Data Management, Semantics and Personal Health Apps for Staying Safe in COVID-19[1]

Dimitrios G. Katehakis, Angelina Kouroubali, Georgios Kavlentakis,
Nikos Stathiakis, Fokion Logothetidis, Yannis Petrakis,
Vassilis Tzikoulis, Stavros Kostomanolakis, Haridimos Kondylakis
Institute of Computer Science, FORTH, Heraklion, Greece
{katehaki, kouroub, gkab, statiaki, fokion, petrakis, tzikoulis, kostoman, kondylak}@ics.forth.gr

Abstract. The ongoing coronavirus pandemic, is affecting the lives of millions of people, while changing our society by establishing new norms for social life, business, and traveling. The digital health domain has already tried to respond to the pandemic challenges, by the rapid development and release of mobile apps aiming to "flatten the curve" of the increasing number of COVID-19 cases. In this paper, starting from our own developed app to support citizens staying "Safe in COVID-19", we present our vision on how semantics and data management could highly contribute, along with personal health apps, to the secondary usage of available data in order to support effective disease management, prediction and increase the collective knowledge on the disease.

1 Introduction

The coronavirus disease 2019 (COVID-19) is an infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) [1]. Governments worldwide, in order to address the ongoing pandemic of COVID-19, have taken confinement measures that have resulted in an unprecedented disruption of lives and work for millions of people [2]. Measures have focused on the reduction of the spread of the epidemic and the minimization of the load of morbidity and mortality so that health care systems remain functional [3].

Key control measures include contact tracing, followed by treatment or isolation. For symptomatic patients, the following minimum set of data needs to be collected that includes information about date of symptom onset, referral criteria (based on clinical severity and presence of vulnerability factors), contact isolation status (at home, at the hospital, or at other self-isolation facility), and whether a sample has been taken (date of collection). The monitoring phase ends 14 days after the contact's last exposure to a new case, or if the contact develops COVID-19. In the latter case, monitoring is extended, not only for medical purposes but also for public health purposes so that isolation status is properly maintained, test results are directly shared with interested parties, and social patterns are analyzed.

However, patient data when available are not in the appropriate structure or form to be readily used by health applications available to citizens and health care providers. Real-time relevant health data is not even available to citizens to help them make basic decisions, such as going to a healthcare provider or going to work, etc. Healthcare professionals want to know how their patients' health is evolving in real time. Decision makers are not able to monitor citizens who report relevant symptoms and have not been tested with a diagnostic test for COVID-19 as well as how these cases evolve.

In response to the need to rapidly perform contact monitoring, many digital tools have been developed to assist with contact tracing and case identification [4]. Despite the fact that it is mobile solutions that enable the automatic detection of contacts, saving precious hours of work of public health staff, still several concerns have been raised from the very beginning in regards to legal and technical safeguards [5].

Non-functional specifications essential for the delivery of trustworthy apps are relevant to compliance with GDPR provisions, role-based access to patient depending on end-user roles, ensuring accuracy and security of the data, the ability to communicate with other applications/ registries using international standards (e.g. COVID-19 registries, citizen and healthcare professional identification service, etc.), as well as compliance with approved medical protocols.

To tackle these problems a solution named "Safe in COVID-19" has been developed, already published in [6], and is based upon existing work on personal health record systems [7, 8, 9] and the development of integrated care solutions to effectively support personal health management and public health [10].

This paper presents our vision of how digital technologies can help governments address epidemics such as COVID-19. It elaborates on the requirements necessary so that digital platforms can act as outbreak response tools. These include appropriate and effective data management and semantics as well as personal health apps that address the needs of citizens to effectively support contact tracing while staying safe in COVID-19. In addition, we highlight the existing technological, political and social barriers that need to be overcome for the effective digital management of the pandemic.

2 Relevant Work

Mobile technology has been leveraged in a number of ways to control the spread of COVID-19. During the past few months, mobile applications have been widely developed to facilitate self-assessment at home, training, information sharing, contact tracing, and decision making, swiftly offering effective and usable tools against the COVID-19 pandemic [11].

