


# Exploring the experiences of people and family carers from under-represented groups in self-managing Parkinson's disease and their use of digital health to do this

Digital Health  
Volume 8: 1–15  
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DOI: 10.1177/20552076221102261  
journals.sagepub.com/home/dhj  


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## Abstract

**Introduction:** Digital health is thought to enable people to better manage chronic conditions, such as Parkinson's. However, little is known about how people from under-represented groups with chronic conditions use digital health to self-manage.

**Objective:** The objective of our study was to explore the experiences of people and family carers from under-represented groups in self-managing Parkinson's, including their use of digital health to do this.

**Methods:** Semi-structured interviews (n = 18, including four dyadic) were conducted remotely, with 16 people with Parkinson's and six family carers in 2020–2021. Participants were purposively sampled from under-represented groups: belong to an ethnic minority, or having significant physical or sensory impairment. Interviews were audio-recorded, transcribed and analysed using thematic analysis.

**Results:** Three main themes of importance were developed: 'self-management support', 'digital health use to support self-management' and 'identity, attitudes and characteristics'. Participants received medical, psychological, social and practical self-management support. Some participants used digital health resources, e.g., Parkinson's UK website. Digital literacy was the biggest barrier to using digital health, regardless of background, often dependant on previous occupation and confidence. Few ethnic minority participants thought race or culture alters self-management ability and most believed there was no need for digital health interventions to be tailored to an individual's race or culture. Some felt inclusivity was important in terms of diverse images of people. A range of considerations were identified to optimise digital health, such as assistive equipment for people with sensory impairment.

**Conclusions:** Barriers to using digital health for self-management were primarily dependent on personal factors including digital literacy and attitudes but rarely race or culture. We recommend the optimisation of digital health interventions by providing assistive technology at low cost, and visual inclusiveness should be promoted by including images of people from diverse backgrounds.

Submission date: 15 October 2021; Revision date: 5 April 2022; Acceptance date: 5 May 2022

## Introduction

Parkinson's is a progressive neurological condition affecting approximately 127,000 people in the UK<sup>1</sup> and in 2016 an estimated 6.1 million people worldwide.<sup>2</sup> A wide range of motor and non-motor symptoms can result in reduced quality of life, increased disability, and unplanned hospital admissions.<sup>3–5</sup> Health disparities in Parkinson's

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exist related to race and socioeconomic status. For example, a review concluded African Americans experienced a lack of access to care and inclusion in research compared to white people.<sup>6</sup> Another study found African American people living with Parkinson's recorded greater disability and disease severity compared to white people, while the same was seen for those earning less than \$30,000 compared to people earning more than \$70,000.<sup>7</sup>

Self-management has been suggested as a key component of chronic condition management, such as Parkinson's.<sup>8</sup> A recent systematic review highlighted seven effective components relevant to self-management in Parkinson's, including: medication management, physical exercise, self-monitoring techniques, psychological strategies, maintaining independence, encouraging social engagement, and providing knowledge and information.<sup>9</sup>

Digital health approaches use modern technologies and digital services in healthcare and provide a potentially effective way to deliver self-management support to patients, via devices such as mobile phones, patient monitoring devices, wireless devices and personal digital assistants.<sup>10</sup> Self-management using digital health has been demonstrated to provide some benefits to illness outcomes in several chronic conditions including asthma, diabetes and cardiovascular disease, although our understanding of the exact components that make them effective remain unclear.<sup>11</sup> Benefits include improved markers of self-care, quality of life, medication use, health care use and effects on symptoms.<sup>12</sup> In addition, there are potential benefits in terms of providing greater access and saving costs in healthcare.<sup>13</sup>

Digital health has been encouraged internationally as integral to delivering fair healthcare.<sup>14</sup> However, multiple structural, contextual and individual factors can lead to inequity, which affect health experiences, digital engagement and outcomes, e.g., patient satisfaction.<sup>15</sup> This inequity affects some groups of people more than others. For example, people with physical, sight or hearing impairment may not be able to use digital health resources that are not adapted for their needs.<sup>16</sup> A systematic review showed people from ethnic minority groups were less likely to use electronic health record systems, influenced by barriers such as negative experiences of using electronic portals, for example due to not receiving a response to patient-initiated messages.<sup>17</sup> The e-health literacy framework provides a method to assess an individual's ability to use, engage and benefit from e-health technologies;<sup>18</sup> including the individual's ability to use digital health. This includes seven domains (Table 1). A deficit in any area can lead to barriers in using digital health and cause health inequalities.

Little is known about how older people from under-represented groups with complex health needs experience digital health services, including those from ethnic minority backgrounds or with sensory or physical impairment. A

**Table 1.** Seven domains illustrating an individual's ability to use digital health.<sup>18</sup>

| Domain | Individual's ability to use digital health                 |
|--------|--|
| 1      | Ability to process information                             |
| 2      | Engagement in own health                                   |
| 3      | The ability to engage in digital services                  |
| 4      | Feeling safe and in control                                |
| 5      | Motivation to engage in digital services                   |
| 6      | Access to technology                                       |
| 7      | Having digital technology that suits an individual's needs |

survey of 2900 older people with at least one chronic medical condition, found older Black, Latino and Filipino people had less access to digital tools, less experience in digital tasks and had less confidence in using the internet for health information and advice, compared to younger and white non-Hispanic older people.<sup>19</sup> This was supported by a recent study that also showed those from African American backgrounds were frustrated by their lack of access to digital health information, reporting a strong desire to become more familiar with it.<sup>20</sup>

Although the components for effective self-management in Parkinson's are known,<sup>9</sup> there is limited research exploring how people from under-represented groups use digital health in self-management, including those from ethnic minority backgrounds or with sensory or physical impairment. As family carers often deliver care and are key in enabling self-management, it is important to capture their experiences, as they may need to assist the person with Parkinson's to use digital health.<sup>21</sup> Our aims were therefore to explore the experiences of people and family carers from these groups in self-managing Parkinson's, including their use of digital health to do this. This included perceptions, barriers, enablers and design elements that would facilitate digital health use.

