

## Mediator – enabler for successful digital health care

Janne Lahtiranta Ph.D.

Department of Entrepreneurship and Management, University of Turku, Finland

**Janne Lahtiranta, Department of Entrepreneurship and Management, University of Turku, FINLAND. Email: [janne.lahtiranta@it.utu.fi](mailto:janne.lahtiranta@it.utu.fi)**

### Abstract

It is no news that as in any other field of industry, digitalization is changing health care. This change is ongoing and profound as it affects every aspect imaginable; from provisioning to funding, and from roles to responsibilities. The magnitude of this change is such that some label it as the ‘health care revolution’. Not all individuals are ready for this ‘revolution’. Some rebel against it while others are simply not able to cope with it. Regardless of the underlying reason, it can be estimated that in the near future, roughly 10 % of the population in the OECD countries will drift outside the reach of the modern electronic health care services. These individuals, the digital orphan, need to be brought back in order to prevent the future of health care from becoming more marginalized and discriminatory than it is today. Mediators, individuals in the crux of health care and technology, are one way to prevent this unwelcome eventuality from coming true. In the following, the focus of examination is on the mediators and mediation. The role of a mediator is critically examined from different perspectives, and a framework for mediation is presented.

**Keywords:** delivery of health care, healthcare systems, digital divide

### Introduction

It is a commonly accepted view that the field of health care is changing due to economic and societal drivers. One of the key drivers is the ageing societies [1], that has a major economic impact on the funding (especially in the countries with tax-based financing for health systems), and on demand (changes in population size, age, race and ethnicity). On societal side, one of the most notable outcomes of this change is the re-delegation of care. Instead of placing health care professional ‘in charge’, responsibilities related to one’s care are gradually shifted in the hands of the patient (or one’s relative).

This re-delegation is particularly visible if we look into the patient-physician relationship that has changed during the last 20 years – and still is. The so-called paternalistic (or traditional) model was a prevalent one until the turn of the millennium. Now, other models [2] such as the partnership and autonomous models are gaining traction. One reason for this are the changes in the patient attitudes. Similarly to other fields of industry, patients (especially in private and occupational health care) expect to get the service on their terms – particularly when it comes to time and place. From the service provider side, another reason emerges from responsiveness as health service providers around the

world strive to make their health systems more effective [3].

A key enabler in this change is technology. Electronic health services coupled with different devices, such as activity trackers and smart body analyzers, alter the geographical and spatial dimensions of health care. In practice, the technology of today already extends the 'reach' of health care, from traditional confines of the service provider to homes and hobbies, and from (doctor's) appointment to everyday life. In this, the health care is becoming ubiquitous and transparent; properties envisioned for the ICT already in the 90s.

This development that is still ongoing, has some drawbacks that need to be addressed before the electronic services become primary (if not even only) way of conducting affairs in the field. The banking sector is already ahead of the curve when compared to the health care, as electronic service have already become the norm in the OECD countries [4,5]. The problem is that, in the core of the health service delivery has always been the patient whose preferences are a priority (for example in relation to consent). The advance of electronic services in the field of health care is rapidly challenging this setting as face-to-face services are being gradually replaced by their electronic counterparts, such as the self-care and digital value services currently developed in Finland [6]. In this kind of situation, the health care decision makers must ask themselves how the patients who prefer the 'old way' – or are simply unable to use the electronic services – can be reached. Unless this question is answered soon, we face a very real threat of placing a heterogeneous group of people into the 'fringe' of modern health care.

### Research setting

This paper is based on the findings of two national projects in Finland. The first one, MyWellbeing (2008-2010) focused on implementing a tool for citizen-centric health care service. In the project a concept for a Personal Health Record (PHR) that could be used for managing personal health services, and related information, was defined. Parts of the concept were tested in the

second project, Coper-pilot (2011-2014) as part of developing new electronic services for cardiac patients in the city of Turku, Finland. This paper is a revisit to the findings as it seeks an answer to concerns of the cardiac patients who took part in the development of the new services (34 patients, of the age 47-81 years). During the Coper-pilot, some of the patients brought up a dilemma that is in the core of this paper: "how can I use these [new electronic] services if I don't use computers?" While this question is abstract and even a vague one, it opens up a discussion on motivation, skills, and capabilities. What is needed if one or more of these is missing and still the individuals are expected to use the technology? This is the starting point of this paper that bases on empirical research and available literature, and builds up a case that may hold an answer to a problem that is current today.

