

1 [Abstract](#)

2 The conceptual ambiguity of public trust in the healthcare system poses problems for
3 governance and public trust measurement. Therefore, we aimed to answer: what is public
4 trust in the healthcare system?

5

6 We conducted in the context of the English NHS an analysis of online news with readership
7 comments concerning the care.data initiative; a secondary analysis of interviews about
8 participants' experiences and perceptions of biobanks; and an analysis of public focus groups
9 about perceptions of the 100,000 Genomes Project. Further, we engaged with existing
10 conceptual work and trust theory. This resulted in a full conceptual framework of public trust
11 in the healthcare system.

12

13 Public trust is established in anticipation of net benefits. Public trust legitimises the actions of
14 the healthcare system as well as encourages the public to participate in healthcare-related
15 activities. Further, levels of public trust are affected by spillover effects from high or low levels
16 of public trust in other parts of the government system. Last, many actors inside and outside
17 the healthcare system influence public trust.

18

19 Future research needs to translate this conceptual framework into policy guidelines and a
20 measurement scale, as well as to validate the conceptual framework for healthcare systems
21 other than the British NHS.

22

23

24 Key Words:

25 Public trust in the healthcare system, health data, health policy, qualitative research,

26 conceptual framework, scale development

27

28

29

30

31

32

33

34

35

36

37

38

39

40

41

42

43

44

45 1. Introduction

46 Trust is vital for the effective functioning of healthcare systems. We trust and follow the
47 advice of our doctor with the expectation to recover from illness; as research participants, we
48 trust that our sample will contribute to the advancement of treatment for our children; in
49 both guises, we trust that our medical records will be stored safely and be treated
50 confidentially; and as the public, we trust that effective health policies are in place and that
51 the healthcare system is governed in such a way that it can respond to the needs of all of us.

52

53 In recent years, studies explored trust as a relational construct between the public and the
54 healthcare system. They showed that high levels of public trust are generally associated with
55 system legitimacy, low transaction costs and improved health, and higher levels of social
56 cohesion (Gille, Smith, & Mays, 2014). Further, the level of public trust can be an indicator of
57 the need for system reform (Abelson, Miller, & Giacomini, 2009). Similarly trust theory
58 underlines the importance of trust for societies, where high levels of public trust are
59 associated with prosperity and perceptions of safety (Fukuyama, 1996; Papakostas, 2012).

60

61 The value of public trust explains why the public responds with outrage to healthcare system
62 scandals. Examples from the British National Health Service (NHS) include, the neglected
63 computer software updates that, had they been performed, could have contained the
64 WannaCry ransomware attack in 2017 which compromised NHS performance for days
65 (National Audit Office, 2018); the failed implementation of the care.data programme in 2016
66 stopped by strongly expressed public concerns in relation to privacy, data security and the
67 default opt-in (Hays & Daker-White, 2015); the Mid-Staffordshire scandal of 2006-2009 which

68 highlighted a cultural crisis in parts of the NHS leading to poor quality care (Holmes, 2013);
69 and the three doctors who were penalized in 1998 after the death of 28 babies at Bristol Royal
70 Infirmary (Hutchison Jacqueline, 2015). Public trust was a topical issue during the debates
71 following each of these and other scandals.

72

73 To be able to build public trust in healthcare systems, to measure public trust and to
74 formulate health policies that foster public trust, we need to understand what public trust is.
75 Despite the growth of trust research, there is no common understanding of what constitutes
76 public trust in the healthcare system (McKnight & Chervany Norman, 2001; Rolfe, Cash-
77 Gibson, Car, Sheikh, & McKinstry, 2014). Existing conceptualisations focus largely on the
78 patient-doctor relationship. Such conceptualisations omit the influence of other system
79 actors and the contribution of the public itself to public trust and they are not directed at the
80 level of the system (Gille, Smith, & Mays, 2017). This observation is equally true for existing
81 measures that purport to measure public trust (Anand & Kutty, 2015; Egede & Ellis, 2008;
82 Straten, Friele & Groenewegen, 2002). A psychometric review of these measures revealed
83 that such instruments are based on an understanding of public trust as a relational concept
84 between the individual patient and selected parts of the healthcare system. This implies that
85 such conceptual frameworks in fact measure individual trust and are applicable to *patients* as
86 opposed to the *public* including healthy individuals. Further, the conceptual frameworks that
87 underlie the reviewed measures neglect other actors in the health care system and public
88 sphere which influence levels of public trust (Gille, 2017, Chapter 3). These observations call
89 for further research and the development of more precise instruments based on a clearer
90 understanding of the construct of public trust. Tying in with our previous publication in this

91 journal (Gille et al., 2017), we now aim to answer: *what is public trust in the healthcare*
92 *system?* by presenting a full conceptual framework of public trust in the healthcare system.

93

94 **2. Methods**

95 Throughout, we followed psychometric guidelines emphasising the importance of a full
96 conceptual framework. We reviewed conceptual frameworks of public trust in healthcare
97 systems (Anand & Kutty, 2015; Egede & Ellis, 2008; Straten, Friele, & Groenewegen, 2002).

98 Further, we read trust theory (Erikson, 1950; Frevert, 2013; Fukuyama, 1996; Gambetta,
99 1988; Giddens, 1990; Hardin, 2002, 2006; Hartmann, 2011; Luhmann, 2000; Misztal, 1995;
100 Montinola, 2009; O'Neill, 2002, 2003; Papakostas, 2012; Seligman, 1997; Sztompka, 1999).

