

Sound trust and the ethics of telecare

Citation for published version (APA):

Voerman, S. A., & Nickel, P. J. (2017). Sound trust and the ethics of telecare. *Journal of Medicine and Philosophy*, 42(1), 33-49. <https://doi.org/10.1093/jmp/jhw035>

DOI:

[10.1093/jmp/jhw035](https://doi.org/10.1093/jmp/jhw035)

Document status and date:

Published: 01/02/2017

Document Version:

Accepted manuscript including changes made at the peer-review stage

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
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- The final published version features the final layout of the paper including the volume, issue and page numbers.

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Sound Trust and the Ethics of Telecare

Sander Voerman & Philip Nickel

Author details:

Dr. Sander A. Voerman (corresponding author)

Department of Philosophy & Ethics

Eindhoven University of Technology

P.O. Box 513

5600 MB Eindhoven

The Netherlands

s.a.voerman@tue.nl

Dr. Philip J. Nickel

Department of Philosophy & Ethics

Eindhoven University of Technology

Running title (38 chars):

Sound Trust and the Ethics of Telecare

Abstract (123 words):

The adoption of web-based telecare services has raised multifarious ethical concerns, but a traditional principle-based approach provides limited insight into how these concerns might be addressed and what, if anything, makes them problematic. We take an alternative approach, diagnosing some of the main concerns as arising from a core phenomenon of shifting trust relations that come about when the physician plays a less central role in the delivery of care, and new actors and entities are introduced. Correspondingly, we propose an applied ethics of trust, based on the idea that patients should be provided with good reasons to trust telecare services, which we call *sound trust*. On the basis of this approach, we propose several concrete strategies for safeguarding sound trust in telecare.

Keywords:

trust in medicine, web-based telecare, informed consent, sound trust

Sound Trust and the Ethics of Telecare¹

1. Introduction

Health information, monitoring and coaching are increasingly offered to individuals via web-based *telecare* services. These services take many forms, such as systems for home medical (self-)monitoring and testing, online questionnaires with personalized feedback, personal coaching websites, or combinations of these.² Many have touted the benefits of web-based telecare, such as increasing self-reliance of patients, reducing hospital visits and admissions, and improving health while holding out the promise of reducing the societal costs of chronic illness (Peetermans et al. 2004; Struijs & ten Have 2013, 242; Liang et al. 2011; Verberk, Kessels & Thien, 2011).

However, the increasing adoption of web-based telecare services has also raised a number of ethical concerns, including the possible reduction of contact between patient and clinician, increased reliance on remote support workers for delivery of care, the possible lack of expertise or context-sensitivity of automated diagnosis and medical judgment, the burden or responsibility imposed on the patient, the patient's understanding of the functions and limitations of the system, the security of her medical data, and worries about surveillance (Peetermans et al. 2004; Struijs & ten Have 2013; EFORTT 2011). In our own interviews we have identified some additional concerns such as interruption of care when technical and clinical support for a web-based service is discontinued, and ambiguity about whether telecare is a medical therapy.³

¹ Thanks to Felicitas Kraemer, Manuela Luitjes, Marianne Boenink, Shannon Spruit, and two anonymous reviewers for *JMP* for their helpful comments and contributions. This article was based on research funded by the Netherlands Organization for Scientific Research (NWO).

² These services, offered in many forms by many providers, share some common characteristics. They allow the physician to keep track of patients at a glance, flagging potentially dangerous situations, and allows patients to acquire knowledge and habits that help them manage their chronic illness. Along the way, patients receive feedback giving an overview of data such as blood pressure readings or progress in managing adverse health events. Some experimental systems also incorporate diagnostic and coaching functionalities that assist or take over some tasks from the physician, using algorithms derived from existing evidence-based clinical treatment guidelines (Larburu et al. 2013), or use contextual awareness of the patient and her environment to provide adaptive, personalized recommendations (Lin 2013).

³ Interview patient, 13 May 2014; interview insurance company representatives 15 July 2014, 10 September 2014.

