NEXT FRONTIER FOR HEALTH SYSTEMS: LEARNING FROM PATIENT'S BEHAVIOR AND FUZZY FACTORS IDENTIFICATION

Shengjing Sun
PMQ research group, ETSII,
Universidad Politécnica de Madrid,
Madrid, Spain.
shengjing.sun@alumnos.upm.es

Xiaochen Zheng
PMQ research group, ETSII,
Universidad Politécnica de Madrid,
Madrid, Spain.
xiaochen.zheng@alumnos.upm.es

Joaquín Ordieres-Meré *
PMQ research group, ETSII,
Universidad Politécnica de Madrid,
Madrid, Spain.
j.ordieres@upm.es

Irène Georgescu
Université de Montpellier,
Montpellier, France.
irene.georgescu@umontpellier.fr

Étienne Minvielle
I3-CRG,
École Polytechnique,
Paris France.
etienne.minvielle@polytechnique.edu

ABSTRACT

This paper aims to explore challenges and opportunities that technology brings when applied to understand effects that patient's behaviour has in relationship with evolution of the disease. The paper will review the contributions from the Internet of Things (IoT) paradigm, but also it will consider alternate sources to collect feelings and interests which are related to the big-data dimension, like social media exploration, etc. Based on the current status of the technology some managerial considerations are discussed as well. Two questions are addressed: The first one highlights technological limitations from the current and fragmented approach, including concerns related to privacy and ownership. In response, the paper proposes a holistic framework helping in easing the IoT use by proposing integrated solutions to several of the identified concerns. The second one is related to the patient's motivation for adopting such IoT solutions. Some future researches is identified to explore the impact of "easy to use" technological solutions on patients motivation in sustainable adoption.

***K*eywords** Patient behaviour · Internet of Things · Semantic model · Distributed Ledge Technologies · Social Networks

1 Introduction

There is a significant industry which develops products that facilitate the delivery of health services in the primary care setting and in people's homes. There are different dimensions which have not a hard and fast definition. It is possible to identify care delivered at home as well as 'community care' when patients are treated in settings such as their local general practitioner. Hospitalization is unavoidable for people with severe illnesses or in need of surgery, but many chronic conditions, however, can be managed just as well in the community.

Inpatient hospital cares are expensive. Different sources show that many older people are admitted to hospital inappropriately and stay longer than necessary. As institutional care can cost 10 times as much as home care, it is clear

*Corresponding author (Prof. Ordieres's URL: http://biba.etsii.upm.es/jom/). Orcid code: 0000-0002-9677-6764

that community care is preferable where appropriate. This is relevant because of Europe's aging population means that more people will require care. Now, more than ever, it is essential to find ways to make the most efficient use of health-care resources.

There are continuous effort in providing products or services that enable people to better manage their disease or health condition themselves and minimize their use of hospital care. Although these efforts continue to increase, it is also true that Patient's decision to discharge "at own risk" (AOR) is becoming a common event that health care providers will face in their practice, that is recognized as 'against medical advice' [1].

All those evidences reinforce the idea that the process of care as well as the related outcomes are going to be dependent on patients' behaviors. However, not enough information is available in regards to the effective impact of specific activities because of lack of knowledge. There are some studies that have primarily focused on establishing the feasibility of measuring activity and associating such activity levels with beneficial outcomes. Indeed, the sample size is hardly limited (< 50 patients), therefore, generalization capabilities are somehow limited. Just as an example, activity-monitoring devices that record free-living walking behavior may be helpful in quantifying levels of ambulation and provide insights into important symptoms such as fatigue in multiple sclerosis patients [2]. In the same way, the first study investigating the use of a wearable activity tracker on post-surgical mobility recovery during hospitalization was carry out and published by the Mayo Clinic [3]. A meta-analysis of activity monitor-based counseling studies with diabetes patients concluded that activity monitor-based counseling had a beneficial effect on physical activity, blood glucose, systolic blood pressure, and body mass index [4]. However, there is a lack of evidence demonstrating the effectiveness of activity monitors in chronic disease (e.g., osteoarthritis, cardiovascular diseases, type 2 diabetes mellitus, and chronic obstructive pulmonary disease) [5]. Studies have found modest short-term activity improvements and weight loss resulting from monitor and pedometer use [6], but it is not clear that these results are sustained over extended periods.

