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Sharing of personal health information for secondary use: A scoping review from the perspective of trust

Georgios Tsirozidis
Aarhus University, gets@mgmt.au.dk

Sune Dueholm Müller
University of Oslo, sunedm@ifi.uio.no

Keld Pedersen
Aarhus University, keldp@mgmt.au.dk

Jodyn Platt
University of Michigan, jeplatt@UMICH.edu

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Georgios Tsirozidis
Aarhus University, Department of Management, Fuglesangs Allé 4, Aarhus, Denmark
gets@mgmt.au.dk
Sune Dueholm Müller
University of Oslo, Department of Informatics, Gustadalleèn 30, Oslo, Norway
sunedm@ifi.uio.no
Keld Pedersen
Aarhus University, Department of Management, Fuglesangs Allé 4, Aarhus, Denmark
keldp@mgmt.au.dk
Jodyn Platt
University of Michigan, Department of Learning Health Sciences, 300 N Ingalls St, Ann Arbor, USA
jeplatt@umich.edu

Abstract

The adoption and use of health information systems depend on gathering of personal health information (PHI), and trust is considered a prerequisite for sharing PHI for secondary use. However, empirical PHI research is often not explicit about the trust's antecedents. This article aims to evaluate and enhance the conceptualisation of trust's antecedents in empirical research involving PHI sharing. First, an analytical lens encompassing commonly acknowledged trust antecedents was constructed based on the general trust, IS and HIS literature. Secondly, a scoping literature review was conducted, encompassing 75 empirical PHI articles. Thirdly, these articles were analysed using the analytical lens. The analysis indicates 1) all included antecedents are relevant within PHI sharing research, 2) their use in the empirical literature is inconsistent. 39 of the 75 articles do not include any of those antecedents in their research instruments. Based on the review, key recommendations for conceptualising trust's antecedents are proposed, to improve empirical PHI research.

Keywords: Trust, Health Information Systems, Information Sharing, Scoping Literature Review, Confidentiality, Privacy

1. Introduction

Health information systems (HIS) have the potential to address some of the challenges facing healthcare. Recent advances in information technologies, such as big data analytics, artificial intelligence, and mHealth, offer a plethora of new possibilities for managing healthcare (Cavallone & Palumbo, 2020) and improving the diagnosis and treatment of diseases (Wolf et al., 2019). However, new HIS solutions require the accumulation of personal health information (PHI), a necessity which is thought to be accompanied by a "dark side", raising

concerns about transparency, security, fairness and privacy (Aaen, et al., 2022; Mikalef et al., 2022; Pool et al., 2020). While those concerns can hinder PHI sharing, trust has been thought to be a major enabler of it, as it has been shown to increase users' intention to share their information for Covid-19 contact tracing (Hong & Cho, 2023; Lin et al., 2021), or for participating in a sustainable health system (Hillebrand et al., 2023).

Despite the significance of trust as a necessary foundation of initiatives involving the collection of PHI, its conceptualisation as a construct in health services research has been problematic, especially with regard to its antecedents (Taylor et al., 2023). Moreover, the conceptualisation of trust and its antecedents in HIS research is seen as underresearched and fragmented, necessitating their further studying and development (Mpinganjira, 2018). Past literature reviews on trust and PHI sharing have not focused on the conceptualisation of trust's antecedents or have not included a wide range of PHI uses (Hutchings et al., 2020; Shen, Sequeira et al., 2019; Stockdale et al., 2018). In this paper, we present a current assessment of the conceptualisation of trust's antecedents in PHI-sharing research and provide a theoretical framework to support future HIS research involving trust. Specifically, we seek to answer the following research questions:

RQ1: *How have the antecedents of trust been conceptualised in empirical studies involving PHI sharing?*

RQ2: *How can HIS studies improve their conceptualisation of trust's antecedents?*

To answer these questions, we:

1) Develop an analytical lens that encompasses relevant antecedents of trust, by drawing on general trust literature - especially the work of Mayer et al. (1995) - and past IS and HIS literature. We elaborate on the constructs included in the analytical lens in section 2.

2) Identify and analyse empirical PHI sharing literature through a scoping literature review. The literature review methodology, including how the articles are analysed, is described in section 3. The analysis focuses on a) the degree to which the general trust antecedents in the analytical lens are relevant within the domain of PHI sharing, and b) the degree to which the antecedents are explicitly integrated in the research instruments used in the empirical PHI sharing literature.

3) Report and synthesise our findings, and arrive at context-relevant suggestions for researching trust. This is described in sections 4 and 5.

Consequently, our study delivers theoretical and practical insights. From a theoretical standpoint, we elaborate and expand on the model of (Mayer et al., 1995), study its application in the context of PHI sharing, and propose context-relevant directions for researching trust. Those recommendations can improve the conceptualisation of trust's antecedents in HIS studies concerning PHI sharing, thus providing the tools for more meaningful research on trust, in targeting the pertinent problem of the "dark side" of HIS. From a practical perspective, our findings can be utilised to assist HIS managers in better understanding the formation of user trust in this unique context. As trust is an important element of IS success, focusing on the key factors that form it can be a fruitful direction in increasing HIS adoption and use, and, ultimately, in realising the potential of novel information technologies in healthcare.

2. Theoretical Background

This section defines trust and describes the antecedents of trust included in the analytical lens that we use to analyse the empirical PHI articles.

2.1 Definition of Trust/Original Model

Trust is usually conceived as a multidimensional construct (e.g., McKnight et al., 2002; McAllister 1995). As McEvily and Tortoriello (2011) summarise, trust is thought to operate in three distinct ways: perceptually, as an expectation about another party (trustworthiness beliefs); volitionally, as a willingness to put oneself into a vulnerable position (trusting intentions); and behaviourally, as a risk-taking act (trusting behaviours). In 1995, Mayer and colleagues presented a model of trust (hereafter the MDS model) that described trust's antecedents and downstream relations with risk-taking actions. The MDS model is considered seminal in trust literature (Dirks & De Jong, 2022; McEvily & Tortoriello, 2011), and has been also widely used within the IS literature.

The MDS model provides a definition of trust which comprises those perceptual, volitional and behavioural manifestations:

[trust is] *the willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party* (Mayer et al., 1995, p. 712).