The relation of these worries to standard methods and theories in medical ethics is unclear. Some academic commentators have not attempted to provide backing justification for these concerns, but have instead left them as a list of questions (EFORTT 2011). Others have attempted to group them under a familiar system of bioethical principles, consisting of the “Four Principles” of Autonomy, Beneficence, Nonmaleficence, and Justice (Perry, Beyer & Holm, 2009; Perry et al. 2010; this “principlist” approach originates in Beauchamp & Childress 2009), but these attempts have been criticized for miscategorizing certain concerns such as privacy and surveillance risks (Sorell 2011).⁴ However, an additional striking thing about the list is that most of the items on it are better described as *anxieties* or *concerns* rather than violations or near-violations of ethical principles or theories. They have to do with the lack of full acceptance of a set of practices associated with telecare, or as we shall put it, the lack of *trust*. The relevance of trust may be inferred from the following two observations. (1) If patients and others, when confronted with the people, institutions, practices and technologies comprising telecare, *trusted* all these component entities, then some of the worries might disappear completely, although surveillance, security, reduction of personal contact, and continuity-of-care worries would remain. (2) If we add an additional condition to the trust so that people need to have *sound* trust, i.e. well-grounded trust, then it is hard to see how such trust would be compatible with being placed under surveillance or having one’s data left unprotected could be permitted. Hence it seems that a requirement that people be given the basis for sound trust provides a promising alternative starting point for the ethics of telecare.

In what follows we show that the trust-based approach provides the critical leverage to diagnose various concerns and generate distinctive and concrete recommendations. In the next section, we argue that a number of the seemingly diverse concerns about telecare are exacerbated by a shift in the *relations of trust* between patient, clinician, and other parties, relations which become visible when we compare the practice of telecare to the traditional scenario of intramural care. Correspondingly, we formulate a normative

⁴ We have in mind “smart” web-based systems that are semiautonomous, and do not merely consist of communicative media (e.g., telephone or videophone contact with a clinician). Bauer (2001), Perry, Beyer & Holm (2009), Perry et al. (2010), EFORTT (2011), and Sorell & Draper (2012) give accounts that focus on the ethics of in-home monitoring, which is what “telecare” often refers to in the UK. In the Netherlands and increasingly elsewhere, “telecare” refers to a broader and increasingly mobile range of networked diagnosis, monitoring, coaching and treatment services enabled by ICT (information and communication technology).

requirement that integrates some of the issues: to provide the patient with *good reason to trust* the main parties and services in this new scenario. This provides a structured justification for a set of recommendations, which we discuss in the final section of the paper.

2. The Importance of Trust

Trust is an attitude of willingness to rely on another person, institution or entity to act in ways that respect one's interests.⁵ According to one widely accepted philosophical approach to trust, the attitude consists of a set of expectations about how another person or entity will, and should, behave (Holton 1994, Faulkner 2007, Urban Walker 2006, Nickel 2009). These expectations are of two complementary kinds: *predictive* expectations about how a given entity is likely to behave, together with *normative* expectations about how the entity should behave (Faulkner 2007). Often this trust is based on the perception of an alignment of interests and values between trustor and trustee: when the interests and values of an entity on which I rely do not overlap with my own interests and values, I cannot rationally and wholeheartedly trust it (Hardin 2006, McLeod 2002). My expectations of others are based on an understanding of others' interests, motivations, and values, and this is often communicated via social information such as a shared understanding of the roles and responsibilities of different persons and institutions (Cook 2005; Maznevski & Athanassiou 2003). An additional feature of trust emphasized by Baier (1986) and Jones (1996) is that trust gives the trusted person *discretion*: trust is not compatible with direct control and monitoring of the trusted person. It implies that the trusted person is given latitude to respect the trustor's interests.

Traditionally, this latitude is given to a physician in a familiar, clinical context. Although trust has not been highlighted in the existing ethical literature on the ethics of telecare, it is widely acknowledged to be a particularly important value in medical care, especially within the doctor-patient relationship (O'Neill 2002; Beauchamp & Childress 2009; Hall 2005; Mechanic & Meyer 2000; Thom, Hall & Pawlson 2004; Calnan & Rowe 2007). People tend to have strong trust in clinical institutions generally and physicians in particular (Van der Schee, Groenewegen & Friele 2006; Calnan & Sanford 2004). Reliance on other aspects of care such as medication, equipment, and laboratory analysis is often thought to occur *via* the clinician, in the institutional context of the clinic. In this traditional scenario,

⁵ Thanks to an anonymous reviewer for suggesting the last part of this formulation, as well as the emphasis on discretion.

the clinician plays a gatekeeper role. The patient need not make separate judgments whether to rely on these other aspects of care. She can trust her clinician to notice (or help her notice) whether something is not functioning as it should. According to this view, patient trust in these various elements of care is *mediated* by trust in the clinician.