### The digital orphans

Especially in popular media and entertainment, digital orphan has a variety of definitions. For example, Alan Brough, a radio host and a comedian based in Australia defines a digital orphan as "a child whose parents are so obsessed with their smartphones that they have completely forgotten that they have a child" [7]. Another definition is provided by Philippe Aigrain who discusses in his blog about individuals who have grown into the digital world of today, while their parents and teachers have been largely absent from it [8]. While both of these definitions have merit, an alternative definition that is more befitting to the field of health care, can be formulated.

In health care, "orphan" is a widely applied concept. The concept is applied to terms such as orphan diseases (conditions that affect only a small percentage of population) and orphan drugs (pharmaceutical agents that are developed to treat orphan diseases). The concept is also applied to patients – orphan patients. These are patients without the Most Responsible Physician (MRP), a practitioner who is most responsible for the in-hospital care of the particular patient [9]. If we apply the concept of orphan patient to the digital world of

today, and to health services that are turning digital, we can make the following definition.

### **Digital orphan**

*“An individual who is unable, or unwilling, to use electronic services or devices in relation to one’s health or wellbeing.”*

While this definition is a broad one, it addresses the changing field of health care on two levels. One, the primary actor is an individual, not a patient. This signifies that the electronic services are not necessarily related to a specific condition or care, but may be preventive by nature (for example, a periodical digital health checkup). The take on the nature of the services is further underlined in the definition, as health is coupled with wellbeing. In this the definition covers services – even condition-specific applications – that are uncommonly related to the services provided by health care organizations of today.

Two, a digital orphan is regarded as an individual who may not be able to use services or devices, or is simply unwilling to do so. In this, the element of choice is present as competence and capabilities are not only limiting factors. This broadens the definition beyond time; even if at some point in the future technology becomes “technology for all” in terms of skills and ease of use, digital orphans may still exist. The definition for a digital orphan is also bi-directional. While individual’s skills and attitudes play a major role, the definition also implies that services related to health and wellbeing can be mediated by technology. In this, emerging trends such as digital doctors and use of Artificial Intelligence (AI) are taken into account.

In order to estimate how many people are in the risk of becoming these kinds of digital orphans, pariahs of the modern times, we need to look into the current trends and statistics.

In Finland, the public media has recently brought up problems related to the Internet use by the elderly. In the news [10], the current estimate on the internet illiterate (i.e. people who do not use internet enough in

order to gain and maintain a degree of competence) is 28 % of the population. In other words, more than every fourth person in Finland today is in a risk of becoming a digital orphan. Considering the country’s reputation as an advanced country in terms of use technology, the number is high. Understandably, the number is higher in the older age groups (31 % of people over 75 years), but interestingly the age of division is 44. In Finland, nearly 100 % percent of the people under 44 years use the Internet [10]. Still, those older than that will be using health services that are turning digital for a long time.

On a wider scale in the OECD countries, 82 % of individuals between 16-74 years used the Internet in 2015. Use of the Internet has rose sharply over the last decade. In 2006 only 60 % of the adult population used the Internet. In Iceland, Norway, Denmark and Luxembourg over 95 % of the adult population nowadays uses the Internet, while in Turkey and Mexico roughly half of the adult population uses the Internet. As in the case of Finland above, there are wide differences for older generations. More than 80 % of seniors (65-74 years) use Internet in Denmark, Iceland, Luxembourg and Norway, while less than 10 % use Internet in Mexico and Turkey. All in all, 81.6 % of people in the OECD countries use the Internet, 66.9 % use daily, and 50 % use the Internet via mobile or smartphone. [11]

If we look deeper into the technology infrastructures, namely into broadband communications, we can see the following developments. The fixed broadband penetration rate in the OECD countries has increased to 29.05 % (Q4/2015) from 12.76 % (Q4/2005). Wireless broadband penetration rate has increased to 90.32 % (Q4/2015) from 32.31 % (Q4/2009). As a related indicator, the percentage of households with computer at home has increased to 77.2 % (2012) in the OECD countries from 45.7 % (2000). [12]

Interestingly, if we look into the discussed indicators, or to other ones related to the use or acquisition of data, we can make one generalization. While the amount of ‘high-tiered’ countries in terms of penetration rate (90 % or more) is increasing, the development amongst these countries slows down (even regresses). For ex-

ample, in the case of Luxembourg, the penetration rate of Internet access has increased only 2.3 %-points over the last years (2013-2015). In the case of Denmark, the rate has decreased 1.4 %-points during 2014-2015. While there is one exception, Norway where the rate has increased 3.5 %-points during 2014-2015, the general trend is that the development slows down. Other key indicator in this area, access to computers from home, shows similar developments. [12]

On the basis of this analysis, a hypothesis can be made. In the near future (5-10 years), approximately 10 % of the population in the OECD countries is in a risk of falling into the fringe of modern health care as they are not able or willing to use the related technology. While this is just a hypothesis with a wide margin of error, the numbers are still significant. In Finland alone, where the population is approximately 5.5 million (November, 2016), there are more than half a million individuals who are in a risk of becoming digital orphans.

