questionnaire, apply it to respondents and conduct quantitative psychometric validation, what Hunt37 has called the “rush to measurement”28. This study avoided these pitfalls by conducting a comprehensive qualitative validation of the SDoHST, informing both item development and instrument adaptations.

The strengths of the study include the comprehensive questionnaire development and validation conducted with both patient and stakeholders focus groups, following state-of-the-art methodological recommendations for qualitative validation24. The limitations of this study include potential bias due to purposive22, and self-selection sampling39. For example, individuals who agree to participate in research studies usually have a higher income and educational attainment40. It is possible that the patients who accepted to participate in the focus groups had fewer unmet needs compared to those who did not participate in our study. In this case, the patients involved in the focus group might have indicated that no more items were needed to address their unmet needs, while patients with unmet needs (who did not participate) might have potentially suggested new items. In any questionnaire development and validation process, the research design should aim to include respondents with all levels of the construct being measured (i.e. patients with and without unmet needs)13. If the convenience and self-selection sampling include only a segment of the population (e.g. only patients without unmet needs), the findings regarding the validity of the questionnaire are potentially biased. Finally, data collection occurred within a hospital setting amidst the Covid-19 pandemic; as such, focus group scheduling and attendance was impaired due to continually changing restrictions, resulting in a small sample size. The lack of a medical officer in the stakeholder group was a limitation. The inclusion of an individual with lived experience in the stakeholder group might have strengthened decisions made to update the tool, particularly with regard to the wording suggested by stakeholders. We chose to recruit people living with cancer to the patient group. We did this as we aimed to validate the tool in a group of adults with a chronic disease predominantly treated in hospital, of which cancer is an exemplar. Future studies should further investigate the SDoHST with other stakeholder and patient focus groups to confirm the current findings regarding face and content validity, acceptability, item comprehension, among other psychometric properties.

Conclusion

The patient focus group recommended the addition of an explanatory paragraph to improve face validity, and highlighted the importance of reliable transport and internet access. The stakeholder focus group recommended using language that carries less stigma to this particular community and incorporating questions surrounding cultural, linguistic, and spiritual needs. Both groups agreed that brief social determinants of health screening questions cannot capture the full extent of an individual’s disadvantage. As far as we are aware, this is the first SDoHST to undergo thorough psychometric evaluation, including a qualitative validation component to improve the tool in the initial stages of instrument development.

Transparency

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Declaration of financial/other relationships

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants, or patents received or pending, or royalties.

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Author contributions

PHRS, KEN, MB, and BP were responsible for conception and design of the work. PHRS, KK, LJ, and BP were responsible for analysis and interpretation of data. All authors (PHRS, KEN, MB, BP, KK, and LJ) contributed to drafting and revising.

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