

1 **Collecting and sharing self-generated health and lifestyle data: Understanding barriers for people**
2 **living with long-term health conditions – a survey study.**

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16 **Abstract**

17 *Background*

18 The growing popularity of collecting self-generated health and lifestyle data presents a valuable
19 opportunity to develop our understanding of long-term health conditions (LTHCs) and improve care.
20 Barriers remain to the effective sharing of health and lifestyle data by those living with LTHCs which
21 include beliefs around concepts of Trust, Identity, Privacy and Security (TIPS), experiences of stigma,
22 perceptions of risk and information sensitivity.

23 *Method*

24 We surveyed 250 UK adults who reported living with a range of LTHCs. We recorded data to assess self-
25 reported behaviours, experiences, attitudes and motivations relevant to sharing self-generated health and
26 lifestyle data. We also asked participants about their beliefs about TIPS, stigma, and perceptions of risk
27 and information sensitivity regarding their health and lifestyle data.

28 *Results*

29 Three quarters of our sample reported recording information about their health and lifestyle on a daily
30 basis. However two thirds reported never or rarely sharing this information with others. TIPS concerns
31 were considered to be 'very important' by those with LTHCs when deciding whether or not to share self-
32 generated health and lifestyle data with others, with security concerns considered most important. Of those
33 living with a LTHC, 58% reported experiencing stigma associated with their condition. The greatest
34 perceived risk from sharing with others was the potential for future harm to their social relationships.

35 *Conclusions*

36 Our findings suggest that, in order for health professionals and researchers to benefit from the increased
37 prevalence of self-generated health and lifestyle data, more can be done to address security concerns and
38 to understand perceived risks associated with data sharing. Digital platforms aimed at facilitating the
39 sharing of self-generated health and lifestyle data may look to highlight security features, enable users to
40 control the sharing of certain information types, and emphasise the practical benefits to users of sharing
41 health and lifestyle data with others.

42

43 **Introduction**

44 There are approximately 19 million people currently living with a long-term health condition (LTHC) in
45 the UK.¹ The Department of Health in England has defined a LTHC as “*one that cannot currently be cured*
46 *but can be controlled with the use of medication and/or other therapies*”.² With the prevalence of LTHCs
47 expected to rise in the coming decades,³ it is essential that we develop strategies to enable both healthcare
48 systems and individual patients to better manage health and care in the UK.

49 One solution to help manage the increasing prevalence and cost of long-term care is the use of
50 eHealth, defined as the enhanced use of digital information and communication technology (ICT) in
51 healthcare.⁴ The increasingly ubiquitous nature of technology has meant that eHealth and related tools can
52 provide a convenient means for collecting and sharing objective patient-generated data in real time.⁵ For
53 example, the use of wearable devices to track and monitor health and wellbeing has risen significantly in
54 recent years.⁶ Widening the channels through which health data is collected and shared between patients
55 and healthcare professionals (HCPs) may have particular significance for those living with LTHCs,
56 enabling best use of the infrequent and limited contact time that such patients typically have with relevant
57 HCPs.⁷ For example, patients with conditions such as diabetes report having as little as three hours of
58 contact time a year with HCPs, with the majority of their health needs being self-managed.⁷ Benefits to
59 patients from sharing *self-generated* health and lifestyle data with others include the potential for greater
60 autonomy and better overall health outcomes. ‘Self-generated health and lifestyle data’ covers a broad
61 range of data types from a varied list of data sources. This may include handwritten records of information
62 about sleep, diet or use of medication, as well as encompassing information collected via wearable medical
63 devices such as heart rate, blood sugar and levels of physical activity. Sharing such health and lifestyle
64 data with others has been linked to better health management, due to those who share being more likely to
65 implement better self-care than those who do not.⁸ In a study of patients with epilepsy, the perceived
66 benefits of sharing health data with others included gaining a better understanding of seizures and learning
67 more about symptoms and treatment.⁸ Those who share via community platforms such as PatientsLikeMe
68 perceive the greatest benefits to sharing as having the opportunity to learn about their symptoms and to
69 understand the side effects of their treatment.⁹ Furthermore, a recent study of patients with rheumatoid
70 arthritis found that collecting and sharing self-generated health data led to consultations being more
71 focussed around their actual data, making patients feel that they are receiving more personalised care.¹⁰ In
72 the same study, the perceived benefits to public health surveillance and research from the collection and
73 sharing of self-generated health data were reported to be the identification of disease patterns and long-
74 term trends that would otherwise be concealed amongst the daily fluctuation of symptoms.¹⁰ Increasing the
75 scope and availability of self-generated health and lifestyle data may allow the application of big data
76 practices to public health in order to conduct exploratory analyses to identify patterns across previously
77 separated disciplines (such as among public health research, healthcare, biology, ecology and
78 demography).¹¹ Big data practices can be defined as the structured, sophisticated and rapid analysis of large
79 complex data sets.^{11, 12} This may help to provide a multidisciplinary approach to understanding health
80 phenomena beyond the capabilities of single disciplines. The benefits of this big data approach may be to

81 optimise the delivery of care for individual patients by providing information to support decision making
82 and care planning by HCPs. This will require greater levels of sharing across multiple data points to
83 facilitate appropriate and necessary research.¹³ In order for both the data provider and others (through
84 results of public health research) to fully benefit from such developments, the safe and effective sharing of
85 health and lifestyle data with others should be encouraged.¹⁴

86 It is noted that while the use of self-generated health and lifestyle data for improved care is
87 presented as a patient-centred, low-cost health solution, it has the potential to add to the increasing
88 workload of HCPs. If the information is not available in an accessible and appropriate manner, it can
89 require excessive time to analyse or make sense of the data provided. It is especially important to be
90 mindful of this fact at a time when HCPs are under immense pressure in response to the COVID-19
91 pandemic. Potential concerns have been raised about the reliability and accuracy of patient-generated data
92 presented to HCPs.^{15, 16} Research suggests that HCPs themselves have doubts about the reliability of the
93 health technology available to the general population.¹⁷ These concerns may create difficulties for HCPs
94 when they are required to judge the utility of data provided during health consultations. This highlights the
95 need for clarity surrounding how best to integrate self-generated health and lifestyle data into the delivery
96 of care.

97 Additionally, it is important to appreciate the technological preferences and abilities of individual
98 patients before asking them to actively collect, monitor, share and manage their health data. This may help
99 to avoid burdening individual patients with unwelcome responsibility.¹⁸ Though collecting health data can
100 sometimes be conducted passively by digital devices, research into the perspectives of those living with
101 multiple LTHCs found that, in some cases, managing self-generated health and lifestyle data can become
102 a time-consuming burden that exacerbates the struggles of existing illnesses.¹⁹ Therefore, supporting
103 patients to effectively share self-generated health and lifestyle data requires close consideration of patient
104 technological preferences and must be delivered without over burdening the data gatherers or HCPs.

105 It is suggested that in order to benefit from large quantities of self-generated health and lifestyle
106 data, people with LTHCs should be supported and encouraged to collect and share information about their
107 health.¹⁴ Despite the potential benefits of sharing self-generated health and lifestyle data with others, a
108 number of barriers have been identified that prevent the acceptance of these data sharing practices. For
109 instance, as electronic health data become increasingly integrated into healthcare systems, there is an
110 increased potential for privacy breaches and misrepresentation, negatively influencing end user trust.²⁰ In
111 this research we will discuss concerns surrounding concepts of Trust, Identity, Privacy and Security (TIPS)
112 adopted from research into privacy and security perspectives.²¹ TIPS concerns play an important role in
113 facilitating sharing of health data via technology applications.²¹⁻²⁴ For example, trust has been identified as
114 a key factor for increasing the likelihood of patients sharing health information for the purpose of
115 participating in research, whereas lack of trust has been shown to decrease willingness to share.²⁵ By
116 identity issues we refer to individual concerns about identifiers that are attributed to a person that may be
117 used to interact with both physical and digital worlds. For example, identifiers in the physical world may
118 refer to one's name, location, self-representations and factors relevant to someone's face-to-face

119 interactions. Digital identify refers to identifiers relevant to one's personal data and online presence.
120 Privacy and security concerns refer to issues surrounding the ability to maintain the private and secure
121 storage of personal data and information. Such concerns have been found to be negatively associated with
122 patient willingness to share health information with others.²⁰ In recent years, there has been increasing
123 interest in the role that such TIPS concerns play in the sharing of health and lifestyle data among those
124 with LTHCs. For example, in a qualitative study of the experiences of patients with HIV (an example of a
125 LTHC that is associated with experiences of stigma),^{21, 26} TIPS concerns were found to be central to
126 perceptions of sharing health data with others.¹⁷

127 In addition to TIPS concerns, information sensitivity has been found to impact both privacy
128 concerns and willingness to share data with others.^{20, 27} Perceived sensitivity of information has been
129 suggested to be a key barrier to the sharing of health and lifestyle data with others, yet it is difficult to
130 define and measure.²⁸ Furthermore, fears and perceived risks surrounding the unwanted disclosure of
131 health data may cause some individuals to expect harmful consequences as a result of sharing information
132 they deem to be sensitive.²⁰ When deciding whether or not to share health information with others,
133 individuals may first weigh up the benefits to sharing against the perceived risks.²⁸

134 Finally, people who live with conditions that are typically associated with stigma may anticipate
135 potential discrimination, harm or negative labels when considering whether or not to share health
136 information with others.²⁹ Stigma can be both internal (felt stigma or self-stigmatisation) or enacted
137 (external or discrimination) experiencing unfair treatment from others.³⁰ Both internal and enacted stigma
138 can influence the way in which patients develop trust and may choose to share their self-generated health
139 and lifestyle data.^{26, 31-35} A number of health conditions are frequently associated with experiences of
140 stigma,³⁶ such as living with HIV,^{21, 37} mental health problems,^{36, 38} and chronic pain.³⁹ People living with
141 LTHCs who anticipate stigma associated with their condition(s) may be more reluctant to share their health
142 data which could potentially prevent them from receiving an appropriate level of care.^{31, 40} Our specific
143 interest in stigma aligns with the objectives of the broader research programme. This survey study is
144 conducted as part of a UK EPSRC funded programme ("INTUIT: Interaction Design for Trusted Sharing
145 of Personal Health Data to Live Well with HIV", 2020)⁴¹ examining TIPS concerns around the sharing of
146 self-generated health and lifestyle data primarily among those living with HIV, but also looks to investigate
147 TIPS concerns among those living with a range of other LTHCs. The INTUIT project aims to identify
148 TIPS concerns and to design tools that remove the barriers to collecting and sharing self-generated health
149 and lifestyle data in order to improve the health and well-being of stigmatised populations.

150 Given the increasing prevalence of LTHCs, and the potential benefits of utilising self-generated
151 health and lifestyle data, it is paramount that health systems understand the attitudes and perceptions of
152 those living with LTHCs in order to promote the beneficial sharing of health and lifestyle data. To address
153 this, we have conducted a quantitative survey of the attitudes and behaviours of people living with a range
154 of LTHCs with respect to the sharing of self-generated health and lifestyle data with others. This study
155 forms part of a wider programme of research exploring TIPS concerns around self-generated data sharing
156 to inform supportive and trusted technology designs for managing LTHCs (INTUIT).⁴¹ Our study aim was

157 threefold: (i) to identify the extent to which TIPS concerns relevant to the sharing of self-generated health
158 and lifestyle data with others are reported by those living with a range of LTHCs; (ii) to explore if
159 perceptions of risk and information sensitivity are associated with data sharing perceptions and behaviours,
160 attitudes towards sharing, and TIPS concerns; and (iii) to examine the impact of stigma by identifying
161 behavioural and perceptual differences between those who report experiences of stigma and those who do
162 not, and by exploring the relationship between perceived stigma and the sharing of self-generated health
163 and lifestyle data. Finally, we address the role that these insights may play in designing future digital
164 platforms for enabling trusted, private and secure health data sharing in a range of settings.