## Methods

### Design

A qualitative study using semi-structured interviews was used to develop a better understanding of thoughts on self-managing Parkinson's and using digital health to do this; and explore in depth the experiences of people living with Parkinson's from under-represented groups and their family carers.

**Table 2.** Inclusion criteria.

|                         |                  |  |                     |
|-------------------------|------------------|--|---------------------|
| Person with Parkinson's |                  | Family carer of someone with Parkinson's |                     |
| AND                     |                  |  |                     |
| Ethnic minority         | Sight impairment | Hearing impairment                       | Physical impairment |

### Recruitment procedure

For community recruitment, invitations were sent in the post with a patient information sheet from medical practices. Interested practices conducted electronic list searches and used the inclusion criteria to identify suitable people. This was complimented with recruitment from neurology outpatient clinics at one tertiary hospital and a district hospital in a high ethnic minority population, identifying those that specifically met our inclusion criteria (Table 2). We also recruited via a local Parkinson's UK group email.

Interested participants were encouraged to contact the research team via email, post or telephone and were then screened over the phone against the study criteria (Table 2) and given an opportunity to ask questions. Interviews were offered individually, but if the person with Parkinson's requested to be interviewed with their family carer at the same time, a dyadic interview was conducted. In some cases, only carers were interviewed as some people with Parkinson's did not or could not take part in interviews, due to advanced symptoms or cognitive impairment. Interviews were scheduled, and information sheets/consent forms sent by post or email to participants' homes. Verbal consent was taken on the day of the interview, audio-recorded and uploaded to a secure NHS computer. Participants were purposively sampled and the research team felt a minimum of 15 interviews would be adequate to capture a diverse range of views, guided by the concept of information power.<sup>22</sup> This includes considering the aim of the study and the richness of the information collected to answer the aim of the study.

### Inclusion and exclusion criteria

Participants had a Parkinson's diagnosis or were a family carer for someone with Parkinson's. The person with Parkinson's was also either from an ethnic minority background, or had a sensory (sight or hearing) or physical impairment that affected activities of daily living or quality of life.

People were excluded if they did not have mental capacity to provide informed consent or if deemed inappropriate by their General Practitioner (GP), specialist nurse or neurologist due to a medical or social concern.

### Data collection

In total 17 people with Parkinson's and seven family carers were recruited; however during screening one family carer and person with Parkinson's withdrew as they were concerned about being recorded and confidentiality. In total 16 people with Parkinson's and six family carers were interviewed during 18 interviews, four were dyadic. One interview was conducted face to face in January 2020 but the research was paused from March 2020- August 2020 due to the COVID-19 pandemic and ethical approval was sought to conduct interviews remotely. Face to face interviews were not possible during the pandemic and participants were given the option to have the interview via telephone or video call. DN offered all participants technical support before the interview to ensure they felt comfortable having the interviews remotely. Out of the remaining 17 interviews, 12 were conducted via telephone and five via video call, using Zoom from August 2020-March 2021. For those with hearing impairment Zoom was preferred as lip reading was important to aid communication.

Interviews followed a topic guide developed by the authors with input from people with lived experiences, who advised on wording of questions and piloted the topic guide (Appendix 1). DN, an academic GP from an ethnic minority background, conducted 15 interviews, JP, an academic geriatrician, conducted two interviews and one interview was conducted by both DN and JP. Both interviewers had experience in working with people with communication difficulties. Demographic information was collected at the start of the interview, including age, ethnicity, residential status, marital status, country of birth, education level and work.

All interviews were audio-recorded and transcribed verbatim. DN checked all transcripts against the original audio file for any discrepancies.

### Data analysis

Transcripts were imported into NVivo version 12 to facilitate analysis.<sup>23</sup> Inductive thematic analysis was used to analyse our data and develop themes.<sup>24</sup> The multidisciplinary team included two academic primary care physicians (DN, KW), an academic neurologist (AS), two researchers from a psychology background (ND, MA), an academic geriatrician (JP) and a researcher from a nursing/psychology background (JR). DN initially coded all data from seven interviews and reviewed field notes made after the interviews, to produce an initial list of codes. This was refined with input from ND and MA after they had reviewed three transcripts each. DN analysed the remaining transcripts and developed initial themes. The interpretation, meaning and saturation of each theme was discussed with the whole team, allowing all team members to contribute

to results and revised iteratively over several discussions. Although we were not guided by data saturation for our sample, but more by information power, we did not feel that we were capturing new information by the 18th interview and that we were able to address our aim.

### Patient and public involvement

Three lay members with lived experience of a long-term condition, who also belonged to under-represented groups, were part of the advisory group for this study and were consulted throughout the research process. They provided input on devising the research question and provided feedback on the topic guide (Appendix 1), leading us to ask direct questions on how race and ethnicity influences self-management. Results were also discussed, and they provided a 'quality check', ensuring that our results aligned with their experiences. PPI also provided input into dissemination, contributing to conference abstract and reviewed the final version of this manuscript.

### Ethics approval

The study was approved by the Health Research Authority, Rec reference 18/L0/1470, IRAS project ID: 235545.

