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# Culturally and linguistically diverse oncology patients' perspectives of consultation audio recordings and question prompt lists

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Abstract

Objective
Ethnicity and migrant status results in disparities with cancer burden and survival; with communication difficulties cited as the main barrier to access. Our research team tested a communication intervention package comprising consultation audio-recordings (ARs) and question prompt lists (QPLs) for Low English Speaking (LES) patients with cancer. This study explored LES patient experiences, preferences, and recommendations regarding the communication package.

Methods

Participants completed a questionnaire and qualitative interview regarding ARs and QPLs. Eligibility criteria comprised: aged ≥18 years old; a consultation with an oncologist between 1st June 2015 and 1st April 2016; an Arabic, Cantonese, Greek, or Mandarin professional interpreter booked for that consultation; and randomised to receive the communication intervention.

Results
Eighteen patients completed the qualitative interview and 17 completed the questionnaire. Fifteen reported listening to the AR at least once. Participants reported that QPLs and ARs provide support and assist with remembering and understanding medical information. Both resources were seen as having applicability beyond the oncology setting in regards to improving health service delivery and continuity of care. However, patients felt that individual tailoring of the resources should be considered. Patients also found it useful to share ARs with family.

Conclusions
The LES participants in this study considered the ARs and QPLs useful for most but not all contexts. Recommendations regarding delivery and use highlight that these resources should be tailored and patient-driven. Further, patients foresaw a range of additional uses for consultation ARs within the broader healthcare context.

## Introduction

Despite rapid gains in cancer treatment, there are still disparities in survival rates and cancer burden due to factors such as ethnicity and migrant status (1). Migrants face worse outcomes in survival, health-related quality of life and psychological well-being (2). Communication difficulties have been cited as a barrier to access and participation; migrants in Australia and Europe report a lack of appropriate information, inadequate communication due to reduced time in consultations, and fear of a foreign healthcare system (3-9). Time pressures in consultations have resulted in suboptimal provision of information to migrants, regardless of interpreter presence (10), and significant numbers of migrant patients have incorrect understanding regarding their cancer diagnosis (11). Further, limitations in literacy and health literacy, including understanding of a foreign healthcare system, can further compound difficulties with understanding and remembering health information (12). While research data cited is country-specific, communication barriers and lack of understanding regarding novel healthcare systems can be potentially universal for migrants within new host countries. This is of increasing concern, as global migration is expected to rise (13).

In order to provide equitable global healthcare, appropriate interventions must be developed to address these disparities. A systematic review identified a lack of interventions designed to improve participation of low-English speaking (LES) patients with cancer in their healthcare journey and decision-making (14). Effective interventions such as consultation audio-recordings and question prompt lists exist to improve health literacy, information recall, and participation in healthcare amongst English speaking patients, but there have been few attempts to transfer these benefits to LES patients (15-17).

### Consultation audio-recordings

Consultation audio-recordings (ARs) involve creating an audio-recording of a patient's consultation (using a Dictaphone or similar) and providing this AR to the patient so that they can listen to it again at home. ARs are reported to be helpful for remembering, understanding, and clarifying clinical information for English-speaking patients and their families (18-23). Patients place high value on ARs (19, 21), and exhibit increased participation in future appointments (24). AR interventions have been found to be feasible to run in a clinical setting with English-speaking patients (23), and have been piloted in LES patients (25). The benefits of providing consultation ARs may be dependent on the type and/or content of the consultation (19).

### Question prompt lists

Question prompt lists (QPLs) comprise a structured list of questions that patients may wish to ask their health professional, usually developed from review of consultations and/or patient focus groups (22, 26). QPLs have been found to give English-speaking patients an established means, and permission, to engage in their healthcare; and increase the number of questions they ask in oncology consultations (15, 26). QPLs have also been used to improve communication in interactions between health professionals and English-speaking patients from different ethnic backgrounds (27). While QPLs have been shown to be of benefit in English-speaking cohorts, patient preference regarding the method and timing of delivery has not yet been determined (15).

Our research team previously developed and piloted a communication intervention package comprising consultation ARs and QPLs to improve care for Arabic, Greek, Mandarin, and Cantonese-speaking patients with cancer (25). We have since completed a phase II multi-site randomised controlled trial (RCT) with the refined intervention and a larger sample of Australian -Arabic, -Greek,

-Mandarin, and -Cantonese-speaking cancer patients, to assess the feasibility of implementing this into a clinical setting. As part of this study, a qualitative sub-study explored LES patients' experiences, preferences, and recommendations regarding the refined communication intervention. This paper reports the results of this qualitative sub-study. The following research questions guided investigation:

What are LES patient perspectives and experiences of using the consultation AR and QPL?
What are patient preferences regarding method, timing, and delivery of consultation ARs and QPLs?

## Method

The trial was conducted through two outpatient oncology clinics in Melbourne, Australia. Relevant ethics committees gave approval. The trial was registered through the Australia and New Zealand Clinical Trials Registry (trial ID: ACTRN12616001538437). All participants provided both audio-recorded verbal consent and written consent in their own language.

