Towards a broader conceptualisation of 'public trust' in the health care system

Abstract

Public trust lacks a precise, theoretically grounded and empirically tested definition, despite the increasing research interest and widespread use of the term in relation to different health care systems as well as other societal institutions. The mass media as well as the scientific community use the term public trust as if there is a common understanding of its meaning. As this is evidently not the case, this article proposes a broadening of an existing conceptualisation of public trust for use in health care system and policy research drawing on wider scholarship on trust from outside health care. In doing so, it further develops an existing conceptualisation of public trust in the health care system as a basis for discussion. In this conceptualisation, the origin of public trust is understood to be in the public sphere, which is situated between the individual, the health care system, the state and other societal institutions. Public trust in the health care system is influenced not only by the health care system itself, individuals' experiences of it and its media image but also by discourse in the public sphere about individuals' experiences and the system as a whole. This conceptual framework now needs empirical validation.

Keywords: Health Care System, Individual Trust, Public Trust, Public trust in the health care system

Introduction

Research has increasingly shown that many different aspects of the effective functioning of the health care system depend on the existence of a reasonable level of public trust in the system. Examples of health care system activities where public trust matters most obviously are vaccination coverage, health care provider choice, the use of the internet to identify health related information, or participation in biomedical research (Gille *et al*, 2015; Green, 2004; Haddow and Cunningham-Burley, 2008). As described by Brown (2008), the increased interest in public trust among health care researchers can partly be explained by a sequence of scandals covered in the media and the government responses that followed designed to act against the perceived betrayal of public trust. Prominent examples in the UK National Health

34 Service (NHS) are the cases of retention of organs without consent at Alder Hey children's
35 hospital, unacceptably poor quality paediatric cardiac surgery in Bristol in the 1990s, the
36 Beverly Allitt affair where children were deliberately harmed and murdered on a ward in the
37 early 1990s, the homicidal general practitioner, Harold Shipman, in the early 2000s and the
38 quality failure at Mid-Staffordshire hospital in the late 2000s (BRI Inquiry, 2001;
39 Brykczynska, 1994; Francis, 2010; Redfern *et al*, 2001;TSO, 2005). These scandals led to
40 changes in the health care system in the attempt to regain trust and prevent future scandals.
41 The changes focused on increasing the level of monitoring of performance and the quality of
42 care with the aim of increasing transparency and accountability (Brown, 2008). However, in
43 contrast to these examples, where experience of individual harm led to a public debate about
44 trust, the recent public debate on 'care.data' in the English NHS provides an example where
45 ahead of any individual harm, the public has strongly expressed low trust in a prospective
46 NHS project. 'Care.data' was introduced to the general public early in January 2014 via a
47 leaflet, 'Better information means better care', delivered to all households in the country.
48 'Care.data' aims to collect and share information about individuals' care to improve the
49 quality of care for all. Yet the initiative, which would link hospital and general practice
50 patient data anonymously at the individual level, has struggled to win public acceptance in the
51 face of concerns about the trustworthiness of the programme to keep sensitive information
52 secure and the potential for commercial gain to be made from patients' personal data (Carter
53 *et al,* 2015; NHS 2014; Pollock and Roderick 2014).
54 Cases like these have led to an increase in research about the role of trust in health care
55 systems or parts of health care systems as distinct from the large body of earlier research into
56 trust at the level of the personal encounters between individual patients and health care
57 professionals (Blendon *et al,* 2014; Calnan, 2004; Jovell *et al,* 2007; Larson and Heymann,
58 2010; Ozawa and Stack, 2013; Platt and Kardia, 2015; van der Schee *et al,* 2007). In this
59 research, a number of terms are used interchangeably to describe trust other than at the inter-
60 personal level (Gille *et al,* 2015). We will use the term most widely used in the mass media
61 and scholarly writing in this context, namely, public trust. In the mass media, the term public
62 trust is widely used in relation to many different societal issues. In addition to the health care
63 system, these include lately discussion of the financial crisis, scandals around governments'
64 security service surveillance or leaks of private information from governments and private
65 companies. At present, it appears that the term public trust primarily appears in association
66 with negative headlines. It generally hints at the need for the public openly to discuss public

67 trust because it is perceived to be threatened. However, such use of the term 'public trust'
68 assumes a common understanding of the term which is evidently not the case.
69

