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1 **Understanding the attitudes and experiences of people living with potentially**
2 **stigmatised long-term health conditions with respect to collecting and sharing health**
3 **and lifestyle data.**

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14 **Abstract**

15 **Background:** The emerging landscape of patient-generated data (PGData) provides an
16 opportunity to collect large quantities of information that can be used to develop our
17 understanding of different health conditions and potentially improve the quality of life for those
18 living with long-term health condition (LTHCs). If the potential benefits of PGData are to be
19 realised, we need a better understanding of the psychological barriers and facilitators to the
20 collection and beneficial sharing of health and lifestyle data. Due to the understudied role that
21 stigma plays in sharing PGData, we explore the attitudes and experiences of those living with
22 potentially stigmatised LTHCs with respect to collecting and sharing health and lifestyle data.

23 **Methods:** This study used semi-structured interviews and a card sorting task to explore the
24 attitudes and experiences of people living with potentially stigmatised LTHCs. 14 adult
25 participants who reported having a range of conditions were recruited in England. Template
26 analysis was used to analyse interview transcripts and descriptive statistics were used for the
27 card sorting task.

28 **Results:** The findings present four overarching themes: Preferences for collecting health and
29 lifestyle data, Importance of anonymity, Expected use of data, and Sources of emotional
30 support. Participants illustrated a general willingness to share health and lifestyle data however
31 there were some notable differences in sharing experiences, varying both by information type
32 and recipient group. Overall, participants did not identify health-related stigma as a barrier to
33 collecting or sharing their personal health and lifestyle data.

34 **Conclusions:** We outline a number of preferences that participants feel would encourage them
35 to collect and share data more readily, which may be considered when developing data sharing
36 tools for the future.

37 **Key words:** data sharing, patient-generated data, long-term health conditions, trust, identity,
38 privacy, security, stigma

39 **1. Introduction**

40 Recent decades have seen a steady increase in life expectancy in many high-income countries
41 across the world.¹ Most of the rise in life expectancy has been attributed to declining rates of
42 mortality amongst older adults as a result of improvements in healthcare.² In coming years, it
43 is expected that life expectancy will continue to increase in industrialised nations, raising
44 growing concerns surrounding the impact on healthcare.³ Increase in life expectancy does not
45 necessarily translate into health improvements overall, prompting interest in the study of long-
46 term health conditions (LTHCs).⁴ In England, as many as 20 million people are currently living
47 with a LTHC, defined by the Department of Health in England as “*one that cannot currently*
48 *be cured but can be controlled with the use of medication and/or other therapies.*”^{5, 6} It is
49 further projected that the number of individuals living with four or more chronic conditions in
50 the UK is likely to double between 2015 and 2035.⁷ Managing the impact of LTHCs has far
51 reaching implications for both the individual affected and society as a whole.⁶ The demands of
52 managing a LTHC can have a detrimental effect on an individual’s quality of life.⁸
53 Furthermore, these demands contribute towards the growing costs of providing long-term care
54 in the UK (both in terms of health and social care) with annual government expenditure
55 estimated at £48.3 billion.⁹

56
57 In order to tackle the challenge of LTHCs, empowering individuals to take an active role in
58 managing their own health is essential.⁸ Some patients report taking great value from having
59 the opportunity to actively engage in the collection of health and lifestyle data.¹⁰ The ever
60 increasing availability of technology has enhanced the ability of people living with LTHCs to
61 record, monitor and track their activity, symptoms and experiences.¹¹ Around the world, there
62 is a growing body of research exploring the potential benefits of using patient-generated health
63 data (PGData) from electronic devices to improve patient outcomes in a range of conditions
64 such as diabetes, obesity, heart disease, as well as other chronic conditions.¹² For example, in
65 a randomised control trial of 100 heart failure patients, the use of a digital device for self-
66 monitoring of weight, blood pressure and ECG readings was found to increase reported quality
67 of life through improved self-care.¹³ Furthermore, in a study of 66 metastatic breast cancer
68 patients, 74% reported that using an electronic tablet helped them to remember symptoms,
69 enabling them to share health information with their clinician.¹⁴ Increasing engagement with
70 the collection and sharing of health and lifestyle data has the potential to improve the
71 management of LTHCs, utilise the experiences of patients for the benefit of others, as well as
72 contribute to the understanding of different conditions.¹¹ This aligns with the clear commitment

73 of the NHS to providing a digital future in which patients become active participants in ‘citizen
74 health’ to both benefit from and contribute to their national health service.^{15, 16} For this vision
75 of a technology-focussed health system to materialise, it is likely that patients will be required
76 to actively collect, monitor, share and manage their health data. However, people have varying
77 preferences with respect to collecting and sharing their own data. It is important to understand
78 these preferences to avoid burdening individuals with unwelcome responsibility.¹⁷ For
79 example, research into the perspectives of those living with multiple LTHCs found that
80 managing PGData has the potential to become a time-consuming burden that adds to the
81 struggles of their existing illnesses.¹⁸ Older adults may also struggle with PGData. Recent
82 research has highlighted a number of barriers to the uptake of mobile-based mental health
83 interventions among older adults.¹⁹ Such barriers can add to the effects of the ‘digital divide’
84 in which those with insufficient access, knowledge or propensity to successfully manage digital
85 health tools may be less likely to experience positive health outcomes. The reliance on digital
86 solutions during the COVID-19 pandemic has shone a spotlight on the digital divide,²⁰
87 therefore any health initiatives that look to enable the increased use of PGData must be mindful
88 of issues of digital exclusion.¹⁶

89
90 While digital health tools and services are often presented as low-cost and patient centred,
91 many have the potential to add to the increasing workload of Healthcare Professionals (HCPs).
92 Supporting patients to effectively share health and lifestyle data with their HCPs means
93 considering the tools used, the data collected and the format for sharing.²¹ Increased sharing of
94 PGData inevitably leads to increased contact with healthcare services. This is being considered
95 at a time when HCPs are under huge pressure, exacerbated by the COVID-19 pandemic. The
96 most frequent users of hospital services use a disproportionate amount of healthcare resources
97 and yet their high level of received care does not always correspond with a high level of need.²²
98 This pattern of use is worsened by the virtual health initiatives made necessary by COVID-19,
99 with some patients receiving excessive levels of care while others miss out on vital services.^{22,}
100 ²³ In summary, it is important to ensure that supporting and encouraging the beneficial sharing
101 of health and lifestyle data does not unnecessarily burden patients or healthcare providers.
102 These considerations highlight the need to understand attitudes, experiences and preferences
103 relevant to the sharing of health and lifestyle data with others.

