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QUESTIONNAIRE

a. Please confirm if you are:

- Visually Impaired.
- Carer or Family member of someone that is visually impaired.
- Rehabilitation professional working with those that are visually impaired.

b. Registration Status:

- Severely sight impaired (SSI)
- Sight impaired (SI)
- Difficulties with vision but not registered
- Not applicable

c. Please select your age group category:

- Under 40 years
- 40-49 years
- 50-59 years
- 60-69 years
- 70-79 years
- 80+
- Prefer not to say

d. Do you use any of the following (select all that apply):

- Desktop computer
- Laptop
- Smartphone
- Internet
- Voice activated technology/equipment
- None of the above

Q1: In your opinion, what is the most important information and/or support that someone with visual impairment needs to be given?

Text box to type answer

Q2: In your opinion, where are the best sources of information about visual impairment?

Text box to type answer

Q3: How do you access information about visual impairment?

Text box to type answer

Q4: Do you think accessing information about visual impairment from a computerised digital-assistant would be helpful? –please give your reasons.

Text box to type answer

Q5: In your opinion, what form of digital assistant would be most accessible? (for example: something that works on a computer? Or works on a phone? Or a Stand-alone device?) – please give your reasons.

Text box to type answer

Any additional comments you would like to make? (Optional)

Text box to type answer

END

Thank you for completing this questionnaire.

INTERVIEW SCHEDULE (v1)

STUDY: AIVI – A virtual rehabilitation assistant to offer timely and relevant information and advice to individuals with visual impairment.

The main aim of this research study is to investigate whether personalised rehabilitation and adaptation support for individuals with visual impairment (VI) can be provided by a digital computer-based personal assistant designed to offer relevant information to those with VI. The first phase of the project will identify and prioritise the information that those with VI need to help support their rehabilitation and adaptation to sight loss, and investigate how they receive this information. This data will be used to inform later phases of the project which will include the design, building and evaluation of a prototype device.

The participants recruited into this study will undergo in-depth semi-structured interview carried out by an appropriately qualified person. The interview will involve questions that aim to identify and prioritise the information that those with visual impairment (VI) need to help support their rehabilitation and adaptation to sight loss, and explore the best ways of providing that information.

Broad objectives:

1. To determine the information needs of those with VI in terms of rehabilitation, advice and support.
2. To explore how those with VI source and receive information, the preferred formats for information and any barriers to obtaining information.
3. To investigate attitudes to use of technology and what those with VI would want from a digital personal assistant.

The interview schedule outlines the proposed topics/questions that will be explored during the interview, which is expected to last up to one hour. However, this is an outline and the interviewer may deviate from the schedule and develop the questioning if it exposes information that may benefit the aims of the research study.

Socio-Demographic/health Data:

Age

Gender

Occupation (or previous occupation if retired)

Residential status (e.g. Living alone/Partner/Family)

Registration status Y/N, (If Y, SI or Severely SI)

Diagnosis/Condition(s) causing sight loss

Use of computer/smartphone/internet

AIVI Interview Topic Guide v1.1
16-11-20

Topics for discussion (not necessarily in this order or exhaustive):

INTRODUCTION

- *Introductions and Consent procedures: Note that this will be recorded separately to maintain confidentiality.*
- *Describe purpose: e.g. the purpose of this discussion is to find out about the information and advice that you have found most useful in relation to helping support you with your sight loss.*

INFORMATION NEEDS

- What questions did you have about your sight loss/eye condition? Initially/subsequently.
- What information were you given about your sight loss? Initially/subsequently.
- Best information/advice given, any information/advice that was not useful.
Information that you would have found helpful but didn't receive?
Question(s) you would ask now?
- What did you find most helpful to you in coming to terms with your vision loss?
- Timing of advice/information.
- Format/provision of information. Ease of accessing information/barriers to accessing information.

Additional questions/topics for rehabilitation professionals:

- *What are the questions most asked by clients in regard to their sight loss/rehabilitation?*
- *What information do you feel is most beneficial to those adapting to sight loss? Initially/subsequently.*
- *How do you decide what information to give to your clients and at what stage?*

ATTITUDE TO TECHNOLOGY

- Feelings about using technology to access information. Trust the device/information?
- Advantages/disadvantages of using technology to access information.
- What would you want from a digital personal assistant?
- Preferred format of device. What should it look/sound like?
- Would you use a device like this? What would help/encourage you to use it regularly?
- Any concerns about using digital personal assistant? Privacy/confidentiality/security.
- Provision. When should it be provided? Where from? To everyone or just certain people?

