

1 **Understanding the Barriers and Facilitators to Sharing Patient-Generated Health Data**
2 **Using Digital Technology for People Living with Long-Term Health Conditions: A**
3 **Narrative Review**

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15 **Key words:** Data sharing, patient-generated health data, digital technology, long-term health
16 conditions, trust, identity, privacy, security, stigma.

17 **Abstract**

18 Using digital technology to share patient-generated health data has the potential to improve the
19 self-management of multiple long-term health conditions. Sharing these data can allow patients
20 to receive additional support from healthcare professionals and peer communities, as well as
21 enhance their understanding of their own health. A deeper understanding of the concerns raised
22 by those living with long-term health conditions when considering whether to share health data
23 via digital technology may help to facilitate effective data sharing practices in the future. The
24 aim of this review is to identify whether trust, identity, privacy and security concerns present
25 barriers to the successful sharing of patient-generated data using digital technology by those
26 living with long-term health conditions. We also address the impact of stigma on concerns
27 surrounding sharing health data with others. Searches of CINAHL, PsychInfo and Web of
28 Knowledge were conducted in December 2019 and again in October 2020 producing 2,581
29 results. An iterative review process resulted in a final dataset of 23 peer-reviewed articles. A
30 thorough analysis of the selected articles found that issues surrounding trust, identity, privacy
31 and security clearly present barriers to the sharing of patient-generated data across multiple
32 sharing contexts. The presence of enacted stigma also acts as a barrier to sharing across multiple
33 settings. We found that the majority of literature focuses on clinical settings with relatively
34 little attention being given to sharing with third parties. Finally, we suggest the need for more
35 solution-based research to overcome the discussed barriers to sharing.

36 **Introduction**

37 Over the last several decades there has been a substantial increase in life expectancy across the
38 industrialised world due to advancements in digital technology and medicine, as well as
39 successful public health initiatives (1, 2). Despite this achievement, an ageing society has come
40 with a rise in the prevalence of long-term health conditions (LTHCs)(3). Many LTHCs are
41 supported by continuous self-monitoring and management. Advancements in digital
42 technology have provided the opportunity for people to collect, manage and share personal
43 health data to better manage their own health and achieve better health outcomes and quality
44 of life. People living with LTHCs often record, monitor and manage personal health data,
45 which encompasses a broad range of personal health information such as medication
46 adherence, health and lifestyle practices and experiences of health, that patients may choose to
47 share with others. These patient-generated health data (PGData) have the potential to improve
48 the self-management of multiple conditions and, when shared with healthcare providers,
49 improve the provision of care (4, 5).

50

51 There are multiple benefits to sharing PGData. Sharing these data can lead to a feeling of
52 increased support when interacting with peer communities (others living with the same or
53 similar condition), family or friends, as well as leading to better healthcare decision making in
54 patients (6, 7). Using PGData from electronic devices has been shown to improve patient
55 outcomes in a range of conditions such as diabetes, obesity, heart disease, and other chronic
56 conditions (8). For example, in a study of cancer patients, the use of a digital app on an
57 electronic tablet helped to improve patients' recall of symptoms and enabled the sharing of
58 health information with clinicians (9). Cancer patients have also been reported to be willing to
59 share PGData with cancer registries where they recognise the benefits for personal health
60 management and population health (10). Patients who share PGData via digital platforms such
61 as PatientsLikeMe report the greatest benefits to sharing as being able to learn more about their
62 symptoms and to understand the side effects of their treatment (11). Furthermore, the increased
63 sharing of PGData with third parties may allow big data public health practices to identify
64 previously concealed patterns among the reported experiences of multiple LTHCs, which may
65 help to optimise the delivery of care for individual patients (12, 13). Ultimately, the use of
66 PGData in the management of health conditions enhances understanding and generates a
67 holistic picture of one's personal health and disease management (14, 15).

68

69 There are a number of factors that facilitate the sharing of PGData, such as individual altruistic
70 tendencies and the seeking of social support (16). Conversely, factors that are considered
71 barriers to the sharing of PGData include poor health literacy and the perceived burden of
72 having to manage data associated with one's condition(s) (17). The growing prevalence of
73 digital technology in the transmission of personal health data would suggest that issues
74 surrounding Trust, Identity, Privacy and Security (TIPS) are likely to be an increasing and
75 evolving concern. For example, TIPS concerns have been found to be critical when seeking to
76 facilitate the sharing of PGData among those living with HIV (18). This narrative review is
77 conducted as part of a UK EPSRC funded programme ("INTUIT: Interaction Design for
78 Trusted Sharing of Personal Health Data to Live Well with HIV", 2020)(19) examining TIPS
79 concerns around the sharing of PGData primarily among those living with HIV, but also looks
80 to investigate TIPS concerns among those living with a range of other LTHCs. The INTUIT
81 project aims to contribute towards removing barriers to collecting and sharing PGData in order
82 to improve the health and well-being of stigmatised populations. The sharing of PGData raises
83 multiple TIPS concerns for those living with LTHCs and may hold particular significance for
84 those with potentially stigmatised conditions due to fears of discrimination or other harmful

85 consequences. People who anticipate experiences of stigma as a result of their LTHC(s) are
86 likely to be more guarded when reporting their experiences of health, which may prevent them
87 from receiving an appropriate level of care (20, 21). Therefore, understanding the role that both
88 stigma and TIPS concerns play in the sharing of PGData with others, by those living with
89 LTHCs, may help to promote effective data-sharing practices, potentially leading to improved
90 delivery and self-management of care.

91
92 The potential benefits of PGData for understanding a range of health conditions and for
93 optimising delivery of care may help to support the rising prevalence of LTHCs. The use of
94 PGData has the potential to transform the delivery of healthcare and to improve the
95 management of countless LTHCs (4). However, cultivating an ecosystem that protects the
96 interests of patients and builds confidence that healthcare systems will use personal information
97 responsibly presents unique challenges to researchers, designers and policy makers working in
98 digital health. To realise the benefits of PGData we must first understand the barriers and
99 facilitators to sharing using digital technology for people living with LTHCs. To address this,
100 we have conducted a narrative review of previous literature addressing TIPS concerns and the
101 role of stigma in the sharing of PGData via digital technology by those living with LTHCs.
102 The research questions directing this narrative review are (i) do TIPS concerns present a barrier
103 to the successful sharing of PGData using digital technology by people living with LTHCs;
104 and (ii) what is the impact of stigma on the sharing of PGData via digital technology by those
105 living with LTHCs? By addressing these research questions, we aim to discuss barriers and
106 facilitators to the effective sharing of PGData across multiple contexts: sharing with clinical
107 staff, public health surveillance, researchers, peer communities, friends, social networks and
108 other third-party organisations.

