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**Citation:** Taylor, J. J., Subramanian, A., Freitas, A., Ferreira, D. M. & Dickinson, C. M. (2023). What do individuals with visual impairment need and want from a dialogue-based digital assistant?. *Clinical and Experimental Optometry*, 106(6), pp. 656-665. doi: 10.1080/08164622.2022.2159791

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**Link to published version:** <https://doi.org/10.1080/08164622.2022.2159791>

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1 **RESEARCH**

2 What do individuals with visual impairment need and want from a dialogue-based digital  
3 assistant?

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16

17 ***Additional Information:***

18 This work was presented as a poster at The Association for Research in Vision and  
19 Ophthalmology (ARVO) Conference, May 2022, Denver, Colorado, USA.

20

21 ***Key words:*** Visual impairment, information needs, artificial intelligence, digital assistant,  
22 conversational agent, virtual assistant

23

24 **ABSTRACT**

25 **Clinical Significance:** Optometrists are well-placed to provide helpful advice and guidance to  
26 patients with visual impairment (VI), but may not know how best to do this. The availability  
27 of a reliable and comprehensive conversational agent to which patients could be directed would  
28 be a valuable supplement to clinical intervention.

29 **Background:** The Artificial Intelligence in Visual Impairment (AIVI) Study is a proof-of-  
30 concept study to investigate whether ongoing information support for people with VI can be  
31 provided by a dialogue-based digital assistant. The phase of the AIVI Study reported here  
32 explored the different dimensions of the information-seeking behaviour of individuals with VI:  
33 in particular their need for information, the methods for obtaining it at present, and their views  
34 on the use of a digital assistant.

35 **Methods:** Qualitative data were collected from 120 UK-resident adults who responded to an  
36 online survey; who were either visually impaired (86.7%), a carer or family member of  
37 someone with VI (5.8%), or a professional involved in the support of those with VI (7.5%). In  
38 addition, 10 in-depth 1:1 semi-structured interviews explored opinions in more detail.  
39 Thematic analysis was used to analyse the findings.

40 **Results:** Analysis of information needs identified 7 major themes: ocular condition; equipment,  
41 technology and adaptations; daily activities; registration; finance/employment; emotional  
42 support; and support for the carer. Participants used a wide variety of methods to access  
43 information from many sources, and explained the barriers to access. Participants accepted the  
44 merit of a dialogue system aiding in a goal-directed search for specific information, but  
45 expressed reservations about its abilities in other areas, such as providing emotional support.

46 **Conclusions:** Participants highlighted potential benefits, limitations and requirements in using  
47 a digital assistant to access information about VI. These findings will inform the design of  
48 dialogue systems for populations with VI.

## 50 INTRODUCTION

51 Globally, over 596 million individuals have visual impairment (VI) based on their presenting  
52 distance visual acuity.<sup>1</sup> In the UK the number of individuals with visual impairment (VI) is  
53 estimated to be 1.93 million<sup>2</sup>: or about 3% of the adult population<sup>3</sup>. The combination of the  
54 social and emotional<sup>4</sup>, and functional<sup>5</sup> impact of VI, has been shown to have a significant  
55 bearing on many aspects of an individual's life. In the UK, help and support for those living  
56 with VI is provided by a complex multi-agency system consisting of a wide range of  
57 organisations including hospitals, Social Services, charities, commercial companies and  
58 volunteer groups. However there is no standard care pathway<sup>6</sup> and accessing these services,  
59 and the advice they provide, can therefore be complex and difficult<sup>7</sup>.

60 For those individuals who are eligible for certification as Sight Impaired (SI) (VA<6/60) or  
61 Severely Sight Impaired (SSI) (VA<3/60), the subsequent registration<sup>8</sup> can be a gateway to  
62 both financial benefits, and an assessment of needs by a rehabilitation worker. In addition, it  
63 may include referral to an Eye Clinic Liaison Officer (ECLO), also sometimes called a sight  
64 loss adviser. ECLOs can facilitate understanding of the regulatory processes, and ensure that  
65 "care continues beyond the medical treatment of the clinic"<sup>9</sup>. However 43% of UK  
66 Ophthalmology departments have no accredited ECLO in place<sup>10</sup>. As there are less than 100  
67 ECLOs in the UK<sup>9</sup> with each seeing around 1100 clients per year<sup>11</sup>, it is apparent that not all  
68 individuals with VI can access support from this source. It is also important that individuals  
69 have ongoing support, as their requirements are likely to change considerably over time even  
70 if their eye condition remains stable<sup>12</sup>. Of course, even if individuals are told about different  
71 types of support, it does not mean that they will be willing to engage with it<sup>13</sup>, although for  
72 some, an initial lack of acceptance of their diagnosis will be overcome in time, and they would  
73 benefit from information at a later date.

