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The Role of Data in Health Sciences Ecosystems:
Experiences Within a Psychoeducation-Oriented IT Platform

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ABSTRACT

This chapter aims to provide an overview of the importance of data governance in digital ecosystems in the province of healthcare and to place special emphasis on the significance of taking business processes into account from the early stages of development of this type of solution. It should be borne in mind that business processes are not only those that produce economic benefits, but also those that provide added value for the entire ecosystem and make it sustainable over time. The chapter ends by exemplifying the above discussed approach in a specific use case of a platform initially conceived for the psychoeducation of formal and informal caregivers. Said platform has been conceived using a business process modelling approach focused on data exploitation from the early stages of development, which has allowed services, stakeholders, and potential users of the ecosystem to be extended far beyond the initial ecosystem goal.

INTRODUCTION

In the digital transformation that most organizations and countries are undergoing, data plays a key role. In fact, the technological revolution brought about by the new digital era pursues an adaptation to the new way of doing business that, both at a technical level and in terms of organizational culture, poses great challenges to companies and administrations.

As a strategic asset of any kind of organization, data are essential in this massive digital transformation effort. Information systems in complex environments, such as health, have a data-intensive component that requires merging, synthesizing, representing and visualizing data with interfaces so users can interact and employ data for high-impact decision making. All data management processes, from acquisition to visualization, should be carefully considered for exploiting health ecosystems strategic value.

Far from offering a partial view of the end user, when launching digital transformation processes they should be oriented towards a more complete view of the end user. It is not so much a matter of enriching information from a traditional point of view, but of broadening the vision by applying a sociological perspective. The goal is to know their needs in a personalized way, transcending the typical segments to provide appropriate responses to the reality of each one of them. At this point, data management requires strategies that target a people-oriented vision, leaving the product in the background.

Within this approach, optimal data management requires an integration of information that strikes a balance between the internal and external spheres of the health ecosystem. A well-known fact within the business province is that the success of tactical actions depends to a large extent on their implementation from a global vision. However, this approach is generally omitted when developing ecosystems in the health sector domain, as they are usually focused on providing services for the patient end user but forget the rest of the stakeholders when it comes to ecosystem exploitation. In addition, health ecosystems commonly start from small projects with a view to scaling up, but technology decisions are not aligned with a defined IT strategy. Ultimately, this strategy should be framed by data governance in line with the ecosystem goals, with a strong end user focus.

Within health ecosystems, aligning organizational objectives with technological capabilities is the big challenge. Fundamentally, it is essential to adapt processes accordingly, as well as to guarantee data quality, integration, adaptation to the digital ecosystem security and strategic use. This is a complex process that requires a great deal of effort and involvement from the entire ecosystem actors. Striving for it is the key to developing health ecosystems that success after deployment. Among other advantages, it not only allows to drive research initiatives more efficiently, but also to use analytics to respond quickly and accurately not only to end users but to all ecosystem actors' needs.

Within the health sciences environment, it is important to effectively carry out the necessary transformation to change the business model by taking advantage of the benefits offered by technology.

BACKGROUND

Digital health is one of the most important challenges in the province of healthcare. Major international bodies such as the World Health Organization are strongly committed to the potential of data and digital technologies to solve health problems. The Organization's Global Digital Health Strategy (2020 - 2024) promotes improving people's health through the incorporation of digital solutions as to involve and engage the participation of all stakeholders in digital health. As an example, during the last decade the

European Union has invested heavily in R&D by funding several proposals for platforms focused on the healthcare sector that has given rise to some open source solutions: LinkSmart (Lamprinakos et al., 2015), OpenAAL (Wolf et al., 2010), UniversAAL (Hanke et al., 2011), Net4Care (Christensen & Hansen, 2012). However, these early developed solutions were mainly focused on providing software media and ontologies for the integration of different telehealth medical devices following standards.

Taking the private sector into account, digital health is a very promising market, using existing resources and developments available in the cloud. Thus, large companies such as Microsoft (Microsoft, 2021) or Philips (Philips, 2021) have been developing their health service platforms in recent years. Other examples of commercial platforms are: Salesforce Health Cloud (Salesforce, 2021), OpenTeleHealth (OTH, 2021) or DXC Open Health Connect (DXC, 2021). As a concrete example of the opportunities that arise in the exploitation of data and digital technologies in the health sector, the latter solution from DXC has recently (April 2021) been sold to the privately held Dedalus Group for about $450 million.