104
105 It is suggested that in order to benefit from large quantities of PGData, people with LTHCs
106 should be supported and encouraged to collect and share information about their health.²⁴

107 However, despite the potential benefits to sharing PGData, a variety of obstacles prevent the
108 widespread acceptance of these emerging data collection practices. Concerns about the security
109 of sharing private information may prevent beneficial sharing. In the UK, the extensive
110 disruption to the NHS that resulted from the 2017 WannaCry incident demonstrated that even
111 large healthcare institutions are not immune to cyber-attacks.²⁵ The effect of such high profile
112 attacks can erode public confidence in the ability of certain organisations to protect personal
113 data.²⁶ The perceived security of personal information can have special significance for those
114 living with potentially stigmatised conditions, due to fears surrounding the disclosure of health
115 status and concerns about confidentiality.^{27, 28} A range of health conditions are associated with
116 significant stigma,²⁷ such as living with HIV,^{29, 30} mental health problems,^{27, 31} and chronic
117 pain.³² People living with LTHCs that are typically associated with stigma may anticipate
118 discrimination, harm or negative labels when considering whether or not to share health and
119 lifestyle information with others.³³ People living with LTHCs who anticipate stigma associated
120 with their condition(s) may be less open about their experiences of health which could
121 potentially impede them from receiving an appropriate level of care.^{34, 35} Experiences of stigma
122 can impact the way in which those living with LTHCs choose to share information. For
123 example, previous research suggests that those who anticipate health-related stigma may seek
124 to use online forums because they provide an accessible platform through which personal
125 information can be disclosed anonymously.³⁶ A failure to sufficiently protect the digital
126 identities and data of those living with a stigmatised condition could leave patient identities
127 exposed in the physical world, opening the possibility to discrimination and other harmful
128 consequences of stigma. This study is conducted as part of a UK EPSRC funded programme
129 (EP/R033900/2)³⁷ examining trust, identity, privacy and security concerns around the sharing
130 of self-generated health and lifestyle data primarily among people living with HIV, but also for
131 those with other potentially stigmatised conditions. Considerations of trust, identity, privacy
132 and security have been found to be essential when seeking to facilitate data sharing in those
133 living with HIV.²⁹ In this study, we examined whether these issues play a role in the attitudes
134 and experiences of those living with other potentially stigmatised LTHCs.

135

136 Given the breadth of the emerging PGData landscape, and the broadly held concerns
137 surrounding the privacy and security of health and lifestyle data, research suggests that people
138 are eager to have control over what information is shared and with whom.³⁸ Understanding
139 individual sharing preferences may provide insights into how the collection of health and
140 lifestyle data can be better supported and encouraged. This has particular importance for those

141 living with potentially stigmatised LTHCs due to the influence that anticipated stigma can have
142 on their attitudes and experiences of sharing health and lifestyle data. Previous research has
143 considered sharing attitudes and experiences among people living with particular stigmatised
144 health conditions (such as HIV,^{29, 39, 40} Diabetes,⁴¹⁻⁴³ and Mental Health conditions⁴⁴⁻⁴⁶) or has
145 focused on a single sharing context,^{18, 47} or a specific tool or platform.^{44, 48 43, 49} In this study,
146 we examine the broader experience of sharing by those living with a range of potentially
147 stigmatised LTHCs across multiple sharing contexts to gain a clearer understanding of the key
148 overarching issues. Therefore, the aim of this study is to explore the attitudes and experiences
149 of people living with potentially stigmatised LTHCs with respect to collecting and sharing their
150 personal health and lifestyle data across multiple contexts. This will help to identify key
151 psychological facilitators and barriers to the beneficial sharing of health and lifestyle data.

152

153 **2. Method**

154 **2.1. Participants**

155 This study was approved by the Department of Psychology Ethics Committee
156 (17949) at Northumbria University. Participants were invited to participate in the study through
157 social media (Twitter and Facebook), a local mental health charity (nondisclosed to protect
158 patient identities), as well as advertising through the university intranet. The recruitment
159 process invited people living with potentially stigmatised LTHCs to participate in the study.
160 A LTHC has been defined as an incurable condition that is managed through medication or
161 treatment.⁵ Advertising for this study invited individuals to participate who reported having
162 one or more LTHC known to be associated with health stigma. These conditions included Type
163 2 Diabetes, mental health conditions, eating disorders and some sexually transmitted infections
164 (e.g. Genital Herpes). However, to include those participants who anticipate health-related
165 stigma as a result of their LTHC, but whose condition may not typically be associated with
166 stigma, recruitment left open the possibility for individuals to self-define their own LTHC(s)
167 as being potentially stigmatised. There were no restrictions on gender, sexual orientation or
168 upper age limit, but participants were required to be aged 18+ and currently residing in the UK.
169 The study recruited 14 participants (four men and 10 women, all cisgender). The mean age of
170 participants was 42.7 years (ranging from 22 to 65) and all were white British with the
171 exception of two participants (one Lebanese woman and one woman who declined to specify
172 their ethnicity). Each of our sample reported one or more of the following potentially
173 stigmatised LTHCs: Arthritis, Chronic Obstructive Pulmonary Disease, Complex Post-
174 Traumatic Stress Disorder, Coronary Heart Disease, Depression, Emotionally Unstable

175 Personality Disorder, General Anxiety Disorder, Genital Herpes, Inflammatory Bowel Disease,
176 Mental Health Conditions, Myalgic Encephalomyelitis, Thyroid Disease, and Type 2 Diabetes.

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178 **2.2. Data collection**

179 **2.2.1. Interviews.** All participants took part in semi-structured interviews, conducted
180 using a schedule designed to explore participant attitudes and experiences relevant
181 to collecting and sharing health and lifestyle data. Prior to the interview,
182 participants were given an information sheet to enable them to provide informed
183 consent. The researcher asked participants about their preferences for collecting
184 information about their health and lifestyle and their attitudes and experiences of
185 sharing this information with others. Participants were asked about what, how and
186 why they collect information about their health and lifestyle. Interviews then
187 addressed participants' contact with health services by asking what and how they
188 share information with HCPs and their attitudes towards doing so. Interviews also
189 explored attitudes and experiences of sharing health and lifestyle information with
190 a broad range of recipients, such as charities, peer support groups, family, friends
191 and work. Participants were asked about how they would feel about their personal
192 health and lifestyle information being shared with other groups, such as with
193 pharmaceutical companies, academic research, health charities, or other
194 commercially interested organisations. Finally, interviews asked participants
195 about their experiences of health-related stigma with respect to their attitudes and
196 experiences of sharing with others. Twelve interviews were conducted face-to-
197 face, one was conducted via Skype and one was completed via email exchange.
198 Interviews lasted between 33-90 minutes with an average interview time of 58
199 minutes. Interviews were digitally recorded and subsequently transcribed
200 verbatim. During the transcription process, all identifying information was
201 pseudonymised with participants subsequently being referred to by participant
202 number.