In the MDS model, trust is shaped by expectations for the trustee. These expectations are derived from a cognitive assessment of the trustee's perceived trustworthiness (hereafter

trustworthiness), which comprises three dimensions: ability, benevolence, and integrity. Most often synonymous with competence (McEvily & Tortoriello, 2011), ability refers to the trustor's notion that the trustee possesses the necessary skills and competencies within a specific domain. Benevolence is "the extent to which a trustee is believed to want to do good to the trustor, aside from an egocentric profit motive" (Mayer et al., 1995, p. 718). Integrity refers to the trustee's morality, promise-keeping and honesty (Mayer et al., 1995). The MDS model contains another factor, propensity to trust (hereafter propensity) which is represented both as a moderator of the relationship between trustworthiness and trust, and as a direct predictor of trust. Propensity is described as a person's general inclination to trust others, and it is based on the personality, experiences and culture of the trustor (Mayer et al., 1995; Schoorman et al., 2007).

2.2 Additional Antecedents and Underlying Constructs

Over the years, literature reviews have studied trust both theoretically and through its use in empirical research. Notably, investigating interpersonal trust in organisational settings, Lyu and Ferrin (2018) based their literature review on four categories of antecedents: trustor-related factors (incl. propensity to trust), trustee-related factors (incl. ability, benevolence and integrity), contextual factors (incl. network and culture), and relationship factors (incl. relationship length, communication, and similarities). The remainder of this sub-section elaborates on constructs that fit into the latter two categories, or that are relevant in the context of PHI sharing and IS research.

Confidentiality and Privacy

Two of the most widely used antecedents of trust not originally included in the MDS model are confidentiality and privacy concerns. Past IS literature has studied the relationship between privacy concerns and trust in information-sharing contexts (Bansal & Nah, 2022; Kehr et al., 2015; Wu et al., 2012; Dinev & Hart, 2006). This relationship is particularly pronounced in healthcare (Sterckx et al., 2016) and has been supported empirically (Busch-Casler & Radic, 2023; Belfrage et. al., 2022; Platt & Kardia, 2015). Some researchers have operationalised confidentiality as a dimension of trust, as in the case of the Wake Forest scale (Hall et al., 2001), a particularly influential scale for measuring trust in healthcare (Platt et al., 2018). According to Hall et al. (2001), confidentiality refers to a patient's assurance that their private information will be protected, used properly, and will not be used against them.

Temporal influences on trust

Although trust can be seen as a state or an attitude, it is not static (Korsgaard, et.al., 2018). Indeed, the MDS model does not present trust as static, but instead proposes an iterative and dynamic development of trust through a feedback loop. A subsequent meta-analysis has pointed out the positive relationship between the length of a relationship and trust (Vanneste et al., 2014), while similar discoveries suggest an influence of past interactions with a party on perceived trustworthiness, as summarised in (Kramer, 1999). Specifically in IS research, past studies have shown a positive influence of repeated interaction with an IS element on trust (Cheng et al., 2016; Komiak & Benbasat, 2006). Recent theorising regarding trust building at different stages of a relationship has proposed heuristics, cognition and affect as bases of trust, as the length of a relationship increases (Baer & Colquitt, 2018; Lind, 2018; van Knippenberg, 2018).

Culture and third parties

As previously described, propensity is believed to have roots in both one's personality and experiences, and in their culture (Schoorman et al., 2007). IS literature has studied the impact of culture on trust, finding direct and moderating effects of culture on trust in IT artifacts (Vance et al., 2008). Particularly pertaining to the disclosure of personal information, direct (Wu et al., 2012) or moderating (Jenkner et al., 2022) effects of culture on trust have also been observed.

Even though the MDS model studies trust between two parties, the trustor and the trustee, the role of third parties has attracted the attention of trust scholars, pushing trust outside the isolated dyadic relationship (Dirks & De Jong, 2022). Based on trust transfer theory (Stewart, 2003), past research has studied the transfer of trust from one party to another, including from a healthcare provider to a HIS, when asked to share PHI (Busch-Casler, 2023; Esmaeilzadeh, 2019a). Concerning the present literature review, such an influence appears relevant, as it is common for a trusted third party (e.g., the family doctor) to requests the PHI on behalf of another entity (e.g., a national healthcare database).

Based on the original MDS model and the additional sources mentioned above, the analytical lens applied in this scoping review includes the following antecedents of trust: ability, benevolence, integrity, propensity, confidentiality, time, culture, and third-party influence.

3. Review Methodology

3.1 Searching the Literature

The Web of Science, Scopus and PubMed databases were searched by one author in March of 2021. The search fields included keywords pertaining to data sharing, health information, attitudes, empirical studies and trust (for the complete set of keywords see appendix A). This search provided a total of 981 articles, of which 693 were retained after the removal of duplicates. A second filtering through the Mendeley desktop citation manager (v.1.18) was conducted, by searching the titles, abstracts and keywords of the articles for "trust" (truncated), "mistrust", and "distrust", using the built-in search function. This yielded a total of 508 articles. In the next phase, the articles were screened for fit by noting the publication type of each and by reading the abstract. Here, particular attention was paid to inclusiveness, by erring on the side of caution, as advised by (Okoli & Schabram, 2012). The articles had to satisfy all of the following criteria:

- They reported empirical findings using primary data. Any literature reviews identified were excluded from this scoping review, although they aided the subsequent article search.
- They concerned perspectives, opinions, or decisions regarding PHI aggregation, reuse, disclosure, sharing, linking, or other similar action.
- The information requested or shared was for secondary uses (i.e., for inclusion in Electronic Health Records, research participation or similar reasons – not for the immediate treatment of the responder), as this is the focus of our scoping review.
- Trust, distrust or mistrust were used to inform the research instrument or were mentioned in the empirical findings. References which were merely superficial were not considered.
- They studied patients or members of the general population as trustors (i.e., articles measuring opinions of only physicians or other stakeholders were excluded).
- The sharing of information concerned living adults and affected only the responders (subjects must have been self-consentees to assure a direct link between trusting beliefs and personal risk of sharing). Studies on people with intellectual disabilities were also excluded.
- The responses in the reported studies were collected in the years 2001-2021 (both years inclusive), to ensure recency.
- They were published in journals or books, with a full-text version in English.