Additional questions/topics for rehabilitation professionals:

- *How do you think a digital personal assistant could be used to help someone adjusting to sight loss? What do you think individuals with VI would want from a device?*
- *How could it supplement/replace/integrate with existing service provision?*

CONCLUSION

- Are there any additional comments you would like to make about...
- Closing/thanks for taking part.

ANALYSIS

The survey responses and interview transcripts were combined, and analysed using thematic analysis. This analysis method involved a sequential multi-stage process that included familiarisation with the survey data set by re-reading the transcripts, initial manual coding of the data, grouping codes into themes (by JT), reviewing themes (in discussion with research team), and naming and defining themes. In the final stage of report production appropriate quotes were chosen from the dataset which justified the research findings. Illustrative quotes were assigned by participant number, with designations of “QP” and “IP” being used to represent questionnaire and interview participants respectively. This is an extended illustrative data set of quotes for all the topics discussed in the paper.

Table 1: Information topics described as most important for those with visual impairment.

Themes	Illustrative quotations
<p>Ocular condition</p>	<p>QP16: <i>“As much information as possible about the condition, why it has occurred, and what can be done to alleviate sight loss or prevent it’s deterioration”</i> .</p> <p>QP49: <i>“A full and understandable explanation of their problem and how it might affect them now and in the future”</i> .</p> <p>QP76: <i>“Simple information about the eye condition, treatment, monitoring and the effect on daily life”</i> .</p> <p>QP79: <i>“A full understanding of their condition, its prognosis and steps the patient can take to mitigate the effects”</i> .</p> <p>QP15: <i>“Information on current and future research being conducted and implications for future treatment”</i> .</p> <p>IP2: <i>“(I)...was diagnosed pretty quickly with the earth-shattering news... that I was going to lose my central vision in both eyes very rapidly and I didn’t understand what that meant. I had no knowledge of macular disease ...and didn’t understand that you could lose central vision but maintain peripheral sight”</i> .</p> <p>IP4: <i>“...all of a sudden I’ve got this real issue and I can’t see properly, why had that happened? ...I would like to know about the condition. What is it? ...What causes that? ...What treatment would I need? ...How long would that treatment go on for?”</i> .</p> <p>IP10: <i>“I think one of the things that they (people with VI) lack sometimes, is a layman’s understanding of their pathology, and how it might change, or not change”</i> .</p>
<p>Equipment, technology and adaptations</p>	<p>QP10: <i>“Clear objective guidance around what is possible and support on fully leveraging technology to enable greater access to digital services and the employment market”</i> .</p> <p>QP13: <i>“...every individual with sight loss should know there are many applications, online websites, technologies and products available to assist with day to day living”</i> .</p> <p>QP22: <i>“both access to technology and more important help to use it to best ability...”</i></p> <p>QP26: <i>“which devices could help you, including magnifiers and up to date technology”</i> .</p> <p>QP66: <i>“familiarisation and training in the use of technology and equipment to access everyday life”</i> .</p> <p>QP106: <i>“Information about how to make the most of residual sight including equipment and techniques like eccentric viewing”</i> .</p>