203 **2.2.2. Card sorting task.** Following the interview, participants were asked to
204 participate in a modified version of a comfort card sorting task.²⁹ This task
205 provides a visual analogue scale, similar to those used in previous health research
206 to allow participants to provide a comparable measure of their attitudes and
207 experiences.^{29, 50} This method was used in addition to the semi-structured
208 interviews to provide additional means through which participants could express

209 and rate their attitudes towards sharing different categories of health and lifestyle
210 information with a range of recipient groups. Participants were presented with
211 cards containing a single piece of personal, health or lifestyle information (total n
212 = 27). Participants were also presented with seven different recipient groups:
213 HCPs, public health/research, other people with a similar condition, family,
214 friends, work, and social media. Participants were asked to sort each of the
215 information types into ‘Yes, willing to share’, ‘Unsure’, or ‘No, unwilling to
216 share’ for each recipient group and were asked to think aloud so that explanations
217 could be captured. Due to missing data and some participants not completing the
218 task, card sorting task data were collected for 11/14 participants (all excluding
219 participants 4, 5 and 14).

221 **2.3. Data Analysis**

222 **2.3.1. Interviews.** The participants’ responses were assessed by conducting a
223 Template Analysis of the transcripts. Following a Template Analysis approach
224 allows the researcher to identify and define *a priori* themes that depict topics and
225 concepts that are of interest and relevance to the study.^{51,52} Template Analysis has
226 much in common with other forms of thematic analysis, most notably Framework
227 Analysis.⁵¹ However, although these approaches can be implemented to meet
228 many of the same research needs, the most notable difference is that Template
229 Analysis provides a more detailed development of the coding structure.⁵¹ This
230 method was chosen to help organise the breadth of experiences of those living
231 with potentially stigmatised LTHCs with respect to the *a priori* themes dictated
232 by the research program (see below). Furthermore, Framework Analysis may be
233 considered more theoretically focussed and most suited to applied policy
234 research,⁵³ whereas Template Analysis is often used in a wider variety of research
235 settings and is now well embedded in qualitative healthcare research.⁵⁴ This
236 chosen technique allowed for the initial analysis to focus on developing concepts
237 that have been previously associated with health information sharing behaviours,
238 such as trust, identity, privacy and security.^{38, 55, 56} Throughout the analysis, key
239 themes were expanded, or even discarded if they were found not to accurately
240 portray the participants’ responses. This allowed for additional themes to come to
241 light and for a more diverse range of ideas to represent the overall participant
242 account.

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The process of developing the initial template began by reviewing the content of each transcript. A preliminary thematic coding of the transcripts was conducted in alignment with *a priori* themes, whilst allowing the increasing familiarity with the transcripts to guide the addition of new themes. Clusters of new themes and topics of interest were further analysed to produce superordinate themes. These were used to construct the initial template. This initial template was then applied to the interview data and subsequently modified to consolidate the themes and structure. This was discussed amongst all members of the research team to ensure that the resulting template reflected a collective analysis of the participants' responses. The final version of the coding template led to the selection of four themes representing the participants' experiences and attitudes towards the collection and sharing of health and lifestyle data. Verbatim extracts from the transcripts are presented and discussed below to illustrate the findings.

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2.3.2. Card sorting task data. The participant responses to the card sorting task were coded numerically ('*Yes, willing to share*' = 3, '*Unsure*' = 2, '*No, unwilling to share*' =1) to provide a score for each combination of information type and recipient group. The data for each of the 11/14 participants that completed the task were then combined to provide an analysis of the overall sample's sharing preferences with respect to information type, recipient group and each combination of the two.

