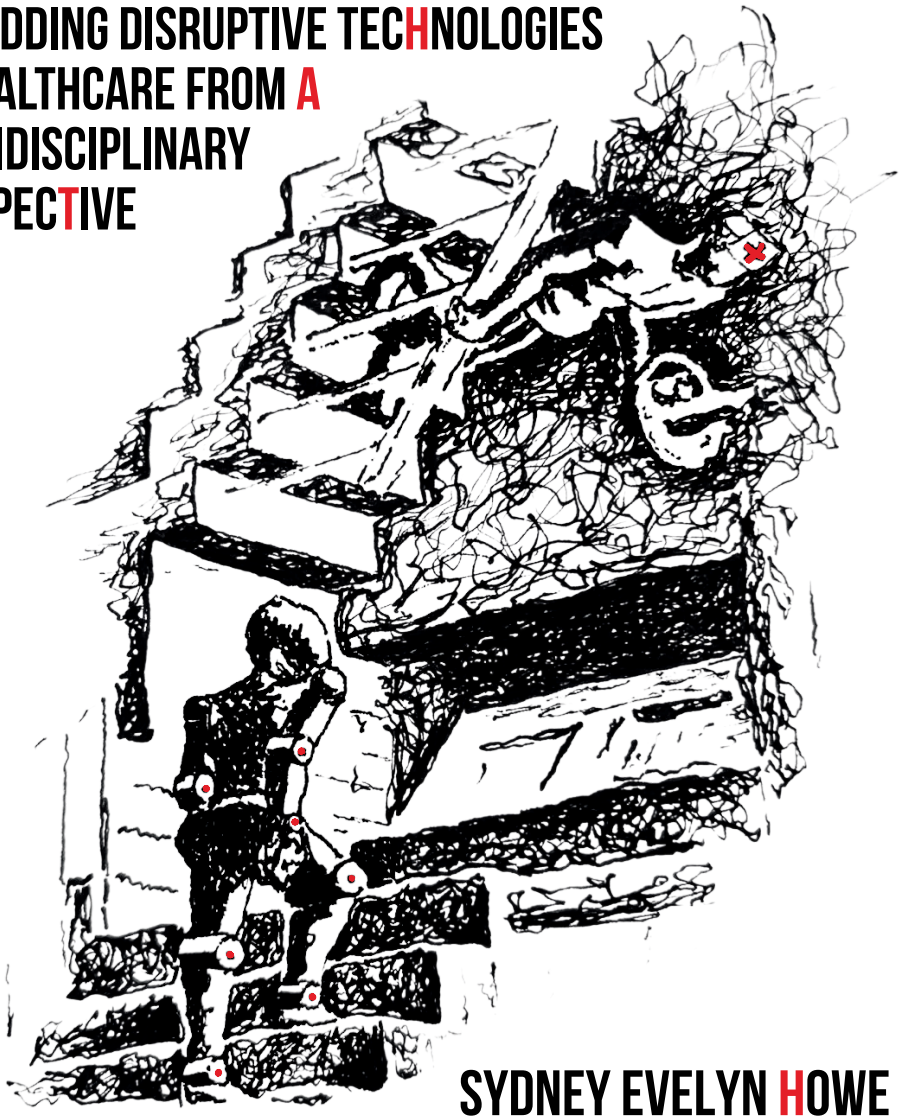
# TAKING CARE (FOR GRANTED)

## EMBEDDING DISRUPTIVE TECHNOLOGIES IN HEALTHCARE FROM A MULTIDISCIPLINARY PERSPECTIVE



SYDNEY EVELYN HOWE

# TAKING CARE (FOR GRANTED):

## EMBEDDING DISRUPTIVE TECHNOLOGIES IN HEALTHCARE FROM A MULTIDISCIPLINARY PERSPECTIVE

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Taking Care (for Granted)
Embedding Disruptive Technologies in Healthcare from a Multidisciplinary Perspective

Zorgen (voor lief nemen)
De integratie van disruptieve technologie in de gezondheidszorg vanuit multidisciplinair perspectief

Thesis

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by

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Erasmus University Rotterdam

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# INTRODUCTION

In M.C. Escher's 1953 lithograph, "Relativity," part of the artist's impossible architecture oeuvre, human figures climb staircases and go about their business in seemingly-separate dimensions, all visible within the same frame. A staircase going up for one figure forms the ceiling for another; one figure opens a door on a wall that for another forms the floor. As viewers of the lithograph, we are the only ones who seem to find anything strange about this reality; the figures themselves are undisturbed even when passing each other at different orientations on the same staircase. The moments of transition between these realities are so smooth we feel maybe we have seen it wrong and it is our eyes that are causing the strangeness, not the image. Only upon examining those places where lines form both staircase and ceiling does it become possible to fully grasp the strangeness of what we are seeing. We are momentarily suspended between two realities on an ambiguous boundary that transforms as we shift our gaze from one side of the transition to the other.

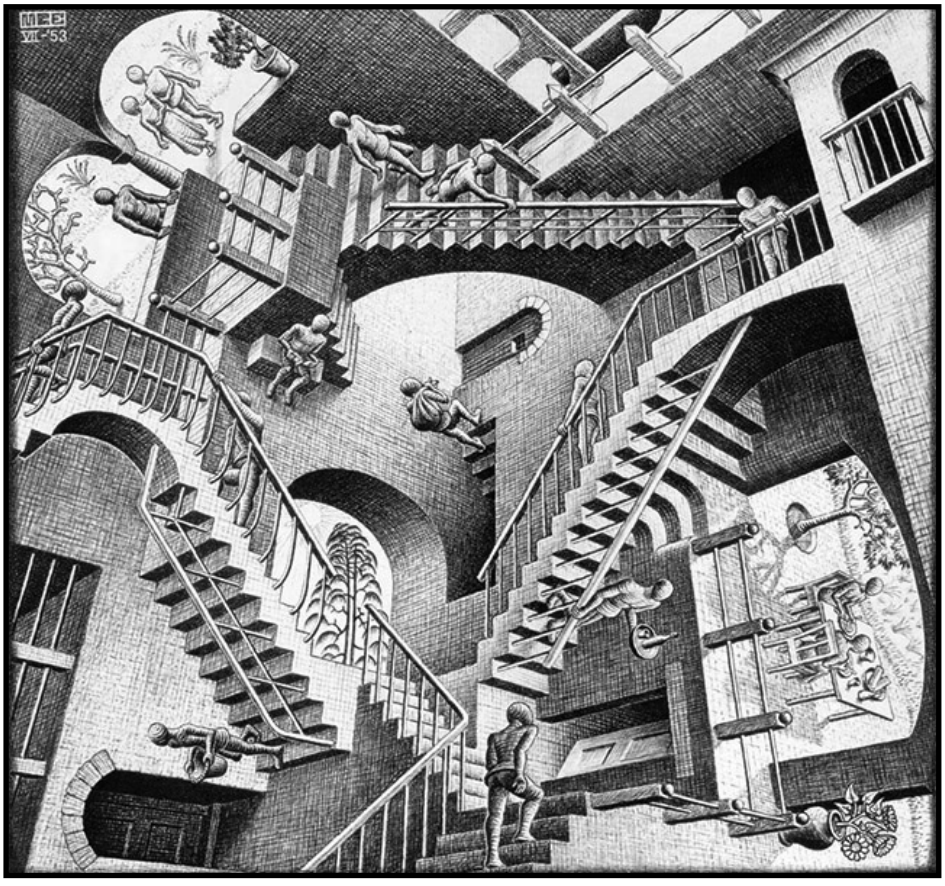


**Figure 1** "Relativity" by M.C. Escher, 1953

These ambiguous boundaries allow us to look behind the curtain of our own taken-for-granted perspective. We assume that our interpretations of the lithograph from our first glance will hold. When our assumption is proven false, we look for the mistake. It is only by accepting all perspectives in full that can we see that there is no mistake: we simply made the assumption that a drawing must be entirely understandable from a single perspective.

Ambiguous boundaries bother us for good reason: encountering one forces us to question the validity of our own perspective. Beyond lithographs depicting impossible architecture, these kinds of ambiguous boundaries can be produced by introducing disruptive technologies into long-established systems. When technologies are not yet taken for granted, we find ourselves in a liminal space between old ways of working and the beginnings of a possible future. This period of change and ambivalence is uncomfortable because we must grapple with technological transgressions of established symbolic, normative, and cognitive categories (Smits, 2006). Strong reactions to such 'monstrous' technologies (ibid.) are common but ambivalent: such technologies can provoke both fear and deep reverence in different audiences. Generative artificial intelligence (AI), for instance, blurs boundaries between human and machine and transcends previously taken-for-granted trade-offs between originality and economy (Fox, 2016) by producing work that appears to be both human and creative more efficiently than a human could create such work. This ambivalence extends to human perceptions of AI that position it as both an "existential threat" to humanity (Fox, 2016; Galanos, 2018) and a panacea for societal problems (Bleeker, 2024; Cadario et al., 2021; Fox, 2016) impeded primarily by the public's (unjustified) skepticism (Buch et al., 2018).

As a technology is domesticated (Smits, 2006), it can move away from this monster/miracle dichotomy and towards taken-for-grantedness. However, the process of assimilating 'monstrous' technologies necessitates reconciling or reworking deeply-held pre-existing assumptions (Smits, 2006). For instance, cultural categories defining what makes us human may need to be reconstructed, but cultural context can impact how easily these categories can be transmuted to include a new technology. In France, cultural values around food service make the idea of a robot feeding nursing home residents problematic (Satariano et al., 2018); however, in Japan, cultural values around shame and politeness (Parks, 2020), combined with beliefs about inanimate objects containing spirit (Jensen & Blok, 2013) seem to have facilitated the introduction of robots in everyday life as servers at restaurants.

Until assimilation, however, people seek ways to make this liminality and ambiguity more manageable. In attempt to ease discomfort, we are often drawn into overly-simplistic binary debates about whether a technology is a threat or a godsend, natural/unnatural, or an agent of utopia/dystopia. Will the use of big data in healthcare solve all our problems or threaten good medical care...or is something in-between possible (Stevens et al., 2018)? Is bioidentical hormone treatment more natural than previous versions of hormone replacement therapy, and therefore an acceptable treatment for menopause symptoms (Fishman et al., 2015)? Is the staircase facing

up or down? Instead, it would be more pragmatic to focus on anticipating and grappling with the cultural categories drawn into question by new technologies (Gjodsbol et al., 2024), rather than attempting to resist the tide of innovation or force technologies to fit into existing categories (Smits, 2006). In this thesis, I examine the ambiguities between technologies and the normative and cultural categories they disrupt, and how we, as humans, manage these ambiguities, in order to better understanding how disruptive technologies become embedded (or not) in healthcare.

## EMBEDDING TECHNOLOGIES IN HEALTHCARE

This book explores how technologies become embedded[1] in healthcare and the ambivalent impacts of new technologies on healthcare systems. Pressure on healthcare systems worldwide is increasing due to aging populations and rising costs (Amann et al., 2020; Angelis et al., 2017; Greenhalgh et al., 2018; Maguire & Murphy, 2022; Yang et al., 2022). Sustainable healthcare from a financial and staffing perspective is an especially hot topic in the Netherlands (Werner et al., 2021). As in many countries in the global north, the proportion of ageing adults in the Netherlands is increasing quickly in relation to younger people and people are living longer, but spending more years living with chronic disease (Poos, 2024). Healthcare expenditure for this demographic, especially in the last year of life, is also increasing rapidly (Werner et al., 2021). The WHO estimates that by 2030, OECD countries could experience a deficit of more than 4 million healthcare workers, despite extensive growth in the healthcare sector (*WHO Health Workforce, 2016*). Solutions for improving qualified personnel retention have become a focal point for studies of shortages in the Netherlands (de Vries et al., 2023; Van Merode et al., 2024). Healthcare spending topped €100 billion in 2019 and has been increasing for decades, outpacing economic growth (Werner et al., 2021). At the same time, the societal sustainability of the current solidarity system may be waning due to concerns about rising costs and access for future generations (Werner et al., 2021).

In recent years, the development of disruptive[2] technologies for healthcare has taken off vigorously (Andreassen et al., 2018; Angehrn et al., 2020) define a disruptive technology as one that that

1 For the purposes of this book, I use the term "embedding" to describe the entire process of a technology becoming accepted, adopted, implemented (by institutions), used (by end users), integrated (into everyday practice), and entrenched (taken-for-granted as standard of care) in the healthcare system. This is a pragmatic decision, as the other option would have been inventing a difficult-to-pronounce acronym like AAIUIE. Portions of this process are described using one of the other words listed above.

2 While the term "disruptive technology" has become something of a corporate cliché at the level of "synergy" or "thinking outside the box" (please see the cult classic "Office Space" for a complete compendium), I still find this to be a useful category for describing my focus for this book. Because so much of our lives could be considered "technology" (for instance, a pencil might fall in this category just as easily as a smartphone) it is important to be clear that the health technologies I explore in this study are more similar to MRI machines than bed pans (not that there is anything wrong with studying bed pans. Bed pans are essential, they just are not the topic of this study). In the interest of further excluding bed pans, I clarify that this book explores technologies that are currently in the process of disrupting, because I'm sure bed pans were very disruptive whenever someone first realized they would improve life significantly for both the bedridden and their caregivers.

"changes the performance metrics, or consumer expectations, of a market by providing radically new functionality, discontinuous technical standards, or new forms of ownership"(Nagy et al., 2016) p.122), thereby changing the bases of competition for firms (Danneels, 2004), and upsetting the equilibrium of the existing institutions (Christensen, 2011), processes, and technologies. Disruption is also not binary: a technology can be more or less disruptive. The degree of disruption depends on a variety of factors including context, hype (Strange, 2024), social forces (De Wilde, 2000), and practical use, in addition to technical capacity. By using this extended definition, I hope to cover many aspects of disruption without focusing only on implications of disruptive technologies for corporations.

Over the past decade, new technologies ranging from surgery robots (Pugin et al., 2011), to remote cardiovascular monitoring technologies (Stewart et al., 2024), to decision assistance systems powered by AI have been developed for and/or introduced into daily practice within healthcare systems. These technologies promise to complete particular technological tasks, and often are quite successful in doing so. The assumption, often made explicit, is that these technological capabilities will improve effectiveness of health care (Boverhof, Redekop, Bos, et al., 2024), increase efficiency (Greenhalgh et al., 2018), reduce work burden for healthcare staff (Stewart et al., 2024), improve the safety of care (Khanna et al., 2022), provide a cost-effective alternative to standard care practices (Cadario et al., 2021; Khanna et al., 2022), increase access to care (Vervoort et al., 2022) by allowing healthcare staff to care for more patients (Cadario et al., 2021), and streamline care practices across hospital systems (Yang et al., 2022). Disruptive health technologies, such as applications using some form of AI, are often viewed as solutions to maintain acceptable levels of care and improve health outcomes in the face of this pressure for many countries, explicitly so in the Netherlands. In August 2024, Dutch Health Minister Fleur Agema told the Telegraaf, "AI is like a Swiss army knife in healthcare," continuing, "I will do everything I can to make this revolution happen as soon as possible"(Bleeker, 2024).

Based on the break-neck pace of technological developments and integration, and the certitude, inevitability, and gravity of language (such as words like "revolution") used around technology in healthcare, it can seem that disruptive technologies are the obvious solution to many problems in the healthcare system. A report on the sustainability of Dutch healthcare from a financial, staffing, and societal perspective from the Netherlands Scientific Council for Government Policy (WRR) challenges this line of thinking: "Offsetting this optimism, however, are analyses identifying technology as one of the main drivers of rising spending in the [healthcare] sector"(Werner et al., 2021, p.31). There are several reasons why this may be the case. Firstly, new technologies are usually more expensive than old technologies, especially in the short term. Second, new technologies rarely replace care but rather complement care or provide new forms of care. This may be because new technologies create new uncertainties which can complicate key processes, generating epistemic uncertainty. Therefore, providers often return to the original way of working, rather than fully integrating new technologies or processes (Carboni et al., 2023; Sheard et al., 2017). Finally, many

new technologies improve effectiveness and access to care, potentially making it possible to treat patients who are otherwise untreatable, thereby addressing previously unmet need, but adding to care volume (Vervoort et al., 2022; Werner et al., 2021). In the Netherlands, health technology assessment (HTA) is used to explore the effectiveness and cost-effectiveness of these interventions; however, HTA practices and timelines were designed with pharmaceuticals developed by large corporations in mind, not medical technologies created by smaller companies (Boverhof, Redekop, Visser, et al., 2024; Farah et al., 2023; Kroneman et al., 2016; Michels et al., 2024). Despite providing substantial gains for health and healthcare, it does not appear that new technologies are improving the financial stability of the system, and that they are likely, at least in some respects, exacerbating issues associated with healthcare system sustainability (Pammolli et al., 2012; Polder, 2018; Werner et al., 2021). So why are disruptive healthcare technologies still primarily viewed, developed, and implemented as drivers of efficiency and cost-effectiveness?

## NARRATIVES AND PRACTICES OF HEALTHCARE TECHNOLOGIES

As a form of disruptive technology, artificial intelligence (AI)-driven technologies in particular are often viewed (and marketed) as solutions to problems related to both work burden for healthcare staff and access to adequate care for patients (Suchman, 2023). Here, I discuss the narratives and marketing tactics involved in these views. I explicitly explore "narratives" in addition to "claims[3]:" narratives, to borrow the definition from Greenhalgh & Hurwitz (1999) move beyond claims. Unlike claims, narratives have a beginning, middle, and (implied) conclusion and presume that narrators and audiences have different points of view. Additionally, narratives are concerned with what happens to people, even if the narrative is about, for instance, a very expensive cardiac monitoring wearable powered by AI. Importantly, narratives can also change depending on the audience: a narrative that clarifies the world for one audience might make another feel the world has been turned upside down. Finally, a good narrative adheres to the classic "show, don't tell" rule; it is absorbing for the audience and invites interpretation (Greenhalgh & Hurwitz, 1999).

Narratives of disruptive technologies in healthcare are complex: often it is difficult to distinguish between demand that originates with healthcare providers, such as hospitals, and demand "designed" by health technology developers; it is not always clear what is marketing and what is the culture priming a particular perspective of technology. Furthermore, the same story can be told in different ways using different discourses (Stevens et al., 2018). These discourses may lead to different conclusions about how technologies can or should be used (for instance, as a way to save money or improve quality of care). Narratives both frame (Wehrens et al., 2021) and expand upon the role of technology in healthcare: for instance, a technology in development may not yet

3 A claim is much simpler than a narrative in that it is "an assertion open to challenge." (Merriam-Webster. (n.d.). Claim. In Merriam-Webster.com dictionary. Retrieved January 24, 2025, from https://www.merriam-webster.com/dictionary/claim)

have been shown to be effective, but a narrative that emphasizes its possibilities can shape whether and how it is explored in clinical trials or implemented in the real world, and even what we can or should expect from it at an ethical level (Wehrens et al., 2021). In this way, narratives can help structure our thinking (Jasanoff & Kim, 2009) at the same time that our thinking structures narratives (Jasanoff & Kim, 2013), producing sociotechnical imaginaries[4] that both guide and are guided by the development of technology. As narratives become embedded in our worlds, they can also shape those worlds in concrete ways, "hardening categories" of objects that may not be discernible without our tools of measurement (Verran, 2010): consider, for instance, how sleep quality is changed from an experience into a number by the measurements of a smart watch. Like the impossible architecture of an infinite staircase, social practices thus simultaneously shape and are shaped by innovation. In other words, techno-solutionist narratives (Morozov, 2013) encourage us to expect a great deal from technological developments. Those expectations inform the futures we can imagine (Selin, 2007), which is why they should be carefully and critically assessed.

In our current environment, techno-solutionist narratives of the future of healthcare prevail: the healthcare system will be more resilient and/or help more patients and/or produce faster results and/or provide higher-quality care as long as technology X is implemented with great speed[5]. Importantly, the power of techno-solutionist narratives in defining how we consider health technologies is not usually a result of company overreach. For obvious legal reasons, companies are usually quite specific and conservative about what their technology can do on a technical level and rarely make wild or fantastical claims directly[6]; techno-solutionist narratives only begin to run away with the cart in the process of extrapolating the implications of a new technology for healthcare practice. This extrapolation is clearly encouraged by technology developers for financial reasons (you need a buyer for your product to keep the lights on). However, it is also produced by other healthcare stakeholders' practices, healthcare and technological infrastructures, and narratives that exist both within the healthcare system and society at large. Put differently, technological 'solutions' are currently introduced within a culture and context that enthusiastically and often uncritically supports technical, quantitative solutions to social problems. Idealized narratives of

4 Sociotechnical imaginaries are "collectively imagined forms of social life and social order reflected in the design and fulfillment of nation-specific scientific and/or technological projects" (Jasanoff and Kim, 2009, p. 120).

5 In my experience, all health technology marketing materials make more sense with Daft Punk's "Harder, Better, Faster, Stronger" as a soundtrack ("Work it harder, make it better, do it faster, makes us stronger: more than ever, hour after hour, work is never over."). This makes for a rather intense experience, so I recommend listening to Florence + the Machine's "Free" afterwards ("Sometimes I wonder if I should be medicated...if I would feel better just lightly sedated..."), both to decompress and to facilitate your rumination on how many of the problems health technologies are purporting to solve are techno- or iatrogenic in the first place.

6 The rhetoric of Elizabeth Homes of Theranos about the quack "Edison" machine being a clear (and criminally convicted) exception.

technology and quantification (Jain & Ahlstrom, 2021) (Sætra, 2023) are now so embedded in our culture at large (Milan, 2020) that they have become taken for granted[7].

A misalignment in expectations is therefore not necessarily a symptom of a problem that should have been solved earlier (Hoffman, 2017), but a moment to question an assumption that was taken for granted. Techo-solutionist narratives may support rapid introduction of new technology, but they also make it difficult to problem-solve and adjust when a technology inevitably runs into unanticipated issues in everyday (healthcare) practice. The assumption promoted by these narratives is that technology must be cost-effective and labor-saving, and that it should work without human intervention (Carboni et al., 2023). When these assumptions are challenged, it can be difficult for health systems to adjust how a technology has been implemented, especially if the cost outlay was significant. The classic Collingridge dilemma describes this more succinctly: impacts cannot be sufficiently predicted before a technology has been embedded in healthcare, but as a technology becomes entrenched (which could manifest as social acceptance, institutional acceptance, and/or financial investment), it becomes significantly more difficult to control or change (Collingridge, 1980).

To further illustrate how misalignments between narratives and practices play out for healthcare technologies, I turn to two examples of disruptive technologies currently used in healthcare.

### EXAMPLE 1: DIGITAL CHECK-IN KIOSKS

Digital check-in kiosks were introduced at a Dutch hospital. These kiosks were implemented to improve efficiency and allow the hospital to reduce front desk staff. At a practical level, the kiosks were not accessible for a wide variety of patients who were regular hospital visitors (such as patients with limited eye sight or low tech literacy), and even when the kiosks worked as intended, patients experienced less interaction, more responsibility, and more stress. In some cases, these differences were positive: some patients felt more in control of their care. For others, important elements of care that would have been managed in an interaction with a human were lacking, such as catching patients early who were doing poorly and obtaining appropriate assistance. Importantly for the goal of increasing efficiency, the kiosks appeared to transfer some elements of front desk work not only onto patients, but onto other healthcare workers (including doctors), who were required to manage more patients who had ended up in the wrong place. These issues do not signal that check-in kiosks were an inherently problematic idea; rather, the kiosks illuminated important services provided by

7 We barely notice when AI chatbots like ChatGPT rewrite our own thoughts in the hyperbolic "anywhere, anytime" pep of Silicon Valley advertising copy; in many ways, the tone and tenor of tech company narratives have become as natural to us as our own voices. This imported narrative of technological innovation influences the way healthcare stakeholders think about new technologies, even thousands of miles and an ocean from where much of that technological narrative originates. For instance, as a California import myself, perhaps my San Francisco Bay Area roots explain why I find it relatively easy to spot unfiltered ChatGPT output in student work: in one paragraph, I'm reading the slightly awkward and perfunctory language of a Dutch bachelor's student writing an essay in English for the first time, and by the next paragraph, I feel like I'm listening to a tech bro in a polo shirt and hoodie mansplain his start-up idea to me over expensive IPAs at a Mission district hipster bar in 2010.

front desk personnel that contributed to the functioning of the hospital, but which were not visible until those workers were absent (Loukili et al., 2024)[8].

### EXAMPLE 2: NEW IVF TECHNOLOGIES

Add-on technologies related to improving in-vitro fertilization (IVF), such as time-lapse imaging, are becoming increasingly common. Time-lapse imaging was designed to help IVF professionals identify the most viable embryo for implantation. However, these kinds of IVF technologies are notoriously difficult to evaluate definitively from an evidence-based medicine (EBM) perspective. This is partly due to the complexity of attributing changes in live birth rates to minor add-on technologies, and partly due to IVF practice being primarily technologically-driven, rather than evidence-driven: procedures are often introduced at clinics years before they are fully evaluated using EBM protocols. EBM evaluation requires significant time compared to the pace of development of new IVF technologies, such that the evaluated technology is often already obsolete by the time evaluation is complete. For time-lapse imaging, there are no conclusive randomized control trials (the pinnacle of the EBM evidence hierarchy) demonstrating that these technologies fulfill their intended purpose. However, time-lapse imaging may have other uses throughout the IVF process, such as allowing providers to "babysit" the embryo remotely, or prepare patients earlier if an embryo is not developing normally, potentially improving quality of life for both providers and patients during treatment.

IVF providers therefore walk a fine line when legitimizing these technologies, especially to patients. While they engage with narratives of EBM and the concerns raised in public debates about non-evidence-based technologies, they tinker with narratives about the purpose of time-lapse imaging, and challenge both live births as a metric for IVF clinical success and the categorization of time-lapse imaging as an "add-on treatment." These nuanced narratives of legitimation allow providers to reconcile gaps between practices and narratives of technology when providing care to patients (Perrotta & Geampana, 2020).

The narratives of the value added to healthcare by each technology are challenged in the practice of healthcare, which is complex in ways that could not be addressed upfront by the technology. A mismatch between the function of a technological system and practice of healthcare work is often the only way to reveal these "silent errors"(Ash et al., 2004). Sometimes, the technology works exactly as intended: patients find their way to appointments quickly without help from a human; IVF professionals use time-lapse imaging to identify the best embryo for implantation. However, both technologies also add complexity to care by changing existing practices or requiring new practices from both patients and healthcare providers. Patients who cannot manage the technology must find a human to help them who

8 A metaphor for this conundrum comes from my previous life in theater: the success of a theatrical production depends on a good stage manager. However, a stage manager's job is essentially to remain invisible while solving problems and running the show, and therefore, their work is routinely undervalued...until the dress rehearsal falls apart three days before opening and everyone wonders who said "Macbeth" in the theater and invited the bad luck in. The theater isn't cursed, you just asked an inexperienced volunteer (or, stepping out of the metaphor for a moment, a technology) to do the job of a seasoned professional for free (or, a one-time purchase fee).

was not designated as a helper originally; IVF providers must construct nuanced narratives for patients and outsiders about the provider's use of a controversial technology. New practices emerge to manage situations created by the introduction of technology which were not anticipated before the technology was introduced. In these ways, the technology does not relieve work burden or even necessarily improve care: it merely changes the ways in which the problem is addressed, and by whom. Simultaneously, the shift in work burden is invisibilized as work is "fauxtomated" (Carboni et al., 2023): with digital kiosks, there may be no "check-in staff," but outside the entrance hall, other healthcare workers are now redirecting lost patients and answering logistical questions. The work is still done, but in a way that serves the "myth of human obsolescence" (Taylor, 2018) and denies extent to which human labor is required in order to make "automation" work (Carboni et al., 2023).

In a sense, the more simplistic narrative of each technology "collapses"(Lvovsky, 2018) the complexity of healthcare. Many possible ways of caring for patients and producing good health outcomes are omitted to simplify the story of how the technology adds value to healthcare (Henriksen & Bechmann, 2020). In other words, the narratives of these technologies instead select one possible care pathway as "truth," which parallels how truth is constructed in algorithmic decision-making (Henriksen & Bechmann, 2020; Jaton, 2017). Algorithms are governed by sets of rules and built-in assumptions called "ground truths"[9] designed to allow the algorithm to make clear choices among multiple possibilities (Jaton, 2017). As such, the process of algorithmic decision-making negates any other possible pathways in a quest for a single, clear recommendation. These pathways become automatically defunct as soon as they are not chosen, just as other ways of knowing can be drowned out by convincing narratives. In much the same way at a social level, health technologies often reduce existing pluralism in healthcare work to a single possible pathway, invisibilizing (Ash et al., 2004) the labor of making that pathway possible (Carboni et al., 2024; Loukili et al., 2024). The use of health technologies and narratives surrounding them thereby exclude different ways of knowing and doing healthcare, reducing care work to an algorithmically-solvable problem.

Understanding the embedding process of disruptive technologies therefore involves recognizing and reconciling taken-for-granted narratives, identifying how these narratives align (or often, do not align) with practices involving the technologies, and recognizing how technologies become part of or reshape existing technical, institutional, and medical infrastructures, both within healthcare systems and within the contexts in which health technologies are developed. The taken-for-granted nature of these processes usually renders them invisible; the benefit of taking something for granted, after all, is that you do not have to think about it anymore. Their strangeness is only visible in comparison: new technologies clash with old standards of (ethical) care (Loukili et al., 2024; Morley et al., 2020); narratives about what a technology does do not align with how people

9 "Ground truths" are databases of inputs and outputs that govern algorithmic behavior and are shaped by socio-material practices and values (Janton, 2017). In other words, the nature of "truth" in computer science is unironically pre-constructed in order to allow algorithms to make decisions in relation to a predetermined "truth."

use that technology in practice (Barker, 2011; Granja & Machado, 2020); new technological tools do not necessarily fit neatly into existing ways of working in healthcare (Farah et al., 2023; Perrotta & Geampana, 2020; Sheard et al., 2017). At the moments when these different narratives, practices, and infrastructures collide, we must reconcile two taken-for-granted yet conflicting understandings of the world into a cohesive whole. How do we make, for instance, a machine-learning algorithm and existing patient care protocols work together in practice?

The work of embedding technology can thus be imagined as the process of the "Relativity" figures deciding together how to approach a single staircase. Do they agree on a single direction to walk on the stairs? Do they continue to use the stairs differently and ignore the strangeness this creates? Or do they scrap the stairs all together and build something else? Any of these options is potentially possible, functional, and pragmatic; however, coming to any conclusion, even if the final decision is to keep the status quo, inherently requires questioning taken-for-granted ways of doing and thinking via interaction with opposing and equally taken-for-granted ways of doing and thinking.

## FRAMEWORKS FOR UNDERSTANDING HOW TECHNOLOGY IS EMBEDDED IN HEALTHCARE

The use and implementation of new health technologies is never as straightforward as narratives often suggest. As demonstrated through the examples above, technologies often run into obstacles during the embedding process and can produce unintended side effects both at the level of individual patients, or the healthcare system as a whole. Frameworks are one way that researchers, policymakers, developers, and other healthcare stakeholders can make sense of this complexity. Frameworks can help researchers anticipate obstacles (Holden & Karsh, 2010), plan for the trajectory of the embedding process more accurately (Bramo et al., 2022), analyze factors that may impact implementation (Yang et al., 2022), or understand why there were problems after a project has been abandoned (Greenhalgh et al., 2010b).

The history of acceptance, adoption, and implementation studies is long (Nilsen, 2015). Frameworks in these fields not only include approaches to studying new technologies but the implementation of guidelines in healthcare practice, such as the Consolidated Framework for Implementation Research (CFIR)(Damschroder et al., 2022); such guidelines are often essential to understanding the embedding of disruptive technologies (Edelman et al., 2025). Diffusion of innovation (Rogers et al., 2014) and the consolidated framework for implementation research (Damschroder et al., 2009) have informed the development and proliferation of both niche and systemically-oriented frameworks. Both kinds of frameworks come in many permutations. For instance, there are frameworks designed to produce understandings how technologies come to be accepted by users, such as the Technology

Acceptance Model (TAM)(Yarbrough & Smith, 2007), and adopted by healthcare professionals, such as the unified theory of acceptance and use of technology (UTAUT)(Dwivedi et al., 2016). More systemically-oriented frameworks include the Technology-Organization-Environment framework (TOE)(Yang et al., 2022), and even a framework designed to study technologies that were *not* embedded successfully: the framework for non-adoption, abandonment, scale-up, spread, and sustainability of health technologies (NASSS)(Greenhalgh et al., 2017). Each framework contains basic assumptions built into both its approach to health technologies and its methodology that influence the perspective from which a researcher can use the framework to understand how technologies are embedded in healthcare. These different assumptions can also impact what is left unseen and unchallenged within the embedding process (Allers et al., 2024).

However, even when technologies are developed with potential challenges in mind and planning for implementation is thorough and thoughtful, there are always unintended consequences when technologies are embedded in healthcare. In this book, I focus on these unintended and unseen consequences, exploring complexity in the healthcare system using several methods and paradigms. In this way, multiple ways of understanding and producing knowledge in the healthcare system, or epistemological pluralism (Ward et al., 2015), can be taken into account, producing a deeper understanding of how institutions, people, and technologies interact in the context of healthcare.

An important question to consider here is *why* there are so many unintended consequences when embedding disruptive technologies and why these consequences are not adequately predicted in advance of implementation, as we saw in the examples of time-lapse imaging for IVF and digital hospital check-in kiosks. The heart of this conundrum is deeply human, not technological. To function in the world, we need to take familiar aspects of our environments, practices, and knowledge for granted (Garfinkel, 1964). Even at a biological level, this capacity is necessary: it helps us to stay prepared to manage any threats that may emerge in the future by prioritizing what is new and different and allowing the routine and mundane to recede into the background (Boyle & Vedantam, 2024). This process of taking things for granted invisibilizes certain practices and elements of our environments and knowledge to us (Latour, 1987): we do not notice *when* we are taking things for granted, or even *that* we are taking things for granted. This makes it extremely difficult to study taken-for-grantedness; the infrastructure in which we operate is usually invisible until it is interrupted or contested in some way. Only when we notice two figures walking up an Escher staircase in different orientations can we begin to question the impossibility of the architecture as a whole.

In this book, I focus on the taken-for-grantedness that supports existing infrastructures in both technology and healthcare (Star & Ruhleder, 1996). New technologies struggle with a liability of newness (Bitektine & Haack, 2015; Suchman, 1995), amplifying the importance of fluctuating expectations (Borup et al., 2006; Selin, 2007), and resulting in more contestation than established technologies. Because of this, disruptive technologies must address concerns about legitimacy that

are taken for granted once a technology has been established as a standard of care in healthcare practice. I therefore use legitimacy as a lens to explore the practices, narratives, and relationships involved in embedding disruptive technologies in healthcare.

## LEGITIMACY

While there are many definitions of legitimacy, and thus many possible perspectives, this study centers organizational and sociological concerns. I therefore start from the seminal definition from Mark C. Suchman (1995): "Legitimacy is a generalized perception or assumption that the actions of an entity are desirable, proper, or appropriate within some socially constructed system of norms, values, beliefs, and definitions" (p. 574). I focus specifically on taken-for-grantedness as a primary source of legitimacy: "To the extent that it is attainable, this kind of taken-for-grantedness represents both the most subtle and the most powerful source of legitimacy identified to date. If alternatives become unthinkable, challenges become impossible, and the legitimated entity becomes unassailable by construction"(Suchman, 1995). Utilizing insights from political science (Hurd, 1999), management and organization studies (Haack et al., 2014), and anthropology (Navaro-Yashin, 2009), I add that legitimacy is always relational, in that it occurs between at least two entities, which can include actors, institutions, and/or technologies (Hurd, 1999). Relationships, in this way, can thus be interpreted as the infrastructure (Star & Ruhleder, 1996) supporting legitimacy.

While legitimacy studies most commonly use narrative-centered approaches, my approach moves beyond narrative to include practices, affect, and relationships, without devaluing the importance of narratives and perceptions in the production of legitimacy. I therefore add to previous work demonstrating that legitimacy relationships have affective qualities, for instance, in the context of public policy within relationships among institutions involved in transnational governance schemes (Haack et al., 2014). "Affect" refers to emotive qualities or sensations that "may move through the subject"(Navaro-Yashin, 2009), but are not necessarily known to the subject: for example, even though a technology may not be able to "feel[10]," it can still have affective qualities in relationship to human actors. Affect therefore facilitates a focus on legitimacy relationships among human and non-human actors (such as technologies or institutions)(Latour, 1987), rather than on legitimacy as a cognitive task (Suchman, 1995) performed by humans.

This conceptualization of legitimacy facilitates the study of embedding of disruptive technologies in healthcare in several ways. First, a legitimacy lens enables analysis at the micro (individual), meso (institutional), and macro (health system) levels. Second, this lens allows for analysis of how

10 These sorts of human-non-human affective relationships may be most culturally visible in how we conceptualize children's beloved stuffed animals. "Real isn't how you are made,' said the Skin Horse. 'It's a thing that happens to you. When a child loves you for a long, long time, not just to play with, but REALLY loves you, then you become Real" (Margery Williams Bianco, *The Velveteen Rabbit*).

legitimacy may evolve over time, rather than focusing on the status of a particular technology at a specific moment in time. By focusing on relational infrastructure, practices, and narratives, legitimacy allows me to make visible dissonances between taken-for-granted narratives and practices that may impact healthcare in unforeseen ways when new technologies are introduced.

## CASE STUDY: SKINVISION

This book contains two chapters dedicated to a case study of a disruptive new health technology. SkinVision is a skin cancer risk assessment smart phone application that uses a convolutional neural network (a form of artificial intelligence) and the smartphone's camera to assess the cancer risk of user-made photos of skin lesions. It produces a binary classification (high-risk or low-risk) and is trained using thousands of photos of skin lesions, assessments from dermatologists, and histopathology reports. Teledermatologists review any photos without a clear assessment. SkinVision advertises a sensitivity (correctly identifying cancerous lesions as high-risk) of 95% (SkinVision, 2025b; Udrea et al., 2020); however, more recent validity studies show closer to 87% sensitivity (T. Sangers et al., 2022), and lower specificity (correctly identifying benign lesions as low-risk) of around 70%(T. Sangers et al., 2022).

SkinVision is a particularly interesting case of a new technology in the process of becoming embedded in the healthcare system for several reasons. Firstly, the app is designed to be used by patients, whereas most medical devices are designed for use by medical professionals (Fuchs et al., 2017; Judd et al., 2010). A medical device for which patients are end users adds a layer of social complexity: the device exists for the user outside of a zone of professional knowledge and therefore must be accessible to lay people because its use is not mediated through a medical professional.

Secondly, the SkinVision app has been implemented in the Dutch healthcare system via a critical mass of insurers, rather than formal approval by the Dutch HTA agency Zorginstituut Nederland (ZIN). This is not particularly unusual, but rather emblematic of an approach many smaller medical technology companies must take without the financial resources of large corporations. Despite being on the market with CE and dermatologist association approval for several years, this book contains the first formal health technology assessment of the app. As such, the app is representative of the pathway of many disruptive technologies, which are often developed in a start-up context.

Thirdly, SkinVision uses machine learning to make assessments and therefore must navigate both a well-developed narrative (Smits, 2006) and the hype surrounding AI technologies for healthcare (Emanuel & Wachter, 2019). These kinds of powerful narratives have an outsized impact on how funders, users, and decision-makers engage with the technology (Selin, 2007). This makes the differences between narratives and practices related to SkinVision all the more salient.

Finally, the SkinVision app adds something new to a healthcare interaction. Rather than replacing an existing process, such as a radiologist looking at scans (Boverhof, Redekop, Bos, et al., 2024), SkinVision produces a new kind of medical interaction during skin cancer risk assessment and diagnosis. It neither replaces the doctor (the patient must still visit a doctor for diagnosis) nor performs the same function as a doctor (because it cannot have a social interaction with the patient). It therefore also disrupts existing social interactions within the standard of care, making it an interesting case from both an ethnographic and HTA perspective.

## PRODUCING KNOWLEDGE FROM DIFFERENT PERSPECTIVES

This study is about the narratives, practices, and infrastructures involved in the embedding of technology in healthcare and is relevant for several different fields trying to make sense of and influence this process. From an HTA perspective, acknowledging the complexity of misaligned narratives and practices clarifies the relevance and urgency of ex ante assessments of effectiveness, cost-effectiveness, and other indicators that may help model possible futures (EUnetHTA, 2016). From a Science & Technology Studies (STS) perspective, a focus on "moments of breakdown"(Star & Ruhleder, 1996) drives critical scrutiny of narratives around technology and an inclination to study how technologies are produced and used in practice (Latour, 1987).

My research mixes methods and paradigms, thereby allowing multiple ways of knowing to coexist and inform each other, rather than ignoring or attempting to control for differences in output among methodologies, and centering unintended consequences when embedding technology in healthcare. Synthesizing multiple ways of knowing to glean insights that are greater than the sum of the insights produced purely within each epistemology is part of the work of incorporating disruptive technologies into the healthcare system. It has also been the work of my PhD. This book is based on the premise that fully understanding how health technologies are embedded in healthcare practice involves both knowledge of the multiple perspectives involved in the embedding process, and the ability to move among the perspectives of stakeholders who work only within one perspective themselves. To understand what this looks like at a conceptual level, I return to Escher's lithograph, "Relativity."[11]

### PLURALISM

"Relativity" can be construed as a visual representation of the complexity of dealing with ontological and epistemological pluralism in healthcare (Canali & Lohse, 2024; Turner, 2011). Epistemological pluralism refers to different ways of knowing and understanding the world (Mol, 2002; Ward et al., 2015): for instance, a quantitative researcher may choose to answer a question such as "how can we improve health outcomes for patients?" through statistical analysis; a qualitative researcher may

11 For more detail about the daily practices of working between epistemologies, see Chapter 6 about Mixed Methods Anonymous, the group of fellow PhDs who helped ground me when I felt like I was working inside impossible architecture.

choose to do so through observations of patients and interviews of healthcare providers (Akrouh et al., 2024). Both produce valid and potentially useful knowledge about the question, even though that knowledge is likely to be quite different.