### Participants

Patients randomised to the intervention group in the phase II feasibility RCT were automatically included in the qualitative sub-study (see 'Procedure' below). Patient eligibility criteria for the RCT comprised: aged ≥18 years old; a consultation with an oncologist between 1st June 2015 and 1st April 2016; and an Arabic, Cantonese, Greek, or Mandarin professional interpreter booked for that consultation. Patients were excluded if they were: participating in a therapeutic clinical trial; too unwell; hearing, vision, or speech impaired; self-identified as non-literate in their primary language; or had a diagnosed cognitive or psychological disorder that would preclude participation.

### Procedure

Patients were screened through interpreter booking requests and medical record. Study information was posted to potentially eligible patients, who were then approached via telephone by a bilingual research assistant (RA). All study information and materials were translated by accredited translators using the European Organisation for Research and Treatment of Cancer forward-back translation protocol (28) and given to patients in their preferred language. For the purposes of the RCT, participants were randomised 1:1 within their language group to either intervention or control (stratified by recruitment site and sex). Participants randomised to intervention received the communication intervention package (AR and QPL) and consequently participated in the qualitative sub-study that is reported in this manuscript. Participants randomised to control did not participate in this qualitative sub-study. Intervention participants received their QPL upon arrival to their oncology appointment and were encouraged to read it in the waiting room and to ask their clinician questions.

All participants had their consultation audio-recorded using a Dictaphone. Immediately after the consultation, intervention participants received a copy of their consultation AR on USB or CD. Participants completed a telephone semi-structured interview (SSI) with a bilingual RA two weeks after their consultation. Intervention participants also completed a digital recording use questionnaire (DRQ) two weeks after their consultation to assess the extent to which they utilised the AR. Control participants received a copy of their consultation AR after their study participation was complete. Full procedures for the phase II RCT will be reported elsewhere.

### Communication intervention package

#### Question Prompt Lists

The QPL included 77 questions covering: diagnosis, prognosis, cause, treatment, nutrition, diet, finance, sexuality, transport, and complementary therapies (29). The QPL was available in English, Arabic, Greek, and simplified and traditional Chinese. The QPL comprised one double-sided, custom designed A3 page folded into an A4-sized booklet.

Audio-recorded consultations

Appointments with medical, radiation, or surgical oncologists were audio-recorded. Consultations were classified as one of three different consultation types: 'first in hospital', 'first with specialist', and 'post-scan, surgery, or other work-up'. Other consultation types, such as mid-treatment review appointments, were not considered appropriate for AR as piloting suggested they were less information-dense (25). All participants had access to a computer or a CD player in order to listen to the AR.

Measures

Semi-Structured Interview (SSI)

The SSI contained two parts: the first part was relevant only to the RCT and was designed to elicit information regarding the content of the audio-recorded consultation. This component of the SSI is described in detail elsewhere (30). The second part of the SSI contained the 10 interview questions for the qualitative sub-study and was designed to elicit feedback about the AR and QPL (Table 1). Control participants did not complete these questions as they could not provide intervention feedback and were not participants in the qualitative sub-study.

Digital Recording Use Questionnaire (DRQ)

The DRQ was adapted from the Digital Recording Use Semi-Structured Interview into a paper and pencil self-report questionnaire (31). The DRQ consists of 4 multi-choice items which assess the number of times a patient listened to part or all of the AR, and the number and type of people who listened. A fifth, free-text response question assessed perceived benefits and drawbacks of the AR.

Analysis

All SSIs were audio-recorded. Bilingual RAs listened to these audio-recordings and directly transcribed patient's feedback into a detailed English summary. Answers to the free-text question in the DRQ were translated verbatim into English by a bilingual RA. These summaries and translations were uploaded to NVivo11 (QSR International, Melbourne, Victoria, Australia) for concurrent data management and analysis.

Interpretive description was selected for analysis as it provides practical outcomes for clinical health services improvement (32). Analysis was conducted by a monolingual, English-speaking researcher (RLS).To support interpretive reliability of the analysis, particularly as they had been summarised into English from another language, all codes, categories, and themes were reviewed by a second researcher (AH), and discussed until agreement was achieved (33). Demographic and clinical variables and responses to the multi-choice DRQ questions are reported using descriptive statistics.

Results

Of the 107 eligible patients who were approached, 47 consented to the RCT. Eighteen of these participants were randomised to receive the intervention (QPL and AR) and all eighteen participated in the qualitative sub-study (3 Arabic, 4 Cantonese, 3 Greek, 8 Mandarin). Screening and consent rate data for the RCT will be reported elsewhere. All eighteen participants completed the SSI, and

seventeen completed the DRQ. One participant (Cantonese) did not return the DRQ. See Table 2 for participant demographics and types of consultations audio-recorded.

Audio Recording use

Results from the multi-choice DRQ questions

Two patients stated not listening to the AR at all. The rest (n=15) reported listening to the AR at least once. Four participants listened twice, two listened 3 times, and one listened 4 times. Seven participants reported re-listening to portions of the AR: three re-listened to one portion once (one participant did this with their doctor); one re-listened to one or more portion/s twice; two re-listened to one or more portion/s 3 times; and another re-listened to one or more portion/s 5 times.