There are limitations when the previous related experiences and similar ones are considered, mainly because of their significance and the lasting periods adopted into the studies. The meaning of this is that the management dimension is more needed than ever, not only because of providing understandable links to the different experiences with different configuration and parameters, but also because the identification of needs and barriers and, in such case to identify convenient solutions. Actually, both aspects require significant managerial contributions, on one side, better capabilities to understand the patient's behaviors as well as sentiments, feelings and attitudes as they can have significance on the evolution of their diseases. On the other side, because to have larger datasets, it becomes even more relevant to have patient empowerment regarding the data they produce. So, a clear managerial vision is needed to propose convenient integration capabilities from data arriving from different sources, while ownership is kept on the generator side. This is exactly what this paper aim to address, by combining a managerial perspective with a technological one.

From a managerial standpoint, all this evolution can be analyzed under the concept of "patient motivation". Indeed, the use of IOT, to be routinely adopted, requires a high and sustainable motivation from patients. Theories about "patient motivation" have been validated by decades of empirical research by experimental psychologists and behavioral economists in a variety of settings, both in health care and elsewhere. When motivation to undertake an activity is high, intrinsic motivators are particularly effective. Extrinsic motivators work best where motivation is low, typically when tasks are tedious, monotonous, or far from the usual activity of the individuals concerned. In this particular case it is needed to highlight the limitation of IoT adoption like the opt-out decision from patients because of many reasons, including physical and cognitive limitations, but also beliefs.

In the specific case of the IOTs' use, the focus is on intrinsic motivators developed by patients. As Ryan and Deci have argued [7], these intrinsic motivators can be :

(i) ease of use,

(ii) promoting autonomy (i.e. feeling, a sense of choice or freedom from coercion, as when a behavior is either interesting or personally meaningful),

(iii) enhancing mastery of competences (i.e. feeling effective and capable in one's actions),

(iv) and increasing relatedness (i.e. feeling belongingness and connectedness with others).

Then, a more specific point is to understand how the "ease of IOT use" can play a role for activating these intrinsic motivator. A better ease of use can certainly improve the motivation. Meanwhile, other criteria can play a role (e.g. skills to use the IOT and translate the information in practical behaviors for improving the health status, shared feedback with patients of the same clinical condition, promotion of a self-management approach as advocate by many patients.)

2 Literature Review on IOT and ease of use

Modern health systems are embracing information technology (IT) in ways that can make services more convenient for patients. eHealth is the use of Information and Communication Technology (ICT) tools and services in health and health-care delivery. Such tools and services are increasingly used by both health-care professionals but also for patients, and are playing a significant role in improving the health of European citizens, changing how they manage their health and receive their health-care services.

Much of the industry efforts are focused on wearable devices, where different devices have been used in different applications or diseases. It is possible to mention Essential Tremor measurement [8, 9], Activity monitoring regarding type 2 diabetes mellitus and cardiovascular diseases [4]. Blood pressure monitoring [10] or hear rate monitoring [11], among others.

However, the information captured have their own limitation, as passive monitoring devices do not capture all free-living physical activity. For example, Fitbit© users found erroneous characterization of true activity due to infrequent or sporadic use and compromised accuracy due to predominant hand motion activities (playing the drums and cooking), driving or cycling, and long or short stride length. In most instances, wearable devices are improving in terms of user experience, which includes extended battery life, easier synchronization via Bluetooth and WiFi, inclusion of additional sensor measures, and aesthetics from the wearable device itself and corresponding companion applications. However, the level of sustained use of wearable devices is ultimately dependent on the disease, patient behavior, and measurement need.

With technological advancement, it is expected that manufactures will respond to these limitations. Improved portability and ease of use, such as that offered in newly developed smart watches, could facilitate routine data gathering. Physical activity estimations can be enhanced if there is an accounting of a range of indoor and outdoor activities, different walking speeds, and types of ambulation (walking, jogging, running). Indeed, advanced deep learning technologies can contribute to this identification [12].

There are studies assessing the patient experience and their major concerns can be summarized [13]:

- technical difficulties (e.g., installation of device or software).
- intention/willingness to monitor activity (e.g., willingness to use an activity monitor).
- opinions towards wearing the device (e.g., pleasant, or frustrating to wear).
- the general attractiveness of the device.

In contrast, the comfort in attaching or wearing the device, as well as the usefulness of activity monitoring, were rated high on the usability scale. The majority of consumer-accessible wearable devices are not part of a formal disease management program with a clearly reported time of use period and specific goals. The inclusion of effective behavior change components in a programmatic manner may drive positive outcomes more than wearable use alone [14].