165

166 **Method**

167 Our study was approved by the Department of Psychology Ethics Committee at Northumbria University
168 (ethical approval number 26581). Our measures, predictions and study protocol are registered with the
169 Open Science Framework (osf.io/h3mjv/). We surveyed 251 UK participants, aged 18 or above, who
170 reported living with a LTHC. We recruited participants via the surveying platform Prolific as it is a
171 company that offers a high-quality participant pool of research-participant volunteers. We used Prolific's
172 pre-screening criteria, which allowed us to ensure that only those who had self-reported living with a LTHC
173 had access to our survey. An a priori power analysis indicated that a sample size of 211 was required to
174 detect a small to medium effect of .2 for a bivariate correlational analysis with power of .90 and an alpha
175 of .05. This would allow us to conduct an independent correlational analysis across measures of perceived
176 stigma, TIPS concerns, willingness to share with others, perceived stigma and sharing behaviours.
177 Therefore, to account for the possibility of missing data, our final recruited sample size was 251
178 participants. We conducted data quality checks by ensuring that responses for age and gender in our survey
179 were consistent with responses given on participants' Prolific profiles. Attention checks ensured that
180 participants took a minimum of eight minutes to complete the survey. We excluded one participant because
181 they took over three hours (192 minutes) to complete the survey. Therefore, our final sample contains 250
182 participants: 166 females, 80 males, two non-binary and two who preferred not to report their gender, aged
183 18-77 (mean age = 39.20, SD = 14.78). See tables 1 and 2 below for full participant details.

184

185 *Personal Information*

186 Participants' age, gender, ethnicity and sexual orientation were recorded. Participants were asked to
187 confirm that they had a LTHC and to indicate the nature and duration of their condition(s). A dropdown
188 list of LTHCs was presented to participants, taken from recent research into LTHCs in the UK Biobank
189 cohort.⁴² Participants could provide multiple responses or self-describe their LTHC(s). If participants stated
190 that they are living with more than one LTHC, they were asked to indicate which condition they consider
191 to be their 'Primary LTHC'. If a participant felt that more than one condition is fundamental to their
192 primary health needs, their primary health condition was categorised as 'Multiple LTHCs'.

193

194 *Self-Generated Health and Lifestyle Data behaviours*

195 Participants were asked how often they record their own health and lifestyle data and the type of self-
196 generated data they record. Participants indicated the frequency of data collection (selecting ‘never’, ‘when
197 the need arises’, ‘less than once a month’, ‘monthly’, ‘fortnightly’, ‘weekly’ or ‘daily’) for a list of 17
198 separate categories of self-generated health and lifestyle data developed from previous literature (for
199 example ‘effects of medication’, ‘blood pressure’, ‘heart rate’, ‘sleep patterns’, ‘diet’ and including the
200 option to self describe additional categories).⁴³ Participants were asked what method(s) they use to record
201 or monitor their health and lifestyle data, selecting answers from nine predefined methods and devices
202 developed from previous research (for example ‘mobile phones’, ‘wearable activity trackers’ and
203 ‘handwritten records’ and including the option to self describe additional methods; see preregistration
204 document for full questionnaire details (osf.io/h3mjv/).⁴⁴ Participants also indicated how often they share
205 different types of self-generated health and lifestyle data with others, and with whom.

206

207 *Experiences of sharing health data*

208 Participants rated how positive and beneficial they have found experiences of sharing self-generated health
209 and lifestyle data with others (rated on a five-point Likert scale from ‘extremely negative/ detrimental’ to
210 ‘extremely positive/ beneficial’). Participants also rated the extent to which they consider recording their
211 health and lifestyle data helps them to understand their condition(s) and whether they think others can
212 benefit from their data (rated on a five-point Likert scale from ‘not at all’ to ‘a great deal’).

213

214 *Motivation for sharing*

215 Participants indicated the extent to which five separate aims motivate them to share health and lifestyle
216 data with others. Participants were asked to what extent they share health and lifestyle data with others in
217 order to improve their own health, to improve the health of others, to receive emotional support from
218 others, to provide emotional support to others, or to receive practical support to help manage their
219 condition. Participants responded by stating the extent of their agreement with five statements about their
220 motivation to share health and lifestyle data with others (rated on a five-point Likert scale from ‘strongly
221 disagree’ to ‘strongly agree’).

222

223 *Perceptions of risk*

224 Participants indicated their levels of perceived risk associated with sharing health and lifestyle data with
225 others. Participants were asked the degree to which they agreed with 12 statements about risk (rated on a
226 five-point Likert scale from ‘strongly disagree’ to ‘strongly agree’). These statements were divided into
227 the following categories: general risk, social risk, privacy risk, psychological risk, physical risk, and
228 monetary risk. These categories were based on factors of perceived risk that have been identified by
229 previous literature as relevant to the sharing of health and lifestyle data with others.⁴⁵⁻⁴⁷

230

231 *Trust, Identity, Privacy and Security (TIPS) concerns*

232 Participants were asked the extent to which particular factors relating to TIPS concerns are important when
233 deciding whether or not to share health and lifestyle data with others. Three factors were considered for
234 each concept of Trust, Identity, Privacy and Security (TIPS); these were selected based on previous
235 findings from a related study conducted as part of the broader research programme²¹ and unpublished
236 qualitative findings from our research team into the TIPS concerns of those living with LTHCs.
237 Participants were invited to rate their importance on a five-point Likert scale ranging from ‘Not at all
238 important’ to ‘Extremely important’). For example, about trust, we asked participants how important it is
239 to be familiar with the recipient in order to share personal information. Questions on trust also investigated
240 how the relevance of requested information influences trust in the recipient, as well as asking if mutual
241 disclosure of information is important to those with LTHCs. Statements about identity concerns addressed
242 the use of pseudonyms and investigated the perceived importance of having the option to manage digital
243 identity and control one’s online presence. Questions addressing the importance of privacy asked about
244 the need for anonymity when sharing and the ability to select and control how personal data is shared.
245 Finally, security questions asked about the perceived importance of dependable data storage, the ability to
246 manage access to personal data and the need for digital and physical safeguards to protect health and
247 lifestyle data.

248

249 *Attitudes towards sharing - rating activities*

250 Participants completed rating activities to indicate their willingness to share different information types
251 with different recipient groups. These rating activities were divided into seven tasks by recipient group
252 (HCPs, Public Health and Research, Other People with the Condition, Family, Friends, Work and Social
253 Media). For each recipient group, participants were asked to rate their willingness to share 12 information
254 types (contact information, a photo of themselves, demographic information, medical information,
255 consequences of illness, mental health information, sexual health information, other health information,
256 substance use, sleep, diet and nutrition, and exercise). Rating was conducted on sliding scales from zero
257 (completely unwilling to share) to 100 (completely willing to share). This method was developed from
258 previous research that used a visual analogue scale to provide a normalised measure of 0-100 to rate how
259 comfortable a participant would feel sharing particular identity attributes in different sharing contexts.²¹

260

261 *Stigma*

262 Participants were asked if they felt they had experienced stigma as a result of their health condition(s). If
263 participants had previously stated that they have multiple health conditions, they were asked to indicate
264 which of their selected conditions were relevant to their experiences of stigma. Participants’ perceived
265 level of stigma associated with their LTHC(s) was measured using the Stigma Scale for Chronic Illness
266 (SSCI-8).⁴⁸ This scale rates stigma across eight items on a five-point Likert scale. Total scores range from
267 eight to 40, with higher scores indicating higher levels of perceived stigma.

268

269 *Information sensitivity scale*

270 Perceived sensitivity of health and lifestyle data was measured using the Workplace Information
271 Sensitivity Appraisal (WISA).⁴⁹ This 17-item scale consists of five subscales pertaining to perceived
272 information sensitivity: Privacy, Worth, Consequences, Low proximity interest by others and High
273 proximity interest by others. This scale has been found to have strong psychometric properties and has
274 been used to measure perceived sensitivity of health information.⁴⁹

275

276 *Technology preferences*

277 Finally, the survey asked about preferences for the technological sharing of self-generated health and
278 lifestyle data via a digital platform. This addresses part of the broader goals of the INTUIT research
279 programme to design digital tools that remove the barriers to collecting and sharing self-generated health
280 and lifestyle data in order to improve the health and well-being of stigmatised populations. Participants
281 were asked their perceived importance of 11 technological features of digital platforms (usability,
282 appearance, connectability to other devices, connectability to other applications, storage, pattern
283 recognition, social interaction, security, access, anonymity and trustworthiness) when considering whether
284 or not to share health and lifestyle data with others via a digital platform. Participants indicated their degree
285 of perceived importance for each factor on a five-point Likert scale, ranging from 'not at all important' to
286 'extremely important'.

287

288 Full details for our questionnaire are available as part of our pre-registration on the Open Science
289 Framework (osf.io/h3mjb/).

290

291 *Analysis*

292 All statistical analyses were performed using SPSS software version 26 with the exception of factor
293 analysis and modelling being conducted using AMOS version 26. Analysis across measures that collected
294 data via five-point Likert scales used Spearman's rho tests for correlational analysis. Collated scores for
295 overall TIPS concerns, overall willingness to share and overall perceived risk were treated as continuous
296 variables. Therefore, independent t-tests were used to examine differences in these variables between those
297 who reported experiencing stigma associated with their condition and those who did not ($N_{\text{stigma}} = 145$, $N_{\text{no-}}$
298 $\text{stigma} = 105$).

299 Factor analysis was conducted for our measures of TIPS, Perceived Risk, Perceived Stigma (SSCI-
300 8 scale), and Perceived Sensitivity of Information (WISA scale) to determine which measures should be
301 treated as unidimensional, and which measures reflect multiple factors. Firstly, the 12 item TIPS measure
302 was shown to have high reliability (Cronbach's $\alpha = .84$). The initial factorability of the 12 TIPS items was
303 then examined using several criteria. All 12 items correlated at least .3 with at least one other item,
304 suggesting acceptable factorability (see supplement, Table S5). Secondly, the Kaiser-Meyer-Olkin (KMO)
305 measure of sampling adequacy was .82 (above the recommended value of .6) and Bartlett's test of
306 sphericity was significant ($X^2(66) = 1166.58$, $p < .001$) suggesting the items are structurally related.
307 Finally, the communalities were all above .49 confirming that each item shares common variance with

308 other items. Principal components analysis was used to identify if TIPS concerns should be analysed by
309 individual factors. Initial eigen values indicated that three factors explained 30%, 13 % and 9% of the data
310 variance. A single factor solution was preferred because of the ‘levelling off’ of eigen values after the first
311 factor, as well as the fact that factors did not load in accordance with the theoretical categories of individual
312 TIPS concerns. Furthermore, interpreting TIPS concerns as a single summed score follows
313 recommendations that sum scores are most acceptable when using exploratory scales and can allow the
314 analysis to preserve the variation of the original data.⁵⁰

315 A similar approach was taken for the 12 items of perceived risk associated with sharing self-
316 generated health and lifestyle data with others, which indicated high internal consistency (Cronbach’s $\alpha =$
317 .90). All items correlated well with others (see supplement, Table S6, KMO score = .86, Bartlett’s Test
318 was significant ($X^2(66) = 1670.38, p < .001$), and communalities were all above .52. A single factor
319 solution that explained 48.76% of variance in the data was preferred. Therefore, subsequent treatment of
320 perceptions of risk used total summed scores of perceived risk, averaged to fit the existing scale parameters.