Ontological pluralism (Tummons, 2020) or multiplicity (Mol, 2002), on the other hand, refers to different ways of existing in the world. The same person may be a patient in one setting, health professional in another, and a technology user in yet another setting. These differences impact the ways in which people and institutions interact with this person, and how this person interacts with the world: their identity in a particular context informs how they move through the world. Similarly, a cell phone can be both a camera and a medical device (and sometimes both at the same time), depending on which app is open being used and who is using the cell phone. In the lithograph, each figure can be seen to represent a different way of being, defined by different centers of gravity. One figure's wall is another figure's floor. They may exist in the same space, but the space is not the same for each figure.

Ontological and epistemological pluralism can help explain important differences in the construction and deployment of knowledge within different research methods and paradigms. For example, quantitative positivist methods focus on testing hypotheses through quantifiable variables, or qualitative variables made measurable (Campillo-Artero et al., 2018; Fuchs et al., 2017; Lupton, 2015; Stevens et al., 2018; Verran, 2010). This requires a different view of the world and how knowledge is produced from qualitative constructivist methods that explore themes through observations, constructing knowledge through iterative processes of data collection and theorization (James P Spradley, 2016; Van Maanen, 2011; Ward et al., 2015). These underlying epistemological differences not only impact how research is done (and thus, how knowledge is produced), but what kind of knowledge *can* possibly be produced. Ethnography cannot tell us if a new health technology is cost-effective; statistics cannot tell us how a new technology disrupts power hierarchies in medicine.

Epistemological differences can have wide reaching impacts. For instance, qualitative research is currently accorded lower status by everyone from researchers to patients to policymakers, and is viewed as less persuasive than quantitative evidence (Lupton, 2015), even when qualitative constructivist methods are better suited to the topic at hand (Maguire & Murphy, 2022). This focus on quantification has spilled into lay conceptualizations of what constitutes good healthcare as well: at Erasmus Medical Center in 2023, a patient medical supplies provider advertised their products with "Meten is Weten" or "measurement is knowledge," demonstrating just how pervasive this particular epistemological approach to data has become (Stevens et al., 2018). While this perspective is a boon for quantitative positivist research in some respects, it is not without its downsides. For instance, much like companies wrestling with the hype of AI, expectations of such research can become so overblown that researchers may need to dedicate significant time and resources clarifying the boundaries around what their methods are capable of saying about the world (Granja & Machado, 2020).

## COMPARING APPROACHES

I use a spectrum of methods, including several ethnographic approaches, Q-methodology (Watts & Stenner, 2012), Critical Interpretive Synthesis (Dixon-Woods et al., 2006), and cost-minimization analysis in this book (see Table 1). However, I find the differences between ethnography and HTA to be particularly emblematic of the ways in which epistemological differences generate complexity in healthcare research, and thus, in our understandings of how healthcare systems work.

**Table 1:** Methods and Paradigms

| Chapter | Methodology | Paradigm | Data collection period | Data | Methods and analysis |
|---|---|---|---|---|---|
| **2 Literature Review** | Critical Interpretive Synthesis | Qualitative, constructivist | 1.5 years | 793 abstracts; 97 articles | Iterative Boolean and by-hand search through identified journals, thematic analysis |
| **3 SkinVision Ethnography** | Ethnography | Qualitative, constructivist | 3 years | 25 professional healthcare stakeholders, 68 app users, 5 documents | Participant observation, remote observation via video, unstructured interviews, focus groups, Iterative abductive thematic analysis |
| **4 Health Technology Assessment (HTA)** | Full health technology assessment with cost-minimization study | Mixed (quant/qual), positivist | 4 years | Literature sources, randomized control trial results including over 20,000 health insurance customers, public costing data, previously-collected qualitative data, 5 expert interviews | Cost-minimization analysis, thematic analysis of qualitative data |
| **5 Explainable AI (XAI)** | Q-methodology | Mixed (quant/qual), constructivist | 1 year | 37 professional healthcare stakeholders (q-sorts, interviews) | Focus groups, literature review, q-methodology q-sort inclusions with interviews centroid factor analysis with varimax rotation |
| **6 Mixed Methods Anonymous (MMA)** | Autoethnography, ethnography | Qualitative, constructivist | 3 years | Diary entries over 3 years, 24 MMA meetings with minutes, provided by 3 autoethnographers | Autoethnographic diary-keeping mixed methods anonymous meetings, cross-ethnographer abductive thematic analysis |

Ethnography can allow for deeper analysis of institutional complexity and anticipation of unintended consequences of embedding technology (Greenhalgh & Swinglehurst, 2011). Ethnography is

particularly useful when studying a field in which knowledge is co-created from multiple perspectives, as is the case for health technologies: in its aim to "make the strange familiar and the familiar strange"(Miner, 1993), ethnography requires researchers to question assumptions that are implicitly folded into any technology development process and their own understandings of how healthcare and technology (should) work. This is not to say, however, that ethnography as a method is necessarily open to multiple ways of understanding and producing knowledge, or epistemological pluralism (Ward et al., 2015). I find ethnography particularly useful in this context because it explicitly encourages the researcher to explore different kinds of knowledge and ways of knowing as research subjects (Mol, 2002), rather than ignore or attempt to control for the differences[12].

A new definition of HTA (O'Rourke et al., 2020) now explicitly includes the importance of input from multiple disciplines and the implications of conducting a study from a particular perspective. However, because HTA derives its validity through methodological precision, these perspectives and disciplinary contributions are understood within a predefined methodological framework. For instance, if an HTA includes a cost-minimization study, researchers assess the costs of a technology from a "societal" perspective or a "healthcare payer" perspective, depending on the audience for the final assessment. These different perspectives define the scope of the data involved in the study but are not the basic purpose and point of view of the assessment. Metaphorically, the Relativity figures using HTA may be looking at the problem from the top or the bottom of the staircase, but no one is upside down. Different dimensions of value, in this definition of HTA, are thus covered through diversity of data and outcome measures, rather than through epistemological or ontological pluralism (in which different forms of knowledge production may lead to different answers to the same question).

It follows that these different epistemologies also generate different modes of acting on the world. Different methods are used to pursue different research goals, which, in turn, shape the results produced by research. For instance, HTA methodology is designed to support the goal of comparing two (or more) possible care pathways to help decision-makers choose the best option. This clearly will provide a different output from, for instance, Q-methodology, which is designed to generate a rigorous typology of subjective opinions on a specific subject. While different research outputs can be used to complement each other, it is not possible to use Q-methodology to compare two possible care pathways, any more than HTA can generate a rigorous typology of opinions. The question of methodology is therefore about more than epistemology; it is also about asking what we want the research output to do in the world.

12 Because I am a pluralist, I cannot be a purist. Ethnography is stronger than other methods at recognizing the pluralism of embedding medical technology, but its strengths also have "unintended consequences." Specifically, ethnography takes a long time, it tends to steer researchers towards critique over practical utility, and it produces results that are difficult to generalize. In short, we need multiple methods to understand the world. Nobody's perfect.

## RESEARCH QUESTIONS AND AIMS

Despite all of the talk of complexity in this introduction, the goal of this book is quite simple: to better understand how technology becomes (or does not become) embedded in healthcare. The main research question I seek to answer in this thesis is:

*How do disruptive technologies become embedded in the healthcare system?*

I use three sub-questions to further operationalize this question:

*What is the role of narratives in the embedding of technologies in the healthcare system?*
*What is the role of practices in the embedding of technologies in the healthcare system?*
*What is the role of infrastructure in the embedding of technologies in the healthcare system?*

I therefore position this book as a counterpoint to the beguiling narratives of technosolutionism[13]. I seek a conversation about health technology that takes for granted the centrality of people, the importance of context, and complexities of healthcare provision.

## OUTLINE

The following chapters cover five separate empirical studies, each of which contributes a particular perspective on the embedding of disruptive technology in healthcare. A focus on legitimacy allows me to explore how disruptive technologies that wrestle with liability of newness can impact taken-for-granted narratives, practices, and infrastructures.

Chapter 2 explores the meaning of legitimacy within the context of health and technology. It reviews and critically synthesizes existing scholarship on the concept of legitimacy as it relates to health and technology. Through a series of synthetic constructs, this chapter produces a novel conceptualization of legitimacy in health and technology based on literature from three disciplines within social science. This chapter asks, "How can legitimacy of health and technology be conceptualized?" and explores the roles of narratives, practices, infrastructure in conceptualizations of legitimacy pertaining to health and technology.

Two chapters in this book deal with the case study of SkinVision as a specific disruptive health technology. I consider SkinVision to be disruptive due to both how the hype around AI-driven technologies impacts narratives about the app in ways that are distinct from, for instance, a teledermatology-only app with similar capabilities, and due to the ways in which practices and healthcare infrastructures must adapt in order to accommodate the app. Chapter 3

13 "It's complicated" as a universal result for all ethnographic research may be a running joke among anthropologists, but this appears to be an instance of a stereotype holding an important (if, ironically, simplified) grain of truth.

ethnographically explores how SkinVision interacts with the healthcare system at a macro, meso, and micro level through the lens of legitimacy. This chapter asks, "What can we learn from moments of legitimacy breakdown about the assumptions guiding the embedding of an AI-based technology in the Dutch healthcare system?" Chapter 4 examines this same interaction through the lens of health technology assessment. This chapter further investigates the value and importance of integrating deep social and organizational research into health technology assessments of disruptive technologies. Through two different methodological and paradigmatic perspectives, I explore the complexity of how the SkinVision app has become embedded in practice and is understood by stakeholders through narratives within the infrastructure of the healthcare system.

Chapter 5 circles back to deal with issues of meaning that arise in the complex context into which health technologies are embedded. Explanations are seen as a way of managing issues of understanding and trust when dealing with AI health technologies, and the desire for explanations can be a signal that a technology is perceived as disruptive (through narratives) or is actively disrupting existing practices and infrastructures[14]. However, the meaning and purpose of explainability for AI varies greatly depending on the audience. This chapter asks, "What are the meanings of and preferences for XAI among professional healthcare stakeholders in the Netherlands?" Using Q-methodology, a mixed method that deploys both statistics and interpretive data, this chapter generates a typology of perspectives on explainable AI held by healthcare professionals in the Netherlands, bridging both disciplinary narratives and gaps in communication in practice within an inherently collaborative field.

In Chapter 6, I reflect on my position as a researcher. This chapter discusses the daily practices of transdisciplinary researchers through collective autoethnography, the affective qualities of these practices, and the infrastructural and organizational aspects of transdisciplinarity that shape them. This chapter asks, "How is transdisciplinary research done?" and explores what it means in practice to be a figure moving among these different perspectives while remaining inside the lithograph of impossible architecture.

Chapter 7 presents the discussion and conclusions of this thesis. In this chapter, I synthesize the different perspectives found in the first six chapters to outline the theoretical, practical, and methodological implications of my research and suggest a research and policy agenda as we continue to embed technology in healthcare.

14 For instance, despite similar technological complexity, calls for explanations of MRI machines have not historically been nearly as loud as calls for explanations of AI-driven healthcare tools.

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# CHAPTER 2

# LEGITIMACY AS SOCIAL INFRASTRUCTURE:

## A Critical Interpretive Synthesis of the Literature on Legitimacy in Health and Technology

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## INTRODUCTION

Technological innovations and healthcare delivery have become increasingly intertwined in recent decades (Ancker et al., 2012; McDougall et al., 2016). With each promising innovation, new questions are raised about how to integrate the technology into health domains, and the social implications of doing so (Fishman et al., 2015; Lehoux et al., 2017; Licht & Licht, 2020; McDougall et al., 2016; Mittelstadt et al., 2016; Perrotta & Geampana, 2020; Petersen et al., 2015). This problem has given rise to evaluation processes such as health technology assessment (HTA) (Cleemput et al., 2012) and a range of government institutions, such as the National Institute for Health and Care Excellence (NICE) in the UK, to help make decisions about appropriate use of technologies in various healthcare contexts (Russell & Greenhalgh, 2012).

Questions of legitimacy are implicit in debates about embedding technologies in healthcare, and these implicit questions about legitimacy permeate literature about health and technology. While there is limited conceptual work on legitimacy in health and technology specifically, within the small body of work that exists, legitimacy is explored through a wide range of theoretical lenses and conceptualizations.. However, there is no consensus about what legitimacy is or how it works, nor is there much conversation among different branches of literature. Across social science disciplines and medicine, legitimacy is affiliated with many concepts, including "acceptability"(Ward et al., 2019) "reasonableness"(Wamsiedel, 2018), and "transparency"(Licht & Licht, 2020; Mittelstadt et al., 2016); these terms are sometimes conflated with legitimacy itself. Definitions of legitimacy range just as widely, especially among different disciplines: in Organization & Management Studies, legitimacy is often defined as "normative appropriateness"(Haack et al., 2014; Suchman, 1995), though Science & Technology Studies and Medical Anthropology & Sociology include definitions such as "the acceptability of claims to authority"(Lovbrand et al., 2011; Selin, 2007) and "accountability for reasonableness"(Russell & Greenhalgh, 2012) when the term is defined at all. Some disciplines, such as Organization & Management Studies, follow a strong tradition of explicit theorization of legitimacy, while others, like Medicine, usually do not explicitly problematize or define the word "legitimacy," though legitimacy and similar concepts may play a large role in discussions in the field. Within the same discipline, some authors use legitimacy interchangeably with other concepts (Fishman et al., 2015), while others focus on a single sub-category of legitimacy developed from a narrow line of theoretical thought (Fredriksson & Tritter, 2017). Given the breadth and depth of the literature on legitimacy in health and technology, it is clearly an important topic. A cross-disciplinary conceptualization of legitimacy that can be applied to questions about embedding technologies in healthcare would allow for deeper understanding of these processes.

We chose to focus on legitimacy for several reasons. Legitimacy specifically is widely used but poorly defined within multiple fields studying health and technology, and points towards social and organizational processes. Even though legitimacy is clearly important in studies of health and technology across many disciplines, it is abstract and there is very little cohesion both within and across social science disciplines around how it is produced, and how it is used.

To understand the role of legitimacy in relation to the embedding and governance of technology in healthcare, we flesh out the different ideas and underlying assumptions authors bring to the Organization & Management Studies, Science & Technology Studies, and Medical Anthropology & Sociology literature. This article explores three research questions: 1) What does legitimacy mean in the context of health and technology? 2) How is legitimacy produced? 3) How is legitimacy used to explain the challenges of embedding technologies in healthcare? Based on a synthesis of literature, we develop a novel conceptualization of legitimacy as social infrastructure. This allows us to focus on the aspects of legitimacy related to norms, materialities, semiotics, and specific relationships among stakeholders and larger systemic contexts.

Existing frameworks guiding policy intentions around technology adoption in healthcare often do not reflect the realities of everyday practice, nor is the focus on the social processes of embedding technologies in healthcare (Wehrens et al., 2020). Current models and frameworks for embedding technologies (in healthcare), such as the Unified Theory of Acceptance and Use of Technology (UTAUT)(Dwivedi et al., 2016) and the technology acceptance model (TAM) (Holden & Karsh, 2010; Yarbrough & Smith, 2007), provide useful information about the judgments and perceptions of various actors in relation to a specific technology. While these models provide useful insights into actors' *intention* to adopt, as well as the ethical considerations they may perceive and institutional norms they may face, they do not often explain how and why certain technologies are (not) adopted and/or accepted *in practice* among particular groups, and thus can provide only limited governance support (Greenhalgh et al., 2017). Most technology adoption and acceptance models deal primarily with behavioral intention (Holden & Karsh, 2010; Yarbrough & Smith, 2007). These models attempt to explain individual behavior intentions (as a proxy for actual behavior) through analysis of a variety of factors, which can include beliefs, attitudes, perceived control, and perceived norms. This leaves substantial gaps, including the lack of attention to external factors impacting the embedding process (Yarbrough & Smith, 2007) and any difference between behavioral intention and practice. Focusing on the impact of legitimacy within technology embedding processes can help fill these gaps by allowing for more comprehensive and nuanced conversations about technology adoption and acceptance.

## A CROSS-DISCIPLINARY LEGITIMACY CONCEPTUALIZATION

The goal of this review is to produce a theoretical synthesis of how legitimacy of health and technology is conceptualized. We hope to generate theoretical insights that will allow for a cross-disciplinary approach to legitimacy. To do this, we use the Critical Interpretive Synthesis (CIS) review method to produce a cross-disciplinary understanding (Carboni et al., 2022) of how legitimacy is produced and maintained without privileging one discipline's theoretical traditions over another's (Dixon-Woods et al., 2006).

We use Organization & Management Studies (OMS), Science & Technology Studies (STS), and Medical Anthropology & Sociology (MAS) as a disciplinary framework to understand the different strands of reasoning within legitimacy studies. OMS includes the most clearly developed theorization of legitimacy as a concept and several of the best-known review articles (Suchman, 1995; Suddaby et al., 2017). Legitimacy studies is a well-defined sub-area of OMS research that explores legitimacy in the context of management, entrepreneurship, and institutional endeavors. OMS primarily focuses on how legitimacy works at the level of organizations and institutions, rather than among individual people or through technologies.

STS explores the social and cultural implications of science, technology, and technology development (*The Handbook of Science and Technology Studies*, 2007; Woolgar, 2016). STS tends to focus on controversies, the unforeseen implications of technology development and adoption, and "black box" technologies (Latour, 1987) that inhibit full understanding. This contributes to a strong disciplinary interest in legitimacy, particularly of technology and medicine. STS centers interactions with technologies and technical change in legitimacy discussions, rather than separating the motivations of human actors from technologies and practices.

Though medical anthropology and medical sociology (MAS) developed from different traditions, they have partially converged in the study of medical cultures and interactions from a qualitative perspective (Conrad, 1997), which is also the focus of legitimacy studies in MAS. MAS generally takes a skeptical view of taken-for-granted institutions. Many studies explore the impact of this taken-for-grantedness on people who are harmed by or left out of these institutions and systems. This leads to a natural questioning of legitimacy and deeper exploration of baseline assumptions, particularly in a healthcare context. Together, these disciplines explore health and health technologies with less focus on institutions and more focus on humans and connections among them. We hope that greater synthesis of different conceptualizations of legitimacy could provide a more holistic perspective about how and why technologies are (not) embedded in healthcare that integrates ideas from outside current frameworks based on adoption, acceptance, and implementation.

This review does not focus on ethics, though some articles that deal with ethics are included in this review. Within ethics, there is general consensus that legitimacy in health and technology is produced through ethical judgments and values-based reasoning (Boada et al., 2021; Crawford, 2016; Dawson & Verweij, 2014; Tomlinson et al., 2011). While there is more cohesion in ethics than in other disciplines that deal with legitimacy, the scope of literature is narrower and generally limited to moral or ethical legitimacy (Mittelstadt et al., 2016; Morley et al., 2020). Legitimacy is often defined in ethical terms across several disciplines, including management, STS, and health policy. Articles with an ethical focus on (healthcare) technology adoption usually prioritize normative and moral dimensions of legitimacy, which may or may not be related to other aspects that contribute to overall legitimacy, like utility or social acceptability (Baeroe & Baltussen, 2014). While moral legitimacy is an

important dimension of the subject, it has also already been studied and reviewed extensively, and is far more clearly defined within the literature than other dimensions of legitimacy. Therefore, we chose to focus on other aspects of legitimacy to fill gaps in the existing social science literature. Second, our review does not center legal approaches. Legal literature defines legitimacy according to principles of a participatory democracy (Schmidt, 2012). Because the focus of this review is about social processes rather than democratic principles, we have chosen to center other means of legitimacy production (and thus, other branches of literature), while acknowledging that democratic principles can play an important role (Lovbrand et al., 2011; Martin, 2008).

## METHODS

In a research landscape that increasingly encourages and necessitates interdisciplinary collaboration, a Critical Interpretive Synthesis (CIS) (Dixon-Woods et al., 2006) allows us to develop a richer conceptual frame that can bring these different disciplines into conversation with one another (Borst et al., 2022; Carboni et al., 2022). The CIS method specifically addresses the limitations of conventional systematic reviews in cases where the objective is to generate a critical analysis of a body of literature (Dixon-Woods et al., 2006). It draws on a tradition of qualitative inquiry: rather than summarizing literature using pre-identified key concepts, CIS uses an inductive, iterative process to interpret data, develop key concepts, and synthesize concepts with data through the process of the review itself (Timmermans & Tavory, 2012). CIS therefore produces a critical interpretation of the data reported in literature which allows questioning of taken-for-granted assumptions (Dixon-Woods et al., 2006).

We found CIS to be a particularly appropriate review style for an exploration of legitimacy in health and technology because, unlike traditional review styles, CIS is adept at dealing with "a large, amorphous and complex body of literature" (Dixon-Woods et al., 2006). CIS synthesizes findings in a way that is both conceptually valuable to researchers and useful in informing policy. Furthermore, the CIS review style can manage the abstract nature of legitimacy across three disciplines without reducing the complexity of existing literature.

CIS is methodological and rigorously structured. However, it is also labor-intensive compared to other review styles and deprioritizes transparency and full replicability available through systematic reviews. As in other kinds of interpretive research, different researchers using the same materials may have come to different conclusions and full transparency of analysis cannot be expected at the same level as quantitative studies. We chose the CIS method in service of greater interpretive flexibility and conceptual depth, and because it allows us to account for the diversity of qualitative research without privileging a small range of studies that meet specific (and, in this case, less relevant) methodological standards.

Despite many empirical papers that address some aspects of legitimacy in relation to health and technology, there is a much more limited number of articles dealing with legitimacy in the domains of health and technology at a conceptual level. Therefore, we adopted broad definitions of both technology and health, including as many articles with strong legitimacy theorization as possible.. "Health" here refers to "human health and well-being"; "technology" includes "any devices, machinery, or equipment developed for the application of scientific knowledge which may impact human health." We acknowledge that there are potentially many other ways to operationalize these concepts that could be relevant to this review and healthcare in general (Berntsen et al., 2015). Given the broad, conceptual focus of the review, as well as the wide range of distinctive technologies considered, we introduced two measures which allowed us to provide clear focus. First, we zoomed in on conceptualizations of legitimacy; it was outside the scope to examine the specific empirical contexts and details of these conceptualizations (i.e. the use of specific technologies within specific health practices). Second, looking at specific disciplines proved helpful to demarcate boundaries around our topic. We use academic disciplines as the basis of our theoretical categories to give structure to a broad and abstract review, following in a strong disciplinary synthesis tradition established by other CIS researchers (Borst et al., 2022; Carboni et al., 2022).

Our review was conducted in four cycles (Borst et al., 2022). In the first cycle, we conducted an exploratory search in relevant journals with many articles on legitimacy in the context of health and technology. Using this search and subsequent iterations, we refined inclusion criteria (for instance, a threshold for legitimacy theorization) to determine a list of disciplines, journals within each discipline, and articles within these journals that would be part of our review (see Appendix A for more details). In the second cycle, we read and coded included articles directly from the text, then grouped codes into thematic areas. Third, we analyzed legitimacy in health and technology within each discipline through interpretive disciplinary summaries. Finally, we developed a synthesizing argument across all three disciplines, based on these interpretive summaries.

## SEARCH STRATEGY

Journals within each discipline were selected for the review manually. Given the interdisciplinary nature of this review, we sought to include relevant journals within each discipline from a wide range to ensure diversity of perspectives.

The first author first ran an initial search in Google Scholar, Web of Science (WoS) using the terms "legitimacy" "health" and "technology". However, it became clear that regardless of how specific the search criteria became, the majority of records returned through a database search would not include deep conceptualizations of the term "legitimacy." This is because this term is commonly used across many disciplines as an unproblematic descriptor of technologies, legal processes, narrative choices, medical decisions, policies, and institutions. Therefore, we switched to

a more iterative, manual strategy for discipline, and subsequently, journal selection. The first author searched through a few of the major journals (based on impact factor or prior knowledge of the review team) in more depth to understand whether studies addressing questions of legitimacy in a specific discipline generally included deeper conceptualization. This method allowed us to narrow down the disciplines to be included (see Appendix A for more details).

**Table 1:** Selected Journals

| **Organization & Management Studies (OMS)** | **Science & Technology Studies (STS)** | **Medical Anthropology & Sociology (MAS)** |
|---|---|---|
| Journal of Business Venturing | Science as Culture | Medical Anthropology |
| Journal of Management Studies | Science, Technology and Human Values | Medical Anthropology Quarterly |
| Organization Studies | Social Studies of Science | Anthropology & Medicine |
| Organization Science | Social Epistemology | Qualitative Health Research |
| Administrative Science Quarterly | Journal of Responsible Innovation | Critical Public Health* |
| Health Care Management Review | AI & Society | Sociology of Health & Illness |
| Strategic Entrepreneurship Journal | Big Data and Society | Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine |
| Health Care Analysis | Risk Analysis | Social Science and Medicine* |
| Strategic Organization | Information Communication & Society | Sociology-The Journal of the British Sociological Association |
| European Journal of Public Health | Research Policy | Sociological Theory |

*interdisciplinary journal (some articles included within STS)

Upon selection of disciplines, journals were included first based on impact factor: the top 10 journals in each discipline according to WoS formed the base of the list. These journals were then screened for topical relevance, and lower ranked journals were excluded when the topic was not relevant. Finally, journals were added from library guides created by universities strong in the field, especially if no definitive rankings were available from WoS (Science and Technology Studies) or there was too much disciplinary overlap in the rankings (Medical Anthropology and Sociology). This resulted in a list of approximately 20 journals per discipline. We then screened all journals for legitimacy, health, and technology results in order to produce the final list, prioritizing journals that contained significant theorization and conceptual work around legitimacy (see Appendix A for more details).

## SELECTION PROCESS

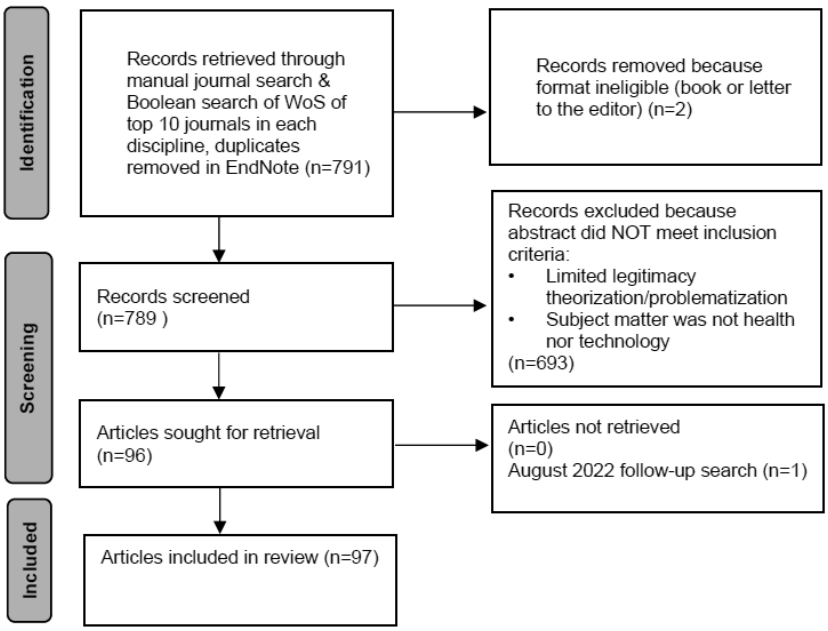


**Figure 1:** PRISMA flow diagram of inclusions

791 abstracts were selected for initial review in April 2021. Articles were sorted based on inclusion criteria: an article was included if there was evidence of explicit theorization or problematization of legitimacy in the abstract and the subject of the article was health and/or technology. A final search for more recent articles was run in August 2022, resulting in one additional inclusion. See Appendix A for more information about inclusion criteria.

## TRIANGULATION

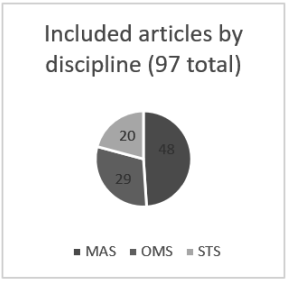


**Figure 2:** Included articles by discipline

The first author Sydney Howe (HW) read all 791 abstracts and categorized them according to the inclusion criteria as "include," "exclude," or "review." The last author Rik Wehrens (RW) reviewed 10% of the total articles' abstracts at random (every 10$^{th}$ article when arranged in alphabetical order by author name, n=79). The resulting inclusion list closely matched SH's selection. In the seven disagreements, the two reviewers came to a joint decision about each contested article and edited the inclusion criteria. SH then reviewed the abstracts again. With no disagreements following this protocol,

the literature list of 96 articles was finalized in March 2021, with an addition of one article in August 2022, bringing the total to 97.

## SYNTHESIS METHODS

The goal of our initial analysis was to develop "synthetizing constructs" for each discipline, which "build on the explanations and interpretations of the constituent studies, and are simultaneously consistent with the original results while extending beyond them" (Dixon-Woods et al., 2006). To accomplish this, SH first coded themes across a random selection of 30 articles spread equally across the three disciplines in Atlas.ti. Inductive coding began with words taken from the article text. We made an exception for deductive codes relating to assumptions made as part of our "critical and reflexive approach" to this review (Dixon-Woods et al., 2006); for instance, coding whether articles discussed legitimacy as a process, perception, or asset, based on our background understanding of existing legitimacy theorization across multiple disciplines. SH grouped codes by theme within each discipline. This thematic analysis was performed with the help of tables of code co-occurrences, generated in Atlas.ti, which showed overlap of unique codes within each document; this allowed us to understand when codes could be combined into a theme. We also used network visualizations, which helped us understand how different aspects of legitimacy may relate to one another on a broader scale (see Appendix B for an example of one of these visualizations). This process allowed reviewer SH to maintain a differentiated perspective on each discipline and acted as a memory aid for the reviewer given the volume of literature. SH then wrote summaries of the approach to legitimacy within each discipline, which were discussed with RW. SH coded the remaining articles using Excel while editing the disciplinary summaries as necessary. See Appendix A for an example.

SH developed a synthesizing argument that could connect constructs of legitimacy across all three disciplines. SH tested the fit of different conceptualizations with the disciplinary summaries and then explored the development of these metaphors with RW. After SH had read 90% of the articles, no further edits or additions to the disciplinary summaries or synthesizing argument were necessary, likely indicating data saturation.

# RESULTS

## ORGANIZATION AND MANAGEMENT STUDIES

### WHAT DOES LEGITIMACY MEAN?

The basis of legitimacy epistemology in OMS can be traced to Mark Suchman's highly influential 1995 paper. His definition of legitimacy still forms the basis of most subsequent theorizing in this field:

> *"Legitimacy is a generalized perception or assumption that the actions of an entity are desirable, proper, or appropriate within some socially constructed system of norms, values, beliefs, and definitions" (Suchman, 1995).*

This definition builds from and expands on Max Weber's understanding of legitimate authority, among other conceptualizations (Ruef & Scott, 1998), focusing on the application of Weberian legitimacy concepts such as "tradition, affectual attitudes, value, and legality"(Weber, 2019) within a "socially constructed system of norms, values, beliefs, and definitions" (Suchman, 1995). Bitektine & Haack (Bitektine & Haack, 2015) further expanded on the Weberian connection to Suchman with a multi-level legitimacy theory that differentiates among legitimacy judgments at the individual and collective levels (Haack et al.). Because of strong theoretical cohesion in this discipline, authors draw generously from these theoretical traditions, and most legitimacy subtypes are variations of normative legitimacy. Normative legitimacy deals with the norms, systems, and underlying assumptions that result in an institution, technology, or system being considered legitimate, and is generated through systems and social processes which may not be made explicit until there is a legitimacy crisis (Ruef & Scott, 1998).

This definition is notable for its understanding of legitimacy as a perception of actions based on socially-constructed norms and implicit conceptualization of legitimacy as a taken-for-granted state. Perhaps more important, however, is what is left out: because legitimacy is "generalized," it is not dependent on materialities or physical space, nor does the definition of legitimacy change specific to relationships among institutions or individuals. Our critical interpretive analysis shows that these kinds of assumptions seem to help determine the lines of reasoning for most OMS legitimacy scholars included in this review.

Our analysis shows that OMS legitimacy studies constitute a cohesive body of literature in which theoretical contributions are made incrementally. For instance, most authors outline exactly how they are adding to the existing literature (usually based on the Suchman definition) in a specific way. For instance, articles often divide legitimacy into evermore granular categories like "network legitimacy" (Provan et al., 2004) and "actional legitimacy" (Wilmot, 2004) or focus on a particular aspect of the Suchman definition to explore in more depth, such as "normative appropriateness" (Haack & Sieweke, 2018). It is therefore easy to trace the lineage of theory. However, because every article adheres to the same framework, there is less diversity of thought. In light of this, a division could be made between technology literature and healthcare literature. Technology literature, usually with an entrepreneurship bent, tends to focus on audience perception and innovation framing through discourse, by teaching entrepreneurs how to appeal through discourse to different kinds of funding audiences (Fisher et al., 2017). For example, entrepreneurs seeking crowd-based funding are advised to make "contribution claims" emphasizing identity and added value to the funding community, rather than institutional ties or the significance of potential scientific or social

advancements that may legitimate the entrepreneur to other audiences (Greg Fisher et al., 2017). Healthcare literature focuses mainly on institutional legitimacy, for instance, by examining the negotiations involved in academic health center mergers (Kitchener, 2002) or the role of physician executives in institutional contexts (Hoff, 1999). For example, Kitchener (2002) emphasizes that even as new sources of legitimacy for an academic health center became necessary in the wake of both a merger and changing environment, the aim was to create an "aura" of legitimacy within a new institutional logic; in other words, even though the source of legitimacy changed, it was still defined through institutions (Kitchener, 2002).

### HOW IS LEGITIMACY PRODUCED?

Based on the literature reviewed for this study, conceptualizations of legitimacy production in OMS fall into three categories. Legitimacy-as-process, or legitimation, is "an interactive process of social construction" (Suddaby et al., 2017), often with clearly delineated steps towards generating legitimacy (Girschik, 2020; Johnson et al., 2006). Articles using this conceptualization tend to track change over time (Cattani et al., 2017; Haack et al., 2014; Patala et al., 2019), for instance, by examining the legitimation journey of a single innovation over decades (Cattani et al., 2017). Legitimacy as perception or "a social judgment, an evaluation, a socio-cognitive construction" (Suddaby et al., 2017) is used most frequently in relation to audiences or the question "legitimate to whom?", usually when examining innovations within larger organizational contexts (Alexy & George, 2013; G. Fisher et al., 2017; Golant & Sillince, 2007). Finally, a legitimacy-as-property conceptualization, in which legitimacy is viewed as an asset to be gained, increased, or lost (Suddaby et al., 2017), emphasizes how an entity gains legitimacy rather than differences between (il)legitimate entities; this conceptualization appears to play a smaller role in more recent work. Legitimacy as process and perception are often used simultaneously within the same paper; there is acknowledgement that both perspectives can offer valuable insights. For instance, McKnight & Zietsma (2018) describe the process through which new ventures can achieve "optimal distinctiveness"(a perception) through framing and collaboration strategies (a process). Similarly, Garud et al. discuss entrepreneurial storytelling as a legitimation process that relies on audience perceptions, thereby promoting an understanding of audience perceptions as part of analyses of different narrative techniques, which are framed as processes of legitimation (Garud et al., 2014; McKnight & Zietsma, 2018).

### HOW IS LEGITIMACY USED?

Within the literature reviewed, we noted that legitimacy is often assumed in OMS to be necessary for resource acquisition and is mostly relevant in an institutional setting. Because resource acquisition is the *raison d'être* of business in capitalism, legitimacy is considered essential. All literature included in our review aims to explain legitimation journeys or to advise institutions and entrepreneurs on how to move towards legitimacy. The stated goal is often to advance legitimacy theory within OMS, rather than explore empirical evidence beyond specific case studies.

Our analysis shows that nearly all legitimacy problems in OMS are framed as problems of categorization: either an institution/innovation has been mis-categorized by its intended audience, or it has not yet been categorized (Alexy & George, 2013). Because of this, there are several articles that deal with the paradox of legitimacy for disruptive innovations: the innovation must conform to a category to be seen as legitimate, but it will not be seen as necessary unless it also distinguishes itself within the category (Fisher et al., 2017; Garud et al., 2014; McKnight & Zietsma, 2018). Articles often describe how entrepreneurs can strike this balance or analyze how an older innovation navigated the paradox. For instance, Reuf & Scott (1998) produced a multidimensional model of legitimacy designed to help hospitals use knowledge of legitimacy norms and categorization to "attract managerial legitimacy"(Ruef & Scott, 1998). Other authors provide articles that, while academic, can also be interpreted as how-to guides for entrepreneurs attempting to formulate narratives for different audiences. Articles in this category posit that entrepreneurs must fit the narrative to the correct category of both the legitimacy problem (Garud et al., 2014) and the audience's perspective (Fisher et al., 2017).

Articles discussing specific innovations often explore problems of categorization through "institutional logics" (Fisher et al., 2017; Kitchener, 2002; Patriotta et al., 2011), or the forms normative legitimacy may take within a particular institution. These articles acknowledge that different institutions have different norms, and therefore, entrepreneurs and innovators must adapt their storytelling to "fit" with the institution. Our analysis of the OMS literature showed that institutions that are taken-for-granted have no narrative flexibility. Thismeans that any changes made not only require buy-in from professionals but also immediate practical implementation of changes (such as shifting patient education responsibilities from doctors to nurses) to avoid becoming mired in default institutional processes (Reay et al., 2013). However, an entrepreneurial venture wrestling with liability of newness (McKnight & Zietsma, 2018) has nearly endless opportunities for narrative reframing and limited risk of stagnation in (non-existent) institutional processes (Fisher et al., 2017).

### SUMMARY

In short, OMS seems to heavily theorize granular definitions of legitimacy, derived mostly from normative legitimacy. Most articles describe how organizations can move from illegitimate to legitimate status. Legitimacy must be negotiated at multiple levels and can be conceptualized as a process, perception, and/or asset. Based on our initial analysis, legitimacy in OMS rests on taken-for-grantedness and categorization according to institutional logics; it is hampered by liability of newness (Alexy & George, 2013) and difficulties fitting into an institutional logic or other category.

We now move on from the critical interpretation phase of CIS methodology and towards synthesis. We develop synthetic constructs to metaphorically unite major themes within each discipline. While the OMS line of reasoning is somewhat homogeneous, our interpretive analysis shows that there is acknowledgement that different institutions use different systems of thought, or institutional logics, to judge and negotiate legitimacy. Stakeholders must navigate these different systems by fitting themselves into clear categories. However, the system by which legitimacy is judged and negotiated is rarely (fully) navigable to any one stakeholder.

In this way, navigating legitimacy in OMS is like using a highway system. The roads themselves (in this case, pathways to legitimacy) are clear and concrete but can only be used by particular categories of vehicles in particular locations, in the same way that, for instance, that entrepreneurs must use particular discourses (roads) to legitimate their invention to certain audiences (locations) (Cattani et al., 2017; Fisher et al., 2017; Garud et al., 2014). The metaphor of the highway system allows us to capture OMS' conceptualization of legitimacy as a rule-bound system of connections, driven by institutions. The highway system metaphor shows us that the OMS perspective on legitimacy is unusual for how fully theorized and comprehensive it is. However, in the same way that mapping a highway system alone does not describe everything that happens on the road, this metaphor also helps us articulate gaps in OMS theorization. OMS focuses on pathways to legitimacy, institutional involvement, and categorization; however, it can be difficult to explore of moments of legitimacy breakdown, unexpected contradictions within legitimacy journeys, and the influence of materialities on legitimacy within the concrete and bounded pathways that make up legitimacy conceptualization in OMS.

## SCIENCE AND TECHNOLOGY STUDIES

### WHAT DOES LEGITIMACY MEAN?

Within the legitimacy literature reviewed, nearly all STS articles dealt with healthcare or science practices on the edge of scientific validity or public acceptance, usually by focusing on controversial technologies. Authors seemed to pay significant attention to the audience for these controversies. Innovations explored within STS also include changes in healthcare and scientific systems or discourses, for instance, the process of creating new institutions within an academic environment (O'Kane et al., 2015).

In this way, it seems that legitimacy in STS can only be discussed easily when it is in question. This may be linked to STS's longstanding focus on controversies as strategic locations of research and the STS tendency to "stay with the trouble" (Haraway, 2010). Taken-for-grantedness may be considered such an integral part of legitimacy that it raises red flags in a discipline that is highly sensitive to unintended consequences.

However, in the STS literature reviewed, legitimacy itself is rarely the subject of an article. Our interpretive analysis shows that legitimacy still undertheorized in STS, in that many articles do not reference other legitimacy literature or define the term. When legitimacy is explored in depth, authors tend to deal with it as a type of knowledge co-produced at the site of controversy between human and non-human actors. For instance, two articles examine the demarcation of boundaries in discourse about future-facing technologies; in these articles, narratives about nanotechnology and forensic science both impact and are impacted by developments in the technology (Granja & Machado, 2020; Selin, 2007). For instance, Selin (2007) demonstrates that even if a single vision of the future of nanotechnology is accepted by scientists over all others, competing visions may still have an impact on the direction of technological development via other avenues, such as governance and funding (Selin, 2007) We interpret this as evidence that legitimacy is co-produced between the narrative around new scientific disciplines and concrete innovations within those disciplines.