An additional but relevant aspect to be considered when monitoring people's parameters is privacy. Most of surveys reflect that about 80% of consumers express privacy concerns about personal data-sharing [15]. These concerns are realistic, especially in an era of GPS technology, which could potentially reveal sensitive personal activities. Indeed, in Europe, because of the General Data Protection Regulation (GDPR), which equally affects all the member states, there are additional user rights. The coverage of GDPR is extensive and, as far as it states in its article 7 that "the principle of confidentiality should apply to current and future means of communication", this includes the Internet of Things. Moreover, the article 5 poses specific safeguards in machine-to-machine communications. While not all Internet of Things applications are about personal data, like for instance the more Industrial Internet of Things (IIoT) applications, it happens in many other use cases. It is clear that as the market share for IoT solution is growing worldwide (including Europe), this is a relevant aspect that requires detailed management. Although the concern about privacy does exist, it is also true that surveys show differentiated opinion when the the focus is to help doctors to improve care. Therefore, it has been reported that [16] 94% of responders would also be willing to share their health information on social media such as PatientsLikeMe, if it would help other patients like them, and 92% of responders would be willing to share information to help researchers learn more about their disease. To this end, insights from motivational theories are very helpful and they need to be taken into account [17].

The wearable approach is not the only one to be considered, as there is potential value in learning patient's feelings and beliefs. One way to learn about these aspects is to learn about throughout patient's social network. Therefore, there studies analyzing the relationship between Lung Cancer and social networks [18]. It can also be found in [19] a study aimed to identify young adult Korean cancer survivors' individual- (psychological distress, stigma, sociodemographic variables, and cancer-related variables) and network-level factors (relationship type, social support type) that influence discussion of their cancer experiences.

From the previous analysis it becomes clear that people are concerned with their own data privacy but, still, they want to share if the purpose is meaningful and convenient guarantee is provided. Then, the challenge is now better established, and it is to gain larger dimension by getting broken the data silos, but only when data owners become empowered regarding the data they produce. The study[20] discussed the potential in childhood health-real ed research by harnessing data from social media data and wearable devices. The integration of wearable sensors and multiple social networks also showed crucial importance to various applications such as Quantified Self tendency and personal wellness profile learning[21]. However, multiple data sources are characterized by high degree of heterogeneity, common data model need to be build to make those heterogeneous data interoperable. This need to be considered for configuring new solutions.

Ontology based semantic data modeling have provided successful results in activity recognition[22], environmental data modeling[23] and social media data analysis[24]. Domain ontology provides structured vocabularies to explain concept and relations in between, which enables to addresses data heterogeneity and interoperability concerns in cross-modal data fusion.

Based on the previous literature review, it does make sense to expend efforts looking to integrate wearable datasets with stigma spreed through the social networks. This approach will provide a more comprehensive context to potentially understand the relationship between the disease and patient behaviors. Therefore the research question for this work can be formulated like,

RQ 1: To what end the IoT and other technologies can help to consistently clarify the patient's behaviour.

Based on this hypothesis, the objective of this paper is to define a better "ease to use IOT's framework" as a prerequisite for studying the patients' behaviors.

3 Methodology

There are several aspects to be addressed for bringing a consistent framework able to gain convenient context for integrated distributed collaborative solutions. The first one is related to the creation and use of semantic models for automated IoT resource and subsequent data integration at run time. The second one is related to the adoption of a robust, open, distributed, scalable, and transaction free database, enabling the data sharing procedure. The third one is related to owner controlled privacy, which according to the literature review is a strong demand, sometimes combined with strong willing of sharing when data usage is well understood and supported. Different schemes of data sharing would be a beneficial, including permanent and static storage but also streaming data sharing. Last but not least, different business models must be capable of being operated, as diversity is always a concern.

Based on the identified requirements, the way of proceed in the present research is to address all the components in the framework making it possible to deal with the major concerns identified and provide some relevant attributes,

- Implement Privacy by Design.
- Allow free and low latency transactions with low computing cost.
- Provide quasi-linear scalability.
- Enable synchronization to data streams.
- Capabilities for micro-payments in case of interest.
- Distributed database and Data encryption with different private keys.
- Enable owners' awareness.

The adopted methodology for this research is the action research able to build a conceptual framework. The *conceptual framework* [25] is understood as a network of interlinked concepts that together provide a comprehensive understanding of a phenomenon or phenomena. The concepts that constitute a conceptual framework support one another, articulate their respective phenomena, and establish a framework-specific philosophy. Conceptual frameworks possess ontological, epistemological, and methodological assumptions, and each concept within a conceptual framework plays an ontological or epistemological role [26]. The ontological role relate to knowledge of the "way things are," or "the nature of reality."

