

1 **Title page**

2 Barriers and facilitators to the implementation of audio-recordings and question prompt lists
3 in cancer care consultations: a qualitative study

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33 **Abstract**

34 **Objective:** Question prompt lists (QPLs) and consultation audio-recordings (CARs) are two
35 communication strategies that can assist cancer patients in understanding and recalling
36 information. We aimed to explore clinician and organisational barriers and facilitators to
37 implementing QPLs and CARs into usual care.

38 **Methods:** Semi-structured interviews with twenty clinicians and senior hospital
39 administrators recruited from four hospitals. Interviews were recorded and transcribed
40 verbatim **and** thematic descriptive analysis was **utilised. used to identify barriers and**
41 **facilitators to implementing each communication strategy.**

42 **Results:** CARs and QPLs are to some degree already being initiated by patients **but not**
43 **embedded in usual care**. **Systematic** use should be driven by patient preference. Successful
44 implementation will depend on minimal burden to clinical environments and feedback about
45 patient use. CARs concerns included: medico-legal issues, ability of the CAR to be shared
46 beyond the consultation, and recording and storage logistics within existing medical record
47 systems. QPLs issues included: applicability of the QPLs, ensuring patients who might
48 benefit from QPL's are able to access them, and limited use when there are other existing
49 communication strategies.

50 **Conclusions:** While CARs and QPLs are beneficial **for patients**, there are important
51 individual, system and medico-legal considerations regarding usual care.

52 **Practice implications:** Identifying and addressing practical implications of CARs and QPLs
53 prior to clinical implementation is essential.

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56 **Keywords:** Communication, patient-centred care, cancer, audio-recording, question prompt
57 lists, qualitative

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66 1. Introduction

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68 Approximately 130,000 people are diagnosed with cancer in Australia every year [1].
69 Receiving a cancer diagnosis and medical information is often a shock and treatment decision
70 making may be overwhelming. During consultations, clinicians aim to provide patients with
71 information about their condition and possible treatments and engage patients in treatment
72 decisions [2, 3]. **Equally, in order for patients to appraise their circumstances and to**
73 **participate in treatment decisions in an informed manner, they will need a sound**
74 **understanding and recollection the information provided [4]. Therefore, effective**
75 **communication involves engagement of both parties and consists of the following**
76 **components: build a patient-doctor relationship, listen to the patient, gather**
77 **information, understand the patient's perspective, share information, reach agreement**
78 **on plans and provide disclosure [5].**

79 ~~Patient-clinician communication is complex, particularly in difficult areas such as~~
80 ~~when breaking bad news.~~

81 **Irrespective of this knowledge, cancer patients do not necessarily achieve their**
82 **preferred level of participation [4]. Thus, ~~More effective~~ communication strategies which**
83 **focus on patient participation can ~~may~~ enhance patient engagement in decision making,**
84 **satisfaction, ~~and~~ preparedness and ~~reduce anxiety and depression~~ emotional outcomes [6-**
85 **8]. ~~With growing numbers of cancer patients and limited resources, it is critical that~~**
86 **~~communication interventions known to be effective in improving patient outcomes~~**
87 **~~should be integrated into usual care.~~ Two examples are consultation audio-recordings**
88 **(CARs) and question prompt lists (QPLs).**

89 CARs are usually made using digital recorders, with a copy provided to the patient
90 after the consultation to take home, and a copy retained for medical records [9]. Patients who

91 receive a CAR, compared to those who do not, generally have a clearer understanding of their
92 cancer treatment, greater information recall and greater involvement in subsequent
93 consultations and decision-making [9] [11]. CARs also support patients to convey medical
94 information and can facilitate treatment discussions with family members [10].

95 QPLs consist of a structured list of questions that patients may wish to ask about
96 illness, treatment and supportive care. Patients are typically given the QPLs before their
97 consultation so they can identify questions which are important to them [11]. **and Cancer**
98 **patients consider QPLs to be a useful communication aid QPLs as it can prompt them**
99 **to ask more questions increase the number of questions patients they ask that and**
100 **physicians provide more information when cued by questions, particularly with about**
101 **difficult- to- broach topics such as prognosis and treatment cost [12-14].**

102 Despite evidence supporting the use of QPLs and CARs, there is little indication that
103 these strategies are routinely used in clinical practice [9, 12]. Additionally, there is little
104 published data regarding **provider and organisational issues and** concerns related to routine
105 implementation **although they can influence utilisation [9, 11]. Thus, it is important to**
106 **obtain organisational and clinical perspectives in order to support successful routine**
107 **implementation of these strategies.** The aim of this study was to explore barriers and
108 facilitators to implementing **an integrated communication initiative, consisting of QPLs**
109 and CARs, in usual care from the viewpoint of clinicians and hospital administrators.

110 **2. Methods**

111

112 This qualitative study used interpretive description methodology [15]. The purpose of this
113 approach is to discover themes or patterns and to understand action, based on experiences, in
114 order to inform clinical knowledge.

115

116 *2.1 Participants*

117

118 Clinicians and senior hospital administrators were recruited from ~~one of~~ four Melbourne
119 metropolitan hospitals where cancer patients are treated. Purposive sampling was used to
120 identify participants for interview, to obtain maximum variation in the experiences of interest.

