

## Trust in Medicine

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### 1. Introduction

In this chapter, we consider ethical and philosophical aspects of trust in the practice of medicine. We focus on trust within the patient-physician relationship, trust and professionalism, and trust in Western (allopathic) institutions of medicine and medical research. Philosophical approaches to trust contain important insights into medicine as an ethical and social practice. In what follows we explain several philosophical approaches and discuss their strengths and weaknesses in this context. We also highlight some relevant empirical work in the section on trust in the institutions of medicine (cf. Ozawa and Sripad 2013). It is hoped that the approaches discussed here can be extended to nursing and other topics in the philosophy of medicine (see Dinç and Gastmans 2013).

### 2. Trust and the Physician-Patient Relationship

The idea of the trusting physician-patient relationship is important to medical ethics, and is thought by some to be foundational (Beauchamp and Childress 2013; Pellegrino 1999; Zaner 1991; Rhodes and Strain 2000). The physician-patient relationship contains inherent inequalities of knowledge, skills, and control of resources, and it treats matters both intimate and potentially of great importance to the patient. In these matters the patient often needs confidentiality and discretion. Because of these factors, the idea that trust is necessary for the relationship to be healthy is plausible, and it has been remarkably resilient even while the technological and institutional complexity of medical practice has vastly increased, and even while the basic norms of the practice have shifted from a paternalistic model to one of information-sharing and participatory decision-making. The resilience of the idea may also be linked to trust's utility in reducing complexity through such transitions: if one trusts one's physician, the resulting division of epistemic labor allows the patient to divert scarce attentional resources elsewhere (see Miller and Freiman in this volume). One could even go so far as to assert that without the existence of some level of trust in physicians' competence and good will, the practice of medicine would not be possible because patients would be unwilling to seek medical care.<sup>ii</sup>

Medical ethics, in keeping with this picture, often models the trusting physician-patient relationship as one in which the physician (the GP, in particular) serves as the trusted gatekeeper for other practices such as delivery of diagnostic and prognostic information, prescription medication, referral to specialists, and the use of technologies for self-care (Voerman and Nickel 2017). Much less frequently studied is physicians' trust in patients, e.g., to

deliver accurate information and to follow through on care routines (Entwistle and Quick 2006). Physicians' trust in patients is a natural counterpart to patients' trust in physicians if we consider the trusting patient-physician relationship as mutual or reciprocal; however, asymmetries of expertise and control have often led medical ethicists to neglect it. The physician-patient relationship, like relationships between other sorts of professionals and their clients, is an asymmetrical fiduciary relationship in which one person is given control over an aspect of another person in some domain, and is obligated to act for the good of the other, putting their own interests second (Rodwin 1995).

In medical ethics, the interest in deriving ethical conclusions from reflection about the nature of the physician-patient relationship has led to a particular focus on the values and normativity associated with trust. Philosophically there is more than one way of trying to analyze this normativity. In order to clarify some promising lines of inquiry, we draw a distinction between three types of theories: *supporting-relations accounts*, *grounded-expectation accounts* and *moral-adequacy accounts*.

The supporting-relations account starts with the assumption that a trusting relationship is good and tries instrumentally to derive the value of other practices supporting trust. For example, Zaner (1991) argues that a trusting patient-physician relationship is a basic good, and that empathy and perspective-taking are required to support it, and are therefore important ethical capacities for physicians.

Trusting relationships, indeed, *are* often goods to be strived for. However, for reasons put forward by Baier (1986) and more recently for the medical context by Hawley (2015), it must be admitted that they are not always beneficial. Trust can provide a fertile ground for exploitation and manipulation, it can be epistemically poorly grounded, and it can lead to unreasonable demands by those who trust, along with unreasonable efforts to meet these demands by those who are trusted. For these reasons, any account needs to take a stand on what makes some instances of trust good or justified, and others bad or unjustified. That task is addressed by the second and third accounts we consider.