The key element of the research is to propose a consistent architecture or conceptual framework. Such a framework is presented in Figure 1, where the central figure of user is the key aspect, as far as she has the right to gain access over the data, otherwise encrypted.

The framework depicts the relationship between the key elements, however the semantic behavioral is consumed on the client side, making it possible the integrated exploitation of data from different sources.

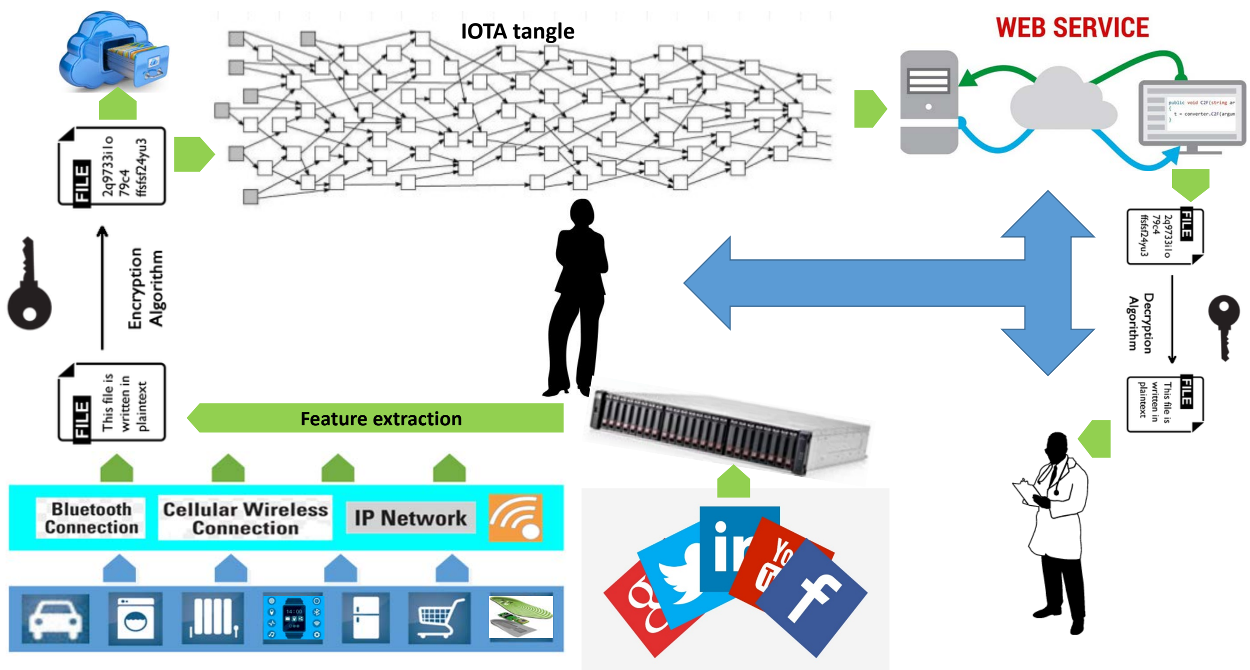

Figure 1: Proposed Framework describing the Knowledge space.

IoT software is required not only to dispose of huge volumes of real-time and heterogeneous data, but also to support different complex applications for business purposes. Based on an abstract information model, information encapsulating, composing, discomposing, transferring, tracing, and interacting in different application fields could be carried out. Combining ontology and representational state transfer RESTful Web service, the platform provides an information support base both for data integration and intelligent interaction.

Based on [27] the concept of Basic Resource (BR) is adopted as basic structure connected to data source with some variations from the original idea. It is also called independent resource related to single object type in the storage. The BR can be mathematically expressed by eq. 1 as depicted in Figure 2 according to the following elements,

$$\begin{aligned} BR &= < \text{URI}, \text{ObjectID}, AS > \\ AS &= \{C_1, C_2, \ldots, C_n\} \end{aligned} \tag{1}$$

- URI stores unique address of a resource, which could be used to locate the resource in the distributed back-end server.
- ObjectID records object ID, which stores the information of a data source, which is mapping to unique Object ID in Object Name Space (ONS).
- AS represents attributes set. AS consisted of several nodes such as aspects, proprieties, features, characteristics, parameters etc., which are related to the conception of domain ontology and are used in the format of the XML schema.

