

Elisabetta Lalumera

## TRUST IN HEALTH CARE AND VACCINE HESITANCY

### *Abstract*

Health care systems can positively influence our personal decision-making and health-related behavior only if we trust them. I propose a conceptual analysis of the trust relation between the public and a healthcare system, drawing from healthcare studies and philosophical proposals. In my account, the trust relation is based on an epistemic component, epistemic authority, and on a value component, the benevolence of the healthcare system. I argue that it is also modified by the vulnerability of the public on healthcare matters, and by the system's credibility. I apply my proposed analysis of public trust in health care systems to the phenomenon of vaccine hesitancy, a tendency to question vaccine policies, and to seek alternative vaccine schedules or to refuse vaccination. Understanding the role of trust and its components can be key to understanding the phenomenon.

### *1. Introduction*

Trust from the public is crucial for health care systems. It is correlated with patient satisfaction (which is arguably beneficial for health outcomes), and it boosts and maintains compliance with prevention policies. On the contrary, distrust in a health care system produces uncertainty and doubt, the need to ask for a second opinion about diagnosis, and to look for 'alternative' medical approaches (Mechanic 1998; Gilson 2003; Calnan, Rowe 2006; Gray 1997). My paper aims to outline a notion of trust that would fit within explanations of how we trust our health care systems, and how it is that sometimes we don't. Only a few recent works in the recent philosophical debate address this specific issue (Nys 2016; Potter 2002; Domenicucci, Holton 2017). The main point I argue for in this paper is that trust in health care systems has two-components, an epistemic and a value component. Health care systems can positively influ-

ence our personal decision-making and health-related behavior only if we rely on their epistemic authority (at many levels, from the nurse to the research group), but also and fundamentally if we assume that the values they act on are the same we would act on. More specifically, I will say that both sharing values with the health care system, and attributing those values are key elements in maintaining the trust relation. I will also highlight the special level of vulnerability that health matters bring to the relation we bear to health care systems, and the role of the system's credibility in sustaining or diminishing public trust.

I apply my proposed analysis of public trust in health care systems to the phenomenon of vaccine hesitancy, a tendency to question vaccine policies, and to seek alternative vaccine schedules or to refuse vaccination (Larson *et al.* 2013). I rely on recent philosophical and empirical work on vaccine hesitancy showing that vaccine-hesitant groups are often neither ignorant of, nor under-informed on scientific issues, but rather they are sceptical about, or disagree with the very values behind pharmacological and clinical studies and behind their application in health care policies. In particular, they are sceptical about medical researchers' autonomy from Big Pharma agendas, and they disagree with the collectivism implicit in vaccination policies, to which they oppose individualism (Goldenberg 2016; Gottlieb 2015; Kata 2012; Skea 2008). This is how the paper is organized. In Section 2 I provide a bird's-eye view of cooperation relations holding in health care systems, and of the main motives behind the current crisis in public trust, mainly drawing from the sociological and health care literature. In Section 3 I spell out the details of a conceptual model of the relation of public trust in health care, which I apply to vaccine hesitancy in Section 4. Conclusive remarks are in Section 5.

## *2. Health care systems and cooperation relations*

The World Health Organization – the coordinating agency for health within the United Nations system – proposes the following (very comprehensive) definition of health care systems:

A health system consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health. This includes efforts to influence determinants of health as well as more direct health-improving activities. A health system is therefore more than the pyramid of publicly owned facilities that deliver personal health services. It includes, for example, a mother caring for a sick child at home; private providers; behaviour change programmes; vector-control campaigns; health insurance organizations; occupational health and safety legislation. It includes inter-sectoral action by health staff, for example, encouraging the ministry of education to promote female education, a well known determinant of better health (Who 2007: 1).

Health care systems vary considerably across countries in many respects, depending on parameters such as overall income, availability of medical knowledge and technology, political organization, funding source, and the relevant social choices. For example – considering Oecd countries only – the state is fully or partially in charge of the health system in most European countries such as the UK, the Netherlands, France and Italy (universal coverage), but not in the US (voluntary insurance system), while other countries adopt hybrid solutions. In fact, whereas in countries like UK and the Northern European welfare states the National Health Care System is perceived by the public as *one* entity, this is not obviously so in the US, where there is a plurality of providers (Hall 2006). Yet despite important differences among them, all health systems aspire to quality health care, universal access, affordability, and choice, in a situation of limited resources. In light of such aspiration, and given such constraint, they share the commitment to undertake policies, and single actions, to ‘promote, maintain and restore’ people’s health conditions and health-related behavior. This is the responsibility they have towards the public (Murray and Frenk 2000; Bohm *et al.* 2009).

Health care systems are complex institutions,<sup>1</sup> involving different stakeholders including governments, medical insurance companies, policy makers, medicine agencies, health practitioners (i.e. doctors, nurses), general and local managers of hospitals, patients, and the public. Market partners also play a crucial role: pharmaceutical companies and technological industries that provide clinical and diagnostic equipment, invest money in developing new products and in marketing them to health care providers at every level, from government to industry agreements (e.g. on the price of vaccines for nationwide prevention campaigns), to the bottom level of individual clinician’s persuasion by representatives (Field, Lo 2009). Works in health care studies and sociology have shown that various relations that facilitate coordination and cooperation have to be in place among all these different stakeholders, for the overall institution of health care to accomplish its goals. These include interpersonal relations among individuals, namely, between individual patients and clinicians (or health care practitioners in general) – the fundamental relation on which a health care system is built –, between one clinician and another, and between a clinician and a manager or a Pharma representative, between a manager and each member of his or her staff. But there are also institutional relations in place, which include patient and public relations to clinicians and managers in general, to a particular health care institution, or to the health care system of one’s country as a whole (Calnan and Rowe 2006: 350).