Platforms like COVIDSafe in Australia [12] for example, offer the ability to document registered isolation, to create a safeguard for isolated individuals, and to allow public health to conduct appropriate analysis and research. COVID Symptom Tracker [13] developed in the US, helps track the onset and progression of symptoms with the goal of shedding light on the nature of the disease, to identify those at risk sooner, to pinpoint virus hot spots and to help slow the spread of the disease. The Global Outbreak Alert and Response Network (GOARN) has developed Go.Data, a software application specifically designed to manage case-contact relationships and the follow-up of contacts [14]. Go.data has been deployed to over 35 countries in support of the COVID-19 Pandemic response. Several countries, such as France, Croatia, Germany, and Norway have already developed e-government apps for their citizens, under the direction or with the endorsement of public organizations.

Technical and privacy issues have been the main reasons for the slow adoption of digital solutions, despite the fact that some concerns have been addressed. In addition, it has been evident in the past few months that location tracking isn't popular. Unfortunately, evidence based assessment of existing apps is still not existent [11]. In addition, most solutions do not comprehensively include a full range of features. An important need includes the development and utilization of decision support tools to assist policy optimization for minimizing negative socio-economic impact, while contributing to the containment of the pandemic. Furthermore, despite the fact that online analytic dashboards for tracking COVID-19 exist [15], currently they present mostly recovered, and confirmed cases and deaths, and although massive numbers of data are collected, they exist in isolated data islands that are not widely available and hence cannot be used to enable further statistical analysis and prediction making.

3 Digital Platforms as Outbreak Response Tools

Mobile apps mostly providing location tracking, are not popular due to the many protocols currently available and their fragmented adoption. However, for such an app to be useful, to begin with, we envision an **interoperability layer** to be available, enabling the various such solutions to exchange data, providing a unifying layer on top of the individual proposed solutions.

To this direction **data FAIRification** is essential. All collected data should be made immediately findable and accessible through fully anonymization and publishing on the web using digital object identifiers (DOIs) and other permanent identifiers. Relevant ontologies and approaches such as the MHA Semantic Core Ontology [16, 17] can be used for semantically uplifting through mapping [18, 19] and/ or annotating available data using ontology terms. This will allow their rapid re-use, enabling a common understanding of the available data and offering a rich set of terms for documenting and adding meta-data to the data provided by the platform.

For enabling interoperability [20], **Fast healthcare interoperability resources (FHIR)** should be used for the representation of the medical data related to COVID-19 [21]. There are already established COVID-19 Patient Reported Outcome Observations [22], that includes the following symptoms: cough, fatigue, pain in throat, dyspnea, headache, diarrhea, nausea, loss of sense of smell, and temperature. FHIR resources (i.e. Problem and Condition resources) are also appropriate for representation of the underlying diseases related to COVID-19. These resources can automatically be published (properly anonymized) through a FHIR Server, further enabling interoperability with existing hospital health systems. The web app for public health authorities and healthcare professionals will consume these data and present to the end user of each application. The citizen's app can also act as a consumer of the FHIR server, in order to retrieve the personalized recommendations [23, 24] that healthcare professionals published to the FHIR server through the healthcare professional web app. Any hospital information system may also act as a data source for our FHIR architecture, since they can publish patient laboratory results for COVID-19 tests into the FHIR Server. Available applications then will be able retrieve the test results from the FHIR server and present them to the end users.

In addition, currently the **decision support tools** available, are limited to dashboards mostly for recovered and confirmed cases and deaths. However, more **intelligent dashboards** are required, enabling the multidimensional exploration of the available data, which will also take into consideration artificial intelligence (**AI) algorithms** and **epidemiological models** to **make predictions** on how the virus is spreading in each geographic region, combining regional, country and health-system data. Instead of raw data AI could work directly on semantically uplifted data, exploiting the semantic correlation in the available data. Being able to predict a few days in advance the number of beds needed is essential for health organizations to have time to organize resources to meet the health needs of their reference population (outsourcing of services, staffing, hotel sanitation, purchase of respirators, etc.).