109

110 **Methods**

111 *Narrative review*

112 Narrative reviews are fast becoming the most common form of literature review across multiple
113 disciplines (22). Though the literature is summarised in a way that is not explicitly systematic,
114 narrative reviews nevertheless provide a comprehensive synthesis of up-to-date evidence for
115 researchers, designers and policy makers working in the field of digital health (22-24). The
116 synthesis of qualitative and quantitative research is critical to ensuring that patient experiences,
117 needs and preferences are understood and taken into consideration when designing and
118 implementing healthcare technology (24). In conducting this narrative review, a scale for the
119 quality assessment of narrative review articles (SANRA) was consulted in order to ensure that
120 it meets the expected standards for this category of review (22). This narrative review aimed
121 to better understand issues of Trust, Identity, Privacy and Security (TIPS) in those living with
122 LTHCs when using digital technology to share their personal health and lifestyle data. This
123 review also explores the role that stigma plays in sharing this data via technology by people
124 with LTHCs.

125

126 *Inclusion and exclusion criteria*

127 This narrative review was conducted by first establishing the inclusion and exclusion criteria
128 for article selection, which was agreed by the whole research team (see Table 1). The LTHCs
129 featured in this inclusion criteria were in line with the wider goals of the INTUIT project and
130 based on the findings of previous research that discussed experiences of stigma among those
131 living with HIV (18, 25, 26), other sexually transmitted infections (27, 28), diabetes (29-31)
132 and Mental Health conditions (32-34). Our inclusion criteria also sought to capture those

133 LTHCs considered most prevalent and impactful on society (cancer, cardiovascular disease and
 134 dementia)(35).
 135

136 *Table 1. Inclusion and exclusion criteria for selecting peer-reviewed articles.*

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Addresses any of the selected LTHCs (HIV, diabetes (types 1, 2 and unspecified), mental health, sexual health, cancer, cardiovascular disease or dementia); and • Includes a type of communication (with peers, with clinical staff or with public health surveillance); and • Includes a form of digital technology (social media, online forums, mobile apps or other digital platforms); and • Addresses the sharing of PGData; and • A barrier to sharing; or • A facilitator to sharing; or • Considers issues surrounding Trust, Identity, Privacy and Security. 	<ul style="list-style-type: none"> • Addresses the sharing of generic health promotion/education/information; or • Focusses on a specific LTHC outside of the selected categories; or • Does not present empirical data.

137
 138 ***The initial search***
 139 The inclusion and exclusion criteria were then applied to an initial search exercise conducted
 140 in December 2019. This initial search was conducted by one member of the research team and
 141 involved a search of the available published literature using the following databases: CINAHL,
 142 PsychInfo, Web of Knowledge and by referring to the reference lists of relevant articles. An
 143 iterative searching strategy was developed as the language and terminology pertaining to
 144 PGData became more familiar to the researcher. Within current health literature, there are
 145 multiple variations of terms that are used to describe PGData, including ‘personal health
 146 information’, ‘personal health data’, ‘patient-authored information’, ‘patient-generated
 147 information’, ‘protected health information’, whereas other literature may simply refer to the
 148 data as ‘medical information’. Combinations of words and strings representing the sharing of
 149 PGData were applied to the selected databases with Boolean operators ‘AND’ and ‘OR’ to
 150 broaden the search. This initial search exercise yielded 2,479 results.

151
 152 ***Refining the search***
 153 One member of the research team collected the initial articles from the various sources.
 154 Duplicates were removed. An iterative process of reading the titles and excluding search results
 155 whose titles indicated that they did not satisfy any of the inclusion criteria or contained a
 156 relevant feature of the exclusion criteria (see Table 1). The abstracts and texts of search results
 157 whose titles passed this initial inspection were then reviewed by three members of the research
 158 team to determine their relevancy in accordance with the full inclusion and exclusion criteria,
 159 thus progressively refining the scope of the initial search.

160
 161 ***Article selection***
 162 Three members of the research team independently reviewed the list of potentially relevant
 163 articles against the inclusion and exclusion criteria. A meeting was held to compare lists and

164 agree which to take forward. Any articles where one member of the team had identified them
165 for inclusion were discussed and a decision made by mutual agreement. One member of the
166 research team meticulously reviewed the full text for articles that the research team identified
167 as potentially (though not certainly) relevant to the directives of the review. For example, for
168 articles that addressed various health conditions, the researcher examined the text to ensure that
169 significant attention was given by the candidate article to the sharing of personal health
170 information associated with LTHCs. This member also extracted any relevant articles from the
171 references of the candidate articles. Each time new articles were identified the three first
172 reviewers would meet and discuss their inclusion. The full research team evaluated and
173 discussed the short list of candidate articles with respect to the selection criteria and were given
174 the opportunity to suggest any articles known to them that had been missed. This process
175 resulted in 19 peer-reviewed articles being selected by mutual agreement.

176

177 ***Updating the search***

178 The search, refinement and selection processes described above were repeated in October 2020
179 to identify further contributions that had been made to the literature since the initial search. The
180 second search produced a further 102 results, four of which were selected for inclusion in the
181 narrative review.

182

183 ***Review***

184 The final dataset comprised 23 peer-reviewed articles. The results from the articles were
185 extracted into Microsoft Excel before NVivo 12 was used to thematically analyse the data. The
186 thematic analysis of the selected articles was undertaken by all members of the research team
187 and involved an iterative review of the findings in consideration of their relevance to the two
188 research questions stated above. All members of the research team mutually discussed the
189 results of the selected articles and subsequent thematic analysis in order to synthesise and
190 present the findings below.

191

192 ***Findings***

193 The review of the selected articles finds that issues surrounding Trust, Identity, Privacy and
194 Security clearly present barriers (but in some cases facilitators) to the sharing of PGData across
195 all contexts (i.e., sharing with clinical staff, public health surveillance, researchers, peer
196 communities, friends, social networks and other third-party organisations). Examples of the
197 specific TIPS issues referred to in the literature, along with a brief overview of the selected
198 articles, are presented and discussed below to provide a review of the literature thus far. Table
199 2 provides a description of all of the articles included in this review.