70 *Social theory on trust*

71 To ground any refinement in understanding of what public trust means in the context of the
72 health care system, it is necessary to look at social theory on trust. One obvious starting point
73 is Niklas Luhmann's definition of trust as a property inherent in relationships that reduces the
74 complexity associated with future uncertainty (Luhmann, 2009, p. 18). Niklas Luhmann has
75 been influential for the understanding of trust through his essay on trust (Luhmann, 2009),
76 and his book chapter on familiarity, confidence and trust (Luhmann, 1988, Chapter 6). His
77 work has been extensively discussed by a number of recent authors (Holmström, 2007; Jalava,
78 2003; Meyer et al, 2008). Nevertheless, Luhmann does not explicitly articulate the way in
79 which the public through social interaction contributes to 'public trust'. This aspect is more
80 central to the work of scholars such as Barbara Misztal, who discusses trust as a social
81 construct (Misztal, 1996). Misztal shows how the understanding of trust has changed as
82 modern societies have developed as well as the increasing difficulty such societies face to
83 attain trust (Misztal, 1996, p.1,9). For Misztal, ''Trust' is not seen as a regulatory mechanism
84 but rather as a public good' (Misztal, 1996, p.2, 12). As Misztal develops her definition of
85 trust as essentially a social phenomenon based on communication, she incorporates Jürgen
86 Habermas' Theory of Communicative Action. According to Habermas, communication is
87 built on mutual trust between the communicating actors. In turn, communication itself
88 coordinates social and political interaction (Misztal, 1996, p.13). Referring to Putnam and de
89 Tocqueville, trust is described as a public good as well as being part of social capital. Trust
90 here is sustained by social interaction and by the actions of an active citizenry. Understanding
91 trust equally as a property of social systems as well as an emerging attribute of individual
92 interaction overcomes the conceptual distinction between trust as a personal property and trust
93 as a systemic property (Misztal, 1996, p.14).
94
95 As a result of reviewing the 'functions of trust', Misztal proposes a synthetic approach to
96 understanding trust as a phenomenon consisting of three types of order. First, there is trust as
97 habitus (producing stable order) translated into practice as habit, reputation and memory. The
98 stable order of trust is a mechanism to cope with uncertainty, as shown for instance in daily
99 routines based on 'stable reputations and tacit memories' (Misztal, 1996, p.102). Second,
100 there is trust as passion (producing cohesive order) translated into practice as family, friends

and society. The cohesive order of trust changed under the impact of modernity from roots of trust in the family to mutual trust in society based on communication (Misztal, 1996, p. 157, 206). Third, there is trust as policy (producing collaborative order) translated into practice as solidarity, toleration and democratic legitimacy (Misztal, 1996, p.101). Central to Misztal's discussion of collaborative order is the concept of civil society as the basis for democratic legitimacy in the modern world (Misztal, 1996, p.212). Since the separation of the 'public' and 'private' spheres has become extreme in Western societies due to fragmentation of society and individualisation of modern social structure, institutional designs of modern democracies must be based on solidarity and trust to counteract the ongoing separation between the individual and society (Misztal, 1996, p.217). She proposes a strategy to support solidarity by a policy of trust designed to satisfy economic interests, embed the cultural view of the relationship between self and state, and facilitate freedoms of association, speech and religion. This strategy should provide reason and trigger people to get involved with each other in the public sphere (Misztal, 1996, p. 219).

Discussing public trust with respect to active citizenship, democracy and solidarity, and stressing its importance for social life in the public sphere are also themes taken up by other theorists of trust such as O'Neill (2002), Fukuyama (1995), Sztompka (1999), Seligman (1997) and Papakostas (2012). O'Neill describes the process of democratic legitimisation in bioethics which increases public trust (O'Neill, 2002, pp. 169–174). Here two ways to increase public trust are discussed both concerned with engaging active citizens in deliberation: small-scale citizen's juries; and large scale citizen's fora and consensus conferences. Similarly, Fukuyama sees trust as 'the expectation that arises within a community of regular, honest and cooperative behaviour, based on commonly shared norms, on the part of other members of the community' (Fukuyama, 1995, p. 26). With this community-focused understanding of trust, he identifies social capital as arising from the prevalence of trust, which requires that individuals in society have norms in common so that they can build public trust. In line with Fukuyama, Sztompka also describes trust as an inherently social phenomenon, and as an important dimension of civic culture and society. He further identifies a strong correlation between quality of life and the presence of generalized trust in a society (Sztompka, 1999, pp. 14–17). Following a line of argument similar to Fukuyama's, Seligman identifies as the two main elements of associational life (which is the basis of social solidarity) confidence in the political system and a shared identity (Seligman, 1997, p. 78). As a last example of this school of thought, Papakostas sees trust as an essential element for the development of the public sphere (Papakostas, 2012). While referring to the

scholars above, Papakostas concludes that individual trust, social capital and social networks are central to the production of trust within societies. These scholars all understand 'public trust' to be a distinct social phenomenon that co-exists with individual trust. For them, in general, public trust is based on shared norms and identity, and developed by communication and the activities of an active citizenry or public, contributing, in turn, to the development of social capital.