It is obvious, that putting such a tool in operation requires **close cooperation with public authorities** for the development and deployment of the solution at a national level, compliance with approved medical protocols, interoperability with national registries for citizen identification and COVID-19, quality assurance, and the existence of the appropriate legal framework.

As already described, t**rust**, along with privacy and interoperability, is a key concern for individuals considering the adoption of personal health systems. As data are expected to be directly shared upon their creation appropriate anonymization techniques should be enforced for sharing information among patients, and their relatives, doctors researchers, policy makers and governments.

To this direction appropriate explanations should be provided to the citizens, encouraging them to use the COVID-19 apps, highlighting their importance for "flattening the curve" and explaining all measures taken to ensure anonymity and confidentiality.

Actual outcomes of relevant applications to a large extend depend on their ability to integrate with other healthcare services and infrastructure. Characteristics that increase their public value go beyond the focus on efficiency and effectiveness to encompass a wider range of characteristics such as the provision of legitimate user orientation, high level of participation, legality, and equity.

Safe in COVID-19 digital platform intends to respond to the challenges presented so far by being based on an extensible architecture, focused on all involved stakeholders including citizens and their families, healthcare professionals and public authorities. The platform addresses user information and communication needs and our vision is through semantic and big data technologies to enable, decision support tools on the collected data, and activates the appropriate proximity tracking protocols when needed. Further details are provided in the next section.

4 Safe in COVID-19

Safe in COVID-19 is an expandable digital platform that was developed in an effort to support national authorities in Greece. The platform provides tools for:

- **Public Authorities** to have a better overview of the actual situation regarding the existence of suspect, probable and confirmed COVID-19 cases by presenting real-time statistics.
- **Healthcare professionals** to manage and communicate with patients providing medical advice based on their patients reported status.
- **Citizens and their families** to record data on symptoms related to COVID-19, carry out self-assessment of their health condition as well as have access to credible, personalized information/ instructions provided by healthcare professionals.

In order to activate the app for a citizen, the user needs to be a confirmed COVID-19 case. Upon activation, the patient can record his/ her daily health status and communicate with healthcare professionals if needed. The contacts traced can also have the app activated for them to monitor the progress of their own health and to support better disease control.

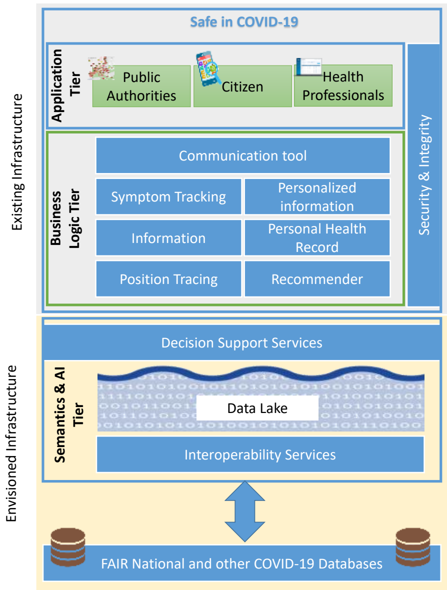

Fig. 1. Existing (gray) and envisioned (yellow) architectural components.

The information that the contact tracing teams gather on each contact are recorded into an internal database and can be pushed into external registries such as the COVID-19 patient registry provided by the national authorities. The platform architecture is shown in Fig. 1 (grey part) and consists of the Application Tier providing the front-end applications to the end-users, and the Business Logic Tier offering the intelligent functionality. All these layers are supported by security and integrity services as described below.

Application Tier. The Safe in COVID-19 solution includes the following applications: a) A web application for public health authorities; b) a web application for healthcare professionals and c) a mobile application (Android/ iOS) for citizens.

The web app for public health authorities aims to give a complete picture of the status regarding the spread of the disease at a national level and the measures taken by healthcare services. Real-time detailed data for the suspected, probable and confirmed cases are presented that can be useful for the surveillance of confirmed COVID-19 cases.

The web app for healthcare providers supports online communication with registered patients in order to provide personalized information and coaching and instant access to patient reported symptoms related to COVID-19 disease for monitoring their health status. The recording of COVID-19 laboratory test results is also supported.