	<p>IP5: <i>"I wanted to ask about adaptations and things for using computer technology and so on..."</i>.</p> <p>IP9: <i>"...they booked me in for a tech assessment, which was the best thing they ever did ...I went and saw somebody who talked to me all about CCTV, ...accessibility software ...and equipment"</i>.</p>
Daily activities	<p>IP4: <i>"I was worried about my driving, would I be able to continue to drive? ...If I wasn't able to drive what was going to happen? ...Would I have to pay for a bus all the time?"</i>.</p> <p>IP4: <i>"I had two young children, ...so I had to factor them in as well and how they would be supported as well"</i>.</p> <p>IP4: <i>"...an audio description of what the shop (destination) is like ...the colour of it on the outside ...any obvious surroundings near it ...after I get off the bus ...which direction do I need to go?"</i>.</p> <p>IP5: <i>"...daily things ...to get through daily life are important, especially with cooking, cleaning and so on..."</i>.</p> <p>IP8: <i>"One of the big things is I had a baby... How does a visually impaired person raise a child?"</i>.</p> <p>IP10: (Talking about what info needs of those with VI are) <i>"...for most ...it's about maintaining their independence"</i>.</p> <p>IP5: (Talking about information from ECL0): <i>"...it's just a whole variety of things ...where can I go for the technology support ...or if I'm looking for ways of trying to organise my banking ...or my shopping...they were able to make some suggestions ...just having that personal conversation I guess"</i>.</p>
Registration	<p>QP15: <i>"Information on possible government support available and registering as sight impaired"</i>.</p> <p>QP47: <i>"Information about the benefits of registering (P.I.P., travel passes, etc)"</i>.</p> <p>IP1: <i>"The first question... was with regards to being certified... what that would mean, as in how it would help me, what were the benefits of being certified and what kind of doors would that open up to different support"</i>.</p> <p>IP5: <i>"I think early on you need the very practical things ...the types of registration, any support you can get from the council ...how to go about getting the Blue Badge for my partner to be able to use that ...and the reduced price fares for train travel and things like that"</i>.</p>
Financial/employment information.	<p>IP3: <i>"...I think there's a real issue suddenly having an income and then not having income..."</i>.</p> <p>IP4: <i>"Would it (visual impairment) affect my work that I was doing at the time? Would I have to take time off work? That was something that was really important to me because I didn't want to lose my job because of this condition"</i>.</p> <p>IP2: (Talking about support at work) <i>"They came in and we discussed overlay"</i>.</p>

	<p><i>software which was exactly what I needed to continue to perform my job... so that I could use all the systems that I was familiar with".</i></p> <p>IP4: <i>"I would have like to have known what my rights were ...for example with my work, ...what my employer should have been doing... and what you're entitled to..."</i>.</p> <p>IP4: <i>"...work is so important ...it's the one thing people don't want to lose ...they want to keep their independence as much as possible"</i>.</p> <p>IP9: (Talking about information needs) <i>"...the biggest thing I wanted to know was: how I can carry on working? The rest of it was irrelevant to me because we had a young family and that was my primary concern was about working, providing"</i>.</p>
<p>Emotional support</p>	<p>QP3: <i>"That you are not alone, that there are others out there like you and how to contact them"</i>.</p> <p>QP39: <i>"Where to go for help, it's scary when you're told you have AMD and it's progressing"</i>.</p> <p>QP71: <i>"Support to deal with shock and fear"</i>.</p> <p>QP86: <i>"Information regarding counselling"</i>.</p> <p>QP96: <i>"Reassurance, empathy, ...opportunities to express worries and fears"</i>.</p> <p>IP3: (Talking about sight loss) <i>"I found it a fairly bruising experience, because... you're in absolute turmoil, your life's upside down, and I think with the emotional stuff, it's very difficult to know what's what"</i>.</p> <p>IP3: (Talking about what information people need) <i>"...I think one of the categories should be about where you can get that emotional support, that may be specific to living with a visual impairment, because actually it's exhausting"</i>.</p> <p>IP3: <i>"...I think one or two of the charities take that view ...it's all that sort of up, up, up, up, up ...I didn't find that helpful. I find ...a bit more realism ...more helpful, or talking to somebody with that experience of being VI"</i>.</p> <p>IP9: <i>"...it's that mind-set you have to change ...that it's what you can do ...not what you can't ...people focus on what you can't do all the time"</i>.</p>
<p>Support for the carer</p>	<p>IP6: <i>"...a whole list of ...how to support your visually impaired family member ...a whole list of what to do and what not to do ...how do you give the best support possible while allowing independence..."</i>.</p> <p>IP6: (Talking about emotional support from the ECLO) <i>"...it was very comforting to me to know he (the ECLO) was there, and if my partner was in a bad way, then he would talk to him"</i>.</p> <p>IP2: <i>"parents of younger children ...need to know that their kid, who's visually impaired, can have a successful career and successful and happy life if they are managed correctly and given the help and support they need"</i>.</p>

Table 2: Overarching themes across topics of information.