Arguably, some of the relations holding among health care stakeholders are better described as relations of *reliance*. There is some agreement in philosophy

<sup>1</sup> The diversity of actors behind health care provisions may suggest that health care is a system of institutions, rather than one institution. Though the point is metaphysically important, my argument in the rest of the paper does not bear on it. I thank a reviewer for this remark.

in viewing reliance as a conceptual ingredient of trust, to which something else ought to be added (Baier 1986; Hardin 2002; Faulkner 2017). Reliance can be non-voluntary, as when an unconscious patient relies on the staff and procedures of the emergency room. It can be directed to objects to which no interest or point of view can be attributed, as when a radiologist relies on her X-ray machine, or on the company that sells it. Reliance has nothing to do with attributing good will to someone or something – a policeman may rely on the kidnapper she captured for bringing her to the kidnapped person’s prison. Consequently, reliance can be in place even when trust is lost (or even straight out absent). In Annette Baier’s example, I may continue to rely on the local food store because I have no other choice, even though I know that it happened to sell poisoned food (Baier 1986: 234). In other words, reliance is a descriptive concept – involving no attribution of values (Faulkner 2017)

The patient-practitioner relation is the most widely studied, by both philosophers and sociologists of health care, among the many diverse cooperation relations involved in a health care system.<sup>2</sup> Philosophers on the patient-practitioner relation have highlighted the competing roles of paternalism and autonomy in shaping the bond. Autonomy refers to the liberal ideal, dating back to Kant and Mill, now adopted by other philosophical stances, that one should live one’s life according to one’s values, desires, and preferences (Buss 2016). In the context of the patient-practitioner relation it is translated as a right to be informed (informed consent) and to choose one’s treatment, at least to some extent (Beauchamp, Childress 2001). Paternalism refers to the ideal of a benevolent and knowledgeable partner who cares for us, and in the name of such caring is entitled to make decisions on our behalf (typically the state, but in this context the health practitioner) (Dworkin 2005). It is often noticed that old-times paternalism of medical staff has been gradually eroded by patients’ autonomy in the last century (see Nys *et al.* 2007 for review; O’Neill 2002).

I have mentioned paternalism and autonomy because I will return to these concepts below. I will now narrow the focus on a less investigated relation in health care, that between the public as a whole and the health care system as an institution. This relation is taking center stage, due to the organizational changes of many health care systems and to the establishment of evidence-based medicine and clinical practice, at the expense of the doctor-patient relation. We are more and more involved with an abstract system of health care delivery, rather than with single individuals. What is the nature of such relation? There is evidence that people continue to *rely* on medical institutions and staff, and to the health care system as a whole in all the cases where no choice is allowed, but a change in public attitude has become evident when voluntary health-related behaviour

<sup>2</sup> The philosophical literature on the patient-practitioner relation is very vast. Seminal works are Katz (1984) and Pellegrino (1988).

is concerned, or when an explicit evaluative judgment is asked for. There is less trust in health care authorities and their policies in many countries (Abelson *et al.* 2009; Calnan, Rowe 2008). In the third Section will propose the case of vaccine hesitancy as a case study.

The causes of the recent crisis of public trust in health care are many, they may vary from country to country, and a complete review is not among the aims of this paper (see e.g. Van Der Schee *et al.* 2007). Here I will nevertheless mention three issues that seem to be invariant. They involve aspects that will become salient in the course of the discussion. First, public trust in health care has been shaken by the intense media coverage of scandals involving medical errors, hidden agendas of Pharma and industry partners, and corruption of managers and practitioners. The thesis of a causal link between the role of the media and the trust crisis is argued for by the bioethicist Onora O'Neill, among others (O'Neill 2002).

Second, people increasingly find themselves in situations where their access to care is limited – for example, reimbursement for a treatment is denied, hospitalization is limited to the minimum, and choice of doctor or hospital is not free. The increasing cost of treatments due to the cost of research and technology, the global economic crisis, the aging of population and the reforms undergone by many national health systems in order to cope with such circumstances – for example, in the UK from the 1980s, in Sweden, and in Italy more recently – explain most cases of limitation of access to care. The result, however, is that some of the public's expectations are not met, and people come to believe that financial gain or at least money saving is what the system actually cares for (Mechanic 1996, 1998; Cribb 2008).

Third, on a larger scale, in high-income countries there is a decline in deference to authority and trust in experts in all fields, which leaks onto medical and health care experts. Defects in scientific communication, and the social composition of panels experts are among the motives of such decline (Whyte, Crease 2010).

In fact, that to restore and to enhance public trust is a priority is well recognized in health care studies and in policy documents – to the point that it may risk to become a platitude or a void cliché (O'Neill 2002; Shore 2007). Trust in health care systems ought to be restored not *just* because it is (partially) lost – as not every lost relation is worth restoring *qua* lost – but because trust is an instrumental good for health care systems, and arguably also for the society in general. Here I will not argue for such claims, but mainly restate them. Trust is an instrumental good for health care systems because some of their goals – mainly, but not only, prevention policies, such as screening tests and immunization – involve voluntary cooperation from the public, and trust facilitates cooperation. It is an instrumental good for society as a whole because – it has been argued – some behaviors motivated by trust in health care system, such as blood and organ donation, contribute to the sense of unity and collectivity that

democratic societies require (Simpson 2012; Gilson 2003). More generally, as health care systems – especially national, publicly funded ones – involve such a large degree of state-citizen interaction, trust in them will inevitably have consequences on public trust in the state itself (Gilson 2006; Fukuyama 1995). However, in order to restore trust from the public, health care authorities together with social scientists and philosophers ought to get clear on what trust is, and how it can be lost, and consequently to envisage specifically targeted strategies addressed to the public (Hall 2006).