74 The requirements of easy access to comprehensive information, at a time of the individual's  
75 choosing, seems an ideal match to provision of information online. Henshaws Knowledge  
76 Village<sup>14</sup>, Sight Advice FAQs<sup>15</sup> and Sightline Directory<sup>16</sup> are examples of such sources in the  
77 UK, although awareness of these resources is far from universal. Access is also an issue with  
78 one-third of individuals with VI reporting their use of devices was limited by their disability<sup>17</sup>,  
79 since it can be difficult to enter queries, or to access search results<sup>18</sup>.

80 The Artificial Intelligence in Visual Impairment (AIVI) Study is a proof-of-concept study to  
81 investigate whether ongoing support for people with VI can be provided by a dialogue-based  
82 digital assistant. The potential applications of conversational agents with natural language input  
83 capabilities are being investigated for a variety of different purposes, across a wide range of  
84 healthcare related fields (for reviews see Laranjo *et al.*<sup>19</sup> and Schachner *et al.*<sup>20</sup>).

85 The phase of the AIVI Study reported in this paper aimed to determine the information needs  
86 of those with VI; explore how they currently source and receive information, and any barriers  
87 to obtaining information; and investigate what they would want from a personal digital  
88 assistant. These findings can be used to inform the design of dialogue systems for the VI  
89 population.

## 90 **METHODS**

91 Two methods of qualitative data collection were used: a survey was used to collect a wide  
92 range of opinions, and interviews were used to explore opinions in greater detail. Participants  
93 were UK resident adults and either: visually impaired; a carer or family member of someone  
94 with VI; or a professional involved in the support of those with VI. Some participants fell into  
95 more than one category.

96 The survey investigated the information needs of people with VI, covering all the aspects in  
97 the model proposed by Moore<sup>21</sup>: that is, what are the topics of information, who provides it,  
98 and in what formats, how do needs differ between individuals, and do individuals have enough

99 understanding of the information, and the wider context, to make appropriate decisions. An  
100 Expert Advisory Group included eye-care professionals, rehabilitation workers and individuals  
101 from a range of charities that specialise in providing support for those with VI (see  
102 Acknowledgements). The Group provided guidance on the content, format and accessibility  
103 of the survey (including the design for compatibility with screen-readers). The initial survey  
104 questions captured participant demographic data and these were followed by 5 free text  
105 response questions exploring aspects of the information needs of those with VI (Figure 1).  
106 There was also a final space for (optional) additional comments. Open questions were used to  
107 allow for a broad range of opinions to be expressed, without the constraints of a pre-determined  
108 options list. The questionnaire (see Supplement) was distributed online through The University  
109 of Manchester using the SelectSurvey platform (*SelectSurvey.NET™*, *ClassApps Inc.*) in  
110 February-April 2021, and publicised through newsletters and/or social media of UK-based  
111 charity partners and through professional networks (see Acknowledgements).

112 In addition, in-depth 1:1 semi-structured interviews were conducted between February-August  
113 2021 to explore opinions in more detail. An interview schedule was developed (see  
114 Supplement) to structure the interviews, in consultation with the Expert Advisory Group.  
115 Participants for the interview were recruited through the Macular Society and professional  
116 network groups. Purposive sampling was used to target a mix of people with differing  
117 demographic and visual status to investigate a range of experiences regarding the information  
118 needs of those with VI, from different perspectives.

119 The survey responses and interview transcripts were combined, and analysed using thematic  
120 analysis<sup>22</sup>. This analysis method involved a sequential multi-stage process that included  
121 familiarisation with the survey data set by re-reading the transcripts, initial manual coding of  
122 the data, grouping codes into themes (by JT), reviewing themes (in discussion with the research  
123 team to ensure the validity of the analysis), and naming and defining themes. In the final stage

124 of report production appropriate quotes were chosen from the dataset which justified the  
125 research findings. Illustrative quotes were assigned by participant number, with designations  
126 of “QP” and “IP” being used to represent questionnaire and interview participants respectively.  
127 An extended illustrative data set of quotes for all the topics discussed in the paper is available  
128 in the Supplement.