321 The SSCI-8 scale of perceived stigma was also shown to have high internal consistency
322 (Cronbach’s $\alpha = .89$). All items were well correlated with each other (see supplement, Table S7), KMO
323 score = .88, Bartlett’s Test was significant ($X^2(28) = 1138.45, p < .001$) and communalities were at .5
324 (except for 1 item). Principal component analysis extracted a single factor which corresponds with previous
325 validation of the scale as a unidimensional measure.^{48, 51}

326 Finally, the 17 items of the WISA scale were examined using a confirmatory factor analysis to
327 determine the model fit for the five previously identified factors (Privacy, Worth, Consequences, Low
328 Proximity Interest, and High Proximity Interest; see supplement, Figure S1 and Table S8) in accordance
329 with the original scale construction and validation.⁴⁹ The scale indicated acceptable internal consistency
330 (Cronbach’s $\alpha = .69$). Goodness of fit for the model was determined using 1) the X^2 goodness of fit statistic,
331 2) the Comparative Fit Index (CFI), and 3) Root Mean Square Error of Approximation (RMSEA). The
332 hypothesised model fit produced a significant X^2 statistic, $X^2(109) = 207.16, p < .001$, indicating poor
333 model fit. However, this test is often criticised for being too sensitive for sample sizes over 200.⁵² The two
334 remaining goodness of fit statistics produced results within accepted thresholds (CFI = .92, RMSEA = .06)
335 indicating that the five original factors should be considered a good fit to the data, in agreement with the
336 original scale construction and validation.⁴⁹ Therefore subsequent correlational analysis across measures
337 treated TIPS, Perceived Risk and SSCI-8 as single dimension measures, whereas perceived sensitivity of
338 health and lifestyle information considered treatment of five separate factors.

339

340 **Results**

341 *Descriptive Statistics*

342 Table 1 presents the descriptive statistics for our sample, whose ages ranged from 18-77 ($M = 39.20, SD$
343 $=14.78$).

Table 1. Sample characteristics for age, gender, ethnicity, and sexual orientation

	Category	Number (<i>N</i> = 250)	Percentage of sample
Age	18-34	108	43.2
	35-49	77	30.8
	50-64	50	20.0
	65+	15	6.0
Gender	Male	80	32.0
	Female	166	66.4
	Non-binary	2	.8
	Prefer to self-describe	2	.8
	Prefer not to say	0	0
Ethnicity	White - English/Welsh/Scottish/Northern Irish /British	220	88.0
	White - Irish	3	1.2
	White - Gypsy or Irish Traveller	1	.4
	White - Any other White background	10	4.0
	Mixed/Multiple ethnic groups - White and Black Caribbean	2	.8
	Mixed/Multiple ethnic groups - White and Asian	2	.8
	Asian/Asian British - Indian	2	.8
	Asian/Asian British - Bangladeshi	1	.4
	Asian/Asian British - Chinese	3	1.2
	Asian/Asian British - Any other Asian background	3	1.2
	Black/ African/Caribbean/Black British - African	1	.4
	Arab	1	.4
	Any other ethnic group	1	.4
	Prefer not to say	0	0
Sexual Orientation	Straight or Heterosexual	204	81.6
	Gay or Lesbian	12	4.8
	Bisexual	28	11.2
	Other sexual orientation	4	1.6
	Prefer not to say	2	.8

344

345 Demographic variables were collected to present the extent of diversity of the recruited sample. Gender
346 showed no effect on frequency of data recording or sharing, overall willingness to share, overall perceived
347 risk from sharing, overall TIPS concerns, levels of perceived stigma or overall WISA scores (see
348 supplement, Tables S12-14). There was no effect of age bracket on these variables with the exception of
349 overall perceived risk from sharing and overall WISA scores. However, post hoc analysis showed no
350 general trend with respect to age bracket (see supplement, Tables S12-14). Therefore, the reporting of
351 subsequent analysis and results will not discuss demographic variables.

352

353 Table 2 presents the frequencies for self-reported LTHCs reported by our sample, along with their reported
354 primary LTHCs. The most frequently reported LTHCs were depression ($n = 88$) and anxiety ($n = 87$). All
355 participants reported between one and nine LTHCs in total, ($M = 2.69$, $SD = 1.71$) and over 60% of our
356 sample reported having lived with their LTHC(s) for more than 10 years. The most commonly reported
357 primary LTHC was ‘Multiple LTHCs’ ($n = 47$), followed by depression ($n = 21$; see Table 2).

Table 2. Reported frequencies for LTHCs and Primary LTHCs

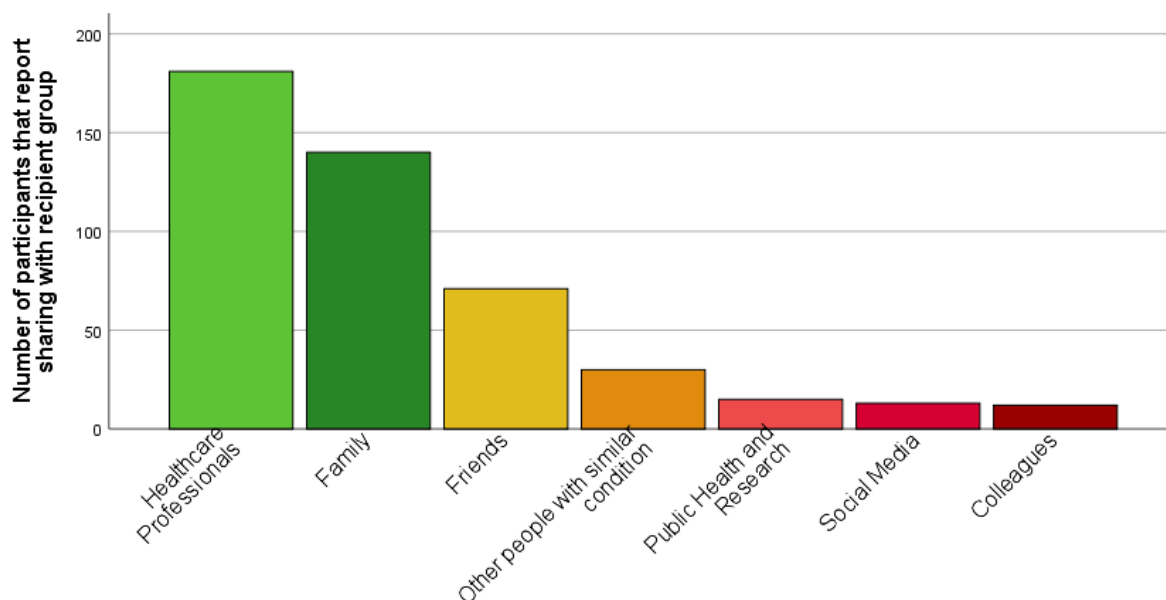
LTHC	Number of reports	Percentage of total LTHCs reported	Percentage of sample	Number reported as Primary LTHC	Percentage of sample reported as Primary LTHC
Acne	16	2.4	6.4	1	.4
Alcohol problems	5	0.7	2.0	0	0
Anorexia or bulimia	2	0.3	0.8	0	0
Anxiety	87	12.9	34.8	13	5.2
Asthma	46	6.8	18.4	17	6.8
Atrial fibrillation	2	0.3	0.8	2	.8
Bronchiectasis	1	0.1	0.4	1	.4
Cancer	6	0.9	2.4	4	1.6
Cardiovascular disease	3	0.4	1.2	1	.4
Chronic fatigue syndrome	19	2.8	7.6	11	4.4
Chronic kidney disease	3	0.4	1.2	1	.4
COPD	2	0.3	0.8	2	.8
Chronic sinusitis	2	0.3	0.8	1	.4
Chronic tissue disorder	2	0.3	0.8	0	0
Coronary heart disease	2	0.3	0.8	2	.8
Depression	88	13.1	35.2	21	8.4
Diabetes (type 1)	7	1.0	2.8	6	2.4
Diabetes (type 2)	12	1.8	4.8	4	1.6
Diabetes (type not specified)	6	0.9	2.4	5	2.0
Diverticular disease	4	0.6	1.6	0	0
Dyspepsia	4	0.6	1.6	1	.4
Endometriosis	11	1.6	4.4	5	2.0
Epilepsy	5	0.7	2.0	3	1.2
Erectile dysfunction	2	0.3	0.8	0	0
Glaucoma	1	0.1	0.4	0	0
Heart failure	3	0.4	1.2	1	.4
Hypertension	19	2.8	7.6	6	2.4
Incontinence	2	0.3	0.8	1	.4
Inflammatory bowel disease	7	1.0	2.8	5	2.0
Irritable bowel syndrome	30	4.5	12.0	4	1.6
Meniere's disease	3	0.4	1.2	0	0
Mental health condition	35	5.2	14.0	6	2.4
Migraine	31	4.6	12.4	5	2.0
Multiple sclerosis	6	0.9	2.4	5	2.0
Obesity	24	3.6	9.6	2	.8
Osteoporosis	6	0.9	2.4	2	.8
Painful conditions	38	5.7	15.2	14	5.6
Parkinson's disease	1	0.1	0.4	1	.4
Pernicious Anaemia	2	0.3	0.8	1	.4
Polycystic Ovary	12	1.8	4.8	3	1.2
Prostate disorders	1	0.1	0.4	0	0
Psoriasis/eczema	30	4.5	12.0	4	1.6
Schizophrenia or bipolar disorder	5	0.7	2.0	2	.8
Sexual health condition	2	0.3	0.8	0	0
Stroke/transient ischaemic attack	1	0.1	0.4	1	.4
Thyroid disorder	16	2.4	6.4	8	3.2
Treated constipation	2	0.3	0.8	0	0
Other condition	58	8.6	23.2	31	12.4
Multiple Long Term Conditions				47	18.8
Total	672	100	268.8	250	100

358 *Recording and sharing self-generated health and lifestyle data*

359 Across all presented information types, the mean participant response was that they record their health and
360 lifestyle data either ‘when the need arises’ or ‘less than once a month’. However, 75% of participants
361 reported recording at least one information type on a daily basis. The most common daily recorded
362 information type was ‘use of medication’ (35% of sample), followed by ‘mood’ (30%) and ‘sleep’ (28%;
363 see supplement, Table S1). The most commonly reported method for recording self-generated health and
364 lifestyle data was via mobile phone (50% of sample) followed by a written diary (42%) and smartwatch
365 tracker (18%; see supplement, Table S2).

366 Of our sample, 48% reported rarely sharing their health and lifestyle data with others, 19% reported
367 never sharing this data with others, 24% reported sometimes sharing, whereas few participants reported
368 often or always sharing their data with others (5% and 3% respectively). Of those who reported sharing
369 their self-generated health and lifestyle data with others (n=202), 74% reported sharing with HCPs, 60%
370 share with family and 34% with friends (see Figure 1).