### *3. Public trust in health care systems*

In this Section I set out some conceptual points about trust, which I believe can be used to cover actual cases of trust and distrust in health care systems from the public. The methodology I employ here can be labeled – I suggest – ‘instrumental conceptual analysis’, in that it aims at individuating the target notion with an explanatory agenda in view, rather than identifying on a priori grounds the true and exceptionless concept of trust. A similar approach (without the label) can be found in Russell Hardin’s work on trust (Hardin 2002), and it is sometimes indicated by practitioners of other fields as the positive contribution that philosophers can bring to scientific and public issues (Whyte, Crease 2010). As I said in the opening, my specific explanatory agenda here is a case of crisis of public trust in health care, namely vaccine hesitancy, which I will discuss in the next Section.

Here, then, is my proposal. Trust in health care from the public is a three-place relation, involving an institution (a community’s health care system), a collective entity (the public), and a field of application.<sup>3</sup> The field of application is what the public trusts a health care system for. It is obviously not coincident with any aspect of life (for example, for our savings we trust banks), and this may be generalized to all relations of trust in institutions, which is not unconditional, but offered in return for benefit (Domenicucci, Holton 2017: 158). The field of application contains whatever pertains to health, namely information (about, for example, the risks of smoking), prevention (as in immunization campaigns, and screening tests), diagnosis, therapy, hospitalization, but also organ and blood donation. Finite as it may be synchronically, the list needs to remain somehow epistemically open from the public’s point of view, because we (the public) often do not know exactly what is good for our health, and even what pertains to it. Trust, in this case as in general, involve what Nancy Potter calls ‘discretionary power’ on the trusted part: to define the precise characteristics and ways of caring (Potter 2002: 37).

<sup>3</sup>The field of application can alternatively be considered as part of the relation itself, or defined by the very nature of the institution involved (I thank an anonymous reviewer for this comment).

By the public I intend here the varied group of consumers, seekers and providers of health to which a health care system addresses its services, which in national health care systems virtually coincides with the whole population. In the course of life, each of us is a consumer of information for their own health, on the basis of which we make choices and decisions about lifestyle (for example, quitting smoke, or not eating beef meat during the so-called mad-cow disease alarm at the beginning of this century); we are all born to be patients and seek the services of health care providers and institutions (at least in two crucial circumstances, birth and death); we are likely also to be caregivers, namely, endowed with the responsibility of taking care of the health of other individuals around us, typically our children, elderly relatives, or partners. Individually, assuming one of the other roles in the course of life has an impact on the relation of trust one bears to the health care system, and collectively they all matter to an analysis of public trust.

It may be objected that there is no such thing as the public, but rather very different groups of people that bear different relations of trust to the health care system. There is ample empirical evidence for these variations – studies on the crisis of trust in health care in the US reports that low income patients versus higher income patients, patients in poorer health versus those in better health, women versus men, and racial and ethnic minorities versus Caucasians trust less their health care system in Europe and US (Shore 2007: 5-7, see also e.g. Halbert 2006; Whetten *et al.* 2006). In analyzing public trust in health care, however, I assume that at least some structural aspects of the relation – aspects related to the kind of factors trust depends on – do not vary if we vary the public (and the specific characteristics of the health care system).

Metaphysically, the public and the health care system are collective agents. Here I borrow from the relevant literature the notion of collective agency; there are several accounts of how an entity such as the public, or an institution like a health care system can be endowed with agency and psychological attitudes (see e.g. List and Pettit 2011; Tuomela 2013). I will not argue for any of those here, but rather assume that at least one is adequate. On this assumption, I submit that trust in health care from the public is an expectation that the system will act at every level with a view on promoting, maintaining and restoring people's health<sup>4</sup>. It is not necessarily (and it is often not) a belief that can be made explicit in words, but rather a willingness to act on such expectation, which manifests itself in decisions and behavior (Holton 1994).

I propose that public trust in health care involves vulnerability in two respects. The first is common to all trust relations, as Baier pointed out: we trust someone because we cannot personally take care of all our material and immaterial goods (Baier 1986). In particular, we trust an institution because we are unable to manage some area of our life by ourselves, as individuals, and in that area we are vulnerable in that we are not self-protected. In this way we trust banks because we are not, or

<sup>4</sup> I borrow the phrase from the Who definition of a health system quoted in Section 2.

we do not feel safe in storing our savings at home, and we care for them; in that respect, we are vulnerable. In addition to this constitutive vulnerability that comes as a presupposition for trust, an additional degree of vulnerability in the health care case comes from the field of application of the relation of trust, namely our personal health, and the health of the members of our family and community. Physical health is the paradigm of what makes us vulnerable as human beings, as a disease is (among other things) a constraint of one's spontaneous action (Nordenfelt 2007). The disease of our children, close friends and relatives makes us vulnerable, too, for they mobilize our deepest emotions. In broader perspective, that of our coworkers, and fellow citizens makes us vulnerable, for arguably a world of sick people would neither be a desirable nor a practically possible world to live in. Thus, the additional degree of vulnerability that we (the public) bring to our relation to a health care system comes from the fact that the trusted good (our health and the health of our dears and fellow citizens) is itself conceptually linked with vulnerability. The double level of vulnerability involved in public trust in health care suggests that values play a vital role in sustaining it – as I will be arguing below (Thomasma, Pellegrino 1998: 65; Bielby *et al.*: 52-60).

