TITLE

The curious case of 'trust' in the light of changing doctor-patient relationships

AUTHORS

Seppe Segers

Heidi Mertes

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ABSTRACT

The centrality of trust in traditional doctor-patient relationships has been criticized as inordinately paternalistic, yet in today's discussions about medical ethics – mostly in response to disruptive innovation in healthcare – trust reappears as an asset to enable empowerment. To turn away from paternalistic trust-based doctor-patient relationships and to arrive at an empowerment-based medical model, increasing reference is made to the importance of nurturing trust in technologies that are supposed to bring that empowerment. In this article we stimulate discussion about why the move towards patient empowerment may not be able to keep clear of the criticism of trust in traditional patient-doctor relationships. First, we explore how such a shift in trust dynamics might corrode patient empowerment in the name of patient empowerment. Second, we examine how a translocation of trust may at best push the 'trust issue' elsewhere and at worst make it harder to evaluate trustworthiness.

KEY WORDS

trust; disruptive innovation; empowerment; mHealth; medical AI; paternalism

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H2020 European Research Council, Grant/Award Number: 949841; European Research Council (ERC) Despite the dominant refrain that it is essential, imperative, a cornerstone or a sine qua non of medical care, trust plays an ambiguous role in healthcare and medical ethics.¹ The doctor-patient relationship has traditionally been regarded as a fiduciary one, in which the patient places trust in the professional, who, in turn, is considered being worthy of receiving that trust.² However, since the second half of the twentieth century, with the arrival of the so-called 'modern medical era', it has been reported that this ethics of trust became increasingly associated with "old-guard paternalism".³

¹ Pellegrino, E. D., & Thomasma, D. C. (1993). *The virtues in medical practice*. Oxford: Oxford University Press; O'Neill, O. (2003). *Autonomy and trust in bioethics*. Cambridge: Cambridge University Press; Sagoff, M. (2013). Trust versus paternalism. *The American Journal of Bioethics*, *13*(6), 20-21; Beauchamp, T. L., & Childress, J. F. (2019). *Principles of biomedical ethics* (8 ed.). Oxford: Oxford University Press; Sheppard, M. K. (2020). mHealth apps: Disruptive innovation, regulation, and trust—a need for balance. *Medical Law Review*, *28*(3), 549-572.
² Chadwick, R. (1997). The future of professional ethics. *Ethical Perspectives*, *4*(2), 291-297; Kelly, T. M. (2018). *Professional ethics*. A trust-based approach. London: Lexington Books.

³ The direct quote is from Hall, M. (2002). The ethics and empirics of trust. In W. B. Bondeson, & J. W. Jones, *The ethics of managed care: professional integrity and patient rights* (pp. 109-126). Dordrecht: Springer-Science+Business Media, B.V. Other discussion of this evolutions can be found in: Pellegrino & Thomasma, *op. cit.* note 1; O'Neill, *op. cit.* note 1; Chadwick, *op. cit.* note 2; Siegler, M. (1985). The progression of medicine. From physician paternalism to patient autonomy to bureaucratic parsimony. *Archives of Internal Medicine, 145*(4), 713-715; Misztal, B.

Testimonials illustrate how, especially by the mid-1980's, there were concerns about the then-present "endemic breakdown of trust" and the way in which the "importance of trust in the clinical relationship was (...) widely criticized".⁴ Pellegrino and Thomasma mention "an ethics of distrust [that] has been gathering force."⁵ Siegler noted how the "Age of Paternalism", which was premised on trust in the physician's moral stature, came under fire by a competing model based on autonomy, patient education and patient rights.⁶ According to Sherlock, this "emphasis on patient rights" escalated into "a direction opposite of that of the intimate relationship in which (...) trust [is] nurtured."⁷

⁴ Sherlock, R. (1986). Reasonable men and sick human beings. *The American Journal of Medicine*, 80(1), 2-4.

⁵ Pellegrino & Thomasma, *op. cit.* note 1, p. 65.

⁶ Siegler, op. cit. note 3, p. 714.

⁷ Sherlock, *op. cit.* note 4, p. 3. While some "extreme anti-paternalists" – to use Brewin's term – may display a vehement aversion of trust, this should not be taken as an exponent of a homogeneous perspective on this matter. Indeed, the emphasis on autonomy has not monolithically led to a wholesale attack on trust. One would need a full historiographical account of the evolution of the relationship between trust and paternalism to capture the diverse ways in which trust has been evaluated

A. (1996). *Trust in modern societies. The search for the bases of social order*. Malden: Polity Press; Rothman, D. J. (2001). The origins and consequences of patient autonomy: A 25-year retrospective. *Health Care Analysis, 9*(3), 255-264; LaRosa, E., & Danks, D. (2018). *Impacts on trust of healthcare AI*. Paper presented at the proceedings of the 2018 AAAI/ACM conference on AI, ethics, and society, New Orleans, LA, USA.

Interestingly, many of today's discussions about medical ethics, mostly triggered by so-called 'disruptive innovations' in healthcare, again illustrate the ambiguous role of 'trust', as it now reappears on the scene as an asset to enable empowerment, rather than as a criticized element in a presumedly asymmetrical relationship.⁸

throughout the years, and it is hard to measure this association in a decisive way. Hall's analysis of how trust increasingly "fell into disfavor or was reinterpreted in rights-oriented terms" provides good orientation. With respect to the 'rights-oriented reinterpretation of trust' it is, for instance, relevant to refer to what both Veatch and Childress & Siegler called the 'contractual model' of the doctor-patient relationship, which serves as a foil for the 'paternalist model', and in which patients function as autonomous contractors. While this model does not abolish trust altogether – it is still there as a presumptive basis for the contractual context – its role is much more limited when compared to the so-called paternalist model. Brewin, T. B. (1985). Truth, trust, and paternalism. *Lancet*, *2*(8453), 490-492; Hall, *op. cit.* note 3, p. 111; Veatch, R. M. (1972). Models for ethical medicine in a revolutionary age. What physician-patient roles foster the most ethical relationship? *The Hastings Center report*, *2*(3), 5-7; Childress, J. F., & Siegler, M. (1984). Metaphors and models of doctor-patient relationships: their implications for autonomy. *Theoretical Medicine*, *5*(1), 17-30.