265

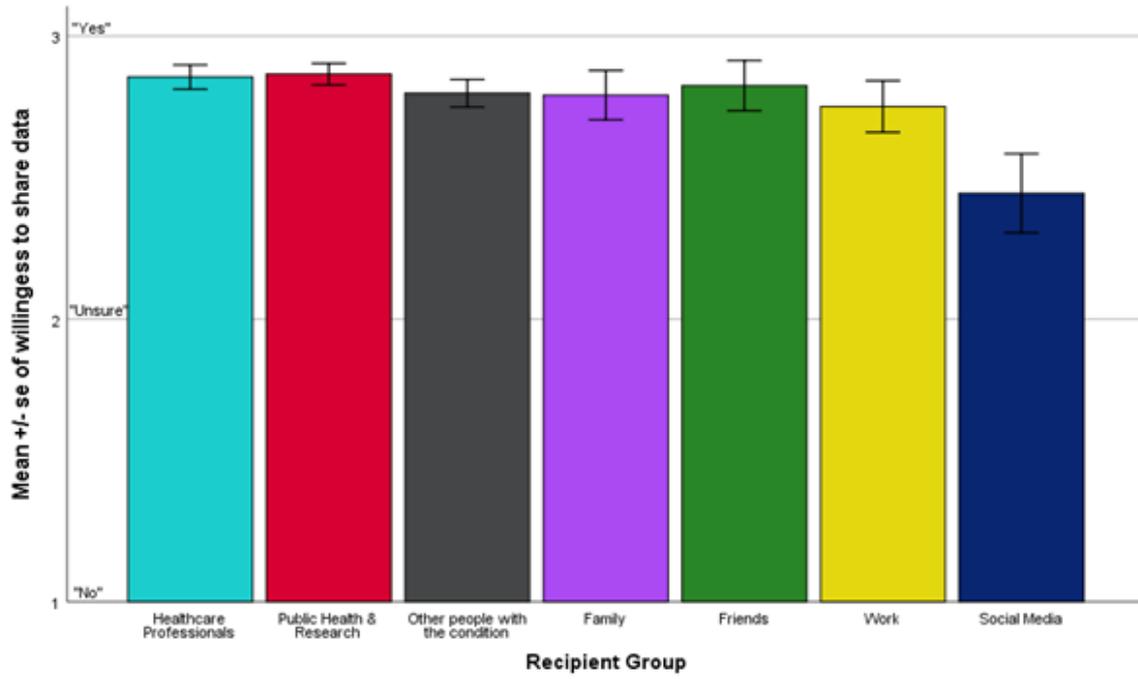
3. Results

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3.1. Card sorting task data

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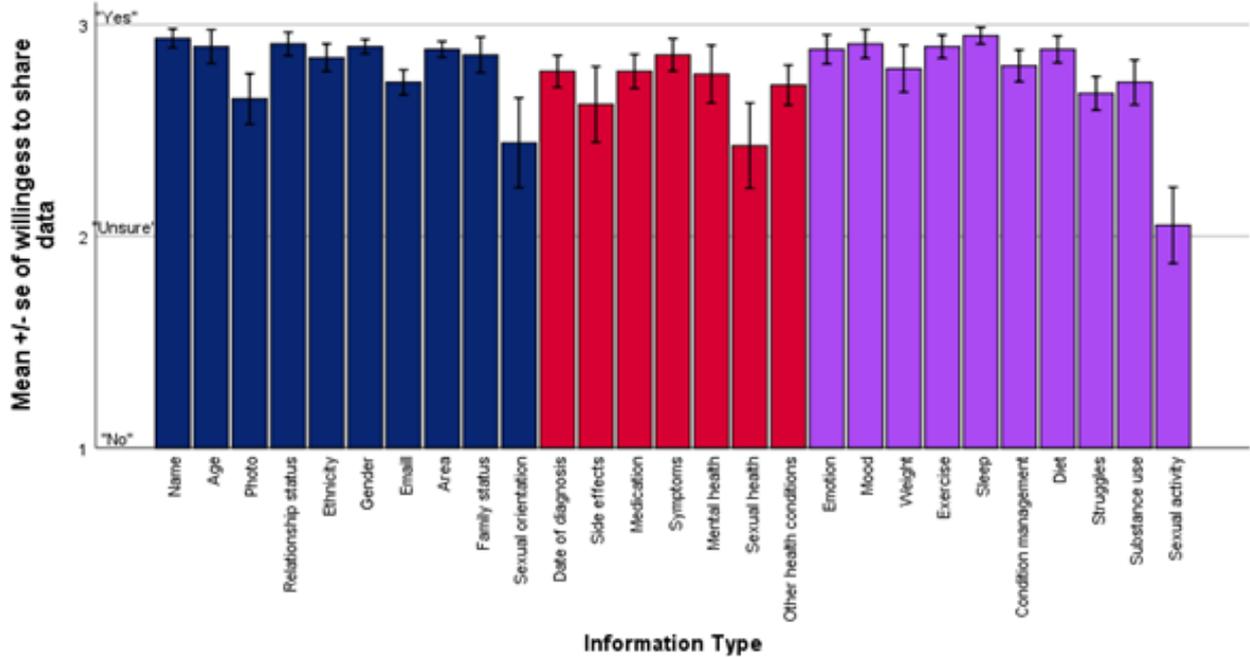
Table 1 presents the combined sharing preferences of our sample for each combination of information type with recipient group. Overall, participants indicated that they were broadly willing to share most information types with most recipient groups.



276

277 **Figure 1. Mean participant willingness to share information by recipient group**

278 Figure 2 presents the mean scores for participant willingness to share by information type. Our
 279 sample reported being most willing to share information pertaining to sleep (M = 2.95, SD =
 280 .13), as well as their own names (M = 2.94, SD = .15), and least willing to share information
 281 about sexual orientation (M = 2.44, SD = .70), sexual health (M = 2.43, SD = .67) and sexual
 282 activity (M = 2.05, SD = .60).



283 **Figure 2. Mean participant willingness to share information by information type**
 284 Note. Information types are categorised into Blue = Personal data, Red = Medical data, and Purple = Lifestyle data.
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 286

287 A repeated-measures ANOVA determined that mean sharing scores differed between recipient
 288 groups, $F(2.46, 24.66) = 4.44, p = .02$, and between information types, $F(3.29, 32.85) = 4.67,$
 289 $p = .01$. However, post hoc pairwise comparisons using the Bonferroni correction showed no
 290 significant differences in mean sharing scores across recipient groups or information types.
 291 This contradictory finding between the significant global effects and the non-significant
 292 pairwise comparisons is most likely explained by a lack of statistical power due to the limited
 293 sample of 11 participants.

294 3.2. Interview transcripts

295 In this section, we report the findings of our interview study by presenting the four themes that
 296 were highlighted from our template analysis as best expressing the overall narrative of the
 297 transcripts: Preferences for collecting health and lifestyle data, Importance of anonymity,
 298 Expected use of data, and Sources of emotional support. An overview of each theme,

299 accompanied by a representative example from the transcripts, is presented in Table 2. Each
 300 theme is presented, defined and explored in detail below.

301 **Table 2. Definition of themes and examples**

Theme title	Definition	Example quotation
1. Preferences for collecting health and lifestyle data	The extent to which collection preferences influence willingness to manage and share data.	<i>“Certainly that is what is missing in the trackers I have seen, so you can put in your own symptoms so you can make it relevant to you if it then has a way of identifying patterns.”</i>
2. The importance of anonymity	The extent to which participants expressed the importance of controlling their anonymity when considering whether to share health and lifestyle information.	<i>“I felt like it was an anonymous space that I could just get my thoughts completely out and I didn't have to hold back.”</i>
3. The expected use of data	The influence that the expected use and treatment of personal data has on an individual's willingness to share information, and how this may vary when considering different recipient groups.	<i>“I would not be happy with sharing any data to be used as a profiting mechanism.”</i>
4. Sources of emotional support	The different sources of support available and the extent to which perceived sensitivity of information, and recipient reaction, impact willingness to share.	<i>“I tend to share more with friends than family. It's a lot easier to share with people who you know will understand.”</i>

302

303 **3.2.1. Preferences for collecting health and lifestyle data**

304 Participants described their experiences of different methods used for the collection and sharing
 305 of data and discussed their desired preferences for future technology design. Seven participants
 306 reported using traditional (analogue) methods for recording health and lifestyle data. These
 307 participants highlighted the utility of keeping a physical journal. Despite many stressing the
 308 difficulty of consistently engaging with a written journal, participants noted its utility for
 309 sharing information with HCPs.