Themes	Illustrative quotations
<p>Targeted information (specific to the individual)</p>	<p>IP2: (Talking about information needs) <i>"...the information is particular to you, your age and your interests ...don't give me a leaflet because that is going to be generic".</i></p> <p>IP9: <i>"...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".</i></p> <p>IP5: <i>"...I think it is the practical things people need first of all and then once people know ...the kind of situation that you're in and what you want to do then you can ask more".</i></p> <p>IP9: <i>"...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".</i></p> <p>IP8: <i>"...everybody's an individual".</i></p>
<p>Accessible format</p>	<p>QP23: <i>"It's not a question of what information (is needed) but of the availability of information in a useable format".</i></p> <p>QP24: <i>"Ability to have audio information available..."</i></p> <p>QP94: <i>"...It should not be possible for anyone working in an eye clinic to hand out information to someone with sight loss without finding out if they can read that information".</i></p> <p>QP36: <i>"...on the internet is... good (source of information) as long as the websites are designed accessibly".</i></p> <p>QP36: <i>"...good information, properly laid out and the correct font, size and contrast, will be readable and adequate for their (people with VI) needs".</i></p> <p>QP58: (Talking about accessing information) <i>"Mostly via desktop where I can control the size of screen content and print".</i></p> <p>QP14: <i>"I'm sick and tired of being asked to send documents and photos and application forms online, when I don't have or can't use the technology to do so".</i></p>
<p>Timing (and quantity)</p>	<p>QP113: <i>"...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".</i></p> <p>QP79: <i>"...because VIPs experience a bereavement process on diagnosis some can't absorb information at that point from a Dr or ECLO".</i></p> <p>QP116: <i>"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".</i></p> <p>QP111: <i>"There is a process of mourning and acceptance to go through for many</i></p>

people new to sight loss, this is normal and it can be hard to take in information while this is happening”.

QP36: “...I don’t think that this (information) should be given all at once because it is too much to take in for many people –there should be a way of “feeding” it to people when they are ready to find out more”.

QP21: “Info about local sources of support as soon as diagnosis is confirmed”.

IP1: “...when you are newly diagnosed, in those beginning stages of a journey with low vision or blindness, you may not be ready to hear certain... bits of information or certain types of advice”.

IP1: “...everyone goes through different stages... there’s certain stages of accepting, grieving, a journey of sight loss... and everything you go through, a lot of the stages are the same but we all go through them at different stages... some people will be ready for the support at the beginning and other people won’t”.

IP2: “...from diagnosis in 2007 to finding out what (support) was available ...was a good few months of not knowing, so had that window been closed ...and they had signposted me at the point of diagnosis, that could have saved me a lot of aggro”.

IP3: (Talking about first losing sight) “...it was quite sudden, I literally woke up one morning and couldn’t read the newspaper... so there was a lot of shock. If they don’t think they can cure you their interest is lost immediately really... so I was kind of told to go away and just get on with it... for the first three months it was very, very difficult. I eventually got support from one of the sight loss charities”.

IP3: “like a lot of people these things are quite sudden, and I think you ...just need to kind of get your head together, and just work out what information you’d like”.

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”.

IP5: (Talking about getting too much information in the early stages of sight loss) “...one day I got ...3 or 4 phone calls on the same day from different people giving me advice and information about technology and support services... It became too much, I couldn’t retain it ...I felt I really needed to kind of have it spread out ...or have people send me follow-up information to summarise what they had gone through”.

IP6: (Talking about getting information from a rehabilitation worker) “...he’d clearly been waiting for the moment when it was right for us to ask. So I think it’s that. Again, everybody is different ...the point at which people want to learn things is going to be different”.

IP9: “...the first thing I had to do was actually admit and come to terms with the fact that my sight was that bad. That was my biggest problem initially ...because I spent a lot of time covering it up”.