Existing conceptualisation of public trust in health care systems

When reviewing both the theoretical and the empirical literature on public trust in a range of areas, including health care system and policy research, it becomes evident that, unlike the theorists summarised above, there is little clear definition of public trust. One of the rare exceptions is the analysis by Van der Schee *et al* (2007) who present a conceptualisation of 'public trust in health care' in the context of a cross-country comparison of public trust in the health care systems of Germany, the Netherlands, England and Wales (see Figure 1)

<FIGURE 1 HERE>

In their conceptualisation, public trust in the health care system is seen as shaped by: a) the interpersonal trust between the patient and health care professionals (the underlying level of trust that prevails at this micro level); b) the mass media's image of the health care system and its knowledge network, where activities such as the reporting of crises and scandals may have a strong influence on 'public trust'; and, c) 'institutional guarantees and the actual availability of good quality care.' (Van der Schee *et al*, 2007, p.57). Van der Schee *et al* argue that all of these factors, as well as the relationship between the actors in the health care system, need to be set in their social context (van der Schee *et al,* 2007, p. 57). This implies that the construct is likely to change its precise shape in different social and cultural settings. Five years earlier, public trust in the health care system had been defined slightly differently by one of the same authors as: '… a generalized attitude based on personal experience in trust situations, on direct communication of other people's experience and on mass media communication.' (Straten *et al*, 2002, p. 223). It is argued by another of the same group of authors that one of the common features of definitions of public trust in the health care system is that: 'all embody the notion of expectations: expectations by the public that healthcare providers will demonstrate knowledge, skill and competence; further expectations too that

they will behave as true agents (that is, in the patient's best interest) and with beneficence, fairness and integrity. It is these collective expectations that form the basis of trust' (Calnan and Sanford, 2004, p. 32).

Van der Schee *et al*'s, 2007, conceptualisation of 'public trust in health care' provides a good starting point for public trust research from a health care system perspective, but has some limitations. It builds entirely on the triangular relationship between the individual, health care system representatives (i.e. all types of staff) and media coverage that generates interpersonal trust and then public trust. This conceptualisation starts at the individual level and develops a notion of public trust from this level upwards, shaped by the nature of the health care system's interaction with the individual, and the broader media image and representation of the health care system. The conceptualisation omits other social sectors and industries, which have recognizable impacts on the health care system, such as the national and multi-national private sector (e.g. pharmaceutical companies, consulting companies, insurance companies or IT companies), health care advocates (e.g. non-governmental organisations), or religious organisations. The strong influence of pharmaceutical companies on the health care system and the public has been increasingly critically discussed in recent years (Abraham, 2010). The so called socio-technical '*pharmaceuticalization'* of society provides opportunities for pharma industries to shape both their market and health care systems (Williams *et al*, 2011). With the increasing technological development of society, as well as of the health care system, the health care system itself has been opened up to new phenomena such as the internet, e-health, data sharing, foreign health care industries and, simultaneously, its complexity has increased.

Furthermore, the conceptualisation omits, to a large extent, the influencing dynamics of the public itself on public trust. The public, as discussed below, is arguably the main driver of public trust, as individuals, forming the public, discuss and exchange their experiences and perceptions of trust in the health care system, and their perceptions of what forms public trust. Further, changing levels of public trust in the health care system may change patients' behaviour, for example by influencing their health care choices rather than causality always running in the opposite direction from the individual to the public. Thus Van der Schee *et al*'s, 2007, conceptualisation can be expanded and developed to take into account the greater complexity and openness of the health care system, and the increase in publicity given to the nature and level of public trust.

The conceptualisation thus seems to be too much focused on the relationship between the health care system and the individual, which is a limitation when the focus is a phenomenon that exists at the level of the public. For example, Arendt's (1958) definition of that which is 'public' points to something other than what is described in van der Schee *et al*'s (2007) conceptualisation. Whatever is 'public' appears in public and can be seen and heard, in principle, by everybody, has the widest possible publicity, is common to all and is distinguished from the private (i.e. personal) realm (Arendt, 1958, pp. 50-58). What is 'public' becomes manifest, for example, in public goods, of which public trust can be understood to be one (Misztal, 1996,pp. 12-32; Seligman, 1997, pp. 97–99). This would not apply to individuals' interactions with the health care system since these are largely private encounters, despite the fact that public trust also develops indirectly and partly from these interactions, as argued below.