200

201 ***Table 2. Overview of all included papers***

202

203 From the selected studies, many focus exclusively on specific LTHCs: diabetes (types 1, 2 and
204 unspecified; n = 4), HIV (n = 4) and mental health (n = 4). One study specifically addresses
205 patients who manage multiple chronic conditions (MCC) and the remainder of the studies
206 comprise participants who have a range of different LTHCs (n = 10). One study looking at
207 type 1 diabetes reports the perspectives of adolescent participants (12 - 17yrs)(31) and the
208 remaining studies are of adults participants (18 – 84yrs). The majority of the included studies
209 explore the sharing of PGData with healthcare providers and electronic health record
210 management (17, 26, 29, 30, 33, 34, 36-39), with some including sharing of data with a wider
211 network including public health and researchers (40, 41). Three of the studies look at the
212 implications of sharing PGData online through social networking sites such as Facebook (16,
213 31, 41). One study looks at Grindr and the sharing of HIV status (42), whilst the other HIV

214 related studies look at health information technology more broadly (25, 26). The following
215 sections discuss the results in relation to the research questions driving the review.

216

217 **RQ1: Do TIPS concerns present a barrier to the successful sharing of PGData using**
218 **digital technology by people living with long-term health conditions?**

219 This narrative review finds that multiple TIPS concerns present barriers to the sharing of
220 PGData via digital technology by those living with LTHCs. Distrust in the proposed recipient
221 of PGData inhibits sharing via technology. Trust is often shaped by patients' previous
222 experiences of sharing and, in a clinical context, can be facilitated by confidence in the
223 healthcare institution or team with whom sharing is proposed. The desire by patients to control
224 and self-manage their digital identity also impacts on patient willingness to share PGData with
225 others. However, the review suggests that the use of pseudonyms can offer a successful strategy
226 for facilitating sharing of PGData online by those living with LTHCs. Privacy and security
227 concerns present clear barriers to sharing PGData via technology. Privacy concerns are
228 reported as being the main reason patients may choose not to share PGData in a clinical context,
229 though these concerns mostly relate to the potential for future sharing with external third
230 parties. Anticipated security breaches by patients also present a barrier to the sharing of PGData
231 with others, whereas believing that digital technology has sufficient safeguards in place is a
232 facilitator to sharing PGData via technology. A more detailed discussion of individual TIPS
233 concerns is given below.

234

235 **1. Trust**

236 Here we address the degree of trust or distrust that is established between an individual and the
237 proposed recipient of their PGData. A quarter of the articles discussed 'trust' in relation to the
238 sharing of PGData (17, 18, 26, 30, 31, 33, 42, 43). In the majority of these papers, trust as a
239 barrier to the sharing of PGData centred on *distrust of the recipient*. When sharing with
240 healthcare providers and clinical staff, distrust can be shaped by previous negative experiences
241 for people living with multiple chronic conditions (17). Distrust is also developed when
242 patients are asked to provide information that they deem to be highly personal and irrelevant
243 to the given context (30). On the other hand, developing and building trust with recipients is
244 considered a facilitator to the sharing of PGData and is supported by familiarity and confidence
245 in the healthcare institution and healthcare team (25, 26). Where, for example, Teixeira et al.
246 (26) report on willingness to share data for patients living with HIV:

247 *"Patients reported having a great deal of trust in their HIV care team. Trust in their*
248 *care team to deliver high-quality medical care and feeling that providers spent enough*
249 *time with them were each associated with patients' willingness to share PHI [protected*
250 *health information] with both clinical and nonclinical staff at their primary clinic"*
251 (Teixeira et al., 2011)

252 The majority of the papers examine PGData sharing within a clinical context, focusing on the
253 barriers and/or facilitators to sharing with HCPs via digital technology. In this setting, trust is
254 a key issue that makes patients more likely to share PGData with trusted recipients. Kelley et
255 al. (33) report how sharing PGData improved the relationship and trust between patients and
256 their clinicians, with student participants reporting how they used PGData to provide proof that
257 they were doing exactly what they said they were. We know that higher levels of patient trust
258 in HCPs are associated with more beneficial health behaviours, fewer symptoms, and higher
259 quality of life (44). Conversely, a lack of trust in HCPs can prevent patients from sharing some
260 forms of PGData and engaging with HCPs in face-to-face settings (45).

261

262 This review indicates that trust remains an important factor in PGData sharing via digital
263 technology. Most papers focussing on a clinical setting examine data provided by patients that

264 constitutes personal health information that they have chosen to incorporate into their
265 electronic health records (EHR). In general, these studies indicate patients are happy to share
266 most information with HCPs but less so with non-clinical staff (26). The focus on the EHR as
267 a digital artefact provides common ground for the patient and the HCP. Shared data can
268 underpin improved communication between patients and HCPs encouraging a more patient-
269 centred approach although such artefacts also have the potential to disrupt the doctor-patient
270 relationship (46). The few papers that focus more on the sharing of self-tracking data with
271 clinicians (33, 39) contrast the perceived benefits experienced by patients with the more
272 negative or sceptical feelings towards the data expressed by HCPs.

273

274 Trust as a barrier to sharing is discussed less often outside of the context of sharing with HCPs.
275 A notable exception is Warner et al. (42). In discussing the importance of mutual self-
276 disclosures in the development of trust, Warner et al. (42) note that the features of mobile apps
277 do not always support trust in their users. Uncertainties over the disclosure of patient-provided
278 health information (i.e., HIV status in the mobile app dating environment, whereby people do
279 not disclose, or report their last sexual health check as a long time ago) can cause distrust of
280 other people living with HIV. A further study which addresses the role of trust outside of a
281 clinical context is provided by Bussone et al. (18). This study explores the concerns of those
282 living with HIV when sharing personal health information with their peers and finds that trust
283 in digital sharing platforms can be enhanced when it is associated with a recognised HIV
284 charity or trusted medical organisation. This study also describes how strong privacy and
285 security measures are vital for building trust in such peer-sharing platforms.

286

287 **2. Identity**

288 The literature discusses digital identity in terms of concerns regarding identifiers relevant to
289 one's personal data and online presence. The conscious management of digital identity online
290 has an impact on patient willingness to share PGData with online social networking sites such
291 as Facebook (16, 30, 31, 42, 47). People living with diabetes, mental health or HIV expressed
292 a desire to withhold PGData relating to their condition from their wider social network (16, 31,
293 42):

294 *“Many participants reflected on the undesirability of contributing any health-related*
295 *content to Facebook, since this platform was seen primarily as a space for the conscious*
296 *construction of a positive identity. As such, the inclusion of references to diabetes or*
297 *mental health could jeopardise this.” (Fergie et al., 2016)*

298 This is further supported by Bussone et al. (18) who explore attitudes towards sharing among
299 those living with HIV and find that participants report a strong desire to self-manage certain
300 aspects of their digital identities by sharing individual attributes of identity if anonymised:

301 *“They indicated willingness to share digital identity attributes, including gender, age,*
302 *medical history, health and well-being data, but not details that could reveal their*
303 *personal identity.” (Bussone et al., 2020)*