Information systems in complex environments, such as health, have a data-intensive component that requires merging, synthesizing, representing, and visualizing into interfaces with which users interact for high-impact decision making. All data management processes, from acquisition to visualization, therefore take on an essential role in exploiting their strategic value.

In recent years, technological ecosystems (Kapoor et al., 2021) (Senyo et al., 2019) (Marcos-Pablos & García-Peñalvo, 2019) have emerged as an evolution of traditional ICT technology platforms. The concept of technological ecosystems is based on biological ecosystems, promoting the interaction of a set of actors on a common technological platform that results in a series of solutions or services. Based on this biological foundation, one of the fundamental characteristics of technological ecosystems is their ability to evolve, allowing for the rapid development of new capabilities and fostering innovations that may be unforeseeable by the original platform design. The evolutionary nature of technological ecosystems allows to evolve from simple or fragmented, patient-centric services into highly complex integrated services provided by multiple stakeholders through well-elaborated collaboration mechanisms.

A recent systematic review focused in Technological Ecosystems in the province of Care and Assistance (Marcos-Pablos & García-Peñalvo, 2019) identifies the following opportunities of delivering health through technological ecosystems: remote access to the relevant care records, more effective and assisted clinical decision making, real-time monitoring of structured patient care delivery and opportunity for patient, family and informal caregivers participation in health and care processes. In addition, all the data that could be extracted from the ecosystem information exchange (considering privacy and security issues) allows the establishment of new business models that could attract other stakeholders even not directly related to the health and care provision.

However, the same review shows that there are still many challenges and gaps that need to be fulfilled for providing the above opportunities in a consistent way, as the maturity of many technological ecosystems in the health sector are far from their relatives in other areas. In general terms, the main ecosystem architectures employed in the health sector are cornerstone and infrastructure-based ecosystems. This means that these ecosystems are generally built around a central IT platform, where the governance of the ecosystem and the ecosystem's data is highly centralized. This often results in a lack of means to model the inclusion of new software and hardware developments that do not follow the templates provided by the ecosystem software orchestrator, hindering the incorporation of new potential stakeholders.

The beforementioned gaps have a negative impact on the ecosystem business model. In these types of ecosystems, the business structure is generally omitted and merely relies on existing business models developed for other fields such as software-based ecosystems. The business processes are only oriented towards providing health services to the patient, causing a lack of involvement of additional stakeholders in the ecosystem development, which in turn hinders data exploitation capabilities. This final-user-centric model, rather than stakeholder-centric, makes it complicated to develop business models once the platform has been implemented and to attract other ecosystem actors. Thus, business processes are reduced to patients and families care providers (individuals or organizations) using the ecosystem services. However, scarce attention is given to other business processes such as: IT support and maintenance; providing training for end users, health professionals or health-technology developers; develop ecosystem data and analysis tools (such as dashboards) for health managers; or even allowing third parties to incorporate non-health specific added services.

As the key for information systems no longer resides in their internal infrastructures, but in extracting insights from the data, it is increasingly necessary to actively being able to adapt health ecosystems' business processes and services to allow exploiting digital health (Mahajan et al., 2021). This includes facing two fundamental challenges: the immense variety of data sources available, and the wide variety of types of data to be integrated (from the most structured, such as clinical data, to the most unstructured, such as social networks) (Vo et al., 2021). Exploiting health data requires a well stablished data governance, which in turn relies on a good organizational ecosystem structure. However, as for many health ecosystems, there is also a lack of an organizational structure to govern the ecosystem data, which has a negative impact when it comes to attracting stakeholders such as health authorities and governmental organizations (Christensen et al., 2014). Although the process of delivering health and care is quite generic, complex digital health services are difficult to generalize due to different factors such as geography, legislation, demographics, patients' health, or social conditions, etc. Health ecosystems rarely consider this variability from an organizational perspective. They do not provide the necessary links between the software and business structures, and lack of an adequate organizational structure to govern the exchanged data. To mitigate these issues, health ecosystems should feature a high degree of modularity while using established standards, and consider other aspects such as data ownership, security, privacy etc. (Kanwal et al., 2021).

The above gaps can be seen as opportunities for enhancing current health ecosystems and data exploitation models, applying big data paradigms to capture a more realistic view of digital health. Links between health provision, software and business should be established from the very beginning of ecosystem development, incorporating the organizational and business structures during meta-modelling the ecosystem software structure and taking them into account in the data health specific ontologies could help to reduce these gaps.