Grounded-expectation accounts hold that whether trust is good or justified depends on whether the expectations implicit in one's trust — for example, the expectation that my physician will prescribe me the best medicine for treating my illness — are based on sound or unsound reasons. Such an account emphasizes that people take on moral responsibilities by creating expectations in others. Tim Scanlon (1998: 300) expresses the relevant moral principle as follows: "One must exercise due care not to lead others to form reasonable but false expectations about what one will do when one has good reason to believe that they would suffer significant loss as a result of relying on these expectations." Scanlon's principle is about reliance rather than trust, but it can be extended to trust because it is even more exploitative or manipulative to create false expectations in another person when they are relying on one *trustingly*, than when they are relying on one strategically or reluctantly (see Goldberg in this volume). On a grounded-expectation account, physicians take on responsibilities by creating expectations of professionalism, expertise, and commitment to promoting the health and well-

being of the patient. They must then exercise due care to live up to the expectations they have created.

A grounded-expectations account can also add the claim, put forward by Manson and O'Neill (2007), that patients can and should place their trust intelligently, by making sure that their expectations are well-informed: "Trust is well placed when it is given to trustworthy claims and commitments, and ill placed when it is given to untrustworthy claims and commitments" (160). This implies that intelligent trust is based on cues that are reliably or rationally linked with trustworthiness: "Anyone who seeks to place and refuse trust intelligently must try to discriminate the various claims and commitments that agents make. I may trust a genetic diagnosis if it is based on reputable tests ... but not if it is based on quirky views of heredity" (ibid.: 165). Implicit in Manson and O'Neill's example are two importantly different kinds of objects of trust within the patient-physician relationship: one is the physician herself, and the other is the medical care that she mediates and for which she is the gatekeeper, including such items as genetic tests. Other versions of the grounded-expectations account stress the importance of social context, including institutions and technology, in grounding people's trusting expectations. Rather than focusing primarily on the agency and intelligence of the patient in placing trust, the focus is on the broader idea of "sound" or "healthy" trust, in which the patient's environment guides and provides epistemic grounding for her expectations. By providing institutions and informational cues that reliably "track" trustworthiness, policymakers and designers facilitate sound trust (Voerman and Nickel 2017). (See O'Neill on "Intelligent Trust" and Scheman on trust and trustworthiness in this volume.)

A positive feature of grounded-expectation accounts is that they derive conclusions in medical ethics from the normativity of commitments and expectations, not directly from controversial ethical theories or domain-specific medical ethics principles. However, it is doubtful whether such accounts are sufficient to include all the moral features that contribute to a healthy trust relationship. According to Annette Baier (1992) the idea of reasonable expectation-formation cannot distinguish between healthy and unhealthy trust relationships because one person can trust another reasonably as the result of unfair power relationships that give her few other options. In this way, a person's reasonable expectations can be exploited or rendered fragile in ways that do not actually render the expectations themselves unreasonable or unjustified. Baier (1992) also holds that the expectations-based view is too *rigid* to account for what matters to trusting relationships. A physician who faultlessly lives up to a list of expectations but fails to *care* for the patient in a broader sense is less trustworthy than a physician who uses her discretion wisely to promote the wellbeing of the patient but fails to perform exactly as expected along the way.

That is where moral-adequacy accounts exhibit their strength. They hold that there are norms for the moral decency of trusting relationships that do not derive from expectations. Baier's view, for example, proposes a transparency test of the moral decency of trust, meant to distinguish between exploitative and non-exploitative trust. According to this test, "trust is morally decent only if, in addition to whatever else is entrusted, knowledge of each party's reasons for confident reliance on the other to continue the relationship could in principle also be entrusted" (Baier

1986: 128). Other versions of the moral adequacy account focus on other adequacy tests of trust. For example, Carolyn McLeod's (2002) theory of trust, developed in part to analyze trust in medicine, holds that trust is morally adequate when it is based on shared values and moral integrity. We may need to tweak these accounts when applying them to trust in the *institutions* of medicine rather than in individuals (a kind of trust we discuss in section 4). However, the argument stands that an individual could sometimes have good pragmatic and epistemic reasons to trust the institution of medicine as well as to trust individual physicians, even if the both the institution and the physicians within it were exploitative in their motives. We therefore need a further moral test to determine morally sound trust in both kinds of entities.