304 An alternative strategy for managing digital identity is discussed by O’Kane et al. (30) who
305 describe how some people living with either type 1 or type 2 diabetes are happy to share their
306 PGData under pseudonyms in specific health related online forums provided they get the
307 support they need in return:

308 *“The use of social media seems to be a fine balance between openly sharing sensitive*
309 *medical information whilst also remaining in control of what is considered private. If*
310 *you want to talk about the worst thing that you've done to your diabetes, or you are*
311 *really ignoring it, or you're in a dark place, you can share that information without*
312 *sharing your name, without alerting your employer to your potential issue or alerting*
313 *your family even. You can keep those feeling private but share them publicly in a way*

314 *gets the support without putting you out there like you're waving a flag saying 'I'm*
315 *diabetic and I want everyone to look at me!' right? – Patient 14” (O’Kane, 2013)*

316 The management of digital identity is closely linked to how well patients manage their
317 condition, even when seeking out support. When the perceived management of the condition
318 is considered poor, some patients are less likely to share their data. Among adolescents with
319 type 1 diabetes, Vaala et al. (31) report, *“Those who consider posting health-related*
320 *information online face a tension between pursuing health-related goals, such as obtaining*
321 *advice or emotional support, and maintaining a favorable impression as someone who is*
322 *healthy and competent it seems the balance may shift in favor of the latter among adolescents*
323 *who are struggling with glycemic control.”* Other studies investigating the sharing behaviours
324 of people living with diabetes (type unspecified) with public health researchers have discovered
325 that patients with better self-reported measures of glycaemic control are more likely to share
326 their data (41).

327
328 Warner et al. (42) report on the reflection of HIV disclosure and identity management as some
329 study participants note how they perceive the sharing of a person’s negative HIV status and
330 last test date as a way to show off to other users on Grindr, where one participant states, *“I just*
331 *don’t like it. It’s like giving yourself a pat on the back for being lucky or ""better"" than other*
332 *people”*.

333
334 In terms of sharing PGData with online social networking sites, identity and privacy are key
335 issues. People living with LTHCs want to be able to withhold PGData relating to the condition
336 from their wider social network and to exert control over what data they share and with whom.
337 For people with LTHCs these needs reflect changing patterns of engagement with social
338 networking sites and online support groups (48, 49). Sharing PGData may occur in a temporary
339 or intermittent manner, depending on the nature of condition and the type of PGData shared,
340 which often varies in relation to the stage of the illness or health condition (50). Many people
341 with LTHCs are less likely to share PGData when they are perceived to be managing their
342 condition poorly (41) and blaming and shaming can often be a core experience for people with
343 diabetes on online forums (51).

344
345 ‘Digital personhood’ (a term used to discuss recognition of a human being as having status as
346 a person in the electronic realm) can be impacted by illness, resulting in pre-and post-illness
347 personas (52). Managing our identities across different contexts is often difficult when
348 engaging in social interaction online, a term recognised as ‘context collapse’ (53). People with
349 LTHCs may have to work harder at their online communication, making more conscious
350 decisions about what PGData to share and what to withhold, in order to shape or maintain their
351 preferred digital identity or presentation of self (54). Separating out more generic social
352 networking sites such as Facebook from specific, often anonymous, online health support
353 groups is one strategy. Newman et al. (55) show how people with LTHCs manage their PGData
354 sharing between online health communities and Facebook; Facebook is used to present a
355 positive identity of self-control, whilst an online forum, by contrast, affords a space to be more
356 open about expressing personal difficulties.

357 358 **3. Privacy and security**

359 Privacy and security issues refer to concerns raised by patients surrounding the preservation of
360 individual privacy and the ability to provide secure storage of personal data and information.
361 Privacy concerns are discussed as a barrier to the sharing of PGData in the majority of articles.
362 Agaku et al. (36) report that privacy and security concerns are the main reason why some
363 patients withhold their PGData from healthcare professionals. In addition, the authors report

364 concerns about the security of information whilst being ‘electronically transferred’ or ‘faxed’,
365 as well as ‘the perception that a patient had very little say in how their PGData was used’ are
366 all associated with significantly higher odds of withholding personal information from a
367 healthcare professional (36). Similarly, Caine and Hanania (40) report that patients express
368 having less choice over what is shared with third-party organisations, e.g., health insurance
369 companies. The request by patients for granular control over sharing of PGData and medical
370 information is common across many articles (29, 30, 36, 40, 42, 56) and informed consent is
371 requested to enable the patient to make decisions about who to share their data with (36, 40).
372 Bernaerdt et al. (56) find that this desire for granular control in certain patient groups is often
373 present despite a lack of awareness of the value or meaning of medical data to third parties.
374 This evidence suggests that patients need to be better informed of the consequences and
375 implications of sharing personal health information with third parties.

376

377 Torabi and Beznosov (47) note that privacy risk perceptions of people living with LTHCs are
378 context dependent. Many authors also highlight the perceived sensitivity of PGData to the
379 patient, and that how a person feels about their physical and mental health at the time of sharing
380 impacts privacy risk perception (30, 32, 40, 41, 57). One particular study looking at multiple
381 conditions and sharing PGData from Electronic Health Records (EMR) reports,

382 *“There was not one potential recipient (e.g., primary care physician) with whom all*
383 *patients wanted to share all of the information in their EMR with unconditionally. This*
384 *was the case for both groups of participants: those with highly-sensitive health*
385 *information in their EMR (21 participants) and those without highly-sensitive*
386 *information (nine participants).” (Caine & Hanania, 2012)*

387 However, some patients expect healthcare professionals to have complete access, despite the
388 sensitivity of data, *“they need to know everything that is going on in your health”*(30).

389 Hartmann et al. (32) describe how patients may wish to minimise the potential risk of data
390 being used against them by third-party organisations:

391 *“Individuals want to keep control of such sensitive data and just do not want to share*
392 *it with everybody or more precisely with third-party agents from whom negative*
393 *consequences could arise from, such as German public health insurance, for instance.*
394 *People are worried about being tracked at places that indicate risk behavior or self-*
395 *damaging behavior, which could result in financial consequences (e.g., higher*
396 *insurance rates or loss of treatment reimbursement).” (Hartmann et al., 2019)*

397 Concerns over sharing PGData with HCPs typically focus on the potential for the data to be
398 shared more widely with third-party organisations, and the review indicates that patients are
399 keen to be able to control or limit this wider sharing to protect the privacy of their data.