⁸ Sheppard, *op. cit.* note 1; Voerman, S. A., & Nickel, P. J. (2017). Sound trust and the ethics of telecare. *The Journal of Medicine and Philosophy*, *42*(1), 33-49; Myskja, B. K., & Steinsbekk, K. S. (2020). Personalized medicine, digital technology and trust: a Kantian account. *Medicine, Health Care, and Philosophy, 23*(4), 577-587; Lee, S. S. (2021). Philosophical evaluation of the conceptualisation of trust in the NHS' Code of Conduct for artificial intelligence-driven technology. *Journal of Medical Ethics*. doi:10.1136/medethics-2020-106905.

While the criticism of the centrality of "trust in the physician's technical skills and moral stature"⁹ accompanied the criticism of medical paternalism as something that should be restructured on a more 'empowering' foundation, in present-day discussions, trust is reintroduced as a constituent for making such an empowered healthcare relationship possible. That is to say, today, trust plays a central role in discussions about the ethics of innovative technologies relying on widespread generation and sharing of health data to enable personalized medicine, like smart device-paired wearables, health apps and artificial intelligence (AI) in medicine, where questions emerge about whether and how these technologies will be able to generate trust among healthcare users.¹⁰ These innovations have been presented as facilitators of patient empowerment, so to make individuals more independent from physicians in taking care of their own health proactively.¹¹ There is the idea that patients will be able to gather medical information themselves from different sources. In the present discussions about these technological innovations, trust re-enters the scene, then, not so much as a

⁹ Topol, E. (2015). The patient will see you now. New York: Basic Books, p. 20.

¹⁰ Sheppard, *op. cit.* note 1; Lee, *op. cit.* note 8; Voerman & Nickel, *op. cit.* note 8; Myskja & Steinsbekk, *op. cit.* note 8; Durán, J. M., & Jongsma, K. R. (2021). Who is afraid of black box algorithms? On the epistemological and ethical basis of trust in medical AI. *Journal of Medical Ethics.* doi:10.1136/medethics-2020-106820; Starke, G., van den Brule, R., Elger, B. S., & Haselager, P. Intentional machines: A defence of trust in medical artificial intelligence. *Bioethics.* doi: 10.1111/bioe.12891.
¹¹ Sheppard, *op. cit.* note 1; Schmietow, B., & Marckmann, G. (2019). Mobile health ethics and the expanding role of autonomy. *Medicine, Health Care, and Philosophy, 22*(4), 623-630.

feature of an asymmetric relationship, but rather as a necessary condition upon which the adoption of these (expectedly empowering) technologies seems to depend.

This yields a peculiar observation: While in traditional doctor-patient relationships the trust expected of patients in healthcare professionals has been associated with an inordinately paternalistic acceptance of medical authority, trust of patients in the said innovative technologies is now expected and presented as a crucial step towards patient empowerment. In other words, to turn away from a trust-based doctor-patient relationship and to arrive at a medical model based on empowerment, increasing reference is made to the importance of nurturing trust in the technologies that are supposed to bring that empowerment. This appears to imply that patients are shifting their dependence, and the locus of their trust, towards technological intermediaries.

The general (and moderate) aim of this paper is to map out this ambiguous role of trust in medical ethics and to explore whether this technology-induced move towards patient empowerment keeps clear of the criticism of the shape that trust had taken in traditional patient-doctor relationships. In doing so, a more defined (and somewhat more audacious) venture will be to investigate whether/why trust can be found to be problematic in traditional medical relationships, but unproblematic in healthcare users' interaction with technological platforms that are supposed to bring empowerment from such traditional patient-doctor relationships. To give a start to a broader discussion, we offer exploratory reasons why such a position may be untenable. First, we contemplate that such a shift in trust dynamics may come with a risk of corroding patient empowerment *in the* *name of* patient empowerment. Second, we consider how patients' trust is reoriented towards some other source or medium, and that with an increased focus on trustworthiness, such a reorientation may at best push the 'trust issue' elsewhere (rather than solve it), and at worst make it harder to rationally evaluate trustworthiness due to more complex interactions and networks.

TECHNOLOGICAL INNOVATION AND TRUST RHETORIC

We recognize that 'trust' contains multitudes. Still, the ubiquitous use of 'trust' in response to innovations and changing medical contexts does not seem to be hindered by the conceptual complexity of grasping its meaning. We will not pretend to offer a definition that covers all species of 'trust', yet a philosophical account that is relatively uncontroversial assumes that trust involves expectations not only about how another entity *will* behave, but also about how it *should* behave.¹² On this reading, a trustor (the one who trusts) will believe to also have the normative entitlement to hold the trustee (the one who is trusted) to those expectations.

As far as our own normative interpretation of this concept is concerned, it is important to clarify that it is not our aim to argue 'for' or 'against' trust. We agree that something is at stake in ethical terms when the role of trust is debated in the praxis of medicine. We endorse the ethical view that trust has instrumental value in a healthcare context to the extent that it

¹² Voerman & Nickel, *op. cit.* note 8; Walker, M. U. (2006). *Moral repair. Reconstructing moral relations after wrongdoing.* New York: Cambridge University Press.

denotes the confidence that medical actors will reliably abide by values that are congruent with those of healthcare users.¹³ Thus, as regards the normative rationale for trust, we sympathize with those bioethical views that emphasize the importance of trust, not only in terms of its therapeutic value in 'traditional' healing relationships between a patient and a physician, but also in the context of public health data production, collection and usage.¹⁴ In line with this, and given the importance that trust seems to have in our practical lives, we concur that the current revival of attention for trust can be regarded as a prima facie welcome development.¹⁵

As said, in the face of up-and-coming innovative technologies, the value and role of trust in the context of (changing) patient-doctor relationships is indeed (re)gaining ethical attention: Several authors have recently turned

¹³ This is the ethical framework for trust that is upheld by Beauchamp and Childress' popular principles-centered approach and it is in agreement with the theoretical clarification that was recently presented by Holland and colleagues. Beauchamp & Childress, *op. cit.* note 1; Holland, S., Cawthra, J., Schloemer, T., & Schröder-Bäck, P. (2021). Trust and The Acquisition and Use of Public Health Information. *Health Care Analysis.* doi:10.1007/s10728-021-00436-y.