As defined above, BR is the basis of the resource model that contains the connection information and mapping relation with with data storage.

There is nothing against that web-services able to track specific comments or emotions throughout social networks can also inject their transformed content in accordance to the selected ontology.

By means of generalization, combination, and transformation operation, BR could be used to construct configured resources which could be transformed into RESTful web-services for business purposes. There are two kinds of configured resources: generalization resource (GR), based on the BR ;and composed resource (CR), which are configured based on BRs by combining their definition, for different purposes (see Figure 3).

Combining ontologies and RESTful Web services, a comprehensive platform can be established not only for an IoT-based application development but also for IoT object semantic management.

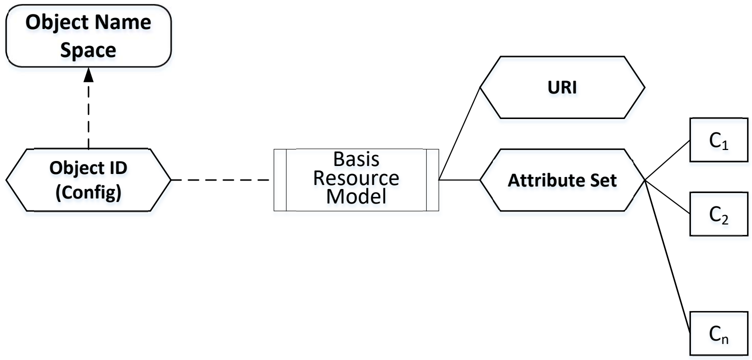

Figure 2: Relationship between the Basic Resource components.

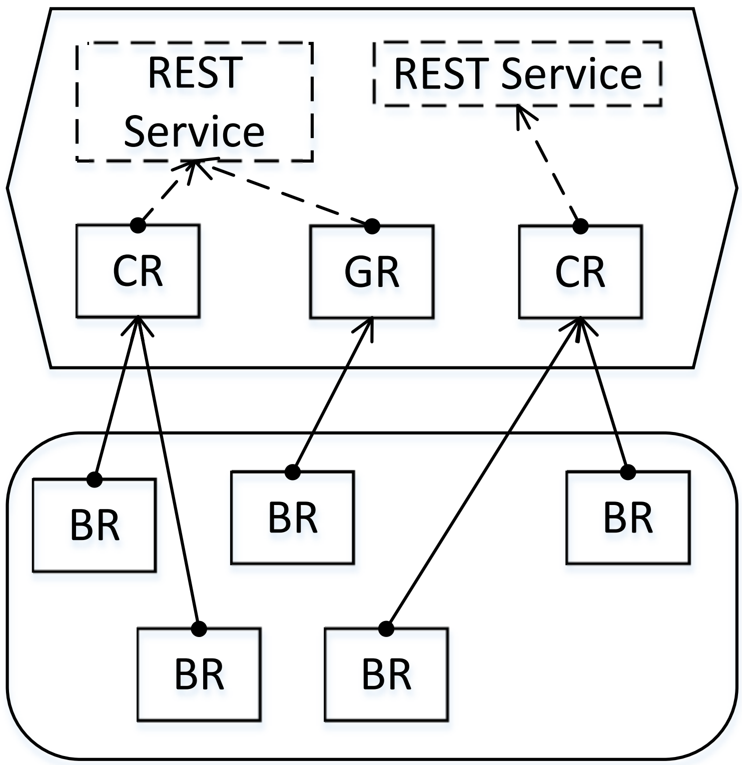

Figure 3: Usage of Basic Resource components to provide RESTful webservices.

The combination of ontologies is a necessary activity nowadays [28, 29], as they continue to grow. The alignment among ontologies allows defining individual correspondences between their concepts, based on measures of lexical or structural similarities. Normally the alignment is studied among whole of the concepts of two ontologies. To think in the best alignment for each concept, a multiple combination of ontologies in order to get the biggest benefit or enrichment in the objective ontology can be made.

4 Results

The adoption of such framework will enable the injection of data coming from different IoT and wearable devices into the adopted Distributed Ledger Technology (DLT) based IOTA®technology.