310 *“I started keeping a diary of the side effects of the medicine as well as any joint pain*
 311 *so that when I go in to see the nurse I would remember to tell her my experiences since*
 312 *at first I would feel so overwhelmed and emotional that I would forget to tell her all the*
 313 *details and ask her all the questions I had.” [Participant 14]*

314 This highlights the utility of basic methods of data collection and how they can facilitate
 315 healthcare interactions. Participants also described using more creative handwritten methods,
 316 either to track their feelings and experiences or as a form of catharsis and expression.

317 *“There's one thing I do track. I, kind of, track my moods... What I have is I've got a...*
 318 *It's not in a numerical way. I do a morning doodle. I draw and write what's in my mind*
 319 *every morning, and I've got a reflective journal. I do a gratitude journal, so I do all of*
 320 *that.” [Participant 11]*

321 *“Because I’m quite visual I’ll often draw smilies or just doodles, which reflect the day*
322 *as I’ve experienced it.” [Participant 1]*

323

324 In contrast, eight participants reported using digital devices accompanied by a range of
325 applications to record, track and monitor symptoms and other health related information.

326 *“With my medications I have had some heart rate issues so this also has the heart rate*
327 *tracker, so I can watch that to make sure it’s not trying to go way high, it’ll drop*
328 *sometimes. I use just the health app on my iPhone to track my cycles and symptoms*
329 *involved with that, and trying to figure out when exactly things are going to start, and*
330 *when I can expect to feel the worst.” [Participant 13]*

331 Participants described using digital devices to collect a range of health-related data and that
332 this process helped them to self-manage their condition(s). Although the perceived utility of
333 digitally recording and sharing data varied by participant, many stated that they would be more
334 willing to use technology if certain preferences were met. For instance, roughly one third of
335 participants indicated that the ability to combine traditional handwritten methods with the use
336 of digital devices would make data recording and sharing more convenient.

337 *“I have an iPad that has an app that allows me to hand write into it, I use an Apple*
338 *Pencil, and I find that I retain the information better if I can write it out by hand vs than*
339 *type it. And I am horrible at typing, so you know this is kind of the best of both worlds.”*
340 *[Participant 13]*

341 *“That’s kind of what the bullet journal method says, it’s about analogue tools are still*
342 *valid in a digital world.” [Participant 1]*

343 In addition to incorporating analogue methods into a digital platform, participants also
344 expressed a desire to combine multiple existing applications for added convenience.

345 *“You find you can get very, very specific apps and you can just end up swamped with*
346 *apps... Something that would be more streamlined and in principle something that*
347 *could bring things together would be really useful.” [Participant 1]*

348 *“Some sort of marriage between physical tracking but also being able to track you*
349 *know major symptoms would be very very helpful. And if there is an app out there that*
350 *does that, then I haven’t found it, and I have probably gone through just about every*
351 *app possible.” [Participant 13]*

352 The advantage of merging different applications was described as being to combine existing
353 sources of information which could provide fresh insight into the interplay of various health

354 and lifestyle factors. Participants highlighted this as being a key goal for using technology to
355 better understand their condition and how best to manage it.

356 *“Certainly that is what is missing in the trackers I have seen so you can put in your*
357 *own symptoms so you can make it relevant to you if it then has a way of identifying*
358 *patterns, have you noticed that two days after this happens you crash or if you eat an*
359 *avocado you feel better.” [Participant 8]*

360 *“So, if I could map my activities with my symptoms, I would find that really useful, or*
361 *if I’ve spent a day in the office looking at the computer screen and I haven’t moved very*
362 *much, how does that impact my next day, so I could better manage things.”*
363 *[Participant 5]*

364

365 Overall, participants highlighted a need to be able to combine traditional methods of data
366 collection and expression with existing applications in a convenient and integrated way.
367 Participants described their motivations for using such technologies in terms of being able to
368 better understand the interaction between different health and lifestyle factors so that they could
369 improve the self-management of their condition.

370 **3.2.2. The importance of anonymity.**

371 This theme refers to the extent to which participants expressed the importance of controlling
372 their anonymity when considering whether or not to share personal health and lifestyle
373 information. Almost all participants identified the ability to remain anonymous as an enabler
374 of sharing. Online health message boards were highlighted as a platform on which anonymous
375 sharing can take place.

376 *“I shared quite a lot of information. In fact, I probably overshared. I felt like it was an*
377 *anonymous space that I could just get my thoughts completely out and I didn't have to*
378 *hold back in any way because it's a group of people who would already understand*
379 *what I'm going through.” [Participant 12]*

380 The ability to remain anonymous was described as enabling uninhibited sharing without being
381 concerned about the impact of expressing one’s experiences. Ensuring that an individual’s
382 anonymity could be protected was also reported as enabling the sharing of personal information
383 with recipient groups that were otherwise distrusted, such as pharmaceutical companies,
384 advertising firms and other commercial interests.

385 *“In terms of advertising, I think it's something that I don't have any control over*
386 *anything at the moment, so that's already going on. As long as I was anonymous ... So,*

387 *if it's in terms of pharmaceutical companies, as long as I was kept anonymous as a*
388 *person, that wouldn't bother me so much.” [Participant 12]*

389 Although 11/14 participants expressed concerns about the perceived practices of commercially
390 interested companies, anonymity acted as an enabler of sharing, including with third parties.
391 Despite distrusting or disapproving of certain industry practices, guaranteeing that one’s name
392 would not be ascribed to the data appeared to mitigate some concerns about sharing.

393

394 The importance of anonymity was also expressed in relation to concerns about shared data
395 being linked back to an individual’s ‘real life’.

396 *“My concern would be more about people in real life seeing it than people who were*
397 *just online. I suppose my other concern about online is how findable I am. If I did put*
398 *something and I had all the privacy settings in the world... Having my double-barrelled*
399 *surname and what I do... My clients will search for me.” [Participant 11]*

400 Participants were concerned about information that is not shared anonymously being available
401 to those in their private, social or professional lives. Even in cases where an individual’s name
402 may accompany shared data, so long as the participant felt that this would remain distinct from
403 their ‘real life’, a sense of anonymity could still be maintained.

404 *“If it is for research, I am assuming it is not yourself, not someone I know, that I am*
405 *then disclosing all my stuff to, then it is anonymous, even though its got your name*
406 *attached to it they don’t know you so I would feel anonymous so I would be quite happy*
407 *to share all of them.” [Participant 8]*

408

409 When discussing the possibility and effects of potential breaches of anonymity, half of all
410 participants expressed significant concerns. However, there was uncertainty as to what
411 participants could do in response to such a breach.