After applying the above criteria to the article abstracts, 175 articles were deemed fit for main-text screening. The main-text screening applied the same criteria used for the abstract screening, reducing the article pool to 59 articles. The references of literature reviews identified in the initial search were examined (manual backwards search) and led to the inclusion of a further 16 articles, based on the same criteria and a main-text examination, bringing the final number of articles to 75 (Figure 1).

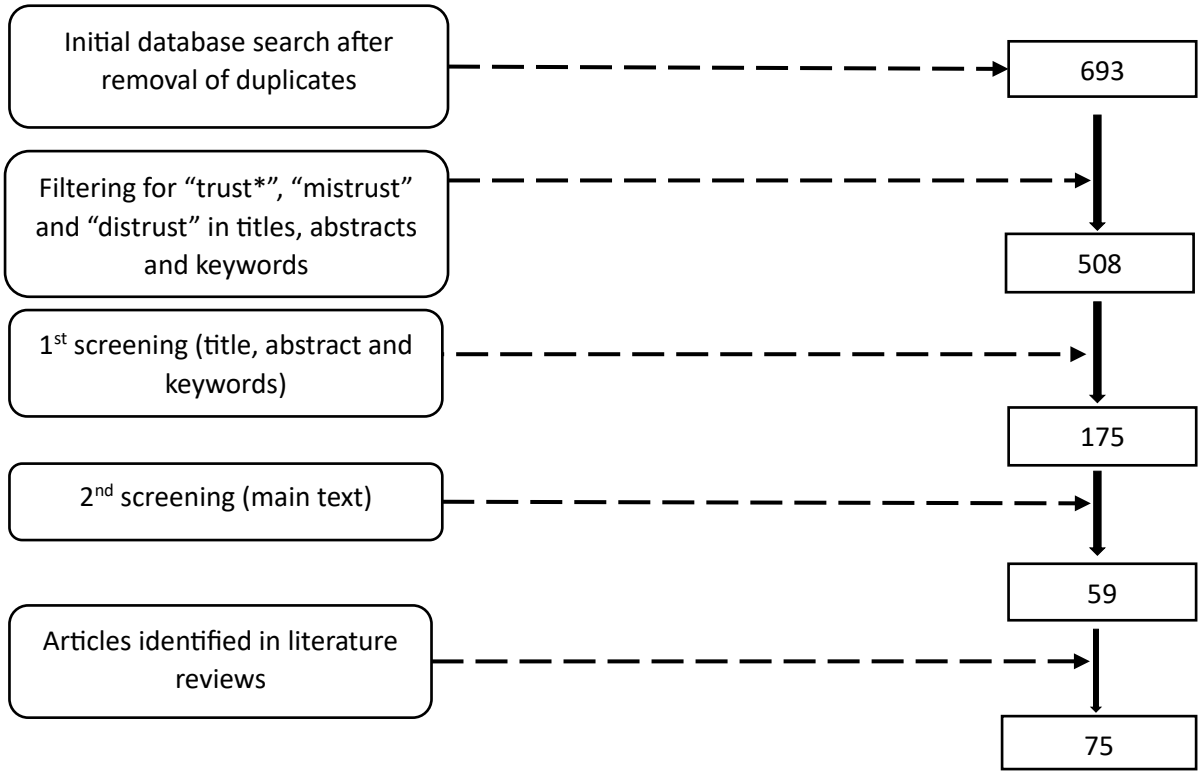

Figure 1. The literature searching process

3.2 Analysing the Literature

This scoping review used the analytical lens (figure 2) containing the antecedents of trust based on the literature presented in section 2. The reviewed empirical papers were deductively analysed based on the analytical lens.

Each construct of the analytical lens was matched to a code, with each code comprising several sub-codes (see Appendix B). To avoid situations where two identified constructs were named differently but referred to the same construct (and vice versa), the coding was based on the essential definition of the constructs, instead of how they were labelled in the articles.

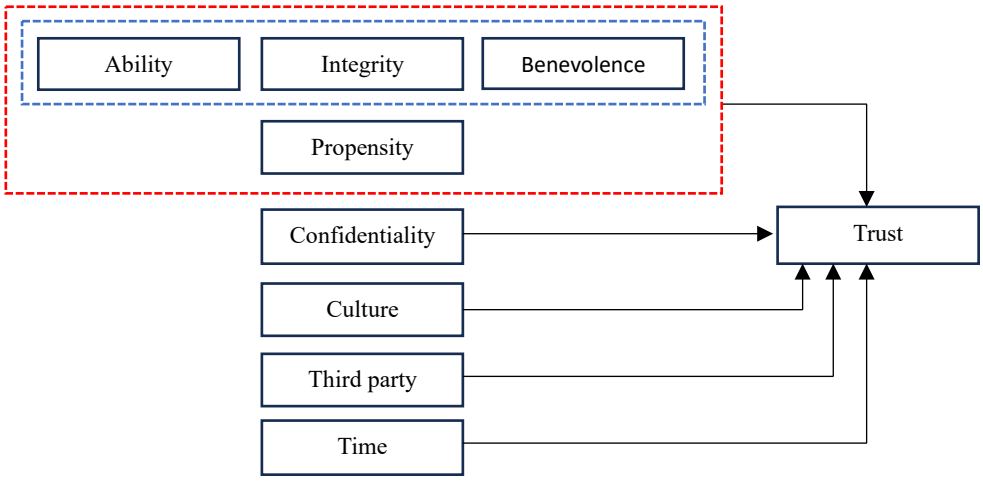

Figure 2. The analytical lens (antecedents of trust) (the MDS model antecedents enclosed in red, trustworthiness dimensions enclosed in blue).

Each article was marked for the inclusion of a construct/code. Multiple identifications in the same article did not affect the reported results. All data were extracted manually by one reviewer.

Two kinds of analyses were performed, one for each of the two research questions.

The analytical lens is partly based on research contributions, especially the MDS model, that are external to the domains of HIS and PHI sharing. To assess whether the antecedents included in our analytical lens can be used to improve the conceptualisation of trust's antecedents in HIS research (RQ2), the first analysis primarily focused on the results reported in the reviewed literature. For each of the reviewed articles, it was determined whether the article reported that an antecedent included in the analytical lens had a significant influence on trust, or showed high reliability if it was used as a dimension of trustworthiness. The results of this analysis should indicate the relevance of the antecedents in the analytical lens, in the context of PHI sharing.