## Results

Sixteen people with Parkinson's and six family carers were interviewed, including four dyadic interviews (range: 49 to 76 min) and 14 individual interviews (range: 27 to 65 min). Six people with Parkinson's (PwPD) had sight impairment, four had hearing impairment and six had physical impairment due to their Parkinson's, such as difficulty in walking. Nine were from an ethnic minority background. Further participant characteristics are seen in Table 3.

We developed three key themes with subthemes, which are presented to correspond with the order they were addressed in the topic guide (Appendix 1), these were: self-management support, digital health use to support self-

**Table 3.** Participant characteristics of people with Parkinson's and their family carers.

|       | Person with Parkinson's<br>N = 16 (%) | Family Carer N<br>= 6 (%) |
|-------|---------------------------------------|---------------------------|
| Age   |                                       |                           |
| 50-59 | 19                                    |                           |
| 60-69 | 19                                    | 50                        |

(continued)

**Table 3.** Continued.

|                            | Person with Parkinson's<br>N = 16 (%) | Family Carer N<br>= 6 (%) |
|----------------------------|---------------------------------------|---------------------------|
| 70-79                      | 43                                    | 50                        |
| 80+                        | 19                                    |                           |
| Sex                        |                                       |                           |
| Male                       | 63                                    | 33                        |
| Female                     | 37                                    | 66                        |
| Living situation           |                                       |                           |
| Alone                      | 19                                    | 0                         |
| With spouse                | 63                                    | 100                       |
| With wider family          | 12                                    | 0                         |
| Sheltered accommodation    | 6                                     | 0                         |
| Duration of Parkinson's    |                                       |                           |
| 0-4 years                  | 19                                    |                           |
| 5-9 years                  | 38                                    |                           |
| 10-14 years                | 31                                    |                           |
| 15-19 years                | 6                                     |                           |
| 20+ years                  | 6                                     |                           |
| Ethnic group               |                                       |                           |
| White British              | 50                                    | 67                        |
| African Caribbean          | 19                                    | 33                        |
| South Asian                | 19                                    | 0                         |
| European                   | 6                                     | 0                         |
| Latin American             | 6                                     | 0                         |
| Recruitment method         |                                       |                           |
| Community                  | 69                                    | 100                       |
| Hospital                   | 25                                    |                           |
| Parkinson's UK group email | 6                                     |                           |

**Table 4.** Themes, sub themes and number of codes.

| Themes  | Sub-themes   | Number of phrases coded |
|---|--|-------------------------|
| Self-management support                       | Medical management support and information               | 32                      |
|   | Psychological and Social support                         | 38                      |
|   | Support to maintain a healthy lifestyle with Parkinson's | 45                      |
|   | Practical Support  | 23                      |
| Digital health use to support self-management | Digital health use to support self-management            | 84                      |
|   | Digital health considerations                            | 89                      |
| Identity, attitudes, and characteristics      | Positivity   | 44                      |
|   | Living in the present                                    | 26                      |
|   | Importance of independence                               | 38                      |
|   | Race, ethnicity, and culture                             | 54                      |
|   | Community shaping illness perceptions and behaviours     | 37                      |

management, and attitudes and characteristics. A summary of themes and subthemes are seen above (Table 4). Quotes are reported by a person with Parkinson's (PwPD) or a family carer (C).

### Self-management support

Participants discussed current experiences of support across a range of self-management needs, few of which involved digital health directly and there were similarities between the groups. This theme of general self-management support is divided into four subthemes.

#### Medical management support and information

Medication was seldom mentioned as being most important, although medications were described as helpful in reducing motor symptoms. Many participants from all groups wanted alternatives to use alongside medication, for example due to associated side effects, and pro-actively sought alternatives such as cannabidiol (CBD) oil. Some participants sought medical information from Parkinson's UK magazines and websites, which they felt improved their knowledge of the condition.

Doctors were appreciated and helpful in answering questions related to self-management and established medication. Participants from all groups particularly valued the role of the Parkinson's nurse, who provided timely

support, enabling self-management and helped participants feel less anxious about their condition. However, due to geographic variations not every participant had a designated nurse. One participant mentioned that they were only introduced to a specialist Parkinson's nurse when their care was transferred to a large tertiary hospital, and explained the positive difference the nurse had made:

the Parkinson's nurse um that I can – I can phone anytime ... she might say, "Oh, your medication needs to be uh a bit different. I'll speak to the neurologist..." she's-she's really good. PwPD 10 (Male, 60)

The specialist nurse is usually the first point of contact for people with Parkinson's in the UK and participants therefore used the nurse as a conduit to get advice from their consultant. Some felt specialists are very busy and less approachable. For example, one participant with hearing impairment said their specialist typed and rarely looked at them in consultations:

I'm probably quite nervous and um I don't hear her very well. She is busy writing notes and talking to me, and I need people to look – look at me, like you're looking at me now. PwPD 08 (Female, 72)

Therefore, participants and in particular those with sensory impairments did not always say everything they



wanted in consultations because they did not feel their doctor was approachable.

### *Psychological and social support*

All groups received psychological support from several sources. Some participants also received antidepressants from their GP to help manage depression and anxiety. Overall, this was seen as helpful and had other positive effects, such as improving sleep:

And now that he's on an antidepressant for the night as well, um that helps to calm down some of the anxiety, because he was having a lot of anxiety. C 05 (Female, 63)

Those who attended exercise classes or social groups found these provided psychological support through social interactions, which was seen as important for self-management. A few participants attended Parkinson's specific support groups in person or via forums but most attended more general support groups, where they could meet a wider range of people.