Both Habermas' and Arendt's work on the public and the public sphere have significantly influenced today's understanding of the term 'public' and need to be brought into any definition of 'public trust' (Calhoun, 1992; Crossley and Roberts, 2004; Seligman, 1997; White, 1990). The ideal process of discourse in the public sphere was described by Habermas in his account of the so called 'ideal speech situation' which he defined as based on foundations of communicative ethics (White, 1990, Chapter 3). Two propositions are crucial in Habermas' view of communicative ethics: first, that 'normative validity claims have cognitive sense' and therefore can be considered as true claims; second, that the validation process requires dialogue and cannot be conducted as an abstract monologue (White, 1990, p. 48). According to Habermas, it is essential for the development of a consensus that the rules for the 'ideal speech situation' are adhered to, as follows:

1. Each subject who is capable of speech and action is allowed to participate in discourse.
2. a) Each is allowed to call into question any proposal.
   b) Each is allowed to introduce any proposal into the discourse.
   c) Each is allowed to express his attitudes, wishes, and needs.
3. No speaker ought to be hindered by compulsion – whether arising inside the discourse or outside it –from making use of the rights secured under 1 and 2. (White, 1990, p. 56)

Further, the arguments brought forward in the discourse need to fulfil four criteria of validity, namely, that they are comprehensible, true, authentic and morally right, as well as appropriate

237 (Cukier *et al*, 2004; Denzin and Lincoln, 2005; Habermas, 1995). If the rules of the 'ideal
238 speech situation' as well as the validity claims are met, the discourse has the best chance to
239 lead to a consensus. In turn, this discourse has the potential to legitimise public trust.
240 Habermas' work has been successfully applied to the context of the health care system and is
241 proven to be valuable for discussions on the role of the 'public' in health care systems
242 (Chaudhary *et al*, 2013; Scambler, 1998; Stevenson and Scambler, 2005). All these strands of
243 thinking have contributed to the conceptualisation set out below.
244
245 Building on van der Schee *et al*'s, (2007) conceptualisation and understanding of public trust
246 in health care systems, influenced by Arendt's and Habermas' work on the nature of the
247 public sphere, as well as Habermas' work on discourse, and Luhmann's and others' work on
248 trust discussed earlier, and taking a Western view of health care systems (e.g. inspired by
249 reflecting on the British NHS and German health care system), we now present a more
250 elaborated conceptualisation for discussion and eventual empirical testing (Arendt, 1958;
251 Habermas, 1990, 1991, 2014; Jakowatz and Habermas 2008; Luhmann, 2009).
252

253 *A revised conceptualisation of public trust in the health care system*

254
255 The proposed conceptual framework (Figure 2) attempts to conceptualise 'public trust in
256 health care systems' by giving due recognition to its origins in the public sphere. While the
257 conceptualisation has yet to be used to guide empirical work, there are a number of pieces of
258 research that shed light on different segments of the proposed conceptualisation. These
259 include research on trust relationships between patient and doctor, trust in health care
260 programmes such as vaccination, trust in health information systems such as biobanks, trust in
261 government institutions and trust in the mass media including the communication of health-
262 related news (Ahern & Hendryx, 2003; Coleman *et al* , 2009; Feudtner, 2004; Goold *et al*
263 2006; Hall *et al,* 2001; Kelly *et al,* 2005; Ozawa and Stack, 2013; Picard and Yeo, 2011;
264 Tutton *et al*, 2004; van der Schee *et al*, 2012). In Figure 2, public trust in the health care
265 system is understood to be trust developed in the public sphere as a consequence of discourse
266 in public about people's experiences and perceptions of the health care system, as well as a
267 broader discourse shaping trust, grounded in the common health values and health norms of a
268 society. In turn, the public sphere is defined as situated between the individual sphere, the
269 health care system, the state, and other market and non-market institutions.
270

