Abstract

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

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

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

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

Key Words:

Public trust in the healthcare system, health data, health policy, qualitative research, conceptual framework, scale development

1. Introduction

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

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

The value of public trust explains why the public responds with outrage to healthcare system scandals. Examples from the British National Health Service (NHS) include, the neglected computer software updates that, had they been performed, could have contained the WannaCry ransomware attack in 2017 which compromised NHS performance for days (National Audit Office, 2018); the failed implementation of the care.data programme in 2016 stopped by strongly expressed public concerns in relation to privacy, data security and the 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

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

2. Methods

Throughout, we followed psychometric guidelines emphasising the importance of a full conceptual framework. We reviewed conceptual frameworks of public trust in healthcare systems (Anand & Kutty, 2015; Egede & Ellis, 2008; Straten, Friele, & Groenewegen, 2002). Further, we read trust theory (Erikson, 1950; Frevert, 2013; Fukuyama, 1996; Gambetta, 1988; Giddens, 1990; Hardin, 2002, 2006; Hartmann, 2011; Luhmann, 2000; Misztal, 1995; Montinola, 2009; O'Neill, 2002, 2003; Papakostas, 2012; Seligman, 1997; Sztompka, 1999). However, new qualitative data was central in this research (U.S. Department of Health and Human Services, et al., 2006; Lohr, 2002). We analysed three national level English NHS case studies covering biomedical research and mass data storage. They were chosen because trust in the system as opposed to trust in individual staff was highly likely to be prominent. Further, we decided to undertake secondary analysis of datasets collected for other purposes, as we wanted data sources where the participants were not specifically sensitized to the issue of 'public trust' and were not asked to discuss public trust. This way trust was more likely to emerge unselfconsciously. Based on our experience, there is a risk that specifically probing for trust immediately shapes the response in an unhelpful way if the goal is to develop a conceptual framework empirically.

Case Study I: analysing online news readership comments on care.data.

The care.data programme aimed to link patient information collected by primary and hospital NHS providers to deliver a better picture of the paths patients take through the system, and to analyse quality and costs for service improvement. Due to public and professionals' concerns expressed in the media, principally about data confidentiality, the programme was cancelled in 2016 (Department of Health and Social Care & Freeman, 2016).

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

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

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

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

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

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

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

How we conceptualised public trust from the three data sources

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

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

FIGURE 1 HERE

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

How we developed a full conceptual framework of public trust in the healthcare system

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

Ethics

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

3. Results and Interpretation

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

Conceptualising themes

TABLE 1 HERE

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

Active regulatory systems

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

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

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

Anonymity

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

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

Autonomy

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

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

Benefit to others

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

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

Certainty about the future

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

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

Familiarity

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

Yeah. I would not have trusted them. That's down to your personal experience. (100,000 Genomce Project case study)

General perception of security

This complex theme comprises of for example, the existence of security measures which protect medical data against unlawful data access; IT competence of the government or general practice to run an IT system; and a local storage place for personal data. This sense of trust in local settings might be linked to a sense of pride in local areas over remote areas (Haddow & Cunnigham-Burley, 2008). Also, hacking must be prohibited.

…as an IT professional I have zero confidence that there is any way to effectively secure this data…. (Care.data case study)

Gut feeling

All other conceptualizing themes appear to represent a calculated decision process about whether one should trust or not. However, considering wider trust research, it is worth reflecting that intrinsic motivations can have an effect on trust (Dane, Rockmann, & Pratt, 2012). In behavioural economics, irrational choice is a recognised phenomenon (de Jonge, 2011). This is why we expanded the conceptualisation to account for intrinsic motivations.

Health system benefit

The public trusts that the healthcare system makes advances in science and thereby improves quality of care. This theme is closely linked to the content of the case studies, as an advance

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

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

Information quality

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

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

Personal benefit

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

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

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

Privacy

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

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

Public financial benefit

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

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

Recognised potential of the healthcare system

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

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

Respect

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

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

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

Time

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

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

Effect themes

TABLE 2 HERE

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

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

Framing themes

TABLE 3 HERE

Basic level framing themes

These themes describe fundamental actions or circumstances of society itself.

Communication

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

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

Risk

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

Risk was expressed in quotes such as:

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

Reason to trust

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

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

Individual level framing themes

These themes are related to the individual through deep-rooted traits, belief systems or human action in general.

Human error

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

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

Fear

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

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

Religion and afterlife

Religion and afterlife mediate trust. Faith in God and trust in humans are distinct concepts (Seligman, 1997). However, the data suggest that faith influences a trusting relationship. Faith seems to frame trust, as it pre-determines whether a person is likely to trust a certain programme, to the extent that the programme is in line with the person's own beliefs.

> *I think the, the point at which I carried a card was really [er] not being precious about my own body organs, for instance, and not believing in an afterlife, or that my organs would affect it even if I did.* (Biobank case study)

People's world view

People's world view, expressed by axioms, proverbs and what people think is 'natural', pre-determines their basic attitude towards trust:

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

Public level framing themes

The public level theme develops in the public sphere.

Public mood

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

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

Governmental level framing theme

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

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

Strength and Limitations

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

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

Generalisability

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

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

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

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

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

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

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

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

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

5. Conclusion

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

Disclaimer

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