The evaluation of past conceptualisations of the antecedents of trust in empirical PHI research (RQ1) was informed by the research instruments employed in the collected articles. To that end, the collected articles' methods sections were studied. In this analysis we focused on the degree to which the reviewed articles explicitly integrated one or more antecedents of the analytical lens in their research instruments (e.g. surveys), either as separate constructs or as dimensions of a composite one. The results of this analysis should indicate how extensively each trust antecedent included in the analytical lens has been explicitly used in the research instruments of extant, empirical PHI research.

4. Results

4.1 General Findings

The 75 collected articles were published between 2005 and 2021. 35 studies employed quantitative, 29 qualitative and 11 mixed methods. The most common research instrument was the survey (38 studies), followed by interviews (21 studies), focus groups (18 studies), and deliberations (3 studies). Out of the 75 studies using unique samples, 37 studies took place in the USA, 7 in England, 5 in Australia, 4 in Canada, 3 in Switzerland, 2 in Scotland, 2 worldwide, and 14 in other countries or across one or more countries. The participants were asked their opinions on a wide range of uses of their information, including use for or participation in medical research, biobanking, genomic and DNA research, Electronic Health Record systems, collection of administrative data, and access to medical records. The responders were either sampled because they belonged to the general population (44 studies), or they were approached through their patient status or their proximity to other patients or health institutes, hospitals, or other similar places (33 studies).

4.2 Relevance of the Antecedents Included in the Analytical Lens

To evaluate the relevance of the antecedents included in the analytical lens, we looked at the empirical evidence showing their influence on trust in the context of PHI sharing. 51 articles included at least one antecedent of the analytical lens, and are presented in tables 1 and 2.

The three trustworthiness dimensions (ability, benevolence and integrity) were widely associated with positive trusting attitudes. Each of them was present in nearly half of the collected articles that included at least one trust antecedent included in the analytical lens. Considering that they were mostly mentioned spontaneously by the responders, their influence on trust appears to be fundamental. Propensity was also present, but much less frequently than trustworthiness. In total, of the 51 articles, only 13 have no mention of any of the above four antecedents in their results. Although it is not always clear whether the four constructs of the MDS model influence PHI sharing directly or through the mediation of trust, it is nevertheless evident that they play a significant role in the PHI-sharing process.

Antecedent	Count	References
Ability	21	Alaqra et al. (2018); Bosisio et al. (2021); Bussone et al. (2020); Carson et al. (2019); Damschroder et al. (2007); Darquy et al. (2016); **Esmaeilzadeh (2019a); **Esmaeilzadeh (2019b); Harle et al. (2018); Jones et al. (2020); Jones et al. (2017); Kerns et al. (2013); **Kettis-Lindblad et al. (2006); **Li et al. (2014); Mozersky et al. (2020); Papoutsi et al. (2015); **Platt et al. (2018);

		Shen, Sequeira et al. (2019); Spencer et al. (2016); Stablein et al. (2015); **Teixeira et al. (2011)
Benevolence	24	Bussone et al. (2020); Carson et al. (2019); Damschroder et al. (2007); Darquy et al. (2016); De Vries et al. (2019); **Esmaeilzadeh (2019a); Greenhalgh et al. (2008); Harle et al. (2018); Jones et al. (2020); Jones et al. (2017); Kerns et al. (2013); Lemke et al. (2010); **Li et al. (2014); Lysaght et al. (2020); Mählmann et al. (2018); McGuire et al. (2008); **Platt et al. (2018); Pratap et al. (2019); Shen, Sequeira et al. (2019); Slegers et al. (2015); Spencer et al. (2016); **Teixeira et al. (2011); Trinidad et al. (2010); Weng et al. (2019)
Integrity	22	**Abdelhamid (2018); Alaqra et al. (2018); Bosisio et al. (2021); Bussone et al. (2020); De Vries et al. (2019); **Esmaeilzadeh (2019a); **Esmaeilzadeh (2019b); Greenhalgh et al. (2008); Harle et al. (2018); Jamal et al. (2014); Lee et al. (2016); Lemke et al. (2010); **Li et al. (2014); Lor and Bowers (2018); Mählmann et al. (2018); Merson et al. (2015); Mozersky et al. (2020); **Platt and Kardia (2015); Pratap et al. (2019); Shen, Sequeira et al. (2019); Slegers et al. (2015); Trinidad et al. (2010)
Propensity	8	Bosisio et al. (2021); Jones et al. (2017); McGuire et al. (2008); **Mello et al. (2018); **Platt et al. (2018); **Platt and Kardia (2015); Shen, Sequeira et al. (2019); Spencer et al. (2016)

Table 1. Main antecedents from the MDS model (synthesis of articles' results)

****quantitative study**

Apart from those in the MDS model, the other antecedents of the analytical lens were also present in the collected literature results. Confidentiality was the most frequently mentioned antecedent by the responders, with more than two thirds of the articles including references to it. Time-related constructs were also identified, in the form of familiarity, relationship length, and frequency of contact. In most cases their influence on trust was significant and positive, but it rarely was of no significance (Weidman et al., 2019). Cultural influence on trust was also present in a significant portion of the collected literature, usually stemming from the norms or values of the responder's culture, or their minority status. Constructs pertaining to third-party influence were found mainly in the form of trust transfer and trust by proxy.