The mobile application for citizens supports, among other things, the ability to record on a daily basis their health status and communicate synchronously or asynchronously with healthcare professionals in order to receive personalized instructions for managing their health. Initially, the patient registers into the platform and provides an initial self-assessment based on a questionnaire for underlying diseases related to COVID-19 (chronic lung disease, severe heart disease, immunosuppression, diabetes, renal failure, liver failure and morbid obesity). On a daily basis, the patient is prompted to record his/her symptoms which are related to COVID-19 and further self-assessment information using a Visual Analog Scale (VAS). These include cough, sore throat, shortness of breath or difficulty of breathing, fatigue, muscle pain, headache, runny nose or nasal congestion, diarrhea, loss of taste or smell. The patient also records vital parameters related to COVID-19 (body temperature, oxygen saturation SPO2, breathing rate, systolic and diastolic blood pressure and heart beats). Reminders for monitoring symptoms and vital parameters based on medical history and symptomatology help patients to proper use the app. The app also facilitates patient access to laboratory tests results.

Business Logic Tier. This tier consists of middleware services necessary for enabling communication between healthcare professionals and citizens, symptom tracking, managing personalized information and user profiles, general information, personal health records, position tracing, and recommendations. As the Safe in COVID-19 framework is based and significantly extends a fully-fledged PHR system, state of the art communication, user profiling and personal health records come out of the box, whereas the specific COVID symptom monitoring and recommendations along with the position tracking have been implemented specifically for addressing the COVID-19 outbreak. All the services communicate with an internal database to retrieve, update and store data, which are further visualized and presented to the user.

Security and Integrity. The sensitive nature of healthcare information creates unique security and privacy challenges [25]. Safe in COVID-19 modules do not process patient identification data but only the unique code generated pseudo-randomly by the health authority to confirm COVID-19 cases. The data processed have been minimized and encrypted in order to enhance security and privacy. Secure coding principles have been applied and all network communications between the modules are encrypted. In addition, the Safe in COVID-19 app for the citizens is consent-based [26] with full information of intended processing of data. In order to avoid trolling (i.e. entering on purpose false positives, undermining this way faith in the system) users may need to receive appropriate codes when entering data into the app to be confirmed by the server. Position tracking is legitimized by relying on a voluntary adoption by the users for each of the intended purposes.

5 Discussion & Conclusion

This paper presented the overall requirements that are essential in order to develop digital platforms that can act as disease outbreak support tools. Based on this vision, the digital platform Safe in COVID-19 has been presented, as an example of such a tool for public health authorities, healthcare professionals and citizens.

Foreseen benefits for public health authorities include decongestion of healthcare units, provision of real-time information on the evolution of suspected, candidate and confirmed cases, online monitoring of the spread of the virus, and effective decision-making regarding required measures. Benefits for citizens include systematic recording of symptoms, self-assessment, access to personalized information, and instructions and reminders based on their overall health status. Benefits to healthcare professionals include support in managing patients, reduced time for direct contact with patients, more efficient case management, and improved working conditions.

The effectiveness of such a digital platform depends on several, interrelated factors: (i) a comprehensive national epidemiologic strategy articulating instrumental support to the public health system (ii) the model selected (architectural, technological, etc.); and (iii) widespread connection with mobile devices.

Applications such as Safe in COVID-19 bear the potential of providing multiple benefits for the users if governed appropriately. The underlying infrastructure required in order to operate efficiently at a regional or national level is significant, bearing in mind the number of potential links to medical and diagnostic centers around the country and the size of the population under consideration. This of course should be linked to relevant national eHealth initiatives, if it is to be properly scaled up at a national level, in parallel with other means available. The solution supports the return to the "new normal" with less stress and more security for individuals, more direct and safer management of patients by physicians, and better possibilities for monitoring the epidemic by public health authorities. Finally, lessons learned from this experience that could be helpful for the future. Even if the COVID-19 emergency will end soon, such apps will help us to be better prepared in the future.

Acknowledgement

Work presented in the paper was supported by the Center for eHealth Applications and Services, Institute of Computer Science, Foundation for Research and Technology – Hellas.

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