A consequence of the focus on disputed boundaries that we observed in the STS literature seems to be that STS scholars treat legitimacy as mutable. Boundary work (Gieryn, 1983) articles conceptualize legitimacy as a process that happens through negotiation within relationships among people and institutions. Boundary work deals with how people and institutions (re)negotiate changing roles, limits, and responsibilities, often in relation to knowledge practices (Gieryn, 1983). Within our review, most authors seem to use boundary work only as an explanatory framework for discursive strategies, but some articles include writing and practices as instances of boundary work (Jacobson, 2018). For instance, Granja & Machado describe how forensic scientists clearly demarcate their expertise and the limits of their role in the justice system through both discursive strategies and practical performances of accountability such as fastidious record keeping (Granja & Machado, 2020) as a strategy to maintain their legitimacy. While perception can play a role in this process, we found no STS boundary work articles within the literature reviewed that consider legitimacy to be merely an asset. We interpreted this as possible evidence of the STS disinclination to consider any relationship or object to be fixed, and a general disciplinary focus on processes of knowledge production.

### HOW IS LEGITIMACY PRODUCED?

We found that processes of legitimacy co-production of new technologies in health care are described in relationships among a variety of human and non-human actors (Latour, 1987). STS seems to resist explanations that pin legitimacy's presence or absence on a single explanation or strategy. Instead, by examining influence of non-human actors, STS encourages readers to embrace

complexity in legitimacy relationships. For example, Barker (2011) discusses how a drug marketing campaign legitimated a contested illness; McLevey (2015) details how legitimacy goals for policy recommendations change how think tanks make knowledge; and Greco (2004) uses the concept of "scientific ideology" to explore how the placebo effect threatens the legitimacy of scientific rationality in biomedicine. In these examples, the influence of unexpected non-human actors shapes legitimacy in a porous way; this influence adds complexity to legitimacy relationships. These examples thus turn the "expected" legitimacy relationship upside down. Barker shows that a treatment can make an illness legitimate (rather than an illness becoming legitimate and then treatment being developed). McLevey demonstrates that knowledge may be made to legitimize policy recommendations (rather than knowledge first being created and then informing policy decisions). Finally, Greco posits that a biomedical effect can threaten the legitimacy of biomedicine (rather than biomedicine creating biomedical effects that reinforce its legitimacy).

## HOW IS LEGITIMACY USED?

Through our critical interpretive analysis, legitimacy in STS appears to be yet another "two-faced Janus"(Latour, 1987), in that it is co-produced by both taken-for-granted processes and unexpected assemblages, which may appear contradictory. For instance, Brown & Michael (2001) note that the institutional mechanisms for validating scientific discovery play a part in legitimizing medical use of pig organs. However, the authors also find that these taken-for-granted institutional processes are not enough to legitimate transspecies transplantation. Rather, porcine donor organs are legitimated in their interpretation through an unexpected assemblage of institutional processes and scientific and cultural judgments about pigs. While anatomical similarities between humans and pigs legitimate porcine donor organs from a scientific perspective, human-pig differences legitimate porcine donor organs (over, for instance, monkey organs) from a cultural perspective (Brown & Michael, 2001). These apparent contradictions do not threaten the legitimacy of porcine donor organs: instead, the authors interpret these contradictions as necessary to establish legitimacy for a controversial innovation in medicine.

While most articles in STS literature reviewed use the concept of legitimacy to explore complexity in relationships among technologies, ideas, people, and institutions, a small subset of the literature consists of discourse analyses focusing on language as the only vehicle of legitimation (Licht & Licht, 2020; McLevey, 2015). In these articles, there is no room for other means of legitimation, such as non-discursive practices, language-free materialities, or physical space. Additionally, policy-oriented articles about discourse-based legitimation strategies tend to view these strategies as mutually exclusive: "legitimacy can only be achieved if complexity is reduced via language" (Flink & Kaldewey, 2018). This appears to be a radical departure from the assembled view of legitimation present in most STS articles, in that legitimacy is produced by specific arguments designed to convince one party that another is legitimate, rather than *through* the complexity of negotiation among people, technologies, ideas, and institutions. However, both STS subgroups use legitimacy as a relational concept, whether relationships are implied through arguments or complex negotiations.

### SUMMARY

Our analysis demonstrates that STS approaches legitimacy through controversy and contestation. Because of its empirical orientation and wide variety, the way legitimacy is approached in STS cannot be viewed as theoretically cohesive.. We found that STS explores legitimacy as an artifact of knowledge co-production, centering non-human actors and complex legitimacy processes through discourse, practices, or both. In one conceptualization, legitimacy is viewed as a constant and complex negotiation among actors and their contexts. However, discourse analyses often view the complexity of these relationships as a problem for legitimacy rather than an integral aspect of the concept. Despite this divergence, nearly all STS literature reviewed seems to assume that legitimacy is relational and includes non-human actors, contexts, and practices of knowledge production.

Moving towards our synthetic constructs, we posit that in STS, the co-production of legitimacy through both taken-for-granted processes and unexpected assemblages functions like the mutable infrastructure of a computer operating system. The hardware of the computer does not change (much), even though the overall capacity of the computer relies on constant updates of existing software. New operating systems build on what came before while adding something new to stay relevant. Similarly, legitimacy of technologies in healthcare is viewed predominantly as being built on underlying infrastructures, such as evidence-based medicine (EBM) and laboratory protocols. However, it is also considered to be shaped by unexpected influences, like the co-existence of traditional medicines with EBM standards (Cloatre, 2019) and popular conceptualizations of new technologies that do not align with use of those technologies by experts (Granja & Machado, 2020). Furthermore, legitimization of a technology may have unexpected consequences, such as a medicine legitimizing an illness (Barker, 2011). Legitimacy according to STS scholars must be constantly negotiated among (non-)human actors through an iterative process that is most visible at the boundaries. Through the metaphor of computer operating systems, STS emphasizes a dualistic perspective of legitimacy. Legitimacy in STS depends on the mutability and unexpected creativity of practices, actors, and context (software); simultaneously, this "software" of legitimacy must be built on top of pre-existing systems that are much more rarely changed in substantial ways (hardware). Without these pre-existing systems, the knowledge production practices delineated by STS scholars have nowhere to operate.

## MEDICAL ANTHROPOLOGY AND SOCIOLOGY

### WHAT DOES LEGITIMACY MEAN?

Based on our critical interpretation of the MAS literature under review, we found that MAS tends to center relationships among people within larger systems and physical spaces, rather than the nature of the systems or institutions themselves. Like STS, the MAS literature reviewed usually discusses controversies rather than strategies of legitimation.

Because few articles use concrete definitions of legitimacy or conceptualizations that reference any other body of literature, even if they discuss legitimacy issues in depth using empirical evidence, we found legitimacy to be undertheorized within MAS as a discipline. Several articles use terms like "medical legitimacy" (Fishman et al., 2015) or "narratives of legitimation" without definitions (Foley & Faircloth, 2003). Some define legitimacy only in relation to another concept (Hornberger, 2019; MacGregor et al., 2021; Wamsiedel, 2018). More than any other discipline, MAS seems to veer towards legitimacy definitions that are limited by subject and narrow (Gieryn, 1983) in scope: for instance, "Being legitimately on sick leave requires both a certified illness and the inability to perform one's work as a result of that illness"(Flinkfeldt, 2011). In our interpretation, this appears to allow for more empirical grounding but prevents conversation with other literature about legitimacy as a larger concept. Within the MAS literature reviewed, legitimacy is always relative, in that there is no universal legitimacy that works across all contexts.

However, there is still some cohesion visible among a subset of articles in the discipline. Several authors frame legitimacy as a form of "symbolic capital" in the Bourdieuvian sense (Bourdieu & Nice, 2013; MacGregor et al., 2021; Pushkar & Tomkow, 2021) which can be used for resource acquisition. These articles and others also use boundary work (Gieryn, 1983) to describe the legitimacy of professional roles as a negotiation of boundaries mostly through discourse (Jones & Pietila, 2020). In combination with the disciplinary tendency to focus on the disenfranchised, these framings paint legitimacy as a power issue (Martin, 2008).

The literature reviewed seems to prioritize nuanced accounts of both social processes in contested situations and the spaces and materialities that shape contestation of a technology. For instance, in an exploration of medical quackery in South Africa, Hornberger (Hornberger, 2019) shows that even when using medically-useless technologies, providers of these technologies can construct legitimacy to their patients because of contextual elements, such as lower education levels, local beliefs, and problems accessing proven medical treatments. Spaces, materialities, and relativity appear to be especially important in articles about disconnects between policy and practice in professional settings (Sheard et al., 2017). For example, Perrotta & Geampana (2020) explore how in-vitro fertilization (IVF) professionals navigate the disconnect between the standards of EBM and the enthusiasm of patients for the latest technologies. In another account of IVF, Barnreuther (2016) notes that because the research took place in a doctor's private home in India, as opposed to an institutional setting in a Western country, the resulting technical success was deemed illegitimate and went unrecognized in both medicine and research for decades. We find that these kinds of nuanced accounts present a deeper and more empirically-grounded understanding of the meaning of legitimacy in context, despite lack of theorization.

## HOW IS LEGITIMACY PRODUCED?

Our critical interpretation of the MAS literature emphasizes the intertwined nature of practices, discourses, social processes, and materialities in the production of legitimacy. Authors often seem to assume these are impossible to separate from each other without losing meaning. For instance, in a study of the use of restraint in a hospital psychiatry ward, McKeown et al. (2020) examine how boundaries of space (office or patient area), identity (provider or patient), and diagnosis work together to legitimize or delegitimize the use of force in context. In this way, legitimacy is defined, not merely influenced, by the environment in which it is generated (Busfield, 2021).

When legitimacy is conceptualized as a power problem, categorization seems to solidify the standing of already-legitimate actors. Meanwhile, power appears to become less accessible for the illegitimate when professional boundaries are unclear (Lees et al., 2020; MacGregor et al., 2021; Sanders & Harrison, 2008; Weiss & Sutton, 2009) or impermeable to outsiders (Mizrachi, 2002; Petersen et al., 2015; Zavestoski et al., 2004). Common MAS topics include contested illnesses and attempts of patients to receive treatment (Flinkfeldt, 2011; Mik-Meyer & Obling, 2012; Zavestoski et al., 2004) and role negotiations of (non)medical practitioners within the medical establishment (Barnreuther, 2016; MacGregor et al., 2021; Mizrachi, 2002; Nathan et al., 2014; Tovey, 1997). In both cases, power imbalance is usually framed as the primary obstacle to legitimacy, which is necessary for a more egalitarian redistribution of power. Though some authors argue it is possible to have some power without legitimacy (Barnreuther, 2016; Jones & Pietila, 2020; Nathan et al., 2014), the physical location of institutions, people, and technologies still defines flows of resources, manifesting in, for instance, differential treatment of patients at a rural hospital that would be unlikely at an urban hospital due to differences in hospital conditions, rather than patient deservingness (Andersen, 2004). Based on these examples, our interpretation is that MAS and OMS have some overlap in this area, in that both disciplines seem to approach legitimacy as an issue of access to resources.

## HOW IS LEGITIMACY USED?

MAS literature reviewed often examines how legitimacy can flow through the taken-for-granted artifacts of professionalism. These artifacts include prescriptions (Weiss & Sutton, 2009) and complicated-looking fake medical machines (Hornberger, 2019). Because the object itself is imbued with legitimacy through specific qualities in the professional context (e.g. an appearance of being "official" or "high-tech"), artifacts in these articles seem to reinforce the legitimacy of the pharmacist writing the prescription or the practitioner using the machine. Material artifacts may also include larger systems like old IT infrastructures or preexisting contracts that impede desired change within institutions (Sheard et al., 2017), implicitly reinforcing the legitimacy of institutional systems. While these materialities impact potential changes in legitimacy, they are usually not the subject of debate in the MAS literature. Therefore, it seems that the legitimacy of the prescription-writing pharmacist may be contested, but the prescription itself usually is not (Weiss & Sutton, 2009).

## SUMMARY

Our critical interpretation of the MAS literature is that legitimacy in this discipline is a relative and context-dependent concept. Legitimacy is often understood to be intertwined with power relations, but authors disagree about the nature of this connection and its implications. Finally, MAS articles center sites of controversy in which the subject has already been deemed illegitimate by focusing on space, materialities, and relationships. MAS authors appear to use these lenses to question "default" narratives of legitimacy in favor of exploring how and why a technology, system, group, or experience came to be viewed as illegitimate.

Here we develop our final disciplinary synthetic construct. Our interpretive analysis found that in MAS, legitimacy is physical, material, and always relative. Therefore, we employ the metaphor of a building's plumbing: each part of the system, from the pipes to the faucets, performs a different function, which defines both their physical form and location. No two buildings can have identical plumbing systems, because no two buildings, even if constructed similarly, are situated in exactly the same location—thus, they must connect to the local environment in different ways. In much the same way, the materialities of health and technology, and how these materialities interact with spaces and actors, are considered to define legitimacy of health and technology in MAS. A "quack" technology reads as legitimate instead of "fake" because of both its physical form and the spatial context it inhabits (Hornberger, 2019); an innovation like IVF in the "wrong" space may never be recognized as innovation at all (Barnreuther, 2016). In both cases, if we understand legitimacy to be an infrastructure that is dependent on both space and materialities, we can better connect the different underlying systems and elements that comprise legitimacy for health technologies. A sink connected to a sewer line requires multiple specific parts, arranged in a particular way, running through a particular location, in order to function. In the cases noted above, materials, the spaces in which they are developed, and the spaces in which they are utilized must be arranged in particular ways for technologies to be considered legitimate, whether the audience is the international scientific establishment (Barnreuther, 2016) or residents of a rural South African community (Hornberger, 2019). The metaphor of a plumbing system emphasizes the categorical importance of context and physical materials in the construction of legitimacy: in MAS, legitimacy cannot exist without these. This metaphor therefore also helps us understand why MAS generally avoids comprehensive definitions or theorization of legitimacy; other than a few basic building blocks, systems of legitimacy for MAS are essentially viewed as non-transferrable between contexts.

## SYNTHESIZING ARGUMENT: LEGITIMACY AS SOCIAL INFRASTRUCTURE

Legitimacy is omnipresent and important within all three disciplines. However, it is often undertheorized and the subject of many implicit assumptions across MAS and STS literature. In OMS, conversely, increasingly detailed theorization results in the proliferation of "subtypes" of legitimacy with limited empirical support. Our synthesizing argument allows us to bring these different disciplinary traditions into conversation with each other through a new conceptual framework for legitimacy.

**Table 2:** Disciplinary Characteristics: Legitimacy in OMS, STS, & MAS

| | **Organization & Management Studies** | **Science & Technology Studies** | **Medical Anthropology & Sociology** |
|---|---|---|---|
| **Theoretical foundations** | Major focus on theory, granular definitions of legitimacy common; normative legitimacy most prevalent | Some theoretical exploration but limited theoretical cohesion | Limited theoretical exploration, reliance on granular definitions based on empirical evidence |
| **Conceptualized as** | A process (of negotiation); perception; and/or asset | A product of knowledge co-production; a negotiation among human & non-human actors, contexts, and epistemic cultures | A relative & context-dependent concept intertwined with power relationships |
| **Purpose of literature** | Describe how organizations can move from illegitimate to legitimate status | Investigate instances of controversy and contestation | Explore how and why a subject came to be viewed as illegitimate. |
| **Most important related concepts** | Taken-for-grantedness; categorization and standardization | Relationships, taken-for-grantedness, unexpected assemblages | Materialities, relationships, space |

Using the three disciplinary metaphors we developed, we propose that legitimacy can be conceptualized as a social infrastructure, based on Star and Ruhleder's criteria for an infrastructure (Star & Ruhleder, 1996). If we combine the metaphors of a highways system (OMS), computer operating system (STS), and plumbing system (MAS), we begin to see building blocks of an infrastructure that can support an entire city. Each metaphor shows a particular element of city infrastructure (understanding of legitimacy) clearly. However, like a layered map of a city's interconnecting infrastructures, we gain a fuller picture of how legitimacy works in health and technology when we layer the metaphors to view their intersections and divergences. Knowing how computer systems monitor traffic and manage stoplights helps us better understand both computer systems and highways; similarly, an STS understanding of how unexpected assemblages may work with taken-for-granted processes can help us better understand how these unexpected assemblages may impact theory about taken-for-granted processes in practice within OMS. Such a layered map therefore allows for a richer conceptualization in which there is room for different approaches to legitimacy without denying the validity of any single conceptualization.

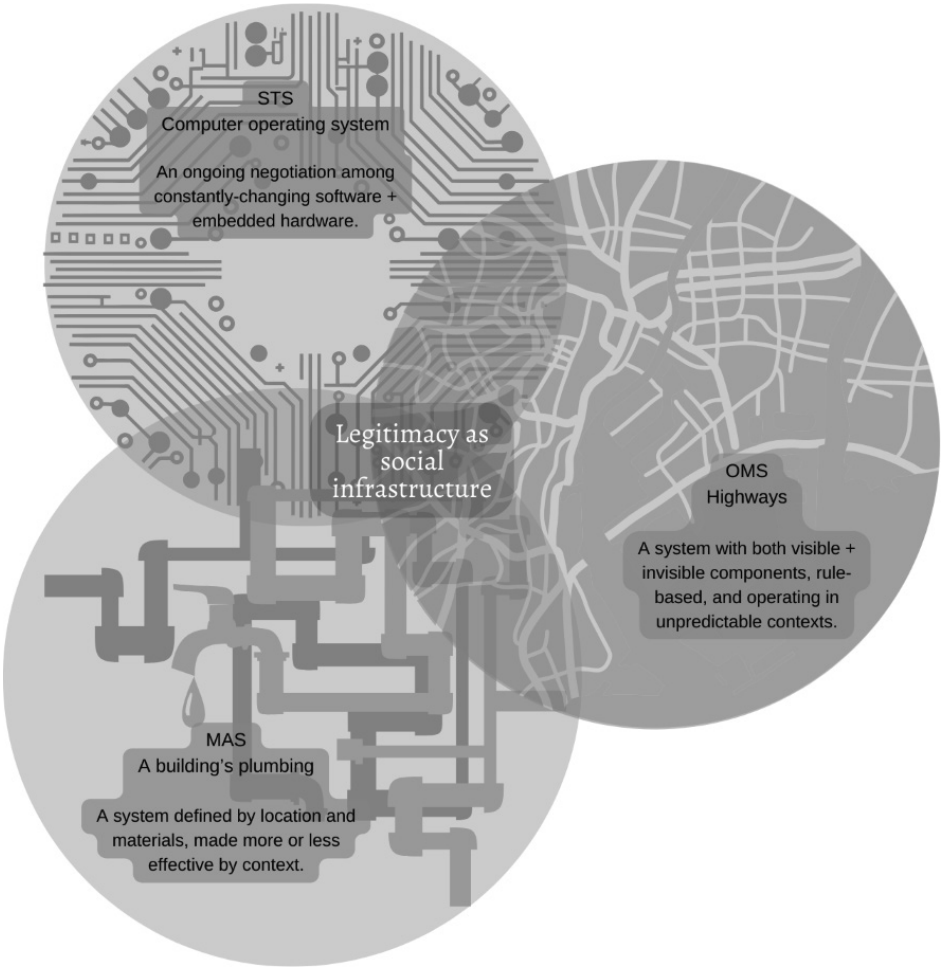


**Figure 3:** Disciplinary Metaphors

Like a physical infrastructure, legitimacy can be understood as a binding fabric that makes possible certain types of relationships among people, institutions, and technologies. In our conceptualization, legitimacy is an inherently relational concept: it can only exist between two or more entities, rather than within the perceptions of a single person or institution. The notion of social infrastructure makes space for legitimacy to exist outside of human judgments, without devaluing the importance of perception in the production of legitimacy. Just as infrastructures consist of both materialities and abstract systems (e.g., roads are made of concrete, but their use is facilitated by traffic laws), social infrastructure melds semiotic, material, and normative aspects of legitimacy and explores how they might work together. Infrastructure thus allows for the integration of disparate and seemingly-contradictory aspects of legitimacy-making. While Star has emphasized that infrastructure is inherently a "relational property"(Star, 2016), we use the word "social" to focus on how legitimacy

supports specific types of relationships among people, institutions, and technologies; in particular, how these relationships are shaped by implicit and intangible norms and values (Monat, 2015). For instance, understanding the nuances and norms of pharmacists' relationships with both doctors and healthcare institutions reveals why a simple policy change allowing pharmacists to prescribe medication legally is not enough to legitimize the practice (Weiss & Sutton, 2009). This moves us away from conversations about legitimacy as a conduit for resources and towards more clarity about how legitimacy acts as a binding fabric within social relationships.

Descriptions of legitimacy across all three disciplines fit Star and Ruhelder's criteria for an infrastructure. For instance, legitimacy is usually only visible "upon breakdown"(Star & Ruhleder, 1996). Contestation and controversy are the only sites of legitimacy exploration in MAS and STS; in OMS, legitimacy is discussed in terms of desired change in legitimacy status (i.e., moving from illegitimacy to legitimacy), and contestation is captured explicitly through concepts like "liability of newness" (Garud et al., 2014; McKnight & Zietsma, 2018). Additionally, maintenance of this social infrastructure happens through continued adherence to legitimizing protocols and norms within relationships; deviations can result in a crisis of legitimacy. In this sense, legitimacy is characterized by strong fit with pre-defined categories and "standards"(Star & Ruhleder, 1996) in many articles (Andersen, 2004; G. Fisher et al., 2017; Flink & Kaldewey, 2018; McKnight & Zietsma, 2018), even when legitimacy itself is not defined. In our conceptualization of legitimacy, norms and values make up the "installed base" into which legitimacy is embedded (Star & Ruhleder, 1996), and are responsible for legitimacy's taken-for-granted nature.

Legitimacy also acts like infrastructure, in that it can be used to invisibly support the work of organizations, technologies, or people (Latimer, 2004; Patriotta et al., 2011; Star & Ruhleder, 1996), often by allowing for acquisition of resources or power (Kwak & Yoon, 2020; MacGregor et al., 2021). In fact, values and norms are often so deeply entrenched and invisible that even the infrastructure supporting them (legitimacy) becomes taken-for-granted and invisible itself. This combination can make it extremely difficult for any contradictory experiences or knowledge to find expression within a society's taken-for-granted, unquestioned truths (Andersen, 2004; Bourdieu & Nice, 2013; Caiata-Zufferey, 2015; Paxman, 2021). Therefore, it is understandable why the moments of crisis when legitimacy is "visible upon breakdown" usually occur when norms and values clash with each other. For example, in Perotta and Geampana's exploration of IVF (2020), new reproductive technologies are a site of legitimacy crisis because they are heavily desired by patients, but cannot adhere to standards of EBM. In this situation, doctors must navigate among the medical value of providing patients with the care they seek, the medical value of providing evidence-based care, and the medical norm of adhering to preset medical standards that may not have kept up with available care options.

Finally, the origins of legitimacy parallel those of any other infrastructure. Legitimacy is built on existing social systems: it "wrestles with the inertia of the installed base"(Star & Ruhleder, 1996) and borrows both strengths and weaknesses from that base, resulting in legitimation by once-functional mechanisms that are now relics. For instance, Sheard et al. (2017) show how desired changes in practices in a hospital setting are stalled by existing social, technical, and bureaucratic systems and entrenched social practices, despite lack of effectiveness of these entrenched systems and desire for change among the people acting within them. Overcoming this systemic inertia requires integration of new practices and systems into the installed base, regardless of the current utility of that base; attempts to completely overhaul entrenched institutional practices or technologies without attention to the installed base rarely succeed.

In all three metaphors, infrastructure serves as a system through which different elements that contribute to legitimacy can negotiate with one another. A social infrastructure conceptualization reflects the nature and parameters of these negotiations.This lens thus allows us to see where different perspectives on legitimacy could provide a more holistic picture of how legitimacy works in practice, encouraging a collaborative approach to conflicting views on legitimacy.

We hope this conceptualization can provide a useful lens to better understand how legitimacy is produced and how it works among institutions, technologies, and people. We aim to move the conversation towards a more holistic perspective on embedding technologies in healthcare that goes beyond models based primarily on judgments and perceptions.

## DISCUSSION

Our conceptualization of legitimacy as social infrastructure allows for deeper analysis and understanding of the meaning, production, and uses of legitimacy when embedding technologies in healthcare. Our review contributes to the OMS literature by bringing in outside perspectives. Cross-fertilization among the three disciplines reigns in the proliferation of legitimacy theory in OMS while providing a better connection with empirical research. STS and MAS literature benefit from grounding empirical exploration within a more cohesive theoretical framework. Our review also helps contextualize studies of legitimacy that are more limited in scope; for instance, while discourse analyses of legitimacy are useful, this review demonstrates that discourse comprises just one aspect of legitimacy production (Foley & Faircloth, 2003; Sapir, 2020; Vaara & Monin, 2010). By allowing for many definitions of legitimacy, the notion of legitimacy as social infrastructure is adaptable enough to produce meaning across disciplines, while providing ways to explore relational, material, and semiotic aspects. By providing a framework through which to explore many conceptualizations and understandings of legitimacy, we hope LSI can facilitate fruitful cross-disciplinary collaborations of legitimacy researchers. Specifically, LSI allows different conceptualizations can co-exist without competing with one another, providing a framework

in which researchers can build on the work of other disciplines without having to disregard the traditions of their own discipline. Additionally, this framework provides value to acceptance, adoption, and implementation researchers and other stakeholders interested in better explaining how technologies are embedded in healthcare. Through an interdisciplinary understanding of legitimacy and a focus on relationships and moments of breakdown, LSI provides a mechanism to study technology embedding both contextually and over time. In this way, LSI produces a more comprehensive understanding of how the interconnected social, medical, environmental, and institutional elements surrounding a technology may interact in ways that impact legitimacy for a given technology, and thus, whether a technology will become embedded in healthcare.

## EMBEDDING BEYOND CURRENT FRAMEWORKS

Legitimacy as social infrastructure provides an alternative to current models describing how technologies are embedded in healthcare. We can use this conceptualization to account for gaps between policy intentions and practices when embedding technologies. Social infrastructure produces a more comprehensive understanding of the issues underpinning technology adoption than frameworks that hinge on trust (Fox & Connolly, 2018; Reddy et al., 2020), transparency (Licht & Licht, 2020; Reddy et al., 2020), and acceptability (Dwivedi et al., 2016), especially when those frameworks are based on behavioral intention (Holden & Karsh, 2010; Nadal et al., 2020; Yarbrough & Smith, 2007). Articles included in this review have shown that the complexities of embedding technologies in healthcare often clash with the best-intentioned policy choices because these frameworks generally do not account for the full scope of legitimizing processes within healthcare delivery systems. This is particularly evident in articles that focus on contested illnesses (Clark & Botterill, 2018; Paxman, 2021; Zavestoski et al., 2004) and professional boundary work negotiations in light of new policies or collaborations in healthcare (Edwards, 2014; Hoff, 1999; Lees et al., 2020; Reay et al., 2013; Vargas, 2016; Weiss & Sutton, 2009). For example, Weiss & Sutton (2009) demonstrate that even though policy changes explicitly allow pharmacists to prescribe medication, actually doing so in practice involved a more complex negotiation of roles and hierarchies to legitimize pharmacist prescribing activities. The new prescribing policy, based on notions of trust and acceptability, is not enough. For patients whose contested illnesses do not meet EBM criteria (Zavestoski et al., 2004), negotiations and individual relationships are essential to access any kind of medical care (Haldar et al., 2016). In this case, EBM criteria designed to increase transparency and trust in medicine prevent patients with real symptoms from accessing necessary care.

The many technology acceptance and adoption frameworks available currently have difficulty explaining adequately how and why some technologies are embedded in healthcare but others are not; in other words, "the literature does not specify the conditions for full use to be achieved"(Nadal et al., 2020). Like legitimacy, these terms are not clearly defined across the

literature (Nadal et al., 2020): "acceptance" and "acceptability" generally are defined in terms of perceptions of (potential) users (Nadal et al., 2020; Proctor et al., 2011), and separate from both "adoption" and "appropriation," which deal with the processes and practices of using the technology (Nadal et al., 2020). Other models aim to identify factors contributing to acceptance of new technologies. The Technology Acceptance Model (TAM) is the most well-known example; it has been adapted and added to by numerous authors since its inception (Davis, 1985; Holden & Karsh, 2010; Nadal et al., 2020; Yarbrough & Smith, 2007). However, like most technology acceptance models, TAM is based on behavioral intention, which has limited utility in predicting actual behavior (Conner & Norman, 2022; Manski, 1990) and does not generally attempt to integrate other systemic or relational aspects of technology acceptance. Within this review, Reay et al.(Reay et al., 2013) demonstrated that gaining discursive buy-in, the focus of behavioral intention models of technology adoption, "is not enough" to legitimize new practices in a clinical setting without action and interpersonal, structural support.

Other frameworks have attempted to integrate socio-cultural aspects of technology acceptance, specifically in low- and middle-income countries, though acceptance still generally focuses on individual users rather than systemic or relational factors (Peiris et al., 2014). More unusually, Greenhalgh et al.'s NASSS framework (nonadoption, abandonment, scale-up, spread, and sustainability)(Greenhalgh et al., 2017), which is explicitly directed at health technologies, attempts to fill gaps left by TAM and other models by focusing on nonadoption and abandonment of technology instead of acceptance. This framework incorporates norms and values to some extent but does not focus specifically on legitimacy and the impact of norms and values on technology development.

The legitimacy as social infrastructure framework (LSI framework) is different from these models: rather than starting with (non)adoption and (non)acceptance of technologies, our conceptualization focuses on the relationships and negotiations that result in (non)adoption and acceptance. If we take legitimacy as a necessary element in technology adoption and acceptance, conceptualizing legitimacy as social infrastructure allows us to understand how adoption, acceptance, and implementation frameworks may work together to explain the process of embedding technologies in healthcare. For instance, rather than conducting acceptance, adoption, and implementation studies separately in a health technology development project, researchers could use the conceptualization of legitimacy as social infrastructure as a framework to iteratively explore the binding fabric of relationships and legitimacy narratives that make up the landscape in which a new technology is being developed and provide advice to decision-makers based on these findings. This focus would also allow project stakeholders to contextualize the results of a traditional acceptability or adoption study to better support the end goal of successfully embedding a technology in healthcare. Doing so would move conversation beyond simple adoption and acceptance, and towards a more holistic perspective about this embedding process based instead on an analysis of legitimacy.

## FOCUS ON RELATIONSHIPS AND NARRATIVES

Momentum for embedding technologies in healthcare often fades due to unforeseen complexities (Wehrens & Bal, 2012) when moving technologies from laboratories to real-world environments. Particularly for mobile health (mHealth) technologies in which social and relational elements play a heightened role, the LSI framework could prove extremely useful in both anticipating and navigating complexity in the real world by describing (changing) relationships and narratives. Legitimacy as social infrastructure could provide a better blueprint that takes contextual factors into account earlier and avoids some of the acceptance and adoption bottlenecks that develop in linear models.

The struggles and unintended consequences of embedding technology in practice have been well-documented in STS and OMS (Barker, 2011; Edwards, 2014; Granja & Machado, 2020; Kannan-Narasimhan, 2014). The LSI framework conceptualizes how these documented struggles impact legitimacy, and thus technology adoption and acceptance. STS understands new technologies (including those designed for healthcare) to be both directional and open-ended (Carboni et al., 2022). Technologies are embodied with certain scripts and ideas, produced both through the development process and purposely in the minds of developers and other stakeholders, impacting how they can be used and when. However, the scripts managing this directionality never fully determine how a technology is used in practice (Carboni et al., 2022; Verran, 2010). Integrating technologies into real world environments necessarily involves tinkering (Carboni et al., 2022; Greenhalgh et al., 2017; Wehrens & Bal, 2012) by users, developers, and other stakeholders, often contradicting a technology's directionality entirely. For instance, as Perrotta and Geampana (Perrotta & Geampana, 2020) demonstrate, new medical technology may be used in ways that contradict its original EBM-derived script, given a particular set of circumstances generated by patients, economics, and the pace of technology development. What happens next is a negotiation that determines how real-world context, practices, and technology scripts interact to generate a legitimacy relationship. Conceptualizing legitimacy as social infrastructure allows us to both understand the nature of these interactions and how they may (not) lead to technology adoption and acceptance in a healthcare setting. For instance, Sheard et al.(Sheard et al., 2017) discuss the complex systems and legitimacy relationships that impact the ability of care providers in the UK to act on patient feedback; this feedback is solicited in the first place to increase trust in and acceptability of the medical system. If we view patient feedback frameworks as a form of healthcare technology, legitimacy as social infrastructure helps us better understand and anticipate the relative importance of backgrounded relational and structural systems (Sheard et al., 2017) that determined whether or not patient feedback was incorporated successfully or not in the healthcare institutional systems under study. An infrastructural understanding reveals how the three issues identified (normative legitimacy, structural legitimacy, and organizational readiness (Sheard et al., 2017; Suchman, 1995)) work together to support or deter change in a complex organizational setting. A binding fabric of relationships ties all of these issues together and clarifies why the quality

of certain relationships is more important than others. This focus also adds to understanding of the phenomenon of "institutional entrepreneurs." Relationships likely play a role in how institutional entrepreneurs avoid being "confined by the status quo," allowing them to change organizations from within despite legitimacy challenges for others (Sheard et al., 2017).

## FUTURE RESEARCH AND APPLICATIONS

Given the utility of this conceptualization in bringing together three very different disciplinary traditions around legitimacy, future research could expand on this work to incorporate perspectives from disciplines such as ethics and law that we could not include here. Additionally, it is possible that legitimacy is usually not explicitly conceptualized in medicine and psychology due to an implicit discipline-wide understanding of the values that underpin the concept. In other words, norms and legitimacy in medicine and psychology may be so closely intertwined with the goal of providing care that legitimacy may not be contested or questioned from these disciplinary perspectives. These kinds of taken-for-granted assumptions make it important to explore the origins, production, and meanings of legitimacy more thoroughly in the psychology and medical fields. Our conceptualization could allow for such investigation in fields in which the language describing legitimacy is either absent or perceived to be self-evident.

Potential applications of legitimacy as social infrastructure in practice have a wide range thanks to the flexibility and adaptability of the conceptualization. For example, to manage risks appropriately, regulators and others must have knowledge and understanding of the subject of regulation, in this case, healthcare technologies. This includes not only technical knowledge, but epistemological understanding of what is seen to constitute valid forms of knowledge, what is being left out, and "system knowledge of the context regulation is operating in"(Black & Murray, 2019). By approaching the embedding of technologies in healthcare as a result of knowledge co-production, the notion of legitimacy as social infrastructure can provide deeper understandings of the systems and context of health technologies. It can then help regulators differentiate valid from invalid forms of knowledge in context. Regulators themselves also experience legitimacy concerns, in that regulation must be legitimate in order to function (Cleemput et al., 2012; Pace et al., 2015). An understanding of legitimacy as social infrastructure could provide regulators with clarity about the practices, decisions, and structures that may impact their own legitimacy. For instance, knowing more about how their relationships with various stakeholders contribute to their legitimacy could help regulators take stakeholders' viewpoints into account at the most impactful moments and more appropriately narrate their decisions for different audience needs.

## LIMITATIONS

Given the broad focus of our topic "legitimacy in health and technology," we included a heterogenous collection of empirical topics within each discipline. While this allowed for a broad discussion of legitimacy in health and technology, we did not produce one overarching definition of legitimacy; rather, we developed a conceptualization that can be used as a framework with the diversity of definitions already available. Similarly, the disciplinary boundaries are somewhat "fuzzy"(Dixon-Woods et al., 2006): OMS is a sub-discipline of Sociology, STS overlaps with both Medical Anthropology and OMS, and MAS is a combination of two disciplines with similar approaches. We found these disciplinary constructs useful because, despite their overlap, they highlight substantial differences among social science approaches to legitimacy.

In addition to the legal and ethical boundaries previously described, in this review, we did not engage with several other topics related to legitimacy of technologies in healthcare. While the word "legitimacy" is used frequently in medicine and health economics, very few articles in these fields define the concept or explore it in any depth. Rather, the vast majority use the word uncritically within a surface explanation of the importance of a problem, either by claiming without evidence that legitimacy is an asset held by organizations, technologies, or people (Benniche, 2019; Brown et al., 2016; Mandeville et al., 2019); or by mentioning that legitimacy of a technology is under threat, but without fully discussing why or how (Myers et al., 2012; Pocock & Stone, 2016). When legitimacy is defined, it is often reduced to a series of related concepts such as "expertise, reciprocity, and trustworthiness" without discussing how these interact to create legitimacy (Penedo et al., 2020) though there are a few exceptions (Cleemput et al., 2012). Due to the general lack of critical exploration, medicine and health economics were excluded as disciplines. This is an area that would benefit from further research using the LSI framework.

For similar reasons, we focused our search strategy within journals known to provide deep conceptualization of legitimacy (see Appendix A for further details). Given the abstract and conceptual nature of our subject, a database search proved inadequate for finding all relevant articles; however, searching only within specific journals, despite rigorous selection, may have biased study findings. We feel the benefits of closely adhering to CIS protocol in this manner outweighed this issue due to our study's interpretive goals and our abstract subject matter.

## CONCLUSION

The notion of legitimacy as social infrastructure provides a deeper understanding of how and why technologies are (not) embedded in healthcare. Social infrastructure focuses on the aspects of legitimacy related to norms, semiotics, materialities, and specific relationships among stakeholders and institutional contexts without excluding or privileging one form of knowledge production over the other. Through this conceptualization, the production and use of legitimacy can be

studied ethnographically by following the social infrastructural networks and relationships that constitute and maintain legitimacy. By moving beyond judgment- and perception-based frameworks, legitimacy as social infrastructure approaches the problem of embedding technologies in healthcare through the lens of knowledge co-production. The LSI framework enables empirical data collection and analysis that transcends disciplinary boundaries without negating the discrete lines of theoretical thought of any one discipline.

Given the interdisciplinary nature of healthcare policy and practice and the wide range of stakeholders involved, clearer and deeper communication around legitimacy could have far-reaching impacts. This could include new frameworks explaining technology adoption and acceptance, greater consensus about what makes a healthcare technology or policy decision legitimate, and strategic direction for decision-makers working with disruptive healthcare technologies within entrenched systems.

## ABBREVIATIONS

**AI:** artificial intelligence
**CIS:** critical interpretive synthesis
**EBM:** evidence-based medicine
**HTA:** health technology assessment
**IT:** information technology
**IVF:** in-vitro fertilization
**JMIR:** Journal of Medical Internet Research
**MAS:** Medical Anthropology and Sociology
**mHealth:** mobile health
**NASSS:** nonadoption, abandonment, scale-up, spread, and sustainability
**NICE:** National Institute for Health and Care Excellence (NICE)
**OMS:** Organization and Management Studies
**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses
**RCT:** randomized controlled trial
**RW:** Rik Wehrens
**SH:** Sydney Howe
**STS:** Science and Technology Studies
**TAM:** Technology Assessment Model
**UTAUT:** Unified Theory of Acceptance and Use of Technology
**UK:** United Kingdom
**WoS:** Web of Science

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# 2.1: APPENDIX: METHODS DETAILS

## DEVELOPMENT OF SEARCH PROTOCOL

To compile a list of relevant disciplines (and journals within those disciplines), the first author first ran an initial search using Google Scholar, Web of Science (WoS), and the EUR library database search tool, using the terms "legitimacy" "health" and "technology". These criteria were then refined to include "artificial intelligence." However, it became clear that regardless of how specific the search criteria became, the majority of records returned through a database search would not include deep conceptualizations of the term "legitimacy," because this term is commonly used across many disciplines as an unproblematic descriptor of technologies, legal processes, narrative choices, medical decisions, policies, and institutions. This was true even for articles in which "legitimacy" could be found in the title, subtitle, or abstract.

Therefore, we switched to a search for journals within particular disciplines known to publish more in-depth explorations of concepts like legitimacy in the context of health and technology. We first searched for journals through databases, specifically WoS and Scimago, selecting journals based primarily on impact factor. However, this did not yield strong results in several disciplines, notably Organization, Management, Policy, and Anthropology (because we could not search for journals in these disciplines within WoS or Scimago that specifically cover health and technology), and Science & Technology Studies (which is not listed as a separate discipline within WoS or Scimago). Therefore, we explored other means of selecting journals for these disciplines, primarily by using expert knowledge compiled by libraries at universities strong in each field in the form of library-based disciplinary guides.

## SELECTION OF DISCIPLINES AND JOURNALS

Journals from within each discipline were selected manually based on the following criteria, which were selected to yield the most results related to theorization of legitimacy, legitimacy-making, and scholarship related to healthcare and technology.

- Journals with significant legitimacy theorization and/or articles with a strong focus on legitimacy, health, and technology.
- Journals with significant topical relevance in Aims and Scope.
- Journals included in curated academic lists of top journals within a given discipline from respected institutions
- (Relatively) high 2019 Impact Factor, as listed on Web of Science's Journal Citation Report or Scimago Journal and Country Rankings

Legitimacy research spans a wide variety of disciplines, and given the interdisciplinary nature of this review, it seemed appropriate to seek to include relevant journals from as wide a range as feasible. Therefore, an initial search for journals included the following disciplines. This review

will include articles published in English or published in translation in an English-language journal after initial publication elsewhere.

### MANAGEMENT AND ORGANIZATION STUDIES

Journals were chosen based on top journals within Erasmus University Rotterdam (EUR) library guide to Management studies. The initial list included journals categorized as General, Organizational, and Strategy/Entrepreneurship. For the purposes of this review, Management & Organization Studies (MOS) includes general management literature, studies of entrepreneurship, organization theory, and more specific studies within management, such as Health Management, because these areas provide both the majority of conceptualizations of legitimacy and are most relevant to technology adoption in healthcare.

### HEALTH POLICY AND MANAGEMENT

Journals were chosen from top journals within EUR library guide to Health Policy and Management.

### SCIENCE AND TECHNOLOGY STUDIES (STS)

A list of journals was compiled through journal guides created by the University of British Columbia, Maastricht University, and University College London. The list edited for journal content (for instance, history of science journals were excluded for relevance). Journals known to the reviewers and likely to publish highly relevant articles were also included.