412 *“Oh yes, I'd be livid. I mean, if I found out about it, I'd be bloody livid, that's for sure.*
413 *I don't know what you do about it these days, though. I suppose that's the thing.”*
414 *[Participant 2]*

415 Despite almost all participants expressing a need for anonymity, those who expressed concerns
416 suggested that they may not be able to control whether their data remains anonymous. To avoid
417 the potential for broken guarantees of anonymity, there was a broad desire for the ability to
418 limit the initial sharing of identifiable information with certain recipients so that the individual
419 may have a greater sense of agency and control.

420 *“You know in the idea of sharing more information, if there was a way to strip*
421 *identifying information out, I would not be afraid to put out more information. Its*
422 *having that like even on PatientsLikeMe I don't put my name on things, a lot of things*
423 *I just sign with initial, there is still enough linked to me that it is scary” [Participant*
424 *13]*

425 This desire to choose to remain anonymous when disclosing certain health data was again
426 described as having the potential to enable sharing. Whether or not participants trusted that
427 their data would remain anonymous depended on the degree of control they perceived they had
428 not to disclose identifying information, as well as the expected use and treatment of data.

429

430 **3.2.3. The expected use of data**

431 This theme addresses the influence that the expected use and treatment of personal data has on
432 an individual's willingness to share information, and how this might vary when considering
433 different recipient groups. When asked to consider with which recipient groups participants
434 would be willing to share, responses were driven by the perceived purpose for the collection
435 of data.

436 *“...again, I think the big question would be ‘What's the purpose? ‘What are you going*
437 *to do with it?’” [Participant 7]*

438 In addressing the expected use of data by recipient group, most judgments were based on
439 whether or not the intended purpose for the use of information was perceived to be in the public
440 interest.

441 *“I wouldn't mind that, because it's all going towards future research, and a lot of*
442 *people with chronic health conditions are very, very happy to help, if it's going to help*
443 *somebody else.” [Participant 6]*

444 *“I think it depends on what the purpose is. If it's for research and helping people, or*
445 *helping medical knowledge or something like that, then that's fine by me. But if it's for*
446 *making money or making an app better or something, then I would have to consider*
447 *that in more detail. It really depends on the person. Charity I'm more fine with, again,*
448 *because it's not for making money.” [Participant 4]*

449 Recipient groups that were deemed to be in the public interest included universities and other
450 higher education institutions, as well as public health organisations such as Public Health
451 England. Public interest groups were discussed in stark contrast to commercially interested
452 organisations, most notably pharmaceutical and advertising companies.

453 *“I would not be happy with sharing any data to be used as a profiting mechanism.*
454 *Accessing health services and treatments is a public right and as such I am against the*
455 *profiting of private companies within this space.” [Participant 14]*

456 This general reluctance to share personal information with commercially interested
457 organisations was not discussed in terms of the specific industry practices, but rather in terms
458 of a broadly held belief that organisations should not be permitted to profit from the sharing of
459 personal health information, and that organisations that seek to do so should not be trusted.

460

461 There were further questions of trust with respect to the expected treatment of shared data, and
462 whether this treatment of data could guarantee the security of personal information.

463 *“It's not a question of not trusting them; it's not trusting their system. ... Yes. Yes, if*
464 *I was doing something bloody stupid and I was talking to my doctor, fine, but if you're*
465 *typing a note into the system, then there's a possibility that system could go under. So*
466 *that was the only one from that.” [Participant 2]*

467 Such concerns about the ability of systems to securely house shared information were not
468 typically addressed by reference to specific events or concerns but rather through the lens of a
469 general lack of trust in the ability of companies to protect private data. Over half of participants
470 expressed fears about the potential consequences of non-secure treatment of their own shared
471 data.

472 *“I would be very concerned about data leaks and security features by external*
473 *companies and I definitely wouldn't want my information sold in any way. That's*
474 *obviously a big one.” [Participant 12]*

475 *“I'd feel extremely vulnerable just on an instinctive level not knowing what that could*
476 *be used for. What agenda the person had for doing that, you just don't know. It's the*
477 *not knowing aspect that gets me.” [Participant 1]*

478 Although most participants did not address specific concerns that they may have with respect
479 to how the misuse of their data could be used against them in the event that it fell into the hands
480 of malicious actors, improper treatment of data was perceived as a real threat. Participant
481 vulnerability to this threat was exacerbated by uncertainties surrounding the expected use of
482 data.

483

484 **3.2.4. Sources of emotional support**

485 This theme refers to the different sources of emotional support available and the extent to which
486 perceived sensitivity of information, as well as the expected reaction of the recipient, impact

487 participant willingness to share. Family was described as providing a key source of emotional
488 support for participants. Although some participants expressed that they would be willing to
489 share all aspects of their health and lifestyle information with certain members of their family,
490 most participants adopted a tailored approach to family sharing, both in terms of what
491 information they would share and with whom.

492 *“It depends who, my friends and family. My dad I don’t really tell much to, because*
493 *he’s really Old School, and sometimes I find it a bit weird to discuss personal things*
494 *with him, especially regarding sexual health and mental health. My mum, with her it’s*
495 *a bit iffy right now, because we don’t really have much of a relationship anymore. But*
496 *I would in the past, but not now.” [Participant 4]*

497 *“Say, so, like, my dad, I wouldn’t share my sex life or my sexual orientation, because I*
498 *think he’d have a heart attack. Substance use, no, other... he knows I drink alcohol,*
499 *struggles. So, actually, substance use, I wouldn’t share with my mum because I use*
500 *cannabis oil to manage my symptoms. I know she’s really against and, obviously, it’s*
501 *illegal, but it’s the only thing that works sometimes, so I’m going to use it, but I wouldn’t*
502 *share.” [Participant 5]*

503 The perceived sensitivity of the information type clearly influenced the willingness of
504 participants to share with certain family members. This particularly applied to information of
505 a sexual nature, information pertaining to substance use and, in some instances, mental health.
506 Two participants described generational factors, or family members being ‘*Old School*’, as
507 determining whether or not they would feel comfortable sharing sensitive information with
508 family. In contrast, participants generally reported being willing to open up more readily to
509 friends when discussing sensitive topics.

510 *“I think most of my friends, if they wanted to know something, I don’t hide many things*
511 *and I quite openly talk about sex life and stuff with my close friends. So, yes, I don’t*
512 *think there’s anything I wouldn’t share.” [Participant 5]*

513 *“I tend to share more with friends than family. It’s a lot easier to share with people*
514 *who you know will understand or be able to empathise regardless of how well you know*
515 *them, I’ve found. I check in with a lot of friends.” [Participant 1]*

516 This openness with friends was described in relation to their expected reaction being one of
517 empathy and understanding. Generally, this expectation enabled a willingness to share with
518 friends, most notably with respect to sensitive information. In contrast, the expected reaction
519 of certain family members was described as a barrier to sharing by just under half of
520 participants in instances where it was felt that sharing may have negative consequences.