121 **Each recruiting site had a project representative who identified and approached eligible**
122 **participants. A total of 37 people were approached and 22 (59%) agreed to take part.**

123 For the first 15 interviews, participants were sought on the basis of obtaining a variety of
124 clinician and senior hospital administrator views across the four hospitals. A further five
125 participants were approached based on their role to explore the findings identified in the
126 initial 15 interviews. Recruitment ceased when no new themes were derived from the
127 interview content (data saturation). The study was approved by the Human Research Ethics
128 Committee of the Peter MacCallum Cancer Centre (LNR/15/PMCC/31) and all participants
129 signed a consent form.

130

131 *2.2 Data collection and analysis*

132

133 Data were obtained through semi-structured individual interviews. Open-ended questions
134 were used to explore participants' thoughts about implementing the communication strategies
135 (CARs and QPLs) into usual practice. Interview questions included: what is your overall
136 impression of QPLs/CARs,; what are your thoughts about implementing QPLs/CARs during
137 initial treatment consultations,; and what might be the positive and negative aspects of
138 QPLs/CARs from your perspective? An **abbreviated version of** an oncologist QPL [16]
139 ~~example-QPL~~ was presented to participants **as an example** if they had no prior experience
140 with this communication strategy. Interviews were conducted **by an experienced**

141 **interviewer (JD, LS, NM or PS)**, face-to-face or via telephone, were recorded and
142 transcribed verbatim.

143 NVivo10 qualitative data analysis software was used for data management [17].

144 Thematic descriptive analysis was used to identify important and consistent themes about the
145 barriers and facilitators to implementing the communication strategies into usual care [18].

146 An inductive approach was used, that is, findings were generated from the data rather than

147 imposing a predetermined structure for the analysis. Analysis began by listening to, and

148 reading, all of the interview transcripts. Next, analysis of the text was used to generate the

149 initial categories (open coding) which were then grouped into sub-themes of related

150 categories. Sub-themes were sorted, synthesised and organised to develop broader themes. To

151 ensure the rigour of the findings [11], a subset (10%) of the transcripts were dual coded (NM

152 and PS) and for all data, emerging sub-themes and themes were discussed with researchers

153 **(PB and TH)** knowledgeable in the area. **This was achieved by discussing the analysis**

154 **during meetings and via correspondence.**

155 **3. Results**

156

157 *3.1 Demographics*

158

159 A total of 22 hospital staff agreed to participate from four hospitals in Melbourne.

160 Recordings failed for two interviews and so findings presented are based on data from 20

161 participants. Interview times ranged from 8 to 45 minutes with a median of 22 minutes. The

162 majority of the participants were male (55%), aged 40-49 (50%), 65% were doctors and 35%

163 senior hospital administrators. **Of the doctors, nine held senior positions such as heads of**

164 **departments, three were medical oncologists and one was a registrar. Six of the senior**

165 **hospital administrators were managers such as CEO's and operational managers, and**
166 **one was a lawyer.**

167 The findings are presented in two parts. Firstly, **a summary of the** barriers and
168 facilitators that applied to implementation of both QPLs and CARs are presented **as themes.**
169 Secondly, findings specific to either CARs or QPLs are reported. **Each theme encapsulates**
170 **a broad concept of the factors that could influence routine implementation. Within**
171 **these, some sub-themes were neither distinctly a barrier nor a facilitator as participants**
172 **identified different aspects or instances which could either support or hinder**
173 **implementation. While the themes are presented individually they do overlap and are**
174 **connected.** Five key themes were generated: 1) clinical context,; 2) requires resources,; 3)
175 communication strategies can alter the interaction,; 4) who sets the agenda for each of
176 communication strategies,; and 5) one size doesn't fit all. Figure 1 illustrates the themes and
177 sub-themes relevant to the implementation of CARs and QPLs.

178

179 [insert figure 1 here]

180

181 **Fig. 1.** Overview of themes and sub-themes.

182

183 *3.2 Clinical context*

184

185 Participants recognised that understanding the context of clinical consultations and the
186 potential implications of CARs and QPLs is critical to integrating these communication
187 strategies into usual care. While all participants interviewed expressed the view that CARs
188 and QPLs were good communication initiatives, they also expressed concern about
189 implementation and what impact it could have within the context of a clinical environment.

190 **For example, some participants described misconceptions about what happens during a**
191 **clinical consultation. In particular, a consultation is not necessarily an uninterrupted,**
192 **quiet, one-to-one interaction and not all diagnostic information may be known at the**
193 **time of the consultation. As such, adhering to QPLs or producing a coherent audio-**
194 **recording may be challenging and a potential barrier. For example, within the public**
195 **health system there are many factors that impact the efficiency of clinical consultations,**
196 **such as over-booked clinics, long patient waiting lists and paper-based medical record**
197 **systems. Thus either strategy that could further lengthen the consultation was not**
198 **welcome.**

199 While the strategies were not implemented as part of usual care at any of the
200 hospitals, participants noted that patients are already using QPLs, CARs and other strategies
201 to aid patient communication (e.g. a summary of the consultation, web-based frequently
202 asked question sections in information sheets). Of the twelve clinicians interviewed, all but
203 one identified that they had experience with one or both strategies such as patient self-
204 generated lists or recording on a smart phone. Table 1 illustrates, with quotes, each of the
205 sub-themes incorporating the clinical context.

206

207 [Insert Table 1 here]

208 *3.3 Requires resources*

209

210 Given that the current clinical context is resource and time poor, several clinicians and
211 administrators raised concerns about the **hospital additional** resources required to effectively
212 implement these strategies **in a sustainable way**. Many participants believed they would
213 increase consultation time, particularly if a patient went through all the questions of a QPL
214 from start to finish or if clinicians were involved in the logistics of recording the consultation.