### PSYCHOLOGY

The reviewer conducted the search protocol within three top Psychology journals based on impact factor (Scimago) and possible relevance of topic within psychology. Because there were few legitimacy results, the reviewer conducted the search across four more journals in possibly-relevant topic areas with high impact factors. This search also yielded limited results.

### SOCIOLOGY

Relevant sociology journals are included on separate categories in the WoS Journal Citation Report: *Sociology* and *Social Science, Biomedical*. These lists also include thematic journals that are not relevant to this project (either thematically, or because they focus primarily on ethics or law). The reviewer was also unable to locate a curated list for Medical Sociology. Therefore, the top Sociology journals were selected by gathering the top 15 journals listed under WoS Journal Citation Report category *Sociology*. The reviewer then integrated this list with relevant (i.e., sociological) titles within the top 15 listed under WoS Journal Citation Report category *Social Sciences, Biomedical*. This allowed inclusion of journals specific to medicine and health sociology. Some journals were included on both lists. The reviewer then ran the search protocol on these journals.

### MEDICAL ANTHROPOLOGY

Medical anthropology is known to the reviewers to include theorization on legitimacy, health, and technology, and was therefore included despite being a sub-discipline within Anthropology is general. This journal list compiled from University of California, Berkeley library (Berkeley hosts one of the original medical anthropology programs and is widely respected in the field, with a specialized Anthropology library). In Anthropology, impact factor is not as relevant as topic area, especially because *Anthropology* and *Social Science: Biomedicine* impact factor rankings include a huge diversity of disciplines, of which Medical Anthropology is a small subset; therefore, relevant journals are more likely to be found on a curated list from a top medical anthropology department.

### MEDICINE

The reviewer searched the Erasmus Medical Center Medical Library database for high-impact general medical journals and medical journals with a focus on technology (WoC, Scimago). The reviewer excluded journals that publish only about biomedical treatment, biology, chemistry/pharmacology. The Lancet was the only top medical journal which contained relevant articles that either pursued legitimacy as a subject of investigation or problematized legitimacy in any way.

### SEARCH PROTOCOL

Within these lists, the reviewer then ran the following search protocol within each individual journal:

- Legitimacy (or legitim* if search tool accepted wildcards)
- Legitimacy AND technology (or technol* if wildcards accepted)
- Legitimacy AND technology AND health (or technol* if wildcards accepted)
- Legitimacy AND "artificial intelligence"
  - If the first two searches yielded very limited results, the reviewer did not proceed with the second two searches. If the journal's title contained "technology" or "health," searches did not include these terms.
- Remove publications with limited results for legitimacy
- The reviewer summarized the results of the journal search protocol within a matrix (for instance "some legitimacy results, no tech, no health") for each journal under consideration.

### EXCLUSIONS AND COMBINATIONS

As a result of this process, Medicine and Psychology were excluded as disciplines within the review. The disciplines provide valuable context for the importance of a review of legitimacy literature, but do not contain significant literature theorizing or problematizing legitimacy in a way that relates to health technology applications. The exception was the Lancet, which returned legitimacy results. In this case, the reviewer may include particularly relevant articles from the Lancet manually in the review. Because there were few journals within Medical Anthropology and some overlap with journals categorized within Sociology (notably, Critical Public Health and Social Science and Medicine), Medical Anthropology and Sociology were combined into one discipline.

Four disciplines were initially selected. However, after thorough review of the descriptions of the journals on the Health Policy & Management list, the most relevant journals were better categorized within Management & Organization Studies. Several journals that emerged in searches for STS and Sociology & Medical Anthropology journals also appeared on the Health Policy & Management list. Therefore, the reviewer decided to eliminate Health Policy & Management as a separate discipline.

## FINAL JOURNAL SELECTION

The top ten journals within the three remaining disciplines (Management & Organization Studies, Science & Technology Studies, and Sociology & Medical Anthropology) were selected based on the following factors, in descending order:

1. Relevance
    a. Many results for legitimacy, preferably with strong emphasis on health and technology, or with strong legitimacy theory results.
    b. Aims and Scope of the journal fits with the aims of the project (does not focus on excluded or irrelevant categories)
3. Presence on relevant academic lists (especially if included on several lists across disciplines)
4. Impact factor
5. Diversity within the discipline

Journals with similar Aims and Scope were kept on lists when these journals returned exceptionally strong results during the search protocol, or if the topic had particular relevance to AI/mHealth in skin cancer diagnosis. However, if search results were not especially promising, the reviewer prioritized diversity within the discipline. In these cases, the reviewer first selected the journal with the strongest results from the search protocol. If these results were also similar, the reviewer chose the journal with the highest impact factor.

There was some question about how to categorize Social Science and Medicine, which appeared on Health Policy & Management, STS, Sociology, and Medical Anthropology lists. It was eventually categorized within Sociology & Medical Anthropology through the following process:

- The reviewer sorted through the abstracts on the first page search results for both "legitimacy" and "legitimacy AND technology." Articles were categorized as follows:
    - Psychology (3)
    - Anthropology (8)
    - Sociology, including discourse analysis (22)
    - Political Science/Policy (9)
    - Health Economics/Evaluation (2)
    - Due to the prevalence of Sociology and Anthropology articles, Social Science and Medicine was categorized as a Sociology & Medical Anthropology journal.

In addition, specific articles known to the reviewer to be seminal works in the field of legitimacy (or in legitimacy, health, and technology) will be included, even if these articles do not appear in the journals under review.

Journals with similar Aims and Scope were included when these journals returned exceptionally strong results or were particularly topically relevant. Otherwise, we prioritized diversity within the discipline to ensure that we captured the full breadth of legitimacy conceptualizations. In these cases, the reviewer first selected the journal with the strongest results from the search protocol. If results were similar, the reviewer chose the journal with the highest impact factor. Two journals (Social Science & Medicine and Critical Public Health) were designated as interdisciplinary due to ambiguous journal aims straddling MAS and STS and high utilization by both MAS and STS scholars. Articles in these journals were included in MAS unless there was compelling evidence that they should be included in STS instead.

## SEARCH STRATEGY

With the help of a librarian, a Boolean search string was developed and run through Web of Science in April 2021. Sydney Howe (SH) conducted a secondary search in each individual journal to ensure all relevant results were included. Search was initially conducted with the help of W.M Bramer, who wrote the Boolean search string to find all results in Scopus. This string yielded 481 results.

### SCOPUS SEARCH STRING

(EXACTSRCTITLE ( "Social Science And Medicine" ) OR EXACTSRCTITLE ( "Anthropology Medicine" ) OR EXACTSRCTITLE ( "Health Interdisciplinary Journal for the Social Study of Health Illness and Medicine" ) OR EXACTSRCTITLE ( " Information Communication Society " ) OR EXACTSRCTITLE ( "Risk Analysis" ) OR EXACTSRCTITLE ( "European Journal Of Public Health" ) OR EXACTSRCTITLE ( "Research Policy" ) OR EXACTSRCTITLE ( "Qualitative Health Research" ) OR EXACTSRCTITLE ( "Journal Of Management Studies" ) OR EXACTSRCTITLE ( "Organization Studies" ) OR EXACTSRCTITLE ( "Health Care Management Review" ) OR EXACTSRCTITLE ( "Social Studies Of Science" ) OR EXACTSRCTITLE ( "Organization Science" ) OR EXACTSRCTITLE ( "Journal Of Business Venturing" ) OR EXACTSRCTITLE ( "Sociology Of Health Illness" ) OR EXACTSRCTITLE ( "Critical Public Health" ) OR EXACTSRCTITLE ( "Social Epistemology" ) OR EXACTSRCTITLE ( "Medical Anthropology Quarterly" ) OR EXACTSRCTITLE ( "Science As Culture" ) OR EXACTSRCTITLE ( "Health Care Analysis" ) OR EXACTSRCTITLE ( "Science Technology And Human Values" ) OR EXACTSRCTITLE ( "Medical Anthropology Cross Cultural Studies In Health And Illness" ) OR EXACTSRCTITLE ( "Administrative Science Quarterly" ) OR EXACTSRCTITLE ( "Sociological Theory" ) OR EXACTSRCTITLE ( "Strategic Organization" ) OR EXACTSRCTITLE ( "Medical Anthropology" ) OR EXACTSRCTITLE

( "Big Data And Society" ) OR EXACTSRCTITLE ( "AI Society" ) OR EXACTSRCTITLE ( "Journal Of Responsible Innovation" ) OR EXACTSRCTITLE ( "Strategic Entrepreneurship Journal" )) AND (TITLE (legitim*) OR TITLE-ABS (legitim* W/10 (health* OR medic* OR technolog* OR AI OR artificial-intelligen* OR machine-learning OR innovat* OR model* OR theor* OR concept* OR framework* OR wellbeing OR well-being OR care OR illness OR cancer)))

Unfortunately, this string yielded results from excluded journals, and no results from three included journals. Ulrich's web showed that these journals should have been listed in both Scopus and Web of Science. As a result, SH conducted a second search of these missing journals in Web of Science (WoS) on February 2nd, 2021.

### WOS SEARCH STRING

(SO=Social Science And Medicine OR SO=Anthropology Medicine OR SO=Health Interdisciplinary OR SO=Information Communication Society OR SO=Risk Analysis OR SO=European Journal Of Public Health OR SO=Research Policy OR SO=Qualitative Health Research OR SO=Journal Management Studies OR SO=Organization Studies OR SO=Health Care Management Review OR SO=Social Studies Science OR SO=Organization Science OR SO=Journal Business Venturing OR SO=Sociology Health Illness OR SO=Critical Public Health OR SO=Social Epistemology OR SO=Medical Anthropology Quarterly OR SO=Science As Culture OR SO=Health Care Analysis OR SO=Science Technology Human Values OR SO=Medical Anthropology OR SO=Administrative Science Quarterly OR SO=Sociological Theory OR SO=Strategic Organization OR SO=Big Data Society OR SO=AI Society OR SO=Journal Responsible Innovation OR SO=Strategic Entrepreneurship Journal) AND TI=legitim*

After discovering that searches of just the missing journals yielded many results in WoS than in Scopus, SH tried searching for journals that had been covered by the Scopus search string and discovered that these also yielded more relevant results in WoS. Therefore, SH translated the search string from Scopus terminology to WoS terminology and ran the search in two parts in order to ensure both elements of the search string were captured equally, as WoS provides significantly less opportunity for detailed searches than Scopus. The WoS search generated more results than the Scopus search (nearly 900) but did not include any results from the excluded journals.

Because of these problematic results from the Boolean search strings, the primary researcher conducted two searches through all included journals individually, using the following search protocol: SH then chose to exclude the terms "model*," "theor*", "concept*", and "framework*" because excluding these terms yielded more results and fewer mistakes, and because the title search alone was likely to find the majority of these larger theoretical articles. This exclusion reduced the number of records from Search 2 by about 300. SH then conducted a final search through each included journal using a revised version of Search 2:

Search 2: journal name + legitim* + technolog* and/or health

There were 224 results for Search 1 and 639 results for Search 2. When combined in EndNote, there were 144 duplicate results.

## INCLUSIONS

Articles that contain:

- Evidence of legitimacy theorization in the abstract either explicitly, or through causal relationship language (such as "these practices generate legitimacy") OR the abstract indicates through discussion of the subject at hand that legitimacy is problematized even if it is not the focus of the article.

AND

- The subject of the article deals with health, technology, or both.

If an article covers only health or technology but not both, the threshold for legitimacy theorization is higher, i.e. only articles with explicit reference to theory of legitimacy or which use causal language to describe a relationship with legitimacy.

## EXCLUSIONS

In reviewing abstracts, criteria for exclusion were refined but not expanded. In cases where legitimacy was only used in the abstract's recommendations section, or when legitimacy was used as an adjective or descriptor in a list of other descriptors (with no other mentions), the article was excluded.

- Abstracts without good evidence of theorization of legitimacy. Specifically, abstracts were excluded if any of the following were true.
  - The abstract focuses entirely on the legitimacy of specific policies (no theorization of the meaning of legitimacy itself)
  - The abstract uses legitim* interchangeably with another term (for instance, "reasonableness" or "acceptability" or "ethical").
  - The abstract mentions legitimacy only in the recommendations section.
  - Legitim* only occurs once within a list of other adjectives or attributes.
  - Legitim* is clearly not a central subject of the article.
- Abstracts that use legitimacy purely in a legal sense (well-covered by other reviews, beyond the scope)
- The subject matter is less relevant (deals with neither health nor technology)

A second reviewer (Rik Wehrens) then reviewed 10% of the total articles at random (every 10th article when arranged in alphabetical order by author name). The resulting inclusion/exclusion list closely matched SH's selection, with a total of seven disagreements. After reviewing each disagreement, the two reviewers were able to come to an agreement on every contested article based on the inclusion criteria. Because all of these disagreements were in the first half of the articles reviewed, it was determined that these were mostly a result of fuzzier inclusion criteria during the first part of the sorting process. As a result, SH went through the first half (up through author last name letter M) to ensure that all articles met two inclusion criteria that were added slightly later in the process:

1. Legitim* in the abstract must not be used interchangeably with another term.
2. Articles that deal only with health or technology but not both are subjected to the higher level of inclusion criteria for legitimacy theorization.

## ANALYSIS

### EXAMPLE

Within STS, codes that dealt with discourse and narrative (such as "scientific discourse" and "assumption: legitimacy is discourse-based") were consolidated into a thematic code "discourse." Consolidating all "discourse" codes made it easier to capture co-occurrences of thematic codes such as "negotiation" or "boundary work," without losing the integrity of the initial coding process in Atlas.ti when transitioning coding to Excel. The Excel transfer made it easier to see connections among the codes more clearly, as noise was reduced. When a code co-occurrence was unexpected or did not fit, SH returned to the original text to further flesh out and edit the thematic codes as needed. This information was included in the disciplinary summaries, which later became the results section of this chapter.

# 2

# CHAPTER 3

# EMBEDDING ARTIFICIAL INTELLIGENCE IN HEALTHCARE:

## An Ethnographic Exploration of an AI-Based mHealth App through the Lens of Legitimacy

An earlier version of this chapter is published as:

Howe, S., Smak Gregoor, A., Uyl-de Groot, C., Wakkee, M., Nijsten, T., & Wehrens, R. (2024). Embedding artificial intelligence in healthcare: An ethnographic exploration of an AI-based mHealth app through the lens of legitimacy. *Digital health, 10*. https://doi.org/10.1177/20552076241292390

## INTRODUCTION

The potential of new, data-driven artificial intelligence (AI) applications in healthcare has been widely recognized (Angehrn et al., 2020; Grote & Berens, 2020; Smith, 2020; Zaidan et al., 2018). AI-based healthcare applications are being introduced across a variety of medical disciplines, gaining momentum as augmenters of human-based diagnostics (Ahuja et al., 2021; Cadario et al., 2021; Malhi & Yiu, 2021; Morley et al., 2020). AI tools have proven especially promising for image recognition and analysis; clinically-validated diagnostic support tools are now available in disciplines ranging from radiology (Angehrn et al., 2020) to dermatology (Malhi & Yiu, 2021). However, despite strong desire from developers, doctors, policymakers, and patients, many technically-sound and clinically-promising technologies struggle to become structurally embedded in healthcare (Cresswell & Sheikh, 2013; Greenhalgh et al., 2017; Varabyova et al., 2017). Simultaneously, problems caused by flawed technologies that have become embedded have significant financial, medical, and social costs, (Roth, 2023; Varela-Lema et al., 2012) especially in terms of public trust (Adjekum et al., 2018; Seyyed-Kalantari et al., 2021).

Dermatology is considered an especially interesting discipline for AI applications performing image classification due to the large number of clinical image databases available and visual component of diagnosis (Du-Harpur et al., 2020; Hogarty et al., 2020). In an effort provide the right care at the right time and alleviate healthcare budget pressures (Cadario et al., 2021; Schreuder et al., 2022), mobile health (mHealth) applications using artificial intelligence (AI) to facilitate early diagnosis of skin cancer are in particular gaining popularity. Studies of skin cancer risk assessment apps often present potential benefits of these technologies in terms of improved accuracy of detection, better care access for patients, and work burden relief for physicians (Ahuja et al., 2021; Maier et al., 2015; Malhi & Yiu, 2021; Sangers et al., 2021). Yet despite widely recognized potential benefits, it is currently unclear how these technologies may reshape interactions among patients, doctors, and other actors within a healthcare system. Furthermore, it is unclear how these contextual interactions may impact the adoption of the technology in the wider healthcare system. To our knowledge, this study represents the first ethnographic exploration of the adoption, acceptance, and implementation of a skin cancer risk assessment app, and one of the first studies of its kind for any AI healthcare technology.

In explorations of healthcare technologies, existing frameworks for studying technology acceptance, adoption, implementation, and governance provide significant data about parts of the process through which technologies become embedded in healthcare (Dwivedi et al., 2016; Fox & Connolly, 2018; Graeber et al., 2023; Hengst et al., 2023; Holden & Karsh, 2010; Nadal et al., 2020; Reddy et al., 2020; Schoville & Titler, 2015; Virtanen et al., 2023). For instance, the Technology Acceptance Model focuses on acceptance via behavioural intention (Holden & Karsh, 2010), while other frameworks attempt to cover more issues at once using a variety of qualitative methods, such as the non-adoption, abandonment, scale-up, spread, and sustainability framework (NASSS)(Greenhalgh et al., 2017). We use the term "embedding," in the sense of making a process

(such as using technology) a normal part of everyday life (in a healthcare context)(May & Finch, 2009). Thus, we add to these frameworks' understanding of individual processes work together to incorporate technology into healthcare in a way that eventually becomes taken for granted. Even with so much data, researchers, policymakers, and developers still have difficulties determining why some technologies become structurally embedded in healthcare while others do not. For instance, many technology acceptance and adoption studies are based primarily on studies of behavioural intention and other perceptions of the future among participants (Dwivedi et al., 2016; Holden & Karsh, 2010; Yarbrough & Smith, 2007; Yuan et al., 2020), limiting their predictive power for context-based obstacles that are only made visible in practice (Holden & Karsh, 2010). These issues are well known and recently, there has been progress in developing frameworks to account for these gaps, for instance, by focusing on organizational barriers (Bramo et al., 2022) and outcomes not driven by acceptability (Greenhalgh et al., 2010a; Greenhalgh et al., 2017).

However, acceptance, adoption, and implementation frameworks rarely address legitimacy as a primary issue for embedding new technologies, despite ubiquitous use of the term throughout literature on health technology across several social science and medicine disciplines (Barker, 2011; Elshaug et al., 2017; Hornberger, 2019; Licht & Licht, 2020; Reay et al., 2013; Sheard et al., 2017). We argue that legitimacy is a crucial theme in understanding why and how technologies are (not) structurally embedded in healthcare.

We build on Suchman's 1995 seminal definition of legitimacy as "a generalized assumption that an entity and/or its actions are desirable, proper, or appropriate within some socially-constructed system of norms, values, and beliefs" (p. 574)(Suchman, 1995). Drawing from literature within Organization & Management Studies and Science & Technology Studies, we add that legitimacy has an affective quality, in that it may contain sensations and feelings but it is not in itself an emotional quality (Haack et al., 2014). We also add that legitimacy is always relational, in that it occurs between at least two entities (such as actors, institutions, or technologies)(Hurd, 1999). While legitimacy studies related to healthcare and technology have explored legitimacy in depth conceptually (Kitchener, 2002; Sapir, 2020), few studies have focused on explicitly on legitimacy as a means of understanding how and why a new healthcare innovation or health technology becomes (or does not become) embedded (Barker, 2011; Jain & Ahlstrom, 2021). Moreover, many studies view legitimacy of new technologies only in terms of language, or narratives. Limited literature examines how legitimacy is produced through the practical actions and negotiations of many actors within a healthcare system, despite empirical evidence of practice as a key driver of legitimation for new technologies (Barnreuther, 2016; Reay et al., 2013; Sheard et al., 2017). This study does both: here, we focus on legitimacy as essential for adoption, acceptance, and implementation of health technologies through an ethnographic analysis that explicitly centres practices as a primary driver of legitimation. We use both narratives and relationships as context for understanding expectations (Borup et al., 2006) that may help drive assumptions that lead to legitimacy misalignments.

We take as our case study an AI-based skin cancer risk assessment smartphone app. The SkinVision app uses a convolutional neural network to produce a high or low risk rating for users based on images taken with a smartphone camera; photos are also checked by a team of dermatologists. It is trained using thousands of photos for which the diagnosis had been confirmed by a dermatologist or histopathology when available. As of May 2024, the app is reimbursed by several insurance companies within the basic insurance package, providing over 8 million people (CZ, N.D.; Kruis, N.D.; NN, N.D.; SkinVision, 2025b) in the Netherlands with access to the app, even though it does not yet have approval from the Dutch health technology assessment agency (ZIN). Both this app[1] and others have been explored extensively in clinical trials; however, we have found no ethnographic studies of how these apps are integrated into healthcare systems. Using legitimacy as our theoretical lens also answers calls for ethnographic research of AI tools that address ambiguous, subtle, and absent data adequately (van Voorst & Ahlin, 2024).

Studying the role of legitimacy in embedding of AI-based technologies in medical practice empirically can be challenging because elements within a fully-legitimate system can become so taken for granted they are rendered nearly invisible (Haldar et al., 2016; Star & Ruhleder, 1996). A focus on moments of legitimacy breakdown makes it possible to study assumptions and the backgrounded infrastructure (Star & Ruhleder, 1996) supporting legitimacy processes in a complex system such as technology integration in healthcare. Assumptions and backgrounded infrastructure, in the context of this study, can include a wide variety of unquestioned and unnoticed elements in both the narrative around the technology and the medical system. For instance, as other authors have noted, assumptions about health technology usage are built into technology designs (Bagge-Petersen et al., 2022; Gjodsbol et al., 2024; Seaver, 2017), and unspoken assumptions about hierarchies in medicine can make it difficult to shift practices even after change is implemented (Reay et al., 2013; Weiss & Sutton, 2009). We include both assumptions built into the company narrative, and assumptions ingrained within the medical context into which the app is embedded. We consider "breakdowns" in legitimacy to be moments when narrative or context-based assumptions are brought into question or actively contradicted through practices pertaining to the app or users' affective relationship to the app. The existence of moments of legitimacy breakdown does not mean narratives are incorrect, or differences with practices are (necessarily) problematic. Rather, by focusing on these moments, we gain deeper understanding of the nuance and complexity involved in embedding a technology in healthcare because it allows us to observe and thus question baseline assumptions that otherwise go unnoticed during the embedding process.

Therefore, our research question is: what can we learn from moments of legitimacy breakdown about the assumptions guiding the embedding of this AI-based application in the Dutch healthcare system? To answer our research question, we combine a theoretical lens grounded in a long tradition

1 Henceforth, we use the "the company" to refer to SkinVision as a company, and "the app" to refer to the SkinVision skin cancer risk assessment smartphone application.

of legitimacy studies in the social sciences while employing an ethnographic approach to study legitimacy empirically.

We first discuss our study design and methodologies used. We then explore our data with an analysis of the company narrative, folllowed by discussion of how breakdowns between this narrative and practices manifest in the practices of institutions (such as bureaucratic processes), users, and doctors. Next, we examine how affective aspects of relationships between individual users and the app impact legitimacy. Finally, we discuss the implications of our data for technology acceptance, adoption, and implementation from the perspective of legitimacy.



## METHODS

This study was conducted using a wide range of ethnographic methods between 2020 and 2023. These methods included participant observation at general practitioner (GP) practices, dermatology clinics, at work places, and personal homes; narrative interviews and open-ended focus groups with expert stakeholders; autoethnographic observations in fieldnotes; remote ethnographic fieldnotes made using digital tools such as Microsoft Teams and video recordings; and document analysis of research and strategy documents from Erasmus Medical Center (EMC) and the Dutch Health Care Institute (ZIN), regulatory information, and the company's advertising materials, media presence, and website. All participants were informed of the respective roles and positions of each of the researchers involved in the process, as well as the purpose of the research, via the informed consent form, and were invited to ask questions both before and after each study inclusion. Social scientists with extensive ethnographic experience (first author, last author) led study design, data collection, and analysis; medical researchers with some ethnographic training contributed to data collection. Documents analyzed are available to the public. We used the SRQR checklist when writing our report (O'Brien et al., 2014); see Appendix 1 for more details.

This study includes ethnographic observations and fieldnotes from a variety of researchers in the context of a wider collaboration between social scientists at Erasmus University Rotterdam, and medical researchers at Erasmus Medical Center, producing a diversity of perspectives unavailable if all observations had been conducted by a single ethnographer. Our data was collected in a traditionally ethnographic manner: we pursued data collection iteratively and abductively in combination with data analysis, adding more data sources to fill gaps observed in previously-collected data sets (Geertz, 1998). This process, and the observational data itself, was given additional structure by our focus on legitimacy breakdowns. Nevertheless, a key component of ethnographic research is the capacity to allow new themes to emerge from spontaneous and unexpected data points; our focus on legitimacy breakdowns framed, rather than prescribed, the data collected (Nicolini, 2009).

## DATA COLLECTION

Data were collected over a period of three years from a wide variety of sources, and then integrated as a means of studying various components of the larger system over time. Ethics approval was granted by Erasmus University Rotterdam for ethnography and interviews (ETH2324-0010). Informed consent was collected and data was pseudonymized and stored securely to ensure adherence to European privacy guidelines.

### COLLABORATIVE ETHNOGRAPHIC METHODS

Some data were acquired within the context of a pilot study examining the conditions and feasibility for a study of the introduction of the app into primary care in the Netherlands, conducted by Erasmus Medical Center (EMC)(MEC2021-0254,)(Smak Gregoor, Sangers, Eekhof, et al., 2023). This pilot feasibility study was part of an ongoing collaboration between EMC and Erasmus School of Health Policy and Management (ESHPM). Additional data were collected through focus groups and interviews with medical professionals such as doctors, nurses, and administrative staff. Participant observation took place in-person at GP practices.

Some data were also acquired in the context of a study investigating the diagnostic accuracy of the app in a clinical setting, conducted by EMC (MEC-2019-041)(T. Sangers et al., 2022). The app was used to assess lesions after clinical diagnosis and before obtaining histopathology; the use of the app had no impact on patient care or health. Participants observed with malignant lesions were over age 50; student benign control participants were between ages 22-30. Participant observations took place both in-person at Dutch hospital clinics, and remotely via Teams or video recordings when in-person observation was not possible due to COVID-19 pandemic restrictions.

Convenience sampling was used in both studies: ethnographic data was collected from participants who were recruited based on clinical study criteria (T. Sangers et al., 2022; Smak Gregoor, Sangers, Eekhof, et al., 2023). Accuracy Study participants were asked to participate in-person by dermatologists at their appointments for a suspicious skin lesion check; GPP participants were asked to participate by phone or email after contacting their GPs regarding a suspicious skin lesion. Total inclusion time for all participants was between 20 minutes and 45 minutes.

### APP EXPERIENCES ETHNOGRAPHY STUDY

Focused on micro-level relationships (between users and the app), the App Experiences study (AE) provided data about the physical and practical management of the smartphone and the app by individual users, and how the app impacts the patient experience of assessment of suspicious lesions. App users were recruited through personal networks and Erasmus University Rotterdam (EUR) via text message or email using the snowball sampling method. Participation lasted 30 minutes to one hour, and included a short interview and observation while the participant downloaded and registered with the app and used the app to make a risk assessment of a skin lesion of their choice. Participation

occurred in private homes or in closed rooms at the EUR. Participants (n=15) ranged in age from 25-40, were roughly 50% Dutch, with the majority of foreigners originating from elsewhere in Europe. All but one participant had obtained a Masters degree or higher. Participants gave informed consent for participation and audio recording in writing and had the opportunity to comment on their answers. Researchers never recorded medical information provided to the app, nor did this study use or access app photos. This study was funded independently through the lead author's internal departmental funding and received ethical approval from ESHPM (ETH2324-0010).



Additionally, the lead author participated in the study through autoethnographic observations of three skin lesion checks using the app, a GP visit, and a dermatology follow-up. This data was recorded in detailed fieldnotes.

### INTERVIEWS WITH EXPERT STAKEHOLDERS

The lead author conducted interviews with expert stakeholders working in research, health insurance, policymaking, and technology development (n=8). These semi-structured ethnographic interviews (Spradley, 1979) lasted between 30 minutes and two hours and were audio-recorded and transcribed. Some follow-up emails and documents provided during these interviews were also analyzed as data with participant permission.

**Table 1:** Data Sources & Researchers

| Type of inclusion | Conducted by | Number of participants | Date |
|---|---|---|---|
| **Interviews with medical researchers** | Author 1 (female) | 2 | 2020 |
| **Interviews with app company staff** | Author 1 | 3 | 2021 |
| **Autoethnography** | Author 1 | 3 instances (study participant + independent high-risk rating) | 2021, 2022 |
| **Interviews with policymakers and insurers** | Author 1 | 3 | 2023 |
| **App Experiences (AE) ethnography study with individual users** | Author 1 | 15 | 2023 |
| **GP Pilot Study (GPP) inclusions with ethnographic data** | Authors 1, 2 (female), masters students (female, male) | 31 + unspecified doctors + 2 researchers. | 2022-2023 |
| **GPP focus groups** | Authors 2, 6 (male) | GPs (n=5), doctor's assistants (n=3) | 2022 |
| **Ethnographic observations of GPP inclusions** | Authors 1, 2, masters students | 4 (2 patients, 1 researcher, 1 doctor) | 2022 |
| **Accuracy study remote (Teams) and in-person ethnography inclusions** | Author 1 | 9 participants (3 remote), 1 researcher, 1 doctor | 2021 |
| **Accuracy study video inclusions** | Author 1, masters students (female, male) | 9 (4 participants, 4 helpers, 1 researcher) | 2021 |
| **Document analysis** | Author 1 | 5 documents | 2020-2023 |

## ANALYSIS

We abductively moved back and forth among various data sources and theoretical concepts (Tavory & Timmermans, 2014; Wehrens et al., 2021) to account for the breadth and diversity of the data. We continued data collection until saturation was reached. All interviews and focus groups were recorded and transcribed. Observations were either recorded and transcribed or described in detailed fieldnotes (Spradley, 1980); if both existed for an interaction, these were collated before analysis. The final, fully digital data set (including transcriptions, fieldnotes, documents for analysis, recordings, and spreadsheets of metadata) was filed on secure EUR or EMC servers, according to GDPR standards.

The first author then abductively coded this data using thematic analysis techniques (Clarke & Braun, 2017) in a combination of Microsoft Word, Atlas.ti, and Excel. The first and last authors then discussed the first round of coding and initial ideas generated from these codes (Van Maanen, 2011). For example, in one round, the first author coded practices of users that did not fully match the instructions on the company website; within these practices, the first author coded the emotional quality of the interaction. The first and last author then discussed how these emotional qualities may relate to legitimacy. The first author then returned to the data to verify the fit of this idea before continuing to code. Using an iterative process with several more rounds of coding, idea generation, and regular feedback and discussion meetings with the last author, the first author continued thematic analysis until all legitimacy issues observed in the data had been adequately accounted for and described.

Given our approach to legitimacy as an inherently relational concept, we analyzed our data in the context of the particular relationships impacting the embedding of the app in the healthcare system. Within this relational context, breakdowns were especially visible in misalignments between narratives or expectations and practices. Finally, we explored the affective nature of these breakdowns, which was particularly observable in relationships between people and the app, and doctors and patients. A visualization of the themes and subthemes produced through this analytical process can be found in Figure 1.

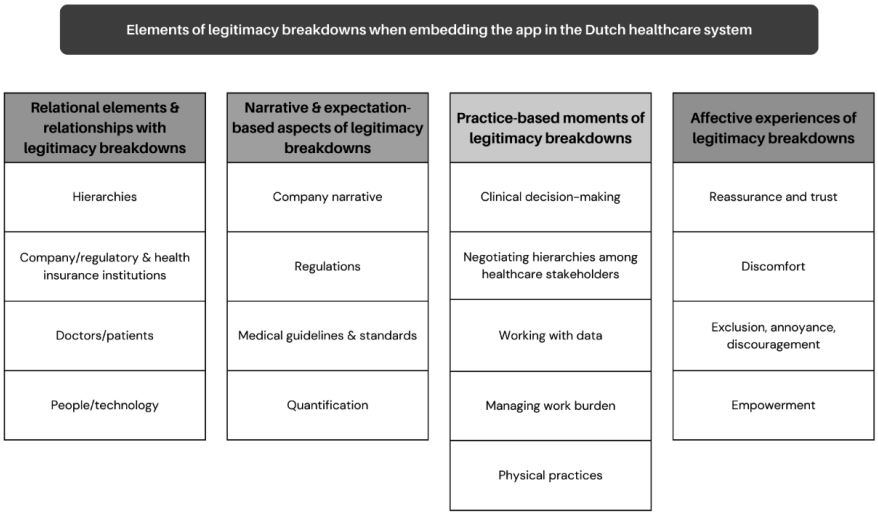


**Figure 1:** Themes and subthemes

## RESULTS

As we consider the embedding of new health technologies in practice through the analytical lens of legitimacy, we focus on the processes and activities through which such technologies gradually do or do not become taken-for-granted. Legitimacy can be understood as a process (Girschik, 2020; Suddaby et al., 2017) that is shaped in the interactions between various stakeholders, the technology, the organizational context and the broader healthcare system requirements in which the technologies is developed. This also includes the narratives about the technology, systems of interaction already present in the context into which a technology is being introduced, and affective responses to the technology-in-use. We analyse 'moments of breakdown' of legitimacy to understand what assumptions impact the process of embedding this new technology in the Dutch healthcare system.

Here, we consider moments of legitimacy breakdown for the app as it moves through different levels of the healthcare system in the Netherlands. Within our results, we gradually zoom in on relationships and interactions involving the app from the macro level to the micro level (Bitektine & Haack, 2015) to guide our readers through the various themes and subthemes identified in our analysis. We start at a system-wide, macro level with a discussion of the company narrative in the context of the Dutch healthcare system. We then move towards a discussion of regulation and insurance practices, and how these practices negotiate between the company narrative and Dutch health care context. From there, we move to a meso-level examination of medical practices in clinics, specifically between GPs and patients, and how the interaction of these practices with narratives and expectations of the app generates legitimacy breakdowns. Finally, we examine

micro-level practices among individual users. We begin with a discussion of physical user practices, followed by an exploration of how expectations about the app, whether defined by the company narrative or by other elements in the user's context, interact with user practices to generate an affective experience for individuals.

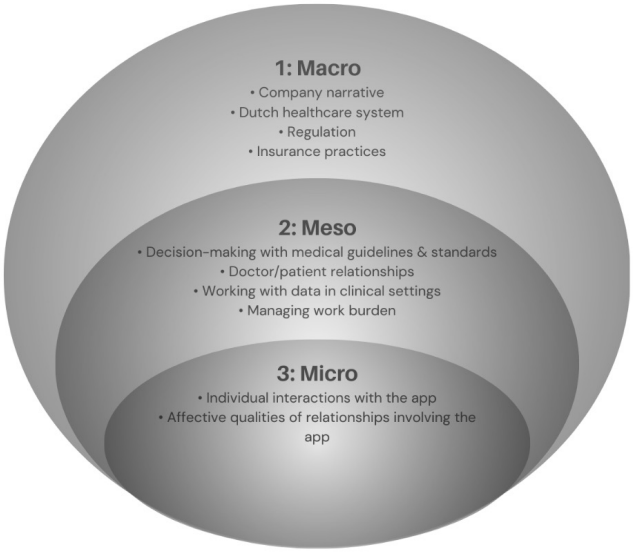


**Figure 2:** Results Structure

## THE COMPANY NARRATIVE IN CONTEXT: ACCURACY, RISK AND INSTITUTIONAL POSITIONING

In the Netherlands, current standard of care for skin cancer risk assessment runs through GP offices. Everyone who lives or works in the Netherlands is legally required to take out a standard health insurance package to cover their medical costs (Wammes, 2020). 95% of Dutch residents are registered with a GP (Wammes, 2020). For a skin cancer risk assessment, a person with a suspicious skin lesion should schedule an appointment with their GP. Depending on the type of cancer suspected, the GP has several options: they can treat the lesion themselves, refer the patient to a dermatologist, or take a "wait and see" approach (Baaten GGG & Smeink P, 2017).

This skin cancer risk assessment app is currently marketed to the entire Dutch population. In this model, individuals can download the app onto their own smartphones and register using their insurance information. They can then use the app without a doctor to perform a skin cancer risk assessment at home. If the app produces a "high risk" result, text on the app recommends that the user make an appointment with their doctor.

The company's narrative describes the app as an efficient, effective, and institutionally-approved solution to an urgent healthcare problem. The company website presents "skin cancer" as a life-threatening risk that must be "caught in time" and the app as an important innovation for early detection that can provide a reliable assessment in "30 seconds" and is "95% accurate." Institutional legitimacy is invoked through language and visuals: the term "regulated" appears four times on the "Explore SkinVision" page alone, "clinically validated" appears twice, and the website is plastered with icons denoting regulatory approvals and partnerships with large, trusted organizations (SkinVision, 2025b). By addressing legitimacy in terms of both medical scientific validity standards and institutional norms, the website appeals to doctors and policymakers. Simultaneously, the company addresses other audiences with an instrumentalist discourse common to start-up culture that positions AI mHealth as a positive, highly reliable change to an outdated healthcare system (Stevens et al., 2018). Combined with a classification of skin cancer as a healthcare "emergency," this discourse appeals to both potential users and investors interested in technological solutions to societal problems. For example:

> *The SkinVision app is empowered by a highly accurate AI algorithm and is supported by an advanced quality system involving the best* ***dermatologists*** *worldwide, which has only one goal: making sure you visit the* ***right doctor*** *at the first sign of risk for skin cancer" (emphasis added)(SkinVision website, accessed 6 May 2024)*

Through an earlier mention of dermatologists, the company implies that dermatologists are "the right doctor" for initial skin cancer screening. Phrasing the problem in terms of "first sign of risk" rather than "first sign of cancer" outlines the company's goal to become universal preventative care. This narrative suggests a threat-aware orientation to both skin cancer and the healthcare system that requires individuals to be proactive to protect their own health, a common narrative around the introduction of new health technologies (Wentzer & Bygholm, 2013).

In practice, however, skin cancer and the app's performance appear significantly more nuanced than this narrative suggests. For instance, the vast majority of skin cancers are forms of basal cell carcinoma (BCC), which grows slowly and only rarely metastasizes (Schreuder et al., 2022). These cancers are therefore not life-threatening, or even particularly "risky" from a health perspective, though they require treatment and their prevalence creates a significant burden on the care system (Schreuder et al., 2022).

Additionally, the algorithm does not work well for people with darker skin tones (Astner & Anderson, 2004) for a variety of reasons, both social and technical (Gloster & Neal, 2006; Kundu, 2012; Lester et al., 2021). Company dermatologists review any low contrast lesions photographed, which includes most lesions on dark skin. The app only assesses photos of lesions and takes symptoms of an individual lesion into account in its recommendations. Skin type and overall skin cancer risk are assessed through separate voluntary questionnaires for the user's knowledge only; these do not inform the assessment of photographed lesions (Smak Gregoor, Sangers, Bakker, et

al., 2023). However, this is not necessarily clear within the app: two AE participants believed their lesion risk assessment was influenced by their skin type questionnaire (Participants 4, 7) before the app was changed to direct paying and insured users to photograph their lesion before filling in the questionnaires in mid-November, 2023.

In terms of scientific validity, "95% accuracy" reflects the app's 95% sensitivity rate in a clinical validation study (Udrea et al., 2020). However, according to this same study, the app's specificity, an important part of "accuracy" in scientific terminology, is significantly lower at 78% (Udrea et al., 2020). This means that the app is relatively good at avoiding false negatives (i.e. rating a cancerous lesion as low-risk) but not as good at avoiding false positives (i.e. rating a non-cancerous lesion as high-risk). However, the reliability of these numbers is somewhat contested (Deeks et al., 2020; K. Freeman et al., 2020) and the numbers do not reflect possible changes in positive and negative predictive values among different populations and settings (T. Sangers et al., 2022). Across several studies, the app has been shown to rate a significant number of benign lesions (Karoline Freeman et al., 2020; Jahn et al., 2022) as "high-risk;" this may lead to unnecessary excisions and care. In one study, researchers observed a six-fold increase in insurance claims for benign skin lesions with "high-risk" ratings from the app, and a two-fold increase in claims for benign lesions with "low-risk" ratings, compared to a control group receiving standard care (Smak Gregoor, Sangers, Bakker, et al., 2023). It is therefore possible that using the app makes patients more likely to seek care regardless of the risk rating.

Despite a company narrative of broad institutional support, the institutional positioning of the app in practice is more ambiguous. On the one hand, the app has CE certification in compliance with the current EU-level regulations of medical devices (though this regulation will soon change (2017)). Several large insurance companies in the Netherlands already reimburse the app in the basic package (other insurers include the app in supplementary insurance packages). After years of opposition to AI for skin cancer risk assessment, the Dutch Dermatology Association released a position statement in 2023 detailing possible benefits and drawbacks of various scenarios for AI mHealth apps but not approving all scenarios or the app's current position in the care system (Wakkee, 2023). The first randomized control trial that would provide evidence at EBM standards is currently in progress (Nijsten & Wakkee, 2021), and the app does not yet have approval from ZIN (which is not unusual for a small company). While the app is clinically validated (T. Sangers et al., 2022), appropriate positioning of the app within the healthcare system is still unclear for both regulators and medical professionals.

### REGULATION AND INSURANCE PRACTICES

While some regulations and insurance practices align well with the company narrative, significant deviations underscore the complexity of embedding a new technology into the healthcare system. Therefore, our presentation of data highlights the moments of legitimacy breakdown, rather than focusing on alignments.