If this risk is fulfilled – even only to a degree – it will not only degrade the function of health ecosystems that are maturing and turning digital, it will also prevent them from functioning in a sustainable fashion after digitalization. It follows from the nature of the problem, that the answer to it is not solely technological as the technology is a fundamental part of it, but of a more complex nature. One possible solution for it is the use of a mediator [13], an intermediary in the crux of health care and technology.

In the following, the forward-looking examination starts with the current intermediary roles in the field of health care. These roles, that are a fundamental part of today's health service landscape, are analyzed using a framework that originates from the field of innovation studies. Later on, a new intermediary role is depicted, and its particulars are discussed in detail. While the examination is primarily a conceptual elaboration, the fundamentals of the investigation are heavily linked into practice. It follows from this, that the result – the new intermediary role – has universal applicability in the field of health care that is turning digital.

## Intermediaries

Intermediaries are not a novel concept. There have been different intermediaries, or 'go-betweens', in the field of health care for a long time. Patient advocates [14] and case managers [15] are prime examples of this role. Even the role of a practical nurse working in home care is intermediary by nature as the work often involves interpreting health-related information to the patient, and helping in making health-related decisions (in everyday life and otherwise). The intermediaries in the field of health care are often 'jobs within jobs'; duties of a particular profession. As such, the intermediary operates within the limits (rules, regulations, etc.) set by the service provider. Individuals working in these kinds of roles can be regarded as provider-side intermediaries.

When it comes to more informal intermediaries who operate on the patient-side, the relatives often take up the task. In practice, this often means that the spouse of an elderly patient acts in the role of a case manager, organizing health-related practicalities, and ensuring that the opinion of the actual beneficiary is respected. Even though it is common that individuals operating in this kind of a role become experts in the health-related matters of the beneficiary (cf. [16]), they rarely have the competence to in making formal and long-term health-related decisions [17], such as detailing a plan of care at home. In general, this lack of competence originates from the missing training in the field; aspects that give professionals competence in handling a variety of conditions and ailments.

Mediators [13] are patient-side intermediaries who bridge the gap between the beneficiary and service provisioning. In other words, between the actual patient and the overall health care delivery (irrespective of the provider organization). Unlike in the case of intermediaries in general, the emphasis on technology expands the role. In addition to health-related affairs, a mediator focuses on the use of technology in the health service delivery. They act as 'conduits' for technology and underlying services. As such, the role is in practice, a hybrid between those of a nurse and a technical support.

A real-world example on the need of a mediator arises from the Electronic Health Records (EHRs) and Hospital Information Systems (HISs). These information systems are essential tools for health service delivery and collaboration between a variety of actors, including health and social service providers, and patients [18]. From the health service provider-side, these systems contain functions relevant for day-to-day clinical work, such as patient particulars, medication, and results from laboratory tests. From the patient-side, the functions are often limited to accessing patient record, and managing consent and authorities. However, as the recent developments in the field show [6], and the EU Digital Agenda states [19], the goal is set further than accessing to patient records.

In recent years, we have started to see solutions that live up to the Digital Agenda [19] – not just in terms of technology, but also patient engagement. These solutions, such as the ones used by the Mayo Clinic (U.S.), expand the reach of traditional health care to everyday lives of the patients in the form of mobile health applications (cf. [20]). As these kinds of allegiances are becoming more and more common, not just between the patient and the provider but also between the employee and employer, the health care becomes intertwined with aspects of well-being and fitness. In this multiform and complex domain that no longer covers aspects related to the traditional health care, a need for a mediator becomes critical.

Today, not in some unforeseeable future, there are individuals who need someone to help them to bridge the gap between them, the new and emerging technologies, and the new ways of health service delivery. In the basest form, this need is realized as a need to fill in a form that is online and not on paper anymore, or as a need to understand what the jargon-filled health records (or cryptic messages from an electronic service) actually stand for. Tomorrow, these same individuals may need help in conducting online health checkups in virtual clinics [6], or in uploading health-related information from applications they are expected to use in managing a disease, such as diabetes or epilepsy.

## A framework for mediation

Dividing intermediary roles into provider and patient sides is often enough. This division acts as a simple way of conveying the practicalities of the role, such as a) for whom the intermediary actually works, b) what kind of laws and regulations are in effect, and c) what we can expect from the role (in terms of expertise and availability). However, if we delve into intricacies of the role and responsibilities, and consider how different intermediary roles align with each other, a more specific framework is needed.