271 <FIGURE 2 HERE>

272

273 Communication, indicated by the solid and broken arrows in Figure 2, in all forms is essential
274 for the functioning of society and the development of trust, and herewith for reducing
275 uncertainty and thence complexity. Communication in the public sphere can be understood as
276 either active dialogue, face-to-face and in web-based fora, or more passive one-way
277 communication, as in the consumption of information and periodic public participation via
278 opinion polls or elections. The media play arguably the biggest role in channelling, filtering
279 and directing information within and outside the public sphere. As a result, the media have a
280 big influence on public trust in all the institutions of society, including shaping public trust in
281 the health care system. To take an obvious example, the media can be influential in shaping
282 public trust in vaccine programmes by amplifying concerns about vaccine damage and
283 polarizing the ensuing debates (Larson *et al*, 2011; Larson and Heymann, 2010). In the US,
284 during the late 1990s, organized parent groups spread misinformation about scientifically
285 unproven links between autism and Thiomersal, a compound containing ethylmercury used in
286 infant vaccine, leading to wide public 'mistrust' in infant vaccines. In turn, this affected trust
287 in the wider health care system, which, subsequently, led to further falls in childhood vaccine
288 coverage. (Larson *et al*, 2011, pp. 527–530).

289

290 However, depending on the information-consuming behaviour of the individual, the mass
291 media are only one of many routes, in addition to social media, blogs, tweets, newsletters,
292 informal networks, etc. by which the individual receives information in relation to public trust
293 and information that influences his/her individual trust and his/her understanding of public
294 trust. The media and communication are interpreted in Figure 2 as a mediator, a connector
295 and an observer to enable and keep discourse in the public sphere alive. Nevertheless, it needs
296 to be recognized that the role of the media in information dissemination can be controversial.
297 For example, Habermas discussed media power in the public sphere and concluded that, if
298 used for opinion manipulation, the public sphere develops into an arena of power where topic
299 selection and the coverage of topics are fought over (Calhoun 1992: 437). While Habermas'
300 model of the public sphere may seem rather abstract and idealised, an adapted understanding
301 of the public sphere does still exist today (Calhoun, 1992; Crossley and Roberts, 2004). It is
302 in the nature of the public sphere that it changes as society and the environment develop
303 rather than disappearing. The clubs, coffeehouses or salons of the 18th century contributed to
304 the classic understanding of how the public sphere manifests itself, as described by Habermas,

305 (Habermas, 1990, pp. 90-107). Perhaps the epitome of this concept of the public sphere is
306 Speakers' Corner in Hyde Park, London, where members of the public come together
307 specifically to discuss openly with one another in public. Nowadays, this is exceptional in that
308 the public sphere is far more likely to be represented by an online discussion forum facilitated
309 by communication networks that do not require the participants in public dialogue to be
310 physically present in the same place (Bohman, 2004). Thus the way that members of society
311 engage in public debate to form the public sphere has changed, as well as the ability and
312 skillset required to conduct discourse. This does not mean that the public sphere has
313 disappeared. It is more that the public sphere has become more dynamic and less physically
314 bounded. The topic-related public sphere seems to develop on demand, customised to the
315 needs of participants and the characteristics of the issue triggering the discussion before
316 vanishing again into a more general public sphere of communication when its raison d'être
317 disappears.
318
319 The constant features that drive different constructs of the public sphere are the underlying
320 communication networks and technologies, as well as the desire of members of society to
321 discuss issues of mutual importance likely to have a large impact on themselves and society
322 itself. For example, the discussion around the English NHS's care.data initiative, mentioned
323 above, was facilitated in the public sphere and was conducted in different, but connected,
324 communication fora simultaneously. These fora were the press, press readers' comments,
325 television, radio, Twitter, public newsletters, theinternet, Facebook and other platforms. The
326 composition of the public sphere in this case was constantly adapting to the discussion of the
327 topic and the needs/wants of the participants. Important to the contemporary understanding of
328 the public sphere is its perceived democratic character; i.e. that it is and should be open and
329 accessible to all, and allow free speech, as outlined in Habermas' definition of the ideal
330 speech situation and communicative ethics, above. The current ideal appears to be the notion
331 that everyone should have the same chance to be able to participate in some form of discourse
332 in the public sphere.
333
334 Turning back to Figure 2, from an individual perspective, the conceptualisation of public trust
335 starts with 'Individual trust in parts of the health care system' where trusting relationships are
336 understood to be a 'complex 'web of interactions'' bridging the individual and institutional
337 levels (Meyer *et al,* 2008, p. 182). This initial focus on individual trust is important, as
338 individuals form the public, and therefore individuals' trust experiences and perceptions, in