Antecedent	Count	References
Confidentiality	37	Alaqra et al. (2018); **Bearth and Siegrist (2020); Beskow and Dean (2008); Broes et al. (2020); Bussone et al. (2020); Carson et al. (2019); Damschroder et al. (2007); Darquy et al. (2016); **Dinev et al. (2016); Esmaeilzadeh (2019b); Grant et al. (2013); Harle et al. (2018); Hill et al. (2013); Jamal et al. (2014); Jones et al. (2020); Jones et al. (2017); Kerns et al. (2013); Lee et al. (2016); Lemke et al. (2010); Lucero et al. (2015); Lysaght et al. (2020); Mählmann et al. (2018); McGuire et al. (2008); Merson et al. (2015); Morin et al. (2005); Mozersky et al. (2020); Papoutsi et

		al. (2015); **Platt et al. (2018); **Platt and Kardia (2015); Pratap et al. (2019); shen, Sequeira et al. (2019); Skatova et al. (2019); Spencer et al. (2016); Stablein et al. (2015); Trinidad et al. (2010); Weng et al. (2019); Willison et al. (2009)
Time	19	Broes et al. (2020); Bussone et al. (2020); Carson et al. (2019); De Vries et al. (2019); **Esmaeilzadeh (2019b); Grant et al. (2013); Greenhalgh et al. (2008); **Herian et al. (2014); Jamal et al. (2014); Jones et al. (2020); Kerns et al. (2013); Lee et al. (2016); Lor and Bowers (2018); Mozersky et al. (2020); **Platt and Kardia (2015); Shen, Sequeira et al. (2019); Skatova et al. (2019); Stone et al. (2005); Willison et al. (2009)
Culture	7	Alaqra et al. (2018); **Dinev et al. (2016); Lee et al. (2016); Lor and Bowers (2018); **Middleton et al. (2020); **Platt et al. (2018); **Weidman et al. (2019)
Third-party influence	8	Alaqra et al. (2018); Bussone et al. (2020); **Esmaeilzadeh (2019a); Kerns et al. (2013); Lee et al. (2016); Lor and Bowers (2018); Skatova et al. (2019); Willison et al. (2009)

Table 2. Additional antecedents not part of the MDS model (synthesis of articles' results)

****quantitative study**

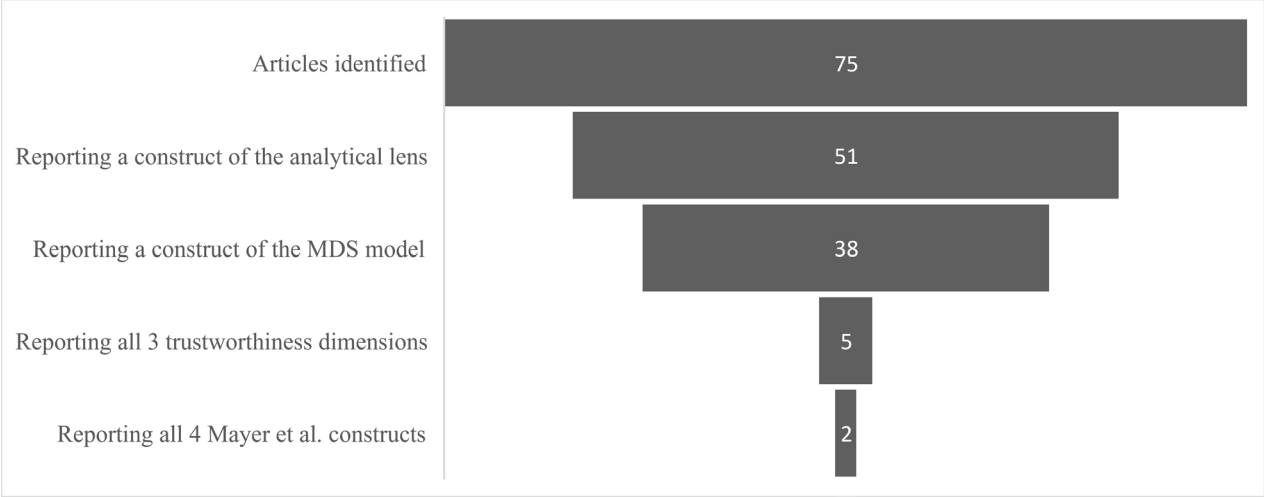

Figure 3. Represented antecedents in article results

From the synthesis of the literature findings (Figure 3) it is concluded that the general trust conceptualisations, especially the MDS model, are applicable in the context of PHI sharing, as most of the antecedents of the model were independently and frequently identified in the results of the literature. Furthermore, confidentiality and time-related constructs to a large extent, and culture and the influence of third parties to a lesser extent, were frequently found to affect trust.

4.3 The Use of the Antecedents Included in the Analytical Lens in Research Instruments

In total, 36 studies informed their measuring instruments (e.g. surveys) by using at least one of the antecedents of the analytical lens. Such occurrences were primarily noted in quantitative studies, and are presented in tables 3 and 4.

13 studies informed their research instruments based on at least one antecedent of the MDS model, either utilizing it as a dimension of trust or trustworthiness to create a trust construct, or operationalising it as a separate variable. Amongst them, seven took all three trustworthiness dimensions into consideration, and six used them to develop the studies' research instruments (Li et al., 2014; Platt et al., 2018; Platt & Kardia, 2015; Platt et al., 2019; Raj et al., 2020; Shen, Sequeira et al., 2019). It is noteworthy that three of those six studies were published by the same first author, who also contributed to a fourth one. Finally, only four studies included all four antecedents of trust in the MDS model (ability, benevolence, integrity, propensity), with three of them published by the same first author. This indicates that the already small number of references is inflated by the persistent work of a small group of researchers. The remaining identified antecedents show a similar relative frequency to the ones noted in the article results' synthesis (see sub-section 4.2). Specifically, confidentiality is represented most often, followed by culture and time, while third-party influence was identified only twice.

From the above, it becomes evident that there is a limited use of the MDS model. Additionally, in a significant portion of the studies, none of the analytical lens' antecedents were identified (Figure 4). While it is not to say that those studies used an uninformed or generic trust models, as a review with a different analytical lens could have identified other important antecedents, this low number is still surprising. Occasionally, an absence of a theoretically rich, multidimensional trust construct was reported by the authors as a limitation of their research (e.g., Abdelhamid et al., 2017; Serrano et al., 2016).