215 Only two participants thought that these communication strategies could reduce consultation
216 time or subsequent discussions (e.g. review appointments or follow-up phone calls from
217 patients and/or family). **Overall, in order to enable routine implementation, resources**
218 **would be required to facilitate these strategies in a clinical setting** (refer to Table 2).

219

220 [Insert Table 2 here]

221

222 *3.4 Alters the interaction*

223

224 Many participants queried whether the implementation of these strategies might impact
225 the communication dynamic within a consultation, particularly in relation to the content of
226 what is said, the quality or nature of the interaction (formal vs non-formal, structured vs non-
227 structured) and trust or rapport building with a patient (refer to Table 3 for examples). As a
228 result of possible alterations to the consultation dynamic, advantages and disadvantages were
229 identified for patients. Participants noted that many cancer consultations are an intimate
230 exchange between doctor and patient about matters of critical importance to the patient. Thus
231 the **intervention's strategies** impact could be both positive (in promoting patient
232 satisfaction) and negative (by making the consultation more formal, factual and reducing
233 intimacy).

234

235 **~~“So I think as long as patients are aware of that that it will alter the consultation,~~**
236 **~~it's likely to have some impact on the consultation and in the ideal world you~~**
237 **~~would go no it won't have any impact but there are time restrictions, the~~**
238 **~~legalities, that might not even be what the patient wishes that happens down the~~**
239 **~~line.” (CAR – Clinician, P2)~~**

240

241 [Insert Table 3 here]

242

243 3.5 *Who sets the agenda*

244

245 This theme is about whom (i.e. patient, clinician, or family) directs the interaction within
246 a consultation, who benefits from the interaction, who determines if the communication
247 strategy is useful or valuable, and as such, who influences the focus or use of QPLs and
248 CARs (refer to Table 4). While every participant was able to identify benefits of QPLs or
249 CARs for patients, many questioned how they would be used in actual practice. Patient
250 benefits identified included: QPLs could serve as a memory aid (for patient and clinicians)
251 and/or a prompt for patients to think about areas for discussion,~~;~~ **and** CARs could aid patient
252 recall and comprehension of information discussed within a consultation, and in relaying the
253 consultation information to a patient's support network. **From a clinician and administrator**
254 **perspective**, the usefulness or value of the communication strategies were discussed in
255 relation to existing communication efforts, whether strategies would actually be used by
256 patients, and evidence of patient benefit.

257 Several clinicians and administrators had concerns about the scope and development
258 of QPLs. Issues raised included:~~;~~ who determines what are valid questions to include in
259 QPLs,~~;~~ what topics are included,~~;~~ how generic or specific are the questions,~~;~~ what sort of
260 language is used,~~;~~ and which population will ~~the~~ QPLs be developed for (i.e. patients,
261 families)? With regards to CARs, questions were raised about who can request that a
262 consultation be recorded and how consent is obtained (if at all).

263

264 [Insert Table 4 here]

265

266 *3.6 One size doesn't fit all*

267

268 ~~Related to the findings of patient benefit and usefulness~~ Many participants had
269 questions and concerns about how each communication strategy could fit and benefit all of
270 the diverse patient circumstances. When participants were asked about implementing QPLs
271 and CARs as an integrated communication initiative during initial treatment consultations,
272 most identified that their use would have to be relevant to the clinical situation, i.e.
273 appropriate for and wanted by the patient. Participants conveyed a preference for these
274 communication strategies to be patient-driven rather than introduced as a systematised and
275 imposed, standard of care (see Table 5). **Thus, a flexible, patient-driven approach would**
276 **more likely be supported in usual care.**

277

278 [Insert Table 5 here]

279

280 Although there were similarities in the benefits and concerns identified regarding joint
281 implementation of QPLs and CARs, distinct issues were also identified for the
282 implementation of QPLs and CARs as discrete strategies.

283

284 *3.7 Audio-Recording*

285

286 CARs were recognised as providing a verbatim record of a clinical consultation,
287 formalising what was previously a private conversation, as a source of “captured”
288 information. Concerns raised by clinicians and administrators related to questions about the
289 status and pragmatic requirements of CARs. Concerns included: what permissions would be
290 required to generate a CAR,; who would be responsible for it,; what would this information

291 be used for, who would have access to it, does it become an extension of the medical
292 records and if so, is it logistically feasible to store within the existing medical record system.
293 An overview of the findings related to CARs is presented in Table 6.

294 While those interviewed identified potential benefits of CARs for the patient, such as
295 supporting recall and sharing information with the family or support network, many
296 participants also raised medico-legal concerns. Clinical participants identified that they would
297 feel uncomfortable and anxious, and that it would change the interaction. Concerns about
298 CARs were based on past experiences of patients who had previously requested a CAR:

299

300 ~~[Mimicking patient saying] “I’m going to record this” and I’d be like oh “okay”.~~
301 ~~I think we link that negative stance.... most of the families who ask for~~
302 ~~recordings are, in my experience, [are] looking for a reason to like maybe~~
303 ~~question what has happened in past.” (Clinician, P22)~~

304

305 Because of the potential medico-legal implications, clinicians and administrators
306 talked about how this communication ~~intervention~~ **strategy** requires disclosure and/or
307 agreement (consent) for all parties involved, such as, the patient, health professional and
308 organisation. Additionally, it was felt important that the hospital keep a copy of the CAR,
309 should this be introduced as standard of care. The information technology and clinical
310 consultation time required to do this were also recognised as important logistical
311 considerations. While some clinicians liked the idea of a patient-owned and initiated mobile
312 application as the vehicle for CARs, the most acceptable solution was one which did not
313 increase clinical consultation time, was easy to use, and accessible to patients and from the
314 hospital record system.