101 However, new qualitative data was central in this research (U.S. Department of Health and
102 Human Services, et al., 2006; Lohr, 2002). We analysed three national level English NHS case
103 studies covering biomedical research and mass data storage. They were chosen because trust
104 in the system as opposed to trust in individual staff was highly likely to be prominent. Further,
105 we decided to undertake secondary analysis of datasets collected for other purposes, as we
106 wanted data sources where the participants were not specifically sensitized to the issue of
107 'public trust' and were not asked to discuss public trust. This way trust was more likely to
108 emerge unselfconsciously. Based on our experience, there is a risk that specifically probing
109 for trust immediately shapes the response in an unhelpful way if the goal is to develop a
110 conceptual framework empirically.

111

112 Case Study I: analysing online news readership comments on care.data.
113 The care.data programme aimed to link patient information collected by primary and hospital
114 NHS providers to deliver a better picture of the paths patients take through the system, and
115 to analyse quality and costs for service improvement. Due to public and professionals'
116 concerns expressed in the media, principally about data confidentiality, the programme was
117 cancelled in 2016 (Department of Health and Social Care & Freeman, 2016).

118

119 In 2015, we collected 58 online news articles (BBC n=2; Daily Mail n=16; Guardian n=14;
120 Independent n=15; Telegraph n=11) with 1625 related readership comments (see Appendix).
121 Most articles were published in February 2014 (n=38). We identified the articles by searching
122 for *care.data* via Google.com or search engines on the newspapers' webpages. We selected
123 the newspapers purposefully to achieve national coverage. Smith and colleagues (2017)
124 explain the value of online fora for qualitative research (Smith, Bartlett, Buck, & Honeyman,
125 2017).

126

127 Case Study II: analysing interviews with biobank participants on their experiences and
128 perceptions

129

130 Biobanks typically collect and store participants' biological samples in repositories for future
131 research (Paskal, Paskal, Dębski, Gryziak, & Jaworowski, 2018).

132

133 Researchers from the University of Oxford conducted 21 in-depth interviews (semi-
134 structured, largely inductive and purposively sampled) with participants across the UK in
135 2011. The participants were involved in different biobanks (Locock & Boylan, 2016).

136

137 Case Study III: analysing focus group interviews on public perceptions of the 100,000
138 Genomes Project

139

140 The Department of Health launched Genomics England in 2013 to advance treatment, benefit
141 patients, create a transparent and ethical data repository, and to kickstart UK's genomics
142 industry. The goal is to sequence, 100,000 genome samples to identify cancers, rare non-
143 communicable diseases and rare infectious diseases (Genomics England, 2018).

144

145 We analysed two public focus group interviews on perception of the 100,000 Genome Project.
146 The interviews were conducted for an affiliated research project Understanding participation
147 in genomics research a collaboration between the Policy Innovation Research Unit and Oxford
148 University Health Experiences Research Group (Policy Innovation Research Unit, 2019).

149

150 How we conceptualised public trust from the three data sources
151 Following the same method for each case study, we conducted an inductive analysis within
152 NVIVO 9 (Elo & Kyngäs, 2008). We searched for the words: trust, confidence, hope, believe,
153 belief, faith, and love. Colloquial speech and literature frequently use such terms as if they
154 are synonyms of trust. Therefore, we broadened the range of possible themes as compared
155 to searching for trust only. Then, we openly coded the text passage around the terms to
156 understand how the terms were used in the argument. We sorted the evolving themes into
157 three categories (see Figure 1): conceptual themes describe the causal characteristics
158 comprising public trust (Wilson, 2005); 'framing refers to the process by which people develop
159 a particular conceptualisation of an issue or reorient their thinking of an issue' (Chong &

160 Druckman, 2007, p. 104); and effect themes describe an effect as a result of the trusting
161 relationship. We formulated *if, then statements* to describe each theme.

162

163 FIGURE 1 HERE

164

165 We synthesized iteratively the themes from the data. In addition, we considered expert
166 feedback after presenting findings at the 2016 Health Services Research UK Conference.
167 Informed by Gille et al. (2017), we grouped the framing themes as: basic level (essential
168 themes for the conceptualisation of public trust); individual level; public level (themes
169 developed in the public sphere); and governmental level. We did not categorize the two effect
170 themes.

171

172 How we developed a full conceptual framework of public trust in the healthcare system
173 First, we compared the qualitative findings with existing conceptual frameworks (Anand &
174 Kutty, 2015; Egede & Ellis, 2008; Straten, Friese & Groenewegen, 2002). Despite some overlap,
175 the conceptual frameworks are in large parts different. This is most likely due to the fact that
176 existing conceptual frameworks focus much more on the patient-doctor relationships.
177 Second, in moments of uncertainty, trust theory helped us to separate conceptual, framing
178 and effect themes. Also, trust theory helped us to understand the generalisability of the
179 findings, and to define the distinctive features of public trust. Where the qualitative data were
180 contradicted by either existing social theory or the domains of previous measurement
181 instruments, priority was given to our data.

182

183 Ethics
184 The data used in the Biobank case study is covered by South Central Berkshire NRES
185 Committee Ref 12/SC/0495. The data used in the 100,000 Genome Project case study
186 is covered by University of Oxford Research Ethics Approval: MS-IDREC-C1-2015-175.
187 The data for the care.data case study are in public domain. London School of Hygiene
188 and Tropical Medicine Ethics approval Ref: 8982 covers this research project.
189

190 3. Results and Interpretation

191 The conceptual framework consists of 15 conceptualising themes which developed from the
192 data analysis and a sixteenth theme that developed from theory only, *gut feeling*, see Table
193 1. Table 2 describes two effect themes and Table 3 shows nine framing themes.

194

195 Conceptualising themes

196 TABLE 1 HERE

197

198 The following describes the themes. There are no weights associated with the themes in
199 terms of their contribution to the conceptual framework.