Of the 15 patients who listened to the AR, seven listened to it on the day of their consultation. Others listened on the following day (n=2), 2-3 days afterwards (n=3), or 4-7 days afterwards (n=4). Ten patients reported listening to the audio recording with one or more other people including: spouse (n=7), and/or other family members (n = 4), or a healthcare professional (n = 1). See Table 3 for further listening data.

Patient feedback: consultation audio-recordings

See Figure 1 for participants' quotes. Verbatim translated quotes from the free-text DRQ question are contained within quotation marks in Figure 1, however, excerpts from SSI responses are not contained within quotation marks as these were summarised into English (not translated verbatim).

An information resource

Overall, participants felt that the AR was useful and valuable for remembering medical information, increasing understanding, and clarifying what was discussed, especially in regards to important issues such as diagnosis/disease, treatment, or test results. Patients felt that the AR would help them with decision-making and identify gaps in information. It was seen as beneficial to have a record of what was discussed, particularly for identifying questions to ask at the next appointment.

Support

Patients felt the AR would provide support at times of confusion or lapses in concentration. People felt their ability to take in information was impaired by the shock of diagnosis, and/or emotional response to hearing bad news. Being able to listen to the AR in the comfort of their home was perceived to reduce the impact that this news had on their understanding of their cancer.

Being able to share the AR with family was described as valuable, useful, and important. Patients discussed playing the AR to family members, especially those who could not attend the appointment. They felt that the AR gave their family the opportunity to be informed. Patients also felt the AR would allow family members who understood English to explain information that was not understood by the patient.

Wider application in health services

Importantly, patients felt that this intervention should not be limited to oncology. Patients thought the ARs could be used in a variety of different ways to improve their care, and the health service as a whole. Perceived benefits included: encouraging doctors to communicate more effectively; and compensating for unsatisfactory interpreting. Participants thought that ARs had the potential to improve their continuity of care. Other health professionals, including those outside the hospital system such as psychologists or GPs, were considered as potential users of ARs; as were researchers

aiming to improve hospital services. Interestingly, a number of patients discussed how they used, or planned to use, the AR as a tool to practice English.

Potential cultural barriers

Some patients did not perceive a benefit in recording the consultations because their family would attend every consultation, as was their cultural norm. Some patients felt that the AR did not overcome the language and/or cultural barriers experienced when communicating with their doctor. Contrary to this, other patients believed that the AR was unnecessary because having an interpreter was a sufficient aid. Some participants felt it was respectful to allow the doctor to make the decisions, and therefore felt that it was unnecessary to study closely what the doctor said.

A tailored, patient-driven solution

Participants varied as to when they thought the AR would be appropriate. Many patients gave specific timing recommendations such as: at diagnosis; treatment decision-making; when receiving test results; treatment planning; immediately after treatment; for advanced disease; or any situation where important information is disclosed. Some patients felt that all appointments were important and worthy of being audio-recorded. Conversely, others felt that AR was unnecessary if not much information was discussed (e.g., during a routine check-up).

One patient felt that listening could lead to depression or feelings of sadness. Several patients found the sound quality of the AR to be poor, and suggested that this could be improved by using better technology.

Patient Feedback: Question Prompt List

Useful resource

Patients spoke about the QPL as being useful, particularly to prompt questions that they had forgotten or not considered. Some patients thought that QPLs should be available to all patients upon arrival, and that it would be particularly useful for people with lower education levels, or newly diagnosed.

Support

As with the AR, it was felt that the QPL would help during the shock and confusion following diagnosis, or before any initial consultation. One Cantonese patient felt that the more detailed the list, the better. The idea of having ‘conditional questions’ was proposed, i.e., ‘If I just had surgery, what questions could I ask’.

Potential cultural barriers

While many patients felt that the QPL was useful, several felt uncomfortable asking questions as they did not want to ‘waste’ the interpreters’ or doctors’ time. Other participants felt that only doctors, not patients, should ask questions. Some patients thought that it was more appropriate to rely on family to prompt question-asking, rather than the QPL. The translation and cultural acceptability of the questions in the QPL were reported to be good.

Tailored approach

The QPL was found to be comprehensive and general enough to be useful in many situations; indeed, a Greek patient used it at later consultations. However, a few patients reported that some questions were not relevant, or too simplistic, particularly for people diagnosed some time ago. Many patients felt that the QPL would be more useful if it were tailored to the individual. Some people said they

were not given sufficient time to read the QPL before their appointment; or that it would be better to spend the time developing their own questions. Interestingly, patients had opposing views regarding the question 'How long will I live for'; one patient felt that this was very important, another said it was a silly question, and a third said it was too overwhelming to read or ask.

## Discussion

Patient perspectives are crucial components of feasibility analysis to ensure that interventions meet expectations, are appropriate, feasible, and useful to the people they are designed to assist. Findings from this study reveal insightful recommendations from LES patients regarding the implementation, delivery, and use of the proposed communication intervention: QPLs and consultation ARs.