¹⁴ Hall, *op. cit.* note 3, p. 110; Woolley, J. P. (2019). Trust and justice in big data analytics: Bringing the philosophical literature on trust to bear on the ethics of consent. *Philosophy & Technology*, *32*(1), 111-134.

¹⁵ To be sure, this does not entail that bioethics is but a procedural activity to vouch for trustworthiness of medical authority, whether it is algorithm-based or not. For a critique of the relationship between bioethical analysis and the focus on trustworthiness, see Franklin, S. (2019). Ethical research - the long and bumpy road from shirked to shared. *Nature*, *574*(7780), 627-630.

to trust-related challenges in the context of algorithm-driven technologies such as mHealth apps and clinical decision support systems, and, more broadly, 'personalized medicine' – which, apart from smart device-paired wearables, health apps and AI in healthcare also encompasses, for example, direct-to-consumer genetic testing and telecare services.¹⁶ Also in the context of precision medicine research, especially in the matter of data collection and sharing, reference to trust is often made.¹⁷ Proponents refer to the empowering potential of collecting and bringing together data of many individuals, mined from electronic patient health records, biospecimens and health-data tracking, in order to find correlations and causal relations and to personalize health risk assessments and management plans.¹⁸ Yet, there are coexisting worries about misuse of those patients' data, in response to which

¹⁸ Topol, *op. cit.* note 9; Juengst, E., McGowan, M. L., Fishman, J. R., & Settersten, R. A., Jr. (2016). From "personalized" to "precision" medicine: The ethical and social implications of rhetorical reform in genomic medicine. *The Hastings Center report*, *46*(5), 21-33.

¹⁶ Sheppard, *op. cit.* note 1; Voerman & Nickel, *op. cit.* note 8; Myskja & Steinsbekk, *op. cit.* note 8; Lee, *op. cit.* note 8; Starke, G., et al., *op. cit.* note 10; Durán & Jongsma, *op. cit.* note 10; Sterckx, S., Cockbain, J., Howard, H., Huys, I., & Borry, P. (2013). "Trust is not something you can reclaim easily": Patenting in the field of direct-to-consumer genetic testing. *Genetics in Medicine*, *15*(5), 382-387.

¹⁷ Ploug, T., & Holm, S. (2016). Meta Consent - A Flexible Solution to the Problem of Secondary Use of Health Data. *Bioethics*, *30*(9); Milne, R., Morley, K. I., Almarri, M. A., Anwer, S., Atutornu, J., Baranova, E. E., ... Middleton, A. (2021). Demonstrating trustworthiness when collecting and sharing genomic data: Public views across 22 countries. *Genome Medicine*, *13*(1), 92.

the nurturing of trust is often cited as a possible solution, facilitated by institutions that are thoughtfully designed in function of oversight, governance and protection.¹⁹ One of the central issues in these discussions, is how the adoption of these technologies will depend on people's trust in these innovations.²⁰

That the successful introduction of new technology (at least partly) depends on the public's trust, has received quite some attention in engineering matters, even to the extent that some authors are now talking about 'trust-washing' to describe the pervasiveness of 'trust-talk'.²¹ As an illustration, consider the current debate about the trustworthy implementation of AI in autonomous systems, characterized by the popular belief that trust is essential because of the so-called 'no trust, no use' concept, which is also starting to find entrance into policy documents.²² Given increasing proposals for medical

¹⁹ Kraft, S. A., Cho, M. K., Gillespie, K., Halley, M., Varsava, N., Ormond, K. E., ... Soo-Jin Lee, S. (2018). Beyond consent: Building trusting relationships with diverse populations in precision medicine research. *The American Journal of Bioethics*, *18*(4), 3-20.

²⁰ Voerman & Nickel, *op. cit.* note 8; Kraft, S. A., et al., *op. cit.* note 19; Sheppard, *op. cit.* note 1; Lee, *op. cit.* note 8; Durán & Jongsma, *op. cit.* note 10.

²¹ Tschopp, M., & Ruef, M. (2020). *Trust and AI - three wrong questions*. Retrieved from https://www.scip.ch/en/?labs.20201112

²² AI HLEG. (2019). *Ethics guidelines for trustworthy AI*. Brussels: European Commission; European Commission. (2021). *Proposal for a regulation of the European Parliament and of the Council laying down harmonised rules on artificial intelligence (artificial intelligence act) and amending certain union legislative acts*. Brussels: European Commission; He, H., Gray, J., Cangelosi, A., Meng, Q.,

use of AI systems, a spillover of such trust-oriented language into medical ethics is perhaps unsurprising.²³ Also in response to the COVID-19 pandemic, there is a noticeable preoccupation with trust, which is evident for instance in the roll-out of digital COVID-19 health certificates and the technological approaches that have been suggested to track contaminations.²⁴

It may be questioned whether the presently championed trust discourse vis à vis these innovative technologies is anything more than a superficial appeal to trust. In response to the dominance of the trust rhetoric, such heightened scrutiny of concepts is desirable, as we do not want ethical debates about the acceptability of innovative medical technologies to be held in terms of empty labels. For one thing, it may seem a category error to suppose trust between individuals and new medical technologies. That is, the main philosophical components of trust (the presumption of value congruence and moral reproach if expectations are not met) seem to pertain to an inter*personal* attitude, not to a relationship between an individual and media

McGinnity, T. M., & Mehnen, J. (2020, 10-12 Aug. 2020). *The challenges and opportunities of artificial intelligence for trustworthy robots and autonomous systems*. Paper presented at the 2020 3rd International Conference on Intelligent Robotic and Control Engineering (IRCE).