	<p>IP9: <i>"...the wrong information at the wrong time is frightening. The relevant information at the right time is uplifting"</i>.</p>
<p>Signposting</p>	<p>QP11: <i>"The most important information is that there are organisations out there that can help if you know where to look"</i>.</p> <p>QP13: <i>"...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"</i>.</p> <p>QP15: <i>"A list of organisations with contact details and NHS support available with details"</i>.</p> <p>QP17: <i>"How to access help and guidance and support. Who to contact i.e. support groups locally sourced. Designated links both electronically and via telephone to companies that are specific to customers that have visual impairment"</i>.</p> <p>QP28: <i>"Where to find what support is available"</i>.</p> <p>QP55: <i>"How and where to get help and information from, what kind of help is available to me, practical, emotional and financial"</i>.</p> <p>QP79: <i>"...signposting to the most relevant sources of on-going support and information"</i>.</p> <p>QP90: <i>"Signposting to charities and/or organisations that can offer support and information"</i>.</p> <p>QP106: <i>"Information about local and national support organisations"</i>.</p> <p>QP108: <i>"Where and how to source support: statutory services (low vision service and sensory support) and charitable bodies"</i>.</p> <p>QP109: <i>"Where to get help, who to contact for advice on managing in the future"</i>.</p> <p>QP112: <i>"Where they (people with VI) can go or who they can contact for advice. Having some form of assessment and subsequent signposting... to help adapt to living with sight loss"</i>.</p> <p>QP113: <i>"Where to access support"</i>.</p> <p>QP117: <i>"Support from local and national bodies"</i>.</p> <p>IP4: <i>"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"</i>.</p>

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

Themes	Illustrative quotations
Sources of information	
<ol style="list-style-type: none"> 1. Online/internet/websites/email. 2. Sight loss organisations/societies/charities. 3. Social media/chat forums. 4. Local authorities/Sensory services. 5. Hospitals. 6. Optometry practices. 7. "I don't know/nowhere". 	<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>QP3: <i>"From the ECLO, local sight loss organisations, local groups"</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> <p>QP36: <i>"Through local and national charities for blind and partially sighted people. On the internet is also good as long as the websites are designed accessibly"</i>.</p> <p>QP49: <i>"Local council sensory services and local VI support charities. Sometimes from the national organisations"</i>.</p>
<ol style="list-style-type: none"> 8. Peer support (in-person and online). 	<p>QP71: <i>"Speaking to others that have gone through it..."</i>.</p> <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>IP1: <i>"...speaking to people who were going through the same thing is the best kind of support you can get emotionally"</i>.</p> <p>IP2: (Talking about peer support) <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>"...by going along to working age forums and meeting other like-minded people, through talking to them, I was able to understand that there was so much more out there"</i>.</p> <p>IP2: <i>"...simple solutions that I particularly need, use and</i></p>

benefit from but I'm learning every day from meeting other people and what they do".

IP2: "...peer support is a free resource ...asking someone to volunteer to offer advice to someone who's going to go through the same problem that they went through".

IP2: "...talking to a person who understands what you're going through is equally as important as being told where to get the right software or right products".

IP2: "...that's where the peer support comes in. A lot of the time you can't think of everything that you might need to live your life smoothly until you come across problems and challenges and then you think there's got to be an easier way to circumvent that problem".

IP2: (Talking about peer support) "...so they can have empathy and understand what that person's going through and offer the, support... 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".

IP3: "...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?".

IP4: "I think support groups are so important ...because they can make you feel as though you're not alone in the situation you find yourself".

IP4: (Talking about info. from peer support) "...we share information on technology, benefits, workplace issues for example ...and people bring things in and share, you know, what they've found really useful".

IP4: "...we meet every other month in a pub and have a meal together and just chat..."

IP5: (Talking about information from peers) "...practical things like cooking and how to do that safely and manage things within the household environment, kitchen ...and things like that".

IP8: (Talking about peer support and using Technology) "...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 ...and they showed me other bits and pieces to make my life easy. So that's I suppose how I got in to smart devices".

Method of Access	
<ol style="list-style-type: none"> 1. Smartphone/Tablet/PC. 2. Telephone (e.g. helplines). 3. Conversations with professionals, friends and family 4. Paper literature (e.g. booklets, leaflets). 5. Conferences/workshops/courses. 6. Radio programmes. 7. Through/with help from a family member/carer. 8. "I don't". 	<p>QP10: <i>"Online. However, my condition has not changed for many years and I think there is still a need from direct professional intervention, especially at the beginning of the diagnosis pathway"</i>.</p> <p>QP29: <i>"All manner of electronic device – PC, smartphone and tablets"</i>.</p> <p>QP61: <i>"...by talking to hospital staff – nurses, technicians and consultants"</i>.</p> <p>QP35: <i>"paper literature and online information from charities and hospital..."</i>.</p> <p>QP102: <i>"Hospital leaflets"</i>.</p> <p>QP6: <i>"large print from societies, enlarging articles etc on tablet, verbally from friends and family"</i>.</p> <p>QP23: <i>"At present mainly from newsletters via email"</i>.</p> <p>QP41: <i>"...with difficulty. I require constant help from someone sighted"</i>.</p> <p>QP56: <i>"On the internet with the help of my wife"</i>.</p> <p>QP77: <i>"I depend on my wife to access information"</i>.</p>

Table 4: Experience of barriers to obtaining information and support.