400

401 On social media use for diabetes support, O’Kane et al. (30) report patients’ changing
402 perspectives on privacy, where social media use is a delicate balance of sharing openly
403 sensitive medical information whilst also having control over what is considered private, based
404 on how vulnerable they feel:

405 *“People may choose to view previously held privacy beliefs as overly cautious and want*
406 *to reveal more about their previous medical history, but they still have their own*
407 *individual levels of comfort. Although Patient 13 would write his diabetes blog under*
408 *his own name and picture as mentioned above, one group interview participant did not*
409 *feel comfortable with this level of privacy. I think it would be alright to share*
410 *information about how your, maybe how your blood sugars go...[...]/but I don’t think it*
411 *is necessary to say your name and your address or anything like that. You can have a*
412 *blog where everyone has a username or something. And then I think it’s really helpful.*

413 *I don't think you really need to identify yourself. – Group Interview Participant*
414 (O’Kane et al., 2013)

415 However, sometimes the interest in maintaining dignity and privacy (on any digital platform)
416 can outweigh the interest in health and subsequently results in patients withholding PGData
417 (30).

418
419 Privacy and security concerns are shown to be significantly influenced by particular
420 demographics (e.g. age and education level), and characteristics (e.g. self-efficacy)(57), as well
421 as the trajectory of a person’s illness and “*other temporally-situated outside influences*”(30).
422 Furthermore, differences between LTHCs may influence the extent to which privacy concerns
423 influence sharing preferences and behaviours. For example, Esmaeilzadeh et al. (58) describe
424 how differences between mental and physical conditions result in differences in sharing
425 propensities:

426 *“Individuals with a physical illness favor higher levels of structure mainly due to*
427 *information quality dimensions (i.e., better understandability, accessibility, and*
428 *usefulness). However, individuals with mental disorders prefer highly structured*
429 *interfaces due to lower psychological risks and privacy concerns.”* (Esmaeilzadeh et
430 al., 2020)

431
432 Nurgalieva et al. (43) also highlight how different conditions may elicit a range of privacy
433 concerns. They show how cancer patients and psychiatric patients were notably hesitant to
434 share via a national digital platform for the sharing of personal health information. This may
435 be explained by certain conditions being more likely to provoke fears surrounding potential
436 stigma or causing family members to worry (43). Further understanding of the influence of
437 both demographic and health condition factors is required so that healthcare organisations may
438 adequately structure their patient platforms to accommodate the differing privacy concerns of
439 patient groups, for example by providing information to patients about how data is going to be
440 used and stored.

441
442 Anticipated security breaches present a barrier to the sharing of PGData (30, 36), whilst in
443 contrast, having confidence that digital technology has safeguards in place is a facilitator to
444 sharing of PGData (36). Patients’ concerns are justified by factors including their previous
445 experiences of digital technology and security breaches occurring both electronically and using
446 paper health records (30).

447
448 Privacy concerns affect sharing PGData in online settings. People with LTHCs have to make
449 judgements about the type and amount of information they share with others, weighing up the
450 contextual integrity of their personal data sharing against potential privacy and security posed
451 by the ‘silent listeners’ on the network, i.e., third-party applications or advertisements (59).
452 Site ownership and funding plays into this directly with peer-sharing resources now being
453 hosted by large pharmaceutical companies, charities, healthcare organisations and individuals.
454 Some data-driven sites such as PatientsLikeMe have been built to support information
455 exchange between patients (11) but their relationship with third-party organisations can cause
456 some users to feel uncomfortable (60). Recent changes to the ownership of such sites may
457 increase concern in this context; for example the acquisition of PatientsLikeMe by the
458 healthcare and insurance company UnitedHealth Group caused some users to express privacy
459 and security concerns regarding their personal data (61).

460
461 In comparison to sharing with HCPs or sharing via social media, there are relatively few papers
462 that focus on sharing PGData within a third-party context. The papers that do examine this

463 context identify privacy and security as key issues (30, 32, 56) and highlight that some patients
464 may have little understanding of the value of PGData to third parties (56). However, clearly
465 more work is needed to understand whether the TIPS barriers and facilitators play a role within
466 this setting. The key messages in this setting are that people want to be able control the privacy
467 of their data and to have the option of changing their consent preferences with regard to sharing.
468 Patients are also more likely to share with organisations that have the potential to impact their
469 health directly and less likely with organisations further from this premise (i.e., researchers,
470 government or health insurance companies). Although the papers examine patients' attitudes
471 towards sharing PGData with third-party organisations, they do not explore differences in
472 sharing behaviours depending on whether or not PGData is anonymised.

473

474 **RQ2: What is the impact of stigma on the sharing of PGData via digital technology by**
475 **those living with LTHCs?**

476 Stigma can be both internal (felt stigma or self-stigmatisation) or enacted (external or
477 discrimination) experiencing unfair treatment from others (62). Anticipated stigma presents a
478 barrier to the sharing of PGData, across multiple platforms and with various recipients (18, 30,
479 31, 36, 42). A range of health conditions are associated with significant stigma (63), such as
480 living with HIV (18, 64), mental health problems (65, 66), and chronic pain (67). People living
481 with LTHCs are at risk of losing out on the benefits of sharing data when affected by stigma
482 and are more likely to withhold information. Both internal and enacted stigma impact the way
483 in which patients develop trust with the recipients of PGData.

484

485 Internal and enacted stigma can create a barrier to sharing PGData, particularly for people
486 living with HIV. When exploring the use of Grindr to disclose HIV status, Warner et al., (42)
487 report how people living with HIV are sometimes keen to withhold this information due to
488 concerns of social exclusion and loss of sexual opportunity. Although in contrast, the article
489 also describes some comments from Grindr users about how stigma can be used as a motivator
490 for disclosure for some men living with HIV as a way to “reduce their stigma exposure”.
491 However, Warner notes,

492 *“Stigma around HIV could lead some users to purposefully misreport their HIV status*
493 *to avoid exposure to stigma. This is reflected in our findings, where users report their*
494 *desire for HIV disclosure choice. In an environment where all users are expected to*
495 *disclose, privacy unravelling around non-disclosures may limit this choice. When all*
496 *said and done, it's forced disclosure that I dislike, or the fact that HIV+ users are*
497 *expected to self-disclose their status straight away. Why should they? (Paraphrased*
498 *comment from NW8)” (Warner et al., 2018).*

499 The majority of findings relating to stigma are of people living with HIV (18, 25, 26, 42).
500 However, in other conditions, authors note how participants express their concerns over their
501 PGData being used against them by healthcare providers and third-party organisations:

502 *“...A woman with a previous psychiatric diagnosis believed her history had been*
503 *misused by ambulance personnel who “put my name in the computer” and diverted her*
504 *to psychiatric care instead of the medical emergency care she was seeking. Another*
505 *individual was concerned about how doctors interpreted the history of sexually*
506 *transmitted infection in his medical record. One woman was strongly motivated to*
507 *conceal her diabetes from her insurer because she was concerned the company would*
508 *raise her premiums.” (Ancker et al., 2015)*

509 *“Individuals want to keep control of such sensitive data and just do not want to share*
510 *it with everybody or more precisely with third-party agents from whom negative*
511 *consequences could arise from, such as German public health insurance, for instance.*
512 *People are worried about being tracked at places that indicate risk behavior or self-*

513 *damaging behavior, which could result in financial consequences (eg, higher insurance*
514 *rates or loss of treatment reimbursement).” (Hartmann et al., 2019)*

515 Among adolescents with type 1 diabetes, an increase in restrictive sharing settings through
516 social media are considered a factor of anticipated stigma when adolescents have higher than
517 normal blood glucose levels (31, 41). Insights into the sharing preferences of previously
518 explored groups, such as those living with HIV and diabetes, may help to guide the further
519 study of the role that stigma plays in the formation of attitudes and sharing behaviours in those
520 living with other LTHCs.