²³ Wu, E., Wu, K., Daneshjou, R., Ouyang, D., Ho, D. E., & Zou, J. (2021). How medical AI devices are evaluated: limitations and recommendations from an analysis of FDA approvals. *Nature Medicine*, *27*(4), 582-584.

²⁴ Leins, K., Culnane, C., & Rubinstein, B. I. (2020). Tracking, tracing, trust: contemplating mitigating the impact of COVID-19 with technological interventions. *The Medical journal of Australia*, *213*(1), 6-8.e1.

or technologies.²⁵ If these technologies do not live up to the normative expectation, would this lead to the reactive attitudes (e.g. a feeling of betrayal when trust is violated) that are distinctive of trust, comparable with those in patient-doctor relationships? If not, this may yield reason to be suspicious of the call for trust in response to these emerging medical technologies in general. Relatedly, one might wonder whether it would be better to regard this relationship as one of reliance rather than trust (even though the interrelation between both concepts may be hard to capture).²⁶ In a recent contribution, Holland et al. have greatly contributed to this matter, and to avoid repetition we essentially refer to their analysis.²⁷ For our purposes, we concur that there is anecdotal evidence of value congruence between the public and healthcare institutions, and that failures of trust in these institutions may indeed elicit the relevant reactive attitudes. In line with Holland and colleagues' analysis, we believe that a charitable reading of calls to build trust in these new technologies may boil down to significant measures to encourage confident public reliance in those institutions that provide and regulate these platforms, and that this can be "augmented" by fostering trust in these institutions by "developing, displaying, and abiding by values which are congruent with those of the public."

²⁶ For a detailed analysis of this distinction, see Baier, A. (1986). Trust and Antitrust. *Ethics*, 96(2), 231-260; and Holland, S., et al., *op. cit.* note 13.

²⁵ We are grateful to the anonymous reviewer for sharpening our position on this matter. The analysis by Holland, S., et al., *op. cit.* note 13, pp. 8-10 has been very helpful in this regard.

²⁷ Holland, S., et al., *op. cit.* note 13, pp. 8-10.

THE EMPOWERMENT MODEL

As noted by Misztal, a renewed significance of the issue of trust can be explained by transitions in socio-cultural conditions.²⁸ In that regard, sociological theory offers some support for the hypothesis that today's heightened focus on trust may be related to a reorganization of established (medical) praxis and the way in which healthcare is delivered.²⁹ However that may be, innovations like mHealth, telemedicine and AI in medicine in general are often cited as part of a broader development that may upend, or at least gravely restructure, the traditional medical model; a development that Eric Topol dramatically dubbed "the road to medical emancipation".³⁰ These innovations' putative ability to empower individual patients to become active participants in their own care has become a popular trope in medical ethics literature.³¹

While 'empowerment' (like 'trust') is a remarkably elusive notion, it has gained prominence in healthcare as part of a move towards more accessible care, via more patient choice and autonomy, away from paternalistic medical models dominated by the views of healthcare

²⁸ Ibid.

²⁹ Misztal, op. cit. note 3; Voerman & Nickel, op. cit. note 8.

³⁰ Topol, *op. cit.* note 9, p. 285.

³¹ Sheppard, *op. cit.* note 1; Juengst, E., et al., *op. cit.* note 18; Schmietow & Marckmann, *op. cit.* note 11; Sharon, T. (2017). Self-tracking for health and the quantified self: Re-articulating autonomy, solidarity, and authenticity in an age of personalized healthcare. *Philosophy & Technology*, *30*(1), 93-121.

professionals.³² Developments in the domain of digital health applications, self-tracking devices, and information technologies like AI tools, fit this picture of a more preventive, participatory and affordable healthcare model in which empowered patients are in charge to see 'their own data on their own devices'.³³

It has been documented that this technology-induced move toward patient empowerment involves a "shifting of trust" in which the process of providing digital technologies directly to healthcare users empowers them to "challenge expert knowledge" and "act for themselves".³⁴ Rose has synthesized this 'empowered consumer' trope as one in which individuals reject paternalism, lose trust in physicians, and feel entitled to make their own decisions about health care.³⁵ Similarly, Schmietow and Marckman have

³² Topol, *op. cit.* note 9; Lemire, M. (2010). What can be expected of information and communication technologies in terms of patient empowerment in health? *Journal of Health Organization and Management, 24*(2), 167-181; Schulz, P. J., & Nakamoto, K. (2013). Patient behavior and the benefits of artificial intelligence: the perils of "dangerous" literacy and illusory patient empowerment. *Patient Education and Counseling, 92*(2), 223-228; Risling, T., Martinez, J., Young, J., & Thorp-Froslie, N. (2017). Evaluating patient empowerment in association with eHealth technology: Scoping review. *Journal of Medical Internet Research, 19*(9), e329.

³³ Sheppard, *op. cit.* note 1; Topol, *op. cit.* note 9; Schmietow & Marckmann, *op. cit.* note 11; Sharon, *op. cit.* note 31; Schulz & Nakamoto, *op. cit.* note 32.

³⁴ Fiore-Gartland, B., & Neff, G. (2016). Disruption and the political economy of biosensor data. In: D. Nafus, *Quantified* (pp. 101-22). Cambridge: MIT Press.