In addition, further research is needed to develop tools that allow the evaluation of the ecosystems' performance with metrics conceived for the health sciences data monitoring (Marsch, 2021). Furthermore, means to make this data available for third parties should be studied (considering interoperability, security and privacy) so that they can exploit them and increase the business model and the value chain. Finally, incorporating and standardizing training actions for care provision, adding new services into the ecosystem, new devices, new software and instructions on how to use all the available tools, should be approached in order to attract not only end users but also third-party developers.

DIGITAL HEALTH ECOSYSTEM IN A NUTSHELL

The adoption of digital health by the traditional actors in the health sector clearly depends on being able to show the value of managing and exploiting data within the health ecosystem. To this end, ecosystem stakeholders need to attain an understanding of the health ecosystem. A good definition of health eco-system is given by Iyawa et al.:

A network of digital health communities consisting of interconnected, interrelated and interdependent digital health species, including healthcare stakeholders, healthcare institutions and digital healthcare devices situated in a digital health environment, who adopt the best-demonstrated practices that have been proven to be successful, and implementation of those practices through the use of information and communication technologies to monitor and improve the wellbeing and health of patients, to empower patients in the management of their health and that of their families. (Iyawa et al., 2016)

To adopt and implement the best-demonstrated practices that have been proven to be successful in other fields, it is necessary to clearly define what the different components of the ecosystem are, how these components interact with each other, and the ontology and semantics of the data that originate from this interaction. The following sections summarize the main characteristics of health ecosystems.

Health Ecosystem Types

In general terms a digital ecosystem is a widespread type of ubiquitous computing environment comprised of different actors, technologies, and services. Digital health ecosystems can be conceived as a subdomain of digital ecosystems, and since it exhibits the same features as those in the digital ecosystems, we can classify health ecosystems adapting classifications employed in other domains, such as the one of digital software ecosystems given by (Knodel & Manikas, 2015). As such, we can distinguish between four types of ecosystems:

- **Cornerstone Ecosystems**: where actors interact on top of a common software platform and usually extend the platform's functionality. Thus, the existence of a technological platform is of central importance for an ecosystem of this type. The structure and governance of this type of ecosystem is usually centralized.
- **Standard-based Ecosystems**: where instead of a common platform, the compliance to standards is the key requirement for contributing to the ecosystem. Usually, compliance to standards is set above the functionalities and concrete realization of the contributions.
- **Protocol-based Ecosystems**: where a protocol API is shared among all actors, providing more flexibility over technical contributions to the ecosystem. Protocols are a less restrictive and more flexible than standards and are usually independent from technology. However, they provide the necessary predefined specification of interaction within actors (e.g., exchange of data, call to software services, etc.).
- **Infrastructure-based Ecosystems**: where a common technology is shared among all actors, providing tools at development time but at the same time maintaining independence on the contributions. Usually, the interaction among actors is on a social level.

Health Ecosystem Structures

Three main structures can be distinguished within digital ecosystems (Christensen et al., 2014) are:

- **Software structure or technological structure**: the structure of software elements and devices that form the core of an ecosystem.
- **Business structure**: how ecosystem actors create value (in a for-profit or nonprofit manner).
- **Organizational structure:** how the interaction and organization of actors and software are governed, which is in turn related and dependent on the ecosystem architecture (e.g., for an actor to provide care services in the ecosystem).

At first glance it may seem that these structures are completely decoupled. Therefore, these structures are often developed by different departments or even different organizations and then integrated into a complete solution. However, it can be intuited how exploiting data in a health ecosystem depends on the three structures simultaneously. The software structure will determine the capabilities to extract, store, share and analyze the data in the ecosystem. The organizational structure will oversee data governance, which in turn will depend on the capabilities that the technology and software structure can offer. Finally, the business structure will determine what data is of interest to the different stakeholders in the ecosystem, and what processes of interaction between the actors will be in place to deliver the desired services to obtain a final system that is both profitable and attractive to the different stakeholders.

Health Ecosystem Actors

One of the main distinctions of digital ecosystems resides in the strong involvement of the different ecosystem actors in value cocreation. For that reason, data exploitation in digital health ecosystems needs the correct classification of stakeholders so to identify the ecosystem's relevant data subject to exploitation.