A relevant question is about trust is what it is grounded on, that is, what makes it reasonable or appropriate (see e.g. Hardin 2002: 90). First, the public's trust in health care is grounded on the epistemic authority of health care practitioners, and of the system collectively taken. As a conceptual point, we can't expect that the health care system would promote, maintain or restore our health unless we assume that it embodies sufficient knowledge, competence, and skills to do so.<sup>5</sup> As a matter of fact, however, given the division of epistemic labor, we assume more than that: we grant epistemic authority to health care systems. Epistemic authority is an asymmetry of knowledge status (Zagzebski 2003). Collectively, a health care system is where all competences and skills that pertain to health should be gathered. Epistemic authority of health care practitioners, and of health systems collectively taken, over the public means that they know more than we do about our health – they are experts, to which we are prepared to defer, without even realizing how many steps of deference we need to make. Consider the everyday case of someone who takes a diagnostic test for a disease, and is tested negative. He knows that because the nurse told her, and the nurse knows because the lab results indicate it, and the lab results indicate it because the lab technician ran the test and interpreted it, and the lab technician knows how to interpret it because she has learned from someone the appropriate technique, and the technique is appropriate because scientists did the research (Schwab 2008: 303). In attributing epistemic authority to health practitioners, we – the public – give them epistemic trust, namely, we are disposed to rely on their knowledge, competence and skills.

<sup>5</sup> I use three terms. 'knowledge', 'competence', and 'skills' to signal that I remain neutral on the philosophical issue of whether knowledge-how can be reduced to knowledge-that, or not.



Epistemic authority and epistemic trust, however, are not sufficient for trust tout court, however, for health care systems are acting subjects, not just knowing subjects. The public perceives them as pursuing goals and embodying values – not merely displaying knowledge and expertise. We trust our health care system and practitioners when we feel confident that they will act on the knowledge, competence and skills they possess in order to promote, maintain or restore our health, and not with other goals in view. In Schwab's example above of the diagnostic test, the trusting patient needs to assume implicitly that the nurse, the lab technician and the researchers who validate the test are neither joking nor cheating. As noticed above, the patients' double vulnerability calls for the system's benevolence. On a larger scale, the point is that the same amount of knowledge, competence and skills possessed by a health care system, collectively taken, can be employed in different ways, depending on the system's non epistemic goals. If the goal were just to reduce costs, for example, some treatments or exams would be precluded, even if they were known to be necessary. If the goal were to make profit, then treatments or exams sponsored by market partners could be encouraged, even if they were known to be unnecessary.<sup>6</sup> Likewise, if a health care system had other hidden agendas than public health, such as achieving benefits from Pharma companies, then their prevention policies would be oriented by marketing considerations.

Empirical studies have shown that the value component of the trust relation is particularly important at the collective level, whereas at the individual level of the patient-practitioner relation the epistemic component seems to matter more (Calnan, Sanford 2004). The presence of both aspects, I have argued, is however necessary. The blend of epistemic trust and expected benevolence that the public bears towards health care practitioners and the system is strictly connected with paternalism – as paternalism is definitionally linked with benevolence and authoritativeness. On the view I am proposing, then, paternalism has a role in accounting for public trust in health care. But autonomy has a role, too, as I am about to argue with a slightly long detour.

Philosophical accounts have already made clear that trust in general is grounded on some kind of attitude towards the values of the trusted part, starting from Baier's view that trust is 'reliance on the trusted part's good will towards oneself' (1986: 234; Potter 2002: 2). Good will, or 'benevolence' as I said above, however, are too generic to fit the case of health care systems. Consider this example. A national health care system with universal coverage restricts free, completely reimbursed access to a new treatment for Hepatitis C to a small class of patients – those with most severe conditions – because the product is extremely expensive, and unrestricted free prescription would make it economically impossible to sustain other

<sup>6</sup>This is the problem of over diagnosis, currently discussed in the medical and philosophical communities. See e.g. Roger, Mintzker (2016), Carter *et al.* (2015).

forms of prevention and treatment to the population. Is that good will or bad will? Individualism versus collectivism collide in this judgement. From an individualistic viewpoint, any patient could claim to be eligible for the treatment, and criteria for priority setting are highly debatable. On the other hand, from a collectivist viewpoint, privileging that specific pathology at the expense of all others health conditions would be unfair. Moreover, considerations about the reasons why the treatment in question is so expensive complicate the issue further – why didn't the health care system negotiate a better price with the pharmaceutical company? It might be for a hidden agenda of profit, or it might be for an agreement that involved reducing the price of, say, a widely prescribed antibiotics. One's initial good will or bad will verdict could reasonably be reversed when these two possible scenarios are considered.