One way to categorize intermediary roles, and in this case mediation, is to look into activities of an intermediary; what is one's alignment in relation to the target of mediation, what one does and for whom. In the field of innovation studies, Howells [21] has examined different innovation roles categorizing them into organizational roles, and activity roles. In the work [21], functions of an innovation intermediary are divided into 10 categories, ranging from “foresight and diagnostics” to “evaluation of outcomes”. In a more recent work, Stewart and Hyysalo [22] use a simpler three-tiered category that can be applied to a wider range of intermediary activities, including those in the field of health care.

In the framework [22] three categories are presented: a) facilitating, b) configuring, and c) brokering. Summarizing these, facilitating is about providing opportunities to others. The category includes activities such as education, influencing regulations, setting rules, and organizing resources. Configuring refers to technological configuring, but more importantly, it also has a symbolical meaning. Configuring refers to creating a space that facilitates appropriation, such as a cybercafé, influencing individual's goals and perceptions. Lastly, brokering [22] is basically about ‘deal-making’, and can be seen as the most direct way of interaction between different actors. In the field of product development, brokering activities are present when intermediaries set themselves up to support appropriation process, for example when requirements for a new product are discussed, or when a new actor is introduced to a project.

This three-tiered approach [22] fits well to the field of health care. It can be used for analyzing activities of current intermediary roles, and for understanding what kind of activities are missing. For example, a case manager [15] typically coordinates services on behalf of the beneficiary. These activities fall into the category of brokering. As material side is often present as well in the form of medical aids, medication or nursing supplies, case manager tasks are also related to facilitation. Similarly, if a case manager provides instructions to the beneficiary, for example in relation to reimbursement of services, facilitation is also present.

There is one particular category of activities that has not received sufficient attention in the field of health care; configuring. When it comes to electronic health care services, or to different health apps and devices, the users are often on their own. In most cases, they have online instructions and support forums at their disposal – services that require technological proves from the users. As the field of health care is changing, and digitalization affects all aspects of care, configuration is not just about ‘gadgetry’ but about patient engagement and appropriation.

From the perspective of an individual, the health care landscape is turning digital and changing into a ‘health space’ [23] where information, services and devices converge. The ‘space’ is not static, it shifts and changes according to the individual’s current situation and prevalent needs. From this point of view, health care is turning personalized as the primary actor and decision maker is the individual. In order to successfully ‘navigate’ in this space – to conduct health-related affairs – configuring is needed.

Personalized health care is a more complex issue than tailoring services and care according to personal needs and preferences; it is also about shifting duties and responsibilities. In exchange for certain degree of freedom that electronic services can give, the individuals are also expected to carry more responsibilities. Virtual health checkups, online anamnesis, and health diaries are another side of the same coin. From the service provider’s side, patients are seen as (virtual) coopera-

tive partners in the matters of their health (and in some cases, that of their relatives).

These kinds of services are fundamentally patient-side services. In order to understand how different intermediary roles align, position and reach of a role need to be understood. In the field of development and appropriation of new technologies, Stewart and Hyysalo [22] analyze different intermediaries on the basis of how they align between supply and use. For example, if an intermediary operates solely on the supply-side with a specific technology, the alignment can be regarded as ‘thin and short’. On the other hand, if an intermediary operates throughout the field, from supply to use, but with limited context, the alignment can be ‘thin and long’.

In health care, intermediaries operate primarily on the provider-side. Depending on their duties, their alignment in terms of ‘length’ and ‘width’ varies. For example, a nurse advocate [14] who liaises between patients and physicians who treat them, the alignment is typically a short and thin. In comparison, alignment of a case manager [15] is typically ‘wider’ and ‘longer’ one as the covered issues are often related to everyday life at home. Regardless of the alignment, both roles reside on the provider-side. As health services, and related legislation, varies from country to country [24] there is no universal alignment for intermediary roles in health care, and what the actual coverage is may differ.

Informal intermediaries, such as relatives who provide non-medical custodial care, often have a short reach but their alignment is a wide one. Reasons for this are rooted in national legislation and regulations where boundaries for acting on behalf of another person are defined (cf. [25]). Another factor that limits the reach of an informal intermediary is the power imbalance that is often present in the patient-physician relationship [26]. Even though the relationship has changed over the years and still is, there are barriers that prevent the relationship from evolving in a more rapid pace. Reception hours, care guidelines and practices, even the facilities (i.e. hospitals and health centers) uphold the ‘traditional’ views to the relationship [26]. In this kind of a situation, it is challenging to act as a patient-side inter-

mediary with a 'long' reach. Culture, ways of working, and established set of attitudes held by individuals in different roles, will be amongst the primary barriers to overcome in establishing working patient-side intermediary roles.