371



372

373 **Figure 1.** Bar chart showing the sharing of self-generated health and lifestyle data by recipient groups for
374 participants who reported sharing with others (n = 202).
375

376

376 When asked about their overall perceptions and experiences of sharing self-generated health and
377 lifestyle data with others, 42% of participants reported that they felt it was positive overall, only 8% felt it
378 was mostly negative, whereas approximately 50% felt it was neither positive nor negative overall.
379 Similarly, 48% of all participants felt that sharing their health and lifestyle data with others would be
380 beneficial to them, 9% felt that it would be detrimental whereas 43% felt it would be neither beneficial nor
381 detrimental (see supplement, Table S3). When asked what motivates participants to share their data with
382 others, 73% of those who reported sharing self-generated health and lifestyle data with others (n=202)
383 agreed that they do so in order to better manage their own condition and to improve their own health.
384 Whereas, 55% of those that share agreed that they do so in order to improve the health of others. Similarly,
385 57% reported sharing in order to receive emotional support, whereas 49% reported doing so to provide

386 emotional support for others. Finally, 76% of those participants who reported sharing self-generated health
387 and lifestyle data with others agreed that they are motivated to do so in order to receive practical support
388 from others to help manage their condition (see supplement, Table S4). These findings indicate that not
389 only do the majority of participants in this sample see personal data sharing as beneficial for improving
390 their health, but also a large percentage perceived sharing with others as being beneficial for improving
391 the health of others.

392

393 *Perceptions of risk*

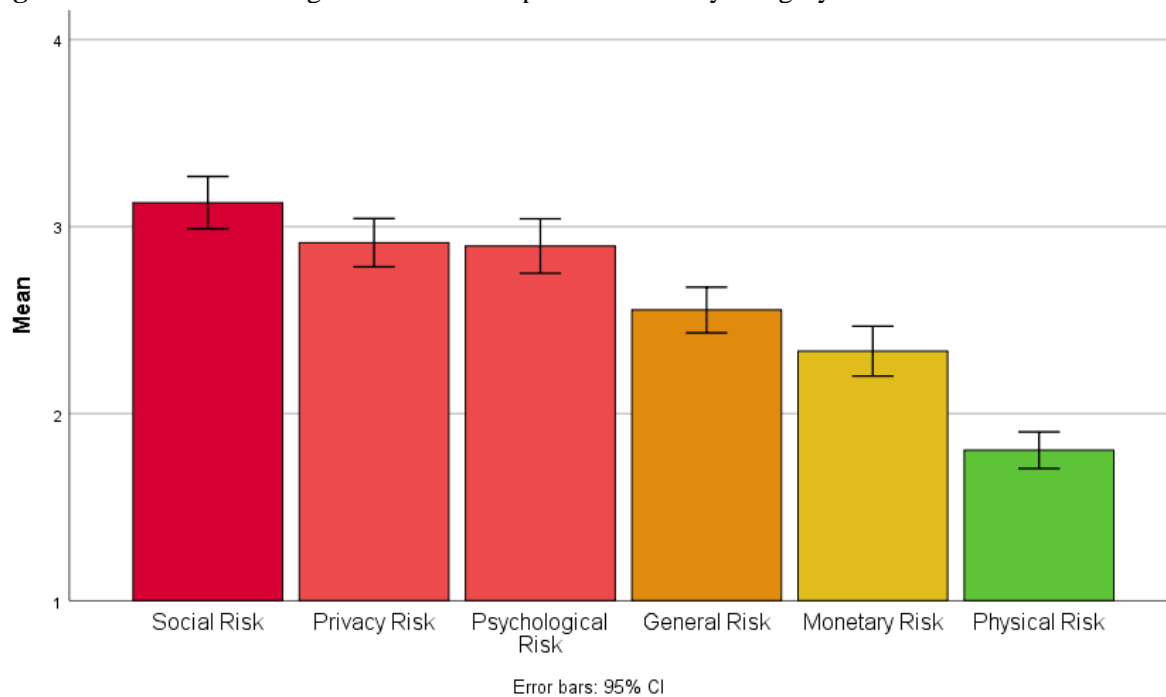
394 Approximately two thirds of our sample agreed that the benefits of sharing self-generated health and
395 lifestyle data with others outweigh the risks. Across all categories of risk, the average participant
396 response (mean and median) was that they ‘neither agreed nor disagreed’ that sharing self-generated
397 health and lifestyle data posed a risk. However, sharing self-generated health and lifestyle data with
398 others was considered to carry greater social risk and less physical risk than other categories of risk (see
399 Figure 2). For example, 54% of participants agreed that sharing health and lifestyle data would cause
400 others to act differently towards them.

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Figure 2. Bar chart showing mean scores for perceived risk by category



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Note: Raw scores were collected on a range from 1 (strongly disagree) to 5 (strongly agree; n = 250).

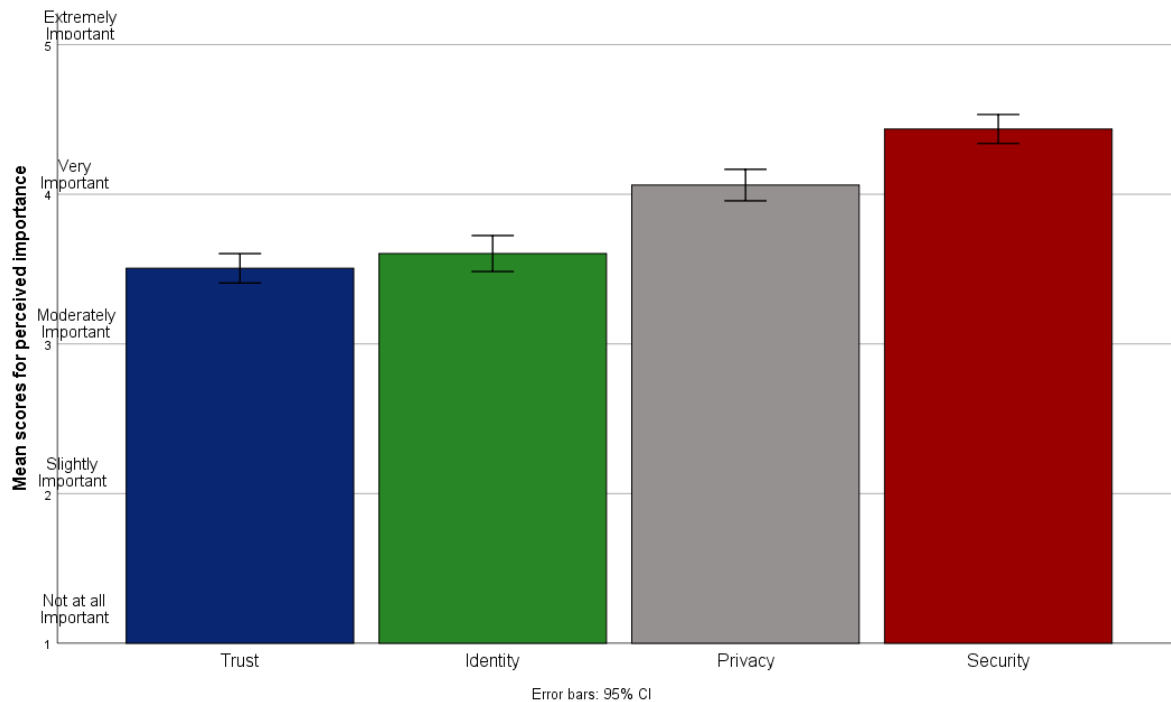
407 Overall perceived risk of sharing self-generated health and lifestyle data with others was negatively
408 correlated with both self-reported frequency of sharing with others ($r = -.18, p < .01$) and overall
409 willingness to share information with others ($r = -.24, p < .001$). Whilst participants reported perceived
410 benefits of sharing self-generated data for improving the health of themselves and others, they also
411 considered doing so to be risky and potentially harmful, with significant social implications.

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TIPS concerns

Participants on average (mean and median) considered statements concerning TIPS to be ‘very important’ when deciding whether or not to share self-generated health and lifestyle data with others. Statements pertaining to the security of health and lifestyle data were considered to be of the greatest importance compared to other TIPS concerns (see Figure 3).

Figure 3. Bar chart showing mean scores for TIPS concerns by category (n = 250).



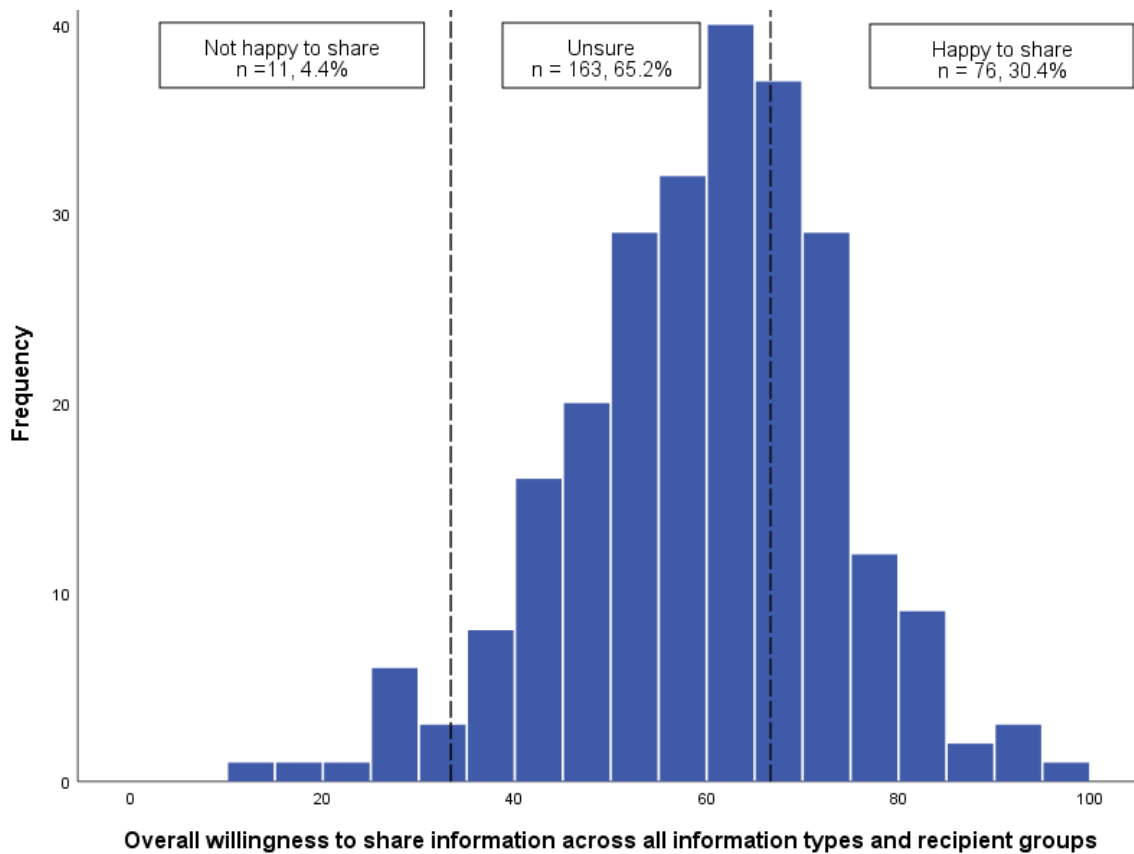
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Overall participant TIPS scores were negatively correlated with self-reported frequency of sharing self-generated health and lifestyle data with others ($r = -.19, p < .01$), as well as with overall willingness to share data with others ($r = -.16, p = .01$).