Antecedent	Count	References
Ability	9	Esmaeilzadeh (2019b); Kettis-Lindblad et al. (2006); Li et al. (2014); Platt et al. (2018); Platt & Kardia (2015); Platt et al. (2019); Raj et al. (2020); *Shen, Sequeira et al. (2019); Teixeira et al. (2011)
Benevolence	11	Beskow & Dean (2008); Esmaeilzadeh (2019a); Li et al. (2014); Overby et al. (2015); Platt et al. (2018); Platt & Kardia (2015); Platt et al. (2019); Raj et al. (2020); Serrano et al. (2016); *Shen, Sequeira et al. (2019); Teixeira et al. (2011)
Integrity	11	Abdelhamid (2018); Beskow & Dean (2008); Esmaeilzadeh (2019a, 2019b); Li et al. (2014); Overby et al. (2015); Platt et al. (2018); Platt & Kardia (2015); Platt et al. (2019); Raj et al. (2020); *Shen, Sequeira et al. (2019)
Propensity	5	Mello et al. (2018); Platt et al. (2018); Platt & Kardia (2015); Platt et al. (2019); *Shen, Sequeira et al. (2019)

Table 3. Main antecedents from the MDS model (synthesis of research instruments) *qualitative study

Antecedent	Count	References

Confidentiality	22	Abdelhamid (2018); Abdelhamid et al. (2017); Andrews et al. (2014); Bearth & Siegrist (2020); Buckley et al. (2011); Damschroder et al. (2007); Dhopeshwarkar et al. (2012); Dinev et al. (2016); Esmaeilzadeh (2019b); *Greenhalgh et al. (2008); Holm et al. (2020);Juga et al. (2021); Morin et al. (2005); Papoutsi et al. (2015); Platt & Kardia (2015); Pratap et al. (2019); Rho et al. (2015); *Shen, Sequeira et al. (2019); *Stone et al. (2005); Weng et al. (2019); Willison et al. (2009); Willison et al. (2008)
Time	5	Esmaeilzadeh (2019b); Herian et al. (2014); Holm et al. (2020); Platt & Kardia (2015); Weidman et al. (2019)
Culture	7	Lor and Bowers (2018); Middleton et al. (2020); Papoutsi et al. (2015); Platt et al. (2018); *Shen, Sequeira et al. (2019); *Slegers et al. (2015); Weidman et al. (2019)
Third-party influence	2	Esmaeilzadeh (2019a); Weidman et al. (2019)

Table 4. Additional antecedents not part of the MDS model (synthesis of research instruments)

*** qualitative study**

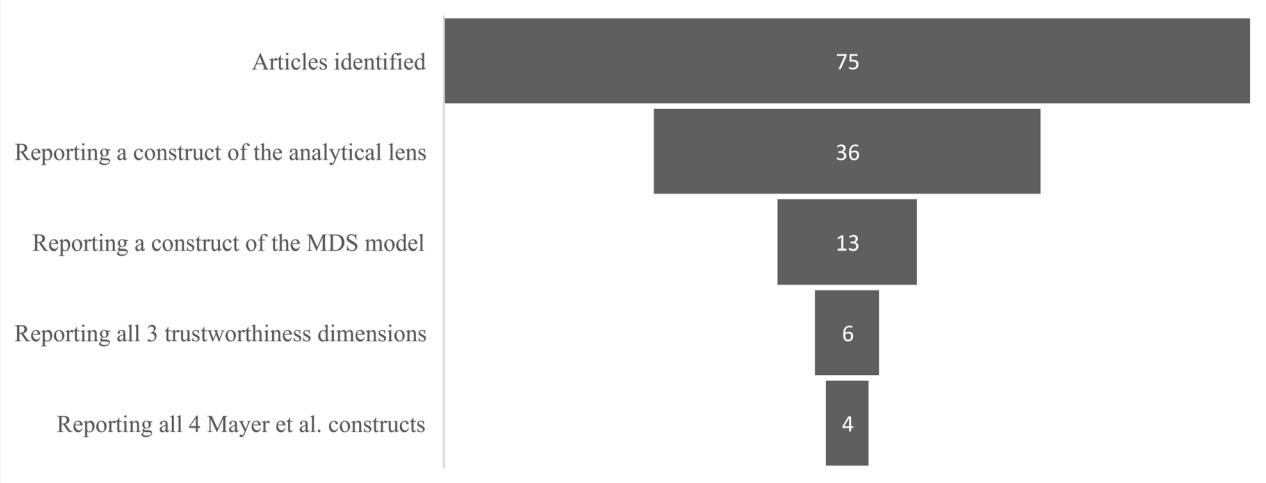

Figure 4. Represented antecedents in research instruments of articles

The results from the analyses of the relevance (4.2) and use (4.3) of the trust antecedents in the analytical lens clearly indicate a mismatch between relevance and use, as all studied antecedents were deemed to be relevant, but 39 of the reviewed empirical articles did not integrate any of them in their research instruments.

5. Discussion

The successful adoption and use of HIS necessitate the disclosure of PHI, which, in turn, is contingent on trust. Understanding trust and its antecedents is, therefore, paramount for researching and facilitating PHI sharing, and numerous empirical studies have investigated trust in that context. However, recent studies have accentuated a persistent need for research on the antecedents of trust (Taylor et al., 2023). This scoping review looked into the broad field

of PHI-sharing research in order to understand what influences trust when people are asked to share their PHI. Our results confirm the significant impact of the MDS model antecedents (ability, benevolence, integrity, propensity) on trust, while confidentiality, time, third-party influence, and culture are also found to be prominent. At the same time, it appears that many empirical studies involving trust have not fully integrated these antecedents into their applied research instruments. Our review offers novel theoretical insight into the relevant antecedents of trust in the context of PHI sharing. Based on our findings, we recommend future directions in HIS research, when trust and PHI sharing are involved. Moreover, we identify important practical implications of our work in HIS management.

5.1 Discussing the Results

With regard to the MDS model, the reviewed studies underlined the significance of ability, benevolence and integrity in building trust. The fact that these three antecedents usually emerged in an unprompted manner by interviewees or focus group participants reaffirms their relevance to trust in the context of PHI sharing. On the other hand, propensity was not identified as frequently. A possible explanation for this may lie in the nature of the construct. In contrast to trustworthiness, propensity focuses on the trustor instead of the trustee. Since the trustee was the main point of focus in most studies, the study of trustor characteristics could have been overshadowed, which is a common trend in trust research (Möllering, 2019).

Of the antecedents not included in the MDS model, confidentiality was the most commonly occurring one. However, the relationship of trust and trustworthiness with confidentiality was not always clear. Some studies conceptualised confidentiality as a precursor of trust (Esmaeilzadeh, 2019a), while others have studied the opposite direction (Dinev et al., 2016), with both finding significant relationships. A review by Shen, Bernier et al. (2019) explored a bidirectional relationship between the two constructs, and found evidence for both directions of influence, while an interview study by Shen, Sequeira et al. (2019) emphasised the same bidirectional relationship. This raises the question whether the construct of confidentiality is an antecedent of trust, a result of it, or a context within which trust operates, a question that has troubled IS researchers in the past (Smith et al., 2011).