In the Netherlands, health insurance is private but highly regulated. The Healthcare Institute (ZIN) "supervises and stimulates the quality, accessibility, and affordability of healthcare in the Netherlands" (van de Sande et al., 2021). Among other legal tasks, ZIN "advises the minister on whether care should be included in the basic benefit package of publicly funded health insurance; to distribute public funds among health insurers based on risk equalization; and improves exchange of digital information between healthcare providers" (van de Sande et al., 2021). While ZIN offers explicit recommendations for coverage under the basic insurance package for approximately 10% of new healthcare services and technologies (including medicine), most of the time, healthcare actors, like insurers, decide on their own what should be covered based on the Healthcare Act (Zorgverzekeringswet)(Zorginstituut, N.D.).

Currently, preventative care is not covered by insurance with exceptions for some screenings and vaccinations based on risk status and/or age group. With few exceptions, GPs act as gatekeepers to all other healthcare, referring patients to specialists as needed. However, ZIN does not have the capacity to review every new health technology on the market. Therefore, discretion is left to insurers about what to include in the basic package when dealing with most new technologies, especially from smaller companies.

This is what has happened with this app. The app's current positioning as preventative care available to anyone on demand makes it an unusual case, and potentially problematic from a Dutch regulatory perspective. Despite lacking the institutional legitimacy of a "formal opinion" from ZIN, the app is reimbursed by several insurers for all members without referral.

> *In the case of SkinVision, one of the larger healthcare insurers decided that they believed it was part of the basic healthcare insurance and they started paying from the basic healthcare. That means that they get a part of your income as an insurer from the insurance. But the major part comes from the government. They collect income tax and pay the healthcare providers for the care they delivered, and insurers get that money back based on the amount of healthcare insured (clients) received. But if you start sending invoices (for the app), you will get a larger share of the pie, so to say, and that's not good. It should be the same for everyone (Health insurer 1).*

Heavy regulation of insurance policies and tax-based contributions to healthcare costs make the app's current reimbursement status somewhat risky on both a legal and financial level if ZIN issues a formal opinion against inclusion in the basic package. Conversely, using other kinds of relationships, i.e. with insurance companies, to maintain legitimacy without official approval may be a successful strategy for a small company that needs income to continue to exist. Without the resources of giant pharmaceutical companies, these kinds of trade-offs can be the only affordable way for smaller tech companies to produce the kind of evidence necessary for formal approval by ZIN (Zavestoski et al., 2004). As it wrestles with the longer and more official avenues necessary to form legitimizing relationships with regulatory bodies in the Netherlands, the company (and the app by proxy) has developed some institutional legitimacy through relationships with a critical mass of insurers.

## GP PRACTICES

Moving towards the meso level of relationships, we now turn our attention to the ways in which the app disrupts standard care for skin cancer risk assessment in practice at a clinical level. We focus here on GPs as the gatekeepers for all secondary care in the Dutch healthcare system (Udrea et al., 2020), and therefore, as the first point of contact for people who use the app in the Netherlands.

### FOLLOWING STANDARD OF CARE

We first explore the "backstage" (Goffman, 1959; Slamat et al., 2024) of interactions between patients and GPs without technology involved. There is significantly more happening during a skin cancer assessment in a GP office than is captured through the app. In this section, we discuss what is under the surface of these interactions that is not captured by the technical narrative of the app's performance.

In the Dutch GP guideline to suspicious skin lesions (Baaten , 2017), the process for how to evaluate skin lesions and treat skin cancer at the GP level is clearly delineated. GPs are the first point of triaging. GPs should do a full body scan for patients presenting with a suspicious lesion. If the GP believes a lesion is precancerous or a low-risk basal cell carcinoma, they should remove it or treat it with methods like a cream or liquid nitrogen, depending on the lesion and location; lesions such as high-risk basal cell carcinoma (Baaten, 2017), squamous cell carcinoma, and melanoma should be referred to a dermatologist for treatment and removal. All excised lesions should be histopathologically evaluated to confirm the diagnosis (Baaten, 2017).

Guidelines can appear to be somewhat "algorithmic" on paper, in that they use a step-by-step process to accomplish a task (Ziewitz, 2017), and thus potentially translatable into computer-based reasoning systems. In practice, a GP's course of action for a suspicious lesion is determined through a conversation with the patient instead of an isolated judgement of the GP about the appearance of a particular lesion; the latter would be more analogous to an app-based risk assessment. These conversations between patients and GPs (GPP) usually encompass far more factors than the skin lesion itself:

> *The doctor listens carefully to the patient's questions and concerns. The patient tells her story and mentions again that she has had radiation therapy (for cancer). After this, the patient says that she's worried about a number of lesions on her skin, and motions to several lesions on her face and throat. She says her partner remarked on a lesion on her back as well. This represents more lesions than the patient had presented to the medical researcher using the app.*
> *The doctor examines the lesions using the dermatoscope. The doctor says not to worry about the lesion on her throat, but she has doubts about the lesions on her face and back. Therefore, she wants to refer the patient to a dermatologist for further advice. The patient answers that she agrees with the doctor, and seems satisfied with the outcome. (GPP, R1 observation, practice 3)*

In this case, the risk assessment from the app was "low." However, in the diagnostic interaction, the doctor accounted for the location and number of lesions, and the patient's medical history, in addition to lesion appearance and complaints. Interestingly, the patient had not presented this entire history, nor all of the lesions to the medical researcher and the app, but instead waited until she could speak to a doctor. In doing so, the patient framed her complaints in the terms most comprehensible to the actor (app or doctor) from whom she sought care.



## PRIVILEGING QUANTIFIED DATA

Most GPs stated that the app's rating would not change their diagnosis. Some mentioned they would not change their diagnosis if they were "sure," but they may turn to the app for "reassurance" when doubtful. However, in practice, the app may have a large impact on the GP's treatment plan, regardless of how "sure" the GP felt about their diagnosis at the start:

> *The doctor examines the patient with a dermatoscope and thinks aloud. She says she suspects that it is an old-age wart. The patient says that a scab has fallen off on the skin spot. She used the app when the scab was still on and got a 'high risk' result. After the scab had fallen off, she used the app again. This time, she says that the result is 'low risk'. I remember that the 'high-risk' result was the one recorded in the study's system...Initially, the doctor says not to worry, but says if the app gives a high-risk result, she would refer the patient to a dermatologist. The doctor states that she assumes a 'low risk' result and indicates that she is still thinking the lesion is an old-age wart. However, she says, because of the earlier high-risk result from the app, she will schedule the patient for a follow-up appointment to remove the skin spot and send it for analysis. I am amazed that the doctor allows her plan to depend very much on the app result. The patient leaves the doctor's office. I let the doctor fill in questions for the medical study on the iPad. Later, when I check the questionnaire again, I see the doctor has completed all questions. However, when asked whether she would adjust her plan based on the risk result, the doctor answered 'No'. This contradicts the doctor's earlier statements! (GPP, R2 observation, practice 2)*

The influence of AI decision support systems on expert opinions is well documented (Bansal et al., 2019; Green & Chen, 2020). In this case, it appears that AI influenced the GP more strongly in practice than she indicated on a survey. While this could be an example of survey user error (Gobo & Mauceri, 2014) or concern for legal liability (Martinho et al., 2021), it is likely that the GP was either unaware of the influence or did not perceive it to be "influence," resulting in the difference between observations and survey data. The app fits easily within pre-existing frameworks that are considered part of good evidence-based medical practice (Perrotta & Geampana, 2020; Stevens et al., 2020), and thus benefits from privileges already accorded to technology and quantification in the practice of medicine. These privileges allow the app to slot into pre-existing taken-for-granted ideas (McKnight & Zietsma, 2018) about the superiority of quanitified data over experiential data and qualitative expertise. This easy fit thus represents a moment of breakdown in legitimacy not for the app itself, but because the veracity of the app's recommendations are so taken for granted

that the app inadvertently subverts the existing supremacy of physicians' expertise over technology recommendations. Rather than using the app as a tool for medical investigation in the way that the GP used the dermatoscope, in this interaction, the app's recommendation took on increased importance. Whether this change resulted from unnoticed influence, or concerns about legal ramifications of contradicting a technological solution's presumed-accurate recommendation, the app's influence on the physician's decision contradicts basic assumptions about medical hierarchies (that human judgment always takes precedence over AI-based decision support).

### MANAGING WORK BURDEN

GP practices also contradict assumptions made in both the company narrative and medical context about AI as work burden relief. Healthcare providers regularly suggested a primary interest in the app as a method of relieving work burden from seeing too many patients. GPs and assistants (GPP) frequently cited anxious patients without good reason to seek care as a source of this extra burden. Some GPs saw this as an opportunity for the app:

> *The GP said that he would like to have the application during consultations for extra certainty in case of doubts about the diagnosis. He would also like it if patients could use the application at home beforehand. Since the app has a high sensitivity rating, if there is then a low risk, he would like to use a low-risk rating to prohibit patients from coming to the consultation hour. (GPP, Observation, practice 3)*

Other GPs however thought the app would make no difference:

> *"The hypochondriacs who have been here ten times with spots and things…like, yes, I can see that you're very worried, but the app won't help with that. I need to get them in the consultation room, provide some nuance." (GP, focus group 1)*

Some GPs noted that impatience when it comes to skin cancer is understandable, even when it puts pressure on the practice:

> *"People don't want to wait long for a spot. Many people have already googled, so don't say you can only see the doctor on Wednesday afternoon…I mean, that's quite a long time." (GP, focus group Practice 2)*

However, there were no GPP participants who fit this "hypochondriac" description. While GPs were sometimes dismissive of a patient's concerns about a lesion, they never indicated that the patient should not have come in for a skin check. In interviews with researchers after a GPP inclusion, GPs always accounted for a reasonable source of an anxious patient's concern (for instance, family history of melanoma). In several instances, the GP believed a lesion (or other lesions on the body) to be high risk and worth a referral to the dermatologist without patient request, even when the app provided a low-risk rating.

These observations suggest that expectations of work burden relief from introduction of AI tools may not align with the experience of work burden in practice for GPs**.** While relief of work burden is not explicitly promised by the app, the company narrative plays into basic assumptions about the use of technology in healthcare, bringing this issue to the forefront. This threat to legitimacy is therefore only made visible when the app is embedded within a workflow in practice, such as at a GP office, when expectations of work burden relief are not met in practice.



## USER PRACTICES

In this section, we explore how practices of individual users dealing with the app reveal legitimacy breakdowns at the microlevel. These breakdowns represent misalignments with assumptions based on both the company narrative and the context of app use, in this case, the personal nature of individuals' smartphones.

People often struggled to use the app alone. Only a small minority of GPP participants were able to successfully use the app at home before coming in for their appointment. Even when assisted by a researcher, several participants were unable to use the app successfully at all.

The reasons for usage issues varied, but the location of the lesion was a primary factor. The app can only use the rear camera of a smartphone for quality reasons. As such, it was impossible for most people to center the lesion and hold the phone steady without the help of a partner, unless the lesion was on their forearms or another easily accessible body part. Lesions on the head universally required a partner's help.

Patients and helpers (including researchers trained to use the app) often physically struggled with the technology, trying with one hand before realizing they needed two to steady the phone in awkward positions. When the app still could not recognize the lesion, participants and helpers usually gave up after a few minutes of struggle; as the husband of a clinic user put it: "Well, we tried" (Accuracy P4). In the Accuracy and GPP studies, medical researchers would step in at this point. In most cases, researchers were able to take the photo; in several GPP inclusions, however, the researcher also could not get the app to recognize the lesion.

While some participants in all studies were happy to ask for help, others made it clear that having to ask for help to photograph a lesion would be a major barrier to using the app:

> *One participant struggled for several minutes alone, despite knowing he could ask for help. "The hell I can't take this photo," he said through gritted teeth. A few minutes later, he succeeded, after contorting himself uncomfortably to try to aim the camera correctly. He smiled and said proudly, "I did it, see, I'm a big boy." Later, he clarified that he meant that if it's about his health, he wants to*

*be fully responsible for it, including taking the photos; asking someone else to do something he feels he should be able to do alone was an absolute last resort (AE P5).*

In this case, the app transferred the responsibility (Schwennesen, 2017) for cancer risk assessment away from the doctor and towards the user, whether because of the language and design of the app based on the company narrative, or because of contextual cues designating smartphones as extremely personal devices (Marchant & O'Donohoe, 2019). Even though this participant said that he has previously gotten lesions checked by a doctor, using the app felt like something he had to do alone. Several other AE participants (3, 9, 12, 13, 14, 15) either resisted help when offered or purposefully did not ask because they felt this was something they had to do alone.

### AFFECT IN USER-APP RELATIONSHIPS

Finally, we zoom in on the affective elements in the interactions between individual users and the app. We analyze these issues as moments of breakdown driven by assumptions based on the company narrative and around expectations of how health technologies should work. Many of these breakdowns are driven by the inability of users to directly interrogate and negotiate with the app. In these moments, affective qualities such as "reassurance" or "annoyance" become more salient for users, but the same kind of interaction can have a very different affective quality depending on the app user and their past experiences with technology and medicine. Affective differences can therefore be insightful in understanding how the app becomes (de)legitimized in the context of specific kinds of interactions between the app, users, and medical professionals.

#### REASSURANCE AND TRUST

All participants in the AE study assessed lesions that they either were unconcerned about, or for which they had already consulted doctor. All stated they would still go to a doctor directly if they were worried about a skin lesion; however, a few participants did see the app as a potential replacement for doctors' visits in the future, if they could trust the technology enough: "(It is) much better than having to go to the doctor. But I don't know if at this point, this is reliable enough to avoid going to the doctor" (AE P13). Several mentioned that though the app may offer reassurance (Liu et al., 2023), it would not convince them a concerning lesion was low-risk. The app is not considered a replacement for the doctor, and most participants echoed this sentiment. While they saw the app as a useful tool, they did not feel it was as trustworthy as a doctor's opinion.

*"If I go to the doctor with this rash, he sees your arm and he has this knowledge, and then he says, okay, yeah, well, let's go for another checkup or let's go to this. With the application, you have the feeling of agency about how to diagnose yourself. Yeah. If you do incorrectly, then you have the feeling that maybe the answer won't suffice, like, for example, with the skin color. And that changes if you would trust it, or if it would replace going to the doctor." (AE P7)*

For this participant, the app is less trustworthy because it is mediated through his own lack of experience and expertise about both AI and skin cancer. He wanted an expert human involved. AE participants who received a teledermatology evaluation (2, 5, 14) found this reassuring; however even this human evaluation still did not replace the value of visiting a doctor if they were truly concerned about the lesion. The diagnostic interactions between doctors and patients are fundamentally different from risk assessment interactions between patients and an app; patients seek care in a medical interaction in ways that they do not in an interaction with a smartphone app. This implies that the app may not be perceived as a legitimate replacement for doctors' visits by patients because the service it provides lacks the human interaction and negotiation integral to doctors visits, regardless of technical capabilities.

In the Accuracy and GPP studies, patients often explicitly stated that they did not trust the app and would always go to the doctor, regardless of app's risk assessment. However, upon receiving a low-risk rating for a lesion, these same patients expressed visible relief (more relaxed physical demeanor, more talkative, smiling), with one explicitly saying, "That makes me feel better!" This phenomenon was noted outside of medical settings as well. An AE participant expressed strong doubts about the usefulness of the app prior to use:

> *The participant holds her phone too far away from her arm at first. The app does not recognize the lesion. "This is complicated," she says, "The flickering (check marks that appear when the camera is well-positioned) is panic-inducing, my banking app does this better." A few seconds later, the app recognizes the lesion and took the photo. The app shows a blue screen while the photo was analyzed. "Huh, low-risk," she said, "Let's see what happens if I tell it it's changing." She aims the phone correctly on the first try, quickly takes another photo, and marks that her lesion has changed in the screen listing possible complaints. The blue screen reappears. "It's taking longer this time," she says, "It's like it's thinking more. That's reassuring somehow." She clarifies later that the reassurance comes from the impression that the app seems to be "listening" when she adds information. "Still low risk," she says, "Interesting. Ok, let's try another lesion, one that I've actually had concerns about." (AE P2)*

While the participant still said she would not use the app when she has easy access to her GP, she said the app surprised her. She had proven the app was "not complete nonsense" to herself through practical use and she thought it may be helpful in certain contexts. Affectively, the app changed from "panic-inducing" tech junk to a mildly anthropomorphic AI device that could "think" throughout the course of her inclusion. This change in affect towards a somewhat reassuring quality also altered the legitimacy of the app in practice for her in ways that would have been impossible without personal interaction with the technology. For many participants, legitimacy was built through practical experience with the app.

### DISCOMFORT

The app includes two questionnaires about skin type and skin cancer risk which require qualitative judgments from users. Most users expressed significant discomfort with these questionnaires and worried that their answers may incorrectly impact the AI rating of individual lesions. These users initiated a conversation with the researcher (who was not a dermatologist nor connected to the company) about how to answer specific questions:

> *P4: "I think that's quite difficult (to choose my skin color) without seeing an example. Like I know I'm not light brown or dark brown or black, but I guess...not ivory white? Maybe something like fair to pale, fair to beige?"*
> *Researcher: "It's your call. It's all very subjective, right, people are being asked to rate their own skin."*
> *P4: "How does your skin respond to sun...That's also a bit difficult...burns moderately?"*
> *(AE P4)*

Some tinkered (Mol et al., 2010) with the technical processes in the app itself, moving back and forth between qualitative questions about lesion symptoms and the final risk assessment while changing their answers to determine how various answers impacted the outcome (Participants 2, 3, 4, 5, and 8). The app's lack of capacity for conversation resulted in an affectively different experience that could not be equated to a visit with a doctor.

### EXCLUSION, ANNOYANCE, AND DISCOURAGEMENT

People also struggled with the administrative set-up of the app. Several AE participants mentioned that if there hadn't been a researcher available to help, they would have just given up. Few GPP participants managed to download and set up the app with their personal details, despite several attempts, before arriving at the GP practice. This period of struggle had an affective quality; participants with less confidence around technology seemed to feel intimidated and excluded as they wrestled with the digital forms, and often gave up quickly even when aided by the researcher (GPP and AE). For one AE participant, medical administrative difficulties were negatively loaded due to personal experience:

> *"All the parts of the admin stuff...are things that more and more I have a strong aversion to, especially for healthcare, because I see how much my parents are struggling with all their healthcare apps. Not remembering the passcodes, the one for my mom, for my dad, then the email is not the same: they are so lost, and it's so much more complicated than it should be, and it's anxiety inducing for them at their age, that (when starting the app) I'm thinking, "Oh God, one more."" (AE P5)*

For another participant with a disability that requires constant contact with the health care system, the administrative and medical sides of the app had almost reversed affects: the medical side produced affects of exclusion and annoyance, while the administrative side felt routine.

*Participant 8 was business-like, calm while she held the phone with both hands to go through the app's sign-up administration, with almost a bored expression on her face. I asked if she was bored. She laughed and said, "It's like filling out another survey…because I used to do it every day. I was part of this trial, and twice a day, I had to do this, and score, like how was your day? Did you do this? How active were you?" She also had trouble getting the app to recognize her chosen lesion. She tried moving the hair on her forearm. She became very still and furrowed her brow, holding the camera steady for at least 10 seconds before declaring it wouldn't work with some frustration. I suggested she move the phone closer to her arm and tilt it. The app took a photo. I mentioned that most people move the phone around when the app doesn't work. She responded, "A lot of the apps have been designed for people who are able-bodied, expecting people to be able not to shake their hands…then there's this loading screen that looks like it needs to be steady in order to work, so that just reinforced it." When asked if this made her feel stressed, she responded, "It's very cynical, but I thought, 'Well, this is fitting, because nothing works in healthcare.' And I wanted to be a good participant." (AE P8)*

A relationship marred by affective discouragement clearly impacts who is able to use the app as intended, making it less likely that groups with lower technological literacy or physical difficulties will be able to use the app (Smak Gregoor, Sangers, Eekhof, et al., 2023). In this case, an affective quality of exclusion becomes realized in practice when participants who feel excluded give up.

### EMPOWERMENT

Given the well-documented evidence that women's health concerns tend to be taken less seriously by doctors for both structural and social reasons (Henry et al., 2020; Perez, 2019), it is unsurprising that some women viewed this app as a self-advocacy tool when dealing with the medical establishment. While men and people with a family history of melanoma occasionally noted during interviews that the app could be used for self-advocacy, they did not propose using it this way themselves with their own doctors.

Several female AE participants under age 30 talked about the app as a stopgap against what they perceive as insufficient care from their GPs. For instance, one woman who had moved to the Netherlands from a highly medicalized healthcare system was interested in the app as a screening tool to bridge the gap between the care she is offered in the Netherlands and the care she is used to at home:

*"Most of the time (being dismissed at the GP) is fine, but I think I'm used to a different system, where if you have a small complaint, they check a lot. I sometimes think, hmm, I'd like to have more information". (AE P4)*

These women stated that they found using the app to be a far more pleasant and "validating experience" (P4) than going to the GP to get a suspicious lesion checked. This was due to both the language on the app that takes their concerns seriously even when providing a low-risk rating, and

the ability to use the app to avoid an unnecessary and potentially stressful in-person interaction with their doctor. These women saw potential benefit in using the influence of AI on expert opinion (Bansal et al., 2019; Green & Chen, 2020) to bolster their position with their doctors in order to be taken seriously (Chopra et al., 2021). As one AE participant put it, "It's like a legitimacy vending machine, spitting out numbers" (AE P15).

As in the example of AI influence on doctor decision-making, younger women using the app as a form of self-advocacy does not represent a breakdown in legitimacy for the app itself. In fact, the practice of self-advocacy aligns well with the company narrative. Instead, this is a breakdown of legitimacy precipitated by misalignment with assumptions about the hierarchy of the medical system. Here again, the app subverts the supremacy of a doctor's judgment, rebalancing power in the relationship between the doctor and patient in a standard medical interaction.

## SUMMARY

Our analytical lens of legitimacy has allowed us to use 'moments of breakdown' within our ethnographic data to understand how the company narrative and existing context-based assumptions within the Dutch healthcare system (mis)align with practices in which the app is used. This focus made it possible to study the unquestioned and unnoticed elements in both the narrative around the technology and the medical system as a whole in relation to the practices and affective experiences of using the app. We identified three particular moments of breakdown that are instructive for understanding such (mis)alignments.

First, lack of (or slow acquisition of) institutional legitimacy through official channels required the company to pursue informal work-arounds (Kannan-Narasimhan, 2014), specifically, developing relationships with individual health insurers, that allowed the company to survive without funding equivalent to a major conglomerate. Second, quantification privilege (Lupton, 2015; Ruckenstein & Schüll, 2017) both increased and invisibilized the influence of the app on healthcare interactions, thereby disrupting assumptions about medical hierarchies and standard measures of quality in patient care. Third, limitations of flexibility and capacity for dialogue in interactions with the app (as compared with human doctors) led to unmet expectations around both work burden and ease of use because the app individualizes responsibility to the user, thereby sometimes creating additional work for both users and doctors. This limitation also increased feelings of exclusion for many of vulnerable users (Neven, 2010).

Below is a visualization of relationships impacting the embedding of the app in the healthcare system; based on our data, we show which relationships contained legitimacy breakdowns.

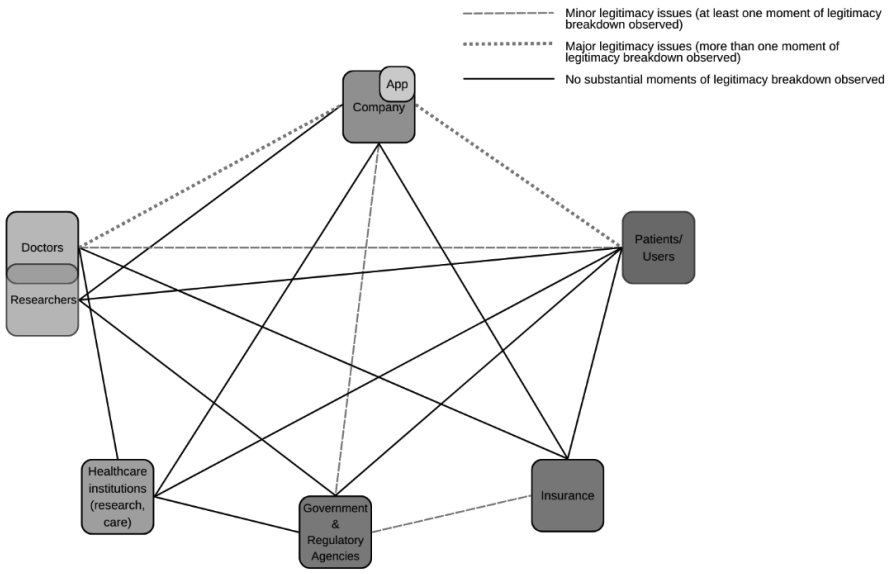


**Figure 3:** Legitimacy-impacting relationships affecting the adoption, acceptance, and implementation of the app in the Dutch healthcare system

Relationships between the app/company and both doctors and patients/users contained the most moments of legitimacy breakdown. However, moments of legitimacy breakdown related to the app were also found between doctors and patients, the company and regulators, and regulators and insurers, and we did not find noticeable breakdowns in all legitimacy-impacting relationships.

## DISCUSSION

In this ethnographic case study of an AI smartphone app for skin lesions risk assessment, we use a legitimacy lens to understand how technology is (not) embedded within a healthcare system. We explored moments of legitimacy breakdown as a means of understanding the assumptions that guide this embedding process. We conceptualized "legitimacy breakdowns" as moments when practices with the app (Nicolini, 2009) and affective aspects of user/app interactions challenged the company narrative or other assumptions within the healthcare context. We then used this conceptualization to analyze the assumptions that guide the embedding of this app in the Dutch healthcare system at a macro, meso, and micro level. Here, we discuss the implications of these assumptions for embedding technology in healthcare, and our contributions to existing literature.

Our study contributes to the literature on legitimacy in health and technology (Busfield, 2021; Granja & Machado, 2020; Perrotta & Geampana, 2020; Ruef & Scott, 1998; van Dijk et al., 2011) by revealing that practical interactions made the app's utility and capabilities salient to certain

users (Graeber et al., 2023), and in some cases, served to help legitimate the app in situations where narratives were ineffective. This supports the findings of prior studies[34,35] that suggest narratives alone are insufficient in understanding the full scope of how legitimacy is produced and maintained, instead exploring legitimacy as a product of practices, discourse, and relationships. Our study contributes a focus on the physical and affective (Navaro-Yashin, 2009) negotiations that impact legitimacy of a health technology to existing approaches that prioritize practices and relationships.

By examining differences between narratives and practices, policymakers and developers can target issues that will likely impact whether a technology is embedded in healthcare or not. Exploring the emotional qualities of user interactions with the technology and taking affective exclusion and discomfort seriously as indicators of user expectations can help developers find and understand issues early. Affective dissonance and non-user experiences are often ignored or marginalized in technology development, user testing, and policymaking around technology in healthcare (Boon & Edler, 2018; Wyatt, 2003); however, as our data and others' work shows, these dissonant opinions are invaluable to anticipation of challenges to technology embedding in healthcare (Jones & Pietila, 2020; Neven, 2010). On a more specific level, we also add to existing literature on algorithm aversion in skin lesion risk assessment (Gaube et al., 2024). We provide a deeper explanation for why patients are consistently resistant to relying on AI rather than a doctor; namely that when narratives and assumptions about AI do not align with affective and practical experiences of AI users in medical practice, the legitimacy of AI as a replacement for human medical care is compromised.

Secondly, our study contributes to the literature on technology acceptance, adoption, implementation, and governance frameworks. These frameworks provide researchers with conceptual and methodological frameworks to explore specific embedding issues with attention to concepts like transparency (Licht & Licht, 2020; Reddy et al., 2020), trust (Fox & Connolly, 2018; Reddy et al., 2020), and acceptability (Bramo et al., 2022; Dwivedi et al., 2016; Graeber et al., 2023; Rouidi et al., 2022; Virtanen et al., 2023; Yarbrough & Smith, 2007). These frameworks are often used to inform decision-making not only for researchers, but for developers and policymakers. To avoid approaching acceptance, adoption, implementation, and governance challenges separately, some literature in this area also covers more comprehensive approaches to technology embedding challenges, such as the NASSS framework (Greenhalgh et al., 2017) and Technology-Organization-Environment when used in healthcare (Yang et al., 2022). Our finding that the process of embedding technology in healthcare is impacted by contradictions between narratives/assumptions and affects/practices builds on this work. This study supports the continued use of these more complex and nuanced frameworks and challenge the applicability of frameworks that focus solely on behavioral intention (Holden & Karsh, 2010; Nadal et al., 2020; Yarbrough & Smith, 2007). We add to these more comprehensive frameworks by presenting a legitimacy lens as a possible strategy for identifying possible embedding issues in advance that could allow researchers, developers, and other stakeholders to better anticipate challenges for embedding in practice from a

socio-technical perspective (Bagge-Petersen et al., 2022; Cresswell & Sheikh, 2013; Mathieu-Fritz & Gaglio, 2018; Stevens et al., 2018).

By foregrounding moments of breakdown in legitimacy through ethnographic data analysis, particularly of practice and affect (Gjodsbol et al., 2024; Lupton, 2017), studies of technology embedding in healthcare can access nuances that may be absent without this perspective. For instance, our results indicate that trust and legitimacy are not the same and that, while trust is an important component in the embedding of technology in healthcare, a healthcare technology may be able to obtain a level of legitimacy without it. This nuance has implications for researchers conducting studies about technology adoption, acceptance, implementation, and governance with a heavy focus on trust (Fox & Connolly, 2018; Licht & Licht, 2020; Reddy et al., 2020), and suggests that legitimacy and trust may best be studied as separate criteria in studies of health technology embedding in general, despite their similarities (Le, 2013; Mathieu-Fritz & Gaglio, 2018). This ethnographic approach to legitimacy could therefore also provide direction to pain points when exploring embedding problems (Cleemput et al., 2018). This would encourage researchers to pursue studies centered on issues related to practical or affective dissonances with prevailing assumptions, and help avoid study designs that take those assumptions for granted.



This study has several strengths: it represents the culmination of a long period (three years) of ethnographic data collection from many sources, including beyond a clinical setting. In clinical inclusions, some observations could have benefitted from more depth and richness; however, in an operational medical context, inclusions had to happen between other work. The composition team, similarly, represents a strength in that diverse perspectives allowed us to incorporate both medical and social science-informed understandings into our ethnography. This in turn required more coordination, potentially limiting the depth of some observations while broadening our overall perspective.

Because we were unable to conduct ethnographic research on site with the company, we focus entirely on interactions between the company and outside stakeholders, rather than on the internal workings of the development, improvement, and implementation strategy at the company. While we believe these external interactions to be most important for the production of legitimacy, we may have missed nuances in company strategy due to lack of internal data.

A map of relationships impacting legitimacy (figure 1) could be used by future researchers as a more structured way to explore embedding technologies in healthcare systems. Future scholars can apply and tailor this to their own studies of (digital health) technologies to search for legitimacy pain points within the relational contexts in which technologies operate. These maps may change over time as technologies move through the embedding process; while our data suggests that legitimacy conflicts may be limited to a relatively small number of relationships that are important to the embedding of a technology in healthcare (see figure 1), this should not be taken to mean that all

relationships without breakdowns observed are free from legitimacy issues. For instance, other studies have shown that within healthcare institutions, relationships among doctors and healthcare administrators can have a large impact on whether a change is implemented within a hospital (Sheard et al., 2017), though we did not observe dynamics like this in our data set, possibly because the app is marketed to individual users and insurance companies, rather than as a healthcare institution-based technology.

As a case study centered around a single technology being embedded in a single location, our study's specific findings may not be generalizable to other empirical studies of AI technologies in healthcare. However, this study has provided important insights into the utility of legitimacy as a lens to understand how technologies become embedded in healthcare and may be considered analytically generalizable (Halkier, 2011), in that our data supports and builds on findings from both the legitimacy literature and literature on embedding technology in healthcare. A legitimacy lens adds to comprehensive frameworks already in use and clearly identifies potential pain points.

## CONCLUSION

The study ethnographically investigated the embedding of a skin cancer risk assessment app in the Dutch healthcare system. We explored moments of legitimacy breakdown as a means of learning about the assumptions guiding the embedding of this AI-based application in the Dutch healthcare system.

We find that while many kinds of assumptions guide the embedding of the app, legitimacy breakdowns occur primarily when practices dissonate with an aligned combination of company narratives and context-based assumptions built into the healthcare system. These breakdowns occur at the macro, meso, and micro levels and have significant implications for the legitimacy of the app in the eyes of users, doctors, and the Dutch government, even when the breakdown occurs outside of direct relationships with the app (for instance, between doctors and patients). These breakdowns have affective qualities for app users which, in turn, influence their (non-)use of the app.

Through this study, we have demonstrated that ethnographic exploration of legitimacy can be a powerful tool as we seek to better understand acceptance, adoption, implementation, and governance of health technologies. We have shown that misalignments of practices and assumptions (narrative or context-based) within relationships at all levels of a healthcare system can challenge embedding goals for health technologies. New health technologies often disrupt existing hierarchies and require a renegotiation of the status quo; however, it is often unclear whether such renegotiations will lead to embedding of the technology or better health outcomes in the healthcare system. A legitimacy lens combined with an ethnographic approach addresses this issue by allowing researchers to pinpoint (anticipated) embedding problems and provide a clear yet nuanced perspective on the relationships impacting legitimacy of a health technology in context.

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## AUTHOR CONTRIBUTIONS (CREDIT)

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- Conceptualization (lead)
- Data curation (lead)
- Investigation (lead)
- Methodology (lead)
- Project administration (AE study and overall ethnography project)
- Visualization
- Writing – original draft (lead)
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Carin Uyl-de Groot
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Marlies Wakkee
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- Writing – review & editing (supporting)

# STATEMENTS AND DECLARATIONS

## ETHICAL CONSIDERATIONS

Ethics approval was granted by Erasmus University Rotterdam for ethnography (App Experiences Study) and all interviews (ETH2324-0010).

General Practitioner Pilot Feasibility Study (AIM HIGH): The study was assessed by the Medical Ethics Committee of the Erasmus University Medical Center (MEC2021-0254). They deemed it as not under the scope of the Medical Research Involving Human Subjects Act (WMO) and exempted it from further ethical approval. Written informed consent was obtained for all participants.

## CONSENT TO PARTICIPATE

Written informed consent was collected from all study participants. Data was pseudonymized and stored securely according to EMC and ESHPM guidelines to ensure adherence to European privacy law.

## CONFLICTING INTERESTS

The Erasmus MC Department of Dermatology has received an unrestricted research grant from SkinVision B.V. Dr. Marlies Wakkee and Prof. Dr. Tamar Nijsten serve on the Science and Dermatology advisory board for SkinVision.

None of the authors received any direct fees for consulting or salary from SkinVision. SkinVision was not involved in the design of the study, data collection, data analysis, data interpretation, or writing of the manuscript. In addition, SkinVision was not involved in the decision to submit this work for publication.

The authors from Erasmus School of Health Policy and Management (Sydney Howe, Prof. Carin Uyl-de Groot, and Dr. Rik Wehrens) declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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# 3

# CHAPTER 5

# EXPLAINING EXPLAINABLE AI FOR HEALTHCARE:
## a Q-methodology Study

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## INTRODUCTION

Technological innovations are increasingly viewed as important tools to manage growing demand on the healthcare system (Amann et al., 2020) due to aging populations (Yang et al., 2022) and healthcare worker shortages (Van Merode et al., 2024). Artificial intelligence (AI) healthcare tools are often promoted as a means to improve patient access to quality care (Yang et al., 2022) and reduce work burden for medical staff (Aung et al., 2021; Stewart et al., 2024). While many definitions exist (Lindgren, 2023), in this study, we consider "AI" to be computer systems that can "display intelligent behaviour by analysing their environment and taking action — with some degree of autonomy — to achieve specific goals"(HLEG), 2018); this definition allows us to focus primarily on current healthcare applications of machine learning and deep learning techniques without excluding other kinds of AI-labeled technologies (Aung et al., 2021; Loh et al., 2022; Molnar, 2022). In healthcare, hype among decision-makers around AI technologies (Bleeker, 2024; Emanuel & Wachter, 2019; Strange, 2024) results in use of the term to describe a wide range of algorithms and applications performing detection, classification, and prediction functions across a range of medical fields (such as cardiology, dermatology, and epidemiology) and practices (such as diagnostics, surgery, clinical practice, and rehabilitation)(Aung et al., 2021; Loh et al., 2022; Secinaro et al., 2021).

The promises of AI for healthcare are expansive. AI applications in radiology have promised to streamline practitioners' workflows and improve patient outcomes through quantification and improved pathology detection (Boverhof, Redekop, Bos, et al., 2024). AI-powered prediction models promise to improve embryo selection for in-vitro fertilization (Dimitriadis et al., 2022), and skin cancer risk assessment apps promise patients access to "the right kind of care" more quickly (Howe et al., 2024). Even when these promises do not align with practical usage of AI in healthcare (Howe et al., 2024), they inform the direction of development for future AI healthcare tools (Carboni et al., 2023).

However, the challenge of explaining and understanding AI decision-making (de Miguel et al., 2020) adds to the wicked problems (Morley et al., 2020) inherent to integrating AI into healthcare. AI can pose substantial ethical, medical, and legal risks (Balay-odao et al., 2024; Carboni et al., 2024; de Miguel et al., 2020; Howe et al., 2024; Morley et al., 2020; Reddy et al., 2020; Stevens & Beaulieu, 2023). Transparency in the medical decision-making process is necessary to adequately manage responsibility, accountability, and liability issues (de Miguel et al., 2020; Licht & Licht, 2020; Mittelstadt et al., 2016; Reddy et al., 2020; Smith, 2020). This need for transparency is threatened by a technology that performs tasks ordinarily requiring human intelligence (Stevens & Beaulieu, 2023) through processes that cannot be adequately interrogated (Licht & Licht, 2020); it is nearly impossible for humans to understand how AI models make inferences, impeding full transparency (Molnar, 2022). Despite these obstacles, healthcare stakeholders are strongly driven towards implementation by the promise of AI solutions to improve care in an overburdened healthcare system (Werner et al., 2021).

Explainable AI (XAI) is often mobilized to address development and implementation barriers related to transparency (Amann et al., 2020; Gerlings et al., 2022; A. F. Markus et al., 2021; Poon & Sung, 2021) and strengthen regulation for AI in healthcare (Amann et al., 2020; Arbelaez Ossa et al., 2022; de Miguel et al., 2020; Vale et al., 2022). XAI can influence trust, acceptability, legitimacy, and likelihood of adoption (Arbelaez Ossa et al., 2022; Kemper & Kolkman, 2019; Licht & Licht, 2020; Aniek F Markus et al., 2021). Recently, the European Union's (EU) AI Act has made explanations a requirement for algorithmic decisions that may "significantly affect" users (Benifei & Tudorache, 2021), such as high-stakes medical decision-making (Vale et al., 2022; van Kolfschooten & van Oirschot, 2024). Given the push towards integration of AI healthcare tools at the EU policy level (van Kolfschooten & van Oirschot, 2024), it is important to determine how governments and healthcare stakeholders can approach explainability responsibly (Bouderhem, 2024; Trocin et al., 2021).



Literature about the meaning and purpose of XAI spans many disciplines, including computer science, social sciences, ethics, law, and public policy (Amann et al., 2020; Angelov et al., 2021; Arbelaez Ossa et al., 2022; Páez, 2019; Vale et al., 2022). Yet despite growing attention, there is limited clarity about what 'explainability' means, especially in healthcare practice. This is partly because explanations can vary according to data type, complexity, and interpretations of AI results: presenting an algorithm's training data, for instance, is less complex than making black-box algorithm decision-making processes interpretable to humans (Licht & Licht, 2020).

The term *XAI* is also used differently across disciplinary traditions. In technical disciplines and law, XAI usually refers to an *algorithm that provides explanation*: essentially, an (AI) algorithm that either explains itself or another algorithm (Angelov et al., 2021; Páez, 2019; Vale et al., 2022). These authors draw clear distinctions among the terms *transparency*, *interpretability*, and *explainability*. While authors writing in ethics or social science acknowledge this technical definition, they focus on *audiences for explainability*, rather than determining whether an algorithm is technically explainable or interpretable. Therefore, they deal with *explanations of AI*, rather than technical explainability (Arbelaez Ossa et al., 2022; de Miguel et al., 2020). Explanations can range from deep technical outputs to operationally-oriented explanations, like training simulations that teach healthcare workers to use AI tools (Balay-odao et al., 2024). Exactly what kind of explanation will un-"black box" an AI technology for a particular audience remains difficult to answer (Gerlings et al., 2022; Licht & Licht, 2020). In this study, we systematically explore the different meanings of and preferences for XAI among professional healthcare stakeholders to better understand the needs of these different audiences.

One point of agreement among healthcare stakeholders seems to be that the purpose of XAI is to improve understanding and trust. Both understanding and trust are viewed as key for effective integration of AI technologies in healthcare (Amann et al., 2020; Aniek F Markus et al., 2021). Understanding is generated by explanations of what an AI tool does and how it works, in a manner appropriate for the audience (Amann et al., 2020; Licht & Licht, 2020). Trust is less well-defined across the literature but

seems to indicate instances when humans feel they can rely on an AI tool to perform a task in a valid way (Balay-odao et al., 2024; Licht & Licht, 2020). However, how understanding and trust can be generated for different audiences through explanations of AI remains underexplored empirically.