### Skills and abilities

Role of a mediator is related to two fields; health care and technology. In terms of health care, the mediators are required to possess a degree of skills and capabilities relevant to the domain. These include skills in medicine and pharmaceuticals, and competence in medical jargon. In the core of the role is supporting personal health decision making (of the beneficiary), and the mediator is expected to possess social acumen as well. It follows from this formulation that a mediator should be able to give advice and answer questions related to the beneficiary's health, and to be able to operate with discretion in circumstances that can be emotionally charged. However, as the field of health care and electronic health services in particular, are expanding to adjacent fields and market segments (such as fitness), the ideal set of skills and abilities of a mediator depend on the needs of the beneficiary.

Regardless of the potential diversity of skills and abilities, there is one required field of skills that is less subject for variation; literacy skills. Of these, health and ehealth literacy skills are of the essence for a mediator regardless of the particular needs of a beneficiary. In the literature, these skills are defined as follows:

#### Health literacy

*"The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."* [27]

#### eHealth Literacy

*"The use of emerging information and communications technology to improve or enable health and health care."* [28]

*"The ability to seek, find, understand and appraise health information from electronic sources and apply knowledge gained to addressing or solving a health problem."* [29]

Looking into these definitions gives a glance to the problems of electronic health services, and other online health resources, such as health information libraries. These resources are of little use if the individuals are not able to use them. In this context, use refers to technological use of media and modality, and to non-technological use. In the latter interpretation, use is about understanding relevance, quality and trustworthiness of the resources (in other words, about literacy).

Through application, health and ehealth literacy skills become intertwined with the concept of empowerment. Regardless of its elusive nature [30], the concept depicts well current developments in the field of health care. The empowered patients are ones who refuse to be in a passive role in health care delivery. Instead, they strive to become more active, taking the matters of health into their own hands. In terms of this mostly welcome change, mediators should be seen as enablers for those individuals who are willing to become more active, but regard technology and digitalization as a barrier that prevents them from achieving their personal aspirations.

### Technology and mediation

Technology has a polarized role in mediation; it is in the core of the problem, but also a part of the solution as well. As a problem, technology creates a barrier between the digital orphan and the electronic health care services. As a solution, technology enables mediation and supports mediator in acting one's role. In the following, some examples are provided.

#### Understanding

In mediation, understanding health-related information and conveying its relevance to the patient is of the essence. In today's health records, understanding does

not come easily. Even though some parts of the patient records are coded and classified using domain standards such as CDA, LOINC and SNOMED, some are in the form of free-form text. These clinical narratives contain essential information about the care of the patient. For example, the narratives often depict in detail what concerned the clinician at the time of care, and provide an accurate description on the events that occurred to the patient prior to the encounter with a clinician.

A problem with clinical narratives is that they are often riddled with domain-specific jargon and abbreviations. Some of these have established ground in the field of care, but others are more related to the practices of the provider unit. A practical example of this is noradrenaline that can be abbreviated as NA, NAd or norad (cf. [31]). In addition, clinical narratives often contain simple spelling mistakes [31]. These factors alone degrade the quality of the clinical narratives. Another factor that needs to be addressed in relation to the use of narratives, is the cross-border health care (primarily EU Directive 2011/24/EU) and health tourism in general, which are both diversifying the sources of health information.

Regardless of the source or language, mediators must be able to understand clinical narratives, and patient records as a whole. In this natural language processing and information extraction technologies can provide a partial answer in the form of proofing, correcting and translating the free-form text. These kinds of tools are already used, for example, in the case of Bulgarian diabetic patients [32]. Language technologies can also be used in mapping coded data into plain text for easier use, and for combining coded and free-form narratives for the purposes of risk analysis and adjustment.

Another method for conducting risk analysis and adjustment emerges from decision support aids, such as the EBMeDS currently put into use in Finland as a part of wider development of personal electronic health care services [6]. These kinds of decision support tools and computerized scripts, can be used by a mediator in formulating a care plan, performing a virtual health checkup on behalf of the beneficiary, or simply in forming an opinion to be presented to the beneficiary. Espe-

cially now as sources of health information are becoming more numerous, decision support systems that aggregate information originating from a wide range of information systems and other sources (such as personal devices), are becoming a vital tool in health care decision making.

### ***Security and privacy***

Especially in today's wired world, security and privacy are complicated issues. In order to use a specific application or service, there is a possibility that personal information must be accessed and distributed. This is particularly true when modern mobile applications are used (cf. [33]). When it comes to personal information, the most sensitive information is often related to one's health and wealth. In practice, this translates into one's financial details, such as transactions, and medical records. Protecting this kind of information and at the same time enabling its safe use by trusted parties is akin to balancing on a razor's edge.