Repeated interaction, long-lasting relationships, and familiarity were, in most cases, positively associated to trusting attitudes, aligning with past IS research (Cheng et al., 2016; Komiak & Benbasat, 2006). Being aware of the temporal influences on trust is essential to the understanding of its antecedents. Propensity, for example, has been theorised to be more

important in the beginning of a relationship, when there has not been enough time for the other antecedents to develop (McKnight et al., 1998). This can be relevant when researching trust in HIS, where the users' familiarity can be low, such as the with the use of AI and chatbots in healthcare.

The influence of culture on trust constituted a significant part of the literature results. A characteristic example is found in (Middleton et al., 2020) where the researchers accentuated the varying trust attitudes towards genomic data sharing across multiple countries. Similar findings were reported by (Dinev et al., 2016), regarding privacy concerns and trust towards Electronic Health Records between citizens in Italy and the USA. These findings reconcile extant IS research on the influence of culture on trust (Wu et al., 2012; Jenkner et al., 2022). For explaining such between-culture differences, one could consider the familiarity of the studied population with the technologies involved with PHI-sharing, or their propensity, which is partly based on culture (Schoorman et al., 2007). The influence of third parties was also observed to affect trust building. For example, trust in a charitable organisation (Bussone et al., 2020) or the government (Alaqra et al., 2018) was found to inspire trust in a HIS, discoveries which are in line with more recent research showing trust in the treating physician translating into trust in Health Information Exchanges (Busch-Casler & Radic, 2023).

Finally, our review reports on previous conceptualisations of trust's antecedents in empirical, PHI-sharing research. Despite the relevance of the antecedents included in our analytical lens, their inclusion in empirical research was inconsistent. The MDS model was not found to be widely replicated, and when its constructs were used, it was done so sparingly and incompletely. Moreover, any replications of it were usually conducted by the same authors. Looking at all antecedents of our analytical lens, confidentiality was the only one broadly present in the measuring instruments used in the included empirical studies. Thus, we see our suggested research directions as a step towards ameliorating this fragmentated conceptualisation of trust's antecedents in empirical PHI-sharing research.

5.2 An Improved Conceptualisation of Trust's Antecedents

A number of literature reviews have synthesised empirical findings in the context of PHI sharing, finding links between trust and the trustworthiness dimensions (Stockdale et al., 2018; Bull et al., 2015), confidentiality (Hutchings et al., 2020; Shen, Sequeira et al., 2019; Stockdale et al., 2018), familiarity (Hutchings et al., 2020; Aitken et al., 2016) and the influence of third parties (Bull et al., 2015). Nevertheless, we are not aware of past reviews that have sought to

construct a conceptual map of trust's antecedents based on a deductive analysis of empirical research, or that have encompassed a broad range of secondary uses of PHI. With the present review we aim at providing the basis for a more complete and meaningful study of trust in HIS research involving PHI-sharing, while also highlighting some practical implications of our findings.

In terms of contributing to theory, based on the synthesis of the collected literature, we argue that the MDS model remains relevant in the studied context, justifying its application in future HIS studies that involve PHI-sharing. In addition, the synthesis of other trust antecedents is a step towards a more cohesive model of trust in the context of PHI sharing, with increased content validity. The frequent and usually unprompted mentioning of constructs such as confidentiality and familiarity suggests that they are naturally relevant, while the cultural context and the influence of third parties are important factors to be considered, and measuring trust without taking them into account might result in incomplete and context-blind models. We, therefore, suggest that future HIS studies incorporate those constructs when researching trust (Figure 2). Apart from an improvement in the understanding of trust in a PHI context, a summation of our suggested antecedents into a trust model can streamline future studies through the standardisation of the research instruments. This could not only make comparisons between studies more efficient, but more meaningful as well (McEvily & Tortoriello, 2011).

From a practical perspective, a richer understanding of trust in the context of HIS and the sharing of PHI that those systems necessitate, can contribute towards substantial improvements in HIS management, for example in relation to public acceptance of new technologies in healthcare. The collection of PHI is burdened by concerns regarding privacy and trust, referred to as the "dark side" of IS (Aaen et al., 2022). Research and reality have jointly shown trust to be necessary in acquiring a social license, a de facto public approval to collect PHI, which is vital for the success of large-scale PHI initiatives (Carter et al., 2015). Our review highlights where possible points of trust failure may lie. By understanding the antecedents of trust, the trustors' concerns can be addressed more clearly and data collection can be carried out more effectively, when the responsible entities navigate in ways that are aligned with the trustors' volitions, insecurities, or objections. Consequently, we believe that our recommendations can be utilised in lowering the barriers of distrust, and contribute towards a more widespread acceptance and adoption of HIS, thus realising the potential of HIS in addressing the challenges facing healthcare.

5.3 Limitations

The main limitation of this study lies in the selection of literature that formed the core of the analytical lens. Although the additional constructs that formed the analytical lens provided some necessary recency and contextual relevance, the MDS model brought a somewhat dated perspective, which originated in a different literature discipline than that of the majority of the reviewed articles. Moreover, there is an absence of emotional factors in the MDS model, as its authors note in their revisiting of the original paper (Schoorman et al., 2007). Indeed, the importance of emotion or affect in trust has been noted in medical (Hall et al., 2001) and information-sharing contexts (Tomlinson et.al., 2020). Finally, articles studying PHI sharing for primary use (i.e., for treating the patient sharing the information), or the opinions of minors, were excluded from this literature review, further limiting the generalisability of our results.