The IOTA®, is an open-source DLT designed to be scalable with zero-cost transaction fees and data integrity to power the future of the IoT, machines and identity solutions. Scalability and feeless transactions are mandatory

Table 1: Architecture of the authorization message for accessing personal data

Message components		
Key	Value	Data Type
Address	IOTA Address to be identified	81 Trytes
TAG	IOTA Tag for message search	Capital Letters
From	Starting date of granted period	Date Time
To	Ending date of granted period	Date Time
Key	Public Key, able to unecrypt messages	Long string
StartD	Initial Timestamp of relevant messages	DateTime
NumMesg	Number of messages to be accessed after StartD	Integer

for any identity-related solution and real-world mass adoption. These factors have been the major bottleneck for blockchain-based DLT. The IOTA distributed ledger approach, named as Tangle, is decentralised, will not require any servers, nor changes to IOTA Reference Implementation (IRI). The Tangle is based on Directed Acyclic Graph (DAG) and Masked Authenticated Messaging (MAM), has emerged as a powerful solution to address the real-world challenges of today. It implements either free, minimum value ($5 \cdot 10^{-7}$ €) or full valuable transactions making it possible to implement such level of dialog.

Actually, IOTA®implements the already mentioned MAM solution, which is very relevant to the application we are interested. This is because it is not needed to continuously send individual transactions to inform about measurements of individual smart sensors related to the building. Through MAM it can be used to publish secure streams of data, and control who has permission to subscribe to these streams. The policy can be implemented in such a way to monetize such data streams according to adopted encryption and cancellation strategies, which involve enough granularity levels to provide context for business model itself.

In MAM only those having the right ChannelID can get the access to read and reconstruct the data stream, as it is encrypted and anchored to the IoTA Tangle. This means that information sent by sensors to a limited audience can be processed and, even, commands can be sent back to the sensor by using the MAM stream as well, which means an extended flexibility for applications.

In order to enforce the privacy dimension through a public data storage, the framework proposes to deliver to the tangle json based messages but encrypted by using asymetric key management in a cryptographic system. In this way the owner can keep the control on their own data and she can give time based granted access to her data by sharing with the interested user an encrypted authorization message. Such message must be provided to a web-service in charge of unencrypt it, gain access to the tangle looking for the address or tag of the relevant messages and applying to them the unencrypt strategy able to return the content of the relevant messages if the current time fits into the granted period. Therefore, the structure of the authorization message, before encryption is presented in Table 1. Then, it will be encrypted by using the public key of the web service and delivered to the interested user. This user will collect the different relevant authorizations to create the interesting connected knowledge and the web-service will be requested to provide the access to it. In this way, the ontological usage of the individual messages can be very helpful.

5 Conclusions

The main conclusion for this ongoing work is that, even though the adoption of IoT is growing because of new adopters but also because of the new sensors being included, still there is a strong limitation in the use of such devices to help in understanding patient's behavior. The partial information gathered from single devices, and the very different contexts involved in the human daily activities make the goal very complex. Therefore, it is a need to work in gathering more sources of evidence, not only physical ones but also those related to feelings, believes, reasoning ways, etc., but also to integrate in a smart way the different available sources. From these perspective, the answer to the research question can be understood in the way that although the IoT technologies can provide significant insights regarding patient's behaviors, such information is not enough and higher degree on combination and integration is required, including semantic interpretation of different dataflows and keeping the management perspective of the proposed configuration.

In this way, this paper proposed a conceptual framework enabling a different schema for sharing private data from user wearable devices as well as other content throughout a public DLT system. As far as privacy is implemented by design in the framework, the owners have the right to grant or deny the access to their data based on limited periods of time. There is no limitation regarding neither the size of messages nor the number of messages being shared as the messages can store the link to an external URI for the objects. Indeed, by using smart contract approach, it becomes also possible for users to implement pay per usage of data, thorough the same DLT system adopted, named IOTA. As this technology enables the streaming option, indeed, it will be possible not to store the data in a permanent way but using the connected user topology to distribute data in streaming, without forcing such data to be in the tangle.

The proposed architecture is not limited to share raw data from devices. It enables as well to record secondary data coming from transformation of primary flow of information, like messages in a social network, after being processed to identify their sentiment or several other aggregations or transformations.

Finally, by adopting such framework the GDPR is fully respected and the framework enables to break the data silo paradigm currently existing and limiting the value creation from data, as they are difficult to connect. In this way, the combination of ontologies and their connection with the RESTful web services can bring additional value by dynamically combining data sources. Therefore, it is expected a significant increase of the management capabilities of the user based knowledge spaces.

With such a "ease to use IOT's framework", we could have a clear basis for future researches on patients' behaviors. The next steps will be to develop study cases for understanding the impact of ease of use in adoption of IOT. Based on Ryand and Deci's approach, we will study how a new generation of IOT's will enhance the adoption of wereable devices.

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