### Information resources and supportive care

Interestingly, people perceived ARs as more than just a memory aid; which is what health professionals have typically thought to be its main benefit (34). LES patients described using the AR in multiple ways, such as to generate questions to ask their doctor, or to help participate in shared decision-making. Patients also used the AR to mediate LES-specific communication barriers such as: improve understanding of the health-system and diagnostic and treatment information, which research shows LES patients often lack (11).

Patients viewed the AR and QPL as supportive components of their care; particularly in mediating shock and confusion, which are commonly reported by patients (35). Being able to share consultation ARs with family and/or friends was described as conveying multiple benefits. Family and friends are often caregivers, and can be heavily involved in treatment decision-making (36). Consultation ARs provide patients with a means to initiate treatment discussions with family (16). Being able to share information and have treatment discussions with family may be particularly important in migrant communities, where families often assume a greater role in decision-making (37). Patients in our study took communication improvements one step further, and spoke about utilising the recording to improve their English skills. This may have additional flow-on effects in terms of improvements with health literacy.

### Improving health services delivery

Patients felt that the act of audio-recording improved the quality of the consultation, reflecting literature hypothesising that clinicians may adopt a more planned, timely, and detailed approach to consultations that are audio-recorded (19). Alternatively, clinical staff have raised concerns that ARs may result in consultations being more formal at the cost of rapport-building and intimacy (34). However, it is possible that some clinicians may feel more comfortable knowing that patients can review all content in an AR and identify areas needing clarification. This may be particularly true when information is interpreted since this increases the complexity of communication.

LES patients' suggestion that ARs be made available to other members of their treatment team is important. Consultation ARs may allow for increased communication between tertiary/specialist care and primary care. Participants noted that emotionally-charged situations impacted their ability to recall information, which may hinder communication about their care with other health professionals. Furthermore, general practitioners, or allied health specialists may not always have access to interpreters. Being able to provide an accurate record of medical information across providers could have many benefits for LES patients. The scope of ARs could be extended to medication information delivery, diet and nutrition guidelines, exercise/rehabilitation programs, or practical healthcare

navigation instructions. Further, in regards to implementation, the universal government/taxpayer funded healthcare system in Australia would be well-placed to support such interventions if delivered through sustainable means.

### Possible barriers

Not all migrant groups experience the same level of communication difficulties (12). Nor do all patients want communication interventions; in some cases these tools directly contradict cultural norms such as not questioning doctors, or utilising assistance only from interpreters or family (38). However, a review of QPL use found that explicit endorsement by physicians increased question-asking by English-speaking patients (11), a tactic which could by employed with LES patient to overcome cultural barriers.

### Clinical implications

As with other AR studies, not all patients listened to the AR or found it useful (23). Previous research has reported that some people were disinclined to listen to ARs as they felt upset by the information or did not want to relive the diagnosis (39). Several participants echoed this sentiment, which suggests that a one-size-fits-all approach to resource distribution would not be appropriate. Further, the participants who did engage with the AR varied in how and when they used it, which supports previous findings (34). Feedback from participants demonstrates that resources should be responsive and flexible to patient preferences, functionality, and delivery/time of use. If implemented into clinical practice, these resources could be patient-driven which might allow patients to tailor the resources to their needs by e.g., selecting the most appropriate questions in the QPL, or by deciding which appointments to AR. Preferences could be sent to clinicians prior to consultations to ensure that information delivered in these often time-sensitive contexts can be tailored to patient needs. Perspectives from health experts support the notion that these resources should be patient driven (34). Further research could also investigate and provide recommendations regarding which appointments would be most beneficial for patients to AR.

### Limitations

This study was conducted with literate Arabic-, Greek-, Mandarin- and Cantonese-speaking oncology patients in two healthcare settings in urban Melbourne, and the participants in this sample represent only a small proportion of the patients eligible for the study. Our results are therefore not representative of all LES patients in Australia, and may be biased towards patients who were more interested in participating in this research. Participants' responses to the SSI questions were transcribed directly into English rather than being transcribed verbatim in the LOTE and then translated. Translation from the LOTE to English may have resulted in missed nuances. Future research could consider employing bilingual staff with professional qualifications in translation and interpretation to analyse the data in the language/s in which it was originally spoken.

## Conclusion

LES patients report consultation ARs and QPLs to be useful in most, but not all, contexts. Recommendations regarding delivery and use highlight that these resources should be tailored and patient-driven, and that it may not always be warranted. This sample of LES migrant patients displayed similar reactions to those of English-speaking non-migrant patients. This is important as it indicates that ARs and QPLs may be appropriate and feasible for LES patients, and so may provide benefits to those facing communication barriers and associated decreased health outcomes.

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Conflict of interest
None declared.