5.4 Future Research

As with any conceptual suggestion, research that collects the highlighted antecedents into a model and empirically validates it is of great interest. At the same time, those same constructs could benefit from further exploration. Despite the prominent role of confidentiality and privacy in PHI sharing, their relationship with trust remains nebulous. To that end, supplementary research capable of causal inference could be particularly valuable, especially when combined with recent conceptualisations of perceived privacy risks (Karwatzki et al., 2022) and privacy concerns (Bansal & Nah, 2022) in IS research. Regarding third-party influence, there is a paucity of empirical, PHI-sharing research, despite the rich theoretical background. Future research can study trust transfer in HIS, in particular how trust can be transferred from a trusted party (e.g., the family doctor) to a new and unfamiliar information technology (e.g., AI-aided diagnostic tools) that requires the patient's PHI. Lastly, a perspective which includes both cognitive and emotional dimensions of trust presents a promising research avenue. Suggested areas include the influence of temporal factors, such as relationship length, on trust, especially since affect-based trust is thought to be very closely linked to the relationship between the trusting parties (van Knippenberg, 2018).

6. Conclusion

Trust is necessary for the adoption and use of HIS. While the MDS conceptualisation is widely represented in the empirical findings of the published PHI-sharing research, most of the reviewed empirical studies are not sufficiently founded on it, with the conceptualisation of trust's antecedents being fragmented and inconsistent. Based on the findings of this scoping review, PHI-relevant directions for studying trust are proposed, incorporating confidentiality,

trust transfer, as well as time-related and cultural factors into the MDS model. These suggested pathways can offer a better conceptualisation of trust's antecedents when conducting HIS studies that concern the sharing of PHI.

Declaration of interests

The authors have no conflict of interest to declare.

Availability of data and materials

The datasets used and analysed for the review are available from the corresponding author upon reasonable request.

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Appendix A

Search terms used for the three databases and articles found.

Database	Scopus	Web of Science	Pubmed
Search terms	(TITLE-ABS-KEY ((data OR information OR record*) W/4 (shar* OR link* OR mining OR disclos* OR reus*)) AND TITLE-ABS-KEY ((health* OR medical OR clinical OR patient) W/4 (record* OR data OR information)) AND TITLE-ABS-KEY (willing* OR intent* OR 27ttituded* OR accept* OR view* OR opinion* OR perspective*) AND TITLE-ABS-KEY (empiric* OR sampl* OR survey* OR qualitat* OR quantita* OR interview* OR longitudinal OR “"case stud”" OR “"cross-sectiona”" OR “"focus group”") AND TITLE-ABS-KEY (*trust*))	((data OR information OR record*) NEAR/4 (shar* OR link* OR mining OR disclos* OR reus*)) AND TOPIC: ((health* OR medical OR clinical OR patient) NEAR/4 (record* OR data OR information)) AND TOPIC: (willing* OR intent* OR27ttituded* OR accept* OR view* OR opinion* OR perspective*) AND TOPIC: (*trust*) AND TOPIC: (empiric* OR sampl* OR survey* OR qualitat* OR quantita* OR interview* OR longitudinal OR“"case stud”" OR“"cross-sectiona”" OR“"focus group”"). Timespan: All years. Indexes: SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI	“"health informatio”" OR“"health dat”" OR“"clinical dat”" OR“"clinical informatio”" OR“"medical record”" OR“"clinical record”" OR“"data sharin”" OR“"patient informatio”" OR“"patient record”") AND (shar* OR disclos* OR link* OR reus*) AND (willing* OR intent* OR27ttituded* OR accept* OR view* OR opinion* OR perspective*) AND (empiric* OR sampl* OR survey* OR qualitat* OR quantita* OR interview* OR longitudinal OR“"case stud”" OR“"cross-sectiona”" OR“"focus group”") AND *trust*
# Articles found	366	236	379

Note: TITLE-ABS-KEY searches the terms in the title, abstract, or keywords of each article. The NEAR/ and W/ are adjacency operators, and the number notes how many words are allowed between the two terms or sets of terms. Asterisks include all truncations of a word and quotation marks require the quoted terms to be found verbatim. For Web of Science, the indexes refer to the searched sub-databases.

Appendix B

Coding scheme of the constructs of the analytical lens, with corresponding examples found in the reviewed articles.

Code	Subcode	Example
Ability	Having expertise/Possessing the necessary knowledge/Having had sufficient training	"I trust that they [NHS] have those skills to keep it anonymized" (Spencer et al., 2016)
	Being generally competent	"[…] you trust people not to be careless in terms of entering information, in terms of leaving perhaps your records on a screen just for other people to look at […]" (Stablein et al., 2015)
Benevolence	Having the trustor's best interest at heart	"It's not [as] if they're up to jack [rob] you or nothing" (Greenhalgh et al., 2008)
	Not primarily seeking profit	"The idea that many fertility clinics are businesses, with financial motivations, negatively impacted on the trust that patients felt" (Carson et al., 2019)
Integrity	Telling the truth	"[…] sometimes they confuse you, and there are many interpreters that sometimes don't tell you the truth […]" (Lee et al., 2016)
	Not withholding information	"some participants discussed that it is important to provide complete disclosure about genetic research to reduce fears and build trust" (Lemke et al., 2010)
	Adhering to morals important to the trustor	"[…] if I had like a tumor removed and they were using it for a biobank for further research and they're using it to do this sort of stuff, it's just against my religion" (De Vries et al., 2019)
Propensity	General trust towards other people	"In particular since we live in a country where things work pretty well, where there is no problem in that respect" (Bosisio et al., 2021)
Confidentiality	Keeping information protected	"I trust them that it wouldn't get out of hand. So I feel pretty comfortable. I feel pretty comfortable and because I think it would be safe kept." (Jones et al., 2017)
	Privacy concerns	"[…] reassurance…it would just be few hands and eyes … so i''s not being passed around" (Grant et al., 2013)
Time	Frequency of contact/ Relationship length/ Familiarity/Experience	"[T]he head pharmacist, h''s been working with me for the last like 25, 30 years and I always refer him to the pharmacist at whatever hospital ''m at […]" (Shen, Sequeira et al., 2019)

Culture	Differences between cultures	"The ''Your DNA, Your Say'' project is a very large social sciences study conducted on global public attitudes toward genomic data sharing. […] The results show patterns of both consistency and diversity across the globe." (Middleton et al., 2020)
	Differences by minority status	"[…] ethnicity (except for Caucasian) is shown to be a significant influence on most measured dependents" (Weidman et al., 2019)
Third-party influence	Trust transfer/Trust by proxy	"[…] many indicated they would trust the governmental authorities and branding of such would be a factor for trusting the system" (Alaqra et al., 2018)