521

522 **Discussion**

523 ***Summary of findings***

524 Trust, Identity, Privacy and Security (TIPS) concerns can present a barrier to sharing health
525 and lifestyle data when using digital technology to share data in multiple contexts. A quarter
526 of the articles discussed the role of trust in sharing PGData. Privacy as a barrier to sharing was
527 present across most articles and across most settings. Other TIPS concerns were more readily
528 identified as barriers to sharing in certain contexts. Identity management was seen as a barrier
529 to sharing more frequently within the context of social networking sites and the issue of security
530 was a barrier to the sharing of PGData with third parties. The presence of enacted stigma acted
531 as a barrier to sharing PGData across all settings although this was most noticeable in relation
532 to HIV compared to other LTHCs.

533

534 The narrative review has shown that TIPS issues are a considerable barrier to the sharing of
535 PGData across all settings. The presence of specific TIPS issues varied by context, such that in
536 certain settings particular barriers were more prominent. However, the literature shows that the
537 majority of research looking at the sharing of PGData has focused on clinical settings with
538 relatively few studies examining attitudes towards sharing with third parties such as public
539 health and research. In clinical settings the key TIPS issue was trust. Distrust in the recipient
540 of the information was highlighted as a key barrier to sharing PGData via digital technology.

541

542 In social network sharing online, we found that identity and privacy concerns were expressed
543 in relation to the self-management of health and concerns regarding oversharing. These issues
544 were key barriers to sharing but there was a lack of more detailed and nuanced information
545 about the kind of PGData individuals were or were not sharing with respect to these concerns.
546 Whilst the focus of this review paper was on the barriers and facilitators of sharing PGData
547 more broadly rather than types of data per se, it was interesting to note that the studies covered
548 a range of PGData. In clinical settings, unsurprisingly the focus was on electronic health
549 records and clinical data, whereas in the social networking settings, the range of PGData was
550 more varied and included more subjective data around mood, sleep and emotions. Despite
551 focussing on stigmatised health conditions, there was relatively little focus on the role stigma
552 played in decisions regarding sharing PGData via digital technology. References to stigma
553 were most prevalent in relation to HIV but far less mentioned with respect to other conditions.
554 Understanding the roles of both internal and enacted stigma regarding the sharing of PGData
555 needs further attention. Much of the discussion surrounding stigma related to the unwanted
556 disclosure of sensitive information. Despite a lack of consensus about what should be
557 considered sensitive information, previous literature suggests five categories of sensitive health
558 data: sexually transmitted infections, HIV/AIDS status, sexual health and pregnancy, mental
559 health information, and substance use (38). However, legal definitions of what constitutes
560 sensitive personal data are often very broad in scope; for example, the European Commission
561 categorises “health-related data” as sensitive personal data (68). Further research may seek to

562 examine how perceptions of information sensitivity among those with various LTHCs affect
563 patient privacy concerns and explore how these concerns may vary across different conditions.

564

565 Whilst we have assumed that sharing is a beneficial activity, it is also worth considering that,
566 as part of supporting the management of PGData, we need to think about how people make
567 sense of their data. We cannot always expect people to be able to successfully interpret their
568 data (34), and collecting and monitoring data can be overwhelming for some people leading to
569 negative health consequences (69). Patients may express varying preferences for managing
570 PGData and have different technological abilities relevant to the skills required to actively
571 record, monitor and manage personal health information. Understanding these patient
572 differences may help to avoid burdening people with the ‘invisible work’ of managing personal
573 health information (17, 70). Managing PGData can also add to the increasing demands faced
574 by HCPs due to the time required to analyse and make sense of the data that patients provide.
575 As well as understanding the role of health literacy in relation to managing PGData (17), and
576 the burden placed on both patients and HCPs, we need to know more about the motivations for
577 both collecting and sharing PGData in different contexts to see if TIPS issues vary accordingly.
578 Understanding more about the types of PGData people with LTHCs are happy to share and
579 how the TIPS barriers might differentially apply to these forms of data would be a useful next
580 step. Finally, there is a need for more qualitative studies in this area, especially in relation to
581 TIPS barriers and facilitators to sharing PGData with third-party organisations as the majority
582 of these studies are based on quantitative data.

583

584 Whilst our review highlights some of the key TIPS concerns that people living with LTHCs
585 have with respect to sharing their PGData, none of the studies evaluated solutions or
586 interventions to overcome these barriers. A few papers discussed participants’ suggestions or
587 desires concerning greater transparency and control over the information. Clearer informed
588 consent to improve the transparency of the sharing process would increase the granular control
589 for participants (30). A growing body of literature, that is beyond the scope of this narrative
590 review, continues to explore technology and policy-based solutions to resolve general concerns
591 about health data to facilitate secure and privacy-preserving sharing (71-73). However, given
592 the specific TIPS concerns that this narrative review highlights with respect to the sharing of
593 PGData by those living with LTHCs, future research may look to investigate how successful
594 those solutions proposed to tackle general concerns about health data are at alleviating the TIPS
595 concerns of those living with LTHCs. Furthermore, though recent research examining dynamic
596 consent models for the sharing of clinical data (blood and tissue samples) in third-party
597 contexts showed promising results in terms of acceptability (74), it remains to be seen how
598 such models would work across more stigmatised health conditions and across more varied
599 PGData types. Although there is still little empirical work in this area, the UK EPSRC funded
600 programme INTUIT is examining TIPS concerns around PGData sharing primarily for people
601 living with HIV but also for those with other stigmatised conditions. The INTUIT project aims
602 to identify TIPS concerns and to design tools that remove the barriers to collecting and sharing
603 PGData in order to improve the health and well-being of stigmatised populations. As part of
604 this project, we are conducting interviews with people living with LTHCs to examine the role
605 of sharing context and health condition in relation to TIPS barriers. This is the first study of its
606 kind to focus specifically on TIPS issues in relation to sharing PGData via digital technology
607 across a variety of stigmatised LTHCs and across a range of different sharing contexts.