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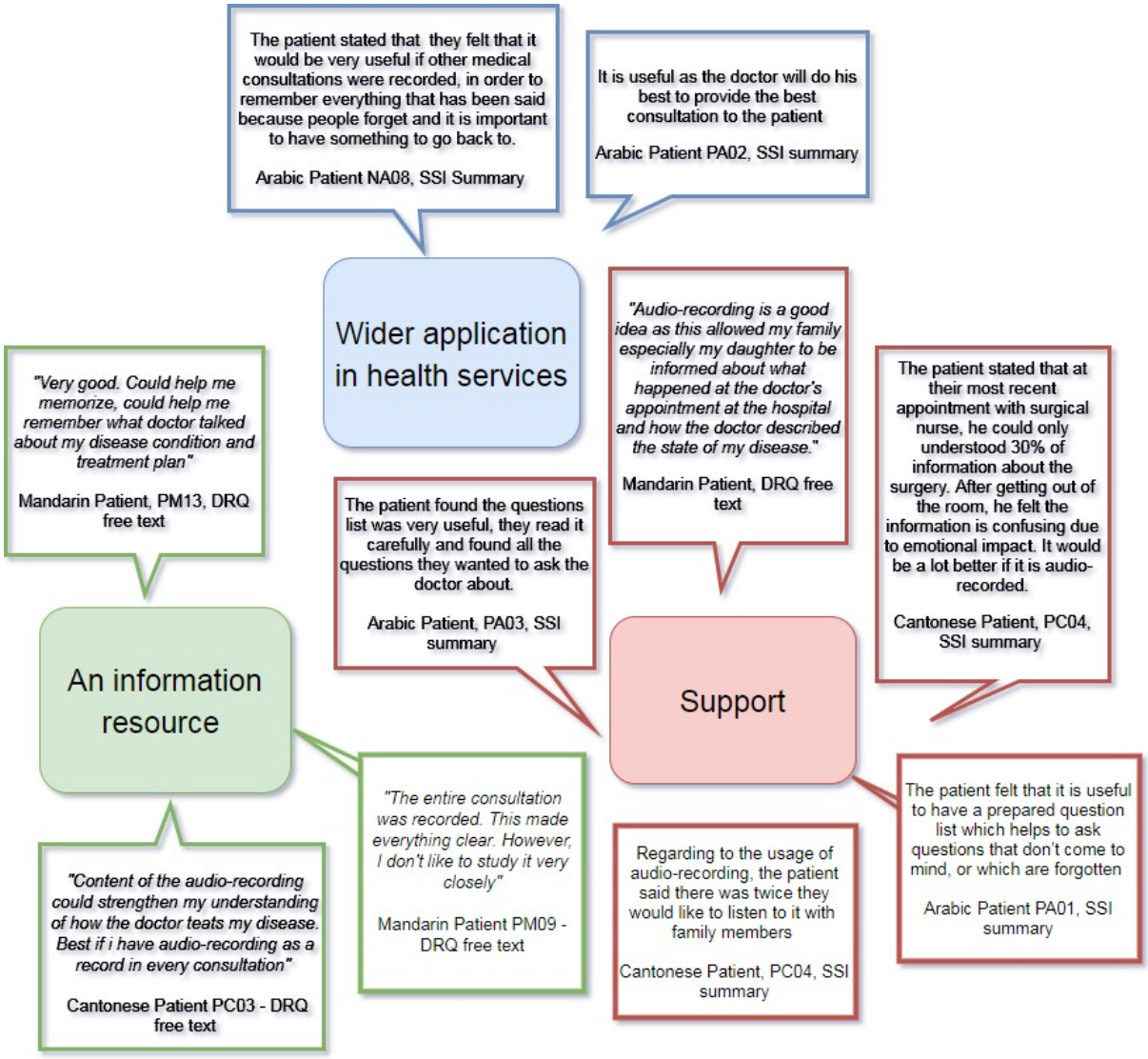



Figure 1: Quotes from patients regarding QPLs and ARs

**Table 1:** Semi-structured research interview (SSI) questions and prompts

| Questions |
| --- |
| 1. What did you like or dislike about taking part in our research study? |
| 2. Did you feel it was a useful sort of appointment to have a recording of to listen to at home? |
| 3. Why did you feel it was/wasn't useful? |
| 4. Would it have been more useful for you to have had a different sort of appointment audio-recorded? |
| 5. What other sorts of appointments would have been useful to have audio recorded? |
| 6. Did you find the Question List helpful? |
| 7. Did it include the sort of questions you would like to ask? |
| 8. Were there any questions missing? |
| 9. Do you feel that it helped you think of questions you wanted to ask? |
| 10. Was there anything that was translated badly? |