Attitudes towards sharing self-generated health and lifestyle data with others

The mean score for overall willingness to share across all information types and recipient groups was 59.51, SD = 14.12 (0 = not willing to share, 50 = unsure, and 100 = yes, willing to share) suggesting that participants were generally unsure about sharing their self-generated health and lifestyle data with others (see Figure 4). For recipient group, greatest willingness to share was reported for sharing with HCPs (M = 84.42, SD = 15.49) and lowest for sharing via Social Media platforms (M = 28.40, SD = 21.73; see Figure 5). For information type, greatest willingness to share with others was reported for sharing demographic information (M = 72.95, SD = 16.57) and lowest for information of a sexual nature (M = 33.07, SD = 20.55; see Figure 6).

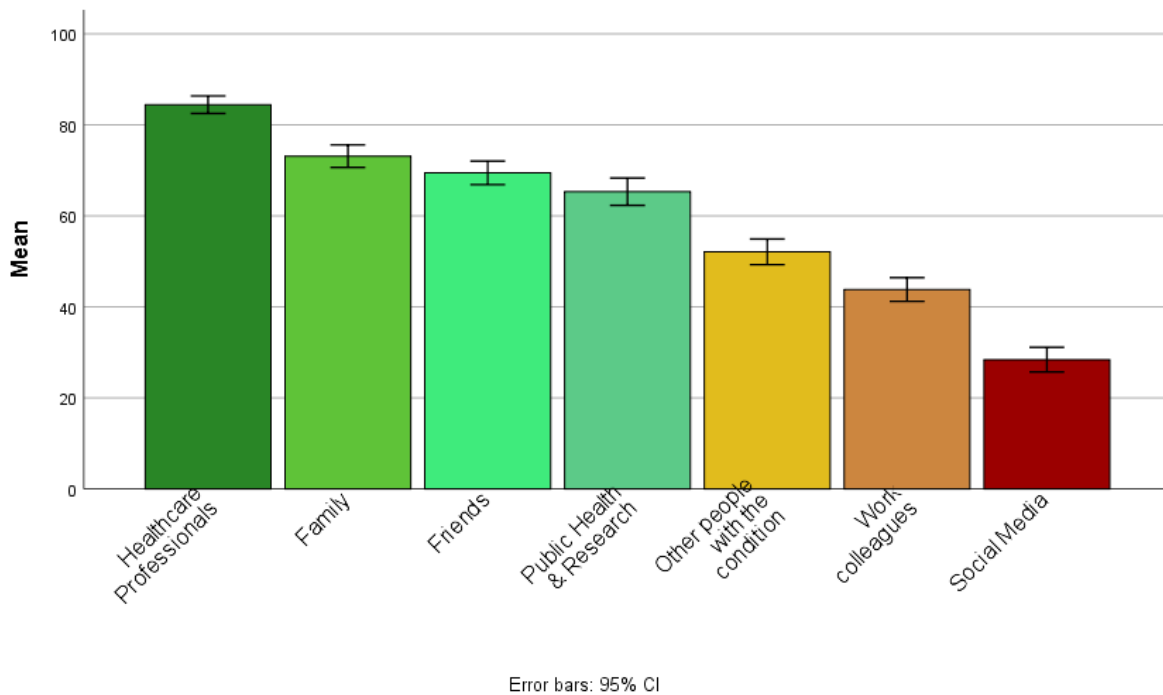
437 **Figure 4.** Histogram showing the distribution of overall willingness to share information across all
 438 information types and recipient groups (n = 250).



439

440

441 **Figure 5.** Bar chart showing mean willingness to share self-generated health and lifestyle information
 442 with others, by recipient group



443

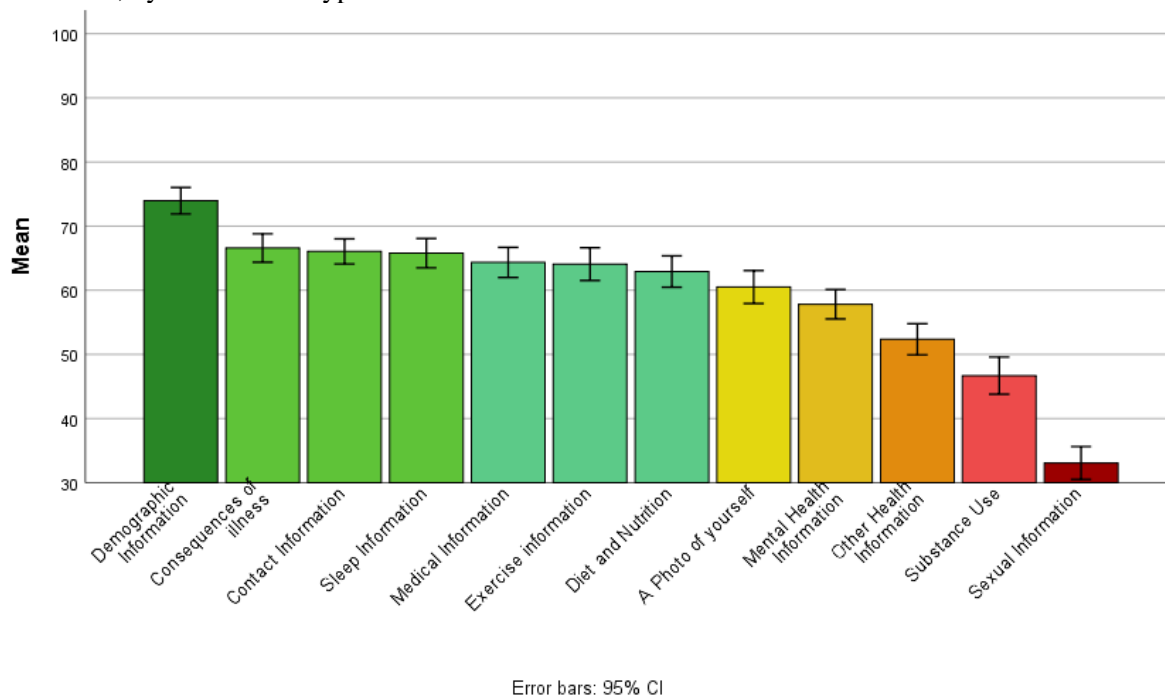
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Note: 0 represents 'not happy to share', 50 represent 'unsure' and 100 represent 'yes, happy to share' (n = 250).

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Figure 6. Bar chart showing mean willingness to share self-generated health and lifestyle information with others, by information type



Error bars: 95% CI

449
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451

Note: 0 represents 'not happy to share', 50 represent 'unsure' and 100 represent 'yes, happy to share' (n = 250).

452

Stigma

453 Of our sample, 58% reported feeling that they had experienced stigma as a result of their LTHC(s). Most
454 notably, 51% of those who reported suffering from anxiety (44 out of 87), 63% of those with depression
455 (55 out of 88), and 66% with a mental health condition (23 out of 35) felt they had experienced stigma
456 because of having their condition (see supplement, Table S9). There was no difference between those who
457 reported experiencing stigma as a result of their LTHC(s) and those who did not with respect to the
458 frequency of data sharing ($t(248) = .21, p = .83$), overall willingness to share with others ($t(248) = .23, p =$
459 $.77$) or overall TIPS concerns ($t(248) = 1.32, p = .19$). However, those who reported experiencing stigma
460 associated with their condition did report higher levels of overall perceived risk from sharing self-generated
461 health and lifestyle data with others ($t(248) = 4.91, p < .001$) and higher overall WISA scores for perceived
462 information sensitivity ($t(248) = 3.47, p < .001$). Similarly, there was a strong positive correlation between
463 levels of perceived stigma, measured by the SSCI-8, and perceptions of risk associated with sharing self-
464 generated health and lifestyle data with others ($r = .45, p < .001$).

465

Perceived sensitivity of health and lifestyle data

467 Total WISA Scale scores were positively correlated with greater total TIPS concerns ($r = .29, p < .001$) as
468 well as with overall perceived risk from sharing self-generated health and lifestyle data with others ($r =$
469 $.34, p < .001$), indicating that greater perceived sensitivity of health and lifestyle data is associated with
470 higher perceived risk and concerns about TIPS. From the individual WISA factors of perceived sensitivity
471 of health and lifestyle data, scores for perceived privacy of data were negatively associated with both self-
472 reported frequency of sharing with others ($r = -.19, p < .01$) and overall willingness to share data with others

473 (r = - .17, p < .01). Scores for perceiving health and lifestyle data as humiliating, embarrassing,
474 discreditable or compromising (the ‘consequences’ factor from the WISA scale) were strongly associated
475 with overall perceived risk from sharing health and lifestyle data with others (r = .52, p < .001).
476 Furthermore, ‘consequences’ was the only factor from the WISA scale to be significantly higher in those
477 participants who reported experiencing stigma associated with their condition ($M_{\text{stigma}} = 2.77$) compared to
478 those who did not ($M_{\text{no-stigma}} = 2.10$; $t(248) = 6.26, p < .001$). Finally, those who perceived their health and
479 lifestyle information as being of interest to their friends and family (the ‘high proximity interest’ factor
480 from the WISA scale) reported more frequent sharing with others (r = .21, p < .01) and greater overall
481 willingness to share with others (r = .38, p < .001). For full correlational results for the WISA scale, see
482 supplement Table S10).

483

484 *Technology Preferences*

485 When asked about the importance of proposed features for sharing health and lifestyle data via a digital
486 platform, the highest mean scores of importance showed a preference for platforms that are trustworthy
487 (M = 4.79, SD = .50; 0 and 5 representing ‘not at all important’ and ‘extremely important’ respectively)
488 and platforms that store data securely (M = 4.78, SD = .54). Whereas, the features perceived to be of least
489 importance were allowing users to store handwritten data (M = 2.18, SD = 1.26) and allowing users to
490 interact socially with others via the platform (M = 2.44, SD = 1.22; see supplement Table S11).

491

492

493 **Discussion**

494 Our findings suggest that a number of factors influence both the frequency of sharing and overall
495 willingness to share self-generated health and lifestyle data with others by people living with LTHCs. The
496 degree to which issues concerning TIPS are considered to be important was negatively associated with
497 frequency of sharing and overall willingness to share. Secure storage, access and the presence of safeguards
498 to protect health and lifestyle data were reported to be the most important of all TIPS issues. Furthermore,
499 greater perceived risk associated with sharing self-generated health and lifestyle data with others predicted
500 lower frequency of sharing and overall willingness to share. The potential for harm to one’s social
501 relationships was considered the most pressing risk associated with sharing self-generated health and
502 lifestyle data with others. The proposed recipient and information type were also found to influence
503 willingness to share. Participants were most willing to share with HCPs and least willing to share via Social
504 Media. For information type, participants reported being most willing to share demographic information
505 and least willing to share any information of a sexual nature. Finally, with respect to the perceived value
506 and sensitivity of information, the extent to which health and lifestyle data was believed to be of value to
507 close friends and family was positively associated with increased sharing frequency and willingness to
508 share. We discuss the implications of these key findings and make suggestions for the future design of
509 digital platforms that look to facilitate the sharing of self-generated health and lifestyle data.