129 The study was conducted in accordance with the Declaration of Helsinki. It received a  
130 favourable opinion from the University of Manchester Research Ethics Committee, and all  
131 participants gave consent.

## 132 **RESULTS**

133 A total of 120 individuals completed the survey: 119 answered all 5 questions, and 69 (57%)  
134 provided additional comments. A total of 10 participants were invited to take part in the  
135 interviews: at this point it was judged that data saturation had been reached. Table 1 shows the  
136 demographic characteristics of the study participants for both the questionnaire and the  
137 interview.

138 The vast majority of the participants had VI: although of those responding to the questionnaire,  
139 49% (51/104) had difficulties with vision but were not registered, whereas all of the  
140 interviewees with VI were registered with 5/8 being SSI. The interviewees were evenly split  
141 between male and female. A broad range of ages were represented in both groups, although the  
142 majority (58.3%, 70/120) of questionnaire responders were 70 years of age or over. In this  
143 group 90.8% of the group had access to the internet and 75.4% had access to a smartphone,  
144 with 58.3% and 53.3% reporting use of a laptop and desktop respectively. All interviewees  
145 reported access to the internet and either a smartphone or computer, and the majority reported  
146 access to, or use of, voice-activated technology.

147

148 **What information is important?**

149 Figure 2 summarises the seven broad themes which emerged as the most important topics of  
150 information. Participants felt it was important to have an understandable explanation of what  
151 their eye condition was, including details of relevant test results, why it had happened, and the  
152 availability and effectiveness of any treatment. Information on the speed and magnitude of  
153 possible future deterioration, and advice on managing their condition were also important (e.g.  
154 how to alleviate symptoms or prevent deterioration, what to do if their condition changes or  
155 deteriorates, how they will be monitored, and if/when to get new spectacles).

156 Participants reported a need for information, advice and guidance on how to perform a wide  
157 range of practical daily living activities (e.g. cooking, shopping, hobbies and looking after  
158 children). Interlinked with this was the need to know about assistive equipment and technology,  
159 and the training to enable devices to be used optimally. Information on the registration process  
160 (i.e. where and how to register) and the benefits (i.e. how registering would help them) were  
161 also important. This was also related to what financial support and government benefits were  
162 available. This included the support to individuals to remain in work; plus the discounts,  
163 concessions and cost saving schemes that are available across a broad range of everyday  
164 activities (e.g. travel and entertainment). Emotional support needs were also identified by  
165 participants, as they expressed the fears and concerns that VI causes. Formal support (e.g.  
166 counselling) was mentioned, but peer support was also very important. Providing information  
167 for people that help support and care for those with VI was also highlighted. This included  
168 signposting to support organisations, and guidance on how carers could provide support while  
169 also allowing those with VI to maintain their independence.

#### 170 **How should information be delivered?**

171 The analysis identified four overarching themes that ran through the seven broad topics of  
172 information (Table 2). Participants often described a distinction between generic information  
173 (applicable to all or many) and targeted information (applicable to the individual, and their

174 condition, interests and circumstances). Whilst generic information was recognised as  
175 important, some participants felt that much of the information they received was too generic  
176 and not specific enough for their needs. The format of information was another key theme  
177 emphasised by many. It was key that information should be in an accessible format, and  
178 frustration was experienced when this was not the case. The timing of access to information  
179 during their sight loss journey was particularly important. There were some that felt they  
180 wanted a lot of information at diagnosis (or as soon as possible afterwards), to avoid any delay  
181 in moving forward. However, more commonly, individuals reported needing a period of  
182 adaptation after diagnosis before being in a position to receive and absorb further information  
183 beyond the initial overview and signposting. Results suggest that people's information needs  
184 evolve during the course of their sight loss, based on circumstances at the time, and when they  
185 are ready to process that information. The timing of information was also linked to the quantity  
186 of information received at different points (i.e. not receiving enough information, or  
187 conversely, being overwhelmed by too much information). It is therefore clear that there is an  
188 important balance to be found between the type and quantity of information someone receives,  
189 and when they receive it.

190 Signposting to sources of support and information was often mentioned by participants. People  
191 wanted to know about relevant sight loss organisations, the type of support they offer and how  
192 to access it. The distinction was often made between national and local organisations, with the  
193 perception being that the former tended to provide more generic advice (applicable to many),  
194 and the latter tending to provide more targeted information (e.g. travel schemes within a  
195 particular locality, or access to local support groups).