200

201 Active regulatory systems

202 The public understands regulation and control as a trust-securing mechanism (Bouwman,
203 Bomhoff, de Jong, Robben, & Friile, 2015). People suspected, fueled by the media, that if
204 private companies such as insurance companies got hold of medical records, they could

205 increase premiums or not insure people (Donnelly, 2014). The other main concern is that
206 private companies should not use NHS medical records for their own profit. The public
207 understands that the data storing organisation need to regulate data access. Also, the
208 government must follow up any breach of data security with disciplinary action.

209

210 *I work for a research company and we currently "extract" data from primary care -
211 the hoops we have to go through to do this are extensive - but I believe they are
212 useful to maintain privacy and limit "mess ups".*

213 (Care.data case study)

214

215 Anonymity

216 Data anonymization is essential to maintain trust. However, the achievability of anonymity is
217 debated by scholars (Kaye, 2012). Kaye (2012) concludes that full anonymity will not be
218 possible and attempts to do so will carry a risk of breach. Accordingly, it would be sensible to
219 discuss and explain openly the benefits and risks concerning identification since this is more
220 likely to build public trust.

221

222 *Faith in anonymisation is key. (Care.data case study)*

223

224 Autonomy

225 Granting personal autonomy about choosing to take part in healthcare supports public trust.
226 Here, autonomy and choice reinforce each other (Dan-Cohen, 1992).

227

228 *Both doctors and governments are getting far too much control over our lives. I keep*
229 *away from doctors. I lost faith and trust in them a long time ago.* (Care.data case
230 study)

231

232 Benefit to others

233 Benefit to others refers to altruistic motivations and actions within the healthcare system,
234 which are understood as an important aspect of public trust.

235

236 *It is all about trust. If I believed that my medical records were being used for the*
237 *greater good, then I would have no problem with it.* (Care.data case study)

238

239 Certainty about the future

240 Mitigating future uncertainty fosters public trust. As trust can be understood as a risky
241 advance payment, a higher degree of certainty about the future use to which personal data
242 will be put should foster greater trust (Luhmann, 2000).

243

244 *I really don't trust this idea, we don't know that promises made now will be kept by*
245 *future governments, or private companies.* (Care.data case study)

246

247 Familiarity

248 As the public comprises of individuals, personal experience builds public trust. Here, personal
249 experience with system representatives encourages trust in the wider healthcare system
250 (Giddens, 1990). On a personal level, familiarity is understood as a building block of wider
251 trust (Sztompka, 1999, p. 124)

252

253 *Yeah. I would not have trusted them. That's down to your personal experience.*

254 (100,000 Genomce Project case study)

255

256 General perception of security

257 This complex theme comprises of for example, the existence of security measures which

258 protect medical data against unlawful data access; IT competence of the government or

259 general practice to run an IT system; and a local storage place for personal data. This sense of

260 trust in local settings might be linked to a sense of pride in local areas over remote areas

261 (Haddow & Cunningham-Burley, 2008). Also, hacking must be prohibited.

262

263 *...as an IT professional I have zero confidence that there is any way to effectively*

264 *secure this data....* (Care.data case study)

265

266 Gut feeling

267 All other conceptualizing themes appear to represent a calculated decision process about

268 whether one should trust or not. However, considering wider trust research, it is worth

269 reflecting that intrinsic motivations can have an effect on trust (Dane, Rockmann, & Pratt,

270 2012). In behavioural economics, irrational choice is a recognised phenomenon (de Jonge,

271 2011). This is why we expanded the conceptualisation to account for intrinsic motivations.

272

273 Health system benefit

274 The public trusts that the healthcare system makes advances in science and thereby improves

275 quality of care. This theme is closely linked to the content of the case studies, as an advance

276 in science should follow donation of samples. Quality of care is a well-recognised theme
277 conceptualising trust in any healthcare setting (Mechanic, 1998).

278

279 *It is hoped that the resulting increase in preventative treatments, coupled with*
280 *improvements in health management, will save billions and improve the quality of*
281 *healthcare.* (Care.data case study)

282

283 Information quality

284 High quality information communicated to the public is important for public trust (Larson,
285 2016). The data suggest that the communicated information should be clear, explanatory,
286 honest and truthful. Further, if the same information is provided by several sources people
287 trust more. To use multiple sources to make a decision to trust is found by other studies (Ek,
288 Eriksson-Backa, & Niemelä, 2013; Hall et al., 2002). Last, the data suggest that people tend to
289 trust what they consider as a reliable source.

290

291 *Thin end of the wedge ... I have no trust in politicians or NHS to tell the truth.*
292 (Care.data case study)

293

294 Personal benefit

295 The theme developed from the expectation of help as the healthcare system should be
296 available to help in case of need.

297

298 *And that is again, to hope to try and find and help xxx is an issue. And are we to do it*
299 *personally, because if we are then going to have a child with someone who is also a*

300 *carrier, you know, potential of having a child with albinism. ... So I think that would*
301 *help in that instance, if you know.* (100,000 Genomes Project case study)

302

303 Privacy

304 Private information should be protected and not be revealed in public. Privacy, is a recurring
305 theme in the context of healthcare, trust, and private data (Damschroder et al., 2007).
306 Concerns about privacy affect the willingness of patients to provide personal information
307 (Walker, Johnson, Ford, & Huerta, 2017)

308

309 *The Government nor its departments can be trusted with private information they*
310 *are useless and incompetent.* (Care.data case study)

311

312 Public financial benefit

313 It was frequently discussed within the case studies that altruistically donated data should be
314 used for the exclusive benefit of the public sector and the public. Similarly, research funding
315 should be related to the healthcare system and not the private sector. People wish that there
316 should be a separation of public and private profit making. It is understood that profit made
317 by public institutions is more likely to be reinvested to serve the public good.