510

511

512 *Those with LTHC(s) report high levels of data recording but low levels of sharing with others*

513 Three quarters of our sample reported recording information about their health and lifestyle on a daily
514 basis, with the most common method of data collection being via mobile phone. This is unsurprising given
515 the recent proliferation of mobile health apps online with more than 250,000 available for download on
516 smart devices.⁵³ However, despite high levels of self-recording of health and lifestyle data, two thirds of
517 our sample reported never or rarely sharing this information with others. Although participants were
518 broadly willing to share health and lifestyle data with their HCPs, they were mostly unsure about whether
519 or not to share for public health surveillance and research. Integrating self-generated health and lifestyle
520 data into public health work is a widespread aspiration internationally.⁵⁴ Data from mobile devices, health
521 trackers and handwritten journals have the potential to document longitudinal health information not
522 ordinarily captured by routine health consultations, and identify causal pathways in health not yet
523 considered.^{55, 56} These new data have significant potential for bridging the gap between a patient's life in
524 and outside of a doctor's consultation room, as well as to empower patients to better manage their health.⁵⁷
525 Participants who reported sharing self-generated health and lifestyle data with others were most motivated
526 to share health and lifestyle data by the potential to receive practical support from others to help manage
527 their condition. This may include receiving assistance to complete daily activities, or extra support in
528 fulfilling work and caring responsibilities when an individual's symptoms make these difficult to manage.
529 Given the range of potential benefits for both individual patients and public health, as well as the reported
530 motivations for sharing data with others, it is critical that we more fully understand the barriers to effective
531 sharing, particularly with HCPs.

532

533 *TIPS concerns are very important when deciding whether to share with others, with Security being the*
534 *most important*

535 Overall, participants considered TIPS concerns as being 'very important' when deciding whether or not to
536 share self-generated health and lifestyle data with others. This supports previous research that found
537 concerns relating to issues of Trust, Identity, Privacy and Security to strongly influence the sharing of
538 health data via Internet-enabled technology.²¹⁻²⁴ Our investigation into the perceptions of those living with
539 a broad range of LTHCs supports the findings of previous research from our broader research programme
540 into TIPS considerations that people living with HIV make when sharing data with each other.²¹
541 Specifically, TIPS considerations are very important to both those with HIV and those living with a range
542 of LTHCs when deciding whether or not to share health and lifestyle data with others. Furthermore,
543 deciding to share is often dependent on the context of the sharing, the type of data being shared, and the
544 proposed recipient.

545 Positive associations were found between the increased perceived importance of TIPS concerns
546 when sharing data with others, and lower frequency of sharing and lower overall willingness to share. This
547 suggests that those with heightened TIPS concerns may be less willing to share self-generated health and
548 lifestyle data with others. Out of the four separate components of TIPS, security concerns were considered

549 most important. Previous findings have suggested that patients in the UK are often worried about the ability
550 of the NHS and public health to guarantee the security of personal health data.⁵⁸ Underlying concerns for
551 the security of personal information have been specifically reported by those living with stigmatised
552 LTHCs.⁵⁹ Security was also reported as a priority when our sample were asked about which features of a
553 digital platform (such as a mobile app) they thought would be most important for encouraging them to
554 share self-generated health and lifestyle data with others. Again, this supports the findings of research into
555 TIPS concerns of those living with HIV when sharing data with each other. Previous research found that
556 participants wanted tight security measures ‘akin to banking apps’ and strict identity verification in order
557 to facilitate the sharing of health and lifestyle data.²¹

558

559 *Heightened perceptions of risk reduce willingness to share*

560 Those who perceived greater risk associated with sharing their health and lifestyle data with others reported
561 lower frequency of sharing and were generally less willing to share health and lifestyle data with others.
562 Of the presented categories of risk (general risk, social risk, privacy risk, psychological risk, physical risk,
563 and monetary risk) social risk was considered to carry the most weight with over half of participants
564 agreeing that sharing health and lifestyle data would likely cause others to act differently towards them.
565 ‘Social risk’ refers to the potential to lose one’s standing in a societal group.⁴⁵ Our results suggest that
566 many of those living with LTHCs believe that sharing certain aspects of their health and lifestyle data
567 would alter the dynamics of their relationships with others. This may help to explain our finding that having
568 the ability to socialise via a digital health data sharing app was described by our sample as one of the least
569 preferred features. Given that the greatest degree of reported concern was for social risks, future studies
570 may look to investigate specific social fears and to explore ways of mitigating the perceived risks
571 associated with potential damage to social relationships. Furthermore, research may look to investigate
572 concerns about social risks in the context of sharing between patients and HCPs; a context where sharing
573 may be considered to pose less of a threat to one’s social relationships than sharing with family, friends,
574 colleagues and those living with a similar LTHC.

575

576 *Perceived sensitivity of health and lifestyle data*

577 Perceived sensitivity of health and lifestyle data overall was positively associated with TIPS concerns,
578 suggesting that the more sensitive those living with LTHCs believe their health information to be, the more
579 concerned they are about TIPS when considering whether or not to share their data with others. From the
580 specific factors of what participants believe makes their data more sensitive, those who perceived their
581 health and lifestyle information as being of interest to their friends and family reported more frequent
582 sharing with others and greater overall willingness to share their data. Family and broader social support
583 have been highlighted as playing a key role in managing LTHCs, suggesting a positive relationship
584 between social support and chronic illness self-management.^{60, 61} Consolidating our results, we suggest that
585 understanding your health information to be of value and interest to those around you makes you more
586 likely to share self-generated health and lifestyle data with others. Given the discussed potential benefits

587 for health and care management, this key finding highlights the important role that family and close social
588 networks can play in promoting the effective sharing of data and helping to manage LTHCs.

589

590 *Those experiencing LTHC-related stigma reported higher levels of perceived risk associated with sharing*

591 Of our sample, 58% reported experiencing stigma as a result of their LTHC(s). Most notably, more than
592 half of participants with anxiety, and roughly two-thirds of those suffering from depression or other mental
593 health conditions reported having experienced stigma in relation to their LTHC. This supports an
594 established body of literature suggesting that despite improvements to mental health awareness in recent
595 years, experiences of stigma continue to be reported by those who manage mental health conditions.^{33, 62,}

596 ⁶³ Reports of experienced stigma among those living with LTHCs are concerning given that such
597 experiences of stigma may have a detrimental impact on health and lead to delays in seeking diagnosis and
598 treatment.^{32, 64, 65} Contrary to our registered predictions, those who reported experiencing stigma associated
599 with their condition did not report lower frequency of sharing compared to those without experiences of
600 stigma. That said, it is possible that this may be explained by the overall low levels of frequency of sharing
601 health and lifestyle data with others reported by our sample. It should also be noted that our sample did not
602 include anyone living with HIV. HIV is typically associated with experiences of stigma,^{21, 37, 66} therefore
603 further research may look to directly compare the experiences and perceptions of stigma reported by those
604 living with HIV, with those living with different LTHCs. However, from our sample, those with
605 experiences of LTHC-related stigma were more sensitive to the potential for negative consequences as a
606 result of sharing health and lifestyle data with others, and reported higher levels of perceived risk. These
607 negative consequences related to the potential for humiliation and social embarrassment which suggests
608 that experiencing stigma associated with your LTHC may make you more fearful of the potentially harmful
609 social consequences from sharing your health and lifestyle data with others. There was also a strong
610 correlation between perceptions of risk associated with sharing and perceptions of condition-related
611 stigma, suggesting that beliefs around stigma are closely related to perceptions of risk.

612

613 *Designing digital platforms for sharing self-generated health and lifestyle data with others*

614 Our study delivers a number of key findings that may inform the design of digital platforms for sharing
615 self-generated health and lifestyle data with others by those living with LTHCs. Firstly, the high degree of
616 self-recording of health and lifestyle data via digital devices, combined with the generally reported belief
617 that sharing this data with others can be beneficial, suggests that there is potential for widespread sharing
618 via digital platforms, provided that key barriers to sharing can be overcome.

619 Our findings suggest that digital platforms that highlight the secure storage, access and presence
620 of digital safeguards to protect self-generated health and lifestyle data may enhance trusted sharing. This
621 was further emphasised by issues concerning security being considered the most important individual TIPS
622 area by people living with LTHCs. Additionally, overall willingness to share via digital platforms may be
623 affected by the categories of information that are requested. People with LTHCs reported a general
624 willingness to share demographic data, but were least willing to share information of a sexual nature.

625 Therefore, digital platforms that provide individuals with control over which categories of information are
626 both recorded, requested and shared may help to enable the trusted sharing of self-generated health and
627 lifestyle data.

628 Participants reported greatest willingness to share with HCPs and were most motivated to share
629 by the potential to improve their health and receive practical support to better manage their condition(s).
630 Digital platforms that emphasise the practical benefits of sharing self-generated health and lifestyle data
631 may encourage increased sharing. This may be achieved by digital platforms presenting users with practical
632 examples of how self-generated health and lifestyle data is used to facilitate improved diagnosis, treatment
633 and delivery of care. Our findings also suggest that demonstrating to the users of such digital platforms
634 how this data could be used to improve the health of others may also enhance trusted sharing. Participants
635 were least willing to share self-generated health and lifestyle data via social media. This suggests that
636 digital platforms designed for the sharing of health and lifestyle data that also look to facilitate broader
637 connections via social media, may be ineffective in encouraging sharing. People may want platforms for
638 sharing their *data* that remain separate from those that support more social interactions. Indeed, the
639 reported technological preferences of our sample indicate that the ability to interact socially via a digital
640 platform for sharing health and lifestyle data is considered to be of little value. This may be due to a general
641 distrust in social media and speaks to the previously discussed concerns about the potential for social harm
642 as a result of sharing self-generated health and lifestyle data with others.

643

644 *Limitations and future work*

645 Our sample reported living with LTHCs that were widely distributed across more than 50 different
646 categories of health condition. Despite adding to the richness and diversity of our sample, due to the small
647 number of participants for each health condition, we were unable to draw meaningful comparisons across
648 different LTHCs. Further research may look to target specific LTHCs of interest to investigate differences
649 between conditions in attitudes towards sharing self-generated health and lifestyle data with others. This
650 will help to determine the extent to which the perceptions and experiences of specific groups differ from
651 the broader category of those living with LTHCs with respect to the sharing of self-generated health and
652 lifestyle data with others. An additional limitation concerning our sample relates to our use of an online
653 recruitment platform, through which participants had already elected to share personal information such
654 as their age, gender, ethnicity and health status. It is possible that participants recruited via this platform
655 may be more willing than the broader UK population to share self-generated health and lifestyle data with
656 others, introducing a potential bias.

657 In addition, the most commonly reported primary care need of our respondents was living with
658 multiple LTHCs. Previous research has suggested that living with multiple LTHCs can threaten one's self-
659 image and identity, lead to experiences of stigma and impaired quality of life.^{67, 68} A recent review
660 examining digital interventions for people living with multiple LTHCs highlighted that there is still little
661 evidence for successful health information technology solutions that improve care for those living with
662 multiple conditions.⁶⁹ Given the increasing normality of living with multiple LTHCs, understanding more

663 about the ways in which people with multiple conditions consider and manage their digital health will also
664 impact upon the design of technological solutions to improve support overall.