315

316 [Insert Table 6]

317

318 *3.8 Question prompt lists*

319

320 QPLs were recognised as a resource to aid patients to gather information, encourage
321 active participation in healthcare decisions, and to discuss and prioritise topics which are
322 important to them during a clinical consultation. While most clinicians and administrators
323 identified that QPLs could benefit patients, they also recognised that patients use other
324 strategies to gather information, for example, accessing printed information, searching on the
325 internet, talking to others, or developing their own list of questions. Additionally, some
326 clinicians identified how they use existing personal communication strategies, **for example**
327 **running through an informal checklist based on clinical experience**, to pre-empt patient
328 questions and provide information before being asked. Figure 3 illustrates the overview of
329 findings specifically related to QPLs.

330 The main concern about QPLs was how to make them relevant to patients' situations
331 and maximise usage given existing communication strategies. For example, should **a** QPLs
332 contain a list of general, broad questions or be developed as a disease or treatment specific
333 resource?

334

335 [Insert Table 7 here]

336 **4. Discussion and conclusion**

337

338 *4.1 Discussion*

339

340 This study provides useful contextual insights from a clinical and organisational
341 perspective to aid understanding of the many critical issues that require consideration prior to
342 implementing QPLs and CARs into routine healthcare. Clinicians reported that some patients
343 already use these communication strategies (i.e. using their own list of self-generated
344 questions, patients using smartphones to record consultations) but systematic access for all
345 patients of these communication ~~aids~~ **strategies** was absent. While there was consensus that
346 these strategies can benefit patients, it was clear that there are several important factors to be
347 considered when developing an implementation plan for their use.

348 Firstly, when implementing these communication strategies into routine care, it is
349 important to consider the current clinical context and that each strategy needs to fit within
350 existing systems and have minimal impact on work practices. To illustrate, if a hospital
351 ~~requires a copy of a~~ **considers CARs as part of the patients medical record, additional**
352 **infrastructure and processes will be required to ensure the car is stored correctly.**
353 **Furthermore, additional** steps will be required during a clinical consult for hospital staff
354 and patients **to support this process** (e.g. communicating that CARs are an option for
355 patients, making sure the equipment works, consenting for this activity, etc). ~~, and additional~~
356 ~~infrastructure and processes will be required to store the CAR, as it is consequently~~
357 ~~considered part of the patients medical record.~~ While there is mixed evidence about the
358 impact that CARs have on consultation **times length** [9], little is known about the ongoing
359 impact and cost of implementing ~~an~~ CARs ~~on~~ **from an** administrative **and** information
360 technology **perspective and other hospital staff**. Interestingly, during an implementation
361 study [19], recording of consultations temporarily stopped as there was a halt on hospital
362 spending and technology supplies could not be purchased (~~i.e. memory sticks, digital~~
363 ~~recorders~~). This highlights the requirement to assess and provide resources necessary so that
364 CARs can be implemented in a sustainable way.

365 Secondly, perceived patient benefits, usefulness or ~~value and which stakeholders~~
366 ~~develop and set the scope of the communication strategy (i.e. who sets the agenda of the~~
367 ~~communication strategy)~~ is another important implementation factor. Similar to existing
368 literature [9, 14], many clinicians and hospital administrators identified the potential benefits
369 for patients when utilising either of these communication strategies. However, participants in
370 this study questioned the extent to which each strategy would be useful or valuable from a
371 patient's perspective in addition to what is being provided in the current clinical context. This
372 finding highlights two areas of interest: which party (i.e. patient or clinician) determines the
373 use of a communication strategy and the translation of research into routine healthcare. While
374 there is some evidence of effectiveness and patient value when these ~~communication aids~~
375 ~~strategies~~ are tested within a research framework [10, 11] when translating these into routine
376 care there can be varying levels of use. To illustrate when evaluating QPLs in routine care,
377 Dimoska et al. [12] reported that 64% (389/606) of patients accepted a QPLs when attending
378 a consultation ~~from in one of~~ four cancer centres [12]. Of those who accepted a QPLs and
379 responded to the survey (n=139), 89% (n=123) read the QPLs and 44% (n=54) used them in
380 the consultation. In a recent review, ~~of QPLs~~ Sansoni and others [14] identified that
381 endorsement or explicit encouragement of QPLs may increase the number of questions
382 patients ask during a consultation. Despite evidence supporting the use of QPLs and
383 clinicians identifying that there are benefits for patients, it is interesting to note that the lack
384 of clinical support can still exist and hinder implementation of a patient-driven
385 communication strategy [12]. Therefore, implementation and use of QPLs can be influenced
386 by clinician behaviour or perception of the strategy. ~~For these reasons, it is important to~~
387 ~~include education with clinicians to promote health literacy and patient involvement~~
388 **Although these communication strategies target patients, it is important to obtain**
389 **clinical buy-in when implementing into routine practice. One way to achieve this is to**

390 pilot, evaluate and to provide **ongoing feedback to clinical staff and administrators about**
391 **patient outcomes utilisation in an ongoing way.**