521 *“Obviously you do talk to your family and stuff about a lot of things, but I think*
522 *sometimes you don’t want to say too much that’s going to start to have an impact on*
523 *their mental health as well. [Participant 6]*

524 *“It’s opening up enough, without completely exposing or getting people to worry. My*
525 *mother, bless her, she... I think I was talking to her on Facebook. She was like, ‘You’re*
526 *not going to worry me, are you?’ Which is kind of fine but is also a little bit like,*
527 *actually, I need to package it up in a way that she can cope.” [Participant 11]*

528 These excerpts illuminate that individuals may sometimes weigh up the benefits of sharing
529 against the negative consequences for those around them. As an alternative to seeking
530 emotional support by sharing experiences with family and friends, just under a third of
531 participants (4/14) highlighted the value of opening up to online communities.

532 *“I think it’s because it’s strangers on Twitter and Instagram a lot of the time, so they*
533 *don’t know you and won’t try to chase you up about if you’re okay. Sometimes you*
534 *don’t want that. You just want to let it go and express yourself, I guess.”*
535 *[Participant 4]*

536 This form of sharing provides a seemingly consequence-free form of emotional support in
537 which an individual can share their experiences without being concerned about the reaction of
538 those closest to them. Sharing with online communities of those who have a similar condition
539 was also described as offering an additional form of support in the form of providing validation
540 for the participant’s reported experiences.

541 *“There is a Facebook group that is actually really useful in terms of just some things*
542 *that you might not even think are part of it, people saying yeah I get that, I get that as*
543 *well and again more from a validation point of view.” [Participant 8]*

544 Those who reported engaging with groups online who may have had similar health experiences
545 to the individual (4/14) described a form of emotional support that may not be available from
546 family and friends. These participants highlighted the value of receiving a sense of validation
547 from those who have had similar experiences. Online communities also provide a source of
548 support external to an individual’s ‘real life’ with which someone may share their experiences
549 more openly without being concerned about harming those around them.

550

551 Finally, it is noted that only one participant chose to highlight the role that health-related stigma
552 plays in their experiences of collecting and sharing health data. This participant reported living
553 with Genital Herpes and described how their anticipation of health-related stigma had a
554 detrimental effect on their willingness to share health and lifestyle data with most recipient

555 groups, other than HCPs. This was seen to limit the channels of ‘emotional support’ available
556 to the participant due to the anticipated reactions of others (including friends, family and those
557 closest to the participant). However, the remaining participants did not identify stigma
558 associated with their LTHC(s) as a barrier to collecting or sharing health and lifestyle data with
559 others.

560

561 **4. Discussion**

562 This study investigated the attitudes and experiences of collecting and sharing personal health
563 and lifestyle information among those living with potentially stigmatised LTHCs. The findings
564 of this study illustrate a general willingness to share most forms of health and lifestyle
565 information with most recipient groups. This was typically described as being motivated by a
566 desire to improve the self-management of the participant’s own condition as well as to help
567 others. That said, there were some noticeable differences in reported sharing experiences,
568 which varied both by information type and by recipient group. Most notably, participants
569 reported being less willing to share health and lifestyle data via social media than with other
570 recipient groups. There was also a general distrust towards sharing data with commercially
571 interested parties, in stark contrast with the broadly held willingness to share with organisations
572 that were deemed to be in the public interest. Although individual participant preferences
573 varied by information type, participants were less willing to share data that they deemed to be
574 sensitive, which was particularly true for information of a sexual nature. Finally, despite the
575 fact that all participants reported living with a potentially stigmatised LTHC, the majority of
576 participants did not identify health-related stigma as a barrier to collecting or sharing their
577 personal health and lifestyle data.

578

579 Across the sample, participants expressed the importance of being able to choose what
580 information is shared, and with whom. This finding is consistent with previous research that
581 suggests that patients desire ‘granular’ control over their health information so that they can
582 actively select what and how it is shared.^{38, 57} This need for control was also expressed by the
583 importance that participants placed on having control over their anonymity. The ability to
584 remain anonymous was shown to enable enhanced sharing, particularly when engaging with
585 online communities. Anonymity has previously been suggested to encourage the sharing of
586 health information online.³⁶ In the current study, the importance of anonymity was often
587 discussed in terms of preventing being identified by those around them. This seems to suggest
588 that remaining anonymous in online communities can facilitate uninhibited sharing, in part due

589 to the perceived distinction between online engagement and ‘real life’. This speaks to the
590 utility of anonymity when managing the boundaries that individuals establish between their
591 separate environments.⁵⁸ The participants’ emphasis on the importance of anonymity did not
592 translate into an absolute unwillingness to disclose personally identifying information. This is
593 supported by participants’ own names being ranked second highest on the card sorting task in
594 terms of overall willingness to share with others. It is suggested that the participants’ concept
595 of anonymity does not simply refer to whether identifying information is disclosed or not, but
596 also addresses the context in which an individual may be identified by others, as well as the
597 degree of control they feel they have over how this is managed. This relates to previous research
598 which has argued that decisions around privacy are not binary, instead they involve nuanced
599 consideration of how personal information is likely to be used, by whom, and the sense of
600 agency experienced by the individual.⁵⁹ The distinction drawn by Raynes-Goldie (2010)
601 between social and institutional privacy described the former as involving other people, often
602 familiar to the individual.^{60, 61} The importance of anonymity described by participants in
603 preventing being identified in one’s ‘real life’ raises concerns about social privacy, whereas
604 the importance placed on anonymity when considering data falling into the hands of
605 commercially interested organisations raises institutional privacy concerns. A more detailed
606 exploration of the contextual drivers of privacy concerns in those living with potentially
607 stigmatised LTHCs may further explain how anonymity acts as a key facilitator for the sharing
608 of health and lifestyle data.