318

319 *They'll see if they can commercialise the, the actual and package it, the whole process*
320 *and sell, sell that to other countries that, that's going to be a massive income boost*
321 *which will then hopefully [ah] be reinvested into other medical research or expansions*
322 *to the current project and that sort of thing because I know they are doing.* (100,000
323 Genomes Project case study)

324

325 Recognised potential of the healthcare system
326 The healthcare system needs to show the potential to fulfill what it is trusted for. Hence,
327 public authorities need to show that they have control over private companies and can
328 prevent private companies from working in the healthcare system solely for their own benefit
329 and not for the benefit of others, as is expected of a public initiative. Furthermore, people
330 trust a structured project. Professionals need to be able to keep up with new knowledge by
331 continuing their education. However, it is also believed that professionals cannot, in fact, keep
332 up with the pace of research output. At the government level, the public trusts representative
333 governance that works for the public and not its own benefit. Referring to research itself,
334 public institutions should lead large scale research. With respect to professional behaviour,
335 self-confident professionals are trusted more. Self-confidence is understood to develop from
336 good professional training. Last, research questions raised by a research project should be
337 meaningful.

338

339 *You - I don't know how well somebody without that confidence, without that –you*
340 *kind of can't have one without the other. Because if you haven't got the education,*
341 *the confidence, you can't do the confidence bit because you actually don't know*
342 *what you're talking about... (Biobank case study)*

343

344 Respect
345 Respect as a theme is often found when conceptualising trust (O'Neill, 2002). This theme
346 developed from a range of themes where data must be accurately entered into the system
347 and donated specimens must be kept in good condition by careful handling. Further, feedback

348 must be provided in a sensitive way. Researchers should only provide the feedback which a
349 participant has consented to. Respected professionals should not compromise their
350 professional reputation to be trusted. Respect for participants describes the respectful
351 interaction of professionals with participants, leading to mutual respect. On a bigger scale,
352 healthcare programmes must be managed responsibly.

353

354 *They respect how I am giving as much as I can of my time and my love. And equally, I*
355 *respect how they are giving their time and their love. (Biobank case study)*

356

357

358 Time

359 The public needs time and should not be rushed when deciding to trust. Also, the trusted
360 should not be rushed. Time is generally important for trusting relationships, as trust cannot
361 be rushed. The role of time for patients' decision making has been stressed in other research
362 as an important part of a trusting relationship (Keating, Gandhi, Orav, Bates, & Ayanian,
363 2004).

364

365 *And if we don't allow the medical profession to make this research and undertake*
366 *experiments on us as, you know, human beings, we're never going to find out, are we?*
367 *So I'm, I'm a great believer that we give them as much time as possible. (Biobank case*
368 *study)*

369

370 Effect themes

371 TABLE 2 HERE

372 Effect themes describe the direct effect of public trust in the healthcare system. Underlying
373 these themes is the general effect of trust as a relational construct that legitimises action
374 (Misztal, 1995). *Participation* and *legitimisation* developed from the heated discussions
375 around the default opt-in of the care.data programme. If the public trusts a programme
376 embedded in the healthcare system, it will consent to take part in the programme. This
377 consent legitimises the use that the programme wishes to make of participants' information.
378 The care.data case study showed the opposite effect, where people opted out of the
379 programme due to a lack of trust. Another effect of public trust is that people feel comfortable
380 to provide personal data to a programme. Participation was discussed frequently in the
381 care.data case study.

382

383 *I'm afraid I don't trust them to do things properly. Nor do I want any information*
384 *related to me shared with Big Pharma, so I'm opting out.* (Care.data case study)

385

386 Framing themes

387 TABLE 3 HERE

388

389 Basic level framing themes

390 These themes describe fundamental actions or circumstances of society itself.

391

392 **Communication**

393 Communication is vital for social interaction and thence for the establishment of trust. If there
394 is no information exchange, it is not possible to build trust:

395

396 *I never received anything through the post about the introduction of this scheme, if*
397 *they can't even send out letters properly I've no faith that they look after my details*
398 *securely.* (Care.data case study)

399 **Risk**

400 Risk, as, for example, technical failure, is inevitably present in healthcare. In trust theory, the
401 relationship of trust and risk is widely discussed since trusting can be understood as '*making*
402 *bets about the future uncertain and uncontrollable actions of others, [it] is always*
403 *accompanied by risk*', p.31 (Sztompka, 1999, p. 31).

404 Risk was expressed in quotes such as:

405

406 *Meanwhile, a risk assessment by NHS England, ..., raises concerns about the*
407 *initiative. ... The extraction of personal confidential data from providers without*
408 *consent carries the risk that patients may lose trust in the confidential nature of the*
409 *health service.* (Care.data case study)

410

411 **Reason to trust**

412 A reason to trust is pivotal. If there was no aim to use personal data in the three case studies,
413 trust would not be needed to legitimise the data use:

414

415 *Trust in government is at an all-time low and the fear that this data will be used by*
416 *private companies for profit is very real.* (Care.data case study)

417

418

419 Individual level framing themes
420 These themes are related to the individual through deep-rooted traits, belief systems or
421 human action in general.

422

423 **Human error**

424 In contrast to risk, as described above, human error develops from human action only and is
425 intrinsically in medicine (Institute of Medicine, 2000). It is not possible to eliminate human
426 error. For this reason, trust needs to accommodate human error. An unrealistic expectation
427 by the trusting that the trusted is free from human error would threaten the relationship as
428 this expectation cannot be fulfilled.

429

430 *Hence the reason I have the view now about sort of, you know, people making
431 mistakes. Everybody makes mistakes. I don't believe anybody in any job sets out in the
432 morning to say, "When I go into work today I'm going to do that wrong. I'm going to
433 really cause an issue today."* (Biobank case study)

434

435 **Fear**

436 According to O'Neill (2002a) in extreme situations, '*fear and intimidation corrode and
437 undermine our ability to place trust*' p.25(O'Neill, 2003). In the context of healthcare,
438 unrecognised fear and anxiety were described as challenging the ability to trust hospital care
439 (Pilgrim, Tomasini, & Vassilev, 2010).