We advocate a hybrid account that sees both grounded expectations and moral adequacy as part of sound, healthy trust in medicine. Developing a moral adequacy test in more detail and applying it to this context is a task for future research. Yet, a moral-adequacy account centered on a narrow conception of the patient-physician relationship may not be the best approach for accommodating the technological and institutional transformations of the practice of medicine in the long term, which may depart substantially from this conception. For example, Baier's theory, by focusing on a mutual awareness test of the moral decency of trust, presupposes that trust obtains between two agents who are each able to form an explicit awareness of the expectations and motivations of the other. In the future it may increasingly be the case that there is no such relationship at the heart of the institution of medicine, and that a relationship-based test is therefore inapplicable to trust in medicine. We return to this scenario at the end of the chapter.

### **3. Trustworthiness and Professionalism**

Professionalism is a phenomenon in which a group of experts who engage in some field of practical activity (education and research, law, medicine, engineering, etc.) develop a shared identity with official standards for membership and a measure of exclusiveness in having the right to evaluate one another's work. Often, professions adopt internal codes of ethical principles (Davis 1991). One line of research in medical ethics has linked professionalism and professional ethics to the trustworthiness of physicians and by extension, trust in them (Pellegrino and Thomasma 1993; Manson and O'Neill 2007; Banks and Gallagher 2008; Kelly 2018). The underlying idea is that the development and continuing identity of professions has, as one of its main purposes, to signal trustworthiness to those who turn to the profession in a situation of need.

Traditionally, the professional ideals of medicine were uniquely paternalistic among the professions. Yet when the paternalistic ideal of the practice of medicine was superseded by an ideal of shared decision making and respect for patient autonomy, trust did not become less important to the practice of medicine. This seems to suggest, perhaps surprisingly, that while trust is essentially bound up with professionalism, it is not strongly affected by the balance of decision making and openness between the professional and the one seeking the professional's services.

These normative ideals of professionalism suggest that the appropriate default attitude towards the medical profession is one of trust. Kelly (2018) presents a systematic theory of the ethics of trust and professionalism, arguing that medicine has an internal functional end or *telos*, relating to a basic human need (health care) in which people have to rely on others' expertise, and that as a consequence, trust and trustworthiness are constitutive goods linked to the medical profession. For Kelly, professions are required, first, to sustain internal standards of behavior and expertise; and second, to guard the reputation of qualified professionals. Both conditions are essential in the long run for maintaining widespread trustworthiness in individual physicians (2018: 63). For Kelly, it is therefore insufficient to focus on the doctor-patient relationship alone as the principal source of the normativity of trust and trustworthiness.

However, the normative ideals of professions themselves bear scrutiny. Critics argue that a more realistic view of the relationship between patient and physician is that between customer and supplier. Since the 1970s medical professionals, historians, sociologists and ethicists have observed and sometimes lamented a shift, spurred by changes in the structure of health care delivery, towards rising costs, increased specialization, an expanding role for technology in medical care, and an increasing presence of direct-to-consumer marketing of pharmaceuticals (cf. Reeder 1972 and Friedler 1997). On this view, not trust, but contractual obligations, oversight, and enforceable regulations should guarantee the customer-patient a high quality of care.<sup>iii</sup>

One may thus argue that taking a selective and strategic attitude toward reliance, or even taking a default attitude of distrust, might be more rational than taking a default attitude of trust. Recent philosophical work provides a substantive account of distrust that distinguishes it from mere lack of trust. On Hawley's (2014) view, distrust is a matter of regarding the distrusted party as being committed to meet certain standards, while also finding that this party fails to meet those standards. (See D'Cruz in this volume.) Such a default attitude of distrust could be justified on a variety of grounds. Worries about meeting a commitment to competence and due care, for example, may be bolstered by the prevalence of medical errors. In the United States alone, medical errors have been estimated in the past to be responsible for between 44,000 and 98,000 unnecessary deaths each year (Weingart et al. 2000). Distrust could also be justified if the general public has reasons to believe physicians fail to meet commitments to ethical impartiality, by being biased in their prescription of certain pharmaceuticals or having financial interests in performing certain kinds of procedures. For comparison, it is useful to consider the financial professions, where widespread misconduct has made it plausible to claim that a default attitude of distrust in banking and investment firms is warranted. If this were to happen in the field of medicine, then distrust in the profession could threaten trust in individual physicians.<sup>iv</sup>