³⁵ Rose, N. (2013). Personalized medicine: Promises, problems and perils of a new paradigm for healthcare. *Procedia*, 77, 341-52.

recently noted that "[e]mpowerment serves as a contrasting foil for medical paternalism and as such has been discussed and shaped in the field of health for some time".³⁶

In this context, the 'empowerment label' is often used as a positive argument in itself, without much conceptual effort to clarify its precise meaning and moral importance. To the extent that empowerment is about enhancing a person's control over determinants that can reasonably be expected to increase one's quality of life, appeals to empowerment may indeed signal a positive moral value.³⁷ At the same time, the focus on empowerment can also be seen as part of a larger evolution from "we medicine" to "me medicine", which also has negative moral implications in terms of a waning attention to the common good in healthcare.³⁸

That said, the emphasis on empowerment in the current medical discourse is complex, as it does not only encompass the supposed need for patients to become less dependent on their doctors, but also an expectation to

³⁶ Schmietow & Marckmann, op. cit. note 11, p. 627.

³⁷ This interpretation is inspired by Tengland's definition of 'empowerment': Tengland, P. A. (2008). Empowerment: a conceptual discussion. *Health Care Analysis*, *16*(2), 77-96.

³⁸ Dickenson, D. (2013). *Me medicine vs. we medicine*. New York: Columbia University Press; van Beers, B., Sterckx, S., & Dickenson, D. (2018). *Personalised medicine, individual choice and the common good*. Cambridge: Cambridge University Press.

be proactive in pursuing what is allegedly good for them and for society.³⁹ It may be added that the involvement of various stakeholders in this complex network - including governments and corporate actors with economic interests – may be a reason to be critical about the motivations with which these parties promote the adoption of these technologies. On a skeptical reading, one might wonder whether this rhetoric should then be read as an argumentative framework with which these stakeholders promote the adoption of these technologies in function of their own interests (and whether this is morally problematic). In the light of this skeptical view, the moral question about whether these developments will indeed yield the positive moral value associated with the notion of empowerment, becomes all the more important.⁴⁰ We cannot take an absolute stance on that matter, but we acknowledge that ethical analysis should be sensitive to concerns about potentially (self-)disciplinary and compulsory effects of these developments, and to the way in which they may distract from broader socio-cultural determinants of health and wellbeing.⁴¹

While empowerment is pictured as a form of liberation which will promote wellbeing, this should not obscure that the promised independence from health professionals comes with a shift towards increased dependence on data-driven technology (we will return to that later). That much of the

³⁹ Prainsack, B. (2017). *Personalized medicine. Empowered patients in the 21st century*. New York: New York University Press.

⁴⁰ Sharon, *op. cit.* note 31.

⁴¹ Sharon, *op. cit.* note 31, pp. 98-99; Prainsack, *op. cit.* note 39, pp. 79-82; Prainsack,

B. (2014). The powers of participatory medicine. PLOS Biology, 12(4), e1001837.

current debates about these disruption and empowerment oriented innovations are now held in terms of 'trust' may be remarkable, considering the medical model for which these innovations are expected to offer counterweight. After all, "the central place of trust" in traditional medical relationships has been "seriously doubted or attacked" by the anti-paternalist movement.⁴² The idea, then, that in the specific context of medical AI applications, for instance, patients should "be able to trust AI in a similar way to healthcare professionals", might seem surprising.⁴³ If in traditional relationships between doctors and patients trust was found to be problematic due to the asymmetry between these two parties, then why would such a trusting attitude not be an issue – and even be desirable – in healthcare users' interaction with technological platforms which are precisely meant to bring empowerment?

WELL PLACED TRUST: UNDERSTANDING, CHOOSING AND THE ROLE OF PHYSICIAN INPUT

The disapproval of the asymmetrical trust in traditional doctor-patient relationships mostly comes from a concern about so-called 'blind' patient trust.⁴⁴ Yet, trust and empowerment need not be antithetical. This can first be considered from a patient perspective: from the side of the trustor/the patients, the act of trust has been linked to a moral obligation "to take charge of their

⁴² Pellegrino & Thomasma, op. cit. note 1, p. 65.

⁴³ Lee, *op. cit.* note 8, p. 2.

⁴⁴ O'Neill, op. cit. note 1; Myskja & Steinsbekk, op. cit. note 8.

own situation, actively seeking and evaluating information and making decisions on this basis".⁴⁵ In Myskja and Steinsbekk's words, this "represents a turn from 'lazy' to active trust," where patient autonomy and empowerment implies a duty to take part in deliberation and decision-making.⁴⁶ Second, from the perspective of the medical authority in which trust is placed (the trustee), it may likewise be argued that trust and empowerment need not be opposites, especially if trust is indeed understood as a genuine moral relationship that obliges the trustee to incorporate the trustor's expectations and values in making treatment decisions. Illustrative of this, is Pellegrino and Thomasma's formulation of a physician's duty to convey health information so that it "empower[s]" patients to make their own choice, based on the most reliable facts and – importantly – placed into the full context of the patient's "own hierarchy of values."⁴⁷ As this also holds for professional responsibilities in the context of traditional patient-doctor relationships, it may therefore seem questionable to frame emerging 'disruptive' medical

⁴⁵ Ibid.

⁴⁶ Myskja & Steinsbekk, op. cit. note 8, p. 582.

⁴⁷ Pellegrino & Thomasma, *op. cit.* note 1, p. 74. This also ties in with the deliberative model of shared decision making put forward by Emanuel and Emanuel and – more specifically – the 'shared rational deliberative joint decision model' put forward by Sandman and Munthe. Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *Jama, 267*(16), 2221-2226; Sandman, L., & Munthe, C. (2010). Shared decision making, paternalism and patient choice. *Health Care Analysis, 18*(1), 60-84.

innovations as a means of emancipation from a paternalistic doctor-patient relationship.

In that sense, it is not trust as such that is the issue, but trust that is presumedly not well placed. O'Neill – who, to be clear, emphasized the ethical importance of trust – documents that critics of traditional doctor-patient relationships defended the view that "only trust that is well placed is given by those who understand what is proposed, and who are in a position to refuse or choose in the light of that understanding."⁴⁸

Considering these two criteria of well-placed trust (understanding, and being able to choose in view of that understanding), it is relevant to explore whether the current (technological) developments in healthcare are an improvement in that respect. In the context of mHealth technology, the ability to understand and apply personalized health information is indeed considered a benchmark of patient empowerment.⁴⁹ Current technological developments feed into the belief that greater information transparency is possible, so that individuals will increase participation in their health and become more empowered healthcare users.⁵⁰ Yet, having access to health information is not synonymous with understanding this information in a way that also improves health-related choices.⁵¹ Thus, if personalized health information has to be

⁴⁸ O'Neill, *op. cit.* note 1, p. 18.