A bit of a sort of TLC when needed, and that actually it's OK if you suddenly start blubbing and pouring your heart out. That it doesn't matter; ... You don't have to worry about it. Everyone understands. And sharing tips and hints, really. C 18 (Female, 73)

Many of those who did not take part in these activities received psychological and social support from family and friends, helping participants feel safe and less stressed about their Parkinson's. Some lived nearby and participants felt they could count on their family for anything.

my daughter – who lives nearby – she's spot on, so if there's anything that I'm not sure about, then she helps me. PwPD 03 (Male, 85)

One participant with physical impairment lived in sheltered accommodation and received social support from other residents. A few participants did not have any of these sources of support and felt isolated. They acknowledged their mood would be better if they did not feel isolated.

### *Support to maintain a healthy lifestyle with Parkinson's*

Exercise was important for self-management and valued most by all participants, even those with significant physical impairment and limited mobility. Exercise was perceived to help with symptom control, overall health and emotional wellbeing (not only Parkinson's):

Um just by being active –if I'm relaxed, sometimes like really relaxed, I can stop shaking. Um and uh exercising. I-I do exercise every day, either by walking, running or doing – you know, I keep active. PwPD 12 (Female, 53)

Many were motivated by family to exercise who also recognised the benefits of exercise. Exercise came in the form of specific classes, the gym, home exercises, walking or housework. Some participants were comfortable using the gym but others were self-conscious or embarrassed by motor symptoms, preferring to exercise at home. Some more affluent participants had access to hobbies that helped them remain active, such as golf or a craft shed at home.

One participant was struggling to fully take part in face-to-face exercise classes due to severe hearing impairment but was able to give a microphone to instructors, helping her fully partake:

I was going to yoga on a chair, and I would give it to the ins-instructor and I was able to hear her much better than I – uh before that, I would copy what other people did and I would always be a couple of seconds behind. But with this microphone, I'm able to um – PwPD 08 (Female, 72)

...Keep up. C 08 (Male, 74)

They had paid privately for this equipment and felt others with severe hearing impairment would not overcome this barrier without the money to pay for technology.

Diet was also important for self-management and to remain healthy. A few participants had or were using supplements, mucuna oil, or probiotics, which they had found out via word of mouth and researched for themselves on the internet. These participants had not discussed these at length with doctors as they felt they would not be able to provide enough information:

my experience is, doctors don't want to talk to you about it because you're dealing with non- um medically-investigated remedies. They haven't been through peer review and so on. Their general response is, 'well, they won't do you any harm', but whether they'll do you any good or not is something that you can't make a statement on. PwPD 01 (Male, 76)

### *Practical support*

Most participants, in particular those with physical and sight impairment, had made adaptations to their homes, including extra railings, additional lighting, and walk in showers. Many were supported in getting these by occupational and physiotherapists, their local council or the charity Parkinson's UK. These and healthcare professionals were

helpful in advising and helping participants with benefit applications and claiming for prescriptions:

there was things that I can claim for prescription-wise that um I-I didn't know was possible, but it's possible. Just things with taxi cards, there was um things with the nurse at [name of hospital], even stuff to do with these specialist um consultant, my GP. PwPD 13 (Male, 58)

For most participants, family and close friends provided a lot of practical support, e.g., with medication administration. Family provided extra support for those with sight and hearing impairment:

My wife reads any correspondence that comes in for me because it's easier than me struggling with it, trying – so reading. PwPD 01 (Male, 76)

Family also supported older participants who were digitally illiterate to access emails or websites. Carers with less family support to help with practical issues felt more burdened compared to those with more family support, and felt guilty about their negative feelings.

Places of work provided equipment, e.g., keyboards, for employed participants. Occupational health was generally found to be supportive and helpful.

So I went straight to HR and I said, "Listen, I've got this." "Oh dear." So they sent me with um the occupational health guy and he sent uh somebody to have a look at my keyboard. PwPD 06 (Female, 56)

Finally, participants with severe sensory impairment used assistive technology to aid their use of digital health, which was helpful. This included a participant with sight impairment who used a keyboard and magnifying software specifically designed for his needs. However, they felt further improvements could be made to the technology as there were limitations, for example, magnifying software reduced the number of words on the screen.

On a PC there's just a magnifying software that you have to play it on – on Windows. Uh but it's a bit fiddly to use, you've got a s-small window that you move around and it's easier sometimes to just to enlarge the whole screen or uh whether you can do that easily. The trouble is, once you make it too big, you're limiting the amount of text you can get in and more dis-disjointed a bit. PwPD 01 (Male, 76)

Those who had assistive technology were more affluent and acknowledged such resources were expensive and therefore not universally available to everyone with sight or hearing impairment.

Uh so there's a whole host of things that are visual aids – electronic. You can run into thousands of pounds' worth of tech equipment. PwPD 01 (Male, 76)

## Digital health use to support self-management

### *Digital health use to support self-management*

Some participants used digital health to search for information on symptoms or management via Google or the Parkinson's UK website. Some also used wearable technology to improve fitness, for example, monitoring heart rate during exercise and at rest. This enabled participants to regularly engage in self-management and improve their general health.

Digital health use depended on several factors, regardless of background. This included confidence in using technology, which was often related to previous occupation and if they had used computers for work.

Oh yeah, I mean, I-I'm literally – I-I'm quite good at these sorts of things, yeah. I was self-taught on the internet – net – on the internet and everything like that, and I don't have a problem. PwPD 15 (Female, 74)

A lack of digital skills was an important barrier; for example, some reported that they would not know how to find reliable websites or what reliable websites looked like. This led to worry about confidentiality and fear of making mistakes:

And, to be honest, I was always a bit frightened in case I – in case I pressed a button that I shouldn't have and um, you know, it was scary [chuckles]. That sounds ridiculous when you know how to – PwPD 11 (Female, 73)

Others did not use digital health and relied on books and speaking to healthcare professionals, as they believed they could be helped more by these sources.