Ecosystem stakeholders' clustering into different groups and their nomenclature has been revisited over the years in different fields. The business environment was the first to worry about the correct typology and classification of stakeholders. Within business, stakeholders' clustering into different groups and their nomenclature has been revisited over the years (Sirgy, 2002), but has generally described three fundamental groups:

- **Primary stakeholders**: have direct involvement in the business activities (i.e. production, management and processes).
- **Secondary stakeholders**: are groups of beneficiaries that influence the success of the activities of primary stakeholders.
- **Tertiary stakeholders**: whose interest arises from indirect benefits from the business. Among tertiary users two subgroups are generally particularly considered: public and government entities. Public entities provide a critical insight into the activities of a business, based on the benefits or risks of its processes on the community. Government entities have the mission to protect and promote the generated value.

Parting from this classification, other stakeholders clustering proposals have been made in the field of health and care ecosystems. For example, in the province of AAL (Ambien Assisted Living), which focuses on making senior users' lives easier and more independent through AI (Ambient Intelligence) based solutions and computing environments and systems, three fundamental types of stakeholders can be distinguished (Nedopil et al., 2013):

- **Primary end-users**: person who is using a product or health service.
- **Secondary users**: people or organizations that that are accessing or using the ecosystem solutions for the benefit of primary end-users. This group benefits directly from AAL products or services by they use, and indirectly when primary end-users' needs for care are reduced (e.g. (in) formal caregivers, family members, care organizations).
- **Tertiary final users**: institutions and private or public organizations that are not directly in contact with the AAL solution, but that in some way contribute and benefit from their organization, budging or assessment (e.g. organizers of public sector services, social security systems, insurance companies, etc).

If considering the ecosystem technological infrastructure, the stakeholder clustering should incorporate additional groups or subgroups of stakeholders. If considering software ecosystems as a reference, five main stakeholder roles can be distinguished (Suortti, 2017):

- **End User**: Person, company, an entity that either purchases or obtains a complete or partial product of the ecosystem or a niche player.
- **Support Service Provider**: help and enable other ecosystem actors to achieve their goals (e.g. internet service providers, research and consulting companies and hardware suppliers).
- **Orchestrator (keystone)**: responsible of the ecosystem governance (e.g. software platform management, actor relationship management and ecosystem health monitoring)
- **Third-party organization**: use the central technology as a platform for producing related solutions or services. They can be sub-based on:
    - Niche Player: responsible for ecosystem innovation and value creation. They develop specialized extensions to the platform and are motivated by business opportunities.
    - External Developer: provides indirect value to the ecosystem through its usage.

Health Ecosystem Data

Digital health systems have evolved from only putting patients at the center of the system to meet their needs, to including technologies that facilitate the recording and exchanging of information in interoperable systems, so that data can be shared between all ecosystem stakeholders. In fact, the strength and future of such solutions lies in developing new means of exploiting the potential of big data, that is, the use of large and wide-ranging amounts of data to enable knowledge discovery and better decision making (Mayer-Schnberger and Cukier 2013). Working with big data involves making use of technologies and tools from a wide variety of disciplines, such as those from text analytics, business intelligence, data visualization and statistical analysis (LHeureux et al. 2017). However, in many cases improving traditional methodologies or creating them from scratch is needed to get the most out of such data.

From a strictly health and care perspective, the strength of digital health lies in exploiting the interaction of data in order to understand how their interactions might be used to both prevent and treat diseases.

The goal is to explore how combinations of these data might be used to early diagnose the disease and monitor its prevalence within populations. Health data can be classified into:

- Biological
- Clinical/medical
- Social/environmental

Examples of biological data include: RNA and protein expression profiles (Catalina et al., 2020) (Wu et al., 2020), genetic information about healthy and disease-affected individuals (Whelan et al., 2020) (Aguiar de Sousa Diana & Katan Mira, 2021), epigenetic data (Karađuzović-Hadžiabdić & Peters, 2021) (Sarno et al., 2021). These data can be acquired from different sources, such as cellular or animal models or human tissues, in which case is often linked to pseudonymized clinical data.

Clinical or medical data typically contain information about symptoms; diagnostic; rates of disease progression (Mahajan et al., 2021); types of treatment given for the disease of interest or for other diseases; the impact of that treatment; the presence of other illnesses and factors. In fact, clinical data are complex multimodal data by nature, and need to be acquired for a large number of cases and controls (Marsch, 2021). Population-based clinical data is generally accessible on much larger numbers of individuals than biological data, such as datasets of medical records or population-based epidemiological studies. However, these data are usually not integrated with a deep biological characterization, and therefore methods for inferring important data must be developed.