392 Lastly, when disseminating these communication strategies into usual care they
393 should be patient-driven, ~~that is patients choose if they would like to utilise a particular~~
394 ~~communication strategy~~, rather than process-driven as a one size approach may not fit all
395 patients' circumstances. **This Patient-driven** also includes patient preference in the
396 development of a strategy and fundamentally who the strategy should be of most benefit to.
397 Patient-clinician communication and gathering information about cancer is complex as each
398 person has different: communication and learning styles, ideas about the communication
399 goals, levels of knowledge, emotional capabilities, and understanding of medical language
400 [2]. Given the multifaceted and dynamic nature of patient-clinician communication, it is not
401 surprising that a standardised ~~strategy (e.g. one QPL for all patients) or one size fits all~~
402 ~~approach (e.g. recording all initial patient consultations)~~ was identified as problematic. In
403 a recent review of QPLs, a range of QPLs were identified for different types of cancer,
404 different treatments, and there was diversity in the number and type of questions listed [13].
405 Additionally, the review reported that there was variability in the reporting of how the QPLs
406 were developed and the inclusion of patient perspectives in the development process [13].

407 Likewise, clinicians and hospital administrators in this study identified that CARs
408 need to fit patient circumstances and that ultimately patients should choose when this occurs.
409 One study randomised patients to a group where they were offered choice of receiving an
410 audiotape of which 4% declined and of those who received an audiotape, one third did not
411 listen to the audiotape 12 weeks post consultation [20]. Although participants in this study
412 could identify patient benefits, many questioned if patients would find it useful and listen to
413 the CAR. In a narrative literature review [9], it was reported that a majority of patients
414 listened to the recording of the consultation (72% weighted average, range 54% to 100%). In

415 contrast, the most frequent reason patients did not listen to CARs was feeling upset by
416 hearing the information (25% of studies) and that information provided during the
417 consultation was sufficient (28% of studies) [9]. In a systematic review [10] which combined
418 CARs and written summary **intervention strategies**, a similar range of patient usage was
419 reported (60% to 100%). While the usage rates are promising from the efficacy literature,
420 findings from translational studies do not achieve the same level of utilisation. For example,
421 **low utilisation rates were reported in** an implementation study which offered a decision
422 and communication aids **package** to new patients with breast cancer [21]. **The**
423 **communication aids** consisted of decision aid booklets and videos, patient question list,
424 CAR, and a summary of the consultation. Of those patients who were coached in the aids,
425 33% (367/1,110) utilised CARs as a communication aid and of those who received a **CAR**
426 **recording**, 60% listened to it. Additionally, a feasibility study which recruited via **general**
427 **non-cancer** outpatient clinics, used broad patient inclusion criteria, and did not prompt
428 patients to replay the consultation, only a third of patients listened to the recording [22].
429 Thus, there is lower usage of both QPLs and CARs when patients choose if they utilise these
430 communication strategies in usual care.

431 The findings from this study extend beyond the previous literature by providing
432 evidence that clinicians can experience anxiety about CARs and concerns about medico-legal
433 implications can be linked to prior patient requests. Thus, it **is** recommended that healthcare
434 organisations undertake due diligence **activities** (e.g. educating staff, consulting with
435 insurers), **and in particular consider** the medico-legal implications **of storing** a copy of
436 CARs **as part of** the medical records. Additionally, the concerns about patients circulating
437 the recording to the wider community and consent requirements are also fundamental to
438 address. One way to potentially deal with these concerns is to incorporate a consent process
439 which communicates each party's rights, obligations and acceptable distribution of the

440 recording. Given that patients currently request to record consultations on an ad hoc basis,
441 healthcare organisations should allocate resources to explore the current medico-legal
442 implications and how to best support all **parties (patients, patient support network,**
443 **clinicians and the healthcare organisations)** with current requests.

444 Finally, while this qualitative study has several strengths, the findings need to be
445 interpreted within the context in which it was undertaken. Results are from hospital
446 administrators and clinicians recruited from metropolitan Victorian hospitals and as such,
447 may not necessarily reflect the views of others based in other locations. Additionally, the
448 opinions of those who did not think that these communication strategies were useful at all
449 were actively sought; however, no participants with this perspective were recruited.

450

451 *4.2 Conclusion*

452

453 This study has demonstrated that clinical and administrative staff can be supportive of
454 integrating QPLs and CARs, either alone or in combination, into cancer clinical
455 consultations. Participants identified a number of benefits for patients and some potential
456 benefits for clinical staff. Despite the **potential benefits of these communication strategies**
457 there are important individual, system and medico-legal **barriers considerations regarding**
458 **which would need further consideration before implementing into their** routine use **in**
459 **clinical** practice.

460

461 *4.3 Practice implications*

462

463 These findings suggest that it is important to identify and address practical implications of
464 CARs and QPLs prior to clinical implementation. In particular for CARs, reducing medico-

465 legal concerns requires a definitive response and clarity of legal implications for hospitals.
466 This is a priority as ambiguity about medico-legal issues will be a persistent barrier to
467 implementation of CARs.

468 Currently QPLs are widely available on websites such as government agencies, not-
469 for-profit support organisations, cooperative trial groups and healthcare groups to promote
470 patient involvement and participation in cancer care. Given that there is such diversity within
471 the cancer population, no one QPL can be suitable for all patients throughout their illness
472 trajectory. Rather, the preferred approach is to sign-post patients to a toolbox of QPLs so they
473 can then choose which set of questions are of most relevance and to identify ways to signal to
474 patients that these communication strategies are available with minimal health service
475 burden. Moreover, the need to assess the optimal use of QPLs (ensuring those most in need
476 and with greatest capacity to benefit are supported and enabled to know about and use QPLs)
477 is also required. Likewise, future research exploring ways to implement CARs or QPLs with
478 minimal burden is needed. **~~in the following areas: 1) developing/tailoring each
479 communication strategy for the specific healthcare environment; 2) identifying how to
480 embed the strategy into routine healthcare in a sustainable way; 3) obtaining additional
481 resources (e.g. technological infrastructure, staff time) required to implement the
482 strategy in an ongoing way; and 4) evaluating and feeding back to clinical and executive
483 staff about the utility and usefulness of each strategy from a patient perspective.~~**

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486 **Informed consent**

487 I confirm all patient/personal identifiers have been removed or disguised so the
488 patient/person(s) described are not identifiable and cannot be identified through the details of
489 the story.