The point of the example – which is actually a real case (Pani, Cammarata 2015) – is that a generic idea of good will should be replaced, in the case of the trust relation between the public and a health care system, with a more specific notion. How can we unpack 'good will' in the case of a health care system, though? This is both a normative and an empirical question. It is normative because it tackles the issue of the normative foundations of health care systems. It is empirical because it dwells into the varieties of health care systems in different countries. It may remain open, however, for the sake of the present discussion, which is about the trust relation that the public bears to health care systems, with the aim of providing a framework to understand it. I submit that the public trusts a health care system when it attributes to them those values that we share, and when we expect that they would act on the same convictions we would act on. This proposal may seem to bear some resemblance to Hardin's 'encapsulated interests' account – for example, I trust the plumber in that my interest in having the sink tap fixed coincides with the plumber interest to have it fixed, so that I will call him again when I need some work to be done (Hardin 2002). As philosophical commentators have argued, there is too much reciprocity and symmetry presupposed in the encapsulated interest view, to cover cases where vulnerability is intrinsically involved, such as the health care case (see e.g. Potter 2002; Nys 2016: 22). What I take from this view, to put it simple, is the idea that trusts requires something in common between the two parts – not just something good on the trusted part, but also some role for the values of the trustee. This is the aspect of *autonomy* that my proposed analysis of public-health care trust includes.

A further point of my proposal is that both sharing values and *attributing* them to the trusted part play a role in sustaining the trust relation. Suppose that a strictly individualistic attitude spreads in the public opinion, so that solidarity and equity are no more considered appropriate values for a health care system to operate on – this is actually what is happening, according to some studies (Ter Meulen, Maarse 2008; Salter 2008). Then, we wouldn't trust a health care system that limits access to an expensive new treatment to favor the common

good, and that would be a case of unshared values. Now suppose the public opinion views autonomy and transparency as fundamental values in health care, but comes to believe (correctly or not) that the negotiation with the Pharma partner for the treatment price was marred by corruption. Here again the public would withdraw its trust, and that would be a case of failure of attribution of shared values to the health care system.

These considerations about the importance of attribution brings me to the final conceptual point about public trust in health care systems. Though normatively it is founded on epistemic authority and value sharing, in fact it correlates with the credibility of the trusted part. Credibility is the capacity to produce in others the impression that one is epistemically authoritative, or good willed, or other positive quality regarding one's competence. The public is willing to grant trust if the health care system is credible enough. A point that has been raised by feminist epistemologists is that science appears less credible when the public feels to be socially underrepresented within scientific research communities – which arguably are mostly formed by white males with a certain social and economic status – and therefore fails to identify with such community. As a more general point, credibility decreases when the receiver of the message fails to identify with the producer and their values (Rolin 2002: 110-115). A different and equally relevant claim is that credibility depends on the pragmatics of communication, namely, on how, when, and where it will be received, and on many contextual elements that call for different pragmatic norms and standards (Origgi 2008).

To sum up, I have argued that public trust in health care systems is a complex relation, grounded on value sharing and attribution of shared values, as well as on the epistemic authority of the trusted part. I observed that it involves a double aspect of vulnerability, and that it varies with the credibility of the health care system. In the next Section I will discuss an example where such trust is failing to hold, or declines, and confront it with the conceptual points I suggested.

#### *4. The case of vaccine hesitancy*

Vaccine hesitancy is a tendency to refuse children vaccination or to adhere to alternative vaccination schedules, despite availability of vaccination opportunities. It has different characteristics in different countries, but with common structural and motivational features, that several health agencies and international organizations, such as Who and EU committees, are now focusing on (MacDonald, Who Strategic Advisory Group of Experts - Sage 2015). In high-income countries such as European nations, Australia, the UK, the US and Canada the main target is the anti-pertussis and the measles, mumps, and rubella (Mmr) vaccines, but newer ones such as meningococcal and Hpv vaccines are involved. As it is well-known, a study by Andrew Wakefield and collaborators published in *Lancet* in 1998

suggested an association between the Mmr vaccine and autism, and the findings were amplified by the media, as they met the expectations of networks of parents in search of a cause for their children's condition. Wakefield's study was retracted in 2002 and officially deemed unethical and fraudulent, but Mmr vaccine coverage has still not returned to the level of before 1998. In 2009-10 many national health care systems recommended vaccination against AH1N1 influenza, in fear of a pandemic that revealed itself to be less serious than expected, and the public opinion reacted with a further decline in vaccine acceptance. Other anti-vaccine theories now popular are (Larson *et al.* 2013; Largent 2012; Goldenberg 2016).

Vaccine hesitancy is a health care priority, because it threatens herd immunity, and puts the lives of the more vulnerable (elderly or immuno-depressed patients) at risk. From the point of view of ethics and political philosophy, it has been qualified as a free-riding behavior, in which a common good (public health, and specifically the absence of an infectious diseases) is exploited without paying one's fair share (Faden, Shebaya 2010; Navin 2013; May 2005). Here I will show that its features qualify it a case of public distrust – or of decline in trust – towards health care systems, that can be explained by employing the conceptual points of the model I proposed above.

*Epistemic trust.* The alleged association between vaccination and autism remains a reason for vaccine hesitancy despite the publication and public dissemination of studies that disconfirm the hypothesis or show the small incidence of adverse effects after vaccination. In a recent paper, Maya Goldenberg analyzed the reaction of the scientific community and health care authorities to Wakefield's vaccine-autism hypothesis, and showed with ample textual evidence that it has been based up to now on the assumption that the interlocutor is 'a passive public, motivated by fear rather than sound judgment, lacking in critical thinking abilities' (Goldenberg 2016: 562). However, she also reported, there is proof of high levels of education of a significant segment the vaccine-resistant public, and of discouraging results of pro-vaccine campaigns based on such ignorance assumption. One part of the explanation is that what the public lacks is neither information nor understanding (at sufficient levels), but the conviction that the health care system that recommends vaccination is the sole epistemic authority to appeal to in matters of health, and to trust for health-related knowledge and competence. Epistemic trust implies deference, while lack or decline of epistemic trust brings one to try to find other experts, and to consider different views. This is what is happening in vaccine hesitancy. Alternative 'experts' (so-called independent researchers in immunology, but also proponents of natural remedies) are being consulted and followed by the public. Another tendency is to avoid deference at all, and rely on one's own experience, for example of having had varicella during childhood without any complication or further harm (see the references in Gowda, Dempsey 2013). Repeated attempts at providing more scientific information on vaccination are therefore bound to fail to defuse vaccine hesitancy because they are perceived by the public as mere opinions, with the same epistemic authority as other views, and even as one's own.