I think uh now I-I think I more, I have to rely on the doctors uh then, because uh from what I can see, um this is uh a condition which uh then just get worse over time. And I think it's the doctors who can help me more now than actually the websites. PwPD 07 (Female, 63)

Many of these participants did not feel the need to access digital health, as they felt they were managing their conditions well without using technology and had not ever considered using technology to support self-management.

### *Digital health considerations*

Participants were asked if and how digital health interventions should be tailored for people from their background,

to support self-management. Common suggestions across all groups included simple and relevant digital health interventions, e.g., by using a decision tree, and general digital skills should be taught to those who are digitally illiterate. Most felt providing support was important, to help people use the technology. All participants wanted videos or images demonstrating instructions, e.g. specific exercises. Some participants across all groups wanted to see images of people like themselves, demonstrating diversity is important:

when you're first diagnosed, if you um – if you've never seen anybody with Parkinson's, you-you've al-always seen a picture of an old man. How are you gonna relate to that? Yeah. So you-you need a diverse uh sort of images. Yeah. I think that's important. PwPD 06 (Female, 56)

When asked about adapting digital health support for different groups, those with sight impairment suggested using audio and large font. Those with hearing impairment suggested being able to adjust sound volume for those with different degrees of hearing impairment. They suggested that videos should have subtitles and faces clearly shown to allow lip reading. Participants with sight and hearing impairment also suggested assistive technologies were useful to help access digital health, such as specially designed keyboards.

I had to get a – a new keyboard that had larger typeface on it for my PC, um but that's an obvious thing, is my eyesight deteriorated, so obviously I need it. You can get s-stick-on numbers and letters for a k-keyboard. PwPD 01 (Male, 76)

Those from different cultures suggested using pictures and videos with clear instructions and to consider translating text and audio into different languages, demonstrating the importance of inclusivity.

but other people from ethnic minorities might need a translator of some sort, maybe. I don't know. Because they're not having that – the resources are harder for them to then access, probably, who don't know the English language. PwPD 06 (Female, 56)

One family carer suggested being culturally sensitive, for example, considering the roles of women and men in different cultures:

I think if you do something, it needs to be plain English, it needs to be available in multiple languages, and it needs to be sensitive, sort of ethnically sensitive, to the kind ... Because a lot of people, especially if they're, I don't know which religions are specific, but some religions are

very unhappy about carers- with carers male and female mixing in terms of support and care. C 18 (Female, 73)

## Identity, attitudes, and characteristics

The final theme was around identity, personal attitudes, and characteristics, and how participants perceived and categorised themselves in relation to self-management and digital health. There were five subthemes.

### Positivity

Most participants from all groups described themselves as 'positive' and perceived themselves as lucky to not have more advanced symptoms, including those with sight and hearing impairment, comparing themselves to others who they perceived to be worse off. Even those who had more advanced symptoms and physical impairment said they were coping 'well' with the condition, despite, for example, one participant taking medication every two hours which sometimes didn't work:

I'm – I'm stable I think, and I feel I can manage...Um well I need medication 24/7...

like when the next sort of medication's due, it doesn't seem to work very well. And I'm-I'm a sort of a bit static then, I can't really do much unless I sort of go and take more tablets and then I sort of kick in a bit more...it's not debilitating or anything, um it's just um – oh, something I've got to live with, I suppose. PwPD 15 (Female, 74)

This positivity and outlook on life encouraged them to self-manage their Parkinson's. Some participants, especially those with significant physical impairment, were hopeful for a cure for Parkinson's, before their condition worsened and this was a motivating factor for taking part in research and using the internet to try and keep up to date with the latest advancements in Parkinson's.

A few participants described themselves as 'negative', did not see themselves as independent and relied heavily on family carer support. These participants appeared to lack motivation, gave up on doing things that they once enjoyed, reported their mood as low and slept a lot:

I've got an exercise bicycle which I should be – be on every day, but I don't. And I don't really – I don't really know why. No. PwPD 09 (Male, 74)

### Living in the present

Participants from all groups commented that they were positive because it would be unhelpful to be negative and would not motivate self-management or the use of digital



health in self-management. One way of remaining positive was to live in the present and not dwell on what could happen in the future, despite knowing Parkinson's is a progressive neurological condition. This affected participants' willingness to access digital health to self-manage symptoms, as they were afraid of what they would read:

Sometimes you – if you Google too much, it's about – it's a bit like hearing the news. All of a sudden um you get scared.  
PwPD 08 (Female, 72)

This meant many participants only wanted to engage in the present and focused on maintaining independence and positivity. If they did not do this, they believed they would be upset, worried and unable to live their lives to the fullest. Fear of the future meant most participants did not want to see people with advanced symptoms, including those with significant physical impairments. They therefore did not attend Parkinson's support groups as seeing people with advanced symptoms caused sadness and made them confront their possible future:

there's a group meeting in [name of borough] town and I'm – I don't want to go because I don't want to see how I'll be in 10, 15 years' time. PwPD 08 (Female, 72)

### Importance of independence

Many participants from all groups perceived themselves to be 'independent':

I've always been this individual, and somebody who can do things for myself and do things for others, so I – I don't re-re-require or demand that sort of – sort of thing from any individual. PwPD 13 (Male, 58)

Independence was also why exercise and diet were highly valued, as these were areas of management they could control. It is also why some older participants did not use health websites, as they saw 'no need to' as their condition was stable. They believed this proves their independence and to them independence was a reflection that they were doing well, there was therefore no need to seek help via the internet for example.