**Table 2:** Patient demographic data for all language groups

| Variable | Arabic | Cantonese | Greek | Mandarin |
|---|---|---|---|---|
| Age (mean, range) | 53 (37-71) | 57 (48-76) | 74 (70-79) | 61 (31-74) |
| Country of Birth (Country, *n)* | Egypt (3)<br>Iraq (1)<br>Lebanon (1)<br>Syria (2)<br>Missing (1) | China (3)<br>Hong Kong (2)<br>Vietnam (2) | Greece (6) | China (18)<br>Missing (1) |
| Cancer Type | *n* (%) | *n* (%) | *n* (%) | *n* (%) |
| Bone and soft tissue | 0 (0) | 3 (43) | 0 (0) | 0 (0) |
| Breast | 3 (38) | 0 (0) | 0 (0) | 0 (0) |
| Gynae | 1 (13) | 0 (0) | 0 (0) | 1 (5) |
| Haem | 0 (0) | 0 (0) | 0 (0) | 1 (5) |
| Head and neck | 1 (13) | 2 (29) | 0 (0) | 1 (5) |
| Lower GI | 0 (0) | 1 (14) | 2 (33) | 6 (32) |
| Lung | 1 (13) | 0 (0) | 0 (0) | 6 (32) |
| Upper GI | 0 (0) | 0 (0) | 1 (17) | 2 (11) |
| Urology | 2 (25) | 1 (14) | 3 (50) | 2 (11) |
| Sex | | | | |
| Male | 2 (25) | 6 (86) | 4 (67) | 12 (63) |
| Female | 6 (75) | 1 (14) | 2 (33) | 7 (37) |
| Relationship Status | | | | |
| Single | 0 (0) | 0 (0) | 0 (0) | 3 (16) |
| Married/defacto | 6 (75) | 2 (71) | 6 (100) | 16 (84) |
| Separated/divorced | 1 (13) | 2 (29) | 0 (0) | 0 (0) |
| Widowed | 1 (13) | 0 (0) | 0 (0) | 0 (0) |
| Employment Status | | | | |
| Working | 2 (25) | 2 (29) | 0 (0) | 0 (0) |
| On sick leave | 1 (13) | 1 (14) | 0 (0) | 3 (16) |
| Not employed | 1 (13) | 2 (29) | 1 (17) | 1 (5) |
| Retired | 2 (25) | 2 (29) | 4 (67) | 9 (47) |
| Home duties | 1 (13) | 0 (0) | 0 (0) | 4 (21) |
| Studying | 1 (13) | 0 (0) | 0 (0) | 1 (5) |
| Other | 1 (13) | 0 (0) | 0 (0) | 1 (5) |
| Missing | 0 (0) | 0 (0) | 1 (17) | 0 (0) |
| Education Level | | | | |
| No formal schooling | 2 (25) | 0 (0) | 0 (0) | 0 (0) |
| Primary schooling | 1 (13) | 0 (0) | 5 (83) | 0 (0) |
| Secondary schooling | 1 (13) | 4 (57) | 0 (0) | 3 (16) |
| Tertiary schooling | 4 (50) | 3 (43) | 0 (0) | 11 (58) |
| Trade/TAFE college | 0 (0) | 0 (0) | 0 (0) | 5 (26) |
| Missing | 0 (0) | 0 (0) | 1 (17) | 0 (0) |
| Living Arrangements | | | | |
| By yourself/independently | 0 (0) | 0 (0) | 0 (0) | 3 (16) |
| With spouse/partner | 1 (13) | 1 (14) | 0 (0) | 4 (21) |
| With spouse/partner and children | 5 (63) | 4 (57) | 3 (50) | 10 (53) |
| With children only | 2 (25) | 1 (14) | 3 (50) | 2 (11) |
| Other | 0 (0) | 1 (14) | 0 (0) | 0 (0) |
| Speak English | | | | |
| Yes | 4 (50) | 4 (63) | 3 (50) | 12 (63) |

| | | | | |
|---|---|---|---|---|
| No | 2 (25) | 3 (38) | 1 (17) | 7 (37) |
| Missing | 2 (25) | 0 (0) | 0 (0) | 0 (0) |
| English Proficiency | | | | |
| Basic | 1 (13) | 2 (25) | 1 (17) | 9 (75) |
| Intermediate | 5 (63) | 2 (25) | 4 (67) | 3 (25) |
| Advanced | 0 (0) | 1 (13) | 0 (0) | 0 (0) |