339 turn, fuel but by no means entirely define, public trust. Individual trust and public trust are
340 linked via individuals' perceptions and experiences of each other as well as their participation
341 in the 'public sphere'. 'Individual trust' in the health care system develops particularly when
342 individuals engage with branches of the health care system, such as their GP or the local
343 hospital, and can be built or undermined in the largely private environment of the clinical
344 encounter in the health care system from personal experience. However, an individual does
345 not necessarily need to have had any personal experience of the health care system to reach a
346 judgement about her/his trust in the system. This is because individuals, whether experienced
347 or not, engage with others in discussion of experiences (their own or those they are aware of,
348 for instance, among family and friends as well as cases of strangers or celebrities reported in
349 the media) and of wider perceptions of the health care system, where this exchange has an
350 influence on their perceived trust in the system as a whole. These trust experiences are further
351 raised in other discussions in the public sphere through active or passive participation in
352 public debates concerning the health care system. From an individual's point of view, two
353 forms of participation in the public sphere are possible, either as an active participant in
354 different physical fora (e.g. as an elected member of a city council) and online fora (e.g.
355 Twitter), thereby directly influencing the discussion, or as a passive participant through
356 opinion polls or by voting in elections, while also reading and consuming the opinions of
357 others. The example of the social media discussion of care.data once more supports the
358 argument for the existence of public discourse that is distinct from personal experience
359 (Hays and Daker-White, 2015).
360
361 As the number and range of participants in this discourse widens and becomes public, the
362 concept of the public sphere which exists between the 'individual sphere', the health care
363 system, the state (authorities, politics) and other societal and economic institutions (e.g. non-
364 governmental organisations, religious bodies, business, etc.) becomes central to the
365 conceptualisation (Chaudhary *et al,* 2013; Habermas, 1990). Within the public sphere, actors
366 with different roles in society (e.g. individuals, health care organisations, third sector groups,
367 politicians, business people, advocates or lobbyists, opinion leaders, etc.) come together to
368 reflect upon their experience and perception of the health care system, from which emerges an
369 understanding of public trust in the health care system. Fotaki describes this trust building
370 consensus discourse at the smaller scale of health care teams or individual provider
371 organisations. Here trust in relation to the values of a team or organisation can be built by
372 consensus (Fotaki, 2014). Similarly, O'Neill describes the process of democratic

373 legitimisation in the field of bioethics operating through deliberations that take place in
374 citizens' fora and consensus conferences, as outlined above (O'Neill, 2002, pp. 169-174).
375 Fotaki's observation hints at the possibility that the individual's perception of trust can be
376 influenced, in particular, by explicit consensus building processes as well as their own
377 perceptions of what individuals consume from the internet, social media, the press, etc.. This
378 observation is important as it links consensus building processes with the development of
379 trust which indicates the possibility of the same processes occurring on a greater scale in the
380 public sphere. Therefore, in Figure 2, public trust is defined as the form of trust that is
381 generated in the public sphere. In other words, public trust is distinct from individual trust as
382 it is generated not from the individual's perception of, and experience within, the health care
383 system but rather is generated within the public sphere itself through public discourse about
384 the individual's own and other people's experiences and perceptions of the health care system,
385 including evidence from research and analysis. This discourse, in so far as it builds a
386 consensus about the health care system, also signifies that public trust can be understood as a
387 public good and is legitimised by the public itself.
388
389 Public trust is also built through the politics associated with health care system governance
390 and political debate influencing the functioning of the health care system. Further, from the
391 state's perspective, public trust in the health care system is influenced by the state's active
392 communication with the public, and by its selection of policies and how they are presented
393 and justified. Last, as the health care system is an open system, other societal and economic
394 institutions, such as third sector organisations, or the business community, have a substantial
395 impact. Their influence on the shaping of public trust in the public sphere needs to be
396 considered. Examples of influence could be industrial lobby groups and third sector
397 organisations' advocacy activities.
398
399 The two 'outputs' of the conceptualisation in Figure 2, namely, public trust emerging from
400 the public sphere, and individual trust emerging from the interactions between the individual
401 and his/her health care providers, both include feedback loops (indicated by the dotted lines).
402 Public trust in the health care system feeds back into all public sphere-associated sectors, and
403 influences the actions and behaviour of affected and participating parties. Individual trust
404 predominantly affects the individual's behaviour, influencing the nature of the future
405 relationship between the individual and his/her health care providers. However, as the
406 individual is potentially an actor in the public sphere, individual trust is not completely

separated from public trust. Both forms of trust are linked by individuals' perception of both and therefore are influenced by these perceptions. Nevertheless, the information concerning topical issues shaping public trust and information on public trust, are communicated from the public sphere to individuals. This implies, that individuals depend on an authentic and objective information chain as well as personal experience for their level of public trust.