665 Finally, future research may look to examine attitudes towards the automatic and unintentional
666 sharing of data with the providers of digital platforms and devices. Many users have little knowledge of
667 how their data is used and shared. A recent literature review suggested that a lack of attention has been
668 given to understanding attitudes towards the sharing of health and lifestyle data with third parties, which
669 suggests the need for future study.⁷⁰

670

671 **Conclusion**

672 Despite those living with LTHCs reporting high levels of daily recording of health and lifestyle data, these
673 data are rarely shared with others. Those with LTHCs are most willing to share with their HCPs, but the
674 overall low levels of sharing suggest a potential missed opportunity for public health professionals to gather
675 valuable information that may provide key insights for improving care at a population level. Personal
676 security concerns were found to present the greatest barrier to sharing; and security has been highlighted
677 as a key desired feature for digital platforms that facilitate the sharing of health and lifestyle data with
678 others. This has direct implications for the design of digital tools that look to facilitate the effective sharing
679 of self-generated health and lifestyle data, and suggests that prioritising dependable security features is
680 likely to encourage sharing. Experiences and perceptions of stigma as a consequence of a person's
681 condition(s) were strongly associated with increased levels of perceived risk relevant to sharing personal
682 health and lifestyle data with others. Participants were most concerned about the potential harm that may
683 be caused to one's social relationships as a result of sharing health and lifestyle data with others. This has
684 implications for the design of digital platforms aimed at facilitating the sharing of self-generated health
685 and lifestyle data and suggests that features that look to incorporate broader sharing via social media may
686 be ineffective in enhancing data sharing. The findings of this study offer strategic considerations for further
687 focused digital health research to address data security concerns in the enhanced use of self-generated
688 health and lifestyle data, and to understand the perceived risks and negative consequences associated with
689 data sharing. Addressing these concerns will be necessary to overcome current barriers and to encourage
690 the effective sharing of self-generated health and lifestyle data by those living with LTHCs.

691

692 **Acknowledgements**

693 This study has been conducted as part of a UK EPSRC funded programme ("INTUIT: Interaction Design
694 for Trusted Sharing of Personal Health Data to Live Well with HIV", 2020; EP/R033900/2), examining
695 TIPS concerns around the sharing of self-generated health and lifestyle data primarily among people living
696 with HIV but also for those with other potentially stigmatised conditions.

697

698 **Declarations**

699 **Conflicting interests:** The authors declare that there are no conflicts of interest.

700 **Funding:** This work is funded by the EPSRC, grant number EP/R 033900/1.

701 ***Ethical approval:*** This study was approved by the Department of Psychology Ethics Committee
702 at Northumbria University (ethical approval number 26581).

703 ***Guarantors:*** RB, LC and ES shall act as guarantors, taking responsibility for the contents of this article.

704 ***Contributorship:*** LC, ES, JG, ST, and AD developed the concept for the study. LC, ES and RB developed
705 the study materials, protocol and facilitated the data collection. RB conducted the data analysis and wrote
706 the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final
707 version of the document.

708 ***Data availability:*** An anonymised data set for this study will be made available on the Open Science
709 Framework (osf.io/h3mjb/) upon publication of this manuscript.

710 **References**

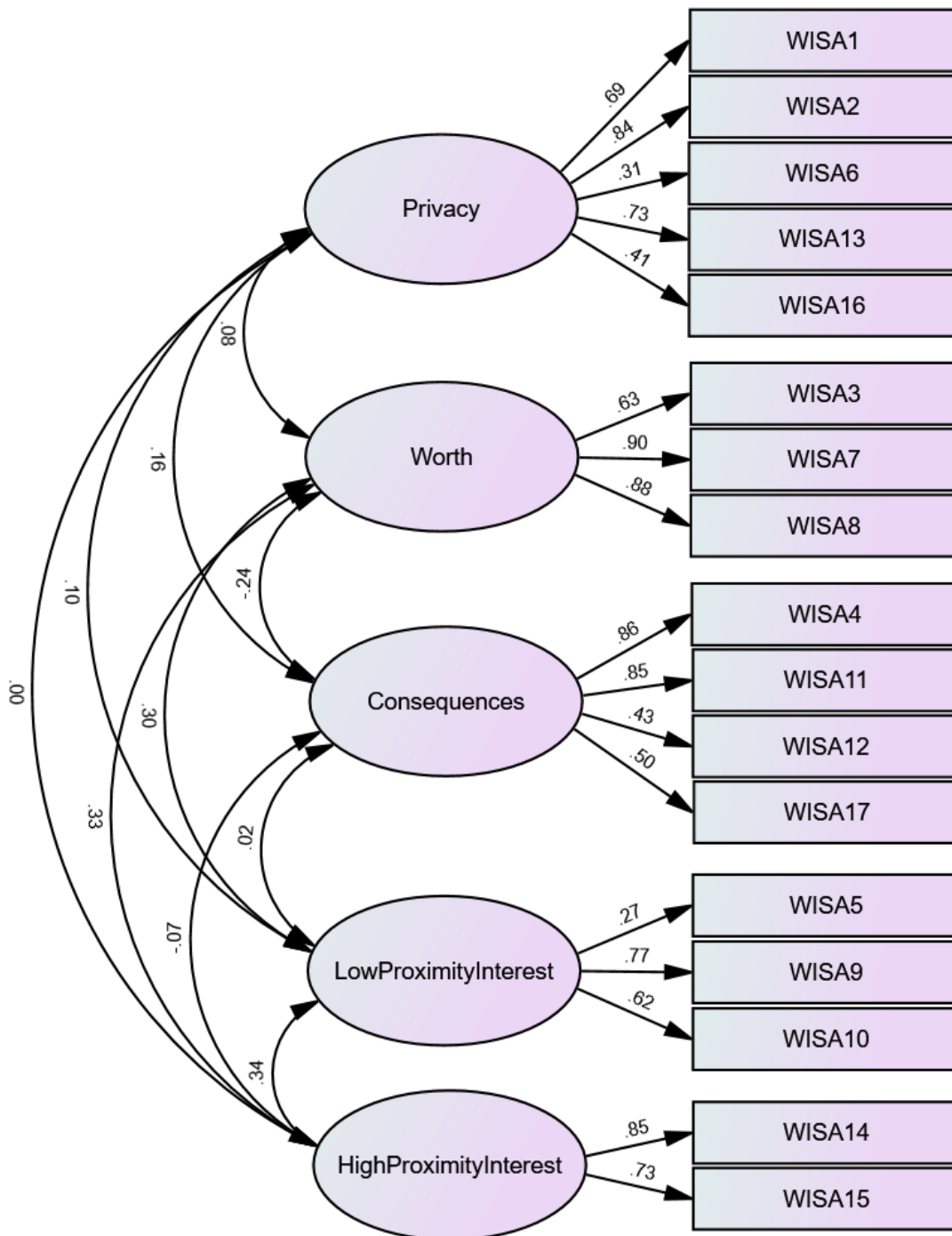
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889 **Figure S1.** Confirmatory Factor Analysis model for WISA scale for perceived sensitivity of information
 890 showing standardised estimates between factors and scale items.

891 **Table S1.** Frequency of daily reported data collection by information type (n = 250)

Information Type	Number	Percentage of Sample
Use of medication	88	35.2
Effects of medication	45	18.0
Pain levels	42	16.8
Blood pressure	8	3.2
Blood Sugar	13	5.2
Heart rate	21	8.4
Diet	57	22.8
Sleep	70	28.0
Exercise	63	25.2
Weight	23	9.2
Mood	75	30.0
Water intake	70	28.0
Alcohol consumption	16	6.4
Recreational drug use	7	2.8
Sexual activity	4	1.6
Location	10	4.0
Other Data	6	2.4

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893 **Table S2.** Frequency of reported data collection by method (n = 250)

Data Collection Method	Number	Percentage of Sample
Physical Diary or Journal	105	42.0
Other handwritten record	33	13.2
Smartwatch tracker	45	18.0
Clip-on activity tracker	1	0.4
Wrist tracker	39	15.6
Chest Monitor	2	0.8
Mobile Phone	126	50.4
E-tablet	5	2.0
Laptop or Desktop computer	39	15.6
Other	31	12.4

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896 **Table S3.** Self-reported beliefs about sharing self-generated health and lifestyle data with others (n =
 897 250)

Belief measured	Number	Percentage of sample
Improves my Understanding		
Not at all	16	6.4
A little	90	36.0
A moderate amount	76	30.4
A lot	46	18.4
A great deal	22	8.8
Benefit to others		
Not at all	27	10.8
A little	92	36.8
A moderate amount	72	28.8
A lot	49	19.6
A great deal	10	4.0
Overall Experience (+/-)		
Extremely negative	7	2.8
Somewhat negative	14	5.6
Neither positive nor negative	124	49.6
Somewhat positive	95	38.0
Extremely positive	10	4.0
Beneficial to wellbeing		
Extremely detrimental	5	2.0
Somewhat detrimental	17	6.8
Neither detrimental nor beneficial	108	43.2
Somewhat beneficial	102	40.8
Extremely beneficial	18	7.2

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901 **Table S4.** Self-reported motivations for sharing by those participants that reported sharing self-generated
 902 health and lifestyle data with others (n = 202)

Motivation measured	Number	Percentage of Sample
Improve my health		
Strongly disagree	12	5.9
Somewhat disagree	13	6.4
Neither agree nor disagree	29	14.4
Somewhat agree	107	53.0
Strongly agree	41	20.3
Improve your health		
Strongly disagree	15	7.4
Somewhat disagree	21	10.4
Neither agree nor disagree	55	27.2
Somewhat agree	89	44.1
Strongly agree	22	10.9
Receive emotional		
Strongly disagree	22	10.9
Somewhat disagree	33	16.3
Neither agree nor disagree	32	15.8
Somewhat agree	86	42.6
Strongly agree	29	14.4
Give emotional		
Strongly disagree	26	12.9
Somewhat disagree	41	20.3
Neither agree nor disagree	37	18.3
Somewhat agree	78	38.6
Strongly agree	20	9.9
Receive practical		
Strongly disagree	8	4.0
Somewhat disagree	13	6.4
Neither agree nor disagree	27	13.4
Somewhat agree	108	53.5
Strongly agree	46	22.8

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Table S5. Inter-Item Correlation Matrix for 12-Item TIPS measure

	T1	T2	T3	I1	I2	I3	P1	P2	P3	S1	S2	S3
Trust1 (T1)	1.00											
Trust2 (T2)	0.46	1.00										
Trust3 (T3)	0.21	0.17	1.00									
Identity1 (I1)	0.13	0.15	0.33	1.00								
Identity2 (I2)	0.24	0.24	0.07	0.42	1.00							
Identity3 (I3)	0.29	0.23	0.12	0.25	0.60	1.00						
Privacy1 (P1)	0.17	0.28	0.26	0.60	0.35	0.30	1.00					
Privacy2 (P2)	0.36	0.26	0.21	0.21	0.42	0.53	0.38	1.00				
Privacy3 (P3)	0.30	0.37	0.12	0.31	0.50	0.40	0.45	0.53	1.00			
Security1 (S1)	0.32	0.40	0.07	0.20	0.32	0.35	0.24	0.39	0.37	1.00		
Security2 (S2)	0.31	0.37	0.11	0.09	0.33	0.46	0.25	0.47	0.36	0.59	1.00	
Security3 (S3)	0.29	0.38	0.09	0.20	0.33	0.37	0.22	0.41	0.37	0.74	0.68	1.00

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Table S6. Inter-Item Correlation Matrix for 12-Item measure of perceived risk associated with sharing self-generated health and lifestyle data

	G1	G2	S1	S2	Pr1	Pr2	Psy1	Psy2	Ph1	Ph2	M1	M2
Generalrisk1 (G1)	1.00											
Generalrisk2 (G2)	0.65	1.00										
Socialrisk1 (S1)	0.49	0.54	1.00									
Socialrisk2 (S2)	0.40	0.50	0.77	1.00								
Privacyrisk1 (Pr1)	0.60	0.58	0.55	0.51	1.00							
Privacyrisk2 (Pr2)	0.41	0.43	0.31	0.24	0.58	1.00						
Psychologicalrisk1 (Psy1)	0.48	0.52	0.59	0.55	0.59	0.33	1.00					
Psychologicalrisk2 (Psy2)	0.48	0.51	0.64	0.51	0.53	0.34	0.79	1.00				
Physicalrisk1 (Ph1)	0.42	0.49	0.45	0.37	0.44	0.34	0.53	0.64	1.00			
Physicalrisk2 (Ph2)	0.29	0.31	0.21	0.23	0.24	0.28	0.22	0.31	0.46	1.00		
Monetaryrisk1 (M1)	0.35	0.41	0.48	0.52	0.34	0.24	0.46	0.43	0.35	0.32	1.00	
Monetaryrisk2 (M2)	0.28	0.39	0.33	0.38	0.29	0.32	0.31	0.29	0.34	0.42	0.66	1.00

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Table S7. Inter-Item Correlation Matrix for 8-Item measure of perceived stigma (SSCI-8)

	SSCI1	SSCI2	SSCI3	SSCI4	SSCI5	SSCI6	SSCI7	SSCI8
SSCI1	1.00							
SSCI2	0.84	1.00						
SSCI3	0.64	0.67	1.00					
SSCI4	0.62	0.67	0.60	1.00				
SSCI5	0.53	0.61	0.43	0.61	1.00			
SSCI6	0.51	0.49	0.53	0.43	0.39	1.00		
SSCI7	0.36	0.37	0.49	0.39	0.39	0.58	1.00	
SSCI8	0.58	0.62	0.54	0.54	0.42	0.44	0.29	1.00

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915 **Table S8.** Confirmatory Factor Analysis for WISA scale for perceived sensitivity of information
 916 showing standardised regression weights for each item and factor.