490

491 **Declaration of interest**

492 Conflicts of interest: none

493

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499 **Contributors and authorship**

500 PS and NM designed the study. All authors contributed towards the execution of the study.
501 NM provided methodological expertise for analysis and PS co-coded the data. NM wrote the
502 first draft with guidance from MK. All authors read, provided critical feedback and approved
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563 **Table 1**
 564 Sub-themes of clinical context.
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Sub-themes	Quotes
Competing demands within a healthcare system (Barrier)	<p>We have to be conscious of the fact that there's limited time in consultations and a large number of patients to be seen. (Clinician, P20)</p> <p>...either you accept that you can't meet that time pressure or you're going to be staying later than you're planned to or you don't spend the time and you don't do things properly. (Clinician, P11)</p> <p>If it takes three weeks to get your toner changed, I don't want to see a great new audio recording system in all the consult rooms because I can't even get a printer to print a label without getting jammed, so you know that that would be a barrier. (Administrator, P12)</p>
Misconceptions about consultations (Barrier)	<p>The law is predicated on there being a nice quiet dialogue like we're having now across the desk in a nice quiet room and you know, we've got as much time as we need to go through all the things. It doesn't happen like that in the real world. (Administrator, P21)</p> <p>You know some of them [consultations] can take up to an hour you know where you're continually walking in and out of the room. So it's disjointed. (Clinician, P10)</p> <p>I guess in medicine there's a lot of aspects of a patient's case that may not be concrete at the time of being seen and often when their picture isn't clear, we have to bring a lot of subjectivity into the...discussion. (Clinician, P22)</p>
Already being used in practice (Facilitator)	<p>Clinician: ... it's not an uncommon thing to be asked, to say "am I allowed to record this conversation for later listening purposes?" and my stance personally is that I'm not too fussed about it. (Clinician, P22)</p> <p>Interviewer: Has a patient ever brought in a question prompt list for a consultation with you?</p> <p>Clinician: Oh yeah, quite often they often bring those prompt list questions. (Clinician, P3)</p> <p>[refer to QPL] I think what's probably new is maybe the mode of the information but it's not a new concept, I have to say I think we already use it in lots of practical ways. (Administrator, P15)</p>
Emotion and mortality (Facilitator)	<p>Particularly in an initial type of consultation, when you drop the bombshell and all they're thinking about is my kids, who's going to look after my kids when I die (Clinician, P1)</p> <p>This comes back to the issue of people feeling overwhelmed when they're having their consultations. There there's a lot of psychological stress. (Clinician, P20)</p> <p>[patients] they will invariably forget things and I guess it depends ...as to what is spoken in [the] initial consultation but it will range from the diagnosis,... the prognosis, whether a patient has got potentially curative disease or the treatment is not curable. (Clinician, P10)</p>

567 **Table 2**
 568 Sub-themes of requires resources.
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Sub-themes	Quotes
Impact on consult time (Barrier or Facilitator)	<p>I guess you know potentially if you've got a patient that goes through every single question quite diligently and is writing things down that potentially might increase the length of time of the consultation. (QPLs - Clinician, P13)</p> <p>Some of the clinicians might argue that it takes longer if they have to go through all those questions but I would be arguing well you should be going through all those questions anyway so I don't think there are any barriers. (QPLs - Administrator, P9)</p> <p>Time. It comes back to time. No it's difficult enough to find a room, get the patient into the room and do all of that. You then tell me it's not going to take you 5 minutes to set up whatever recording you are doing for each patient. Five minutes every 15 patients – that's an hour.... So that's actually ensuring that it's just so automated that it takes no time. (CARs – Clinician, P2)</p>
Cost to implement (Barrier)	<p>So it's about the appropriate use of health dollars and so it has to be... cost neutral to us... Can we get one more staff member so that we can all go home on time and stop doing so much overtime? You know so I think there's there is a real risk there. (CARs – Administrator, P12)</p> <p>This is a system that doesn't have extra time or funding for that....or for all the stuff we do now. So this will be an extra which there is no extra space for. (CARs – Clinician, P3)</p> <p>You get lots of these USBs but it costs money....Remember it's not just the money but it's the effort so someone's got to find that patient copy it onto the stick and then give it to the patient. (CARs – Administrator, P19)</p>
Not sustainable (Barrier)	<p>I think ...in some places certainly in practices I've worked in and perhaps they've dropped off because of the amount of energy it takes. (QPLs – Clinician, P1)</p> <p>The risk is also that ... they [patients] don't find that useful. Maybe use it once and then it drops off. (CARs – Administrator, P12)</p>