Focusing purely on technological aspects and ignoring the primarily ethical and legislative ones such as those related to consent and trusteeship, granting and controlling access to health-related information is not a simple matter. Even though the mediator should have access to personal information of the beneficiary, the access should not be universal or permanent. Still, some basic health-related information is typically needed by the mediator (such as, if the beneficiary has a chronic disease, and what is the current medication). This kind of information can also be characterized as critical; should the information be inaccurate (for example, outdated medication list), the consequences can be harmful for the beneficiary.

What kind of information the mediator needs depends on the specific tasks and duties of the mediator. In order to ensure that the mediator has access to the most relevant information, an age-old principle of information encapsulation could be used [13,34]. In the context of this paper, information encapsulation refers to information aggregates that a) contain a specific set of information (such as current medication or physio-



therapy instructions, and b) are controlled by the beneficiary in terms of use and access (for example, access is granted to a particular mediator for a limited time).

The aggregates may contain sensitive information, and the beneficiary who is a digital orphan, does not possess skills or abilities for protecting them. This implies that alternative methods and guiding rules, or maxims, are needed. The first maxim is that the aggregates are the property of the beneficiary who governs their use (within the limit of one's capabilities). This kind of mastery over information, or *Datenherrschaft* as Koskinen defines it [35], should be regarded as an uncontested right that defines who and where personal information can be (re)used. In this, the second maxim comes into effect; the aggregates should follow the principles of fair and open information management, as defined by the Markle Foundation [36].

A subset of these principles, namely a) openness and transparency, b) purpose specification, c) collection limitation and data minimization, d) use limitation, and e) individual participation and control [36], are of particular interest as they effectively set the ground for information use by a mediator. The first principle, openness and transparency is primarily about awareness. The beneficiaries should be able to know what information is collected about them, what the purpose of the collection is, who can access it, and where the information resides.

The second principle, purpose specification is more instance-specific; the beneficiaries should know why information is collected in the first place, and on each occasion of change of purpose. Principles of collection limitation and data minimization are tightly coupled with the purpose, as they set boundaries to information collection – information should be collected only for the specified purposes in a lawful manner, and personal data should not be disclosed or otherwise used, outside these purposes. [36]

The discussed principles defined by the Markle Foundation [36] are about awareness, participation and control, and as such, they are effectively about mastering information as Koskinen sees it [35]. The beneficiary

should know what kind of information is available for mediation, and they should know where, when and by whom it is used. Conveying this information in an understandable way to a digital orphan, requires literacy skills and social acumen from the mediator. Unless the aggregates are formed automatically on the basis of factors that can be categorized (such as, service provider unit or diagnostic coding), a mediator with similar skills and capabilities is also needed when the actual aggregates are created and modified.

### ***Intermediary co-operation***

Depending on the needs of a beneficiary, it is probable that mediators and other intermediaries co-exist, and they are expected to co-operate. Information encapsulation is one way to support co-operation, but information aggregates alone are not a sufficient method. Like in any field of industry, activities of individuals (in this case, those of intermediaries) can become intertwined with each other. While some activities are isolated by nature, and can be assigned to a single intermediary, others are highly interdependent.

For example, one intermediary can be assigned to managing activities related to beneficiary's physiotherapy. Especially if this is the only form of therapy provided to the beneficiary, activities can be rather independent. However, this is rarely the case as health-related activities are often more multifaceted, and link into the everyday life in the form of costs, compensation, and practical arrangements (e.g., transport). Typical health-related activities are concurrent; they occur within a specific frame of time (such as, between consultations). For example, the beneficiary is expected to undergo five physiotherapy sessions, and go to a laboratory, prior to the next consultation. In theory, some activities could even be parallel; they must be executed within a set frame of time simultaneously.

Regardless of the type of an activity, intermediaries need practices – and practical tools – for initiating, planning, executing, controlling, and closing specific health-related activities on behalf of the beneficiary, and they need to be aware of each other. As health-

related activities can be seen akin to a project [23], common project management practices, and solutions can be of the essence. However, as the owner (beneficiary) of the project and the manager (intermediary) are separate, a degree of sensitivity needs to be maintained. In the case of health-related activities, careful planning is needed on how intermediaries are informed. For example, is it enough to inform other intermediaries that results from certain laboratory tests are expired, or should the other intermediaries be also aware that the beneficiary will undergo new tests in a week, and what these tests will actually be.