I haven't really felt the need and – to go onto the web and the support I'm getting via the NHS is adequate and ha- I'm happy with it. PwPD 03 (Male, 85)

Younger participants used wearable technology to aid self-management, especially related to exercise and diet. This helped them feel more in control of their Parkinson's management:

I use my Health – Samsung Health, I use something else for my steps – daily steps and things like that. And it-it-it tells me, as well, if I – if I app – it tells me as well how long I slept for, what time I should uh – you know, everything to help me have a good night's sleep and um the routine that we should have. PwPD 12 (Female, 53)

For these participants digital health enabled independence by supporting self-management.

### Race, ethnicity, and culture

All interviewed ethnic minority participants felt strongly that digital interventions should not be tailored according to race or culture, and that content should be the same for everyone but pictures/images should be inclusive and include people from a diverse range of backgrounds, to help them relate to it. They felt strongly that Parkinson's can affect anyone and therefore interventions should be the same for everyone:

Like I said, um the condition of Parkinson's doesn't have any colour, it doesn't matter what colour you-you are inside. And it – and it's the thing, we are all God's children, so it doesn't specify whether you're a Black, white, female, tall, short, you know, you know. Um there's no innocence or criminality attached to it, it just happens to anyone at any time...PwPD 13 (Male, 58)

Many expressed that they had not been treated differently in healthcare due to their background. However, on further reflection some recalled instances, related to social/peer- support, where they felt they may have been treated differently because of the colour of their skin, such as a woman who was constantly referred to as 'sister' on a Facebook Parkinson's support group:

like when I joined uh the group on Facebook – the Parkinson's group – one of the admins is – everybody greets us when we are new to the group. And uh one of the admins, he just called me 'sister', and that was odd, you know. ... but I thought, for two or three times, he was calling me 'sister'. Because I'm not – not the only Black person there, but one of the few, if you know what I mean. PwPD 12 (Female, 53)

Most participants strongly affirmed they are British, especially those who had resided in the UK for decades. Despite feeling 'British' they reported that there were times they were not treated the same and have had to cope and adapt to this in the UK. Although participants saw themselves as British, some felt that they are having to explain this when asked about their race and culture.

So somebody was asking me, they say, “Where do you come from?” I say, “Well, I come from Africa,” ... He said, “You are very clever,” I say, “In what way?” he says, “Its taken you just a couple of years, to come here to learn English, to speak English the way you do.” He says, “It’s very clever.” I said, “No, it doesn’t mean that I learnt English when I came here,” I said, “I was already [speaking English], English was a compulsory language from the age five, when we enter school” PwPD 16 (Male, 80)

Some also talked about people from similar backgrounds negatively, for example, that some brought racism on themselves and put their own community down. As an example, a Black man viewed negatively other Black people who did not take the COVID-19 vaccine:

Yeah. Funny enough, most of the families condemning it, silly people... This particular type of people are there in Africa, condemning what the government decides to do or not do. They have their own annoyance with everything, and they find faults with everything that the government do. PwPD 16 (Male, 80)

As most participants saw themselves as British, they felt all medical interventions, including those for self-management, should be the same for them as any other British person. However, several participants thought digital health interventions should consider people who recently moved to the country may speak limited English and need more support accessing and using these interventions:

The people who have stayed here for, either born here or come here at a very early age, they are quite all right with all these things. But people who came a bit late, especially the ladies and the ... I don’t know how well they would be able to handle things on their own. C 17 (Male, 78)

Some talked about ‘others from their country’ who had not been in the UK for a long time and how these people had struggled with access to healthcare and using technology for remote consultations. However, they felt they had not experienced these problems because they had lived in the UK for a long time, were well-educated or spoke ‘good’ English:

No, we haven’t had that problem. But you see, people who have come from Pakistan that are not, sort of, level or homogenous sample, they come from very different, varied backgrounds. Some of the families that came here were not really educated when they came here. C 17 (Male, 78)

### *Community shaping illness perceptions and behaviours*

Participants from all groups reported their own culture and community shaped how they behaved and perceived illness, in relation to their Parkinson’s. Firstly, support from family, the community and faith were important. However, some from ethnic minority backgrounds felt people from their community did not understand Parkinson’s. For example, two African participants felt their community did not think neurological conditions affect Black people:

um the other part of my family is like, “No, no, no, you’re Black, so Black people don’t get Parkinson’s,” and these kind of things. And, you know [chuckles] – which I know is not true, but they-they try to minimise it or some of them, when they see me, PwPD 12 (Female, 53)

This was because images of people they see with Parkinson’s were ‘rich’ or white and in their cultures people with neurological conditions are not very visible in society.

because of the patients, like I said, you see they are just from the rich society,– so I just thought nature advocated that because they have the resources to fight this. PwPD 16 (Male, 80)

An Indian participant had not told anyone in her community about the condition as she feared what people would say and how they would react to her, and stated that she doesn’t want pity, to feel shame or embarrassment:

I-I don’t know what reaction they would give me, you know, if I do tell them... I don’t want to tell anybody yet, you know. I mean, they might not react – they might sort of maybe help me a bit – I don’t know...Um some people, sometimes uh – uh do take it like uh not negatively but um feeling sorry for you, you know, things like that. PwPD 07 (Female, 63)

### **Discussion**

People with Parkinson’s from these under-represented groups used different sources of support to aid self-management. They suggested digital support tools for these groups should be simple, relevant and support should be provided. Many participants viewed themselves as positive and independent, and they also wanted to live in the present. This outlook helped them cope with their Parkinson’s but was also a barrier to seeking digital health support. Perceptions of Parkinson’s and behaviours were influenced by culture and community. Although images of people should be diverse, few ethnic minority participants felt digital interventions should be tailored

according to race or culture because Parkinson's can affect anyone, as most viewed everyone as equal and therefore believed support should be universal.