608

609 **Conclusion**

610 This narrative review has provided a broader perspective on the TIPS challenges faced by
611 people managing LTHCs and has shown that TIPS issues are a considerable barrier to the

612 sharing of PGData via technology by those living with LTHCs across all settings (i.e., sharing
613 with clinical staff, public health surveillance, researchers, peer communities, friends, social
614 networks and other third-party organisations). Distrust in the proposed recipient of PGData,
615 the need to manage one's digital identity and broadly held privacy and security concerns
616 present barriers to sharing in a clinical setting but more research is needed to understand other
617 contexts, particularly sharing with third parties. The presence of internal and enacted stigma
618 has also been shown to impede the sharing of PGData across all settings, although most
619 research in this area has centred on those living with HIV. This highlights the need for further
620 research to consider differences between conditions in experiences of stigma, and to consider
621 how these differences interact with the influence that TIPS concerns have over sharing. Whilst
622 the technological sharing of PGData holds great potential benefits for the health, wellbeing and
623 social outcomes of people managing LTHCs, the TIPS challenges faced by those individuals
624 must be better understood and addressed if interactions with care services, peer support
625 networks, and private organisations are to be optimised.

626

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630 EP/R033900/2), examining TIPS concerns around the sharing of self-generated health and
631 lifestyle data primarily among people living with HIV but also for those with other potentially
632 stigmatised conditions.

633

634 **Conflict of Interest**

635 The authors declare that the research was conducted in the absence of any commercial or
636 financial relationships that could be construed as a potential conflict of interest.

637

638 **Author Contributions**

639 The initial concept for the project was founded by LC, ES and AD. The research questions and
640 search criteria were then developed by LC, ES and EmS and reviewed by other the other
641 authors. EmS conducted the initial search and review and RB conducted the final search and
642 review. LC and ES supported EmS in the shortlisting of papers against the criteria. All authors
643 participated in discussing, revising and editing the manuscript.

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848 *Table 2. Included papers Overview*

Author(s) (Year)	Country of Origin	Aim/Purpose	Long-Term Health Condition (LTHC)	Population	Sharing Data with/ platform	Key findings
Agaku, Adisa, Ayo-Yusuf and Connolly (2013)	USA	This study assessed the perceptions and behaviours of US adults regarding the security of their protected health information (PHI).	Various conditions	n = 1,452 adults	Healthcare professionals (HCPs)	This study reported that most US adults are concerned about the security and privacy of their PHI, and that such concerns are associated with an increased likelihood of non-disclosure of sensitive information to HCPs.
Ancker et al. (2015)	USA	This study investigated how patients with multiple chronic conditions (MCC) manage their personal health records and information sharing with HCPs. This study also addressed how patients perceive their own role in managing their health information.	MCC	n = 22 adults	HCPs	Personal health information management should be recognized as an additional burden that MCC places upon patients. Effective structural solutions for information sharing, whether institutional ones such as care management or technological ones such as electronic health information exchange, are likely not only to improve the quality of information shared but reduce the burden on patients already weighed down by MCC.
Bernaerdt, Moerenhout and Devisch (2020)	Belgium	This study investigated the perceptions and attitudes of vulnerable patients regarding sharing medical information with HCPs and third parties via a digital platform.	Various conditions	n = 14 adults	Digital patient portal for sharing with HCPs and third parties.	Patients expressed concerns about privacy and security risks. Patients were generally unaware of the meaning and value of health data to third parties which resulted in inconsistent views on data sharing. Patients desire granular control over their medical information but believe that this may negatively impact their quality of care. There is a need for more transparency about the potential consequences of sharing data with third parties.

Bussone et al. (2020)	UK	This study investigated the TIPS considerations that people living with HIV make when sharing data with their peers for the purpose of guiding the development of trusted digital tools.	HIV	n = 26 adults	Digital health communities (sharing with peers)	TIPS concerns are central to those living with HIV when deciding whether or not to share personal health information with others. Platforms that are associated with a familiar HIV-related organisation or charity benefit from enhanced trust. Robust privacy and security measures are key to ensuring trust in digital peer sharing platforms.
Caine and Hanania (2012)	USA	The aim of this study was to assess patients' desire for granular level privacy; this includes control over which personal health information should be shared, with whom, and for what purpose. The study also addressed whether these preferences vary based on the sensitivity of health information.	Various conditions	n = 31 adults	Multiple recipients	Patients expressed a clear desire for control over which health information should be shared and with whom. Patients also expressed differences in sharing preferences for sensitive versus less-sensitive health data.
Esmailzadeh, Mirzaei and Dharanikota (2020)	USA	This study aimed to examine the interplay between different chronic health problems and different types of sharing interfaces in relation to patient willingness to share personal health information with HCPs.	Chronic mental illness and chronic physical illness	n = 607 adults	Structure and unstructured interfaces for sharing personal health information with HCPs.	The results described how individuals managing physical illnesses and mental disorders both favour highly structured data entry interfaces for sharing personal data. Mental health patients perceived less psychological risk, and reported lower privacy concerns when using a well-structured data entry interface to record their PHI compared to an unstructured interface.

Fergie, Hunt and Hilton (2016)	UK	The aim of this qualitative study was to explore how engagement with user-generated content can support people with LTHCs, and to explore the factors that limit users' adoption of these technologies.	Diabetes (type unspecified) and Common Mental Health Disorders (CMHD)	n = 40 adults	Social Media	This study highlighted the complexities of users' engagement with user-generated content for support in their experience of LTHCs. The findings highlight the range of considerations which influence production and consumption of health content via social media, particularly around identity management and integrating health content into everyday online practice.
Fuji, Abbott and Galt (2015)	USA	The purpose of this qualitative study was to explore how patients with type 2 diabetes use an Electronic Health Record (EHR) to manage their information for the purpose of self-care.	Type 2 Diabetes	n = 59 adults	HCPs via an EHR	Patients valued being able to store their medical data on one electronic record that was easily accessible. However, most participants did not share their data with HCPs. Patients expect HCPs to have full access to their data without having to personally disclose it. A strong patient-provider relationship is important for the effective adoption of EHRs.
Hartmann, Sander, Lorenz, Böttger and Hegerl (2019)	Germany	The aim of this study was to investigate the self-monitoring and self-management of depression as well as to explore the data sharing preferences of potential users of digital platforms.	Depression	n = 668 adults	Mobile apps	Individuals with depression want to take control of sensitive data, they do not want to share with everyone - particularly third parties. Individuals are concerned about tracking, particularly when they perceive that being tracked to a specific place could be used against them.
Kelley, Lee and Wilcox (2017)	USA	The aim of this study was to investigate student perspectives on self-tracking of mental health and how personal data is used to support mental health and wellness management.	Mental Health	focus group n = 14, survey n = 297 students (18-24yrs)	Multiple recipients via self-tracking technologies	Students were motivated to share data with family and friends as a sense of 'accomplishment' and sharing with peers was motivated by a sense of altruism. Tracking and sharing data with HCPs changed their experience of healthcare visits and improved communication and decision making.