#### 196 **How is information accessed?**

197 Participants commonly reported accessing information using multiple sources and/or multiple  
198 methods, suggesting that no single source provided all their information needs (Table 3).

199 Although use of online information sources broadens access to available information,  
200 participants highlighted the challenges associated with navigating the plethora of information  
201 sources and identifying the most appropriate. Some sources appeared to be associated with  
202 certain types of information (e.g. diagnosis or prognosis of condition, from healthcare  
203 professionals). Other sources were viewed as more multi-faceted, providing information across  
204 a range of the most important topics. Particularly notable was the wide variety of advice and  
205 information sourced through peer support (in organised groups, or as acquaintances or friends).  
206 Peers could describe how they managed with daily activities, their use of new and existing  
207 technology, employment experiences, the benefits process, and the organisations they had been  
208 in contact with. Peers also provided a social connection, and were understanding and  
209 empathetic.

210 The sources of information used, appeared to evolve with time: for example, information from  
211 hospitals tended to be earlier in the sight loss journey, with information from other  
212 organisations following at later stages. The methods which participants used to access  
213 information from the different sources was dependant both on how organisations provided the  
214 information, and on the technology people had access to and were able to use. A broad range  
215 of barriers to obtaining information were described (Figure 3). Sometimes information was felt  
216 to be simply lacking, or it was in an inaccessible format. Difficulties using technology became  
217 barriers to accessing information: other factors included the limited availability and prohibitive  
218 cost of some technology. Participants commonly reported a lack of awareness of what services  
219 were available, and uncertainty as to what questions to ask, particularly in the early stages of  
220 VI. There were some participants who reported not accessing any information, and not  
221 identifying any good sources to go to. The lack of a joined-up approach to the provision of  
222 information, was a source of frustration and stress for some. The global COVID-19 pandemic  
223 leading to the temporary suspension of some services, was a further barrier.

224 **How could a digital assistant be helpful?**

225 Table 4 shows positive and negative opinions on whether a digital assistant would be helpful  
226 to accessing information. The main positive reasons were: ease of use in using voice  
227 recognition (in comparison to difficulties reading or typing) and the timing of access to  
228 information. The timing was important both in terms of continual access (i.e. 24hrs/day, 7  
229 days/week), and obtaining information in a timely way (i.e. fast responses to questions).  
230 Reservations expressed included the reliability and relevance of the information provided, so  
231 provenance was important. There was doubt as to whether the information provided could be  
232 targeted to the individual, and whether certain types of information could be provided via a  
233 dialogue system interface (e.g. difficult/bad news and emotional support). Potential difficulties  
234 with device use, and the impersonal nature of a computerised device, were also mentioned.  
235 Some also felt that a further device was unnecessary for them as they could manage access to  
236 information with existing assistive low vision aids: some suggested that it may become useful  
237 if their condition progressed. Interestingly, the theme of privacy led to potential reasons for  
238 and against the use of a digital assistant. While some reported that they would find it easier to  
239 talk to a device like this without the fear of being judged, others reported security concerns  
240 with respect to personal data and the internet.

241 When questioned about the format/platform for the digital assistant, the preferred choices  
242 covered all possible options. It was therefore more relevant to look at the reasons for those  
243 choices (Figure 4), showing that this was largely due to ease of use, accessibility, familiarity  
244 or functionality. “Ease of use” was often identified based on visual access to the display and  
245 controls, and this may be less relevant for interacting with this system. In general, people  
246 wanted the digital assistant to be available on a range of devices or platforms. This was  
247 primarily because they often have access to multiple devices and/or use different devices for

248 specific tasks or in particular situations: they therefore wanted something that suited their needs  
249 at that point in time.

## 250 **DISCUSSION**

251 This study explored the information needs and behaviour of individuals with VI in relation to  
252 their rehabilitation and adaptation to sight loss. In particular, the information they deemed most  
253 important, the current methods they use to access it and how they would view the use of a  
254 dialogue system as a supporting device. Many of the sources of information reported by  
255 participants were in broad agreement with those reported in previous studies (see e.g. Beverley  
256 *et al.*<sup>23</sup>). The barriers to accessing information were also similar (for a review see Lam & Leat<sup>24</sup>)  
257 despite the relative familiarity of responders with technology. The wide variety of information  
258 sources reported by participants may be reflective of the lack of a formal support pathway,  
259 leaving individuals to use their own initiative to source the information they need<sup>7</sup>. Peer support  
260 (both in organised groups and informal one-to-one relationships) was repeatedly identified as  
261 an extremely important, and very adaptable, information source. The advice is often trusted by  
262 those with VI, because it is drawn from the lived and relevant experience of others with VI.  
263 The topics of information that participants identified in this study were also very similar to  
264 those identified in previous studies<sup>23,25-27</sup>, falling into the category of “social information”  
265 which is that required to function in everyday life<sup>21</sup>. The exact spectrum of information  
266 priorities varies between individuals and they want targeted information (in terms of topic,  
267 timing and quantity). Despite the reservations of participants, this personalisation is an aspect  
268 which digital assistants are well-placed to deliver<sup>28</sup>, although providing the appropriate level  
269 of granularity in responses is challenging<sup>29</sup>.