In addition, new efforts for correlating social and environmental data with clinical and biological data need to be developed. Some of these items such as socio-economic status, exposure to various environmental risks, diet, smoking, occupation, cognitive engagement, or exercise are already known to impact risk and/or progression of diseases. As so, the information content of social and environmental datasets is starting to being coupled with clinical and biological data, to explore the correlation between factors in disease prevention, diagnosis, and treatment. Potential sources of data are already available and extensively used for other purposes, such as mobile phone, Internet, or social media usage. These data likely contain information about lifestyle (e.g., diet, alcohol and cigarette consumption, exercise, etc.). In addition, changes over time in the complexity of some parameters such as social engagement can reflect changes in physical and cognitive activity that might describe the early stages of different diseases.

Linking biological and medical data to population-based data provides several benefits and opportunities in health and care provision. These benefits have a direct impact into primary and secondary ecosystem end-users:

- The development of a deeper and better understanding of the broad disease categories and patient population subsets.
- Specific understanding of the correlation between diagnostic criteria and patient subsets.
- Specific and better understanding of risk factors for disease development, potentially accelerating the development of preventive therapies.

In addition, data exploitation through digital health provides other benefits that could be exploited by other stakeholders, such as tertiary end-users:

- Optimizing the use of approved symptomatic therapies, as well accelerating the discovery and development of disease modifying agents for the indication.
- Better understanding of the health economic impact by disease category and patient sub-type, which would provide additional incentives to public and private sectors to invest in research.
- Create new business opportunities for non-pharmaceutical-based approaches to risk factor modification.

Apart from data strictly related to health and care provision, several other non-health-related data that arises from the ecosystem can be of use to other third-parties organizations and service providers. In fact, as digital health relies on a software infrastructure, software business models and approaches to data exploitation can be considered in order to enhance the ecosystem revenue and attract additional stakeholders. For example, in cornerstone ecosystems software providers will be interested in obtaining relevant data on the use of the digital platform for monitoring system performance. Furthermore, as primary and secondary users will seek data that can be easily consumed, they would likely need service providers or data intermediaries. This necessity attracts specialized roles related to data provision, such as data analyzers or data visualizers to help nonspecialized in the data consumption process. Also, as software and technology providers help to promote the interoperability of data and services, developers of medical hardware and software solutions (e.g., orthopedics, biomedical measuring systems etc.), can benefit from data on the evolution of patients as a result of the use of their devices or services.

A PRACTICAL APPROACH TO DIGITAL HEALTH DATA EXPLOITATION

In this section we present an example of the development of a technological ecosystem in the province of health, taking into account the business processes involved in the exploitation of data so that the ecosystem can be sustainable over time.

The starting point is an already developed generic framework of a technological ecosystem developed as support of services for the management of corporate knowledge. This framework has been set up in different environments (García-Peñalvo et al., 2018) (García-Holgado & García-Peñalvo, 2019), mainly in the province of e-learning. From a technological point of view, the framework allows the complete design and development of a technological ecosystem platform, in line with state of the art in software architectures. It has a strong evolutionary component whose architecture can be valid for different contexts, and that allows the integration of other software tools, as well as the development of new services that provide added value to the ecosystem.

Said framework has been successfully adapted to the care domain with the objective of providing comprehensive and remote support for the needs of formal and informal care providers (e.g., family members) of dependent older people with dementia. The aim was to provide a platform that allows (in) formal caregivers to develop and enhance their caregiving competences, as well as to mitigate the negative effects produced by caregiving activities such as physical and mental stress and social isolation.

The proposed framework adaptation has been incrementally developed, using a cornerstone architecture but considering the three main ecosystem structures, namely software, business and organizational. This approach proves the importance of modelling the business and organizational structures alongside the technological infrastructure during early stages of the ecosystem development. Thus, rather than a purely patient-centric approach looking for a "business-first" revenue (traditionally followed within health ecosystems), the software structure is directed by the business structure, but the business processes are determined by the software components and the actors added value chain and organizational relationships. Software components build the technological infrastructure as the core of a software ecosystem. Second, the organizational structure governs the interaction and organization of actors and software, providing means to develop software-based services in the ecosystem. Finally, the business structure allows actors to create value within the ecosystem.