⁴⁹ Schmietow & Marckmann, op. cit. note 11.

⁵⁰ Vezyridis, P., & Timmons, S. (2015). On the adoption of personal health records: some problematic issues for patient empowerment. *Ethics and Information Technology*, *17*(2), 113-124.

⁵¹ Ibid.

understood for trust to be well-placed, it is at least relevant that in the context of participatory medicine this understanding can be complicated by the quantity of the data and the difficulty to interpret it.⁵²

A possible solution is to keep physicians in the loop of medical supervision. In that way, healthcare professionals can funnel health information to make it better understandable and help healthcare users make respective choices.⁵³ Yet, two considerations need attention here.

The first one is mainly practical and is largely an effect of technological particularities. To the extent that the technologies under consideration are algorithm-based, the infamous 'black box problem' may be a complicating factor. That is, deep learning in AI may entail the inability to explain how an algorithm reaches a recommendation or diagnosis. This is an often cited obstacle for both physicians and patients to trust these systems.⁵⁴ As Watson and colleagues have pointed out: "[i]f doctors do not understand

⁵² Juengst, E., et al., *op. cit.* note 18; Townsend, A., Leese, J., Adam, P., McDonald, M., Li, L. C., Kerr, S., & Backman, C. L. (2015). eHealth, participatory medicine, and ethical care: A focus group study of patients' and health care providers' use of health-related internet information. *Journal of Medical Internet Research*, *17*(6), e155.

⁵³ Juengst, E., et al., *op. cit.* note 18; Townsend, *op. cit.* note 49; Fiske, A., Buyx, A.,
& Prainsack, B. (2020). The double-edged sword of digital self-care: Physician perspectives from Northern Germany. *Social Science & Medicine*, *260*, 113174.

⁵⁴ Durán & Jongsma, *op. cit.* note 10; Watson, D. S., Krutzinna, J., Bruce, I. N., Griffiths, C. E., McInnes, I. B., Barnes, M. R., & Floridi, L. (2019). Clinical applications of machine learning algorithms: beyond the black box. *BMJ*, *364*, 1886.

why the algorithm made a diagnosis, then why should patients trust the recommended course of treatment?"⁵⁵ In response to this, it may be countered that there is no moral duty on physicians to be able to fully explain the inner workings of the algorithm. The moral importance of physicians' involvement would much rather stem from the expectation that they possess the medical competence to evaluate whether the system's recommendation is reasonable (given a certain diagnosis), and – importantly – that they discuss this recommendation with the patient in view of the latter's personal values.⁵⁶ From the perspective of autonomy and empowerment, this may actually be more important than the ability to explain the algorithm itself. Moreover, as the 'end of medicine' encompasses more than doing what is technically appropriate, algorithm and mobile application based technology may be said to lack a caring dimension: while algorithm-driven technologies mainly (if not solely) analyze users' biomedical data, trust in a physician is (ideally) vindicated by the professional's prudent attitude, focused on the patient's interests, not only in terms of what medical knowledge dictates, but also in terms of interactive engagement with the patient's values and a basic attitude of respect.⁵⁷

The second consideration, then, targets the normative question about the scope of the so-called empowerment-oriented goal to 'take charge of one's own care' and the limits as to how far one can go 'doctorless'. On the one hand, one may find it ironic for an anti-paternalist, empowerment

⁵⁵ Watson, D. S., et al., *op. cit.* note 54, p. 3.

⁵⁶ Durán & Jongsma, *op. cit.* note 10.

⁵⁷ Pellegrino & Thomasma, *op. cit.* note 1.

oriented turn in healthcare to accept a return to some form of (mild) paternalistic interference, with still an influential role for physicians to channel health information and – mostly under the flag of nonmaleficence – censor uninterpretable or irrelevant information to patients.⁵⁸ On the other hand, minimizing the involvement of healthcare professionals in the decision process feeds worries about threatening patient autonomy and reintroducing paternalist arrangements by replacing the old 'doctor knows best' by a new – as McDougall has called it – "computer knows best" model.⁵⁹ This is especially so in the light of the above mentioned worry that the health information may be too much and too hard for patients to understand and possibly obstruct alternative choices if the recommended treatment contravenes the patient's own conception of wellbeing.⁶⁰ From that perspective, an "absolutization of autonomy,"⁶¹ originally in the name of patient empowerment, might in fact end up corroding patient empowerment. In other words, if empowerment-based ambitions to 'take charge of one's own care' are to be interpreted as attempts to maximally limit the residual need to

⁵⁸ Juengst, E., et al., *op. cit.* note 18.

⁵⁹ One may think, for instance, of suggestions to deliver tailored health interventions based on algorithms directly to a user's mobile device; see e.g. Topol, *op. cit.* note 9; Darcy, A. M., Louie, A. K., & Roberts, L. W. (2016). Machine learning and the profession of medicine. *Jama, 315*(6), 551-552. For McDougall's quote: McDougall, R. J. (2019). Computer knows best? The need for value-flexibility in medical AI. *Journal of Medical Ethics, 45*(3), 156-160.

⁶⁰ Durán & Jongsma, op. cit. note 10; McDougall, op. cit. note 59.

⁶¹ Pellegrino & Thomasma, *op. cit.* note 1, p. 72.

rely on the discretion of healthcare professionals, efforts to escape paternalism might backfire.