However, philosophers and social scientists doing empirically-informed work have noted that the practice of web-based telecare introduces a new network of people and agents, and a different assignment of responsibility for care (Schermer 2009; Oudshoorn 2011; Pols 2012). First, telecare involves new actors, such as service providers, clinical telecare support staff, software designers, and the system interface itself (Oudshoorn 2011), all of whom take on new responsibilities in the delivery of care, thereby changing the roles of physicians, nurses and others. Second, these shifting clinical responsibilities introduce new roles and responsibilities for patients themselves, such as the need to download software and use monitoring equipment daily. In doing so they take over tasks previously carried out by clinical staff (Schermer 2009, Oudshoorn 2011).

These changes disrupt the normative expectations that patients have toward their doctors and others, creating more complex trust relationships and raising worries about these relationships. Trust has been found to be especially salient to medical care during times of institutional change, such as the introduction of managed care or reforms to a national health service (Mechanic 2001, O'Neill 2002, Calnan & Rowe 2007). With telecare, this goes beyond the threat to trust posed by managed care: the idea is that a partly automated system mediates care *outside the walls of the hospital or surgery, and without the direct presence of the clinician*. The patient becomes directly and independently involved with elements of care that are less under the influence of her clinician and less integrated into the clinical infrastructure. On a daily basis, the patient interacts with a partly-automated online service maintained by a third party. This patient's clinician is not in a position fully to understand, monitor or supervise the patient's interaction with this system. Furthermore, the patient may have difficulty formulating reasonable expectations of the system. In other words, patient trust in the telecare service is no longer subsumed under, or mediated by, her trust relationship with her clinician. Furthermore, because the service operates in the patient's everyday environment (home, workplace, etc.), it is no longer part of the trusted physical context of the clinic. It is no surprise, then, that telecare would threaten patients' feeling of confidence in giving *discretion* over his or her medical interests and well-being. For the role of a person who exercises such discretion is diminished and made more complicated by the practice of telecare.

This general line of reasoning is augmented by specific concerns about the interests of different parties involved in the envisaged transformation brought about through the use of telecare. Hospitals, insurance companies and the state have interests in telecare that diverge from those of individual patients, arising in part from strong incentives to increase quantifiable productivity as measured by “billable” treatments, or decrease costs in line with governmental incentive structures. Through its direct-to-patient mediating role, telecare can potentially be used to limit costs, improve clinician productivity, facilitate medical research, collect useful data, and centralize delivery of care to a smaller number of larger hospitals.^{6,7} It can also prioritize health or public health over the individual goals of the patient. These shifts of interests can in principle impact the patient through a gateway that is no longer closely guarded by clinicians. Although the underlying motive to make health care more efficient is valid and important, this situation may not facilitate patient trust.

On the basis of this analysis, we propose that worries about trust and trustworthiness can be logically related to many of the ethical concerns mentioned in section 1. *Reduction of contact between patient and clinician and increased reliance on remote support workers for delivery of care* are aspects of the loss of the physician as a trusted gatekeeper of care and the introduction of many new entities about which our expectations are uncertain. *The possible lack of expertise or context-sensitivity of automated diagnosis and medical judgment* relates to the fact that the web-based telecare service operates autonomously of the physician and outside clinical walls. *The burden or responsibility imposed on the patient* has to do with the fact that it is now the patient who has to carry out a routine by interacting with the telecare system and support workers, independently of the physician. This puts *the patient’s understanding of the functions and limitations of the system* under additional pressure. *Ambiguity about whether telecare is a therapy* relates to uncertainty about what roles and expectations we can attribute to it, i.e. what standards we should use in calibrating our trust. Is it a stand-in for the physician, or is it a stand in for managed care and efficiency? In this way, a number of the ethical concerns mentioned earlier are plausibly held to be linked with a shift of role responsibilities and associated expectations, away from the clinician and toward the patient herself, toward the

⁶ Interview clinician, 7 January 2014; Interview telecare developer, February 21 2014; Interview clinician, 13 January 2014.