### **Artificial mediator**

We see new technological marvels around us every day. AI, social robots, language technologies, even quantum computing are already here – or just around the corner. There are already different AI adaptations in the field of health care, especially in the field of analyzing complex medical data [37], and without doubt we will see more in the near future. Due to the pace of technological advance, we must ask – what about artificial mediators? We are already seeing technological artefacts that are anthropomorphic [38] and capable of mimicking human-like behavior on many levels (voice, expressions, body movements, etc.). However, health-related issues can be emotionally challenging, acting as a mediator requires social acumen and an ability to “walk on thin ice” in terms of interaction. Due to these specific requirements, it remains to be seen if and when we can see artificial mediators, and how they are implemented. In this, the options are open, ranging from voice-based assistant such as Amazon Alexa [39] to a biomimetic replica seen today only in popular science fiction.

### **How to enable mediation**

If the economic realities are set aside, there are different ways to enable mediation. Basically the alignment, position and reach of a mediator define how mediation can be enabled. If we look into the current duties of a practical nurse, mediation as a function of home care is one option as there is already some overlap. For exam-

ple, in the case of a chronic heart problems, health promotion and teaching (in other words facilitation) are often integral part of the duties of a practical nurse (cf. [40]). In Finland, first steps into this direction are already taken as a specialist nurse training called “Digital Nurses” started in the fall 2016 [41]. The training incorporates skills and abilities required from a mediator (namely, ehealth and technology literacy).

If the role of a mediator is a ‘job within a job’ for a health care professional, such as a practical nurse, the original characterization of mediator as a patient-side intermediary becomes contested. If the role is implemented as a part of home care, funded by the state or municipality, it resides on the provider-side and is similar to that of a case manager. This is a real challenge to the alignment of the role. One way to enable mediation in a more sustainable fashion, is to implement the role as a stand-alone service, provided by the private or third sector. In this kind of a setting, the beneficiary may be able to exercise freedom of choice, and choose the provider according to personal preferences. With this kind of a service, the health care (and social) service provider, the mediator, and the beneficiary remain as separate actors in terms of duties and responsibilities. When it comes to equal access to mediation, use of service vouchers [42,43] can be a valid subsidy scheme.

Another way to consider how mediation can be enabled is regard mediators as trusted persons, authorized by the beneficiary. This is already the case with elderly persons who have handed over practicalities related to their health to their children or to their spouse. In this informal setting, the mediator resides outside the framework of organized care in terms of duties and responsibilities. However, this interpretation is problematic as the mediator does not necessarily possess any of the skills or abilities required from a mediator. The mediator may not be able to interpret the clinical terminology to the beneficiary, and the support for health-related decision making of the beneficiary may base of second-hand experiences and anecdotal knowledge [17] instead of actual domain expertise. In this setting, the mediator is just a layperson, lending hand to another one. If a mediator in this setting comes from the third sector, such as from a specific patient

organization, the level of expertise may be significantly higher.

A halfway solution may emerge from multimediation; cooperation of different mediators (and other intermediaries) acting on behalf of a single beneficiary. With a mixed setting, health-related endeavors that require specific skills and abilities could be assigned to a professional, and the remaining ones to a layperson. However, as mediator is a role related specifically to the use of technology, a mediator cannot be a digital orphan – a degree of technological competence must be present. In addition, it should be stated that regardless of the composition of multiple mediators, the self-determination of the beneficiary should not be undermined.

When the feasibility and even meaningfulness of mediation are evaluated, it needs to be understood that all benefits are not economic by nature. Instead of analyzing how much money has been saved with the use of virtual clinics and online health checkups, other quality factors such as reduced stress and quality of life in general should be taken into account as well. In the case of intermediaries, and mediators in particular, efficiency and successful delegation of work are also important quality factors. This is particularly true in the case of intermediary cooperation and multimediation, which can have disruptive effect on overall performance if the delegation of duties and responsibilities fails.

### Potential downsides

A mediator is first and foremost an attempt to address an issue that is fundamentally a generation problem of today. The way the problem is approached is inherently humane one – an end-user is substituted by another, a more competent, one. However, as time passes and generations come and go, there will still be digital orphans. How many and what kind of remains to be seen. If we focus on the problem today, and on the proposed solution, there are some potential downsides that need to be acknowledged.

First of all, mediators cost.

In the economic landscape of today, enabling mediation from a purely financial perspective is a challenge. Public sectors throughout the world are struggling with the economic burden of increased costs and decreased income (fiscal sustainability). It follows from this that it is problematic to compensate costs of mediation from the public funds; more so as they accumulate health expenditure that is already high. If mediation is offered as a stand-alone service and the costs are covered by the beneficiaries themselves without any compensation by the public sector (including government insurance programs), then the problems are more ethical by nature. Mediation as a “premium” service is principally unequal as those without sufficient wealth are unable to acquire it.

Secondly, mediators may muddle the picture.