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577 **Table 3**
 578 Sub-themes of alters the interaction
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Sub-themes	Quotes
Content of the interaction (Barrier or Facilitator)	<p>[Audio-recording] has the potential of just altering the way you do the consultation. It will be an accessible piece of evidence therefore ... I would probably spend less time dealing with the psychological component of that patient and more time dealing with the delivery of fact... you will alter what [you] say but you will probably specify far more. (CARs – Clinician, P2)</p> <p>I would imagine that some practitioners might may not always say what they otherwise might've said.... think it will, if anything, probably get practitioners to be very correct in what they say, which you may argue is actually quite a good thing. Maybe they may choose their words very carefully. (CARs – Administrator, P18)</p>
Quality or nature of the interaction (Barrier)	<p>But you do have the potential that you remove some of the human interaction. Let me run through the checklist. I will answer of each of your ten questions which are down there and that's fine... and that's with anything where you've started to get too much structure in a doctor/patient consultation. (QPLs – Clinician, P2)</p> <p>Well if I'm having a conversation with someone and I know I'm being recorded, either audio recorded or video recorded, I think I'd probably behave differently than if I'm not. Not vastly different... I think I would still convey the same information I think it's probably more formalised and less personal actually. (CARs – Clinician, P11)</p> <p>Would it affect the quality of the interaction? So if that's an intimate sort of session between the professional and the patient and that [its] big brother..... recording it does it sort of have a perverse effect on the quality of that exchange... It could, I'm not saying it would but it could. (CARs – Administrator, P7)</p>
Rapport or the relationship (Barrier or Facilitator)	<p>I wonder whether it does increase satisfaction and trust of the clinicians?...you know if the clinician is willing to be recorded, then it may improve confidence in what they're saying - that they're not going to be trying to pull the wool over their eyes. (CARs – Clinician, P6)</p> <p>I think it does once again put a relationship on a back foot quite early on. Like if I can imagine how I would feel if someone came in and the first few things they said to me was, "I'm going to record this" and I'd be like oh okay. I think we link that negative stance... Yeah I think it does change relationship a little bit. I'd be a little bit put off at the start. (CARs – Clinician, P22)</p> <p>I guess that can be a bit more confronting if patients are asking you up front about prognosis and are they going to be cured. (QPLs – Clinician, P13)</p>

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583 **Table 4**
 584 Sub-themes for who sets the agenda.
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Sub-themes	Quotes
Patient benefits (Facilitator)	<p>But from a patient point of view it's often quite good because they do get a chance to have that demonstration of what questions that might be useful thing to ask. (QPLs – Clinician, P3)</p> <p>When people get a shock diagnosis or shock news they can forget some of these so I think it's a good prompt for patients and for clinicians to make sure that you're addressing these very valid and common concerns. (QPLs – Clinician, P13)</p> <p>The good thing is that the patient can then take it away and revise what's been said and actually have a chance to go over it because there's often a lot of confronting information to generate and acquire in a very short period of time.' (CARs – Clinician, P3)</p> <p>We know that patients will probably only pick up a handful of the information you give them therefore, it gives them a chance to review that. Also as well they can ask a relative to come along as ...that can work both for their own information. (CARs – Clinician, P2)</p>
Usefulness/value (Barrier or Facilitator)	<p>Advocating for the end user is going to be so important because healthcare is notorious for being completely unable to understand the experience of the end user. So they will say we think this is great for our patients. We're going to develop this information, it's going to be amazing and then of course there's no uptake because it's not what they want to do in the first place. (QPLs – Administrator, P12)</p> <p>I guess I'm not sure there's a requirement to audio-record. I then wonder who's going to sit back and listen to an entire conversation again...It would be good if there was some sort of literature or something to demonstrate that it was useful. Then I would be convinced of the utility of it. (CARs – Clinician, P11)</p>
Scope and development (Barrier or Facilitator)	<p>If the patient has a question and it's legitimate....we need to address it so...regardless of you know whether you think it's relevant or not ... What you think they want to know may be different to what they want to know. (QPLs – Clinician, P10)</p> <p>I can tell you that some cultural groups will go ballistic if they find that their parent for instance is being given a list of questions to ask the doctor about the cancer when they when their opinion is in fact that the patient should be asking a minimal number of questions. (QPLs - Clinician, P20)</p> <p>I am querying is it the patient who's asking for this ability to record or is it their accompanying relative?... I agree as long as the patient is truly making that decision autonomously and it's not really under the duress of an accompanying relative. (CARs – Administrator, P21)</p> <p>I think one needs to go into a thing like this with some care and some thought and probably ensure that this is something agreed to by both the practitioner and patient. (CARs – Administrator, P18)</p>