Themes	Illustrative quotations
Accessibility	
<ol style="list-style-type: none"> 1. Lack of relevant information 2. Format of information 3. Staff don't have the time 4. Technology <ol style="list-style-type: none"> a. Access to technology b. Use of technology c. Cost of technology 5. Pandemic 	<p>IP4: <i>"...the only written information that looks like there is around all focusses on AMD. There's nothing on DMO... they don't really have stuff on other conditions really".</i></p> <p>IP1: <i>"...a lot of sites aren't accessible... you're unable to zoom in... you can't change the background to make it less bright... anything that's on a white background to me is awfully glary... there's still a lot of websites out there that are far too inaccessible".</i></p> <p>IP1: <i>"...often when someone's diagnosed with impaired vision... and they are looking at a piece of technology that isn't going to be supplied to them free of charge by an organisation... they (companies) can't produce these items... at a low cost for the person wanting to buy them".</i></p> <p>IP1: <i>"...there are some amazing pieces of kit out there but the majority of them are far too expensive for the people who need them the most".</i></p> <p>IP2: (Following diagnosis)... <i>"I just couldn't see to read. It was all very blurry in the centre and so... written information was no good to me".</i></p> <p>IP2: <i>"...because no website is consistent and finding a link to click on or finding something or being able to browse a page is incredibly difficult because we can only spot read".</i></p> <p>IP6: <i>"...when my partner lost his sight it was just at the beginning of the pandemic, and there was nobody we could go to. So we had to do our own research ...and find out what to do".</i></p> <p>IP5: <i>"February/March last year was just when the corona-virus restrictions were coming into place and suddenly it was much more difficult to get in contact with people ...you couldn't get people to make a visit, and it was a long time until another outpatient clinic ...so that was difficult".</i></p> <p>IP5: <i>"...I thought I was very competent with computers ...but it's almost as if I am having to learn it all over again through the accessibility routes and I don't always find them as accessible as they supposedly are".</i></p> <p>IP9: (Talking about info. received from Hospital) <i>"Very little. Very little. I had an ongoing repeat appointment with the hospital, but it was all about monitoring and measuring</i></p>

	<p><i>...very little on what you could do outside of medical treatment... It always fascinated me why there was all this stuff on the notice board that nobody could see. Quite bizarre really”.</i></p> <p>IP5: (Talking about using technology to access information) <i>“...I’m all for that, but I struggle with what is available and how it operates”.</i></p> <p>IP4: (Talking about eye condition and treatment) <i>“...I would like to have known a bit more... but they’re (doctors) under pressure and they can’t answer all these questions ...in the timeframe they’ve got”.</i></p>
Awareness	
	<p>IP4: (Talking about information needs) <i>“...the problem is, you don’t know what you need until you’ve found it”.</i></p> <p>IP2: <i>“...the answer to most questions is out there, it’s just two problems; one, the person doesn’t know to ask that question and two, they don’t know where to look”.</i></p> <p>IP6: <i>“...when you don’t know what you don’t know, you don’t know what you need to know ...you just don’t know what there is to find out, so you can’t find out because you’ve got no idea”.</i></p> <p>IP2: <i>“...solutions are out there, it’s just not everybody has the resources to find them or know to ask the right questions”.</i></p> <p>IP3: <i>“...you tend to pick things up as you go on... you know, because there are loads of things you just don’t think of because ...especially when it first happens ...you’re just trying to keep the basics running”.</i></p> <p>IP5: (Talking about accessing information) <i>“...it’s difficult because I don’t know what I need to know really, it’s like, what’s the term? ...the unknown unknowns?”.</i></p> <p>IP9: (Talking about discovering available Tech/LVAs) <i>“...you are just not aware it exists ...if you don’t tell someone, they don’t know”.</i></p> <p>IP9: <i>“...your barrier is actually you don’t know it’s there initially ...your second barrier is probably accessing the right information ...and your other barrier, after all that, is the cost of everything further down the line”.</i></p> <p>QP16: (Talking about information sources for VI) <i>“...unless you have an impairment or know someone with a problem, most people don’t think about it, so when the problem</i></p>