#### **4. Trust in the Institutions of Medicine**

The institutions of medicine include pharmaceutical companies, public health agencies, health insurers and other managed care providers, as well as hospitals, physician professional

organizations like the American Pediatric Association, etc. Hall et al. (2001: 620) point out that people's trust or distrust in one of these entities can impact their trust or distrust in the others in a wide range of ways. Although there is a large empirical literature aimed at measuring and understanding patients' levels of trust in individual care providers, like their primary care doctor or their nurse, there has been less empirical research on trust in medical institutions or the medical profession as a whole.

There is a sharp difference between trust in the institutions of medicine and trust in particular physicians. This is due to two key features of institutions: unspecificity and impersonality. There is broad consensus on the kinds of things patients expect their physicians to do and be, including but not limited to acting beneficently, maintaining their knowledge and skills; protecting patient confidentiality; respecting patient autonomy, etc. (Mechanic 1996, Rhodes 2007). These expectations may arise from both personal knowledge of the physician, as well as an awareness of what they stand for as medical professionals. For institutions of medicine, these expectations and the obligations they ascribe to different actors become more unspecific, since we are discussing a wide variety of roles and groups, governed by varying interests, institutional norms, and legislation.

In addition to being unspecific, trust in institutions is impersonal. Like interpersonal trust (see Potter this volume), it involves a complex of expectations based on the perceived interests, motives and past behavior of the institution. However, it is also based on the norms and functional aims that govern and define institutions and the roles within them, rather than on personal characteristics of goodwill or responsiveness to the trustor's reliance. An institution is not capable of having personal motives and characteristics in a literal sense. For that reason, the interaction of social, legal, technological and political forces, rather than good will and individual intentions, governs the effect of the institutions of medicine on individuals.

For some theorists, these reflections provide reason to doubt whether institutions are genuine objects of trust, either because they wish to reserve the concept of trust for explaining cooperation in terms of the individual motives of two or more interacting agents (Hardin 2006), or because they think that genuine trust conceptually requires affective or reactive attitudes that are out of place when extended beyond individuals (e.g., Faulkner 2011). For our purposes here, we do not wish to claim that trust in institutions is "genuine" or is the same as trust in individuals, but we do assume that there is an important normative phenomenon here: the functions and norms that govern institutions provide a reason for reliance that is not merely strategic or predictive. To put it in Hawley's (2014) terminology, institutions can have normative commitments that are either met or unmet in one's reliance on them. This makes the language of trust and distrust fitting.

Even if we did reserve the notion of genuine trust for relationships between individuals, institutions would be important to trust because they frame these relationships (Mechanic and Schlesinger 1996). Particular ways of organizing and institutionalizing the delivery of medical care can promote or undermine patient's trust in individual physicians, as Brown & Calnan (2012) have shown in the case of mental health care institutions. Davies and Rundall (2000)

argue that *managed care*, in particular — defined as the effort to control cost, quality, and access to care through principles of management (Kongstvedt 2009) — has the potential to undermine patient’s belief that physicians can be trusted. Furthermore, they argue that the extent to which patients *should* trust their physicians is partially dependent on “the organizational, financial, and legal situation within which their health care is delivered” (Davies and Rundall 2000, 613). They point to several ways in which managed care undermines the trust between patient and physician, through what can be labeled a reverse halo-effect. They cite research showing that patients in managed care see their physicians as having divided loyalties between patient needs and interests and the demands of other institutions with economic motivations.