609

610 Where the purpose of the use of participant information was perceived as being aligned with a
611 broader public interest, all participants were particularly willing to share. Public health and
612 research was the recipient group with whom our sample was most willing to share. This was
613 generally explained by participants’ motivation for their own information to be used to benefit
614 others. Almost all participants drew a sharp line between their willingness to share with ‘public
615 interest’ groups and ‘commercial interest’ groups. This was clearest in the overwhelming
616 aversion to sharing personal information with pharmaceutical companies which may be
617 indicative of an ongoing ‘trust crisis’ within the pharmaceutical industry in general.⁶² Recent
618 concerns over the proposed central NHS digital database drawing on data from GP records in
619 England indicates ongoing concerns regarding trust, transparency and the potential misuse of
620 patient data.⁶³⁻⁶⁵

621

622 In addition to the impact that anticipated use of information had on a participant's willingness
623 to share, the expected reaction of recipients strongly influenced attitudes towards sharing. This
624 was most apparent when weighing up whether or not to share certain categories of sensitive
625 information with family, friends or other people with a similar condition. Despite there being
626 no clear consensus about what constitutes sensitive information, previous research has
627 suggested five categories of sensitive health data: sexually transmitted infections, HIV/AIDS
628 status, sexual health and pregnancy, mental health information, and substance use.⁴⁷ Several
629 participants discussed both sexual health and substance use as particularly sensitive and the
630 three least shared information types from the card sorting task all related to sex. There were
631 often clear differences in participants' willingness to disclose sensitive information with family
632 compared to friends. Some participants explained this by suggesting that sharing with friends
633 tended to accompany a greater expectation of understanding, especially with respect to
634 sensitive information and may explain why the results of the card sorting task show a slight
635 preference to share with friends over family. The reluctance of some participants to share with
636 family was further explained by concerns that sharing information with certain family members
637 may provoke a negative reaction, either by causing distress to the recipient or by prompting
638 them to take unwanted action. Again, this relates to the importance of managing boundaries
639 between different environments. In addition to the discussed role that anonymity plays in
640 allowing participants to manage boundaries, sharing with those who have a similar condition
641 provides an opportunity to disclose experiences without expecting consequences in one's 'real
642 life'. Primarily, online health communities can validate an individual's experiences and
643 provide a sense of understanding. Although not all participants expressed a willingness to
644 engage with online communities, such groups provide a valuable alternative to sharing with
645 family and friends.

646

647 The findings illustrated a clear desire for agency in self-managing LTHCs and a general
648 willingness to share health and lifestyle data with a range of sources. Despite a broad interest
649 in engaging with technology to facilitate the beneficial collection and sharing of data,
650 participants highlighted that technology can be both a help and a hinderance. The flexibility of
651 being able to combine traditional methods of data collection with digital storage and analysis
652 appeared particularly attractive to participants. This desire for the integration of resources
653 extended to wanting the ability to combine the benefits of a range of existing applications and
654 devices. This combining of methods and devices would not only improve the ease with which
655 information could be recorded and shared, but could also be used to detect patterns that occur

656 across previously separated categories of data. The potential for pattern recognition and
657 broader analysis may provide additional agency to those managing LTHCs and help them to
658 better understand their experiences. Given the overall motivation to share information for the
659 purpose of benefiting others, if people felt that engaging with this technology could improve
660 the understanding of their condition, they may be more motivated to share.

661

662 The majority of our sample did not highlight health-related stigma as being central to their
663 attitudes and experiences of collecting and sharing health data. Therefore, contrary to
664 expectations, the experience of stigma was not emphasised in the analysis of participant
665 responses as a key barrier to sharing. It is noted that the one participant that did stress the role
666 that stigma plays in their reluctance to share health information reported having a sexually
667 transmitted infection. Our findings highlighted that information pertaining to sexual health and
668 activity is often considered to be very sensitive, which may account for the heightened sense
669 of stigma reported by this participant. It was also expected that participants who reported
670 having a mental health condition may also highlight the impact of stigma on their experiences.
671 Despite increased mental health awareness in recent years,⁶⁶ as well as a complex change in
672 public attitudes towards a range of associated conditions,⁶⁷ a broad body of literature suggests
673 that both public stigma and self-stigma continue to have a detrimental effect on those suffering
674 with mental health.⁶⁸ That said, a third of our sample reported living with mental health
675 conditions and yet chose not to stress the influence that stigma has on their accounts of
676 managing their mental health. This suggests that living with a condition typically associated
677 with stigma does not inevitably cause people to feel stigmatised by their health status.
678 Furthermore, previous research has suggested that, where stigma is present, many labelled
679 individuals actively resist feelings of being stigmatised whilst learning to manage the demands
680 of their condition.⁶⁹ As individuals become more accustomed to dealing with long-term illness,
681 some may begin to view their experiences through a lens of normalcy and not associate them
682 with existing stigmas. Overall, this suggests a more complex relationship between stigma and
683 PGData sharing and one that warrants further investigation.

684

685 A potential limitation of this study is that participants' initial agreement to take part required a
686 certain level of trust in opening up to researchers about their health. Several participants
687 reported a close familiarity with academic research due to the proximity of their own work to
688 research activities. This may in part be due to the recruitment of participants through university
689 channels. This initial agreement and familiarity may go some way to explaining the overall

690 willingness to share data for the purposes of research. Future studies may seek to explore
691 whether or not there is still a general willingness to share with public health and research
692 organisations in participants that are not as familiar with their practices. Furthermore, previous
693 research has found that socioeconomic variables such as income and education are often
694 associated with levels of trust in public health and health information more generally.^{70, 71}
695 While this study did not collect the socioeconomic backgrounds of the participants, future
696 studies may look to capture perceptions of those living with LTHCs from a range of
697 socioeconomic backgrounds to explore the role that various demographic factors may play in
698 forming attitudes towards sharing.

699

700 **5. Conclusion**

701 This study adds to a growing body of literature that seeks to understand the experiences of
702 those living with LTHCs. Our research has focussed on the attitudes and experiences of those
703 living with potentially stigmatised LTHCs with respect to collecting and sharing health and
704 lifestyle data across multiple contexts. Our findings suggest that having the option to remain
705 anonymous prompts a willingness to share health and lifestyle data, particularly in online
706 communities. Willingness to share is often determined by the perceived purpose for the use of
707 data and, when sharing, people may seek emotional support from a range of sources depending
708 on the sensitivity of the information they wish to disclose. We have outlined a number of
709 technological preferences that participants felt would encourage them to collect and share data
710 more readily, which may be considered when developing tools for the future. Identifying the
711 factors that facilitate engagement with sharing technologies may help to harness large amounts
712 of valuable data that can be used to improve the management of LTHCs. This has significance
713 for understanding the underexplored experiences of those living with potentially stigmatised
714 LTHCs, in order to support and encourage the beneficial sharing of health and lifestyle data.

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