Therefore, knowledge of the explanation's audience is essential for producing explanations that improve trust and understanding. Healthcare stakeholders arrive at interactions with AI with different ideas and assumptions about what explanations entail (Greenhalgh et al., 2023; Licht & Licht, 2020); these assumptions may even conflict among stakeholders for a single AI tool (Arbelaez Ossa et al., 2022). Divergent needs, values, and knowledge bases (Stevens et al., 2020) make designing explainability guidelines challenging; necessary information for one audience could be an impediment for another. For instance, an explanation for untrained audiences that draws attention to the complexities of AI may create distrust (Licht & Licht, 2020; Stevens & Beaulieu, 2023), whereas an explanation with too little information for highly-technical audiences may also backfire. Similarly, different audiences may place different priorities on privacy compared to accessibility of data for training purposes, leading to values conflicts (Gerlings et al., 2022). Even relative desire for explanations among stakeholders can signal a deeper values conflict: for instance, in one study, doctors with deep pre-existing trust in tech companies found a focus on explainability to be detrimental to maintaining efficiency in medical practice, while other doctors saw explainability as a necessary part of medical professional development whenever AI is used (Martinho et al., 2021). Therefore, XAI must meet the needs of multiple audiences (Amann et al., 2020; Gerlings et al., 2022; Licht & Licht, 2020), though these may change over time with views of participants and technological developments (Licht & Licht, 2020). In healthcare, important audiences may include medical professionals, policymakers, administrators, and patients (Arrieta et al., 2020; Langer et al., 2021).

This study seeks to answer the research question, '*What are the meanings of and preferences for XAI among professional healthcare stakeholders in the Netherlands?*'. We collected data on meanings and preferences for XAI among professional stakeholders responsible for development, adoption, and implementation of new health technologies. We focus on the Netherlands, a healthcare context that is currently experiencing rapid introduction of AI tools, much like other countries in Western Europe (Kroneman et al., 2016). While patient needs and desires are important, most AI tools for healthcare are developed, implemented, regulated, used and/or monitored by professionals (Carboni et al., 2023; Farah et al., 2023), with some exceptions (Howe et al., 2024). Therefore, without these professionals, AI tools are unlikely to enter healthcare in the first place.

Previous authors have systematically studied views of healthcare professionals about (AI) health technologies generally (Balay-odao et al., 2024; Hummel et al., 2024; Ladan et al., 2018). Others have developed cohesive definitions of XAI for healthcare stakeholders (Arbelaez Ossa et al., 2022), or explored differing XAI needs of healthcare stakeholders within case studies (Gerlings et al., 2022). However, none have investigated professionals' preferences for XAI for healthcare systematically.

With this article, we therefore fill several research gaps. First, we use Q-methodology (Watts & Stenner, 2012) to produce a typology of existing views on XAI held by a wide range of professional stakeholders in the Netherlands. Our findings are applicable beyond Dutch borders: in addition to similarities in digitization plans between the Netherlands and other EU countries (Kroneman et al., 2016), the statement set was derived from international literature and focus groups with stakeholders from three European countries. Q-methodology is ideally suited to research on perspectives on XAI within a diverse sector like healthcare; to our knowledge, this is the first such study. Second, we add to literature on XAI across several disciplines by discussing the implications of different preferences for provision of explanations.

## METHODS



We conducted a study of meanings and preferences for XAI among 37 professional healthcare stakeholders. We explore the views of professional stakeholders in the Dutch healthcare system (most of whom are the audience for, rather than purveyors of explanations); therefore, we focus on *explanations of AI*, rather than techniques of XAI (Páez, 2019). While these terminological differences are meaningful, we use "XAI" to refer to both, reflecting how the term was used by most participants.

All participants gave written informed consent for participation and interview recording. Ethical clearance was obtained from the Erasmus School of Health Policy and Management Research Ethics Review Committee (ETH2324-0336 and ETH2324-0175).

### OVERVIEW OF Q-METHODOLOGY

This study uses Q-methodology, a method for the systematic study of subjectivity (Watts & Stenner, 2012), to develop more clarity and coherence (Valenta & Wigger, 1997) around XAI preferences and meanings in healthcare. Using a by-person rather than a by-item approach to factor analyze data (Dieteren et al., 2023) allows for a self-referent form of subjectivity in which the participant determines what is meaningful and significant. The researcher can then generate a typology of such subjectivities by combining statistical methods with qualitative analysis (Kim et al., 2019; Martinho et al., 2021; Stenner et al., 2008; Watts & Stenner, 2012). This Q-methodology study was developed in four consecutive steps: (1) development of the statement set; (2) selection of the participants; (3) interview administration; and (4) analysis and interpretation (Watts & Stenner, 2012). Below, we discuss our approach to each step in this study.

### DEVELOPMENT OF THE STATEMENT SET

To develop a comprehensive set of statements, the scope of the topic, or the concourse (i.e. a corpus of opinions), must first be identified (Martinho et al., 2021). The concourse was produced from several

sources. First, the primary researcher collected statements and opinions through focus groups of partners participating in the AICCELERATE project, a recipient of European Union Horizon 2020 funding consisting of three AI pilots of the Smart Hospital Care Pathway Engine. AICCELERATE partners spanned a variety of healthcare and technologies professions across three European countries (AICCELERATE, 2021). In addition, the primary researcher included statements produced through previous ethnographic research and literature reviews. A total of 148 statements were included in the concourse before saturation was reached (Appendix A).

To identify a comprehensive yet manageable subset of the concourse (Martinho et al., 2021), we used thematic analysis to cluster statements within the concourse. Thematic analysis allowed us to develop a structured and balanced set of statements that covered all major meaning dimensions present in the concourse. During this selection process, our strongest considerations were clarity, diversity, scope, and avoiding redundancy (Martinho et al., 2021). A final set of 34 statements was developed over the course of two working groups (Table 1).

The statement set was pilot-tested with two participants; one had contributed to the concourse and one was new to the study. Based on feedback and results from these pilots, we refined our study protocol but did not add, subtract, or alter any statement.

## SELECTION OF PARTICIPANTS

We used purposive sampling to identify and recruit a varied group of professional stakeholders in healthcare with an interest in AI. Based on literature identifying important stakeholders for explanations of AI (Arrieta et al., 2020; Langer et al., 2021), we focused on hospital administrators due to their pivotal role in technology adoption (Sheard et al., 2017). The final sample of 37 participants was selected based on the expectation that they have a 'clear and distinct viewpoint regarding the problem' (van Exel & de Graff 2005, p. 6). We prioritized diversity in terms of professional role in healthcare, gender, age, and familiarity with AI (Appendix A). For more information about participants, see Appendix A.

## INTERVIEW ADMINISTRATION

The primary researcher led interview administration, with assistance from three other researchers. In the interview, participants were first asked to rank the set of statements onto a normal distribution chart along a continuum from "least agree" to "most agree" (Figure 1) in response to the following question: "AI systems are increasingly used in healthcare. For these systems to be helpful, users (i.e., medical staff, healthcare administrators, and other professionals) need to understand and trust them. In this context, to what extent do you agree with these statements about AI in healthcare?" Participants were instructed to read all statements and place each

statement in one of three categories: 'tend to disagree', 'neutral/don't know' or 'tend to agree'. Next, by category, they read the statements again and placed them on the grid as they saw fit. They were encouraged to place the statements within the grid boundaries, if possible, but deviations were tolerated if participants felt this represented their opinion best.

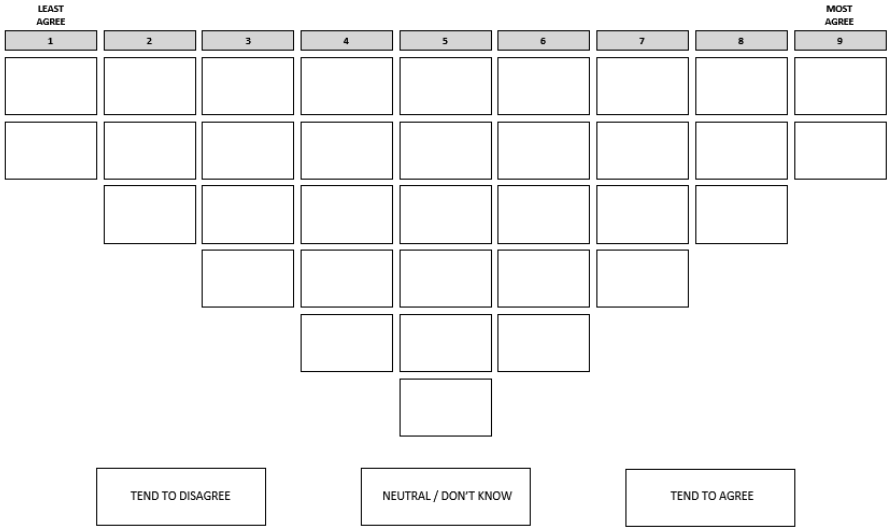


**Figure 1:** Q-sort grid

Data were collected in-person. Participants were invited to talk aloud during the sorting process. Finally, the researcher followed up with questions about statements placed on the extreme ends of the grid, and any statements the participant found particularly interesting or difficult to sort. Any changes that needed to be made to the statement rankings following this discussion were recorded. Finally, participants were asked to describe the meaning of XAI and their preferences for explanations in their own words.

The final data set included 37 rankings and accompanying audio-recorded interviews. The rankings were photographed and later transcribed to Excel, and the interviews were transcribed. The time required for each interview ranged from 25 minutes to 1.5 hours (most required 45-60 minutes).

## ANALYSIS AND INTERPRETATION

Q-methodology employs quantitative factor analysis to distill findings from many variables (i.e., the rankings of statements) to a small number of factors (Valenta & Wigger, 1997). The first step in analysis, factor extraction, summarizes the total findings through a smaller number of representative samples. The next step, factor rotation, aims to simplify the selected factor structure to improve their interpretability as perspectives. The final step involves analysis and interpretation of the factor arrays

(i.e., the weighted average ranking of the statements for each factor) to understand the key features of each perspective and distinguishing features among perspectives (Watts & Stenner, 2012). This step is more interpretive: qualitative explanations of respondents associated with each perspective are used to interpret the quantitative results and enrich the perspective descriptions, though factor scores produce strong boundaries for interpretation (Watts & Stenner, 2012).

Analysis was conducted using KADE (Ken-Q Analysis Desktop Edition) 1.3.1 software (Banasick, 2023), Excel, and Atlas.ti (ATLAS.ti version 22.0.6.0, 2022). The primary researcher extracted factors using centroid factor analysis (CFA) to maximize factor differences (Watts & Stenner, 2012). Four factors were extracted using the following criteria: the eigenvalue must exceed 1 (Appendix A), and at least two individual participants must load uniquely on a factor ($p < 0.05$) (Watts & Stenner, 2012). After applying varimax rotation, each factor was loaded with participants with a significant correlation to the factor ($p < 0.05$). The four-factor solution's reliability was verified using a derivative CFA of the factors produced by the four-, six-, and seven-factor solutions, resulting in clear stability for three factors across all solutions and nuance added to a fourth factor that was split in higher order solutions. Qualitative data from the interviews were coded to the numbered statements in Atlas.ti by level of agreement. Narratives of each factor were then constructed based on the characterizing statements (i.e., the *most agree* and *least agree* statements within each factor) and distinguishing statements (i.e., the statements significantly different in ranking from other factors). These narratives were then compared with factors within higher-order solutions to confirm validity and add nuance; finally, interview data from participants were incorporated into the analysis, further clarifying the interpretation in the language of participants. Each factor thus represents a coherent and distinct perspective on meanings of and preferences for XAI in healthcare.

## RESULTS

Four factors were identified, each representing a distinctive viewpoint on XAI. These factors explain 44% of total variance. Of the 37 participants, 12 loaded onto factor 1, 11 loaded onto factor 2, eight loaded onto factor 3, and six loaded onto factor 4.

**Table 1:** Statements and factor arrays showing the Q-sort ranking for each statement within each factor

| Statement number | Statement | Factor 1 | Factor 2 | Factor 3 | Factor 4 |
|---|---|---|---|---|---|
| **1** | AI performance should be monitored over time. | +4 | +3 | +3 | +4 |
| **2** | Users need to understand the cause of AI failures. | -1 | -1 | +1 | -1 |
| **3** | Users only need to partially understand AI in order to properly use it. | +3* | -2 | -1 | -4* |
| **4** | AI should be fully transparent. | -3 | +3* | -2 | -3 |
| **5** | AI systems should connect technical and medical expertise during development. | +3 | 0 | +3 | -1 |
| **6** | AI should be explained the same way other technologies are explained. | -4 | -4 | -3 | -3 |

| Statement number | Statement | Factor 1 | Factor 2 | Factor 3 | Factor 4 |
|---|---|---|---|---|---|
| 7 | Users need to understand the context in which AI systems are developed and implemented. | -2 | -1 | 0 | 0 |
| 8 | Explanations of AI should be logical. | +1 | -1 | -1 | +3 |
| 9 | Explanations should include the input into an AI system. | -1 | 0 | +1 | -1 |
| 10 | Explanations should include the processes used within an AI system. | -4* | -2 | -1 | -2 |
| 11 | Explanations should include the output from an AI system. | -1 | +2 | 0 | +2 |
| 12 | Users should be able to train to use an AI system. | +2 | 0* | +3 | +2 |
| 13 | Users should be able to ask questions about explanations of AI. | +1 | +1 | +2 | +1 |
| 14 | Explanations of AI should be communicated in an accessible format. | +2 | +1 | +2 | 0 |
| 15 | Explanations of AI should be useful to all users. | -2* | 0 | -1 | +3* |
| 16 | Different users require different explanations about an AI system. | +2 | +2 | 0 | +2 |
| 17 | Users should be involved in the development of an AI system from the beginning. | -1 | -1 | +4* | -2 |
| 18 | Legal requirements for AI explanations are necessary to mitigate the risks posed by AI. | 0 | +1 | 0 | 0 |
| 19 | Within each organization, it should be clear who is responsible for understanding AI systems. | 0 | +1 | -2* | +1 |
| 20 | Explanations should ensure that AI systems are ethically accountable. | 0 | 2* | -2 | 0 |
| 21 | Explanations of AI require a common language between users and developers. | +1 | -3 | -1 | 0 |
| 22 | Users should know when AI is being used. | +1 | 4* | +1 | +1 |
| 23 | Users should know what value AI adds to healthcare. | +3 | 0* | +2 | +2 |
| 24 | Explanations of AI should include statistical evidence. | 0* | -2 | -2 | -1 |
| 25 | Explanations of AI should include alternative interpretations of output. | -1 | +1 | 0 | +1 |
| 26 | Explanations of AI should indicate when to trust results and when to exercise caution. | +4 | +3 | 1 | +3 |
| 27 | The purpose of AI explanations is to improve security for users. | -2 | -2 | -4 | -2 |
| 28 | AI is different from other technologies due to its complexity and ability to change over time. | +1 | 0 | -3* | 0 |
| 29 | Explanations of AI should be limited to only the most essential information. | 0* | -4 | -3 | -2 |
| 30 | Explanations of AI should be relevant and useful to the user's specific context. | +2 | +2 | +4* | +1 |
| 31 | When users accept an AI system, less explanation is required. | 0* | -3 | -4 | -4 |
| 32 | Explanations of AI should meet the expectations of users. | -2 | -1 | 0* | +4* |
| 33 | Explanations of AI should be sensitive to prior beliefs and experiences of users. | -3 | -3 | 2* | -3 |
| 34 | Explanations should be provided to patients when AI is used in their care. | -3* | +4* | +1* | -1* |

In the factor array above, the characterizing statements are rated +3 or +4 (i.e., *most agree*) and -3 or -4 (i.e., *least agree*). Distinguishing statements at a significance of $p<0.01$ are marked with (*). See Appendix A for further detail about statistical results.

Each factor represents a distinct perspective. These are:
Perspective 1: Keep it Practical
Perspective 2: Consent, Regulation, & Risk Mitigation
Perspective 3: Strong Starts
Perspective 4: User Manual Wanted

## KEEP IT PRACTICAL

This perspective prioritizes aspects of understanding related to practical use of the technology. This perspective prefers "need-to-know" information that is operationally applicable to professional users over ensuring that all users have a deep and thorough understanding of AI.

> *I mean, of course we are not going to explain to users that we use either deep learning or K-means clustering or something like that, right? That makes no sense because the user will not understand it any way better than that. (Participant 18)*

For this reason, explanations must underscore the value of the new technology (statement 23: rank +3) to a healthcare professional's work.

Other kinds of explanations requiring more time to implement or education to understand are deprioritized in this perspective. For instance, it is not considered important for patients to receive explanations (st.34:-3): 'They trust the doctor. We use CT scans and MRIs and they don't need to know how that is being operated' (P15). Similarly, neither AI technical processes (st.10:-4) nor full transparency are considered a priority (st.4:-3). Instead, this perspective prioritizes connections between medical and technical expertise during development (st.5:+3) rather than at the level of the explanation.

> *They don't have to understand everything. But to a certain level they have to understand it and know the risks…And if you give information, people should be able to appreciate the value of what is being communicated. (P21)*

Explanations should also indicate when to trust results and when to exercise caution (st.26:+4). These priorities collectively point to a desire for professionals to be able to take responsibility for outcomes by knowing how to use AI tools effectively and when their outputs can be trusted.

## CONSENT, REGULATION, & RISK MITIGATION

Oriented towards law and regulation, this perspective focuses on general guidelines rather than practical usage of explanations and prioritizes ethical and legal accountability. This is the only perspective that prefers full transparency (st.4:+3). Attempts to limit scope of, or access to,

explanations of AI are strongly opposed (st.31:-3, st.29:-4). Explanations are necessary to meet ethical requirements (st.20:+2). As one participant put it:

> *I think professionals must know it's going to support them to make ethical decisions, which they make every day for their patients. And if they can't explain that, they have no idea what they're using. (P13)*

It follows that the most important statements for this perspective relate providing explanations to both users and patients (st.34:+4, st.22:+4):

> *If you're a professional, you want to understand the instruments you're using. You want to be in control. (P14)*
> *It's about new technology. You should know when it's used. (P20)*



These quotes exemplify the perspective's emphasis on disclosure of AI use as a baseline criterion for valid use of an AI technology. Interestingly, this perspective still contains nuances around full transparency. Some stakeholders acknowledged that such transparency was impractical or impossible in interviews; however, they still prioritized it for AI aspects that could be made fully transparent. This seems to indicate a prioritization of general principles or "basics" (P13), over the practical use of explanations, unlike in the first perspective.

This perspective's approach to a common language between users and developers (st.21:-3) is also nuanced. Despite requiring full transparency and disclosure to users and patients, a common language is not considered essential. This may seem contradictory at first glance; however, based on interview data, this seems to indicate an understanding of the limitations of communication:

> *If you assume we speak the same language, then things can keep slipping between two professions that have a lot of jargon... even I must not assume I speak the same language as them, so I have to constantly check, "Do we mean the same thing?" (P24)*

This perspective finds that the practical application of guiding principles is beyond the scope: this would involve agreeing on details that will likely vary depending on the project and stakeholders involved. Instead, agreement on guiding principles is all that can be established outside of a particular project.

In sum, this perspective views AI as inherently risky and advocates for the establishment of guiding principles to ensure it is used safely, legally, and ethically.

## STRONG STARTS

This is a holistic perspective focused primarily on development and implementation. This perspective values information about the development of AI tools, such as user involvement (st.17:+4), the connection of medical and technical expertise during development (st.5:+3), and the capacity of users to train to use an AI tool (st.12:+3). This perspective does not find that explanations increase the security of end users (st.27:-4); rather, trust is built through strong development and implementation practices at the start of a project:

> *It's not the purpose (of explanations) to improve the security. For me, it's more that you use it in a right way. Security kind of has to do with the legal part and I'm not really concerned about the legal part for all of this. I'm concerned that (AI) has added benefits, healthcare-wise. (P28)*

The idea that less explanation is required when users accept an AI system (st.31:-4) is strongly opposed in this perspective: "You know, I'd say more explanation is required" (P3). Similarly, this perspective finds that partial information is insufficient (st.29:-3), reemphasizing the goal of fully understanding the development and implementation process.

However, while this perspective finds that AI's capacity for change is not different from any other technology (st.28:-3), it also does not believe AI can be explained in the same way as other technologies (st.6:-3). Interviews suggestthis is because this perspective considers all technologies to be unique: "I didn't know there was one way to explain all technologies" (P3), with some room for AI exceptionalism within specific parameters.

Overall, this perspective prefers to focus explanations on the development process, and use explanations to address issues that arise during development and implementation. The primary purpose of XAI, therefore, is twofold: 1) aid the development and implementation process, and 2) explain that history once the technology is in use.

## USER MANUAL WANTED

This perspective prioritizes deep understanding. Partial understanding is unacceptable (st.3:-4). To achieve deep understanding, explanations must be useful to all users (st.15:+3), but simultaneously, different users may require different explanations (st.16:+2). Participants did not see these two statements as contradictory, but rather, an indication that many different explanations must be provided:

> *These two are quite similar to me: explanations of AI should be useful to all users, and different users require different explanations about AI systems. It's about stakeholder management. Administrators need different kind of explanations than the doctor who's using it. So that is so, so, so true. And then*

*next to it was the data that should be useful to all users. If you're making something that's not useful then you need to throw it away. (P22)*

This perspective prioritizes utility of explanations to users (st.8:+3, st.26:+3), such as ensuring explanations are logical (st.15:+3) and meet user expectations (st.32:+4) ("...so they understand why to use it" (P25)), over full transparency (st.4:-3). This perspective views explanations as something users can return to when they need it (for instance, a "user manual" (P9)). Therefore, a good explanation must also be updated in tandem with the AI tool (st.1:+4). This perspective does not want AI explained similarly to other technologies (st.6:-3), though this may not be an indication of AI exceptionalism: as one participant put it, "I don't think that all technologies are well-explained"(P22). Instead, AI explanations represent an opportunity to improve explanations for technologies generally. For this perspective, that means making all possible information available to users.



## DISCUSSION

We have conducted a rigorous and systematic empirical study of professional perspectives on XAI for healthcare, focused on the meaning of explainability and its importance for healthcare applications. While prior studies have considered perspectives of medical doctors on AI for healthcare in general (thus touching on explainability within certain perspectives)(Martinho et al., 2021), or explored different perspectives on XAI in medicine via the literature (Amann et al., 2020), to our knowledge, this is the first systematic, empirical study of professional perspectives on XAI for healthcare. We included a broad sample of professional healthcare stakeholders whose perspectives are likely to influence the embedding of AI in healthcare to produce a typology of nuanced and distinct perspectives. The first perspective, *Keep it Practical*, focused on promoting appropriate use of AI in medical practice which may or may not require explanations. *Consent, Regulation, & Risk Mitigation* focused on codifying general principles of AI use in healthcare through explainability requirements. For *Strong Starts,* the purpose of explanations is to assist stakeholders during the AI tool's development and implementation, and explain the development and implementation process to users. *User Manual Wanted* prioritizes interpretability and comprehensiveness of explanations. It may not be possible to address all perspectives' values within a single explanation, despite overlapping aims. For instance, *Keep it Practical* values conciseness in an explanation, while *User Manual Wanted* values comprehensiveness: these may be mutually exclusive.

By drawing clear distinctions among perspectives on XAI, we synthesize several strands of the literature examining requirements for XAI in medicine (Amann et al., 2020; Arbelaez Ossa et al., 2022; Gerlings et al., 2022; Poon & Sung, 2021). Both medical literature about AI tools and literature exploring the opinions of medical professionals about AI often include forms of *Keep it Practical*. For instance, Angehrn et al. 2020 focus on operational concerns when implementing AI tools in clinical practice; "explainability" is directly referenced only briefly in the context of EU-level legal requirements. Forms of *Consent, Regulation, & Risk Mitigation* are often found in legal

and regulatory literature. For example, Smith (2020) discusses how explanations of clinical AI can support accountability, responsibility, and liability: empirical examples are discussed in relation to improving guideline. A version of this perspective promoting regulation to manage distrust in private companies was also found in a Q-methodology study examining medical doctors' views on AI for medicine (Martinho et al., 2021). *Strong Starts* is most reflected in ethics and some science and technology studies literature: Morley et al. (2020) reflect on ethical concerns throughout development and implementation processes and at different levels of interaction (i.e. institutional, personal) with AI; again, empirical examples relate primarily to governance. While there is some correlation between *User Manual Wanted* and technical guides on explainability (i.e. Molnar (2022) provides detailed technical instructions for XAI), other elements, like the philosophical implications of different XAI approaches (Fleisher, 2022), can be found in philosophy of science literature.

Most previous studies prioritize either operational concerns or reflections on accountability. The different perspectives reflect this divide as well. *Keep it Practical* is more focused on operational concerns related to implementing specific AI solutions in medical practice; this aligns with findings from several empirical studies (Angehrn et al., 2020; Balay-odao et al., 2024; Martinho et al., 2021). *Consent, Regulation, & Risk Mitigation* and *Strong Starts* focus on guidelines necessary to ensure algorithmic accountability, a topic most often explored in ethical and legal literature (Kemper & Kolkman, 2019; Licht & Licht, 2020). The focus of *User Manual Wanted* on comprehensiveness aligns with deep explorations of technical (Molnar, 2022) and philosophical (Fleisher, 2022) principles of AI but does not clearly prioritize either operational concerns or guidelines.

Within the literature, articles focused on operational concerns often uncritically deploy preexisting definitions of XAI and related terms, with limited attention to how audiences may interact with explanations (Angelov et al., 2021). On the other hand, more reflective analyses usually do not extensively explore how such findings can be practically implemented (Páez, 2019). While some empirical social science literature on ground truths (Henriksen & Bechmann, 2020; Jaton, 2017) deals with both operational concerns and accountability reflections, these are uncommon, as are studies using real-world evidence to explore the practical impacts of explanations for different audiences (Gerlings et al., 2022). Our study offers a path towards reconciling this divide in the literature at a practical level. Rather than focusing on either operational concerns or accountability reflections, the four perspectives in our study indicate that explanations must account for both to varying degrees. The extent to which an explanation deals with operational concerns and reflections on accountability depends on what information will foster understanding and trust for the specific audience of that explanation.

An important finding for the future provision of XAI for healthcare was that all perspectives were found throughout a range of professions, AI experience levels, and ages, suggesting that the XAI needs and preferences of different audiences cannot be assumed based on these factors. Despite clear correlations to discipline-specific perspectives within the XAI literature, our study indicates that colleagues with similar

professional backgrounds and AI experience may hold different perspectives on XAI for healthcare. This was evident beginning with the first focus group during statement set development and remains an important lesson for those working on AI in healthcare. Furthermore, contradicting stereotypes about older technology users, age did not appear to impact explanation desires: participants over age 50 loaded onto every perspective. This suggests preferences of different demographics and professions are likely more diverse than implied in the literature, supporting our call for future research to focus on real-world data exploring the impacts of XAI for different audiences.

Our study makes clear that one-size-fits-all explanations are not adequate for all stakeholders involved in adoption and implementation of AI health technologies. Each perspective represents different values and meanings placed on explainability for healthcare (Greenhalgh et al., 2023; Oldenhof et al., 2025). These different values and meanings can impact the development, acceptance, adoption, and implementation of AI (and other technologies) for healthcare beyond the issue of explainability. To generate trust and understanding among all stakeholders and adequately inform decisions around AI health technology adoption, explanations of AI must be tailored to the needs and values of different audiences.



## STRENGTHS, LIMITATIONS, AND FUTURE RESEARCH

In this study, we focused exclusively on professional healthcare stakeholders. However, patients are potentially an important audience for XAI; further research is needed to explore patient perspectives. Additionally, while 37 participants is common for a Q-methodology study (Dieteren et al., 2023) and the concourse was developed in an international context, the four perspectives identified here should nonetheless be considered a reflection of a studied sample of professionals (Appendix A). Future research can expand these findings to other contexts to explore how perspectives differ, for instance, in countries where healthcare is organized differently.

Furthermore, these perspectives should not be considered monoliths. Within the perspectives, some participants held divergent views on specific statements. Some divergences may be due to differences in statement interpretation, while others represent value differences within each perspective. Additionally, no participants loaded fully and uniquely on a single perspective, indicating that people likely hold views that align with aspects of more than one perspective. This is expected within Q-methodology (Watts & Stenner, 2012) as an exploratory technique. Therefore we do not draw quantitative conclusions about demographic scale or distribution of perspectives. Rather, we demonstrate the diversity of meanings of XAI in use in healthcare and provide a typology of perspectives likely to be present within AI healthcare project stakeholder groups.

Finally, opinions are rarely stable over time (Gobo & Mauceri, 2014); this may be especially true for rapidly-evolving technologies like AI. Specifically, several participants mentioned explicitly their answers may differ significantly if they participated in the future, when AI healthcare tools

are more developed. Therefore, this study represents a typology of opinions held by professional stakeholders as AI technology for healthcare emerges. Still, the method and perspectives are likely to remain applicable for future research on XAI for healthcare, though updates to the statement set and findings may be necessary. Repeating this study in other contexts in the future might clarify perspectives on XAI at different states of development, adoption and implementation.

## CONCLUSION

Our findings indicate that XAI needs differ among professional stakeholders in healthcare. These differences impact explanation provision and demand further attention from healthcare professionals, regulators, technology developers, and researchers. Attention to users' practical needs, mitigation of risk through guidelines, attention to development and implementation practices, and comprehensiveness were identified as important values necessary to generate understanding and trust of AI technologies in healthcare among professionals. Despite differences, perspectives shared some commonalities, including a belief in the importance of monitoring AI performance over time and providing explanations even after the technology is accepted. Furthermore, all perspectives viewed AI as a new frontier in technology, deserving of increased attention from the healthcare sector.

This typology can be deployed within transdisciplinary collaborations. This study provides a means through which professionals can better understand the content of different perspectives, making it easier to communicate about XAI. Here, we provide language to discuss XAI across disciplines, knowledge-levels, and preferences without elevating one perspective over another. We hope the perspectives outlined in this study can provide a starting point for designing trustworthy and understandable explanations for a variety of healthcare stakeholder audiences.

Together, these findings reiterate the importance of establishing what XAI should entail at the beginning of a research collaboration or technology development process. This study makes clear that perspectives on XAI cannot be assumed based on participant characteristics. Explicit questions must be asked to align expectations within collaborations working on AI applications for healthcare.

This does not negate the commonalities we found amongst perspectives. The four perspectives have significant similarities (correlation coefficients ranged from 0.26 to 0.44), indicating that despite important differences, there is common ground for professional collaborations without necessarily requiring compromise on fundamental values.

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## DECLARATION OF INTEREST

The authors report there are no competing interests to declare.

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# 5.1: APPENDIX: METHODS DETAILS

## CONCOURSE DEVELOPMENT: FOCUS GROUPS AND LITERATURE REVIEW

At the end of the grant period during which focus groups were conducted, the primary researcher, a trained actor and director, used theater-based methods such as a physical lineup game to increase opportunities for knowledge co-creation in focus groups (Leavy, 2008), prioritizing diversity of opinions and deep discussion to obtain the widest and most detailed variety of meanings and preferences for XAI possible.

The first focus group was conducted in person at the AA PROJECT meeting in Rome in September, 2023. 16 participants (including medical, administrative, ethics, and technical stakeholders) discussed the meanings of and preferences for XAI over 45 minutes and produced written materials that were included in analysis. The lead author also participated in the larger two-day meeting in which this focus group took place, which helped provide context for the focus group data.

The second focus group was conducted online in February, 2024. This group included 9 participants from medical, technical, social science, and ethics backgrounds, with some overlap with participants in the previous group, and lasted 1.5 hours. The group discussed practicalities of implementation, in addition to the meanings of and preferences for XAI, and produced written materials that were included in the analysis. This focus group explored the topic more deeply thanks to both the length and lessons learned during the previous focus group.

Statements were also drawn from academic literature on the of meanings of XAI (Goebel et al., 2018; Licht & Licht, 2020; Miller, 2019; Mittelstadt et al., 2016; Morley et al., 2020 among others) were included, as were statements drawn from technical, marketing, and policy documents (Benifei & Tudorache, 2021; Molnar, 2022; SkinVision, 2025, among others) relevant to XAI in a medical context.

## STATEMENT SET

**Table 1:** Final set of 34 statements and themes covered

| Theme covered | Category | Topic | # | Statements |
|---|---|---|---|---|
| **Meaning** | Understanding | Performance monitoring | 1 | AI performance should be monitored over time. |
| | | Failure | 2 | Users need to understand the cause of AI failures. |
| | | Necessity | 3 | Users only need to partially understand AI in order to properly use it. |
| | | Complete | 4 | AI should be fully transparent. |
| | | Med-tech connection | 5 | AI systems should connect technical and medical expertise during development. |
| | AI exceptionalism | Differences in explanation needs | 6 | AI should be explained the same way other technologies are explained. |
| | Development context beyond the technical | Environment of development | 7 | Users need to understand the context in which AI systems are developed and implemented. |
| | Reasoning, consisistency, reliability | Logic | 8 | Explanations of AI should be logical. |
| | Transparency | Input | 9 | Explanations should include the input into an AI system. |
| | | Process | 10 | Explanations should include the processes used within an AI system. |
| | | Output + validation | 11 | Explanations should include the output from an AI system. |
| **Practice** | Framing | Experimentation / training | 12 | Users should be able to train to use an AI system. |
| | | Ability to interrogate | 13 | Users should be able to ask questions about explanations of AI. |
| | | Format | 14 | Explanations of AI should be communicated in an accessible format. |
| | Accesibility | General | 15 | Explanations of AI should be useful to all users. |
| | | Specific audience | 16 | Different users require different explanations about an AI system. |
| | Collaborations and relationships | Developers and users | 17 | Users should be involved in the development of an AI system from the beginning. |
| | Accountability / responsibility | Legal | 18 | Legal requirements for AI explanations are necessary to mitigate the risks posed by AI. |
| | | Practical | 19 | Within each organization, it should be clear who is responsible for understanding AI systems. |
| | | Ethics | 20 | Explanations should ensure that AI systems are ethically accountable. |

| Theme covered | Category | Topic | # | Statements |
|---|---|---|---|---|
| **Approach** | How to collaborate | Common language | 21 | Explanations of AI require a common language between users and developers. |
| | Know when AI is in use | Know when AI is in use | 22 | Users should know when AI is being used. |
| | Value added | Value added | 23 | Users should know what value AI adds to healthcare. |
| | Statistics | Statistics | 24 | Explanations of AI should include statistical evidence. |
| **Purpose** | Alternative interpretation | Alternative interpretation / perspective | 25 | Explanations of AI should include alternative interpretations of output. |
| | Mitigating / avoiding risk | Differentiate right or wrong | 26 | Explanations of AI should indicate when to trust results and when to exercise caution. |
| | | Security | 27 | The purpose of AI explanations is to improve security for users. |
| | | Al exceptionalism/ complexity/ability to change over time | 28 | AI is different from other technologies due to its complexity and ability to change over time. |
| | Conciseness | Conciseness | 29 | Explanations of AI should be limited to only the most essential information. |
| | Relevance | Relevance for what user wants | 30 | Explanations of AI should be relevant and useful to the user's specific context. |
| | Acceptance | Acceptance of AI | 31 | When users accept an AI system, less explanation is required. |
| **Audience** | Beliefs | Output meets expectations | 32 | Explanations of AI should meet the expectations of users. |
| | | Bias, different information needs, culture | 33 | Explanations of AI should be sensitive to prior beliefs and experiences of users. |
| | Specific audiences | Patients | 34 | Explanations should be provided to patients when AI is used in their care. |

## PARTICIPANT CHARACTERISTICS

Below, we present tables and figures depicting characteristics of participants. In addition to diversity variables previously discussed, diversity variables noted but not prioritized include national origin and institutional affiliation.

**Table 2:** Participant characteristics

| | |
|---|---|
| **Gender** | |
| Male | 11 |
| Female | 26 |
| **National origin** | |
| Dutch | 33 |
| Non-Dutch European | 2 |
| Non-Dutch non-European | 3 |
| **Educational Background** | |
| clinical informatics | 3 |
| business administration | 1 |
| radiotherapy technician | 1 |
| business administration | 4 |
| biomedical engineer | 3 |
| nurse | 4 |
| lawyer | 2 |
| medical physics expert | 1 |
| finance | 1 |
| information science | 1 |
| pharmaceutical researcher | 1 |
| community pharmacist | 2 |
| GP | 2 |
| GP assistant | 1 |
| computer scientist | 1 |
| bioethicist | 1 |
| political scientist | 1 |
| biologist | 1 |
| dermatologist | 2 |
| statistician | 1 |
| radiologist | 1 |
| designer | 1 |
| embryologist | 1 |

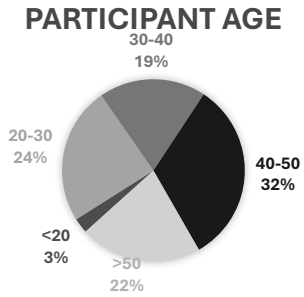


**Figure 1:** Participant profession


**Figure 2:** Participant age

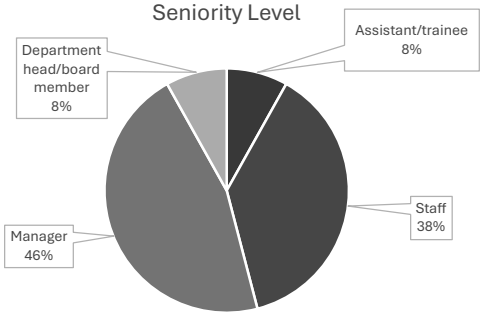


**Figure 3:** Seniority level of participants

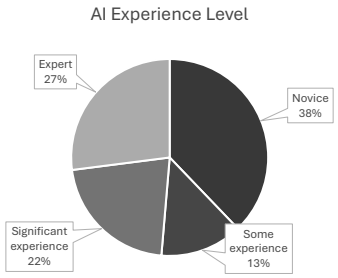


**Figure 4:** AI experience level of participants

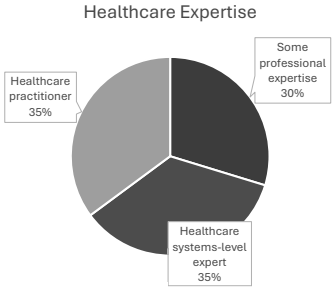


**Figure 5:** Type of healthcare expertise

## ADMINISTRATION OF THE Q-SORT

The q-sort grid and statement set was always presented in English; interviews were conducted in a combination of English and Dutch based on the comfort of participants. Researchers first asked background and demographic questions, especially focusing on the participant's professional role and familiarity with AI. The participant then completed the sorting task. For this portion, participants were first asked to sort statements into three stacks of "Tend to Agree," "Neutral/Don't Know" and "Tend to Disagree;" several participants instead laid their cards in a cloud formation among these three options, allowing for a more granular initial sorting process. Participants were then asked to place the cards from the piles on the grid. Participants were allowed to ask questions throughout this process, which improved the clarity of the intentions of statements for participants (Gobo & Mauceri, 2014).

## STATISTICAL ANALYSIS

All included factors had eigenvalues greater than 1 to ensure the statistical significance of the factor. A factor with an eigenvalue <1 is statistically insignificant as it explains less of the (remaining) variance than a single variable (in this case, the q-sort of a single participant) and, therefore, cannot be said to represent a cluster (of variables)(Watts & Stenner, 2012). For this reason, Factor 5 was excluded from all higher-order solutions. The tables below show statistical results, including the factor arrays representing an "ideal" Q-sort for each of the four factors in the final solution.

**Table 4:** Eigenvalues, variance, participants loaded on each factor

| | Eigenvalues | Variance % | Participants Loaded |
|---|---|---|---|
| **Factor 1** | 8.3916 | 23 | 12 |
| **Factor 2** | 3.4412 | 9 | 11 |
| **Factor 3** | 2.4922 | 7 | 8 |
| **Factor 4** | 1.923 | 5 | 6 |

**Table 5:** Consensus statements: these statements are not distinguishing among any pair of factors. All consensus statements were ranked in the middle of the distribution.

| Nm | Statement |
|---|---|
| **13** | Users should be able to ask questions about explanations of AI. |
| **16** | Different users require different explanations about an AI system. |
| **18** | Legal requirements for AI explanations are necessary to mitigate the risks posed by AI. |



**Table 6:** Factor Arrays showing the Q-sort ranking for each statement within each factor

| Statement number | Factor 1 | Factor 2 | Factor 3 | Factor 4 |
|---|---|---|---|---|
| 1 | 4 | 3 | 3 | 4 |
| 2 | -1 | -1 | 1 | -1 |
| 3 | 3 | -2 | -1 | -4 |
| 4 | -3 | 3 | -2 | -3 |
| 5 | 3 | 0 | 3 | -1 |
| 6 | -4 | -4 | -3 | -3 |
| 7 | -2 | -1 | 0 | 0 |
| 8 | 1 | -1 | -1 | 3 |
| 9 | -1 | 0 | 1 | -1 |
| 10 | -4 | -2 | -1 | -2 |
| 11 | -1 | 2 | 0 | 2 |
| 12 | 2 | 0 | 3 | 2 |
| 13 | 1 | 1 | 2 | 1 |
| 14 | 2 | 1 | 2 | 0 |
| 15 | -2 | 0 | -1 | 3 |
| 16 | 2 | 2 | 0 | 2 |
| 17 | -1 | -1 | 4 | -2 |
| 18 | 0 | 1 | 0 | 0 |
| 19 | 0 | 1 | -2 | 1 |
| 20 | 0 | 2 | -2 | 0 |
| 21 | 1 | -3 | -1 | 0 |
| 22 | 1 | 4 | 1 | 1 |

| | | | | |
|---|---|---|---|---|
| 23 | 3 | 0 | 2 | 2 |
| 24 | 0 | -2 | -2 | -1 |
| 25 | -1 | 1 | 0 | 1 |
| 26 | 4 | 3 | 1 | 3 |
| 27 | -2 | -2 | -4 | -2 |
| 28 | 1 | 0 | -3 | 0 |
| 29 | 0 | -4 | -3 | -2 |
| 30 | 2 | 2 | 4 | 1 |
| 31 | 0 | -3 | -4 | -4 |
| 32 | -2 | -1 | 0 | 4 |
| 33 | -3 | -3 | 2 | -3 |
| 34 | -3 | 4 | 1 | -1 |

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# CHAPTER 7

# DISCUSSION:
## Taking Care (for Granted)

## EXPLAINING, EVALUATING, AND EMBEDDING WITH ESCHER

I began this book with imagery of impossible architecture in the form of the lithograph "Relativity" by Dutch artist M.C. Escher. The paradoxical nature of Escher's staircases work are a metaphorical match for many aspects of my thesis, except in name: as I hope I have shown throughout this book, this work is not, in fact, impossible. This is, perhaps, not obvious: when I give presentations on the transdisciplinary and interparadigmatic (T/I) practices that went into this thesis (Chapter 6), there is almost always at least one audience member who, upon fully digesting the complexity of doing T/I research, wonders whether true T/I research is even possible. I hope this thesis and my work over the past five years have demonstrated emphatically that yes, such research is not just possible but necessary to understand how disruptive technologies become embedded in healthcare, even if we have not yet perfected our approach to this work.