Likewise, as a recent review article concludes, ‘vaccine objectors reject the ‘facts’ presented to persuade them towards vaccination; for the anti-vaccination movement, ‘mis’information is simply their version of information’ (Kata 2010: 1715).

*Attribution of values.* The public expects that a health care system pursues its goals with honesty and transparency, and not with a view to profit of its managers and authorities. What happened in the case of the H1N1 was that the public attributed to health care authorities, including the Who, dishonesty and lack of transparency. By the time the vaccine was available, bought from the Pharma company that developed it, and recommended most national health care systems to the public, the predicted pandemic of influenza had shown to be mild. The possibility was then raised that the industry partner influenced scientists advising the WHO about declaring pandemics, as well as national health care authorities about buying the treatment, and that the whole vaccination campaign was conducted with no sufficient transparency about existing conflicts of interest (Cohen and Carter 2010). Whether the corrupting influence of the market partner and the lack of transparency were real or not, what matters here is the role played by the attribution of (negative) values in sustaining vaccine hesitancy, and thereby exemplifying a case of diminished public trust in health care systems.

*Value sharing.* According to the model I presented above, public trust fails to hold or diminishes not only when there is attribution of negative values to the trusted part, but also when there is value disagreement with the trusted part, a disagreement that matters for the field of application of the trust relation. There is room to argue that such is the case in vaccine hesitancy. Vaccination brings some small amount of immediate harm, especially to a child, e.g. redness, swelling or pain at the injection site, and other minor side effects. Moreover, like any medical treatment, it carries no-zero risk of serious side effects. In the light of this, some parents prioritize their own (or one’s children’s) immediate or short-term interest (receiving no harm) over the interest of the community of achieving herd immunity and protecting weaker groups (Gowda, Dempsey 2013; Gottlieb 2015). This is clear from a quote of Dr. Sears’ popular book on alternative vaccine schedules:

Some parents [...] aren’t willing to risk the very rare side effects of vaccines, so they choose to skip the shots. Their children benefit from herd immunity (the protection of all the vaccinated kids around them) without risking the vaccines themselves. Is this selfish? Perhaps. But as parents you have to decide. Are you supposed to make decisions that are good for the country as a whole? Or do you base your decisions on what’s best for your own child as an individual? Can we fault parents for putting their own child’s health ahead of other kids around him? [...] [W]e can’t really fault parents who think that vaccines are too risky and decide to put their own kids first. We all put our own children first in most situations (Sears 2007: 220, also quoted in Navin 2013: 69).

As noted above, vulnerability is deeply involved in our relation with health care, and parents’ fears of adverse side-effects for children increase vulnerabil-

ity – and rises the demands for trust. Thus, while the health care system embodies solidarity and benevolence towards the weaker ones, this part of the public endorses an individualistic stance, and what has been called parents' prerogative or autonomy in pediatric decisions (Navin 2013; Vermeersch 2009). I am not here going to discuss the moral superiority of either position over the other. My point is that this is a case of value disagreement between the institution and the public, and as such it undermines the grounds of the trust relation.

Finally, I wish to consider briefly the role of credibility of health care systems in the vaccine hesitancy case. As I said above, the phenomenon involves, among other causes, the attribution of negative values (corruption, absence of transparency) to researchers and health authorities, and even governments, for their relationship with Pharma companies that produce and sell vaccines. Attribution of negative values undermines the grounds of public trust, and it additionally diminishes credibility – so that the evidence provided on vaccine safety is dismissed from the start, as tainted. Moreover, several studies in health communication show that the public looks for and receives information about vaccines from very different sources and perspectives, such as public health officials and practitioners, but also friends and acquaintances, celebrities, blogs, and traditional media, and non-health professional sources are perceived as credible by a small, but not insignificant percentage of people. In fact, in spite of efforts, pro-vaccine informative messages from authorities may sometimes even strengthen vaccine-hesitancy tendencies (see e.g. Freed *et al.* 2011; Nyhan *et al.* 2014). One possible explanation, which requires further empirical research, is that they insist to correct false claims about vaccines, but fail to address the public's main concern, namely, fears and worries about adverse side-effects (Gottlieb 2015).

##### *5. Concluding remarks*

In this paper I have proposed a conceptual model of public trust in health care systems that highlights the role of sharing values, and attributing shared values to the trusted part. I also pointed to the importance of credibility of a health care system for maintaining a trust relation with the public. Such elements are arguably connected with a rise in patient's autonomy, and with a decline of paternalism of health care institutions. I have shown that vaccine hesitancy, which is now a health care emergency, can be described as a case of decline of trust in health care. It is not just a side-effect of scientific illiteracy, irrationality, or misinformation from the public's part, factors that may nevertheless have an impact.