	<i>occurs it is very difficult to know where to get information”.</i>
Lack of an organised pathway of support	
	<p>IP1: <i>“...going to different organisations you were getting little snippets of advice and a little snippet from somewhere else”.</i></p> <p>IP8: <i>“Just picking up information here, there and everywhere and putting things together”.</i></p> <p>QP94: <i>“...Sadly, this is fragmented, duplicated, and spread over a wide range of websites etc”.</i></p> <p>QP22: <i>“...Scattergun: frustrating, inconsistent as mood drops if can’t find what I’m hoping for”.</i></p> <p>IP1: <i>“often you’d speak to someone from an organisation... then you’d have to speak to someone else, and you’d have to do that via email or you’ve got to take a call, and the process slows down a lot”.</i></p> <p>IP3: <i>“...I was quite lucky really looking back on it... by accident... and somebody knowing somebody and knowing somebody (else)... A lot of it is around who knows who and being in the right place at the right time”.</i></p>

Table 5: Participant opinions on whether a digital assistant would be helpful.

Themes	Illustrative quotations
Positive aspects	
<p>1. Ease of use.</p> <p>2. Timing of information.</p> <p>3. Privacy.</p>	<p>QP21: <i>“Most certainly as using limited sight to access computer/phone/tablet can be very stressful”.</i></p> <p>QP82: <i>“Yes as sometimes using a screen for a long while makes my eyes tired and gives me a headache”.</i></p> <p>QP119: <i>“Yes that would be easier to access if voice activated”.</i></p> <p>QP42: <i>“Yes definitely. It can be very stressful when your vision changes suddenly. Trying to trawl the internet for information can add to this stress and it would be much easier to be able to use a digital assistant to help with this task”.</i></p> <p>QP47: <i>“Yes, I do. Principally because looking up websites can be stressful and counter-productive for people who are visually impaired. It is a relief to be told things rather than always having to mess about with magnification devices”.</i></p> <p>QP26: <i>“Yes, because it would be easier than typing a question and hopefully would receive a fast response”.</i></p> <p>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></p> <p>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> <p>QP120: <i>“Yes. It could give relevant information that might take a long time to find on the web”.</i></p> <p>QP103: <i>“...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”.</i></p> <p>QP76: <i>“Yes. Such a device would encourage the user to ask any questions, however simple, silly, embarrassing or complicated”.</i></p> <p>IP1: <i>“...having some kind of system where it would direct me to all this knowledge is going to be a massive help to anyone”.</i></p>

	<p>IP1: <i>"...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..."</i>.</p>
Negative aspects	
<p>1. Too generic.</p> <p>2. Difficulty of use.</p> <p>3. Impersonal.</p> <p>4. Trust and provenance</p> <p>5. Privacy.</p> <p>6. Unnecessary.</p>	<p>QP49: <i>"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"</i>.</p> <p>QP14: <i>"No... FAQs etc that are supposedly a "one size fits all" but in practice they don't really help at all"</i>.</p> <p>QP4: <i>"everybody has a different experience and perhaps the computerised digital assistant will not be detailed enough"</i>.</p> <p>QP49: <i>"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"</i>.</p> <p>QP65: <i>"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"</i>.</p> <p>QP71: <i>"...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"</i>.</p> <p>IP6: (Talking about whether chat-bots could provide emotional support) <i>"...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"</i>.</p> <p>QP5: <i>"...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"</i>.</p> <p>QP86: (In response to: would as digital assistant be useful?) <i>"Yes and no. Yes because it can give you the facts, organisations etc. No because it cannot ...offer emotional support"</i>.</p> <p>QP83: <i>"...it would be better to talk to a real person that was interested in your problem"</i>.</p> <p>QP61: <i>"Not really as I would prefer to talk with a human and not a computer"</i>.</p> <p>QP100: <i>"...think it may be too uncaring if I am upset about eye developments"</i>.</p> <p>IP7: (Talking about information from a chat-bot) <i>"...I'd trust it as much as</i></p>