Lafky and Horan (2011)	USA	The aim of the study was to better understand the design implications for EHRs for people living with chronic conditions.	Various conditions	n = 28 adults	Electronic Health Record	Individuals are less concerned about the security of health data (compared with financial data). People living with disabilities are less willing to take measures to secure their health information.
Leventhal, Cummins, Schwartz, Martin and Tierney (2014)	USA	The aim of the study was to assess patient preferences for accessing PGData through a digital system, CareWeb.	Various conditions	n = 105 adults	HCPs	More than half of all participants wanted to share all of their data with HCPs. Only 5 participants out of 105 did not want anyone to view their data in the EHR.
Maiorana et al. (2012)	USA	The aim of the study was to examine how trust (in tech, people and processes) influences the acceptability of data sharing in an HIV related context.	HIV	n = 549 adults	HCPs and other stakeholders via Health Information Technology (HIT)	People living with HIV are widely accepting of HIT. Increased experience and comfort with digital technology, confidence in security protocols, trust in providers and institutions who use the technology enhance understanding of the benefits to patients.
Murnane, Walker, Tench, Volda and Snyder (2018)	USA	The aim of this study was to better understand how people living with Bipolar Disorder use data in condition management and how this may be facilitated by the use of personal informatics systems.	Mental Health (Bipolar Disorder; BD)	n = 22 adults	Multiple recipients via self-tracking technologies	People with BD believe that sharing data with HCPs is standard and supports doctor-patient communication. Sharing with family and friends is important for recognising when patients with BD may need intervention and support.
Nurgalieva et al. (2020)	Sweden	This study explored patient perspectives on what technical, ethical, security, and privacy challenges need to be considered when designing platforms for sharing medical information.	Various conditions and a subgroup of cancer patients	Survey n = 2587 adults Interviews of cancer patients n = 15 adults	A national online platform for accessing personal electronic health information and sharing with multiple recipients.	Few patients chose to share health information through an online platform despite a majority of patients trusting the security of the system. Cancer patients and psychiatric patients were notably hesitant to share online. Different conditions might cause a range of feelings in patients regarding sharing their health information, such as concerns about stigma.

O'Kane, Mentis and Thereska (2013)	UK	The purpose of the study was to explore how chronically ill patients and their specialized care network view their personal medical information privacy and how it impacts their perspectives of sharing their records with HCPs and third parties.	Diabetes (Types 1 and 2)	n = 27 adults	Multiple recipients via Health Information Technology	Diabetes patients shift their perceived privacy concerns and needs throughout their lifetime due to the persistence of health data, changes in health, digital technology advances, and experience with technology that affect one's consent decisions around privacy.
Teixeira, Gordon, Camhi and Bakken (2011)	USA	The aim of this study was to assess the attitudes of individuals living with HIV/AIDS towards having their personal health information stored and shared electronically.	HIV	n = 93 adults	Health Information Technology (HIT)	The majority (84%) of individuals were willing to share their PHI with clinicians involved in their care. Fewer individuals (39%) were willing to share with non-clinical staff. Willingness to share PHI was positively associated with trust and respect for clinicians.
Torabi and Beznosov (2013)	USA	This study explored perceptions of privacy risk when sharing personal health information via online social networking sites.	Various conditions	n = 166 adults	Social Media	The results suggest that the majority (over 95%) of participants share some form of health or lifestyle information, with the "type" and the "recipient" of the shared data being the key factors that affect the perceived privacy risk and the risk-mitigating behavioural responses.
Vaala, Lee, Hood and Mulvaney (2018)	USA	This study aimed to understand the willingness of adolescents to share type 1 diabetes (T1D) information with their peers.	Type 1 Diabetes	n = 134 adolescents (12-17yrs)	Sharing with peers via Social Media	Adolescents were more willing to share how they accomplished T1D tasks than how often they completed them, and least willing to share glucose control status. Sharing/helping beliefs and glucose control were related to greater willingness to share personal health information.
Warner, Gutmann, Sasse and Blandford (2018)	UK	This research looked at the app Grindr and the concerns around HIV disclosure for men living with HIV.	HIV	n = 149 adults	Grindr	The study finds some HIV positive users report keeping their status private to reduce their stigma exposure, whilst others report publicly disclosing their status to avoid being stigmatised by others. Where users keep their status private, concerns that social assumptions may develop around these non-disclosures, create a privacy unravelling effect which restricts disclosure choice.

Weitzman, Adida, Kelemen and Mandl (2011)	USA	This study aimed to test the willingness of an online diabetes community to share data for public health research by providing members with a privacy-preserving social networking software application for rapid temporal geographic surveillance of glycaemic control.	Diabetes (type unspecified)	n = 1136 adults	Health Surveillance Technology (mimicking social networking sites)	Users self-enrolled to use the digital technology and of those who enrolled, 83% added up-to-date glucose data. Sharing was high with 81.4% of users permitting data donation to the community display. 34.1% of users also displayed their glucose data on their profile page. Users selecting the most permissive sharing options had a lower average A1c (blood glucose level) (6.8%) than users not sharing with the community 95% of users permitted re-contact.
Zhang et al. (2018)	China	This study looked at the sharing of personal health information in online health communities for people living with multiple conditions.	Various conditions	n = 337 adults	Sharing with peers via online health communities	Health information privacy concerns, together with informational and emotional support, significantly influence personal health information disclosure intention. Privacy concerns are negatively influenced by two coping appraisals (i.e., response efficacy and self-efficacy) and positively affected by two threat appraisals (i.e., perceived vulnerability and perceived severity).
Zhu, Colgan, Reddy and Chloe (2016)	USA	This study looked at the use of patient-generated data using digital technology in a clinician-patient consultation.	Various conditions	n = 12 adult patients n = 9 clinicians interviews	Self-tracking technologies and sharing data with HCPs	Patients are motivated to collect and share PGData to foster a better understanding of their health and improve clinician appointments. Clinicians largely ignored data brought to consultations in this study. Some clinicians and patients feel overwhelmed by raw data.