The initial framework's software structure is organized into four layers:

- Presentation layer: in charge of providing means for the use of ecosystem services by users inexperienced in the technology.
- Services layer: aims to provide different services to users. Initially considered services were a learning platform, a social network to exchange experiences and a dashboard for data visualization.
- Data Management layer: provides tools for storing and processing the data, a common ontology and semantics as well as mechanisms for data governance.
- Infrastructure layer: provides a set of services that are used by the software components from other layers.

In order to adapt the existing framework into a care ecosystem, the first step was to analyze the ecosystem's value propositions:

The motivation of actors to participate and engage within a medical ecosystem arises from the reciprocal benefits, namely the value propositions that variant types of actors within the ecosystem offer and seek (Litovuo et al., 2017)

To investigate the value propositions, the Business Model Canvas (BMC) developed by Osterwalder and Pigneur (Osterwalder & Pigneur, 2010) was employed. The BMC is a strategic management template used for developing new business models or documenting existing ones. It offers a visual chart for a global description value propositions, infrastructures, actors, and relationships. Osterwalder's approach has proven to be a valuable tool for describing not only commercial business models, but also in many other contexts including health-related ecosystems (León et al., 2016). Figure 1 shows the BMC of the ecosystem.

The second step was modelling the business processes that occur within the ecosystem, taking into account the expected actions that the main actors would carry out. The primary users are mainly (in) formal caregivers and patients. Caregivers sought value is to increase their caregiving competences. Although in this case patients are generally passive beneficiaries, they can contribute content within the social network, either directly or indirectly through their caregivers. A general use-case for a particular caregiver is shown in figure 2.

The definition of a generic use case as shown in Figure 2 allows identifying data that will be relevant for the exploitation of the ecosystem. The data mining is based on the interaction of users with the social network and the teaching-learning platform. The use case starts with an onboarding of new users (caregivers) into the platform. During this onboarding users are requested login data. The possible data requested during the onboarding includes:

Figure 1. Business model canvas of the ecosystem

Key Partners	Key Activities	Value Propositions	Customer Relationships	Customer Segments
-Health and care authorities -Public & private hospitals care institutions -Research institutions -Platform supplier -Platform operator	-Platform design, development, operation and maintenance -Psychoeducation eLearning content definition, development and update -Identification of relevant data from the application of care and psychological activities through the ecosystem -Ecosystem KPIs definition, analysis and visualization	-Improve quality of life of patients and (in)formal caregivers -Improve quality of care -Reduce care provision costs -(in)formal caregivers' accessibility to psychosocial programs and personalized learning itinerary -Social communication and support (relatives, informal caregivers, professional care networks) -Data and analysis for the evaluation of the different care or psychological action protocols -Psychological disorder evolution and trends analysis (personal, geographical, etc.) -Data and analysis of ecosystem usage, user needs and trends -Possibility of incorporate new services or modify existing ones through the ecosystem functionalities	-Psychoeducation training program -Professional medical and care contact -Training on platform usage -Platform content and services updates -Third-parties publishing of care-related services	-Patients/Families -Health & Care providers -Public health authorities
	Key Resources		**Channels**	
	-Ecosystem contents: social network, eLearning platform, mail, dashboard -Hosting infrastructure -Software development expertise -Expert personnel on data analysis visualization -Expert personnel on psychoeducation and eLearning		-Regional/National health contacts -Care institutions & care networks contacts -Social Networks -Web	

Cost Structure	Revenue Streams
-Communications infrastructure -Platform development and maintenance -Platform hosting -IT personnel -Health personnel	-Clients using ecosystem services -IT support and maintenance -Training for clients -Provide ecosystem data and analysis tools -Third parties publishing their care-related services