440

441 *I do not trust the NHS to keep the information safe and secure and I have grave fears
442 it being sold on to private companies.* (Care.data case study)

443

444 **Religion and afterlife**

445 Religion and afterlife mediate trust. Faith in God and trust in humans are distinct concepts

446 (Seligman, 1997). However, the data suggest that faith influences a trusting relationship. Faith

447 seems to frame trust, as it pre-determines whether a person is likely to trust a certain

448 programme, to the extent that the programme is in line with the person's own beliefs.

449

450 *I think the, the point at which I carried a card was really [er] not being precious about*

451 *my own body organs, for instance, and not believing in an afterlife, or that my organs*

452 *would affect it even if I did.* (Biobank case study)

453

454 **People's world view**

455 People's world view, expressed by axioms, proverbs and what people think is 'natural', pre-

456 determines their basic attitude towards trust:

457

458 *I tend to believe in the axiom "What can be done, will be done"* (Care.data case

459 study)

460

461

462 Public level framing themes

463 The public level theme develops in the public sphere.

464

465 **Public mood**

466 Suspicion of the government, fueled, for example, by the global financial crisis, terrorism,
467 surveillance, etc. can transfer to the healthcare system. People compare trust between
468 different systems associated with the government, as the government is understood by many
469 to be the custodian of societal systems and therefore understood to be somewhat
470 accountable. Montinola (2004) described the spill-over effect of distrust from one agency to
471 another (Montinola, 2009). O'Neill explained public suspicion of governments and the
472 resulting threat this poses to public trust (O'Neill, 2003). This mood resonates throughout the
473 care.data case study. Readership comments were often cynical.

474

475 *With so many CRISES going on throughout the land. You would why people get out of*
476 *BED?? We have his CRISIS of confidence, we have the Cost of living CRISIS, we have*
477 *the flooding CRISIS, The cost of Housing CRISIS and so it goes on. CRISIS is obviously*
478 *the Journalist word of the moment. (Care.data case study)*

479

480 Governmental level framing theme

481 The government level framing theme is the seemingly general expectation by politicians that
482 the government should be trusted by the public. This expectation might have a normative
483 character and threatens public trust. Imposing trust logically cannot work. A trusting
484 relationship can only be established freely (Misztal, 1995).

485

486 *Yet another leakage and your financial data is again all over the web. Yet the*
487 *Government expect us to trust a quango to do better with our very personal and*
488 *private communications and records with our doctors. (Care.data case study)*

489

490 Strength and Limitations

491 Our data support the decision to use trust and similar terms as search terms as people use
492 the terms interchangeably in colloquial speech. Consequently, the study remained faithful to
493 this pattern of verbal usage.

494

495 We deliberately used qualitative data that had not been intended for trust research. We
496 consider this as a strength of this study since the nature of the data implies that the data
497 about trust developed in an unself-conscious way. Unfortunately, it was not possible to probe
498 in greater detail to understand the intrinsic motivations in comments on trust or the
499 responses in the interviews. This might explain why the theme of *gut feeling* did not evolve
500 from the data.

501

502 Generalisability

503 The empirical data focus on biomedical research and mass storage of personal health data.
504 However, we also used trust theory and previous trust research in the development of the
505 conceptual framework to increase generalisability. Comparing the findings to other trust in
506 healthcare studies, it appears highly likely that the conceptualisation presented here would
507 be applicable in a range of other health-related contexts (e.g. public trust in organ donation
508 or vaccination). Nonetheless, we are aware that there are a few themes in this study which
509 seem context-specific (e.g. altruism or data use) and other contexts might produce extra
510 themes around the margins of the conceptualisation (e.g. in extreme situations such as
511 emergency care). Nevertheless, the understanding that a healthcare system should serve the
512 public, as it is largely funded by tax in England, is not a unique characteristic of the case
513 studies, but more a cultural and institutionalised understanding of the NHS itself (Ipsos Mori,

514 2015). We are reasonably confident that the conceptualisation should be generalizable across
515 the UK NHS.

516

517 How far the conceptualisation can be used outside the UK remains unanswered. It needs to
518 be considered that in other cultures expressions of trust could be very different. This could
519 result in different themes. Also, concepts are sometimes not equivalent across cultures. It is
520 important to focus on the equivalence of concepts rather than just translation of language
521 when transferring the conceptual framework to other cultures. To transfer the conceptual
522 framework to other cultures necessitates further empirical testing. Trust theory suggests that
523 this conceptualisation will be most applicable to societies with similar norms and values, as
524 well as a similar understanding of what a healthcare system should aspire to be (Fukuyama,
525 1995). The conceptualisation builds on an understanding of an open health care system with
526 different actors in the public sphere (Gille, Smith, & Mays, 2017). It is plausible to suggest that
527 this conceptualisation is likely to be broadly applicable to similar systems (e.g. that of
528 Denmark) and perhaps also to systems that have similar goals but perhaps less similar
529 architecture such as Germany.

530

531 4. Discussion

532 This study aimed to conceptualise public trust in the healthcare system. This research is
533 unique in that it combined three case studies that were deliberately chosen to be outside
534 from personal care settings,. No other conceptualization of public trust in the healthcare
535 system has taken this approach. Further, by combining the empirical case studies with
536 extensive theoretical research as well as analysis of existing conceptual frameworks of public

537 trust in healthcare systems, we were able to develop a comprehensive conceptual framework
538 that is robust and a representation of the trusting relationship between the public and the
539 healthcare system and not the patient-doctor relationship (Gille et al., 2017).