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588 **Table 5**
 589 Sub-themes for one size doesn't fit all.
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Sub-themes	Quotes
Relevant to clinical situation (Barrier or Facilitator)	<p>What it can lose is some of the more complex stuff that what I try and discuss which is more individualised to a specific case which won't be on a prompt list. (QPLs – Clinician, P3)</p> <p>Probably putting together, formulating an appropriate list for the various permutations of clinical scenarios. (QPLs – Clinician, P17)</p> <p>There are some patients who are particularly anxious or there are certain circumstances where you may not want that recorded. So it may vary depending on which patient you see. (CARs – Clinician, P10)</p> <p>It's not a one size fits all and I don't think therefore that we should have a general policy that says yes we're fine with this. I think it should be that individual. (CARs – Administrator, P21)</p>
Choice of use/optional (Facilitator)	<p>I think it needs to be clear that this is a list of things you could ask but it's really up to the patient and the family to decide what out of these they want to ask. (QPLs – Clinician, P20)</p> <p>I think ultimately an optional thing which would be good. I think it would allow people who did want to take a more active approach to get involved but look it's not for everyone. I don't think it's for really for everyone. (QPLs – Clinician, P22)</p> <p>You can say to the patient, bring your iPhone in fact you can just record on it that's fine...Just record on it yourself. Take it if that's what the patient wants. (CARs – Administrator, P18)</p> <p>It should probably be an opt-in process rather than an-opt out process... I mean something that we that we offer and say you know we benefit rather than making it standardised. (CARs – Clinician, P22)</p>
Unintentional consequences (Barrier)	<p>[Patient] they've always listened to what their doctor's said and never questioned anything and to actually you know to be given questions and you know think about that, that might create some anxiety. (QPLs - Clinician, P22)</p> <p>I think we need some sensitivity about the psychological, whether something's going to cause psychological trauma to patients. (QPLs – Clinician, P20)</p> <p>There's obviously a different group of patients who are much more autonomous, who are much have much more involvement in their treatment decisions but I don't think we should underestimate that some people find it stressful to be involved in receiving and making decisions about their care. (CARs – Clinician, P10)</p> <p>To go home and replay over and over ad nausea, this death sentence that in their own minds they've received is not good for their psychological or psychiatric health and wellbeing there will be particular patients where it would not be helpful. (CARs – Administrator, P21)</p>

592 **Table 6**
 593 Consultation audio-recording findings.
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Sub-themes	Quotes
Consent (Barrier or Facilitator)	<p>Ensure that this is something agreed to by both the practitioner and patient...[Patients] have to in some way sign that they've received the recording with some provisions or request that they don't hand it out to everybody or reminded of their own obligations... (Administrator, P18)</p> <p>I think everyone has rights within that consultation. You have to consider each individual's rights. (Clinician, P6)</p> <p>Those who are very afraid of this will refuse to participate in it. (Clinician, P1)</p>
Medico-legal (Barrier)	<p>I think [from] what my experience would be of patients wanting to record is getting a feeling that they are somewhat distrustful of the of the health provider. (Clinician, P16)</p> <p>I could almost guarantee that the biggest issue is going be around the medico-legal questions and doctors would need to be reasonably persuaded that the different legal requirements are met and that there aren't any further implications to that. (Administrator, P18)</p> <p>With all the litigious claims and things which seem to be increasing clinicians would probably be nervous about. (Clinician, P10)</p>
Anxiety (Barrier)	<p>I have to say from a theoretically I can see that it should be fine but personally it frightens me and I guess that... it causes me anxiety. (Clinician, P6)</p> <p>[AR used for legal purposes] I think objectively and realistically that's probably not highly likely but you know it's a little bit of paranoia...or anxiety. (Clinician, P11)</p>
Logistics of recording (Barrier)	<p>There's the logistic aspects of ensuring that it's easy for the hospital to keep a copy of the audio-recording and store it. (Clinician, P2)</p> <p>It's like giving them the record and saying... do we keep part of the record? Because if we do, it's a whole new issue to keep audio recording and how do we attach it to the record which... will be a process which most hospitals I don't think have readily in place. (Administrator, P18)</p>
Limit(less) boundaries (Barrier)	<p>[Consultations] I can think of a couple that I wouldn't want circulating in in cyber space... That is an issue. (Clinician, P17)</p> <p>So much can be done with information these days you know.... you can take you can take a little section of it. You don't have any control over that information. (Clinician, P6)</p>

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598 **Table 7**
 599 Question prompt-list findings.
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Sub-themes	Quotes
Gathering information (Barrier or Facilitator)	<p>[QPL] Usually used by patients that are more information-seeking... there's a clear difference, there's a group of patients who you know have searched and spent hours on the internet searching for information and spoken to friends and quite possibly, gone and got second opinions and come with lots of questions and they want as much information as possible. And then there's other patients that basically really don't want very much information, they just want a summary and then they want to know what I would like them to do and then that's it. (Clinician, P11)</p> <p>[Current patients] if they do bring in a list, it often means that the consultation is much more organised. I think it empowers the patient as they feel that they've got control and that they are directing the interview sometimes rather than the doctor. (Clinician, P5)</p>
Existing strategies (Barrier or Facilitator)	<p>The question list I think is a good a good idea but I would really say that this should be part of written information to patients. (Administrator, P18)</p> <p>Personally have a checklist that's in my head that of commonly unasked questions that patient's invariably have because after a while there are the same talks. (Clinician, P22)</p> <p>I find people come in with their list and at the end of the consultation they say right I've just got to look at my list ah you've answered everything. Pretty common. (Clinician, P17)</p>
Communication fundamentals (Barrier or Facilitator)	<p>It's what position you start from isn't it. So from a lowest common denominator point of view, do I think it's good to introduce? Yes. Would I hope that a lot of the staff, particularly the senior staff in this building, would pre-empt a lot of those questions? Yes...I might be old fashioned but because I think that a lot of things that are sometimes on the prompt sheetsI think if we aren't educating junior doctors that they should be on top of all that stuff anyway. (Clinician, P1)</p> <p>[Doctors] I think some do it better than others. I that's all I'm saying depending on their experience and the nature of the patient...I think it goes back to are doctors good communicators? That's really the question that that precedes all of this, isn't it? (Administrator, P21)</p>
Question specificity (Barrier)	<p>Would you [have] a generic one for [a] cancer consultation?and it has the potential to become more and more specific and that's going to be the issue of what is the appropriate level to have for each consultation. (Clinician, P2)</p> <p>Then working out what's important to them and what's important to their clinical situation. You might end up with a lot of questions that that doesn't apply to you [patients]. (Clinician, P3)</p>