	<p><i>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".</i></p> <p><i>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".</i></p> <p><i>IP9: (Talking about trusting the information from a chat-bot) "...I think it would depend on where it (information) came from".</i></p> <p><i>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".</i></p> <p><i>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?".</i></p> <p><i>QP112: "...I have reservations as I assume digital assistants will require some way of connecting online and this may have security implications".</i></p> <p><i>QP28: "Not at present as I am just able to see with visual aids and enlarging the print".</i></p>
Uncertain	
<ol style="list-style-type: none"> <i>1. Would need to try.</i> <i>2. If it worked.</i> <i>3. If condition got worse.</i> 	<p><i>QP41: "Yes possibly but I would need the experience before deciding".</i></p> <p><i>IP5: "...it's hard to know without trialling it really I suppose".</i></p> <p><i>QP51: "It depends on the system. People tend to use their own terminology when asking questions, the computer would need to understand these".</i></p> <p><i>QP46: "I've never done that and some of the medical terms are difficult to say".</i></p> <p><i>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".</i></p>

Table 6: Participant opinions on digital assistant format.

Themes	Illustrative quotations
Preferred Formats	
Smartphone/Tablet	
<ol style="list-style-type: none"> 1. Ease of use 2. Accessibility 3. Functionality 4. Portability 	<p>QP1: <i>“Personally I prefer a smartphone or tablet. The reason is that I find its use a lot easier. They are also smaller ...(vs laptops/computers)... so if I need to be close to the screen they are easier to use”.</i></p> <p>QP43: <i>“I would use a phone or a laptop, most people have access to a mobile phone or laptop”.</i></p> <p>QP31: <i>“Phone or PC best... (these)... become part of everyday support systems in to which such a digital assistant should be integrated. Stand-alone devices may not be there when you need them”.</i></p> <p>QP47: <i>“Something that works on a phone, as it can move around with you”.</i></p> <p>QP59: <i>“Phone because it is available where ever I am”.</i></p> <p>QP107: <i>“Laptop and smartphone as they are always to hand”.</i></p> <p>QP110: <i>“Phone every time because I see it as more adaptable and more normal to be seen talking to your phone”.</i></p>
Computer/Desktop/Laptop	
<ol style="list-style-type: none"> 1. Ease of use 2. Accessibility 3. Functionality 	<p>QP61: <i>“computer or laptops as phones are too small and difficult to read and operate”.</i></p> <p>QP2: <i>“Computer: easier to adjust font, phone is too small”.</i></p> <p>QP5: <i>“Computer only, phone is too difficult for complex operations... I can’t read emails or internet on my phone”.</i></p> <p>QP8: <i>“Through choice I would use computer as it has a larger screen and better lit so easier to read”.</i></p> <p>QP35: <i>“Probably on my desktop computer would be most convenient as I find my phone too small and a stand-alone device would be another item to mislay”.</i></p> <p>QP106: <i>“I find my PC useful because of its accessibility features and it’s printer...”.</i></p>
Stand-alone device	
<ol style="list-style-type: none"> 1. Ease of use 	<p>QP50: <i>“As my eyesight is deteriorating using the computer will become too difficult. A stand-alone device sounds as though it could be helpful”.</i></p>

<p>2. Accessibility</p>	<p>QP65: <i>"A stand-alone device. My mother does not use a computer and has difficulty accessing the telephone"</i>.</p> <p>QP76: <i>"Stand-alone because all of my support group members could use it. Some do not have a computer, some are not confident using the phone"</i>.</p> <p>QP104: <i>"A phone or stand-alone device. Cannot get near enough to computer to see screen"</i>.</p>
<p>Multiple devices</p>	
<p>1. Choice</p> <p>2. Flexibility</p> <p>3. Accessibility</p>	<p>QP15: <i>"Both a phone and a computer. A phone is handy, but depending where you are it is not always easy to see what you may want to access"</i>.</p> <p>QP22: <i>"...multiple platforms with consistent virtual assistant as we use different tech depending on task"</i>.</p> <p>QP90: <i>"I think it is important to make information accessible on all platforms"</i>.</p> <p>QP3: (Talking about potential device format) <i>"I think this would depend on each person as to what would be best for them on an individual basis."</i></p> <p>QP49: (Talking about potential device format) <i>"That would be very dependent on the person concerned."</i></p>