540

541 Trust frequently appeared across the case studies. Looking at the conceptualizing themes all
542 together, *benefit to others*, *health system benefit* and *public financial benefit* are themes
543 which are at the core of the public interest and probably the distinctive themes of public trust
544 as they refer to a net-benefit for society and the system as a whole deriving from public trust.

545

546 Further, some themes refer to a personal relationship and relate to certain actors (e.g.
547 *sensitive feedback* or professionals as in *professional reputation*). Other themes do not relate
548 to a certain actor (e.g. *local storage* or *privacy*). This shows that public trust is derived both
549 from the presence of individual trust in specific healthcare system representatives, and in
550 more abstract trust in healthcare system organisations and processes. This diversity of
551 themes emerged from analysis of the diversity of the data, ranging from the more personal
552 context of people's direct experience of biobanking, to the less familiar, less directly personal
553 and prospective context of care.data. In the latter case, the data suggest that in a somewhat
554 diffuse context, comparisons are made to known trust relationships.

555

556 Also, several themes relate to a chain of actions and therefore to an entire range of actors
557 despite ostensibly addressing one actor specifically. For example, *active regulatory system*,
558 that might be based on national or international jurisdiction but are applied in a local research
559 facility and are carried out by local professionals. Therefore, many different remote and

560 proximal actors involved in a chain of action need to perform together for the system as whole
561 to be trusted.

562

563 Themes differ in the time periods they refer to: past (e.g. familiarity); present (e.g. active
564 regulatory system); and future (e.g. future benefit). This implies that the information
565 supporting public trust draws from a wide time span. The information develops from personal
566 and shared lived experience and present experience, as well as an anticipated future. It
567 remains unresolved in this research how far a conceptualisation of public trust can be
568 developed based on information from one or two of these three different time periods.
569 Ratcliffe, Ruddell and Smith, 2014 argue that ability to anticipate the future in a positive way
570 is central to the ability to build trust. We hypothesis that the information needed to trust
571 must relate to the past, present and future.

572

573 Considering the themes altogether, public trust develops from ongoing communication in the
574 public sphere and builds on the conceptualising themes which serve to legitimate the trusted
575 system in the eyes of the public, as well as to encourage public participation in the trusted
576 system. It is safe to say that all the conceptualising themes are equally important in principle,
577 though their importance is likely to differ depending on the context. We have no data that
578 would enable us to distinguish between the themes in terms of their relative importance for
579 the conceptual framework. However, most themes are in line with general research on issues
580 of trust implying that public trust is linked to other forms of trust. Further, the findings
581 confirm our previous analysis, as public trust is influenced by many actors (Identifying Ref.
582 deleted.).

583

584 When considering the measurability of public trust and the development of health policy
585 guidelines, the conceptual framework can serve both purposes. Based on our methodology,
586 we are confident that the conceptual framework is a solid starting point to develop a scale
587 that measures public trust in the healthcare system. We hope, that the conceptual framework
588 will guide the development of trustworthy health policy.

589 **5. Conclusion**

590 We conclude that the new conceptual framework of public trust in the healthcare system can
591 guide the development of a future measurement scale and policy. Further, this research
592 stresses the utmost importance of public trust for the functioning of the healthcare system
593 and society. Research is now needed to validate the conceptual framework for healthcare
594 systems other than the NHS in England.

595

596 **Disclaimer**

597 The focus group data used for this research were collected as part of a research project
598 funded by the Department of Health (DH), through its funding of the Policy Innovation
599 Research Unit at the London School of Hygiene and Tropical Medicine. All views expressed
600 are those of the author and are not necessarily those of the DH.

601

602

603 **6. References**

604 Abelson, J., Miller, F. A., & Giacomini, M. (2009). What does it mean
605 to trust a health system?: A qualitative study of Canadian health

- 606 care values. *Health Policy*, 91(1), 63-70.
- 607 doi:<https://doi.org/10.1016/j.healthpol.2008.11.006>
- 608 Anand, T. N., & Kutty, V. R. (2015). Development and testing of a scale
609 to measure trust in the public healthcare system. *Indian journal
610 of medical ethics*, 12(3), 149-157.
- 611 Bouwman, R., Bomhoff, M., de Jong, J. D., Robben, P., & Friele, R.
612 (2015). The public's voice about healthcare quality regulation
613 policies. A population-based survey. *BMC Health Services
614 Research*, 15(1), 325. doi:10.1186/s12913-015-0992-z
- 615 Chong, D., & Druckman, J. N. (2007) Framing theory. In: Vol. 10.
616 *Annual Review of Political Science* (pp. 103-126).
- 617 Damschroder, L. J., Pritts, J. L., Neblo, M. A., Kalarickal, R. J., Creswell,
618 J. W., & Hayward, R. A. (2007). Patients, privacy and trust:
619 Patients' willingness to allow researchers to access their medical
620 records. *Social Science and Medicine*, 64(1), 223-235.
621 doi:10.1016/j.socscimed.2006.08.045
- 622 Dan-Cohen, M. (1992). Conceptions of Choice and Conceptions of
623 Autonomy. *Ethics*, 102(2), 221-243. doi:10.1086/293394

- 624 Dane, E., Rockmann, K. W., & Pratt, M. G. (2012). When should I trust
625 my gut? Linking domain expertise to intuitive decision-making
626 effectiveness. *Organizational Behavior and Human Decision
627 Processes*, 119(2), 187-194.
- 628 doi:<https://doi.org/10.1016/j.obhd.2012.07.009>
- 629 de Jonge, J. (2011). *Rethinking rational choice theory: A companion on
630 rational and moral action*: Palgrave Macmillan.
- 631 Department of Health and Social Care, & Freeman, G. (2016). Review
632 of health and care data security and consent Retrieved from
633 [https://www.gov.uk/government/speeches/review-of-health-
and-care-data-security-and-consent](https://www.gov.uk/government/speeches/review-of-health-
634 and-care-data-security-and-consent)
- 635 Donnelly, L. (2014). Hospital records of all NHS patients sold to
636 insurers. *The Telegraph* Retrieved from
637 [https://www.telegraph.co.uk/news/health/news/10656893/Hos
pital-records-of-all-NHS-patients-sold-to-insurers.html](https://www.telegraph.co.uk/news/health/news/10656893/Hos
638 pital-records-of-all-NHS-patients-sold-to-insurers.html)
- 639 Egede, L. E., & Ellis, C. (2008). Development and Testing of the
640 Multidimensional Trust in Health Care Systems Scale. *Journal of*