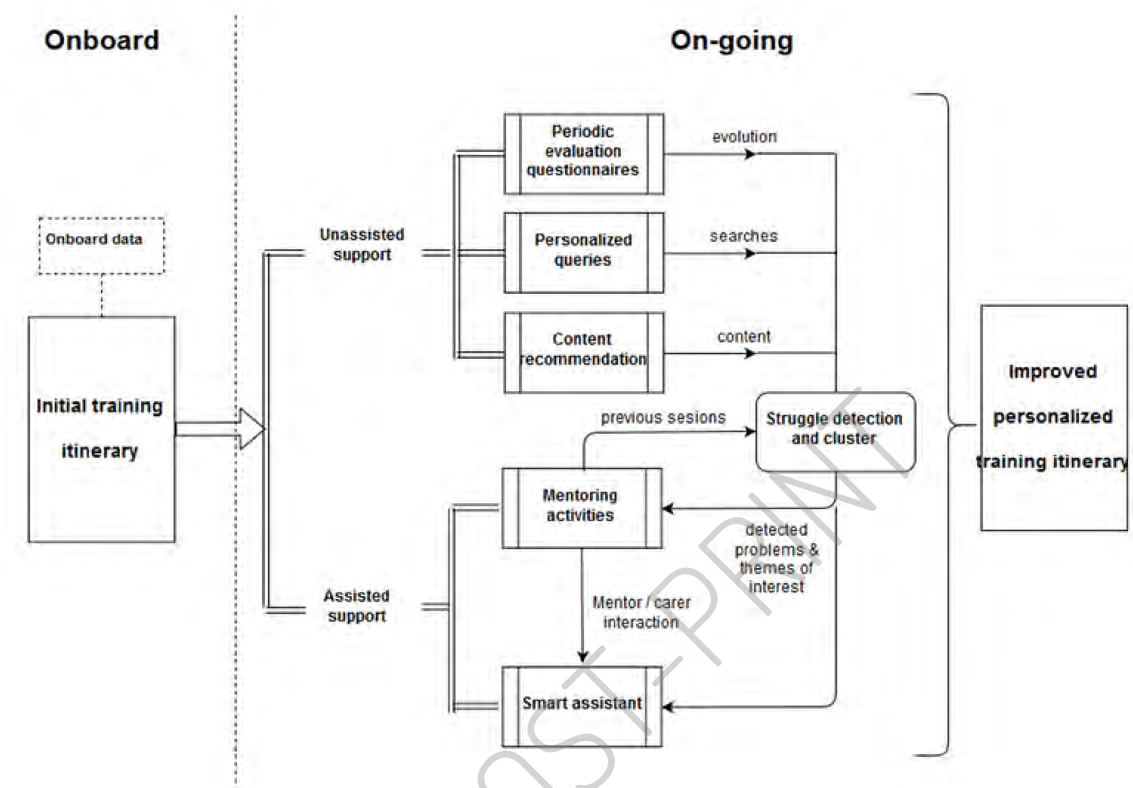
- Caregiver profile: ethnographic and geographic data (age, health status, geographic location), previous caregiving knowledge, family situation (e.g. number of hours spent per day on caregiving).
- Patient profile: ethnographic and geographic data, clinical data (based on the caregiver knowledge

During the ongoing stage, the caregiver can choose between two paths:

- Unassisted support: using tools that allow the user to follow his own learning path without mentoring: evaluation questionnaires, personalized searches, and content recommendation.
- Assisted Support: either provided by experts in the mentoring program that support the caregivers in scheduled sessions or through the social network, or through a Smart assistant that is nourished from the ecosystem interactions answers questions 24/7.

During the onboarding stage, data can be directly collected from the primary users, including ethnographical data and clinical and medical data. These data can be crossed with other patients' databases, provided that they are accessible. This set of data and their interaction with other sources (to a greater or lesser extent) is what generally takes place in developed health ecosystems.

Figure 2. Definition of a generic use case



However, greater utilization of the existing ecosystem data can be achieved by matching the activities of the primary users with the value sought by the secondary and tertiary users and vice versa. In this ecosystem, clinical and medical data can be directly combined with social and environmental data based on the primary users' interaction with the ecosystem services. These data can be extracted by combining different sources of information such as the questions, experiences and use cases shared by users in the social network, the type of teaching/learning contents sought or the training evolution of the caregiver, etc. Thus, the business model for exploiting data should focus on both the ability to extract data from the ecosystem software components usage as well as from the interaction between users:

- **Health practitioners**: their main objective is to improve decision-making by identifying better treatments and discard the least efficient ones. They will seek to detect adherence to treatment, its effectiveness and finally to improve the quality of life of primary users (patients on the one hand and caregivers on the other). With this objective they may combine data obtained from the medical records, with additional knowledge of ethnographical or population-based data obtained from the social network. Although these two types of datasets are usually unlinked, the combination of medical records with other data such as socio-economic status, exposure to various environmental risks such as diet, smoking, occupation, and lifestyle factors such cognitive engagement, would result in better treatment decisions.