⁷ The first of these functionalities is frequently given as a rationale for telecare. The other functionalities were mentioned by various clinicians interviewed by the authors when asked, “What is the function or purpose of this telecare system?”

telecare system, and/or toward auxiliary workers. Since trust is based on these expectations, these ethical concerns are linked with a lack of trust.

In connection with this, we make the observation that if, hypothetically, people had well-grounded trust in the institutions and technologies comprising telecare, some of these ethical concerns would largely disappear. For it is hard to see what is *inherently* wrong with (e.g.) the involvement of new technologies, remote support personnel and third-party companies providing medical care outside the clinical context, so long patients (and workers) are treated fairly and these technologies, institutions and systems function well—and people have reason to be confident of this. Well-grounded trust in a third-party company, a remote support worker, or a smartphone application on the basis of solid information about them alleviates much of the worry about them. The problem is not so much with the underlying situation, as with the fact that the familiar signs and contexts of trustworthiness are missing.

Surveillance, data insecurity, and lack of continuity of health care, on the other hand, are linked with trust in a different way: although the mere fact of trusting those who place you under surveillance or handle data insecurely, or create disruptions in the delivery of care, even on the basis of solid information about them, does not make their actions ethically unproblematic, these actions are incompatible with *sound* trust.⁸ These are problems that our trust-based account would best address in combination with further reflection about the way that respect for confidentiality, freedom from intrusion and continuity are implied by genuine trustworthiness. Sound trust implies being able to count on certain appropriate standards being fulfilled, such as consistent care and concern for privacy. So it is not just that as a contingent matter of fact, people's trust in telecare is partly based on the expectation that they will not fall through the cracks, be spied on or have their data mishandled. These practices are incompatible with well-grounded trust.

In the actual or near-term practice of telecare, by contrast with our hypothetical, people do not yet have sufficient *reason* to trust telecare, partly because it is new and unfamiliar, and partly because there is nobody positioned, in the way that the physician is in the traditional scenario of health care, to be given discretion to respect the health-care related interests of the patient. In response, we propose that a promising general strategy for addressing some of the ethical concerns about telecare is to provide the epistemic basis

⁸ Analogously, even *consenting* to being placed under surveillance or having discontinuous health care would not eliminate all concerns about it. But arguably, a morally legitimate practice of consent is incompatible with these practices.

for *sound trust*. We discuss this further in the next section. This approach will provide a structured basis for a set of distinctive general response strategies for bolstering sound trust, discussed in Section 4.

3. The Concept of Sound Trust

Although trust is commonly mentioned as a value in medical care, it is usually thought of as an instrumental and/or hedonic good. Its psychological features, such as confidence in the physician and compatibility with treatment compliance, are emphasized over its normative and epistemic features, such as well-groundedness and its connection with normative expectations.⁹ Our approach instead focuses on these latter characteristics: trust is indeed a psychological attitude, but it also has an important epistemic and normative dimension.¹⁰ To capture this, we propose the idea of *sound trust*, which refers to the situation that obtains when trust and its component expectations are warranted or justified. It can be thought of as a well-functioning epistemic relation between a trusting agent (the trustor), a trusted agent, system, or institution (the trustees), and a set of actions, tasks, functionalities, or responsibilities that the trustor attributes to the trustees.¹¹ Related ideas have occasionally been used in analyses of bioethical issues: Boenink (2003) uses the term *healthy trust* (“gezond vertrouwen”), where trust is supported by reasons that legitimize it to the patient, to advocate changes to the practice of prenatal screening. A similar idea is also expressed by Manson and O’Neill in their critique of informed consent: “trust is ineliminable in human affairs, yet ... it cannot be intelligently placed unless evidence that is relevant to placing and refusing trust is made available” (2007, 180). In what follows we develop this idea by spelling out more explicitly the kinds of reasons that are relevant to trust, applying the notion to the case of telecare, and providing a number of practical recommendations.

As we remarked in section 2, trust is based on a *predictive* expectation about how the trusted entity is likely to behave, together with a *normative* expectation that this is how the trusted entity should behave. Consequently, the justification of trust must include

⁹ An instrumental view of patient trust traces back to the ancient physician Galen (Mattern 2008, 146). In modern times, see, e.g., Eyal 2012, as well as many of the articles he attacks.