Just as "Relativity" forces the viewer to question their assumptions about something as basic as the cultural imperative that architecture be buildable, I read comments about the impossibility of T/I work as a sign of how something as simple as a few slides on a projector or how Escher chose to arrange some lines on a page can cause us to question our own assumptions. Like the experience of viewing "Relativity," studying the embedding of disruptive technology in healthcare is confusing and full of contradictions that are impossible to reconcile into neat, simple solutions. The initial reaction, to both Escher and the complexity of studying embedding disruptive technologies in healthcare, is often to attempt to parse what we are seeing by looking at it in sections, hoping to find some part that still fits the cultural categories to which our minds cling, but looking at one part at a time misses the point. The lithograph (and the embedding process) as a whole is the work of art: beautiful, complex, and magnetic because of, not despite, its contradictions.

I begin this final chapter with a summary of the findings from the empirical chapters of this book. I then return to a discussion of my research questions and how the results of my research address each question. Next, I reflect on the research process, as well as challenges and limitations of the work presented in this thesis. Finally, I discuss recommendations for research, policy, and practice illuminated by my findings.

## MAIN INSIGHTS FROM EMPIRICAL CHAPTERS

In Chapter 2, I explored the meaning of legitimacy in health and technology as conceptualized within the disciplines of organization and management studies (OMS), science and technology studies (STS), and medical anthropology and sociology (MAS). Across this large body of literature, the concept of legitimacy is omnipresent but often implicit and underdeveloped. I developed distinct metaphors to account for the different ways legitimacy is defined, produced, and used within each discipline: a highway system (OMS), a computer operating system (STS), and a plumbing system (MAS). Each metaphor emphasizes certain aspects of how legitimacy works in health and technology and conceals other modalities, purposes, and uses. By layering these

synthetic constructs, I developed a conceptualization of legitimacy as social infrastructure, a binding fabric of relationships that makes possible certain kinds of interactions among people, technologies, and institutions.

In Chapter 3, I conducted an ethnographic case study of SkinVision, an AI-based skin cancer risk assessment smartphone app, to better understand how a disruptive medical technology becomes embedded within all levels of the Dutch healthcare system. I focused on moments of legitimacy breakdown, contrasting company narratives and healthcare-based assumptions with practices and affectively-charged experiences of professionals and app users. Three major kinds of legitimacy breakdowns impacted the embedding of this app. First, lack of institutional legitimacy led to informal workarounds by the company at the institutional level, such as approaching individual insurance companies and health insurance industry groups. Second, quantification privilege impacted app influence in interactions with doctors by, for instance, allowing patients to produce a form of quantified data to describe experiences previously limited to experiential accounts, resulting in doctors taking patients' concerns more seriously. Third, interactive limits between users and the app contradicted expectations around ease of use and work burden alleviation; this was most obvious in the difficulties users experienced when setting up the app, which required entering insurance information, and always took longer than expected, which caused anxiety among many users. This chapter demonstrated that misalignments of practices and narratives about the app exist at all levels of the Dutch healthcare system and that these misalignments have unintended consequences for the app's embedding in healthcare.



Chapter 4 contained the first full HTA of the same app explored as an ethnographic case study in Chapter 3. This chapter approached the case of the app from a positivist perspective while integrating constructivist data and methodological approaches, with the goal of addressing larger policy concerns around managing uncertainty related to organizational (infrastructural) and social aspects of health technology implementation, in addition to uncertainty related to effectiveness and costs. I examined the claims (and narratives) made about the app against empirical evidence based on real world practices and the app's embedding in the healthcare infrastructure, and compared the app to the standard of care across the domains outlined by the EUnetHTA framework (EUnetHTA, 2016). This chapter found that using the app is currently more expensive than the standard of care in the Netherlands. However, changes to how it is positioned within the infrastructure of the healthcare system, current practices of skin cancer risk assessment, and how the app interacts with those practices at the level of general practitioners (GPs) may make it possible for the app the become cost-minimizing and add more value to skin cancer risk assessment processes. Current problems with how the app is embedded in healthcare, such as costs, increased work burden due to additional and unnecessary GP visits and dermatology referrals, and concerns related to accessibility, could be addressed by revising reimbursement strategy and improving GP treatment decisions.

Chapter 5 returned to misalignments of narratives that can strongly impact the embedding of technology in healthcare. This chapter examined the meanings of and preferences for explainable AI among professional healthcare stakeholders. Understanding and trusting AI is essential to address technical, medical, organizational, ethical, and legal issues, and allow stakeholders to collaborate; explanations that increase the transparency of AI can improve understanding and trust. Policymakers, regulators and technology developers therefore increasingly turn to explainable AI (XAI) to aid acceptance and adoption of AI technologies. However, there is still disagreement about what XAI for healthcare means in practice and what kind of transparency will improve understanding of and trust in AI technologies. This chapter used Q-methodology, a mixed method, to produce a typology of four narrative-based perspectives on XAI: *Keep it Simple*; *Consent*, *Regulation, and Risk Mitigation*; *Strong Starts*; and *User Manual Wanted*. Each distinct perspective represents different values and meanings placed on XAI for healthcare, potentially impacting the development, acceptance, adoption, and implementation of AI technologies within healthcare infrastructure. Specifically, attention to users' practical needs, mitigation of risk through guidelines, attention to development and implementation practices, and comprehensiveness were identified as important values necessary to generate understanding and trust of AI technologies in healthcare among professionals.

Finally, Chapter 6 reflected on the implications of the daily practices of transdisciplinary and interparadigmatic (T/I) knowledge construction necessary to produce this dissertation. Despite strong narratives from funders and universities supporting transdisciplinarity, my research with my co-authors found that infrastructure to support such transdisciplinary research, especially by early career researchers, is often insufficient and that additional practices and work are necessary to conduct T/I research in this context. We identified three translation practices that T/I PhD students use to navigate monodisciplinary and/or monoparadigmatic spaces: *condensing*, *staging*, and *trespassing*. This chapter empirically demonstrated that in practice, transdisciplinarity is enacted by individuals, not teams, and explored how spaces impact perceptions of what counts as legitimate science. Finally, this chapter discusses an ad hoc infrastructure we built in the form of a third space termed "Mixed Methods Anonymous," which allowed us to develop and understand T/I knowledge.

## ADDRESSING RESEARCH QUESTIONS

In the course of this study, I sought to answer the following research question:

### HOW DO DISRUPTIVE TECHNOLOGIES BECOME EMBEDDED IN THE HEALTHCARE SYSTEM?

This book has specifically explored technologies that are currently in the process of disrupting (Nagy et al., 2016). There is no binary here: a technology can be more or less disruptive. Still,

judging whether or not a technology is currently "disrupting" is somewhat subjective[1]. Therefore, in this book, I have relied on cues in narratives, practices, and infrastructure to signal whether a technology is (currently) disruptive. For instance, narratives of technologies that veer in the direction of monster/miracle likely discuss potential for disruption (Selin, 2007; Smits, 2006). Technologies requiring people to actively justify or fundamentally change a practice are disrupting that practice (Granja & Machado, 2020; Perrotta & Geampana, 2020). Finally, the reworking of infrastructure to accommodate a technology signals that the technology has had a disruptive impact on that infrastructure (Carboni et al., 2023; Loukili et al., 2024).

Using the framework of legitimacy as social infrastructure from Chapter 2, we can understand embedding as a process of legitimation. As discussed in Chapter 2, this process of legitimation entails the construction and reinforcement of a binding fabric of relationships that encompasses people, institutions, and technologies. Embedding technologies therefore not only involves technical and clinical outcomes that build on the installed base (Star & Ruhleder, 1996) of existing medical and institutional infrastructures, but also developing an understanding of the audience for a particular technology (Chapter 5), the logic of its stakeholders (Chapters 5 and 6), and the relationships among stakeholders (Chapters 3 and 4).



If we continue to consider the embedding process to be a legitimation journey from liability-of-newness to taken-for-grantedness (Suchman, 1995; Suddaby et al., 2017), then a technology has become truly embedded in healthcare when its presence in the healthcare system and daily practice becomes smoothed over, unobtrusive, and just another part of everyday life, either because the technology is actually seamlessly integrated or because people simply get used to skipping the missing stair[2]. A technology embedded in this way is legitimated and taken-for-granted across multiple levels and multiple domains of the healthcare system (Cresswell & Sheikh, 2013; Sheard et al., 2017), rather than merely in the perceptions of certain audiences (G. Fisher et al., 2017).

To better explore how embedding happens in practice, I divided my main research question into three component questions, each aimed at addressing an important aspect of the embedding process: narratives, practices, and infrastructure. Each chapter addresses these subquestions from different angles and in different ways. Taken together, the chapters form a multidimensional understanding of how disruptive technologies become embedded in healthcare.

1 To borrow another classic definition of an otherwise difficult-to-define abstract phenomenon, with "disruptive technology," it may be as simple as "you know it when you see it."

2 "Skipping the missing stair" is a metaphor originally applied to social groups that choose to work around dangerous behavior rather than address it directly or exclude untrustworthy people ("We can't stop rape if we prize men's reputations over women's safety". The Guardian. London. 1 October 2015. Retrieved 22 July 2025). Here, I apply it as an apt descriptor to problematic-but-thoroughly-embedded technologies in healthcare due to the emphasis on avoiding necessary infrastructural changes and this dissertation's positioning of technologies as actors in a network.

## WHAT IS THE ROLE OF NARRATIVES IN THE EMBEDDING OF DISRUPTIVE TECHNOLOGIES IN THE HEALTHCARE SYSTEM?

The majority of the existing literature on legitimacy in health and technology focuses on narratives (Chapter 2). These studies examine both complete narratives as well as the many components that may add to or help produce narratives through discourse, such as justifications (Andersen, 2004; Busfield, 2021), opinions and views, storytelling (Kushida et al., 2020; Paxman, 2021), claims (Wamsiedel, 2018), and critiques. Narratives within this body of literature are usually designed explicitly to support legitimation of a technology (Garud et al., 2014), health issue (Paxman, 2021), or a practice involving health and technology (Edwards, 2014; Perrotta & Geampana, 2020). In some cases, narratives are explicitly explored as sites of controversy that clash with other narratives (Barker, 2011; Clark & Botterill, 2018; Granja & Machado, 2020) from audiences with different "perceptions"(Suchman, 1995). Sometimes, narratives are used as proxies to explore possible imagined futures (Selin, 2007). In many analyses, legitimacy itself is entirely defined by narratives and is approached as a purely discursive concept (Flink & Kaldewey, 2018; Foley & Faircloth, 2003; Golant & Sillince, 2007).

If we understand embedding disruptive technologies as a legitimation process (Chapters 2 and 3), this overwhelming focus on narrative in the legitimacy literature helps explain why narratives are also a primary source of information in literature on health technology adoption and acceptance. However, in adoption and acceptance literature, comprehensive narratives (Greenhalgh & Hurwitz, 1999) themselves are rarely used as data. Rather, technology adoption and acceptance literature usually relies on narratives constructed from claims and opinions (Hummel et al., 2024; Ladan et al., 2018; Yarbrough & Smith, 2007) derived from surveys (Cleemput et al., 2018; Dwivedi et al., 2016; Gobo & Mauceri, 2014; Holden & Karsh, 2010; Yuan et al., 2020)[3] and structured interviews (Dwivedi et al., 2016), rather than data from observations, experiments, or other kinds of practice-based empirical data. While this approach is respectful of participant opinions and takes their contributions seriously, these studies are often limited in their predictive power because they are based primarily on behavioral intention (as discussed in Chapter 3). Other studies have demonstrated that while behavioral intention has a role to play in adoption and acceptance of technology, additional factors must be considered to adequately predict whether or not a technology will be adopted (Sheard et al., 2017), accepted (Conner & Norman, 2022), or implemented (Cresswell & Sheikh, 2013). However, even when the influence of other factors is acknowledged, such as infrastructural capacity for change (Sheard et al., 2017), interpersonal relationships (Barnreuther, 2016; Reay et al., 2013), or the difficulties of adapting existing practices to accommodate new technologies (Loukili et al., 2024),

3 I include discrete choice experiments (DCEs) in this category: while DCEs can be more reliable than a standard Likert scale (Gobo & Mauceri 2013) in determining how people may make choices in real life, DCEs still rely on stakeholders describing how they predict they would behave under certain conditions in the future, rather than on observations or experiments that look directly at stakeholder behaviour in practice.

narratives and various audiences' perceptions of narratives are still of central importance across both legitimacy literature and implementation, adoption, and acceptance literature (Dopson et al., 2003).

The importance of narratives to the embedding of new technologies is thus clear across many disciplines and subject areas. However, the dominance of narratives in analysis may make it more difficult to parse what is left out when narratives are centered to the exclusion of other criteria for embedding of disruptive technologies in healthcare.

In the research for this thesis, the importance of narratives to the process of embedding technology in healthcare was also clearly evident from an empirical perspective. In Chapters 3 and 4, narratives shaped how stakeholders could conceive of the app's utility. Stakeholders drew on both company-defined benefits and larger technosolutionist (Morozov, 2013) and techno-optimist (De Wilde, 2000) narratives about AI in healthcare to frame their own opinions. Initial data collected from focus groups for Chapter 5 demonstrated that taken-for-granted narratives can invisibilize differences in values and meanings among healthcare stakeholders. When a narrative is taken for granted, it becomes difficult to conceive of the existence of different perspectives, much less question the assumptions underlying the taken-for-granted narrative (Chapters 2 and 5). Therefore, defining the meaning of terms within these narratives explicitly and clarifying values (Charlton et al., 2024; Greenhalgh et al., 2023), even, for instance, a value as simple as the relative importance of conciseness versus comprehensiveness for a particular audience receiving an AI explanation, are necessary to establish common ground in transdisciplinary collaborations (Chapter 5) and facilitate translation among disciplines (Chapter 6).



Narratives that become taken-for-granted rest on an installed base (Star & Ruhleder, 1996) of knowledge and assumptions about how things should or do work. As discussed in Chapter 1, that installed base of assumptions allows us to function. However, this book has demonstrated that we can only move beyond taken-for-granted narratives by questioning some of these basic assumptions. For instance, Chapter 5 demonstrated that perspectives on explanations about AI in healthcare are not determined by participant characteristics such as demographic data or even professional experience. This contradicts assumptions built into taken-for-granted narratives about, for instance, older people and technology, and instead requires that we verify what kinds of explanations would be useful for specific audiences, rather than assuming what kind of explanation is necessary based on demographic characteristics of that audiences.

However, this installed base of assumptions can also be used to foster deeper trust and understanding in a disruptive technology. I add here to previous work in entrepreneurship demonstrating that carefully aligning narratives with audiences expectations can bolster legitimacy of a disruptive technology (Fisher et al., 2017; Garud et al., 2014). If we consider legitimacy to be a form of social infrastructure (Chapter 2), trust and understanding add to the binding quality

of the fabric of relationships (Chapter 5). Providing the wrong kind of explanation to a given audience is not only ineffective for generating trust and understanding (Chapter 5), it can backfire by adding to confusion and generating distrust (Licht & Licht, 2020). If explanations about disruptive technologies that are misaligned with a particular audience's expectations, preferences, and needs, that explanation may not only hinder trust and understanding, but also throw into question positive elements of the disruptive technology that were previously taken-for-granted by that audience (Chapter 5). An explanation that aligns narratives of audiences with the narratives surrounding a disruptive technology increases the legitimacy of that technology.

This book demonstrated that misalignments impacting legitimacy do not only occur between narratives, but also between narratives and practices. From here, I turn to the role of practices.

## WHAT IS THE ROLE OF PRACTICES IN THE EMBEDDING OF DISRUPTIVE TECHNOLOGIES IN THE HEALTHCARE SYSTEM?

'To embed' is an action verb; embedding disruptive technologies in healthcare is a practical endeavor that takes place beyond the bounds of narrative and perception. Therefore, practices are integral to understanding the embedding of technologies in the healthcare system. As discussed in Chapter 6, sociomaterial practices generate knowledge (Nicolini, 2009); the term *sociomaterial* in this context refers to both the importance of social relationships and material objects, tools, and spaces to practices, and subsequently, knowledge production (Leonardi & Bailey, 2008; Pickering, 2010). An analysis of practices involved in the embedding of technologies thus allows for exploration of actions by both human and non-human actors (Latour, 1987), and those actors' interactions with their material and social environments.

However, the practices of embedding technologies are rarely examined in the literature until after a technology has been implemented. This is partially a problem of opportunity: if the technology is not yet in use in the healthcare system, it is much more difficult to find opportunities to observe how people use that technology in practice within a healthcare context. Clinical trials and other medical efficacy studies conducted in controlled environments are sometimes the best proxy for practical observation available; for instance, I conducted ethnographic observations during such medical efficacy studies (Sangers et al., 2022; Smak Gregoor, Sangers, Eekhof, et al., 2023), the data from which inform findings in Chapters 3 and 4. However, clinical trials are designed to test the efficacy of a technology, not provide detailed data on practices, and thus, literature on clinical trials does not generally include this kind of observational data. Furthermore, narratives of evidence based medicine that explicitly privilege certain kinds of data may preclude the inclusion of such observational data as evidence. Evidence not generated in this "ideal" form is categorized as "lower level" and thus less worthy of consideration, if any (Detterbeck et al., 2018). For instance, in my own ethnographic data collection for Chapters 3 and 4, researchers described looking forward to

working with doctors and patients who "cooperate well," anticipating a "smooth" inclusion for the study. They also used less positive language (such as "unfortunately") to describe any technical difficulties using the app and more positive words (such as "lucky") to describe inclusions that went faster than anticipated. These "lucky" and "cooperative" cases thus generally allowed researchers to interfere as little as possible (Smak Gregoor, Sangers, Eekhof, et al., 2023) and adhere more closely to ideals of evidence-based medicine; however, adhering to these ideals necessarily means leaving out or ignoring extra data generated by less-than-ideal inclusions.

Most studies of practices involving disruptive technologies are therefore conducted after the technology is in use in a healthcare setting (Carboni et al., 2024; Loukili et al., 2024; Lupton, 2015) (also see Chapter 3 and 4). These studies often reveal practices that clash with legitimation narratives in ways that can undermine the installed base (Star & Ruhleder, 1996) of assumptions on which those narratives are built (Nicolini et al., 2011); for instance, at one Dutch hospital, digital self-check-in kiosks were implemented with the primary goal of saving resources and labor for the hospital. Instead, the kiosks cost significant money to install and required certain staff to do more labor less efficiently (Loukili et al., 2024).

In qualitative healthcare literature, some studies demonstrate that practices may be intentionally aligned with pre-existing legitimation narratives (for instance, the narrative of evidence based medicine) in an effort to extend the legitimacy of that narrative to cover practitioners and technologies that are either controversial or outright quackery. These practices may include non-medical practitioners using a doctor-like demeanor to interact with clients while using quack medical devices (Hornberger, 2019), filing official documents and complaints with authority figures (Zavestoski et al., 2004), or transforming traditional medicines into forms that align with the accepted appearance of biomedicine such as a pill or syrup, rather than leaves (Cloatre, 2019). These intentional alignments of non-legitimated practices with legitimated narratives allow such practices a measure of legitimacy by proxy (Haack et al., 2014), building on assumptions guiding existing taken-for-granted narratives (for instance, that pills contain medicine).



My empirical data make clear that practices show *how* embedding takes place in the real world, and that this process may be quite different from what is envisioned in narratives (Chapters 3 and 4). For example, company narratives about the ease of use of the technology did not hold true for a majority of participants in Chapter 3, and ultimately increased scepticism of the app for some. Furthermore, technosolutionist narratives about AI that had been applied by both the company and other stakeholders to the app (such as the ideas that the app would be cost-saving and work-burden-relieving) were contradicted by real-world practices involving the app by both users and medical professionals (Chapters 3 and 4).

Furthermore, practices, not narratives, are what ultimately determine the outcomes of using disruptive technologies in healthcare. This is visible in both qualitative and quantitative data. For instance, in Chapter 4, the ways in which GPs respond to the SkinVision app had a much greater impact on both costs and work burden than the app's technical specifications such as sensitivity and specificity. As noted in other studies and in Chapters 3 and 6, practices that matter to the embedding of health technologies are not always visible (Carboni et al., 2023; Loukili et al., 2024), and are sometimes backstaged (Goffman, 1959; Slamat et al., 2024) and concealed by practitioners out of a sense of shame or desire to appear more competent. For instance, some participants in Chapter 3 felt embarrassed by their lack of facility with technology, just as my colleagues and I (Chapter 6) concealed some of our extra work necessitated by doing mixed methods research on disruptive technologies to appear more competent and efficient. These examples show that it is important to empirically investigate real-world practices if the goal is to develop an understanding of *how* disruptive technology becomes embedded in healthcare, not just whether it has potential to become embedded.

As in misalignments among narratives, misalignments between practices and narratives can end up raising questions about the legitimacy of a technology. Legitimacy threats raised by practice-based studies may be more difficult to resolve in part, again, because of timing. Because technologies explored in practice-oriented studies, such as my case studies of SkinVision, are usually already somewhat (though not fully) embedded at the time of research, they have already begun to move from managing liability-of-newness towards taken-for-grantedness (Suddaby et al., 2017). Therefore, making adjustments to these technologies to account for new data gleaned from research on practices is often more difficult (Collingridge, 1980) than for technologies explored through earlier adoption and acceptance studies based on behavioral intention.

Based on the findings of this dissertation, the approach to managing these kinds of legitimacy threats depends more on the perspective and goals of the research than on whether a technology is useful or could be repositioned in the healthcare system in order to become useful. This is because empirical study of practices may bring to light conflicts with pre-existing narratives not only about a disruptive technology (such as the impact of quantification bias on doctor-patient relationships discussed in Chapter 3), but embedded within different epistemological approaches to research on those technologies and the deeply-entrenched assumptions guiding knowledge production within different disciplines. For instance, given the emphasis on critique in constructivist research, legitimacy threats do not necessarily constitute an epistemological threat to the goals of constructivism, as can be the case for positivist research. Constructivist epistemologies, such as those used in science and technology studies (STS) and medical anthropology, can manage misalignments between practices and narratives without threatening research goals, like critique or problematization (Zuiderent-Jerak, 2007). However, positivist epistemologies, which are more dominant in research generally (Chapter 6) and the default within medicine and HTA, may find that such misalignments threaten research goals (such as producing standards of evidence-

based medicine or providing clearcut recommendations or solutions) and thus focus more on how practices can be better controlled and aligned with existing narratives (Wallenburg et al., 2021; Williams, 2020; Wilson-Kovacs et al., 2010). Further implications of each approach, and for mixing these approaches to knowledge production when researching the embedding of disruptive technologies in healthcare, are discussed in my reflection on research choices and methods.

As denoted by the term *sociomaterial*, practices involving disruptive technologies do not take place in a vacuum. The environment (Leonardi & Bailey, 2008), context, and infrastructure (Star & Ruhleder, 1996) in which practices take place determines both which practices are possible and the impact of those practices on the embedding of disruptive technologies in healthcare. Therefore, I now move to the role of infrastructure.

## WHAT IS THE ROLE OF INFRASTRUCTURE IN THE EMBEDDING OF DISRUPTIVE TECHNOLOGIES IN THE HEALTHCARE SYSTEM?

Star and Ruhleder describe infrastructure as a living entity (Star & Ruhleder, 1996) that emerges in practice through ongoing interactions among people, technologies, and existing systems guiding those practices. "Embededness" is the first listed criterion for an infrastructure (Star & Ruhleder, 1996 p.113). If we extend this conceptualization of infrastructure to the embedding of disruptive technologies in healthcare, it becomes clear that to successfully embed a disruptive technology means, at least in part, to make it a part of the infrastructure of healthcare. This also clarifies that "disruptiveness," by definition, is temporally bounded (Star & Ruhleder, 1996 p.112): if a technology is embedded in the infrastructure of the healthcare system, it is no longer actively "disrupting," even if the technology had to disrupt the infrastructure in order to become embedded. For this reason, this book has explored the "embedding" of disruptive technologies as an ongoing process, rather than embedded technologies which were once disruptive.



Existing institutions and organizations are often the only form of infrastructure discussed in legitimacy studies (Bitektine & Haack, 2015; Cattani et al., 2017; Haack et al., 2014; Ruef & Scott, 1998). Institutions, including regulatory bodies, hospitals, and for-profit companies, are also often the primary kind of infrastructure acknowledged in literature on the embedding of disruptive technologies in healthcare (Barnreuther, 2016; Cleemput et al., 2018; de Miguel et al., 2020; Hengst et al., 2023; Sheard et al., 2017; Yang et al., 2022). However, some literature on the embedding of technology in healthcare deals with infrastructure as a technical apparatus that is either a part of the technology under study, or into which the technology must be "sunk" (Star & Ruhleder, 1996 p.113) thereby impacting either delivery of care or the use of the technology (Greenhalgh et al., 2019; Rouidi et al., 2022; van Gemert-Pijnen, 2022). This literature adds complexity to our understanding of interactions between disruptive technologies and infrastructure. Technologies also contain their own infrastructure (Jaton, 2017) and bring their own "installed base" (Star & Ruhleder, 1996 p.113)

into interactions with people, institutions, and other technologies. While some literature does address both technical capacities and institutional structures as forms of infrastructure (Starkbaum & Felt, 2019) and thus treats infrastructure more explicitly as a sociotechnical (Jasanoff & Kim, 2013) phenomenon, the connections among these different kinds of infrastructure and what their sociotechnical nature means for the embedding of disruptive technologies are rarely explored in depth.

In this book, I took a different approach to much of the existing literature on infrastructure as it relates to embedding technologies in healthcare. Rather than focusing on institutions or technical capacity (though these are also covered in Chapters 2-4), I focus on legitimacy itself as a form of social infrastructure, or a binding fabric that makes possible certain relationships among people, technologies, and institutions (Chapter 2). This conceptualization allowed me to take infrastructural dimensions beyond institutions and technical capacity into account, including organizational choices (such as insurance reimbursement strategies and the use of GPs as gatekeepers), laws, regulations, societal values, and relationships among institutions (Chapters 3 and 4). This conceptualization of infrastructure also situates technical infrastructure within the larger social context. For instance, this lens allowed me to explore how the digital interface of the SkinVision app interacts with users in the Dutch context (Chapter 4) as more than practices between human and non-human actors (Latour, 1987). Instead, I examined such interactions as people and technologies navigating and tinkering (Algera, 2025; Mol et al., 2010) with preexisting infrastructure, and the affective qualities these interactions produced (Haack et al., 2014)(Chapter 3). Furthermore, this lens allowed me to examine how infrastructures relate to other infrastructures from an empirical perspective by focusing on moments of dissonance. For instance, Chapters 3 and 4 both discuss how the app uses citizen service numbers (BSNs) to track insurance customers, and implications of this choice beyond insurance reimbursement: not only did use of BSNs affectively alter the experience of the app for many individual participants (Chapter 3), but the automated storage of BSNs resulted in a clash of legal requirements that had to be negotiated by the company and then codified into the app's technical infrastructure (Chapter 4). Through this example, we can see that different (in this case, legal and technical) infrastructures guiding the embedding of technologies in healthcare may also be misaligned, require tinkering in order to fit together, and have unintended consequences for practical use of a technology.

Imagining legitimacy as social infrastructure implies that not only does infrastructure shape practices and narratives, narratives and practices can, in turn shape infrastructure. As demonstrated in Chapter 3, disruptive technologies have the capacity to upend infrastructures in the form of existing hierarchies (such as between GPs and patients; Chapter 3) and require a renegotiation of the status quo (by, for instance, providing alternatives to the standard pathway for seeking care for suspicious skin lesions; Chapter 4). However, it is also rarely clear whether such renegotiations will lead to embedding of the disruptive technology or better health outcomes in the healthcare system. Unintended consequences of these practices and narratives, such as use of the SkinVision app

resulting in GPs referring more patients to dermatologists (Chapter 4) can impact both the ways in which a technology becomes embedded, and the kinds of outcomes that arise from that embedding, in unexpected and profound ways. In the same way that the figures in "Relativity" are oblivious to the strangeness of their environment, so are we often oblivious to the consequences of practices and narratives reshaping infrastructure involved in the embedding of disruptive technologies in healthcare, until we see those impacts in action.

## REFLECTION ON RESEARCH CHOICES AND METHODS

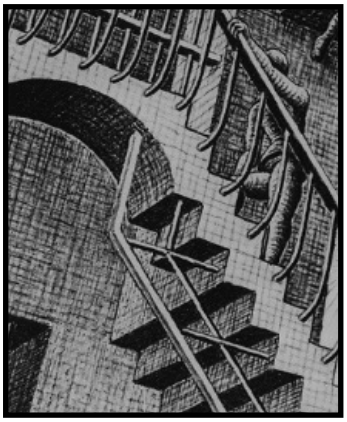
As Chapter 6 demonstrated, using mixed methods always involves compromise. When choosing to explore a topic from multiple perspectives, it is impossible to develop expertise in a single method at the same level as a monodisciplinary researcher in the time allotted for a PhD. In my work, this compromise cut in many directions: I chose, for instance, not to learn how to code in R so that I could devote my resources and time elsewhere, even though R would have allowed me to do more diverse kinds of economic analysis and modeling. For the same reasons, while I used ethnographic methods, I did not spend years fully immersed in the field doing full-time participant observation, as is common for medical anthropologists, which would also have benefitted my ethnographic work by adding detail and analytical complexity. These choices were intentional and were made alongside my supervision team with the scope of the full project in mind. Unlike a monodisciplinary project, we consistently had to question what increased attention and time to one methodology may mean in terms of compromises on attention and time for other methodologies. This practice of *compromising* could therefore be seen as a team-level T/I practice, in addition to the individual practices of *condensing*, *staging*, and *trespassing* discussed in Chapter 6.



Not all compromises stemmed from mixing methods, and many of these have produced both strengths and challenges for this thesis. For instance, as a non-Dutch person, my relative cultural distance from my participants and lack of a lifetime of cultural and social knowledge made me an excellent ethnographic observer in this context and helped me ask questions others had not considered. However, because I lacked this knowledge, unlike a Dutch researcher, I had to spend significant time and energy learning the language, the healthcare system, and Dutch culture in order to conduct research effectively, which again impacted how much time I had to concentrate on other aspects of the project. Therefore, while I was more easily able to pinpoint "sites of controversy"(Akrouh et al., 2024) due to my outsider perspective, I also likely missed nuances that would have been easily visible to a Dutch colleague, especially early on in my ethnographic explorations. Some choices were also made for practical reasons, because I am also a person outside my role as a researcher. For instance, as a mother of young children, long term fieldwork in a foreign country was not doable in the same way it had been during my masters. Even if I had chosen to prioritize immersive research abroad, my study would have been bounded in new ways compared to how I conducted research in Zambia. At the time, without kids, the excellent data I acquired

through months of deep hanging out (Geertz, 1998) cost nothing more substantial than a little time apart from friends and loved ones and a couple plane tickets. The same work would upend my family's life completely if I attempted it today.

A close examination of an Escher lithograph will always reveal inconsistencies and moments when misalignments within the architecture become irreconcilable. Mixing methods is similar: sometimes, findings from different perspectives will simply be incompatible, and no amount of investigation or further analysis will bring them together. We visually accept these kinds of inconsistencies when looking at Escher's impossible architecture for the sake of the experience of the artwork as a whole. I have always found it interesting that Escher never relies on blurring lines or reducing detail to obscure these irreconcilable moments. The lines that make up his lithographs are precise and specific, as though the boundaries where the architecture is less believable are just as important as the paradoxical staircases those boundaries produce.



An awkward moment in full detail from "Relativity:" the place where the upside-down staircase railings meet the ceiling does not work from any other perspective. If the ceiling is also supposed to be a floor for that staircase, why is it curved?

I feel much the same about doing transdisciplinary and interparadigmatic research. Incompatibilities should not be hidden or downplayed. At the same time, the existence of such incompatibilities does not make this kind of research any less worthwhile; without fully acknowledging these misalignments, the picture we create, however complex, cannot be as rich or meaningful, even if we can never reconcile certain aspects.

Despite the incongruities and paradoxes this approach may engender for research findings, taking all parts of the picture together also reveals sometimes-uncomfortable truths about research that can help such T/I projects move forward. For instance, if we truly endeavor to take all research methods seriously and avoid privileging one method over another, it follows that all empirical research is, to at least some degree, subjective, in that the perspective of the researcher and audience matter in terms of how data is interpreted and presented in context. HTA, for instance, often considers many of its methods and/or consideration of parameters to be "objective"(EUnetHTA, 2016), but even in cost-effectiveness analysis, it is standard to include an extensive list of assumptions and conduct sensitivity analysis around variables which are more uncertain. This accounting for such uncertainty implicitly acknowledges the subjectivity of parameters used. Acknowledging subjectivity is obviously far more comfortable for ethnographers, whose research methods build subjectivity and researcher reflexivity into interpretive analyses

(Tsoukas, 2016). However, it is clear that both approaches are designed to manage subjectivity in the empirical research process. This does not invalidate positivist forms of research, or indicate that the approaches are fundamentally incompatible, but rather, requires us to reframe different methodological approaches in terms of goals rather than the supposed objectivity of a particular method. By considering the epistemological goals of each form of research, we can better understand how each approach manages subjectivity in ways that meet those epistemological goals and the goals for a particular research project. It would be difficult to make short, concrete policy recommendations if subjectivity were centered in statistical research the way it can be in ethnography (one cannot calculate p-values (Wheelan, 2013) with anything but numbers[4]). At the same time, it is often impossible to understand the full scope of ethnographic findings without centering such subjectivity because the observations, feelings, opinions, and experiential knowledge that make up the bulk of ethnographic data are clearly subjective and open to interpretation by both participants and researchers.

Focusing on epistemological goals of research also allows us to see that centering misalignments among narratives, practices, and infrastructure is not only far more comfortable in the context of constructivist research, it furthers the goals of constructivist epistemologies, while for positivism, the effect may be the opposite. Contradictions and incongruities between practice and narrative imply subjectivity by suggesting there is more than one possible perspective and therefore, are more likely to be controlled for within a positivist study and centered in a constructivist study (Ward et al., 2015). By centering subjectivity throughout the research process (McChesney & Aldridge, 2019), constructivist studies can meet their goals of critique, reflection, and problematization (Stevens et al., 2020), often in ways that add complexity (Tsoukas, 2016). Positivist research, on the other hand, attempts to control for subjectivity through methodological rigor (Henriksen & Bechmann, 2020) in order to offer evaluations, solutions, and recommendations (Cleemput et al., 2012) aimed at reducing complexity (Tsoukas, 2016). Allowing misalignments to coexist (including between epistemologies themselves, as discussed in Chapter 6) is thus most easily done from a constructivist perspective. In some positivist research, it may be impossible to allow for contradictions to exist and still meet the goals of a particular research project, depending on how the research question was framed and approached.



To manage this complexity during my PhD, I have therefore learned to focus more on goals for particular research projects, and less on methodological and epistemological differences while continuing to acknowledge that those methodological and epistemological differences determine how we understand research goals. I find this approach is more productive for amiable collaboration among different kinds of researchers and for gaining fuller and more complex understanding

4 Though I suppose one could also argue that p-values, as statistical representations of the likelihood of obtaining a result as extreme, or more extreme than, the results obtained in a study, assuming the null hypothesis were true (Wheelan, 2013) are in fact a numerical representation of a probabilistic form of subjectivity. P-values are not, however, a good example of the kind of interpretive subjectivity I have discussed in this section thus far.

rather than attempting to reconcile all differences within a single project. I therefore endeavor to take all methodologies seriously without privileging one over the other, while simultaneously acknowledging that some methodologies are better for studying certain phenomena than others. My purpose in this thesis is to strive for understanding of the full picture, as much as possible, without blurring the lines of the lithograph even when the incongruities become obvious. Pursuit of that fuller, complex picture makes such discomfort worthwhile.

## RECOMMENDATIONS FOR RESEARCH AND PRACTICE

Because the embedding of technologies in healthcare is complex, transdisciplinary, and interparadigmatic, the recommendations for research and practice based on the findings of this thesis must be viewed as part of a full, if not cohesive, understanding of how research and practice work together. This dissertation makes clear that each stage of the process of embedding disruptive technologies in healthcare involves networks (Latour, 1987) and relationships among people, institutions, and technologies; parsing what counts purely as "practice" or "research" again encourages us to focus on only a small part of an intrinsically intertwined picture. Disruptive technologies are often first devised and developed by researchers (Jain & Ahlstrom, 2021; O'Kane et al., 2015; Vrangbaek, 2008); researchers and practitioners work together in transdisciplinary collaborations to further develop and test these technologies (Edwards, 2014)(Chapter 5); and the work of implementation is necessarily a collaborative effort involving many stakeholders and infrastructures, including researchers (Chapters 3 and 4). In this way, separating research from practice in the embedding of disruptive technologies is a bit like only considering the figures with the same gravitational orientation in "Relativity" to be part of the same work of art: doing so would change the meaning of the lithograph, just as considering research and practice to be separate in this context changes how we can understand embedding technologies in healthcare. Therefore, here, I consider research and practice together and provide recommendations for both with the aim of fostering appreciation for multiple approaches and perspectives.

In a similar plea for allowing and acknowledging complexity (Tsoukas, 2016), while different methodologies and epistemologies are useful for different research goals, this dissertation's findings indicate that researchers' use of frameworks as checklists is not enough to understand how technology can be embedded in healthcare (Chapter 4). Instead, analyzing how checklist items interact with one another as well as incorporating data from deeper explorations that may move beyond the scope of the checklist are necessary to zoom out (Nicolini, 2009) to a fuller picture. This approach aligns more closely with the stated goals of many decision-making bodies, such as national HTA agencies (Kleinhout-Vliek et al., 2022), in which many sources of information are considered simultaneously and many values weighed against one another to reach an integrated conclusion (Zwaap, 2017). A checklist approach provides an easy and seductive way out of complexity by allowing researchers to focus myopically on a single aspect of the embedding process. However, this is like focusing on

only one figure on an Escher staircase: it misses the impact of that figure in the context of the full lithograph. Understanding of the implications of embedding a disruptive technology in healthcare is only possible when the interactions among different components are considered as part of the same binding fabric of relationships, just as the innovations of Escher's artwork are only clear when viewing the picture as a whole, not each piece separately.

***Recommendation:*** *Researchers should avoid checklist approaches to evaluations and instead examine how checklist items interact with one another to form a fuller and more complex picture. Decision-makers need to zoom out to take into account this fuller picture and all relevant components. This would align research practices more closely with the stated goals of policy-making institutions, avoid overly-simplistic assessments, and push forward more integrated approaches to evaluation of health technologies.*

STS scholarship has demonstrated for decades that technologies and other non-human actors act on infrastructures, institutions, and other actors with similar capacity as human actors (Latour, 1987). However, this approach to technologies as separate, independent actors appears to have mutated in translation within corporate and cultural narratives of disruptive technologies. We talk about what disruptive technologies can "do," how technologies like AI will solve societal problems, that data is equivalent to knowledge ("meten is weten!"). Missing from these conceptualizations is the deeper understanding of AI as part of a network, or binding fabric of relationships, that includes people and institutions as well. By focusing so heavily on what disruptive technologies can do, we have begun to forget that this doing takes place in the context of infrastructures, practices, and relationships with other actors (human and non-human). Disruptive technologies on their own cannot and do not solve problems. Rather, disruptive technologies may offer solutions accessible through relationships with people, other technologies, and institutions. This social network is what solves problems, not the technical specifications of a machine-learning algorithm.



***Recommendation:*** *For both researchers and practitioners, recentering relationships among people, technologies, and institutions, and focusing on how technologies work together with humans in context to achieve goals, may help avoid some of the misalignments between narratives and practices that are so common for new technologies today.*

Because disruptive technologies are not embedded in a vacuum, building collaborative capacity among stakeholders is important to the success of any research or technology development project. Too often, as Chapter 6 demonstrated, academic collaborations in particular can get bogged down in the details of their methodological differences and encourage oversimplification of complex problems. A focus on goals, rather than methods (Gieryn, 1983), can help avoid collaborative paralysis and improve collaborative outcomes by allowing academics to work together to understand different facets of a complex problem without privileging one method over another.

***Recommendation:*** *When embedding (or researching the embedding of) disruptive technologies, collaborators should engage in boundary work around goals, rather than around professional roles, in order to facilitate transdisciplinary collaboration.*

As shown in Chapter 5, engaging in this sort of collaborative boundary work involves questioning backstaged (Tanner & Timmons, 2008) and implicit assumptions. For instance, clarifying what kinds of explanations are needed for a particular audience would help providers of those explanations reach their goals of improving trust and understanding in AI tools. As shown in the initial focus groups that contributed to Chapter 5 and in the ethnographic findings from Chapter 3, focusing more collaborative energy on ongoing and concrete discussions about goals, values, and meanings of terminology would help avoid many of the obstacles encountered when embedding disruptive technologies at the implementation stage. If misalignments among narratives, practices, and infrastructures are more visible early on, there are more opportunities (Collingridge, 1980) to find organizational or technical solutions to both meet practical needs and work more effectively with existing infrastructure. For instance, earlier attention to practices related to the SkinVision app would likely have revealed practical issues with implementation (such as people with disabilities struggling to hold a smartphone steady enough to take a picture, and GPs feeling pressure to refer app users to dermatology) earlier on, potentially allowing some of these issues to be addressed sooner, for example by repositioning the app in the healthcare system when such a shift may have been legally and financially simpler.