- **Research Networks**: their objective is to acquire new knowledge searching for new solutions to unresolved medical problems investigating the interaction of different factors within the data in order to understand: how they influence the risk for disease or disease expression; how combinations of these data might be used to diagnose the disease or monitor its prevalence within populations; and how these interactions might be exploited to both prevent and treat diseases.
- **Care managers**: care managers as secondary users will also seek to reduce costs and resource expenses. To do so they will seek to acquire data that helps them to improve learning contents, give better support in the training process and consequently improve the mentoring programs. The data of interest for this group will include the progress in the training programs, the churn rate, the number and type of questions raised during the training itinerary, the contents posted in the social network, etc.
- **Public administration and insurance companies**: they will seek for a better understanding of the health economic impact of dementia by disease category and patient sub-type, which would provide additional incentives to invest in dementia treatment and research and to look for preventive treatments. They will be interested in similar data as the health practitioners, but from a broader perspective. They will seek the effectiveness of the care and services provided, for instance from a geographical point of view, considering groups of patients rather than individuals.
- **Pharma**: in terms of drug treatment, some diseases as is the case of dementia are only susceptible of symptomatic treatment. In these cases, big data can provide a better understanding of how to best use the available therapies. The great majority of these patients discontinue therapy because of the benefit to an individual patient is not evident. Having a better understanding of how the patients respond to drug treatment would accelerate the development of novel treatments, providing means to analyze if there is a population-level benefit or a patient subset benefit to encourage the drug treatments and / or associated research.
- **Software and hardware providers**: include both service providers and the healthcare technology sector. Service providers will be interested in obtaining more relevant data on the use of the platform for monitoring system performance (time slots of maximum platform usage, technologies employed for accessing the system, etc.). From the point of view of developers of medical hardware and software solutions (e.g. orthopedics, biomedical measuring systems, etc.), data on the evolution of patients as a result of the use of their devices can be obtained from the social network (e.g., from activities carried out by certain patients with a prosthesis, questions formulated by caregivers about the use of their devices, etc.). On the other hand, they may be interested in including tutorials of their specific devices within the training itineraries.
- **Other**: given the evolutive nature of the ecosystem, the ability to extend its functionality and include new services, as well as the existence of the social network can lead to new business opportunities (e.g. specific advertising content for business focused on the elderly, such as travel agencies, etc.).

As can be seen, starting from an ecosystem in the field of health, although based on a teaching/learning environment, a broader digital health ecosystem capable of attracting a greater number of stakeholders can be achieved in a way that can be sustainable and healthy.

CONCLUSION

In this chapter we have shown an overview of the approach towards data exploitation in digital health ecosystems, so to obtain solutions which are not only focused on the patient but in other potential ecosystem actors. The importance of data and data governance in digital ecosystems in the province of healthcare is fundamental to achieving solutions that can be sustained over time, taking into account the business processes from the early stages of development of this type of solutions. To conclude the chapter, an example of an application of this approach in a health teaching-learning ecosystem has been shown.

FUTURE RESEARCH DIRECTIONS

It should be borne in mind that considering the different business processes and business model opportunities while developing the software structure, provides fundamental "constrains" or characteristics for the software structure, such as the data taxonomy & ontology, the data architecture and the data security and lifecycle, which in turn will determine the data governance and allow to stablish the organizational structure. This means, however, that despite the recent interest in big data approaches, and their clear potential for providing insights into complex diseases, there are important data challenges when trying to apply the above approach for purely medical purposes. One is the uneven distribution of information content. For example, biological datasets usually have large amounts of intensely detailed quantitative information that has typically been acquired only on relatively small, often specialized, cohorts. In many instances, these subjects have been collected for specific reasons, which can make it difficult to cross-referencing information with social or environmental data. On the contrary, it may be difficult to access clinical or medical data for large population groups of ecosystem users that might more accurately reflect environmental or social data evolution.

Bigger limitations arise from the geographical scope of the ecosystem. For example, developing a cross-country or even cross-region ecosystem may produce a boost on data variability due to several factors, which include differences in the clinical data standards, treatment or diagnostic procedures applied, and even differences in the quality or reliability of data even when the same or similar measurement tools are used. They may also include differences in ethnicity, behavior, and environmental exposures. Last but not least, differences between the health and care provision policies may vary between regions, so differences in data availability, ethics and anonymization restrictions for obtaining and processing data makes data exploitation a more complex task than in conventional software platforms.

It can be seen that there are still several challenges to successfully addressing these limitations. However, digital health researchers and developers should overcome these limitations in order to transform current health provision and effectively carry out the necessary transformation to change the business model by taking advantage of the benefits offered by technology.

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