The degree of impairment affected how participants engaged with digital health, for example, it was hard for a participant with severe hearing impairment to access online audio and video material and subtitles were needed. Participants with sight and hearing impairment mentioned they could access digital health due to assistive technologies; however this was expensive and therefore not available to all. It has been reported that people with hearing impairment were more likely to be digitally excluded during the COVID 19 pandemic and change to remote consultations, partly because sign language was not designed to be used 'via a screen'.<sup>25</sup> A study commissioned by Ofcom found similar results to our study, where people with sight loss were aware of assistive technology but the high cost was found to be prohibitive and unless a person was in employment or in education, there were few opportunities to try new software.<sup>26</sup> Training in using assistive technology would therefore give people with sensory impairment an opportunity to use the software, encouraging digital health use. Apart from assistive technology, the World Wide Web Consortium (W3C) provide guidance on how to make digital resources accessible, which can be adopted for digital health intervention development, for example, by using audio description and providing keyboard navigation.<sup>27</sup>

Apart from practical support, participants also mentioned important factors to inform the development of digital health services. Maintaining a healthy lifestyle through diet and exercise was important for most participants, as they felt this would delay the progression of their Parkinson's, a condition without a cure. This view is supported by previous studies, for example, one found people with Parkinson's were more likely to participate in areas of general health maintenance and health promotion compared to people without this condition, but more effort was needed. The authors advised participation in exercise should be promoted, as well as in other health promotion areas, e.g., immunisations.<sup>28</sup> Psychological support was also important to participants in our study, and this was provided by a range of sources including, exercise classes, socials, family, friends and occasionally medication, such as antidepressants. Our study was conducted during the height of the pandemic and there has been a focus on mental health during this time, where the lack of access to services became more apparent for people from minority groups and older peoples' mental health was affected by isolation and anxiety.<sup>29</sup> Participants felt focusing on lifestyle choices during this time improved their mental health, which has also been recommended by other studies that focused on people living with Parkinson's during the pandemic.<sup>29</sup>

It was surprising to find that few ethnic minority participants felt digital interventions should be tailored

according to race and culture. This is the opposite to what is seen in the literature where it is widely accepted they should be tailored for different groups,<sup>30</sup> which can increase engagement and effectiveness.<sup>31</sup> For example, tailoring information on diet and food eaten for different cultures can result in healthier eating habits for certain ethnic minority groups.<sup>32</sup> Previous research also highlights cultural sensitivity is essential for digital interventions to be successful in ethnic minority groups.<sup>31</sup> In our study, although participants did not think tailoring was needed, on further reflection participants felt inclusivity was important in the form of visual representation and also suggested translating text for those with poor English language skills. It is important to consider the interviews occurred immediately after the first wave of the COVID-19 pandemic in the UK, when there was national attention on how the virus disproportionately affects people from ethnic minority backgrounds,<sup>33</sup> highlighting racism and inequalities. This could have affected participants and possibly explains why they strongly affirmed they were British and suggested tailoring should not occur but instead focused on inclusivity and treating everyone as equal.

The 'them versus us' narrative, where ethnic minority participants aligned their identity with the White British majority is seen in 'identity threat' literature, where people who are involuntarily labelled will distance themselves from that label and align with a non-threatening group.<sup>34,35</sup> Participants rejected the 'ethnic minority' categorisation, which has negative connotations with disadvantage, and presented an alternative identity, distancing themselves from that label and aligning with the majority group. A recent study exploring perspectives of middle-class South Asians living in the UK during the COVID-19 pandemic showed participants aligned their identity with the British majority and asserted little difference between the South Asian and white population based on ethnicity alone.<sup>35</sup> When it came to risk of COVID-19, they also drew distinctions between themselves and other people from South Asian communities. For example, they blamed others for their increased COVID risk and described how new immigrants followed less healthy habits, leading to increased risk of contracting the virus. This aligns with the results of our study.

Most participants and family carers wanted to focus on living in the present and did not want to discuss the future or access information via digital health, due to fear of how their Parkinson's would progress. This is supported by findings of a recent systematic review conducted by our team,<sup>36</sup> which found many people with Parkinson's do not want to discuss advance care planning early and the right time depended on patient factors such as their values, goals and care needs. One recommendation was for health-care professionals to invite people to discuss planning ahead early and regularly so that it does not happen

during a crisis. This is also seen in other progressive neurological conditions, such as dementia, where advance care planning usually occurs during a crisis or when death is imminent.<sup>37</sup> Positivity and independence were important to participants. These are also important to healthy ageing, as well as autonomy, dignity and empowerment.<sup>38,39</sup> We found that these qualities helped participants feel more in control of their illness and lives. The findings of ‘living in the present’, positivity and independence in people from these groups are therefore like what has been found in the general ageing population and other groups that are not under-represented.

Finally, many participants with access to a Parkinson’s nurse found them helpful in supporting self-management. However, we acknowledge in many countries this role does not exist, especially in developing countries. We believe digital health could potentially play a role in these places to support self-management, in the absence of a specialty nurse. For example, digital decision aids that provide useful information, advice and sign posting to relevant support.

### Strength and limitations

This study explores the experiences of people from under-represented groups, who are traditionally understudied in healthcare research. Our research team is diverse and from different disciplines which aided interpretation of results. DN is from an ethnic minority background and participants reflected that they felt comfortable discussing sensitive issues with her, such as racism. There was also strong PPI input from underrepresented groups from conception to dissemination, who ensured our topic guide and style of questions were appropriate.