***Recommendation:*** *Researchers and practitioners should devote more energy to ongoing and concrete discussions about goals, values, and meanings of terminology to minimize unanticipated obstacles only uncovered at the implementation stage of embedding disruptive technologies.*

For similar reasons, it is essential that both researchers and other stakeholders consider the context of implementation of a disruptive technology throughout the embedding process, not just at the beginning of development or during the implementation phase, as is currently common practice, despite ongoing calls for more iterative processes that consider context to be as integral to technology embedding as, for instance, effectiveness or technical capacity (Greenhalgh et al., 2017). This may also require reworking some standard research methodologies to accommodate more frequent consideration of context. For instance, HTA processes were primarily designed with pharmaceutical assessment in mind (Boverhof, Redekop, Visser, et al., 2024; Drummond et al., 2015). However, pharmaceuticals act on human biology in ways that can be presumed to be largely similar across different locations[5]. For this reason, medical device assessment cannot immediately be "sunk into"(Star & Ruhleder, 1996 p.113) the infrastructure of pharmaceuticals (Michels et al., 2024): medical devices (including the disruptive

5 Once again, however, there is complexity here. For instance, the mechanism of delivery of a drug matters from a social and infrastructural perspective in profound ways: a patient can take a pill without supervision from a doctor, but an IV drip must be administered by a professional in order to be considered safe.

technologies discussed in this book) generally work not in relationship to biology, but in relationship to people, institutions, and sociotechnical infrastructures. These factors (e.g. near-universal access to GPs in the Netherlands (Chapter 4)), ultimately determine the utility of the most technically sound and cutting edge technologies more so than their technical specifications and whether or not they are shown to be safe and effective in clinical trials.

> ***Recommendation:*** *Researchers and practitioners must consider the context of health technology implementation to be integral to the embedding of a disruptive technology at the same level as effectiveness and technical capacity, rather than approaching context as an add-on component only at the beginning of development or the implementation stages.*

This imperative for iterative and ongoing assessment of health technologies is all the more important given the findings about infrastructure I have presented in this thesis. Not only does context (and infrastructures as part of that context) shape technologies, disruptive technologies shape the contexts (and infrastructures) in which they are implemented. This is perhaps more visible for AI than other disruptive technologies due to the capacity of AI to evolve on its own, remaking its own technical infrastructure, and due to issues like data drift (Loh et al., 2022), which make it possible to see how that technical infrastructure may evolve simply with time and usage, regardless of outside input. However, disruptive technologies do not just reshape their own technical infrastructures: they can also reshape the many infrastructures that make up the healthcare system (Chapter 3), necessitating new practices, and carving of new and unanticipated grooves (Star & Ruhleder, 1996).



> ***Recommendation:*** *Continuous monitoring, not just of the technology, but of its interaction with its context, is necessary to allow researchers and healthcare decision-makers to recognize these changes earlier. This would allow both researchers and practitioners to redirect any unanticipated impacts such that the technology continues to serve the goals of the healthcare system, including improving quality of care, reducing work burden, and reducing costs.*

Finally, the infrastructures involved in this collaborative work currently facilitate the organization of such work along strict disciplinary divisions, and encourage strong divisions between research and practice (Chapter 6). As I have shown throughout this book as a whole, but specifically within Chapter 6, defaulting to such organizational strategies is not supportive of the practice of transdisciplinary and interparadigmatic research, despite narratives from funders and policymakers clearly advocating for T/I research and the desire of many decision-makers and researchers for more T/I research. Not only does this result in extra labor, necessitate the creation of ad hoc T/I spaces, and generate negative affect for T/I researchers, it impedes the creation of truly interparadigmatic research outputs and limits understanding of the full complexity of embedding technology in healthcare within T/I collaborations. Furthermore, disciplinary organization again encourages a focus on professional boundary work (Gieryn, 1983) by method, rather than by goal. This

leads both practitioners and researchers to privilege certain kinds of knowledge and knowledge production over others (exacerbating quantification bias) and invisibilizes the extent of translation labor that makes transdisciplinary collaborations possible. As this book has demonstrated, valuing T/I research within narratives is not enough; practices and infrastructures must also be adapted in order to legitimize these contributions, recognize their value, and remove existing obstacles to collaborations around the embedding of technology in healthcare.

> ***Recommendation:*** *Funders must build practical requirements into calls and reporting requirements T/I research projects that counteract the default disciplinary organization of most research institutions. For these practical measures should include requiring the participation of senior researchers with T/I backgrounds and providing funding explicitly for project management that is separate from funding for PhD candidate work. These measures would both acknowledge and mitigate the increased demands for both expertise and labor that come with truly integrated T/I research and practical projects. T/I collaborations should consider meeting in and/or establishing neutral spaces in which no single method or paradigm is considered the default and T/I researchers and practitioners are considered the guiding experts. Journals that publish T/I work should adapt methodology guidelines to increase flexibility for reporting on T/I research and prioritize peer review from T/I researchers.*

These changes to infrastructure and practice would also, in turn, shift narratives, allowing for more complexity and nuance, and reducing reliance on assumptions about how research should be done, what counts as research, and whose expertise is most valuable within T/I collaborations. In other words, it may be possible to move to an approach to research that values multiple perspectives by default, rather than privileging one perspective over another, through changes to practices within T/I collaborations and the infrastructures in which these collaborations take place. Changes like this could also aid practical collaborations by reducing unanticipated impacts of embedding health technologies.

This dissertation demonstrates that, despite contradictions and complexity, multiple perspectives deployed at multiple levels of the healthcare system are crucial to fully understanding the impacts of embedding disruptive technology in healthcare. Approaching knowledge production in this way involves choosing to embrace the full complexity of the healthcare system and the process of embedding technology within that system. We cannot exclude different ways of knowing; we must allow them to coexist and inform one another, without attempting to control for difference. In other words, we must center the unintended consequences and the paradoxical staircases.

## CONCLUDING REMARKS

For many healthcare stakeholders, but especially technology developers and many policymakers, the only point of studying the embedding of disruptive technologies in healthcare is eventually to embed disruptive but promising technologies in healthcare. However, actually achieving this goal brings us back to the Collingridge dilemma: the more embedded the technology becomes, the more information we have about how it impacts healthcare practice and provision, but the harder it is to change the technology or the way in which it is embedded in the healthcare system. The edges between a disruptive technology and the place in the healthcare system where it becomes embedded may transform from irreconcilable gaps to smooth transitions with enough time; a new groove is carved (Star & Ruhleder, 1996), and we forget there was ever a gap in the infrastructure to bridge in the first place.

And so we find ourselves back in the same position for the next controversial technology, having completely forgotten the affective qualities of a lack of legitimacy: how it felt before now-old technologies were taken for granted. Does anyone clearly remember the affective quality of daily practice in healthcare before the internet was taken for granted? Before MRIs and ultrasound? Before…bed pans? Even if we have historical records of how things used to be done, these appear as quaint artefacts of the "before times" when we didn't have the information and experience we have now. It seems ridiculous to us now that doctors once resisted digital medical records (Nov & Schecter, 2012) and handwashing (Poczai & Karvalics, 2022). We have trouble feeling empathy for surgeons who still prefer open procedures when laparoscopic options are considered so much safer. These judgments are simply representations of the filter through which we pass all historical evidence, even when we ourselves were a part of that history. It is nearly impossible to re-adopt the mindset and lack of information we were working with at the time, rather than filtering these historical records through our current knowledge and experience. Continuing to remember the guiding assumptions and difficulties encountered before new grooves were carved and the infrastructure may be impossible. Perhaps all we can do is trust the lessons recorded during previous iterations of the problem of embedding disruptive technologies in healthcare.



While I don't pretend to be immune from the consequences of shifting infrastructural assumptions, I like to think that the transdisciplinary and interparadigmatic work that has gone into this thesis has provided me with somewhat more capacity to recognize when such assumptions are guiding my thinking than before I started this project. The world from this perspective is broad, unassimilated and undistilled, pluralistic and full of contradictions, and yet still, somehow, operational. Adopting such a multidisciplinary, transdisciplinary, and/or interparadigmatic perspective feels both unsettling and fascinating, much like looking at a lithograph of an impossible staircase. However, choosing to zoom out and examine a fuller picture, and not just the parts that make sense within a particular framework, is essential if the goal of embedding disruptive technology is to improve healthcare. If we allow our perspectives, and therefore our choices, to remain bounded by infrastructure we cannot see and assumptions we do not realize we have made, we risk taking care for granted.

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## SUMMARY

In recent years, the development of disruptive technologies for healthcare has taken off exponentially. The assumption, often made explicit, is that these technologies will help solve complex and wicked problems in healthcare, and relieve increasing pressure on healthcare systems worldwide from aging populations and rising costs. Disruptive technologies like artificial intelligence (AI) promise to improve effectiveness and efficiency of health care, reduce work burden for healthcare staff, make care safer, provide a cost-effective alternative to standard care practices, improve access to care by allowing healthcare staff to care for more patients, and streamline care practices across hospital systems. However, there is a paucity of research demonstrating that these promises and assumptions about new health technologies are realized in practice. This dissertation explores how disruptive technologies, such as artificial intelligence, become embedded in the healthcare system and the ambivalent impacts their use generates when seeking to solve the wicked problems in healthcare systems.

In this dissertation, I examine the practices, narratives, and infrastructures involved in the embedding of disruptive technologies in the Dutch healthcare system. I use the term "embedding" to describe the entire process of a technology becoming accepted, adopted, implemented (by institutions), used, integrated (into everyday practice), and entrenched (taken-for-granted as standard of care) in the healthcare system. The term "embedding" also suggests the importance of both infrastructure and legitimacy to this process: once a technology is fully "embedded" in healthcare, it is taken for granted as part of the infrastructure and thus no longer disruptive. However, it is also no longer easily changed nor, perhaps, even particularly observable within the infrastructure of the healthcare system. I therefore approach the question of how disruptive technologies become embedded in healthcare through the lens of legitimacy.

The process of embedding disruptive technologies in healthcare crosses the boundaries of multiple disciplines and involves a wide range of stakeholders both within and outside of academia. This dissertation posits that multiple perspectives, methodologies, and epistemological paradigms are therefore necessary to fully understanding this embedding process. Through the metaphor of M.C. Escher's "impossible architecture," and specifically his 1953 lithograph "Relativity", I explore the implications of this transdisciplinary and interparadigmatic complexity. This metaphor allows exploration of the assumptions that guide narratives of embedding technologies, and points to a need to allow misalignments and incongruous findings to coexist in service of understanding the full complexity of the embedding process.

Chapter 2 provides a conceptual foundation through a critical interpretive synthesis of legitimacy in health and technology by developing a new theoretical framework for understanding legitimacy in this context. Analyzing 97 articles across the disciplines of Organization and Management Studies, Science and Technology Studies, and Medical Anthropology and Sociology, in this

literature review I develop the metaphors of a highway system, a computer operating system, and a building's plumbing to explore the meaning, production, and use of legitimacy within each discipline. I show how each metaphor emphasizes and deemphasizes certain aspects of legitimacy. Layering these metaphors to view their intersections and divergences provides a fuller picture of how legitimacy works in health and technology and allows me to synthesize the concept of legitimacy as a form of social infrastructure. This conceptualization of legitimacy as a binding fabric of relationships among people, institutions, and technologies makes space for legitimacy to exist outside of human judgments and narratives, without devaluing the importance of perception in the production of legitimacy. Just as infrastructures consist of both materialities and abstract systems, social infrastructure melds semiotic, material, and normative aspects of legitimacy and explores how they might work together. In this way, the concept of legitimacy as social infrastructure allows for the integration of disparate and seemingly-contradictory aspects of legitimacy-making across multiple disciplines and many kinds of empirical work.

Chapter 3 builds on this conceptual work by presenting a three-year ethnographic case study of an AI-based mobile health app for skin cancer risk assessment. This chapter utilizes the concept of legitimacy, omnipresent but underexplored in empirical health technology studies, to examine assumptions guiding the embedding of this app in the Dutch healthcare system. Our analysis focuses on moments of legitimacy breakdown, contrasting company narratives and healthcare-based assumptions with practices and affectively-charged experiences of professionals and app users. Participants include doctors, policymakers, app users, developers, insurers, and researchers.



In this chapter, I identify three key legitimacy breakdowns that hindered the app's embedding: first, lack of institutional legitimacy leads to informal workarounds by the company at the institutional level; second, quantification privilege impacts app influence in interactions with doctors; and third, interactive limits between users and the app contradict expectations around ease of use and work burden alleviation. These results demonstrate that legitimacy is a useful lens for understanding the embedding of health technology while taking into account institutional complexity. This chapter also shows that a legitimacy lens is helpful for decision-makers and researchers because it can clarify and anticipate pain points for the integration of AI into healthcare systems.

Chapter 4 further investigates the embedding of the app in the Dutch healthcare system through a full health technology assessment (HTA), incorporating elements from several HTA frameworks and deep integration of multidisciplinary data. This chapter aims to both support healthcare decision-making, and address larger policy concerns around managing uncertainty about organizational and social aspects of health technology implementation. Combining cost analysis, clinical evidence, ethnography, and stakeholder interviews, this chapter shows that the app is currently more expensive than standard care. However, with changes in reimbursement strategy and treatment decisions made by general practitioners, the app may benefit certain

populations, reduce societal costs around healthcare provision, and add value to skin cancer care in the Netherlands. This chapter emphasizes the need for deeper and more integrated analysis and data collection about the organizational, ethical, and social dimensions of AI implementation to better inform policy and investment decisions.

Chapter 5 circles back to deal with issues of meaning that arise in the complex context into which health technologies are embedded. Explanations are seen as a way of managing issues of understanding and trust when dealing with AI health technologies, but the meaning and purpose of explainability for AI varies greatly depending on the audience. This chapter uses Q-methodology, a mixed method employing both statistical and interpretive research designed to systematically study subjective perspectives, to explore the meaning and importance of explainable AI (XAI) among healthcare stakeholders. Based on input from 37 professionals including clinicians, policy makers, and AI developers, the chapter develops a typology of four stakeholder perspectives on XAI. Each perspective represents different values and meanings placed on XAI for healthcare, potentially impacting the embedding of AI technologies. This chapter suggests directions for more responsive explanation strategies to bridge both disciplinary and practical gaps in communication within the transdisciplinary collaborations necessary to develop and implement AI in healthcare practice.

Chapter 6 reflects on my position as a researcher attempting to capture the complexity of embedding disruptive technologies in healthcare from multiple perspectives. This chapter draws on four years of autoethnographic data from three PhD researchers to examine how transdisciplinary and interparadigmatic (T/I) knowledge is produced by early-career researchers navigating academic and institutional boundaries. This chapter identifies three translation practices—condensing, staging, and trespassing—as key strategies for working across disciplinary divides. It reveals how these practices, while necessary to produce knowledge from multiple perspectives, have affective consequences for researchers, and often involve personal and epistemic compromises. Here, I explore what it means in practice to be a figure moving among these different perspectives while remaining inside the lithograph of impossible architecture. The chapter discusses ad hoc infrastructural solutions developed by T/I researchers to manage this experience and concludes with actionable recommendations for the reorganization of T/I research to improve researchers' wellbeing and capacity to produce societal impact.

This dissertation offers a multidisciplinary, interparadigmatic perspective on how AI and other disruptive technologies become embedded in healthcare through the lens of legitimacy. The findings of this dissertation reinforce the importance of narratives to both legitimacy and the embedding of disruptive technologies across many disciplines and subject areas. However, the dominance of narratives in both data collection and analysis may make it more difficult to parse what is left out when narratives are centered to the exclusion of other aspects of embedding technologies in healthcare, such as practices and infrastructures. I show that narratives that become

taken-for-granted rest on an installed base of knowledge and assumptions about how things should or do work. Some assumptions are necessary to allow us to function and this installed base of assumptions can be used to foster deeper trust and understanding in disruptive healthcare technologies. However, I also demonstrate that we can only move beyond taken-for-granted (but often incomplete or problematic) narratives by questioning some of these assumptions. For instance, by focusing so heavily on technical capacities of disruptive technologies, we have begun to forget that these technologies can only work in the context of infrastructures, practices, and relationships with other actors (human and non-human). Disruptive technologies on their own cannot and do not solve problems. Rather, they may offer solutions accessible through relationships with people, other technologies, and institutions.

In this way, not only does infrastructure shape practices and narratives, narratives and practices can, in turn, shape infrastructure by changing how people, technologies, and institutions interact with one another. This reshaping can have unintended but profound consequences, and it is rarely clear whether the disruption of practices, narratives, or infrastructure will lead to embedding of a technology or better health outcomes. In the same way that the figures in "Relativity" are oblivious to the strangeness of their environment, so are we often oblivious to the consequences of embedding of disruptive technologies in healthcare, until we see those impacts in action. It is therefore essential that both researchers and other stakeholders consider the context of implementation of a disruptive technology throughout the embedding process, not just at the beginning of development or during the implementation phase, as is currently common practice, despite ongoing calls for more iterative processes. Continuous monitoring, not just of the technology, but of its interaction with its context, could allow both researchers and healthcare decision-makers to recognize these consequences earlier, and perhaps redirect the technology such that it continues to serve the goals of the healthcare system.



My empirical data make clear that practices show *how* embedding takes place in the real world, and that this process may be quite different from what is envisioned in narratives. Furthermore, practices, not narratives, are what ultimately determine the outcomes of using disruptive technologies in healthcare. This is visible in both qualitative and quantitative data. It is thus essential to empirically investigate real-world practices if the goal is to develop an understanding of how disruptive technology becomes embedded in healthcare, not just whether it has potential to become embedded. Recentering relationships among people, institutions, and technologies, and focusing on how technologies work together with humans in context to achieve goals, may help avoid some of the misalignments between narratives and practices that are so common for new technologies today.

Misalignments between practices and narratives can also raise questions about the legitimacy of a technology. I show that the approach to managing these kinds of legitimacy threats depends more on the perspective and goals of the research than on whether a technology is useful or could

be repositioned in the healthcare system in order to become useful. Empirical study of practices may bring to light conflicts with both pre-existing narratives about disruptive technologies and healthcare, as well as narratives deeply embedded within different epistemological approaches to knowledge production. While this dissertation demonstrates that different methodologies and epistemologies are useful for different research goals, my findings also indicate that the use of frameworks as checklists is not enough to produce an understanding of how technology can be embedded in healthcare. Instead, analyzing how checklist items interact with one another as well as incorporating data from deeper explorations that may move beyond the scope of the checklist are essential to form a full and adequately complex picture. Furthermore, in the context of transdisciplinary collaborations around disruptive healthcare technologies, a focus on goals, rather than methods, can help avoid collaborative paralysis and improve collaborative outcomes by helping people work together to understand different facets of a complex problem without privileging one method of knowledge production over another.

The world from this multidisciplinary perspective is complex and contradictory, and yet still, somehow, operational. Adopting such a perspective feels both unsettling and fascinating, much like looking at a lithograph of an impossible staircase. However, I argue that choosing to look at the whole picture, and not just the parts that make sense within a particular framework, is essential if the goal of embedding disruptive technology is to improve healthcare. If our perspective on embedding disruptive technologies in healthcare remains bounded by infrastructure we cannot see and assumptions we do not realize we have made, we risk taking care for granted.

## SAMENVATTING

In de afgelopen jaren is de ontwikkeling van ontwrichtend technologieën voor de gezondheidszorg exponentieel toegenomen. De aanname—vaak expliciet gemaakt—is dat deze technologieën zullen bijdragen aan het oplossen van complexe en "wicked" problemen in de zorg, en dat zij de toenemende druk op zorgsystemen wereldwijd door vergrijzende bevolkingen en stijgende kosten zullen verlichten. Ontwrichtend technologieën zoals kunstmatige intelligentie (AI) beloven de effectiviteit en efficiëntie van de zorg te verbeteren, de werkdruk voor zorgpersoneel te verminderen, de veiligheid van zorg te vergroten, een kosteneffectief alternatief te bieden voor standaardpraktijken, de toegang tot zorg te verbeteren door zorgpersoneel in staat te stellen meer patiënten te behandelen, en zorgpraktijken binnen ziekenhuissystemen te stroomlijnen. Er is weinig onderzoek dat aantoont dat deze beloften en aannames rondom nieuwe gezondheidstechnologieën in de praktijk daadwerkelijk worden gerealiseerd. Dit proefschrift onderzoekt hoe ontwrichtend technologieën, zoals kunstmatige intelligentie, worden ingebed in het zorgsysteem en welke ambivalente effecten het gebruik ervan teweegbrengt in het streven om de "wicked" problemen van zorgsystemen op te lossen.

In dit proefschrift onderzoek ik de praktijken, verhalen en infrastructuren die betrokken zijn bij de inbedding van ontwrichtend technologieën in het Nederlandse zorgsysteem. Ik gebruik de term "inbedding" om het volledige proces te beschrijven waarin een technologie wordt geaccepteerd, geadopteerd, geïmplementeerd (door instellingen), gebruikt (door eindgebruikers), geïntegreerd (in de dagelijkse praktijk), en verankerd (als standaardzorg beschouwd) in het zorgsysteem. De term "inbedding" wijst ook op het belang van zowel infrastructuur als legitimiteit in dit proces: zodra een technologie volledig is "ingebed" in de zorg, wordt zij als vanzelfsprekend onderdeel van de infrastructuur gezien en is zij dus niet langer ontwichtend. Tegelijkertijd is zij dan ook niet langer eenvoudig te veranderen en misschien zelfs nauwelijks nog zichtbaar als niet-menselijke actor binnen de infrastructuur van het zorgsysteem. Daarom benader ik de vraag hoe ontwrichtend technologieën worden ingebed in de zorg door de lens van legitimiteit.

Het proces van inbedding van ontwrichtend technologieën in de zorg overschrijdt disciplinaire grenzen en omvat een breed scala aan belanghebbenden, zowel binnen als buiten de academische wereld. Dit proefschrift stelt dat meerdere perspectieven, methodologieën en epistemologische paradigma's noodzakelijk zijn om dit inbeddingsproces volledig te begrijpen. Via de metafoor van M.C. Eschers "onmogelijke architectuur," en specifiek zijn lithografie *Relativity* (1953), onderzoek ik de implicaties van deze transdisciplinaire en interparadigmatische complexiteit voor de inbedding van ontwrichtend technologieën in de zorg. Deze metafoor maakt het mogelijk om de aannames te verkennen die de verhalenverhalen van inbedding sturen, en wijst op de noodzaak om wrijvingen en incongruente bevindingen naast elkaar te laten bestaan om de volle complexiteit van het inbeddingsproces te begrijpen.

Hoofdstuk 2 biedt een conceptuele basis door middel van een kritisch-interpretatieve synthese van de literatuur over legitimiteit in gezondheid en technologie. Hier is een nieuw theoretisch kader ontwikkeld om legitimiteit in deze context te begrijpen. Op basis van 97 artikelen uit de organisatie- en managementwetenschappen, science and technology studies, en de medische antropologie en sociologie, ontwikkel ik de metaforen van een autosnelwegennetwerk, een computerbesturingssysteem en de waterleidingen van een gebouw om de betekenis, productie en het gebruik van legitimiteit binnen elk van deze disciplines te onderzoeken. Ik demonstreer hoe elke metafoor bepaalde aspecten van legitimiteit benadrukt en andere juist onderbelicht. Door deze metaforen te combineren en hun raakvlakken en verschillen te analyseren, ontstaat er een vollediger beeld van hoe legitimiteit functioneert in gezondheid en technologie, en kan ik het concept van legitimiteit beschouwen als een vorm van sociale infrastructuur. Deze conceptualisering van legitimiteit als bindweefsel van relaties tussen mensen, instellingen en technologieën maakt ruimte voor legitimiteit buiten menselijke oordelen en verhalenverhalen, zonder het belang van perceptie in de productie van legitimiteit te ontkennen. Net zoals infrastructuren bestaan uit zowel materiële als abstracte systemen, verenigt sociale infrastructuur de semantische, materiële en normatieve dimensies van legitimiteit en verkent zij hoe deze gezamenlijk kunnen functioneren.

Hoofdstuk 3 bouwt voort op dit conceptuele werk met een driejarig etnografisch casusonderzoek naar een AI-gebaseerde mobiele gezondheidsapp voor huidkankerrisicobeoordeling. Dit hoofdstuk gebruikt het concept van legitimiteit—alomtegenwoordig maar onderbelicht in empirisch gezondheidstechnologie-onderzoek—om de aannames die leiden tot de inbedding van deze app in het Nederlandse zorgsysteem te analyseren. Onze analyse richtte zich op momenten van afbreuk van legitimiteit, waarbij bedrijfs verhalenverhalen en zorglogica's werden geconfronteerd met de praktijk en affectieve ervaringen van professionals en app-gebruikers. Deelnemers waren onder meer artsen, beleidsmakers, app-gebruikers, ontwikkelaars, verzekeraars en onderzoekers. Ik identificeerde drie belangrijke legitimiteitsbreuken die de inbedding van de app belemmerden: (1) gebrek aan institutionele legitimiteit leidde tot informele tijdelijke oplossingen loop bedrijfs niveau; (2) "quantification privilege" beïnvloedde de rol van de app in interacties met artsen; en (3) beperkingen in de interactie tussen gebruikers en de app stonden haaks op de verwachtingen van gebruiksgemak en werkdrukverlaging. Deze bevindingen tonen aan dat legitimiteit een nuttige lens biedt om de inbedding van gezondheidstechnologie, met oog voor institutionele complexiteit, te begrijpen.

Hoofdstuk 4 onderzoekt de inbedding van de app verder via een volledige "health technology assessment" (HTA), waarin elementen uit verschillende HTA-raamwerken worden geïntegreerd en multidisciplinaire informatie diepgaand wordt samengebracht. Dit hoofdstuk heeft als doel zowel besluitvorming in de zorg te ondersteunen als wel bredere beleidsvragen aan te spreken over het omgaan met onzekerheid rond organisatorische en sociale aspecten van technologische implementatie. Door kostenanalyses, klinisch bewijs, etnografie en stakeholderinterviews te combineren, laat dit hoofdstuk zien dat de app momenteel duurder is dan standaardzorg. Met aanpassingen in

vergoedingsstrategieën en behandelbeslissingen door huisartsen kan de app echter waardevol zijn voor bepaalde bevolkingsgroepen, maatschappelijke kosten reduceren en de huidkankerzorg in Nederland verbeteren. Dit hoofdstuk benadrukt de noodzaak van diepere en meer geïntegreerde analyses van de organisatorische, ethische en sociale dimensies van AI-implementatie.

Hoofdstuk 5 keert terug naar de betekenisgeving binnen de complexe context waarin gezondheidstechnologieën worden ingebed. Uitleg wordt vaak gezien als middel om begrip en vertrouwen in AI-technologieën te bevorderen, maar de betekenis en functie van uitlegbaarheid blijken sterk afhankelijk van het publiek. Dit hoofdstuk gebruikt Q-methodologie—een gemengde methode die zowel statistisch als interpretatief is ontworpen om subjectieve perspectieven systematisch te bestuderen—om de betekenis en het belang van uitlegbare AI (XAI) onder zorgstakeholders te verkennen. Op basis van de input van 37 professionals, waaronder clinici, beleidsmakers en AI-ontwikkelaars, ontwikkel ik een typologie van vier stakeholderperspectieven op XAI. Elk perspectief vertegenwoordigt verschillende waarden en betekenissen die aan XAI worden toegekend, met mogelijke gevolgen voor de inbedding van AI-technologieën. Dit hoofdstuk suggereert richtingen voor responsievere uitlegstrategieën om zowel disciplinaire als praktische communicatiekloven te overbruggen in de transdisciplinaire samenwerkingen die nodig zijn om AI in de zorgpraktijk te ontwikkelen en implementeren.

Hoofdstuk 6 reflecteert op mijn positie als onderzoeker die tracht de complexiteit van de inbedding van ontwrichtend technologieën in de zorg vanuit meerdere perspectieven te vangen. Dit hoofdstuk baseert zich op data van vier jaar auto-etnografische onderzoek van drie promovendi om te onderzoeken hoe transdisciplinaire en interparadigmatische kennis wordt geproduceerd door onderzoekers in een vroege carrièrefase die navigeren langs academische en institutionele grenzen. Dit hoofdstuk identificeert drie vertaalpraktijken—condenseren, ensceneren en grensoverschrijding—als sleutelstrategieën om over disciplinaire scheidslijnen heen te werken. Het laat zien dat deze toespassingen, hoewel noodzakelijk om kennis vanuit meerdere perspectieven te produceren, affectieve consequenties hebben voor onderzoekers en vaak persoonlijke en epistemische compromissen vereisen. Hier onderzoek ik wat het in de praktijk betekent om een figuur te zijn die zich tussen deze perspectieven beweegt terwijl men binnen de lithografie van onmogelijke architectuur blijft. Het hoofdstuk bespreekt zowel ad-hoc oplossingen die T/I-onderzoekers ontwikkelen om deze ervaring te beheren, als aanbevelingen voor de herorganisatie van T/I-onderzoek om het welzijn van onderzoekers en hun vermogen om maatschappelijke impact te maken te versterken.

Dit proefschrift biedt een multidisciplinair en interparadigmatisch perspectief op hoe AI en andere ontwrichtend technologieën worden ingebed in de gezondheidszorg door de lens van legitimiteit.

De bevindingen onderstrepen het belang van verhalenverhalen voor zowel legitimiteit als de inbedding van ontwrichtend technologieën in uiteenlopende disciplines en domeinen. Toch

kan de dominantie van verhalenverhalen in dataverzameling en analyse maken dat dingen over het hoofd gezien worden—zoals praktijken en infrastructuren. Verhalen die vanzelfsprekend worden, rusten vaak op een al aanwezige basis van kennis en aannames over hoe dingen zouden moeten of daadwerkelijk werken. Sommige aannames zijn functioneel en noodzakelijk, en kunnen worden benut om vertrouwen en begrip te kweken. Maar ik laat ook zien dat we enkel voorbij vanzelfsprekende, vaak onvolledige of problematische verhalenverhalen kunnen komen door bepaalde aannames ter discussie te stellen. Door bijvoorbeeld te veel nadruk te leggen op technische capaciteiten vergeten we soms dat deze technologieën alleen functioneren binnen infrastructuren, praktijken en relaties met andere actoren (menselijk en niet-menselijk). Ontwrichtend technologieën op zichzelf kunnen en zullen geen problemen oplossen; zij kunnen hoogstens oplossingen toegankelijk maken binnen relaties met mensen, andere technologieën en instellingen.

Infrastructuur vormt praktijken en verhalenverhalen, maar verhalenverhalen en praktijken kunnen op hun beurt infrastructuur hervormen door de wijze waarop mensen, technologieën en instellingen met elkaar interacteren te veranderen. Deze hervormingen kunnen onbedoelde, maar diepgaande gevolgen hebben, en het is zelden duidelijk of verstoringen leiden tot inbedding of tot betere zorgresultaten. Zoals de actoren in *Relativity* zich niet bewust zijn van de eigenaardigheid van hun omgeving, zo zijn wij vaak blind voor de gevolgen van de inbedding van ontwrichtend technologieën totdat deze zich manifesteren. Het is daarom essentieel dat onderzoekers en andere belanghebbenden de context van implementatie in ogenschouw nemen gedurende het volledige inbeddingsproces, en niet alleen aan het begin of tijdens de implementatiefase, zoals momenteel gebruikelijk is. Voortdurende monitoring—niet alleen van de technologie, maar ook van haar interacties met de context—kan onderzoekers en zorgbeslissers helpen veranderingen eerder te herkennen en bij te sturen zodat de technologie de doelstellingen van het zorgsysteem blijft dienen.

Mijn empirische gegevens maken duidelijk dat praktijken laten zien hoe inbedding zich in de werkelijkheid voltrekt, en dat dit proces aanzienlijk kan verschillen van wat in verhalenverhalen wordt voorgesteld. Praktijken, en niet verhalenverhalen, bepalen uiteindelijk de uitkomsten van het gebruik van ontwrichtend technologieën in de zorg. Dit is zichtbaar in zowel kwalitatieve als kwantitatieve data. Daarom is het essentieel om de werkelijke praktijken empirisch te onderzoeken als het doel is te begrijpen *hoe* ontwrichtend technologie in de zorg wordt ingebed, en niet enkel of zij potentie heeft om ingebed te worden. Het hereiken van relaties tussen mensen, instellingen en technologieën, en het richten op hoe technologieën samen met mensen in context doelen bereiken, kan helpen om misalignments tussen verhalenverhalen en praktijken te vermijden die zo kenmerkend zijn voor nieuwe technologieën van vandaag.

Misalignments tussen praktijken en verhalen kunnen ook vragen oproepen over de legitimiteit van een technologie. Ik laat zien dat de aanpak van dergelijke legitimiteitsdreigingen eerder afhangt van perspectief en onderzoeksdoelen dan van de intrinsieke bruikbaarheid van

een technologie of de mogelijkheid deze te herpositioneren in het zorgsysteem. Empirisch praktijkonderzoek kan conflicten blootleggen met zowel bestaande verhalen over ontwrichtend technologieën en de zorg als met verhalen die diep ingebed zijn in verschillende epistemologische benaderingen van kennisproductie. Dit proefschrift toont dat uiteenlopende methodologieën en epistemologieën nuttig zijn voor diverse onderzoeksdoelen, maar dat het gebruik van raamwerken als checklists onvoldoende is. In plaats daarvan is er een analyse nodig van de interactie tussen checklistonderdelen, aangevuld met diepgaandere onderzoeken buiten de checklist om, om een volledig en voldoende complex beeld te vormen. Bovendien kan, in de context van transdisciplinaire samenwerking rond ontwrichtend gezondheidstechnologieën, een focus op doelen in plaats van methoden helpen om collaboratieve verlamming te voorkomen en betere uitkomsten te bereiken.

De wereld vanuit dit multidisciplinaire perspectief is complex en tegenstrijdig, en toch op de een of andere manier functionerend. Het aannemen van zo'n perspectief is zowel ontregelend als intrigerend, vergelijkbaar met het aanschouwen van een lithografie van een onmogelijke trap. Ik beargumenteer echter dat het noodzakelijk is om het gehele plaatje te bekijken—en niet enkel de delen die passen binnen een specifiek denkkader—als het doel van de inbedding van ontwrichtend technologie is om de gezondheidszorg te verbeteren. Indien ons perspectief op de inbedding van ontwrichtend technologieën in de zorg beperkt blijft door onzichtbare infrastructuren en aannames waarvan we ons niet bewust zijn, lopen we het risico de zorg als vanzelfsprekend te beschouwen.

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# PHD PORTFOLIO

## CONFERENCE PRESENTATIONS

2021 Lancaster Intellectual Party (Lancaster, online)
2021 Ethical AI: Perspectives on Law, Regulations, and Policy (Rotterdam, online)
2023 STS Italia: Interesting Worlds to Come (Bologna)
2024 EASST/4S: Making and Doing Transformations (Amsterdam)
2025 NIG: Algorithmic Governance (Ghent)
2025 Data for Policy Europe: Twin Transitions in Data and Policy (Den Haag)

## WORKSHOPS AND TRAINING

### QUANTITATIVE METHODS

2021 iMTA Introduction to Health Technology Assessment (online)
2021 NIHES Review of Math and Statistics (online)
2021 EGSH Quantitative Methods (online)
2021 EGSH Introduction to SPSS (online)
2023 Eu-HEM Introduction to Health Technology Assessment (Rotterdam)
2024 EGSH Q-methodology (online)

### DUTCH LANGUAGE

2021 LTC Nederlands A1 (online)
2021 LTC Nederlands A2 (online)
2022 Tutor Nederlands B1.1(online)
2022 Tutor Nederlands B1.2 (online)
2023 Tutor Nederlands B1.2-B2.1 (online)

### DIDACTICS EDUCATION

2022 RISBO Group Dynamics (Rotterdam)
2023 RISBO Didactics of Delivery (Rotterdam)

### OTHER EDUCATION

2021 EGSH Searching and Managing Your Literature (online)
2023 WTMC Summer School: the Algorithmic (Soeterbeek)
2023 Trust me, I'm not a doctor design-a-thon: AI & Interdisciplinarity (Rotterdam)
2025 Career Swifters

# TEACHING

## COURSES

2023 Tutor, HCM Master: Data Driven Dreams
2023 Tutor, Health Policy & Management Bachelor: Choices & Dilemmas
2024 Tutor, Health Policy & Management Bachelor: Choices & Dilemmas
2024 Tutor, HCM Master Digital Healthcare subtrack: Drivers & Dilemmas

## SUPERVISION

### HEALTH, ECONOMICS, POLICY, AND LAW MASTER'S PROGRAM

Lisandro Arias
Kimberley Boutkan
Eline Bouwhuis
Constantijn Magermans
Marialena Paslaki
Luc van Rijn

### HEALTH ECONOMICS MASTER'S PROGRAM

Morris Gaff

## WORKSHOPS & LECTURES

2022 ESHPM Day: Creative Research Methods (Rotterdam)
2024 Guest Lecture, DIGEC: Integrating AI into Healthcare (Rotterdam)
2025 Guest Lecture, Consumption & Healthy Lifestyles Department: Mixed Methods Anonymous (Wageningen)



## PEER-REVIEWED ARTICLES

Howe, S., Horbach, D., van Rijn, L., Gaff, M., van Exel, J., & Wehrens, R. (2025). Explaining explainable AI for healthcare: a Q-methodology study. *Information, Communication & Society*, 1-19. https://doi.org/10.1080/1369118x.2025.2584148

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## OTHER PUBLICATIONS

Wehrens, R., Howe, S., Demir, E., Prifti, K., Heine, K., & Stamhuis, E. (2021). AI en morele oordeelsvorming: van principes naar het vormgeven van ethische AI-praktijken. *Podium voor Bio-ethiek*.

Howe, S. (2020). Emerging from Lockdown: "Moral Pioneers" in Everyday Practices for Women in Europe and North America. boasblogs: Witnessing Corona Series. In collaboration with Blog Medical Anthropology/Medizinethnologie.

## ANCILLARY ACTIVITIES

2020-2021 Research consultant, Sexual and Reproductive Health & Rights, Amsterdam Institute of Global Health and Development
2021 Journal reviewer, Reproductive Biomedicine and Society Online
2021 Journal reviewer, Health Policy Open
2025 Journal reviewer, Health Policy & Technology
2025 Journal reviewer, Social and Health Sciences

## ABOUT THE AUTHOR

Sydney Evelyn Howe (1987) grew up in the San Francisco Bay Area, California. She graduated from Northwestern University in Chicago, Illinois, in 2009 [with Bachelor of Arts (Honors) in Communication], double majoring in Performance Studies and International Studies. During her years at Northwestern, she was the recipient of the 2008 Naomi Marfleet Cramer Scholarship, 2009 Guetzkow Prize, 2009 Charlotte Lee Award, and a member of the Communication Century Scholars Honors Society. She served two years with AmeriCorps VISTA in San Francisco before moving to Lucknow, India, to work at Study Hall Educational Foundation, an NGO focused on preventing child marriage through education. While in India, she developed a theatre-based critical-thinking curriculum that is still used in a UNICEF-funded outreach program to rural families. Because of this work, she founded an educational consultancy, bringing the curriculum to Cambodia, the United States, and Germany, and teaching communication and critical thinking skills to students at both low-income high schools and top-tier research institutions, including California Institute of Technology, Helmholtz Zentrum, and Ludwig-Maximilians-Universität.

Sydney graduated cum laude with a Master of Science in Cultural and Social Anthropology from the University of Amsterdam in January, 2020. Her thesis explored infertility in Zambia and the ethnography of surveys on sensitive topics as part of a research collaboration among Cardiff University, University of Zambia, and University of Amsterdam. Her fieldwork was funded by Economic & Social Research Global Challenges Research Fund: Impact Acceleration Award, and the Higher Education Funding Council for Wales, Global Challenges Fund. She is the first researcher to publish a study of quality of life for infertile people in Zambia. Since graduating with her masters, she has consulted for several NGOs and research institutions, including the Cardiff Fertility Studies Research Group, Her Choice, and Amsterdam Institute for Global Health and Development.

Sydney pursued her PhD at Erasmus School of Health Policy and Management, working between the Health Care Governance and Health Technology Assessment Departments. Her work focuses on the embedding of disruptive technologies in healthcare from a multidisciplinary perspective. During her PhD, she participated in several trans- and multidisciplinary collaborations, including a collaboration with Erasmus Medical Center on medical technology for dermatology, the AICCELERATE project (Horizon 2020) exploring AI for healthcare, and a collaboration with Erasmus School of Law around responsible innovation for healthcare. She is a founding member of Mixed Methods Anonymous and her work continues to bridge knowledge gaps and reach across academic, practical, and cultural boundaries.

Sydney lives in the Hague with her husband, Thierry, her daughter, Oriane, and her son, Louis.

**Disruptive technologies like artificial intelligence promise to solve wicked problems in healthcare. However, there is limited evidence demonstrating that promises and assumptions about new health technologies are realized in practice. This dissertation explores how disruptive technologies become embedded in the healthcare system and their ambivalent impacts. By examining practices, narratives, and infrastructures through the lens of legitimacy, this thesis draws a picture of the embedding process from a multidisciplinary, interparadigmatic perspective.**

**Revealing the complexities and contradictions involved in embedding disruptive technologies is essential if our goal is to improve healthcare. If our perspective remains bounded by infrastructure we cannot see and assumptions we do not realize we have made, we risk taking care for granted.**