270 The study confirms other challenges and gaps identified previously in the AI-based dialogue-  
271 systems literature. To deliver appropriate information about a wide range of diseases, extensive  
272 data collection of conversations between patients and healthcare professionals is needed to

273 build and evaluate healthcare dialogue systems, but such collection is difficult to obtain due to  
274 data privacy concerns. The lack of training data in such a domain is a challenge when providing  
275 users with relevant information<sup>30</sup>. Healthcare professionals should be involved in designing  
276 such systems, providing data closer to the patient's real information needs<sup>31</sup>. Users have also  
277 previously raised trust as an essential factor in deciding whether to use a system. Opaque  
278 systems tend to decrease user confidence since people tend to be uncertain if the output  
279 information provided is correct<sup>32, 33</sup>. Concerns about the use and storage of personal data are  
280 also prevalent<sup>34</sup>. In order to be accepted in sensitive domains such as health, conversational  
281 interfaces must extend their assistance capabilities and have human-like assistant behaviour<sup>35</sup>.  
282 Users of dialogue systems emphasize the convenience they bring into their daily routine,  
283 significantly simplifying arduous tasks<sup>34</sup>. However, visually impaired users will often have  
284 difficulties discovering new functionalities in these types of systems<sup>36</sup>.

285 It would be a major strength if the digital assistant was able to facilitate undirected search which  
286 was more exploratory in nature, and may be open-ended and iterative<sup>18</sup>. This would address  
287 the needs of some users who are unaware of what support is available and are unsure what  
288 question to ask. In both these aspects, using AI algorithms to provide the digital assistant with  
289 the ability to initiate some of the conversations with the user, may provide a major advantage  
290 over a conventional “internet search” for information. The digital assistant could become a very  
291 useful supplement to existing methods for obtaining information.

## 292 **Recommendations for the next stage of the AIVI study**

293 Through the study analysis, it was possible to identify the following specific requirements for  
294 the next stage of the AIVI study when developing a dialogue system to assist VI individuals:

- 295 1. Relevance via context understanding: The information delivered should be  
296 contextualised within the unique disability setting of the user.

- 297 2. Disability modelling and patient pathway understanding: the system needs to commit  
298 to an ontological (conceptual) model of the clinical problem space and possible  
299 trajectories of support and progression of the condition and rehabilitative process.
- 300 3. To enable highly contextually sensitive and concise answers, achieving completeness  
301 with conciseness.
- 302 4. Transparency, explainability and trust: End-users should know enough about the  
303 system to form a mental model of its operation. Trust will be achieved by  
304 understanding how the information provided by the system is curated, how their data  
305 is stored, and how the answer was obtained.
- 306 5. Accessibility to a diverse audience: The user expects that the system can understand  
307 their utterances and return the answers conveniently and matched to their  
308 understanding level. It should cope with speech and language variations and  
309 communicate back in an accessible discourse.

## 310 **Limitations**

311 There was no attempt here to recruit all types of individuals with VI, and these would be the  
312 subject of follow-up studies. The online questionnaire was biased to responses from those more  
313 familiar with technology, and individuals with communication difficulties were not specifically  
314 recruited. The questionnaire was only available in English, so it is likely that ethnic minorities  
315 were under-represented.

316 Although carers were recruited to the study, and issues regarding support for carers emerged,  
317 the emphasis here was on the individuals with VI themselves (carers were asked about the  
318 needs of individuals with VI, rather than their own needs). Other research studies<sup>37,38</sup> have  
319 investigated the needs of carers, and these needs can be specifically addressed in digital  
320 assistant design.