¹⁰ In this respect we can again draw a comparison with *consent*, where it has been observed that genuine consent requires information and understanding, i.e. epistemic values. Trust is different from consent in the sense that the epistemic basis for trust draws on a different class of reasons, including social and motivation-based reasons.

¹¹ This account thus falls into the class of so-called “three-place” accounts of trust (Baier 1986).

reasons that warrant these expectations. For example, if a patient trusts a telecare service to notify her when she needs to take action, then her trust is sound only when she has reason to expect that such notifications are *likely* to occur, as well as reasons to believe that she is *supposed* to receive notifications. An example of the former type of reason would be that she has consistently received these notifications in the past. An example of the latter type of reason would be that the service comes with a manual that explains the feature of notifications.

Sound trust places two requirements on such reasons. The first is the *basing requirement*: the trustee must have the relevant expectations *in virtue of* or *based on* those reasons in order for those reasons to ground her trust (Korcz 1997). For example, if the home page for the telecare service states that notifications should appear under certain conditions, but the patient expects these notifications without ever having read the home page, then the fact that the homepage mentions these notifications cannot justify her expectation. The second requirement is the *backing requirement*. The reasons must themselves be sound: they must be good reasons, reasons that really back or ground the attitude of trust. For example, if the patient expects something (even in a way that is accurate or fitting) because she has misunderstood the home page or because the home page gives information for which there is no evidence, then her understanding of the home page is not a good reason for that expectation.

A frequent way of expressing the backing requirement is in terms of the *reliability* of a belief-forming process. We can extend this idea to the expectations of trust in telecare: not only must a patient be able to arrive at an accurate or fitting expectation about what telecare will deliver, but this expectation must be the result of a process that non-accidentally tends to produce accurate or fitting expectations. The reasons for her expectations must be good ones in the sense that they are considerations that *reliably correlate with the fulfillment of those expectations*. Although there has been debate about the exact details of a reliability-based epistemology, the broad idea is widely accepted (Goldman 2011).

It is worth comparing what Manson and O'Neill (2007) say about evidence for trust and how we can help provide people with it. Instead of emphasizing reliability, Manson and O'Neill emphasize that we can become more intelligent in placing trust, developing "skills"

of placing trust (as well as offering others evidence for trusting us) (2007, 162).¹² They mention a variety of reasons for trust or “fiduciary binding factors” that can give a person reason to trust: Person S trusts T to do some action x because S believes that T (all quotes from 2007, 165n.):

- a) “has strategic reasons to do x”;
- b) “has prudential reasons to keep S’s trust”;
- c) has an occupation or role likely to make T reliable in doing x;
- d) “values what S values”;
- e) is too stupid not to do x;
- f) “will be monitored and checked by a ... reliable third party”;
- g) “has been trustworthy in the past”;
- h) is endorsed by a third party, who is reasonably thought to be reliable;
- i) believes x “is the morally correct thing to do.”¹³

In their positive argument, Manson and O’Neill focus on just two of these: (f) and (c). They propose a combination of managerial accountability, in which audits and internal control mechanisms are used by an external entity to ensure that certain standards are met (f); and professional accountability, in which “qualifications for professional practice” are required, such as training, certification, and membership in professional associations, in conjunction with a host of more implicit role expectations (c). Although Manson and O’Neill remark in passing that “systems of accountability are not the only way of providing reason to trust” (ibid.), they do not discuss or develop other strategies on this basis.

For the context of telecare, we need a different and broader set of recommendations than Manson and O’Neill offer. O’Neill diagnoses the loss of trust as the result of a mistaken understanding of autonomy and informed consent, as well as the

¹² Manson and O’Neill’s remarks might be taken to imply that patients should need to develop special skills in order to have reason to trust in telecare. This is not part of our view as developed here, but it is a question worth taking up explicitly in relation to usability and the computer skills that might be needed to use telecare effectively.