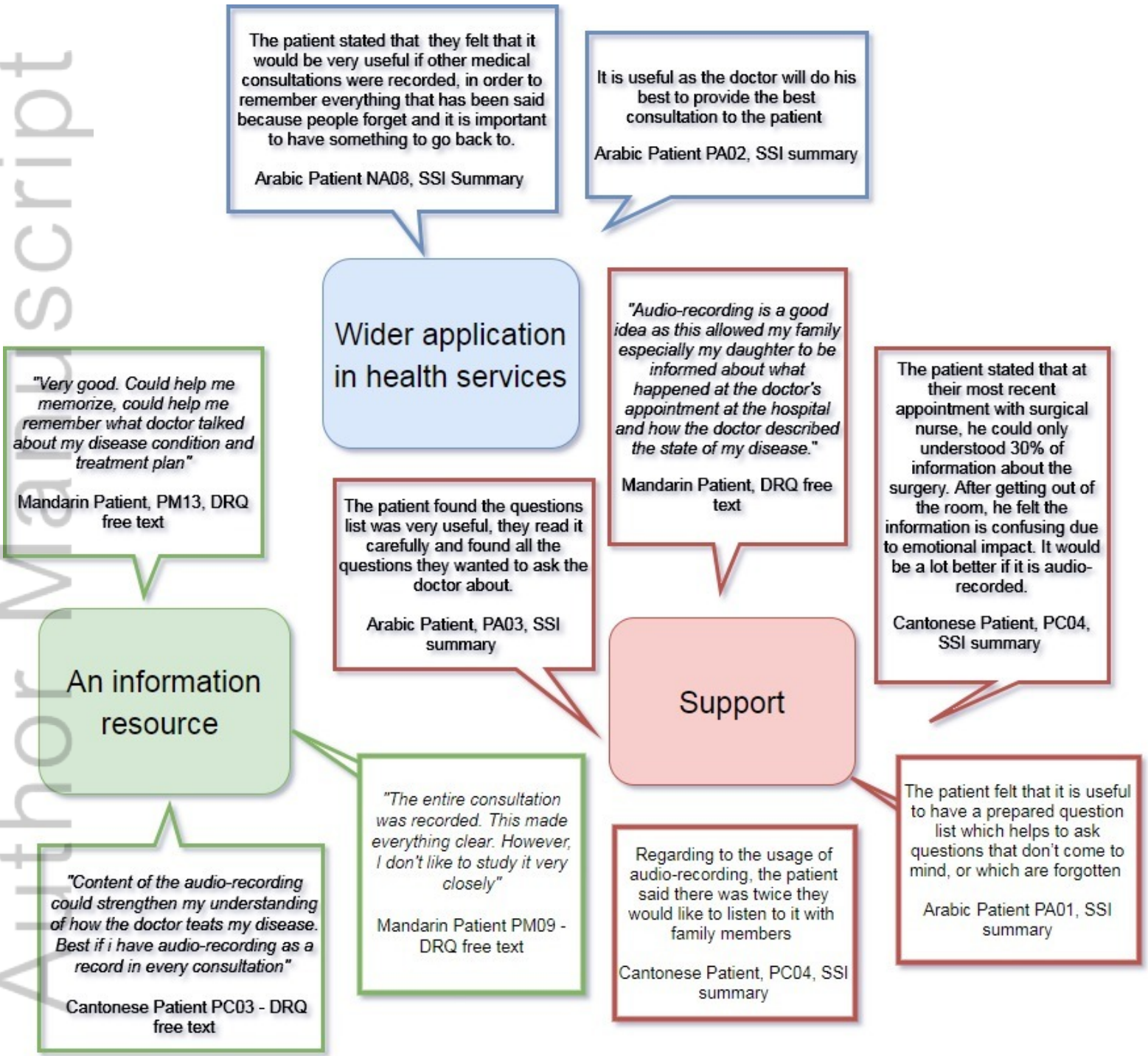
**Table 3:** Audio-recording use (additional appendix attachment)

| Audio-recording listening behaviour | Participants (*n* = 17) |
|---|---|
| Number of times listened to entire recording, *n* | |
| 0 | 2 |
| 1 | 8 |
| 2 | 4 |
| 3 | 2 |
| 4 | 1 |
| Number of times listened to part of recording, *n* | |
| 0 or not reported | 8 |
| 1 | 3 |
| 2 | 1 |
| 3 | 2 |
| 4 | 0 |
| 5 | 1 |
| Number of days after consultation when listened, *n** | |
| Did not listen | 2 |
| 0 | 7 |
| 1 | 2 |
| 2-3 | 3 |
| 4-7 | 4 |
| Who else did you listen to it with, *n*^ | |
| Did not listen | 2 |
| No one | 5 |
| Spouse/partner | 7 |
| Other family member | 4 |
| Health professional | 1 |

*Does not add up to 17 because some people listened on more than one day

^Does not add up to 17 because some people listened with more than one person

Figure 1: Quotes from patients regarding QPLs and ARs




PON_4789_F1.jpg

**Table 1:** Semi-structured research interview (SSI) questions and prompts

| Questions |
| --- |
| 1. What did you like or dislike about taking part in our research study? |
| 2. Did you feel it was a useful sort of appointment to have a recording of to listen to at home? |
| 3. Why did you feel it was/wasn't useful? |
| 4. Would it have been more useful for you to have had a different sort of appointment audio-recorded? |
| 5. What other sorts of appointments would have been useful to have audio recorded? |
| 6. Did you find the Question List helpful? |
| 7. Did it include the sort of questions you would like to ask? |
| 8. Were there any questions missing? |
| 9. Do you feel that it helped you think of questions you wanted to ask? |
| 10. Was there anything that was translated badly? |