- 641 *General Internal Medicine*, 23(6), 808-815. doi:10.1007/s11606-
- 642 008-0613-1
- 643 Ek, S., Eriksson-Backa, K., & Niemelä, R. (2013). Use of and trust in
- 644 health information on the Internet: A nationwide eight-year
- 645 follow-up survey. *Informatics for Health and Social Care*, 38(3),
- 646 236-245. doi:10.3109/17538157.2013.764305
- 647 Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process.
- 648 *Journal of Advanced Nursing*, 62(1), 107-115.
- 649 doi:10.1111/j.1365-2648.2007.04569.x
- 650 Erikson, E. H. (1950). *Childhood and society*. New York, NY: New York,
- 651 NY : Norton.
- 652 Frevert, U. (2013). *Vertrauensfragen : eine Obsession der Moderne*
- 653 (Originalausg. ed. Vol. 6104). München: München : Beck.
- 654 Fukuyama, F. (1996). *Trust : the social virtues and the creation of*
- 655 *prosperity*. New York: New York : Free Press Paperbacks.
- 656 Gambetta, D. (1988). *Trust : making and breaking cooperative*
- 657 *relations*. New York: New York : Blackwell.

- 658 Genomics England (2018). About Genomics England. Retrieved from
659 <https://www.genomicsengland.co.uk/about-genomics-england/>
- 660 Giddens, A. (1990). *The consequences of modernity*. Stanford, Calif:
661 Stanford, Calif : Stanford University Press.
- 662 Gille, F., Smith, S., & Mays, N. (2014). Why public trust in health care
663 systems matters and deserves greater research attention.
664 *Journal of Health Services Research & Policy*, 20(1), 62-64.
665 doi:10.1177/1355819614543161
- 666 Gille, F.; (2017) Theory and conceptualisation of public trust in the
667 health care system: Three English case studies: care.data,
668 biobanks and 100,000 Genomes Project. PhD thesis, London
669 School of Hygiene & Tropical Medicine. doi:
670 <https://doi.org/10.17037/PUBS.04645534>
- 671 Gille, F., Smith, S., & Mays, N. (2017). Towards a broader
672 conceptualisation of 'public trust' in the health care system.
673 *Social Theory & Health*, 15(1), 25-43. doi:10.1057/s41285-016-
674 0017-y
- 675 Haddow, G., & Cunningham-Burley, S. (2008). Tokens of Trust or Token
676 Trust? Public Consultation and 'Generation Scotland'. In J.
677 Brownlie, A. Greene, & A. Howson (Eds.), *Researching Trust and*
678 *Health*.
- 679 Hall, M. A., Zheng, B., Dugan, E., Camacho, F., Kidd, K. E., Mishra, A., &
680 Balkrishnan, R. (2002). Measuring Patients' Trust in their

- 681 Primary Care Providers. *Medical Care Research and Review*,
- 682 59(3), 293-318. doi:10.1177/1077558702059003004
- 683 Hardin, R. (2002). *Trust and trustworthiness* (Vol. vol. 4). New York,
- 684 NY: New York, NY : Russell Sage Foundation.
- 685 Hardin, R. (2006). *Trust*. Cambridge: Cambridge : Polity.
- 686 Hartmann, M. (2011). *Die Praxis des Vertrauens* (Vol. 1994). Berlin:
- 687 Berlin : Suhrkamp.
- 688 Hays, R., & Daker-White, G. (2015). The care.data consensus? A
- 689 qualitative analysis of opinions expressed on Twitter. *BMC*
- 690 *Public Health*, 15, 838. doi:10.1186/s12889-015-2180-9
- 691 Holmes, D. (2013). Mid Staffordshire scandal highlights NHS cultural
- 692 crisis. *The Lancet*, 381(9866), 521-522.
- 693 doi:[https://doi.org/10.1016/S0140-6736\(13\)60264-0](https://doi.org/10.1016/S0140-6736(13)60264-0)
- 694 Hutchison Jacqueline, S. (2015). Scandals in health-care: their impact
- 695 on health policy and nursing. *Nursing Inquiry*, 23(1), 32-41.
- 696 doi:10.1111/nin.12115
- 697 Institute of Medicine (2000). *To Err Is Human: Building a Safer Health*
- 698 *System*. Washington, DC: The National Academies Press.