There are also limitations that should be noted. There may be selection bias, as those who identified as British may have been more likely to participate in the study. Also, the interviews took place remotely and could not be conducted in person (due to the pandemic). This may have led to unintended exclusion of people unable to use telephones or video calls. However, we did recruit mostly via GP surgeries (not online registries) and all potential participants had access to a telephone. Also, our results related to ethnic minorities are not generalisable to all minority groups. We acknowledge there are cultural differences between groups even within the same country, limiting generalisability further. However, the aim of our study was to explore experiences of people from a wide range of backgrounds. We also acknowledge that interviews were only conducted in specific areas of England where participants had good access to Parkinson’s nurses. Results cannot therefore be generalised to areas where the role of the Parkinson’s nurse does not exist or where access to them limited.

### Future research

The results from this study will inform the development of digital health interventions for people with complex health conditions, who may have difficulties engaging with technology. Future research would include interviews with people from different cultural backgrounds and explore how the needs of ethnic minorities based on place of birth and the relationship with attitudes. There should also be further work exploring the experiences of people from other under-represented groups, for example, those from low socioeconomic backgrounds and how intersectionality can impact self-management in long-term conditions, such as Parkinson’s.

### Key recommendations

Recommendations for digital health intervention development emerging from our findings include the following:

1. Digital health interventions should be useful, relevant, and easy to use for people from under-represented groups.
2. Assistive technology and equipment should be provided at low cost if needed to people with sight and hearing impairment to enable them to fully partake in digital health interventions.
3. To promote inclusivity, include images of people from a diverse range of backgrounds.
4. Support should be provided to individuals who need it, to encourage long term use of digital interventions. This also may mean providing more time for people from under-represented groups, who may struggle to use these interventions.
5. Provide basic digital skills to people who lack confidence so that they can use digital health interventions, in particular older people with sight, hearing or physical impairment.
6. Subtitles, font sizes, audio and videos should be considered to ensure people from these under-represented groups can use digital interventions.

### Conclusions

We identified important considerations for optimising digital health interventions to be accessible for people from ethnic minority backgrounds, and those with sensory and physical impairment with Parkinson’s. To aid self-management digital health interventions should be holistic, inclusive and take into consideration the different needs people with Parkinson’s may have.

**Acknowledgements:** NA



**Ethical approval:** The study was approved by the Health Research Authority, Rec reference 18/L0/1470, IRAS project ID: 235545.

**Contributorship:** All authors contributed substantially to the conception, design of the work; or the acquisition, analysis, or interpretation of data for the work; and drafted or revised it for important intellectual content; and approved the final version to be published; and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

**Guarantor:** DN

#### Author contributions:

**Declaration of conflicting interests:** The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Funding:** The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study/project is funded by the National Institute for Health and Care Research (NIHR) School for Primary Care Research (project reference 490).

The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

**Informed consent:** Verbal informed consent was obtained for the interviews, audio-recorded and uploaded to a secure NHS computer.

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**Trial registration:** Not applicable, because this article does not contain any clinical trials.

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- If you are finding your Parkinson's difficult, what do you do?
  - **What, if anything, gets in the way of you managing your Parkinson's as well as possible?**
  - **I understand you have had difficulty with [target clinical feature], can you tell me more about that? (Skip if no disability)**
    - What do you do in these instances?
    - How does this affect how you manage your Parkinson's?
    - How does this affect you:
      - At home? at work? socially? Or relationships with others?
    - What helps you with that/ What resources have helped?
    - Are there ways of coping that you've used previously that you can no longer use now?
2. **[Current help in the management of Parkinson's.]**
    - **What support have you had from people around you or from healthcare professionals?**

Who and what has been most helpful?

    - **Are there any aspects of your background that influence how you manage your Parkinson's? (ask all)**
    - **Do you think coming from the X community influences the way you manage your Parkinson's? (ask if applicable)**
  3. **[Views on using digital health for self management]**

We are developing an **interactive resource tailored to help** people with Parkinson's to stay as healthy and well as possible and which can be used to help people manage their condition better in their own homes. A healthcare professional will support them using this. Some people with long term conditions such as Parkinson's disease use technology, such as websites, to help them manage their condition. For example, the Parkinson's UK website.

    - How confident are you at accessing something like this?
    - Have you used anything like this before?
      - How did you find it?
      - What was most helpful?
      - What was difficult about it?
      - How did you find out about it?
    - (If answer to the above is no) Have you ever looked online for anything related to your health?
    - Did you need any support from people around you or a healthcare professional?
    - **If your condition was to get worse would you use technology or something like this?**
    - If not, what would you use?

## Appendix

### TOPIC GUIDE 1.1: Patients:

1. **[Current condition and self-management of Parkinson's on a daily basis; what are the difficulties?]**
  - **How do you feel that you are managing your Parkinson's?**
    - Which are the most difficult aspects of your Parkinson's for you at the moment?

- 
- In what circumstances would it be possible for you to use technology?
  - **Are there any particular considerations we should make when designing a resource like this for people with *[target clinical feature or from X community]*?**
    - To make it easy to use and access?
    - For people to think it is relevant?
    - Are there any cultural factors we should consider when making this resource?
    - What would be most helpful for people with *[target clinical feature or from X community]*?
  - How important is it to see images of people who look like you in such resources?
  - **What kind of support do you think you would need to use an online resource?**
    - How often and for how long would you need someone to help you?
    - Who do you think would be most helpful?
    - Is there anything we should consider which may affect the way people with *[target clinical feature or from X community]* use this resource?
-