There are no easy operative conclusions to be drawn from what I have proposed. As Annette Baier wrote, trust is 'much easier to maintain than it is to get started and it is never hard to destroy' (1986: 107). The contours of the concept of trust, philosophically described and applied to the public-health care relationship, can draw lines of direction for initiatives aimed at restoring the damaged good, to-

gether with sociological, psychological and organization studies. It is plausible that such initiatives, especially in the case of vaccine hesitancy, should insist on value transparency, carefully planned communication, and ethical education of citizens.

### *Bibliography*

ABELSON, J. *et al.*

- 2009, *What does it mean to trust a health system? A qualitative study of Canadian health care values*, “Health policy”, 91, 1: 63-70.

BAIER, A.

- 1986, *Trust and Antitrust*, “Ethics”, 96: 231-60.

BALKRISHNAN R. *et al.*

- 2003, *Trust and satisfaction with physicians, insurers, and the medical profession*, “Medical care”, 41, 9: 1058-1064.

BIELBY, P. *et al.*

- 2008, *Competence and Vulnerability in Biomedical Research*, Dordrecht, Springer.

BÖHM, K. *et al.*

- 2013, *Five types of Oecd health care systems: empirical results of a deductive classification*, “Health Policy”, 113, 3: 258-269.

BUSS, S.

- 2016, *Personal Autonomy*, in E.N. Zalta (ed.), *The Stanford Encyclopedia of Philosophy* (Winter 2016 Edition) (<<https://plato.stanford.edu/archives/win2016/entries/personal-autonomy/>>).

CALNAN, M., ROWE, R.

- 2006, *Researching trust relations in health care: Conceptual and methodological challenges-an introduction*, “Journal of health organization and management”, 20, 5: 349-358.
- 2008, *Trust matters in health care*, London, McGraw-Hill Education.

CALNAN, M., SANFORD, E.

- 2004, *Public trust in health care: The system or the doctor?*, “Quality and safety in health care”, 13, 2: 92-97.

CARTER, S. *et al.*

- 2015, *The challenge of overdiagnosis begins with its definition*, “British Medical Journal” (<https://ses.library.usyd.edu.au/bitstream/2123/12918/2/The-challenge-of-overdiagnosis-2015.pdf>).

CRIBB, A.

- 2008, *Organizational reform and health care goods: concerns about marketization in the UK NHS*, “Journal of Medicine and Philosophy”, 33, 3: 221-240.

DOMENICUCCI, J., HOLTON, R.

- 2017, *Trust as a Two-Place Relation*, in P. Faulkner, T. Simpson (eds), *The Philosophy of Trust*, Oxford, Oxford University Press: 149-160.

DWORKIN, G.

- 2005, *Paternalism*, in *The Stanford Encyclopedia of Philosophy Edition*, E.N. Zalta (ed.), *The Stanford Encyclopedia of Philosophy* (Winter 2017 Edition) (<https://plato.stanford.edu/archives/win2017/entries/paternalism/>>).

- FIELD, M.J., LO, B. (eds)  
 – 2009, *Conflict of Interest in Medical Research, Education, and Practice*, Washington D.C., National Academies Press.
- FITZPATRICK, M.  
 – 2004, *Mmr: risk, choice, chance*, “British Medical Bulletin”, 69, 1: 143-153.
- FREED, G. *et al.*  
 – 2011, *Sources and perceived credibility of vaccine-safety information for parents*, “Pediatrics”, 127, 1: S107-S112.
- FUKUYAMA, F.  
 – 1995, *Trust: The Social Virtues and the Creation of Prosperity*, New York, Free Press.
- GILSON, L.  
 – 2006, *Trust in health care: theoretical perspectives and research needs*, “Journal of Health Organization and Management”, 20, 5: 359-360.  
 – 2003, *Trust and the development of health care as a social institution*, “Social science & medicine”, 56, 7: 1453-1468.
- GOLDENBERG, M.  
 – 2016, *Public misunderstanding of science? Reframing the problem of vaccine hesitancy*, “Perspectives on Science”, 24, 5: 552-581.
- GOWDA, C., DEMPSEY, A.  
 – 2013, *The rise (and fall?) of parental vaccine hesitancy*, “Human vaccines & immunotherapeutics”, 9, 8: 1755-1762.
- GRASSWICK, H.  
 – 2010, *Scientific and lay communities: earning epistemic trust through knowledge sharing*, “Synthese”, 177, 3: 387-409.
- GRAY, B.  
 – 1997, *Trust and trustworthy care in the managed care era*, “Health Affairs”, 16, 1: 34-49.
- HALBERT, C. *et al.*  
 – 2006, *Racial differences in trust in health care providers*, “Archives of Internal Medicine”, 166, 8: 896-901.
- HALL, M.  
 – 2006, *Researching medical trust in the United States*, “Journal of Health Organization and Management”, 20, 5: 456-467.
- HARDIN, R.  
 – 2002, *Trust and Trustworthiness*, New York, Russell Sage Foundation.
- HOLTON, R.  
 – 1994, *Deciding to trust, coming to believe*, “Australasian Journal of Philosophy”, 72: 63-76.
- KATA, A.  
 – 2012, *Anti-vaccine activists, Web 2.0, and the postmodern paradigm. An overview of tactics and tropes used online by the anti-vaccination movement*, “Vaccine”, 30, 25: 3778-3789.
- KATZ, J.  
 – 1984, *The silent world of doctor and patient*, Baltimore, Jhu Press.
- LARGENT, M.  
 – 2012, *Vaccine: The debate in modern America*, Baltimore, Jhu Press.
- LARSON, H. *et al.*  
 – 2013, *Measuring vaccine confidence: analysis of data obtained by a media surveillance system used to analyse public concerns about vaccines*, “The Lancet infectious diseases”, 13, 7: 606-613.