¹³ Many of these ideas have appeared in earlier literature, although it is not clear whether Manson and O’Neill derive their list from these earlier sources. For example, (a), (g) and (h) are discussed in Coleman (1990). Concerns about preserving one’s *reputation* by being trustworthy are discussed by Pettit (1995) and can be taken to fall under (b). (d) is discussed in McLeod (2002). Hardin (2006) focuses on iterated interactions as modeled by game theory, which again fall under (a) and (b). Hardin also discusses the moral motives of (i). We pick up some of these ideas in the next section.

activities of the media in reporting about health care, particularly in relation to reforms to the national health service in the UK (O'Neill 2002). Manson and O'Neill's own core remedy to the trust problem relies on professional accountability, and is therefore dependent on the familiar role expectations we have toward clinical contexts and physicians. However, we have seen that telecare introduces additional substantial threats to the familiar basis of patient trust, by taking health care outside the familiar and trusted clinical context, making it unclear whether this care is subject to the same standards as normal medical treatment, and reducing the physician's role as a gateway to care. Manson and O'Neill seem to take for granted that there will be a physician who can be given the discretion to ensure that patients' health care interests are respected, and who can ultimately be held accountable for what happens with those patients' health care. However, professional discretion and accountability may be diminished if telecare changes the paradigm for managing chronic care in the way that industry advocates and critics envisage. Patients may have no idea what they can reasonably expect in that scenario, or how they can ground those expectations. We will therefore suggest a broader set of strategies for improving sound trust.

4. Designing for Sound Trust

We propose six strategies for designing institutions and telecare services so that they provide the basis for sound trust on the part of the patient: (a) personal vouching, (b) generalized vouching, (c) incentives for trustworthy care, (d) value sharing, (e) co-construction of function, and (f) facilitating sound user experience. Each of these strategies is based on the idea that *scientific reasons* for the reliability and efficacy of a technical system need to be embedded in a social and institutional context of *reliable manifest reasons* that make the system trustworthy from the perspective of the user.¹⁴ The list is not meant to be comprehensive, but to suggest some representative and promising possibilities, with particular attention to cases where there is already a relevant practice in place but its epistemic value is in question.

a. Personal Vouching

¹⁴ The account is not intended to hyperintellectualize or moralize reasons for trust, making them a matter of explicit reflection or imposing obligations on the person who trust. The point is rather that the reasons are accessible, meaningful *signs* of trustworthiness.

In many cases, an unknown or uncertain entity comes to be trusted because an already-trusted entity vouches for it. In its personal form, a physician or another clinical staff person already known to the patient can vouch for the reliability of a telecare service, so that trust in the physician is extended to the service. This is part of the current practice of telecare: the patient's specialist physician is sometimes (at least briefly) present at introductory events where patients are invited to use the telecare service. Clinicians also sometimes introduce the system personally to patients during a normal consultation.¹⁵

In order to have strong epistemic value, it is essential to personal vouching that (i) the vouching party is already trusted by the patient in a way that is warranted; and (ii) the reputation and integrity of the vouching party is at stake (Coleman 1990, Pettit 1995). Concerning (i), if GPs, specialist physicians or physical therapists are to garner sufficient sound trust to vouch for a telecare system or the third party that maintains it, then a patient must have adequate reason to think that they are competent and caring. In many cases, this is strongly warranted within existing medical practice. However, (ii) is more problematic. Physicians and clinical staff might avoid taking personal responsibility for the functioning of the telecare service. If something were to go wrong, they might actively and effectively avoid a loss of reputation themselves, by pinning responsibility on the third-party provider and not accepting that their own judgment was inadequate. In that case, they are not in a position to offer meaningful personal vouching. To have epistemic value, it must be made clear to the patient that the reputation of the vouching entity is at stake, and that they take partial responsibility for its functioning. When this is not the case and physicians nonetheless vouch for telecare systems, the currency of personal vouching is undermined by counterfeit instances, ruining it as a sign of reliability. Hence the effectiveness of personal vouching depends essentially on the willingness of physicians and clinical staff to stake their reputations on the functioning of the telecare system.

b. Generalized Vouching

Generic forms of vouching not involving personal interaction between patients and individual professionals include visible certificates or signs that are recognizable and whose validity is backed up by an independent inspection authority. Examples are the CE symbol and certification symbols vouching for the healthfulness or safety of food products. The CE symbol, in particular, is relevant because it applies to some of the medical devices

¹⁵ Interview telecare developer, February 21, 2014; interview specialist physician, January 17, 2014.

comprising telecare (European Commission 2015). CE certification requires that the product go through a process of risk analysis and data gathering to ensure safety. Computer applications that provide clinical diagnosis, treatment or measurements are required to have it. Failure to conform to these requirements can result in large fines.