**Table 2:** Patient demographic data for all language groups

| Variable | Arabic | Cantonese | Greek | Mandarin |
|---|---|---|---|---|
| Age (mean, range) | 53 (37-71) | 57 (48-76) | 74 (70-79) | 61 (31-74) |
| Country of Birth (Country, *n)* | Egypt (3)<br>Iraq (1)<br>Lebanon (1)<br>Syria (2)<br>Missing (1) | China (3)<br>Hong Kong (2)<br>Vietnam (2) | Greece (6) | China (18)<br>Missing (1) |
| Cancer Type | *n* (%) | *n* (%) | *n* (%) | *n* (%) |
| Bone and soft tissue | 0 (0) | 3 (43) | 0 (0) | 0 (0) |
| Breast | 3 (38) | 0 (0) | 0 (0) | 0 (0) |
| Gynae | 1 (13) | 0 (0) | 0 (0) | 1 (5) |
| Haem | 0 (0) | 0 (0) | 0 (0) | 1 (5) |
| Head and neck | 1 (13) | 2 (29) | 0 (0) | 1 (5) |
| Lower GI | 0 (0) | 1 (14) | 2 (33) | 6 (32) |
| Lung | 1 (13) | 0 (0) | 0 (0) | 6 (32) |
| Upper GI | 0 (0) | 0 (0) | 1 (17) | 2 (11) |
| Urology | 2 (25) | 1 (14) | 3 (50) | 2 (11) |
| Sex | | | | |
| Male | 2 (25) | 6 (86) | 4 (67) | 12 (63) |
| Female | 6 (75) | 1 (14) | 2 (33) | 7 (37) |
| Relationship Status | | | | |
| Single | 0 (0) | 0 (0) | 0 (0) | 3 (16) |
| Married/defacto | 6 (75) | 2 (71) | 6 (100) | 16 (84) |
| Separated/divorced | 1 (13) | 2 (29) | 0 (0) | 0 (0) |
| Widowed | 1 (13) | 0 (0) | 0 (0) | 0 (0) |
| Employment Status | | | | |
| Working | 2 (25) | 2 (29) | 0 (0) | 0 (0) |
| On sick leave | 1 (13) | 1 (14) | 0 (0) | 3 (16) |
| Not employed | 1 (13) | 2 (29) | 1 (17) | 1 (5) |
| Retired | 2 (25) | 2 (29) | 4 (67) | 9 (47) |
| Home duties | 1 (13) | 0 (0) | 0 (0) | 4 (21) |
| Studying | 1 (13) | 0 (0) | 0 (0) | 1 (5) |
| Other | 1 (13) | 0 (0) | 0 (0) | 1 (5) |
| Missing | 0 (0) | 0 (0) | 1 (17) | 0 (0) |
| Education Level | | | | |
| No formal schooling | 2 (25) | 0 (0) | 0 (0) | 0 (0) |
| Primary schooling | 1 (13) | 0 (0) | 5 (83) | 0 (0) |
| Secondary schooling | 1 (13) | 4 (57) | 0 (0) | 3 (16) |
| Tertiary schooling | 4 (50) | 3 (43) | 0 (0) | 11 (58) |
| Trade/TAFE college | 0 (0) | 0 (0) | 0 (0) | 5 (26) |
| Missing | 0 (0) | 0 (0) | 1 (17) | 0 (0) |
| Living Arrangements | | | | |
| By yourself/independently | 0 (0) | 0 (0) | 0 (0) | 3 (16) |
| With spouse/partner | 1 (13) | 1 (14) | 0 (0) | 4 (21) |
| With spouse/partner and children | 5 (63) | 4 (57) | 3 (50) | 10 (53) |
| With children only | 2 (25) | 1 (14) | 3 (50) | 2 (11) |
| Other | 0 (0) | 1 (14) | 0 (0) | 0 (0) |
| Speak English | | | | |
| Yes | 4 (50) | 4 (63) | 3 (50) | 12 (63) |
| No | 2 (25) | 3 (38) | 1 (17) | 7 (37) |
| Missing | 2 (25) | 0 (0) | 0 (0) | 0 (0) |
| English Proficiency | | | | |
| Basic | 1 (13) | 2 (25) | 1 (17) | 9 (75) |
| Intermediate | 5 (63) | 2 (25) | 4 (67) | 3 (25) |
| Advanced | 0 (0) | 1 (13) | 0 (0) | 0 (0) |

**Table 3:** Audio-recording use (additional appendix attachment)

| Audio-recording listening behaviour | Participants ($n$ = 17) |
|---|---|
| Number of times listened to entire recording, *n* | |
| 0 | 2 |
| 1 | 8 |
| 2 | 4 |
| 3 | 2 |
| 4 | 1 |
| Number of times listened to part of recording, *n* | |
| 0 or not reported | 8 |
| 1 | 3 |
| 2 | 1 |
| 3 | 2 |
| 4 | 0 |
| 5 | 1 |
| Number of days after consultation when listened, *n** | |
| Did not listen | 2 |
| 0 | 7 |
| 1 | 2 |
| 2-3 | 3 |
| 4-7 | 4 |
| Who else did you listen to it with, *n*^ | |
| Did not listen | 2 |
| No one | 5 |
| Spouse/partner | 7 |
| Other family member | 4 |
| Health professional | 1 |

*Does not add up to 17 because some people listened on more than one day

^Does not add up to 17 because some people listened with more than one person