VOUCHING FOR TRUSTWORTHINESS IN COMPLEX MEDICAL NETWORKS

One might reason that going completely 'doctorless' would reinstall a situation in which patients put complete (asymmetrical) trust, not in the physician, but in some other technological source or medium. If, instead, the physician is not completely eliminated from the process of clinical decision-making, the arrival of these alleged empowering innovations may offer an additional source of medical advice, so that trust is no longer completely attributed to one given party. Diffusing trust in this way might indeed offer the patient more latitude in making health decisions based on relatively separate sources of medical advice, though this seems to be morally vacuous – if not unfavorable – when such a decision is not based on an evaluation of qualities that demonstrate that these sources of medical advice are in fact *worthy* of trust.⁶² In this section, we explore how the movement toward

⁶² An emphasis on trustworthiness may also derive from a focus on qualities that assumedly reduce the risks of abuse of trust (or, put in a positive way: qualities that may otherwise indicate that trust is well-placed). Medical needs ultimately have to be translated into action, which in most cases requires the aid of skilled professionals. From this it could be reasoned that trust in the person performing the medical procedure is inescapable, so that a blanket rejection of trust would be pointless. Thus, rather than condemning trust per se, it may be held that it is the risk of abuse of trust that is problematic.

patient empowerment through technology may push the need for trust into a domain where such trustworthiness, however, is more difficult to evaluate and improve.

The current discussions about how innovative technologies in healthcare will be able to generate trust among healthcare users can be read in terms of the qualities of the trustee, in the sense that a focus on trust as an attitude should leave room for a focus on trustworthiness as a property. If, for instance, it is stated that healthcare users must be able to trust in the safety and security of these new technologies, then this may be interpreted as a challenge for these technologies to demonstrate that they are worthy of trust.⁶³ On this reading, emphasis is put on the qualities that demonstrate trustworthiness and which determine whether one can trust the other, so that trust is well-grounded only if the one trusted is in fact trustworthy.⁶⁴

It is sometimes held that the autonomy turn in medicine has brought an increased focus on the importance of trustworthiness.⁶⁵ While this may be true, it is interesting to add that according to Pellegrino and Thomasma the anti-paternalist argument against trust is defective because it wrongfully targeted a "gratuitous concept of global trust."⁶⁶ That is, also in a traditional medical context, patient trust is grounded in attributes that may vouch for trustworthiness, like the professional's expertise, their access to accurate

⁶³ Sheppard, *op. cit.* note 1; Myskja & Steinsbekk, *op. cit.* note 8.

⁶⁴ McLeod, C. (2020). Trust. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy*.

⁶⁵ O'Neill; *op. cit.* note 1; Myskja & Steinsbekk, *op. cit.* note 8.

⁶⁶ Pellegrino & Thomasma, op. cit. note 1, p. 74.

information, and the moral obligation to see the good of the patient as the end of that relationship. More generally, from a broader philosophical perspective, there is relative consensus that competence and willingness to do what one is trusted to do are conditions for trustworthiness.⁶⁷

That said, growing skepticism about trust in physicians has nonetheless stimulated a search for additional ways to secure that medical professionals to whom trust is accorded are also worthy of that trust. One may think of how traditional relationships of trust have increasingly been supplemented with (some would say: 'supplanted by') more formal procedures for securing trustworthiness, like accreditation, professional certification and legal structures. While such factors may not conclusively assure trustworthiness, they might still provide some evidence that medical professionals are worthy of trust.⁶⁸ From the perspective of non-maleficence, installing such safeguards to protect healthcare users from ill-placed trust, and thus potentially from harm, may indeed be morally advantageous. It are such considerations that play out in current approaches to secure trustworthiness of e.g. mHealth, with a professed need to hand out accreditation to unbiased entities.⁶⁹ As noted above, direct understanding – let alone skilled evaluation

⁶⁷ McLeod, *op. cit.* note 64.

⁶⁸ Ozar, A. C. (2014). The plausibility of client trust of professionals. *Business & Professional Ethics Journal*, *33*(1), 83-98.

⁶⁹ Sheppard, *op. cit.* note 1; Quinn, T. P., Senadeera, M., Jacobs, S., Coghlan, S., & Le, V. (2020). Trust and medical AI: the challenges we face and the expertise needed to overcome them. *Journal of the American Medical Informatics Association*, *28*(4), 890-894; van Haasteren, A., Gille, F., Fadda, M., & Vayena, E. (2019). Development

– of health data and critical assessment of its distributors may not be a feasible expectation for non-experts, so that such justifications for trust will indeed have to be sought elsewhere. Input by experts and regulators will be crucial to help users find sources of medical information that has been assessed to be clinically safe, secure to use and evaluated in terms of who gets access to the data.

Skeptics, however, eagerly emphasize that such a formalization of relations to secure trustworthiness merely displaces the issue: with such arrangements, the locus of trust is located elsewhere, i.e. from the physician or medical technology to the experts or watchkeepers who are charged to police them. This may lead to "a regress of mistrust" in which the auditors are in turn subjected to audit.⁷⁰ This is also echoed in Holland et al., who state that increased regulation may be ineffectual since public mistrust of institutions that manage health information is simply "redirected towards institutions responsible for implementing and monitoring the proposed regulatory innovations."⁷¹ Pellegrino and Thomasma rather consider this an illustration of the empirical ineradicability of trust.⁷²

The question then remains whether the point at which trust is eventually placed is 'better-grounded', or based on more trustworthy qualities, so as to avoid that the striving for medical empowerment falls prey

of the mHealth App Trustworthiness checklist. *Digital Health*, *5*, 2055207619886463.

⁷⁰ O'Neill; *op. cit.* note 1, p. 133.

⁷¹ Holland, S., et al., *op. cit.* note 13, p. 3.