- 699 Ipsos Mori (2015). *Public Perceptions of the NHS and Social Care*
- 700 Retrieved from
- 701 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/444783/NHS%20tracker%20acc.pdf
- 702
- 703
- 704 Kaye, J. (2012). The Tension Between Data Sharing and the Protection
- 705 of Privacy in Genomics Research. *Annual Review of Genomics*
- 706 and Human Genetics
- 707 , 13(1), 415-431. doi:10.1146/annurev-genom-082410-101454
- 708 Keating, N. L., Gandhi, T. K., Orav, E., Bates, D. W., & Ayanian, J. Z.
- 709 (2004). Patient characteristics and experiences associated with
- 710 trust in specialist physicians. *Archives of Internal Medicine*,
- 711 164(9), 1015-1020. doi:10.1001/archinte.164.9.1015
- 712 Larson, H. J. (2016). Vaccine trust and the limits of information.
- 713 *Science*, 353(6305), 1207.
- 714 Locock, L., & Boylan, A. M. R. (2016). Biosamples as gifts? How
- 715 participants in biobanking projects talk about donation. *Health*
- 716 *Expectations : An International Journal of Public Participation in*

- 717 *Health Care and Health Policy*, 19(4), 805-816.
- 718 doi:10.1111/hex.12376
- 719 Lohr, K. N. (2002). Assessing health status and quality-of-life
- 720 instruments: Attributes and review criteria. *Quality of Life*
- 721 *Research*, 11(3), 193-205. doi:10.1023/A:1015291021312
- 722 Luhmann, N. (2000). *Vertrauen : ein Mechanismus der Reduktion*
- 723 *sozialer Komplexität* (4. Aufl. ed. Vol. 2185). Stuttgart: Stuttgart :
- 724 Lucius & Lucius.
- 725 McKnight, D. H., & Chervany Norman, L. (2001). *Trust and distrust*
- 726 *definitions: One bite at a time.*
- 727 Mechanic, D. (1998). Public Trust and Initiatives for New Health Care
- 728 Partnerships. *Milbank Quarterly*, 76(2), 281-302.
- 729 doi:10.1111/1468-0009.00089
- 730 Misztal, B. A. (1995). *Trust in modern societies : the search for the*
- 731 *bases of social order*. Cambridge: Cambridge : Polity Press.
- 732 Montinola, G. (2009). *Corruption, distrust, and the deterioration of the*
- 733 *rule of law.*

- 734 National Audit Office (2018). *Investigation: WannaCry cyber attack*
- 735 and the NHS Retrieved from <https://www.nao.org.uk/wp-content/uploads/2017/10/Investigation-WannaCry-cyber-attack-and-the-NHS.pdf>
- 736
- 737
- 738 O'Neill, O. (2002). *Autonomy and trust in bioethics : the Gifford Lectures, University of Edinburgh, 2001* (Vol. 2001, Edinburgh).
- 739
- 740 Cambridge: Cambridge : Cambridge University Press.
- 741 O'Neill, O. (2003). *A question of trust* (Repr. ed. Vol. 2002).
- 742 Cambridge: Cambridge : Cambridge University Press.
- 743 Papakostas, A. (2012). *Civilizing the Public Sphere Distrust, Trust and*
- 744 *Corruption*: Palgrave Macmillan UK.
- 745 Paskal, W., Paskal, A. M., Dębski, T., Gryziak, M., & Jaworowski, J.
- 746 (2018). Aspects of Modern Biobank Activity – Comprehensive
- 747 Review. *Pathology & Oncology Research*. doi:10.1007/s12253-
- 748 018-0418-4
- 749 Pilgrim, D., Tomasini, F., & Vassilev, I. (2010). *Examining Trust in*
- 750 *Healthcare A Multidisciplinary Perspective*.

751 Policy Innovation Research Unit (2019). Understanding participation
752 in genomics research. Retrieved 28.11.2019 from:
753 [https://piru.lshtm.ac.uk/projects/current-
754 projects/understanding-participation-in-genomics-research.html](https://piru.lshtm.ac.uk/projects/current-projects/understanding-participation-in-genomics-research.html)

755 Ratcliffe, M., Ruddell, M., & Smith, B. (2014). What is a "sense of
756 foreshortened future?" A phenomenological study of trauma,
757 trust, and time. *Frontiers in Psychology*, 5(SEP).
758 doi:10.3389/fpsyg.2014.01026

759 Rolfe, A., Cash-Gibson, L., Car, J., Sheikh, A., & McKinstry, B. (2014).
760 Interventions for improving patients' trust in doctors and groups
761 of doctors. *Cochrane Database of Systematic Reviews*(3).
762 doi:10.1002/14651858.CD004134.pub3

763 Seligman, A. B. (1997). *The problem of trust*. Princeton: Princeton :
764 Princeton University Press.

765 Smith, J., Bartlett, J., Buck, D., & Honeyman, M. (2017). *Online Support*
766 *Investigating the role of public online forums in mental health*.
767 Retrieved from [https://www.demos.co.uk/wp-
768 content/uploads/2017/04/Online-Support-Demos-report.pdf](https://www.demos.co.uk/wp-content/uploads/2017/04/Online-Support-Demos-report.pdf)

- 769 Straten, G. F. M., Friele, R. D., & Groenewegen, P. P. (2002). Public
770 trust in Dutch health care. *Social Science & Medicine*, 55(2), 227-
771 234. doi:[https://doi.org/10.1016/S0277-9536\(01\)00163-0](https://doi.org/10.1016/S0277-9536(01)00163-0)
- 772 Sztompka, P. (1999). *Trust : a sociological theory*. Cambridge:
773 Cambridge : Cambridge University Press.
- 774 U.S. Department of Health and Human Services, Human Services, F. D.
775 A. C. f. D. E., Research, Health, U. S. D. o., Human Services, F. D.
776 A. C. f. B. E., Research, . . . Radiological, H. (2006). Guidance for
777 industry: patient-reported outcome measures: use in medical
778 product development to support labeling claims: draft guidance.
779 *Health and Quality of Life Outcomes*, 4, 79-79.
780 doi:10.1186/1477-7525-4-79
- 781 Walker, M. D., Johnson, T., Ford, W. E., & Huerta, R. T. (2017). Trust
782 Me, I'm a Doctor: Examining Changes in How Privacy Concerns
783 Affect Patient Withholding Behavior. *J Med Internet Res*, 19(1),
784 e2. doi:10.2196/jmir.6296
- 785 Wilson, M. (2005). *Constructing Measures. An Item Response*
786 *Modeling Approach*.

787

788

WORD COUNT: 7047