If generalized vouching is to have epistemic value for sound trust in telecare, it must (i) be available and intelligible to patients, (ii) have a clear connection to respect for patient interests, and (iii) be backed effectively by trusted institutions. Various problems with private certification schemes have been noted, such as proliferation of certification symbols and a lack of both transparency and enforceability (Poncibò 2007). Not all of these carry over to state governance schemes like the CE symbol, but there are still some epistemological problems with such a scheme. First, it is doubtful whether patients are aware of and understand the meaning of the CE symbol. This undermines (i). Secondly, the CE symbol only relates to safety, not to the ethical concerns discussed earlier. In this respect it fails to meet criterion (ii), since patient expectations of telecare reasonably go well beyond safety. A third challenge is that in order for such symbols to provide a sound reason, the independent authority must genuinely take responsibility for the trustworthiness of the telecare services by inspecting them or engaging in some other form of effective governance to ensure (ii). But it is hard to see how such an authority can reliably ensure anything beyond basic mechanical safety and efficacy, at least not using standard control mechanisms. Hence the mandate to ensure sound trust extends beyond the means available to a state certification authority. This calls into question whether (ii) and (iii) can be achieved simultaneously. Analogous challenges are likely to exist for other forms of generalized vouching such as that achieved through management accountability schemes.

c. Incentives for the Trusted Entity

A third strategy of designing for sound trust is to make it clear that the entity whose trustworthiness is to be established has strong incentives to perform as expected. These incentives can be positive or negative. Positive incentives for good performance include extending the possibility of future beneficial interaction between trustor and trusted to the trusted entity (Hardin 2006), or reputational benefits conferred on the trusted entity upon performance that increase the likelihood of future beneficial interactions with others (Pettit 1995). Negative incentives include the effective ability to take legal action against an entity in the case of damages (Hall 2005), or the ability to publicize negative commentary causing reputational loss to the entity (Matzat & Snijders 2012).

Currently, however, these types of incentives are not prominently available in the case of telecare. Patients might assume that physicians can benefit from future interaction with companies offering web-based telecare services, or that companies might suffer reputational damage or even legal liability if their services fall seriously short, but this is unlikely to provide a strong basis for believing that telecare services will not be burdensome to the patient and that they are just as reliable as traditional care. In order to strengthen these incentives and make them relevant for individual patients, patients themselves should be able hold telecare services accountable, or see that others can do so on their behalf. An example of this would be a public forum for users of a given telecare service, in which there is the possibility of open criticism and response.

d. Shared Values

A fourth strategy of designing for sound trust is to make it visible to the potential trustor that the would-be trusted entity shares key values with him or her—an aspect of trust stressed by McLeod (2002). A simple example would be for all those involved in the development and deployment of telecare to adopt the “Four Principles” of Autonomy, Beneficence, Nonmaleficence, and Justice (Beauchamp & Childress 2009), making it clear that telecare must meet the same ethical standards as traditional medical care. However, again, in order to have *epistemic* value for the patient, the public adoption of this set of values must be reliably associated with addressing the ethical concerns from our earlier list. It does seem likely that *if* the value culture that we associate with traditional medicine were extended to telecare, this would go some way toward addressing the ethical concerns about it, even if we cannot give a detailed account of the relationship between the Four Principles and those concerns. However, it is not clear that the public adoption of those values would effectively warrant the patient’s trust, in the face of the conflicting interests that are at stake in the promotion of telecare. In the absence of specific sanctions or mechanisms for ensuring that the values are honored, the patient might reasonably conclude that their adoption is, to use a term from the discussion of corporate social responsibility, *window dressing* (Frankental 2001).