- LIST, C., PETTIT, P.  
 – 2011, *Group agency: The possibility, design, and status of corporate agents*, Oxford, Oxford University Press.
- MACDONALD, N., WHO STRATEGIC ADVISORY GROUP OF EXPERTS (SAGE)  
 – 2015, *Vaccine hesitancy: Definition, scope and determinants*, “Vaccine”, 33, 34: 4161-4164.
- MAY, T.  
 – 2005, *Public communication, risk perception, and the viability of preventive vaccination against communicable diseases*, “Bioethics”, 19, 4: 407-421.
- MECHANIC D.  
 – 1996, *Changing medical organization and the erosion of trust*, “Milbank Quarterly”, 74: 171-89.
- MECHANIC, D.,  
 – 1998, *The functions and limitations of trust in the provision of medical care*, “Journal of Health Politics, Policy and Law”, 23, 4: 661-686.
- MURRAY, C.J., FRENK, J.  
 – 2000, *A framework for assessing the performance of health systems*, “Bulletin of the world Health Organization”, 78, 6: 717-731.
- NAVIN, M.  
 – 2013, *Resisting moral permissiveness about vaccine refusal*, “Public Affairs Quarterly”, 27, 1: 69-85.
- NORDENFELT, L.  
 – 2007, *The concepts of health and illness revisited*, “Medicine, Health Care and Philosophy”, 10, 1: 5-10.
- NYHAN, B. *et al.*  
 – 2014, *Effective messages in vaccine promotion: A randomized trial*, “Pediatrics”, 133, 4: e835-e842.
- NYS, T.  
 – 2016, *Autonomy, trust, and respect*, “Journal of Medicine and Philosophy”, 41, 1: 10-24.
- NYS, T. *et al.*  
 – 2007 *Autonomy & Paternalism: Reflections on the Theory and Practice of Health Care*, vol. 5, Amsterdam, Peeters Publishers.
- O’NEILL, O.  
 – 2002, *Autonomy and Trust in Bioethics*, Cambridge, Cambridge University Press.
- ORIGGI, G.  
 – 2008, *Trust, authority and epistemic responsibility*, “Theoria”, 23, 1: 35-44.
- PANI, L., CAMMARATA, S.  
 – 2015, *The Italian Payers’ approach to new anti-hepatitis C drugs*, “Italian Medicines Agency (Aifa) Newsletter”, April issue: 1-2.
- PELLEGRINO, E., THOMASMA, D.  
 – 1993, *The virtues in medical practice*, Oxford, Oxford University Press.
- POTTER, N.  
 – 2002 *How can I be Trusted?: A Virtue Theory of Trustworthiness*, Lanham, Rowman & Littlefield.
- ROGERS, W., MINTZKER, Y.  
 – 2016, *Getting clearer on overdiagnosis*, “Journal of evaluation in clinical practice”, 22, 4: 580-587.

- ROLIN, K.  
 – 2002, *Gender and trust in science*, “Hypatia”, 17, 4: 95-120.
- SALTER, E.  
 – 2013, *Resisting the siren call of individualism in pediatric decision-making and the role of relational interests*, “Journal of Medicine and Philosophy”, 39, 1: 26-40.
- SEARS, R.W.  
 – 2007. *The Vaccine Book: Making the Right Decision for Your Child*, 1<sup>st</sup> ed., New York, Little, Brown and Company.
- SIMPSON, T.  
 – 2012, *What is trust?*, “Pacific Philosophical Quarterly”, 93, 4: 550-569.
- SKEA, Z. *et al.*  
 – 2008, *Avoiding harm to others’ considerations in relation to parental measles, mumps and rubella (Mmr) vaccination discussions-An analysis of an online chat forum*, “Social science & medicine”, 67, 9: 1382-1390.
- SHORE, D.A.  
 – 2007. *The Trust Crisis in Healthcare: Causes, Consequences, and Cures*, New York, Oxford University Press.
- TER MEULEN, R., MAARSE, H.  
 – 2008, *Increasing individual responsibility in Dutch health care: is solidarity losing ground?*, “Journal of Medicine and Philosophy”, 33, 3: 262-279.
- TUOMELA, R.  
 – 2013, *Social ontology: Collective intentionality and group agents*, Oxford, Oxford University Press.
- VAN DER SCHEE, E. *et al.*  
 – 2007, *Public trust in health care: a comparison of Germany, the Netherlands, and England and Wales*, “Health Policy”, 81, 1: 56-67.
- VERMEERSCH, E.,  
 – 1999, *Individual Rights Versus Societal Duties*, “Vaccine”, 17, 3: S14-S17.
- WHETTEN, K. *et al.*  
 – 2006, *Exploring lack of trust in care providers and the government as a barrier to health service use*, “American Journal of Public Health”, 96, 4: 716-721.
- WHYTE, K.P., CREASE, R.P.  
 – 2010. *Trust, Expertise, and the Philosophy of Science*, “Synthese”, 177, 3: 411-25.
- WILHOLT, T.  
 – 2013, *Epistemic trust in science*, “The British Journal for the Philosophy of Science”, 64, 2: 233-253.
- ZAGZEBSKI, L.  
 – 2015, *Epistemic authority: A theory of trust, authority, and autonomy in belief*, Oxford, Oxford University Press.