Reflecting on these points, Goold (2001) emphasizes that the ethics of trust in health care institutions goes beyond the need to support healthy trust in clinicians working within those institutions. She argues that health care organizations are ethically bound to be trustworthy actors in ways that extend beyond the obligations of individual physicians. For example, such institutions may be obligated to safeguard an individual’s “financial well-being in the case of catastrophic illness”, as well as to protect “the health of the community,” not just of the individual (Goold 2001: 29). In terms of the normative accounts of trust presented earlier, such proposals could be seen as part of the moral adequacy of trusted institutions, and therefore as part of healthy trust in medicine. In what follows we zoom in on two specific challenges to meeting this test of moral adequacy for institutions.

### ***Discrimination and Distrust***

One challenge is that some groups have reason to distrust the institutions of medicine. A well-studied example is African Americans in the United States, who have expressed lower levels of trust in medical institutions, clinical care, and medical research (Shavers et al. 2002; Corbie-Smith et al. 1999; Ebony Boulware et al. 2003), and in their physicians (Kao et al. 1998), compared with other groups. Distrust also seems to have played a role in the reluctance of African Americans to become organ donors (Davidson and Devney 1991).

High levels of distrust in medical institutions are thought to contribute to, and be a result of, systematic health and health care inequalities between African Americans and whites in the United States (Ebony Boulware et al. 2003). This distrust has been attributed to medicine’s historic and ongoing racist practices and attitudes (Krakauer, Crenner and Fox 2002). Historically this included the infamous Tuskegee syphilis study, and the forced sterilization of persons deemed “feeble minded” or “promiscuous” as part of a pseudo-scientific practice of eugenics that disproportionately affected minority women in the US until the 1970s. More recently, it has been found that physicians discriminate on the basis of race in their prescribing behavior, being less likely to prescribe opioid pain medication to black patients, potentially based on the assumption that they are more likely to be drug-seeking than whites (Tamayo-Sarver et al., 2003).

Many other groups also experience distrust in medicine because of a history of being stigmatized or shown a lack of respect by health care providers. For example, Underhill et al. (2015) describes such a pattern in the case of male sex workers, and Bradford et al. (2013) describes a pattern of discrimination in the health care of transgendered persons. Such studies emphasize the role that experience plays in one's pattern of trust, and they make it plausible that historical discrimination makes it, in some sense, *reasonable* to take a default attitude of distrust toward the institutions of medicine. This is a challenge that would take years of reconciliation and engagement to overcome.

### ***Trust in Medical Research***

A rather different challenge, specific to the institution of medical *research*, is that medical research does not aim at providing direct clinical benefit to each individual patient. Unlike physicians, researchers aim to produce generalizable knowledge, not to provide a direct benefit to individual research participants. Because of the very nature of scientific research, it is impossible to know in advance all of the possible complications and harms that the participant might experience while participating in a study. In addition, some essential elements of scientific research, such as randomization or the use of placebos, imply that individual research participants may receive differential benefits or no benefits at all through participation. When the researcher is also a care provider, the double identity that results implies an essential conflict of loyalty that can threaten trust. The recent trend toward developing so-called *learning health care systems*, in which scientific and knowledge-generation goals are fully integrated into everyday clinical practice, implies that this double identity has potential ethical implications for medical practice as a whole (Faden et al. 2013). If such systems were widely adopted, the double identity might complicate trust within individual physician-patient relationships, threatening the idea that the *telos* of medicine aligns with the interests of each individual patient.<sup>v</sup>

The phenomenon of therapeutic misconception further complicates trust in medical research. In many cases, people have a natural bias toward thinking that new interventions being studied by science will benefit them. de Melo-Martin and Ho (2008) argue that this is a phenomenon of "misplaced trust". Individuals may have reason to distrust medical research if their trust depends on the natural expectation that medical decisions, even those in the context of research, should always provide individual clinical benefit to them.

In response to this challenge, research institutions and academic medical centers have made efforts specifically aimed at building trust between the medical research community and the general public. This is reflected in large part in research institutions' insistence on adhering to strict research regulations involving human participants (Yarborough and Sharp 2002). Efforts at establishing trust may also need to take additional measures beyond mere compliance to convince the public that researchers are trustworthy and to obtain greater participation in and support for biomedical research. For example, in research with samples stored in biobanks, transparency and communication with research participants is a strategy to build trust. Communicating with donors about the kind of research being performed (and by whom), and about results that may affect or interest them, may help to foster good will and make participant



expectations more realistic, by better communicating the aims, intentions, and interests of those maintaining the biobank.