Item		Factor	Estimate
WISA1	<---	Privacy	.694
WISA2	<---	Privacy	.838
WISA6	<---	Privacy	.310
WISA13	<---	Privacy	.726
WISA16	<---	Privacy	.408
WISA3	<---	Worth	.625
WISA7	<---	Worth	.900
WISA8	<---	Worth	.881
WISA4	<---	Consequences	.858
WISA11	<---	Consequences	.849
WISA12	<---	Consequences	.426
WISA17	<---	Consequences	.500
WISA5	<---	Low Proximity Interest	.267
WISA9	<---	Low Proximity Interest	.774
WISA10	<---	Low Proximity Interest	.623
WISA14	<---	High Proximity Interest	.851
WISA15	<---	High Proximity Interest	.733

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Table S9. Frequency of reported stigma associated with specific LTHCs.

LTHC	Number	Percentage of all LTHCs reported	Percentage of sample with condition	Number of stigma by condition	Percentage of sample report stigma by condition
Acne	16	2.40	6.40	8	50.00
Alcohol Problems	5	0.70	2.00	1	20.00
Anorexia or Bulimia	2	0.30	0.80	1	50.00
Anxiety	87	12.90	34.80	44	50.57
Asthma	46	6.80	18.40	3	6.52
Atrial Fibrillation	2	0.30	0.80	0	0.00
Bronchiectasis	1	0.10	0.40	1	100.00
Cancer	6	0.90	2.40	2	33.33
Cardiovascular Disease	3	0.40	1.20	1	33.33
Chronic Fatigue Syndrome	19	2.80	7.60	9	47.37
Chronic Kidney Disease	3	0.40	1.20	1	33.33
COPD	2	0.30	0.80	2	100.00
Chronic Sinusitis	2	0.30	0.80	2	100.00
Chronic Tissue Disorder	2	0.30	0.80	1	50.00
Coronary Heart Disease	2	0.30	0.80	0	0.00
Depression	88	13.10	35.20	55	62.50
Diabetes_Type_1	7	1.00	2.80	6	85.71
Diabetes_Type_2	12	1.80	4.80	0	0.00
Diabetes (Type not specified)	6	0.90	2.40	2	33.33
Diverticular Disease	4	0.60	1.60	0	0.00
Dyspepsia	4	0.60	1.60	1	25.00
Endometriosis	11	1.60	4.40	5	45.45
Epilepsy	5	0.70	2.00	2	40.00
Erectile Dysfunction	2	0.30	0.80	0	0.00
Glaucoma	1	0.10	0.40	0	0.00
Heart Failure	3	0.40	1.20	1	33.33
Hypertension	19	2.80	7.60	4	21.05
Incontinence	2	0.30	0.80	2	100.00
Inflammatory Bowel Disease	7	1.00	2.80	3	42.86
Irritable Bowel Syndrome	30	4.50	12.00	9	30.00
Meniere's Disease	3	0.40	1.20	1	33.33
Mental Health Condition	35	5.20	14.00	23	65.71
Migraine	31	4.60	12.40	9	29.03
Multiple Sclerosis	6	0.90	2.40	4	66.67
Obesity	24	3.60	9.60	14	58.33
Osteoporosis	6	0.90	2.40	1	16.67
Painful Conditions	38	5.70	15.20	13	34.21
Parkinson's Disease	1	0.10	0.40	1	100.00
Pernicious Anaemia	2	0.30	0.80	0	0.00
Polycystic Ovary	12	1.80	4.80	7	58.33
Prostate Disorders	1	0.10	0.40	0	0.00
Psoriasis Eczema	30	4.50	12.00	9	30.00
Schizophrenia/Bipolar Disorder	5	0.70	2.00	4	80.00
Sexual Health Condition	2	0.30	0.80	2	100.00
Stroke/Transient Ischaemic_Attack	1	0.10	0.40	0	0.00
Thyroid Disorder	16	2.40	6.40	3	18.75
Treated Constipation	2	0.30	0.80	0	0.00
Other	58	8.60	23.20	27	46.55

Table 10. Spearman's rho correlations for WISA factors, Frequency of Sharing, Willingness to Share, TIPS concerns, and Perceived Risk

WISA score	Frequency of Sharing	Willingness to share	TIPS concerns	Perceived Risk
Total	-.086 (.173)	.032 (.610)	.287** (.000)	.338** (.000)
Privacy Factor	-.188** (.003)	-.170** (.007)	.253** (.000)	.257** (.000)
Worth Factor	.009 (.893)	.086 (.173)	.194** (.002)	-.159* (.012)
Consequences Factor	-.104 (.101)	-.084 (.185)	.169** (.008)	.522** (.000)
Low Proximity of Interest Factor	.028 (.662)	.093 (.141)	.107 (.091)	.082 (.197)
High Proximity of Interest Factor	.208** (.001)	.379** (.000)	-.031 (.626)	-.087 (.172)

*P values provided in () for each result. * indicates $p < .05$. ** indicates $p < .01$.*

Table S11. Descriptive statistics for reported technology preferences for a digital platform designed to share self-generated health and lifestyle data with others.

Technology preference	Mean	Median	Mode	Std. Deviation	Minimum	Maximum
The platform is easy to use.	3.95	4.00	4	1.00	1	5
The platform is attractive in appearance.	3.05	3.00	3	1.12	1	5
The platform can incorporate data from multiple digital devices.	3.12	3.00	3	1.22	1	5
The platform can incorporate data from multiple apps.	2.89	3.00	4	1.28	1	5
The platform allows users to store handwritten data.	2.18	2.00	1	1.26	1	5
The platform can identify patterns in health and lifestyle data.	3.64	4.00	4	1.06	1	5
The platform allows users to interact socially with others.	2.44	2.00	1	1.22	1	5
The platform stores my data securely	4.78	5.00	5	.534	1	5
I can control who can see my data on the platform.	4.69	5.00	5	.65	1	5
I can use the platform anonymously	4.20	5.00	5	.99	1	5
The platform is trustworthy.	4.79	5.00	5	.50	1	5

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Table S12. Independent samples t-tests to investigate differences between males (n=80) and females (n=166) for frequency of data recording, frequency of data sharing, SSCI total scores, WISA total scores, overall willingness to share, overall perceived risk from sharing, and total TIPS scores.

		Levene's Test for Equality of Variances		t-test for Equality of Means			95% Confidence Interval of the Difference			
		F	Sig.	t	df	Sig. (2- tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Frequency of data recording	Equal variances assumed	.080	.778	1.921	244	.056	.27288	.14202	-.00686	.55262
	Equal variances not assumed			1.909	153.506	.058	.27288	.14296	-.00955	.55531
Frequency of data sharing with others	Equal variances assumed	2.828	.094	.801	244	.424	.102	.128	-.149	.353
	Equal variances not assumed			.761	137.755	.448	.102	.134	-.163	.367
SSCI total scores	Equal variances assumed	.025	.874	-.799	244	.425	-.728	.911	-2.523	1.066
	Equal variances not assumed			-.792	152.527	.429	-.728	.920	-2.545	1.088
WISA total scores	Equal variances assumed	.268	.605	.933	244	.352	.05637	.06044	-.06269	.17542
	Equal variances not assumed			.918	149.921	.360	.05637	.06141	-.06498	.17772
Overall willingness to share with others	Equal variances assumed	2.577	.110	1.238	244	.217	2.38135	1.92407	-1.40855	6.17125
	Equal variances not assumed			1.171	136.108	.244	2.38135	2.03368	-1.64034	6.40305
Overall perceived level of risk	Equal variances assumed	.294	.588	-1.796	244	.074	-.19310	.10752	-.40488	.01868
	Equal variances not assumed			-1.808	158.865	.072	-.19310	.10679	-.40402	.01782
Total TIPS scores	Equal variances assumed	.323	.570	-1.255	244	.211	-.11044	.08798	-.28374	.06286
	Equal variances not assumed			-1.249	154.269	.213	-.11044	.08839	-.28506	.06418

Table S13. Analysis of variance investigating the effects of age bracket (18-34; 35-49; 50-64; 65+) on variance in frequency of data recording, frequency of data sharing, SSCI total scores, WISA total scores, overall willingness to share, overall perceived risk from sharing, and total TIPS scores (n=250).

		Sum of Squares	df	Mean Square	F	Sig.
Frequency of data recording	Between Groups	1.807	3	.602	.551	.648
	Within Groups	268.733	246	1.092		
	Total	270.540	249			
Frequency of data sharing with others	Between Groups	2.460	3	.820	.940	.422
	Within Groups	214.664	246	.873		
	Total	217.124	249			
SSCI total scores	Between Groups	346.209	3	115.403	2.635	.050

	Within Groups	10774.191	246	43.798		
	Total	11120.400	249			
WISA total scores	Between Groups	2.265	3	.755	3.834	.010*
	Within Groups	48.448	246	.197		
	Total	50.713	249			
Overall willingness to share with others	Between Groups	.173	3	.058	.203	.894
	Within Groups	69.927	246	.284		
	Total	70.100	249			
Overall perceived level of risk	Between Groups	9.323	3	3.108	5.248	.002**
	Within Groups	145.664	246	.592		
	Total	154.987	249			
Total TIPS scores	Between Groups	1.661	3	.554	1.312	.271
	Within Groups	103.762	246	.422		
	Total	105.423	249			

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Significance values provided as P values provided in () for each result. * indicates $p < .05$. ** indicates $p < .01$.

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Table S14. Descriptive statistics for overall WISA scores and perceived levels of risk to investigate differences between age brackets (n=250)

Age Brackets		WISA total scores	Overall perceived level of risk
18-34	Mean	3.0871	2.7415
	N	108	108
	Std. Deviation	.44374	.72415
35-49	Mean	3.2979	2.5411
	N	77	77
	Std. Deviation	.45428	.71834
50-64	Mean	3.1824	2.6133
	N	50	50
	Std. Deviation	.46459	.92823
65+	Mean	3.0392	1.9222
	N	15	15
	Std. Deviation	.28269	.76146

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