e. Co-Construction of Function

Another strategy of designing for sound trust is to explicitly acknowledge or even encourage users of web-based telecare to determine for themselves what these systems are *for*. Patients have different conceptions of what telecare is for than their doctors. For example,

whereas physicians might see the purpose or function of web-based telecare as getting more accurate, comprehensive measurements, monitoring participants in a research project, or reducing the burden of consultation hours, patients might attribute different functions to it such as feeling more in touch with their bodies, providing a way of discussing their health with their partner, enabling them to keep track of what they are able to “get away with” behaviorally without incurring health risks, or as a way of avoiding clinical consultations. Allowing patients to co-construct the function of the technology (and thus not thinking of these functions as *misuses*) is a way of changing what patients normatively expect it to be able to do, and potentially making it more trustworthy from the patient’s perspective. This can occur at the level of system design (participatory design), system functionality (where adaptability of functions is designed into the system), or the practice of using the system (where the patient and others involved in the system come to a shared understanding that they will use the system in a non-standard way). We see this as a further extension of Schermer’s (2009) proposal for a new paradigm of self-management through telecare. In what she calls *concordant self-management*,

The patient is enabled and stimulated to find his own way of living with his condition ... The patient can make his own decisions and choices, which may not always be the most prudent from a medical perspective but might enhance the patient’s overall quality of life or enable him to fulfill important life goals or values. ... The patient’s own views of life, his own values and goals are more prominent and are not automatically identified with medical and health-related goals and values (689-690).

When the patient’s views of life influence a shared understanding of what telecare services are *for*, she has more reason to trust that they will serve her own ends.

f. Facilitating Sound User Experience

After telecare systems have been introduced for some time, it is reasonable to hypothesize that patients will start to base their trust or mistrust on their experiences: whether they have had what they regard as positive experiences with it so far, or whether they have experienced malfunctions or other problems. Given that their personal experience acts as a reason for their trust, the sound trust approach demands that we try to make sure that their experience of use provides them with reliable reasons to accept or reject the system. For

example, if the user has a negative or troubling experience (e.g., she receives advice from a web-based telecare service that causes her to feel or function less well), this should be an important indicator that something may indeed be wrong, and the design should in such case allow the user to also *act* upon that experience (e.g., by turning off this feature of the service or reporting it to the service provider).

Insofar as the user has positive experiences with a system, the challenge posed by the sound trust approach is to provide a context in which such positive experiences also actually count as good reasons to trust the system. As people are notoriously poor intuitive statisticians (Kahneman 2011), there is a natural psychological limit to how far we can push this design goal. Nevertheless, one practical implication that does follow from this consideration is that one should not simply design for a maximally positive user attitude towards the system independently of that system's actual usefulness to the user. This relates to the widely discussed question of how to design so-called "persuasive" technologies in ways that respect user autonomy (Berdichevsky & Neuenschwander 1999; Spahn 2012).

5. Conclusion

We propose that the sound trust account provides a viable alternative approach to many of the ethical concerns mentioned in the medical ethics and social science literature on telecare. In addition, it leads to concrete ethical recommendations tailored to telecare. We do not intend these recommendations to replace well known medical principles or values (such as respect for autonomy or the fair distribution of limited resources). Instead, the sound trust account is about the way in which such values are manifested in the relation between patient and care provider. Upholding medical values presupposes sound trust, and sound trust grows when these values are shared by trustor and trustee.

An ethics based on sound trust is not unrelated to traditional medical ethics principles. The *backing requirement* described at the end of section 3 can be seen as articulating the value of *beneficence*. It implies that the system manifests care: the skills of clinicians, the quality of equipment, and the effectiveness of the chosen form of treatment for the patient in question. It implies that there is good reason to think the trusted system is maintained in a spirit of goodwill toward the trusting person, and that duties of care are fulfilled. In similar fashion, the *basing requirement* helps to articulate respect for autonomy in a practically realistic manner. We have argued that a patient must base her trust on appropriate manifest reasons, which in turn back or ground her trust by implying genuine

evidence of trustworthiness. Patients and doctors must *share* responsibility for treatment decisions, which can be achieved through our proposed strategies of vouching, shared valuing, co-construction of function, etc. When properly realized, these strategies are ways of respecting patients and their relational autonomy: an idea of autonomy that “treats social relationships and human community as central to the realization of autonomy” (Friedman 1997).

Sound trust is relevant to our need, as dependent, vulnerable, relational beings, for good information in our decisions about what and whom to rely upon. As we rely increasingly on forms of health care that are socially and technologically complex—illustrated by the development and widespread deployment of web-based telecare—having good reasons for trust is as important as ever.

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