The distinctiveness of the nature of public trust in the health care system compared with public trust in other sectors of society such as the civil service, the benefits system, or the economy lies in the particularities of the underlying norms and values of society with respect to health and health care. These norms and values shape and guide the arguments about health care and the health care system that take place in the public sphere. They also determine which arguments put forward in the debate about whether the health care system can be trusted are regarded as valid by discourse participants.

The proposed conceptualisation in Figure 2 adds to previous conceptualisations of public trust in the health care system in that it recognizes the public sphere as the cradle of public trust in the health care system while showing how individual trust indirectly influences but does not simply determine the development of public trust. It recognizes that public trust in the health care system is not simply the average of individual trust as if it could be assessed simply by aggregating individual views about the health care system in a large opinion poll. The conceptualisation allows that public trust is a construct originating from the public sphere, which is, in turn, influenced from all sides of society, by the individual, by the health care system, by the state, by the media and by other actors (e.g. religious bodies, business and the third sector). Previous approaches to estimating the level of public trust in the health care system have typically used opinion polls and large-scale surveys to quantify levels of trust. However, this does not necessarily identify public trust. Rather it describes the average level of reported trust of survey participants. Even though it might be that the public debate around public trust has indeed influenced someone's individual trust, it is not clear when examining the results of such surveys, how far the debate has shaped the trust expressed in the survey as against the person's perceptions irrespective of that debate. A survey cannot account for the contribution of the public debate around trust leading to public trust. Public trust is thus more than the aggregation of private experiences and perceptions of trust in health care. Public trust is a consequence of the on-going public discourse on issues influencing the level of public trust. Simply expressed, public trust has two main ingredients: individual members of the

public's personal, family and friends' experience of the health care system; and the discourse, debate and commentary on the health care system that exists distinct from any one individual's experiences. Furthermore, the conceptualisation allows understanding of the health care system as an open system where not only do individual experiences of trust contribute to the development of public trust, but also the state's and other actors' experiences and perceptions and their practices of communication.

Conclusions

To understand and research public trust in the health care system, a more holistic conceptualisation of public trust is needed, that goes beyond a narrow focus on trust solely in terms of individuals' experiences of the health care system. In this conceptualisation, the origin of public trust is understood to be in the public sphere, which is situated between the individual, the health care system, the state and other societal institutions. Public trust in the health care system is influenced not only by the health care system itself, individuals' experiences of it and its media image but also by discourse in the public sphere about individuals' experiences and the system as a whole.

Empirical work is needed to further develop the conceptualisation advanced in this paper, especially since the theories and perspectives informing the development of the conceptualisation come from far outside the health care system. For example, research needs to be conducted to describe the dynamics within the public sphere with respect to health care systems. Further, public trust building (and reducing) discourse relating to the health care system needs to be identified and analysed, including examples discussed earlier such as citizen's juries, consensus development processes, or public consultations. Also, solutions need to be developed, if possible, to begin to measure public trust in the health care system. To enable mutual understanding and transferability of research results, the goal of such work would be to provide the research community as well as patients, professionals and the public, with a theoretically robust and empirically grounded construct as well as a way of rigorously measuring the level of public trust in the health care system.

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642 Figure 1: Conceptualisation of 'public trust in health care' (Source: van der Schee *et al,* 2007,

643 p. 57).