Greater community participation in research is another means of fostering trust, especially among communities that may be vulnerable or wary of the presence of researchers, such as indigenous populations. Yarborough and Sharp (2002: 9) suggest that the general public should have a greater role in determining the priorities and goals of biomedical research that relies on shared resources and widespread participation. One way of doing this, they suggest, is through the creation of community advisory councils which would include members of the general public as well as representatives from research institutions, to debate, critically reflect on, and generate consensus on research priorities and tradeoffs (ibid.:10).

In sum, then, it is useful to talk about trust in the institution of medicine for two reasons. First, different groups' historical experiences with the institutions of medicine strongly affect the trust or distrust that they (reasonably) have towards particular actors such as physicians and medical researchers who operate in the context of those institutions. Second, trust in medicine seems to be well grounded in the underlying purpose of this institution to improve health, but this purpose is complicated and sometimes even called into question by the changing nature of the institution itself. This can have powerful effects on trust within the doctor-patient relationship.

## **5. Trust through Institutional and Technological Change?**

In this chapter we have explored trust within the physician-patient relationship, professionalism and trust, and trust in the institution of medicine. We conclude by reflecting briefly on the future of trust in medicine. As indicated above, the idea of a trusting patient-physician relationship has remained important to how people think about medical practice through a wide range of institutional, scientific and technical, and value changes to the practice of medicine. However, some recent and anticipated future changes in the practice of medicine might be so fundamental that they make interpersonal trust in this relationship less central. Some relevant changes are

- the practice of fully institutionalized care, in which no one physician is in regular contact with a given patient.
- the use of expert and automated systems in which the individual expertise and ability of a given physician is replaced by artificial intelligence; and
- the practice of technologically mediated care, in which the patient does not directly interact with human individuals in order to receive care.

These changes would imply, to varying degrees, that there is no suitable individual human object of trust in the practice of medicine. Although trust in the institution of medicine might remain, trust within the physician-patient relationship would not. There would no longer be a single type of professional or group of professionals (physician, nurse, pharmacist, etc.) with fundamental roles as individuals in the delivery of care. As a consequence, there would need to be more focus on other roles and entities, currently peripheral but already important for the

delivery of health care, such as eHealth and mHealth companies, engineers and software designers, and electronic health records companies.

Theorists of trust would then need to rethink the ways in which the value of trust is still salient to the practice of medicine or whether its focus and nature has simply changed. As indicated earlier, for some scholars, trust is fundamentally interpersonal and these changes would so “depersonalize” medicine as to render genuine trust irrelevant. However, in our view it would still be useful to think about trust in the practice of medicine in such a scenario, because the notion of trust helps bring forward useful questions about the normative and predictive expectations that people have about the technologically and institutionally complex systems that deliver our health care. Human reliance on medicine can be expected to remain constant. Hence our need and desire for such reliance on medicine to be well-grounded and morally satisfactory will also persist, no matter what form the practice of medicine may take.

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<sup>i</sup> This research is affiliated with the Netherlands Organization for Scientific Research Responsible Innovation (NWO-MVI) project "Mobile Support Systems for Behaviour Change," project number 100-23-616.

<sup>ii</sup> Brown and Calnan (2012), in their fascinating study, discuss the particular case of mental health patients who in some cases manage to form fragile trust relationships with professionals within a system under strain.

<sup>iii</sup> For a critique of this view see Pellegrino (1999).

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<sup>iv</sup> While Kelly (2018: 101ff.) is well aware of the conflicts of interest that threaten the trustworthiness of the medical profession, he does not see this as changing the internal *telos* of the profession itself or as giving reason to adopt a different basic stance (e.g., strategic reliance or distrust) toward the medical profession.

<sup>v</sup> This double identity seems to go beyond the “limits to professional trustworthiness” discussed by Kelly (2018: 125ff.).