## 321 **CONCLUSION**

322 Conversational agents could meet an identified need in the provision of personalised  
323 information to those with VI, and offer important advantages including: ease of use (accessible  
324 format), control over the timing, quantity and type of information provided, help with  
325 interpreting the large array of information sources available, and selecting information to help  
326 support those who do not know what to ask about. The findings will be useful for the  
327 development of dialogue systems for the VI population to support disease and rehabilitation  
328 management.

### 329 **ACKNOWLEDGEMENTS**

330 The research was conducted in collaboration with Mark Belcher (Henshaws). We thank the  
331 Expert Advisory Group members (Stevie Johnson (RNIB), Davinder Kullar (RNIB), Simon  
332 Labbett (Rehabilitation Workers Professional Network), Andrew Miller (Focus Birmingham),  
333 Paul Ryb (Macular Society), Dave Steele ("The Blind Poet" <https://theblindpoet.net>) and Dan  
334 Williams (Visualise Training and Consultancy) for their expert advice and guidance during the  
335 research. We also thank the Macular Society and Henshaws for their support in promoting the  
336 online questionnaire.

### 337 **Funding**

338 This research was funded by a research grant from the Macular Society.

### 339 **Competing Interests**

340 The authors report there are no competing interests to declare.

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447 **Table 1: Demographic characteristics of study participants.** (*In the questionnaire, total*  
 448 *participants = 120*). \*For these characteristics multiple categories were possible. # These data  
 449 were not available from the anonymous survey.

Characteristic	Questionnaire	Interviews
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<b>Participant Category*</b>	(n)	(%)	(n)
Visually Impaired	<b>104</b>	<b>(86.7)</b>	<b>8</b>
(+Carer/Family Member)	3	(2.5)	(0)
(+Rehabilitation Professional)	1	(0.8)	(2)
Carer/Family Member	<b>7</b>	<b>(5.8)</b>	<b>1</b>
Rehabilitation Professional	<b>9</b>	<b>(7.5)</b>	<b>1</b>
<b>Registration Status</b>			
Difficulties with vision but not registered	51	(42.5)	0
Sight Impaired (SI)	23	(19.2)	3
Severely Sight Impaired (SSI)	30	(25.0)	5
Not Applicable	16	(13.3)	2
<b>Age Group (years)</b>			
Under 40	3	(2.5)	0
40-49	10	(8.3)	2
50-59	18	(15.0)	3
60-69	19	(15.8)	4
70-79	44	(36.7)	1
80+	26	(21.7)	0
<b>Access to/use of technology*</b>			
Internet	109	(90.8)	10
Smartphone	91	(75.8)	9
Laptop computer	70	(58.3)	8
Desktop computer	64	(53.3)	6
Voice activated technology	41	(34.2)	6
<i>None of the above</i>	3	(2.5)	0
<b>Duration of Visual impairment (years)</b>		#	
Under 5			1
5-10			2
11-20			2
21-30			2
30+			1
Not Applicable			2
<b>Gender</b>		#	
Male			5
Female			5
<b>Living arrangements</b>		#	
Spouse/partner			4
Family			3
Alone			3
<b>Employment status</b>		#	
Employed			4
Unemployed			1
Retired			4
Volunteer			1

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453 **Table 2: Overarching themes across topics of information**

<b>Themes</b>	<b>Illustrative quotations</b>
<b>Targeted to the individual</b>	<p>IP9: “...when I did get information they tend to send out a big book of stuff, but really some of it wasn’t of interest, some of it wasn’t relevant ...it was like a coverall ...daft things of clutter that really weren’t of any use”.</p> <p>IP9: “...because they asked you what you wanted ...they were able to work out what it was you needed, as opposed to just throwing everything at you and saying, see what you make of that”</p>
<b>Accessible format</b>	<p>QP23: “It’s not a question of what information (is needed) but of the availability of information in a useable format”.</p> <p>QP36: “...good information, properly laid out and the correct font, size and contrast, will be readable and adequate for their (people with VI) needs”.</p>
<b>Timing (and quantity)</b>	<p>QP113: “...adaptation to sight loss may take many years and people need support at different times and often to revisit it... more information when ready to absorb it”.</p> <p>QP116: “My experience shows that as you are struggling to process the diagnosis you are not in a good position to look for the information or find it on the internet”.</p> <p>IP4: “You need information... that’s relevant to what you are experiencing at the time because I think you are much more likely to listen and take it in as you’re much more likely to need it”.</p> <p>IP9: “...the wrong information at the wrong time is frightening. The relevant information at the right time is uplifting”.</p>
<b>Signposting</b>	<p>QP11: “The most important information is that there are organisations out there that can help if you know where to look”.</p> <p>QP13: “...there are many support services out there that can help with support, guidance, information, advice and mobility training and this (information) should be easily accessible and provided”.</p> <p>QP55: “How and where to get help and information from, what kind of help is available to me, practical, emotional and financial”.</p> <p>IP4: “I have a bus pass ...in my area, but that’s not what’s available (elsewhere) ...it’s a completely different set up ...it’s important to know what’s available in your own vicinity ...like the support groups ...and local eye health charities ...because they’re the ones that know what’s available”.</p>