Especially for a layperson, it is sometimes a challenge to understand where the responsibilities lie in the health care service delivery. This is also the case in electronic health services as the used technology may create an obfuscating boundary between the health care professional and the patient [44]. There is a very real risk that this complexity increases due to the use of mediators – and associated technology. A potential outcome of this is that it will be a challenge to comprehend what the actual care pathway is, who the related actors are, and how different actors have affected the final health outcome. Furthermore, if health care services that are provided using technology, are mediated to the actual beneficiary by a mediator, there is also a risk that paternalism increases as the mediator is in a similar position of power as a doctor in a paternalistic patient-physician relationship.

Thirdly, mediators may create free rider mentality.

Simplifying, mediation is about doing things on behalf of someone else. In this kind of a setting the beneficiary is allowed to be passive – to “lie back and sit this one out”. Especially if there is a business incentive present in the relationship between the mediator and the beneficiary (i.e. mediation is provided as a paid service), there may not be any reason for the mediator to help and encourage the beneficiary to use electronic services

and related technology. More likely, the situation may be the opposite; there are more customers and a more lasting customer relationship if the beneficiary does not do anything with the technology (assuming that there are no other limiting factors, such as declined cognitive capabilities).

Fourthly, the world is not ready

As briefly discussed, the underlying legislation and practices related to acting on behalf of another person differ from country to country, and the practices may vary even between modalities (for example, different permissions and agreements can be used in text message-based services, than in online services). In addition, the granularity of permissions may vary – the person acting on behalf of another may be able to manage issues related to medication, but is not able to schedule an appointment with a doctor. While these kinds of practices are in place in order to protect the beneficiary, they often hamper the work of a mediator – more so if multiple intermediaries are involved.

## Conclusions

Health care, and especially the way health services are offered, is changing radically. Even fundamental aspects of health care, such as delegation of duties and responsibilities, are in turmoil. Technology is the harbinger of this change, which is equally economic and societal by nature. As economics are changing on a global scale, so are the users who are becoming ‘wired from birth’ as depicted by Brown [45]. Even though electronic services, and the use of different applications and devices, is becoming the norm in most business areas, there will always be individuals who are not able or willing to use them. Especially in the near future, if the technology gains similar foothold in the health care sector as in banking, there is a very real risk that these individuals, the digital orphan, will fall into the fringe of modern health care.

Naturally, there are measures that can be taken in order to lessen the probability and potential impact of this unwelcome eventuality. Supporting and motivating

lifelong learning of health, eHealth, and technology literacy skills is one measure that can help individuals in gaining and maintaining a sufficient level of competence in terms of using electronic health care services – and technology in general. More so, if the support is truly lifelong, starting from comprehensive school, and continuing after retirement – in other words, beyond the point in time where working life calls for competence in the use of technology and helps in maintaining it.

Another measure can be found in design. As major technology developers have already realized, ease of use and willingness to use often go hand in hand. Especially in the case of elderly people who do not necessarily come in contact with the latest technology, continuity and familiarity are aspects that may lower the threshold of using electronic services [46]. If the technology has familiar ‘look and feel’ as it used to – and if the new services follow the existing traditions – familiar flow of events may keep the individual within the reach of electronic services.

However, it is unforeseeable that these measures (or others) will be a sufficient method for completely eradicating digital orphans from the digital world – and it may be that they should not be. From a primarily ethical perspective, it can be argued that individuals should be allowed to take care of their personal health affairs the ‘old way’ (in person) if they choose to do so. At least this way the health affairs will be dealt with. With the discussed intermediaries, this does not mean that the individuals should be excluded from the modern health care.

For now, we need human intermediaries who act as representatives for the digital orphan. These intermediaries, domain-specifically mediators, are individuals who possess a specific set of skills and abilities that enables them to operate in the crux of health care, individual, and technology. Even though there are different intermediaries, such as patient advocates [47] already operating in the field of health care, they operate primarily on the provider-side, and the patient-side intermediaries are practically nonexistent – more so if

the focus is on domain technologies, such as patient portals [48].

The mediators are individuals who work on the patient-side, prioritizing the needs of the beneficiary before those of other actors (such as health service providers), extending the reach of electronic services to cover the digital orphan. In addition to legislation, it is the three factors a) beneficiary, b) health and care, and c) technology that effectively set operational boundaries for mediation, and define what the role encompasses in terms facilitating, configuring, and brokering. Even though traditional services are still an option and in most cases the preferred way of conducting health-related affairs, there is a strong trend towards electronic services. In order to ensure that the health services of the near future are still services for all, and the patients are treated equally, we need mediators. Otherwise, the future of health care may differ from what we expect it to be.

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