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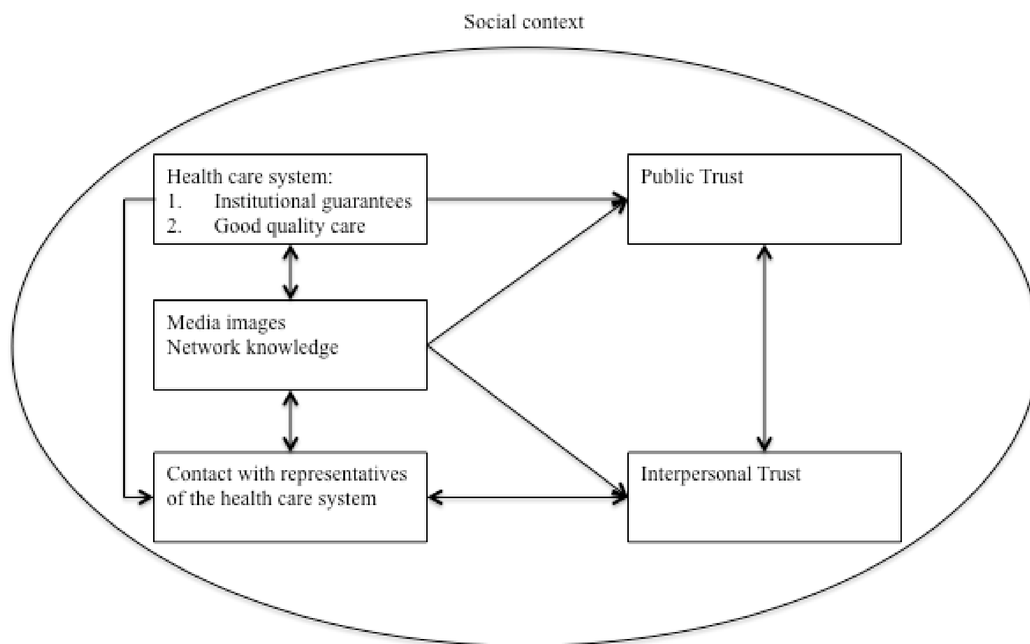

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665 **Figure 2:** Revised conceptualisation of public trust in the health care system.
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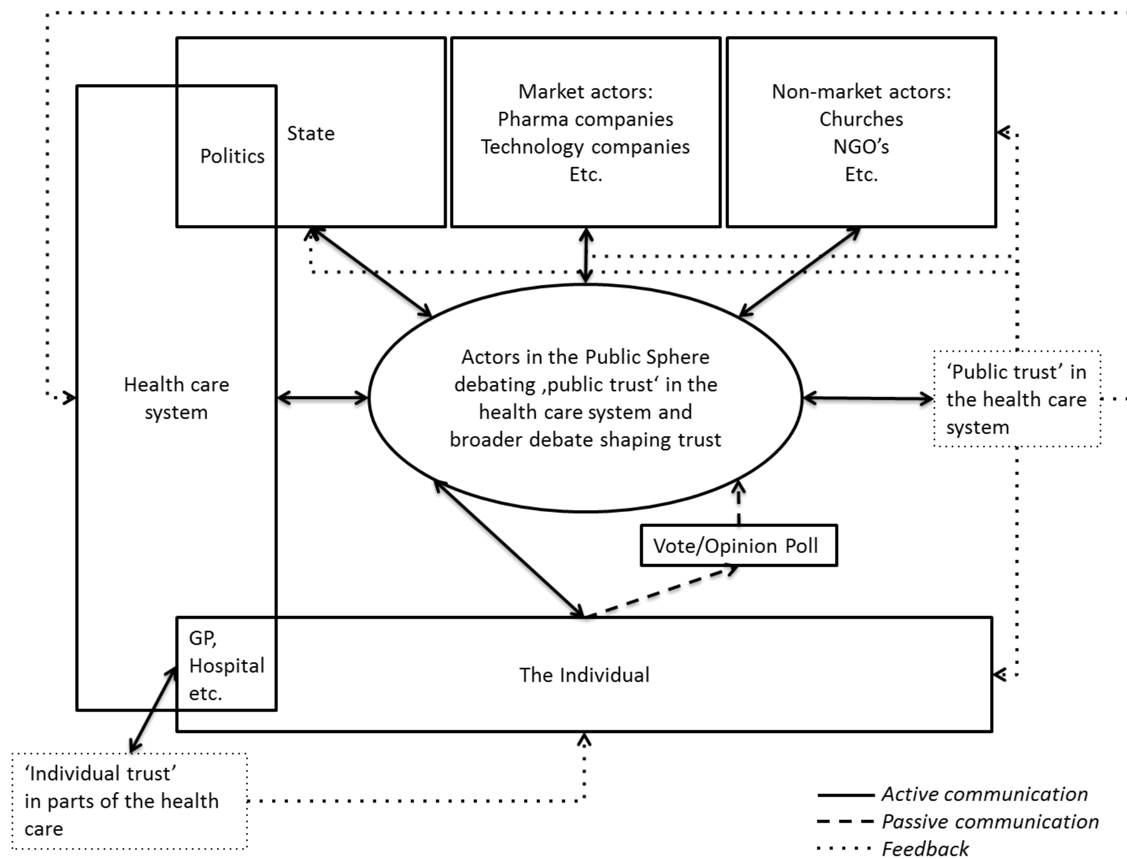

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