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456 **Table 3: Key sources of information and methods of access.**

<b>Themes</b>	<b>Illustrative quotations</b>
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Sources of information	
<ol style="list-style-type: none"> <li>1. Online/internet/websites/email.</li> <li>2. Sight loss organisations/societies/charities.</li> <li>3. Social media/chat forums.</li> <li>4. Local Authorities/Sensory Services.</li> <li>5. Hospitals.</li> <li>6. Optometry practices.</li> </ol>	<p>QP13: <i>“I use websites, helplines, local charities and speak with services provided by my local hospital. I also read blogs to see how other visually impaired individuals are getting on, how they manage and cope and this allows me to pick up tips”.</i></p> <p>QP31: <i>“...Local social services can be very helpful. Local blind charities. Other people with the same condition. A good optometrist is essential, ideally with experience of working with low vision patients”.</i></p>
<ol style="list-style-type: none"> <li>7. Peer support</li> </ol>	<p>IP1: <i>“Personal knowledge... when you’re speaking to people who are either going through the same thing or have been through the same thing, they’re able to advise you a lot better”.</i></p> <p>IP1: <i>“...without people on some of the support groups I wouldn’t have got through that time”.</i></p> <p>IP2: <i>“(Peer support) ...is like-minded people who are visually impaired... and are getting on with their lives and all of them have got their own stories to tell and their own tricks to tell as to how they get on”.</i></p> <p>IP2: <i>“...as a 40-year-old guy I needed to speak to someone who is 40 who’d already done that journey and for them to help me”.</i></p> <p>IP3: <i>“...over the years I’ve built up a little network of half a dozen people through all sorts of things, and I’d ring them up and say, what do you do?”.</i></p> <p>IP4: <i>“...we meet every other month in a pub and have a meal together and just chat...”</i></p> <p>IP8: <i>“...they encouraged me that I would be fine and they quickly showed me the techniques, and I believed them because they were the same as me ...”</i></p>
Method of Access	

1. Smartphone/Tablet/PC.	QP29: <i>“All manner of electronic device – PC, smartphone and tablets”</i> .
2. Telephone (e.g. helplines).	
3. Conversations with professionals, friends and family	QP61: <i>“...by talking to hospital staff – nurses, technicians and consultants”</i> .
4. Paper literature (e.g. booklets, leaflets).	QP35: <i>“paper literature and online information from charities and hospital...”</i> .
5. Conferences/workshops/courses.	
6. Radio programmes.	QP41: <i>“...with difficulty. I require constant help from someone sighted”</i> .
7. Through/with help from a family member/carer.	QP77: <i>“I depend on my wife to access information”</i> .

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460 **Table 4: Participant opinions on whether a digital assistant would be helpful.**

<b>Themes</b>	<b>Illustrative quotations</b>
<b>Positive aspects</b>	
1. Ease of use.	QP21: <i>“Most certainly as using limited sight to access computer/phone/tablet can be very stressful”</i> .
2. Timing of information.	QP82: <i>“Yes as sometimes using a screen for a long while makes my eyes tired and gives me a headache”</i> . QP119: <i>“Yes that would be easier to access if voice activated”</i> .
3. Privacy.	QP47: <i>“ It is a relief to be told things rather than always having to mess about with magnification devices”</i> . QP26: <i>“Yes, because it would be easier than typing a question and hopefully would receive a fast response”</i> . QP10: <i>“Yes. Digital assistants are becoming widely available. On demand access to information is extremely powerful and more cost effective than manning a round the clock helpline”</i> . QP79: <i>“...this would be an invaluable source of information as...it would be available 24/7, can be kept up-to-date unlike hard copy literature and avoids the need for the VIP to remember (information). It would also be more accessible to VIP’s early in their sight loss journey who may be depressed/stressed and don’t want to have to deal with multiple agencies/people”</i> .