⁷² Pellegrino & Thomasma, *op. cit.* note 1, p. 65.

to its own criticism of trust. When we rely on institutions and larger networks of unknown individuals to provide services on which we depend, there seems to be an assumed trust in the "reliable good order" and safety of a mode of organization.⁷³ Yet, to be trustworthy, such assumed trust will have to be vouched for too. Even if one presumes that so-called trusted intermediaries are in place, one should still ask what precisely makes the intermediary trustworthy.⁷⁴ It is desirable that this happens on the basis of rational epistemic and evidential grounds, though it should also be noted that past evidence based on earlier behavior of the trustee does not eliminate the risk of future deviance.⁷⁵

In that respect, it may further be added that when health contexts become socially and technologically more complex, at least as much focus on

⁷⁵ In fact, trust may affect the evidence one eventually accepts as decisive. Trusting is not an entirely rational process, but may rather be based on 'second-hand trust' stemming from factors such as authority, brand familiarity, or reputation of certain sources. This is true for both traditional medical contexts and for changing contexts under the influence of innovative technology. For further discussion, see Gambetta, D. (1988). Can we trust trust. In D. Gambetta (Ed.), *Making and breaking cooperative relations* (pp. 213-237). Basil Blackwell Ltd: Oxford and van Haasteren, A., *op. cit.* note 65; Dwyer, N., & Marsh, S. (2016). To trust or distrust: Has a digital environment empowered users to proceed on their own terms? In W. Reif, G. Anders, H. Seebach, S. Jan-Philipp, E. André, J. Hähner, C. Müller-Schloer, & T. Ungerer (Eds.), *Trustworthy open self-organising systems* (pp. 231-244). Basel: Birkhäuser Basel.

⁷³ Walker, *op. cit.* note 12, p. 84.

⁷⁴ Woolley, *op. cit.* note 14, pp. 124.

oversight structures will be needed as in traditional contexts. While in such complex situations one may still look for particular parties to bear responsibility, this will be more complicated in complex networks. Diffusing trust may make healthcare users less dependent on one particular authority, but growing complexity of networks made up of (possibly indistinct) health institutions, may make it harder to rationally evaluate their trustworthiness. With each node that is added to check for trustworthiness, complexity increases. As an effect there may be a cumulating difficulty to gather information about the parties that make up complex networks, so that for individual patients or their physicians it will become harder to grasp and evaluate the involvement of these additional sources. It has been noted, for instance, that mHealth users have a restricted view over who has access to the health data that are made available to third parties through the use of these apps. On a practical level, then, such usage may lead to a paradox, since "users turn to mHealth to increase self-empowerment, but at the same time surrender power due to this lack of data control".⁷⁶

It may be countered, however, that physicians, even independently of algorithm-based tools, already typically operate technologies for which they have to rely on other actors' role in a broader, complex mode of organization

⁷⁶ van Kolfschooten, H. (2021). The mHealth power paradox: Improving data protection in health apps through self-regulation in the European Union. In G. Cohen, T. Minssen, W. N. Price, C. Robertson, & C. Shachar. *The future of medical device regulation: Innovation and protection* (pp. 63-76). Cambridge: Cambridge University Press.

(technicians, engineers, etc.).⁷⁷ There is no a priori reason to assume that the introduction of algorithm-based systems will fundamentally undermine this, even though increased complexity may, as said, be a reason to proceed with care. For one thing, to prove themselves worthy of patients' trust, physicians (to the extent that they stay in the loop) should use the new technologies in line with their patients' values and expectations.⁷⁸ A possible suggestion to generate and secure trust in such a context is to coordinate medical professionals' input and computer-based recommendations in a parallel manner, in order to calibrate algorithmic suggestions and healthcare workers' insights along with patients' expectations and preferences. A remaining challenge will be to find a balance between securing supervision and avoiding too much complexity due to a (possibly recursive) search for 'sufficiently' trustworthy qualities.

CONCLUSION

Trust plays an ambiguous role in healthcare and we have tried to show that current empowerment oriented innovations complicate this role even more. While in traditional patient-doctor relationships trust of patients in healthcare

⁷⁷ Durán & Jongsma, *op. cit.* note 10, p. 5.

⁷⁸ We will not elaborate on this matter here, since a recent contribution by Debrabander & Mertes discusses in more detail the moral and conceptual issue of value-congruence and patients' preferences in the context of algorithm-based medical technology used by physicians. Debrabander, J., & Mertes, H. (2021). Watson, autonomy and value flexibility: revisiting the debate. *Journal of Medical Ethics*. doi: 10.1136/medethics-2021-107513

professionals has been criticized as a problematic exponent of a paternalistic relationship, patients' trust in the said innovative technologies is nonetheless reintroduced as a crucial step to move away from precisely such paternalistic doctor-patient relationships. We have tried to spell out this observation and have problematized its implications for medical ethics. This problematization bends on the deliberation that the empowerment oriented criticism of trust may fall prey to its own critique.

Although a minimization of doctor involvement may seem alluring to avoid medical paternalism, this may - also from an empowerment perspective - be less desirable than keeping a doctor in the loop of medical decision making, especially in view of the moral importance of understanding health information and of personal valuation of medical options. Such a minimization might install a new form of paternalism, where healthcare users put complete and asymmetrical trust in a given technological medium, and where communicated health information and medical options may be hard to oversee. It is important to avoid that innovations in function of patient empowerment eventually culminate in compromised empowerment.

Diffusing trust among different sources of health information may instead avoid complete dependence on one source of medical information (whether it is the physician or a given innovative medical technology). Diffusing trust is not empowering if there is no reason to assume trustworthiness. The autonomy turn puts a strong emphasis on evidence of qualities that vouch for trustworthiness. Yet, to avoid vulnerability to attacks inspired by its own criticism of trust, the endorsement of empowerment oriented medical innovations will have to be concomitant with an account that demonstrates better grounds which vouch for trustworthiness when compared to traditional doctor-patient relationships. It remains an open question whether trust in said 'empowering' technologies will be based on more trustworthy qualities or not. However, to the extent that individual healthcare users are dependent on experts, agencies and regulators to assess such trustworthiness, the matter of trust may not disappear, but rather move to another locus.

With these considerations we have tried to give a start to an ethical reflection of why the appeal to trust in function of patient empowerment may not steer clear of the criticism directed at trust in traditional doctor-patient relationships.