	<p>QP103: “...may seem like a stupid question to them and they may feel embarrassed about talking to somebody about it but may feel ok talking to an automated service that will not judge. Also ...would be available at any time of the day or night when a person needs questions answered... (alternatively) ...they may need to wait for an appointment which could add to the distress of the patient wanting answers”.</p> <p>QP76: “Yes. Such a device would encourage the user to ask any questions, however simple, silly, embarrassing or complicated”.</p> <p>IP1: “...having to talk about it (visual impairment) over a phone call or face to face can be often quite daunting... (if someone had a personal assistant) ...people will become more relaxed about asking things that they may be felt anxious about asking...”.</p>
<b>Negative aspects</b>	
<ol style="list-style-type: none"> <li>1. Too generic.</li> <li>2. Difficulty of use.</li> <li>3. Impersonal.</li> <li>4. Trust and provenance</li> <li>5. Privacy.</li> <li>6. Unnecessary.</li> </ol>	<p>QP49: “A digital assistant would be better for more generic information, possibly as a way of finding the sorts of information that might be required from a more personal conversation or for finding subsequent more targeted information”.</p> <p>QP14: “No... FAQs etc that are supposedly a “one size fits all” but in practice they don’t really help at all”.</p> <p>QP4: “everybody has a different experience and perhaps the computerised digital assistant will not be detailed enough”.</p> <p>QP49: “Only as an adjunct ... (to other methods) ...Face-to-face/telephone conversations with an experienced person is more likely to provide more focused and nuanced information”.</p> <p>QP65: “No. My mother who is 97 years old does not speak clearly and it is sometimes hard to understand her. She would not be able to use such a device”.</p> <p>QP71: “...I don’t think this would work for me at all...I have hearing aids too and find robotic voices difficult. Humans are easier to converse with”.</p> <p>IP6: “...because ...bots just give recorded answers, and they can’t really be as personal as a human being on the other end of a phone”.</p> <p>QP5: “...concerned that bad or difficult news would be given by a digital means... I think it may be ok for very simple information but not for complex in depth information with emotional impact”.</p> <p>QP86: “Yes and no. Yes because it can give you the facts, organisations etc. No because it cannot ...offer emotional support”.</p>

	<p>QP83: “...it would be better to talk to a real person that was interested in your problem”.</p> <p>QP100: “...think it may be too uncaring if I am upset about eye developments”.</p> <p>IP7: “...I’d trust it as much as I’d trust something I found on a computer (search engine) ...I suppose it will never be the same as speaking (especially if it’s highly technical or medical) ...one would prefer to speak to somebody who is skilled in that field”.</p> <p>IP7: “...there is a lot of rubbish obviously out there (online) ...all sorts of misinformation. But actually... if you ...follow trusted sources ...you can usually work out what’s correct or what’s likely to be correct”.</p> <p>IP4: “I think it’s important that it says where that information has come from, ...it could be just (anyone) saying that information, so it’s maybe not so easy to trust. But if it was from a (trusted source) you’re more likely to believe it ...and know it’s verified information”.</p> <p>IP6: “...I don’t think I’d completely trust a bot ...I think it would need to be saying to the eye liaison officer or rehab worker, my gadget says this, what do you think?”.</p> <p>QP112: “...I have reservations as I assume digital assistants will require some way of connecting online and this may have security implications”.</p> <p>QP28: “Not at present as I am just able to see with visual aids and enlarging the print”.</p>
<p><b>Uncertain</b></p>	
<ol style="list-style-type: none"> <li>1. Would need to try.</li> <li>2. If it worked.</li> <li>3. If condition got worse.</li> </ol>	<p>QP41: “Yes possibly but I would need the experience before deciding”.</p> <p>IP5: “...it’s hard to know without trialling it really I suppose”.</p> <p>QP51: “It depends on the system. People tend to use their own terminology when asking questions, the computer would need to understand these”.</p> <p>QP46: “I’ve never done that and some of the medical terms are difficult to say”.</p> <p>QP34: “At present it is not necessary, but I can envisage that it may become necessary if my vision deteriorates. Then it might allow me to access information... that would otherwise be difficult”.</p>

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462 **Figure Captions**

463 Figure 1: The five free-text questions which were asked in the online survey

464 Figure 2: A graphic representation of the analysis of information topics described as most  
465 important for those with visual impairment, with illustrative quotes..

466 Figure 3: A graphic representation of the analysis of participant experience of barriers to  
467 obtaining information and support

468 Figure 4: A graphic representation of the analysis of participant opinions on digital assistant  
469 format

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