



HAL
open science

Are People Ready to Report Digital Health Ethical Issues in Order to Contribute to Their Resolution?

Magali Robert, Nathalie Baudiniere, B. Séroussi

► **To cite this version:**

Magali Robert, Nathalie Baudiniere, B. Séroussi. Are People Ready to Report Digital Health Ethical Issues in Order to Contribute to Their Resolution?. *Studies in Health Technology and Informatics*, 2022, *Studies in Health Technology and Informatics*, 294, pp.760-764. 10.3233/SHTI220579 . hal-04007920

HAL Id: hal-04007920

<https://hal.science/hal-04007920>

Submitted on 11 Apr 2024

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons Attribution - NonCommercial 4.0 International License

Are People Ready to Report Digital Health Ethical Issues in Order to Contribute to Their Resolution?

Magali ROBERT^a, Nathalie BAUDINIÈRE^a and Brigitte SEROUSSI^{b,c,1}

^a *Agence du Numérique en Santé, Paris, France*

^b *Sorbonne Université, Université Sorbonne Paris Nord, INSERM, Laboratoire d'Informatique Médicale et d'Ingénierie des connaissances en e-Santé, LIMICS, F-75006 Paris, France*

^c *AP-HP, Hôpital Tenon, Paris, France*

Abstract. Although guaranteed by the GDPR, transparency of health data processing may not be fully respected, leading citizens to mistrust eHealth and discard digital health services. Identifying and safeguarding ethics in eHealth services is thus important to promote their development. We conducted a survey to assess the extent of ethical issues induced by the use of digital health services, understand the efforts citizens would be willing to accept for reporting such issues, and evaluate citizens' expectations regarding this reporting. Among 200 respondents, 36% reported having encountered ethical issues with the processing of their health data or with digital health services being poorly inclusive. Faced to ethical issues when using a digital health service, 49% of respondents were rather or very angry, and 33% felt rather or very dependent. Most respondents were ready to report digital health ethical issues if there is a feedback for each report.

Keywords. eHealth services, ethics, health data processing, online survey

1. Introduction

Digital technologies have been introduced, and sometimes imposed, at great speed in many areas of the daily lives of French people, particularly in the field of health. If digital health technology does promise benefits (*e.g.*, helping people book medical appointments more efficiently, completing administrative procedures for pre-admission in a healthcare facility, enable remote consultations, or being monitored continuously outside of consultations), eHealth is not exempt from general concerns that this accelerated transformation could deepen inequalities [1]. In addition, several ethical concerns are associated with the role of big data analysis in personalized healthcare [2]. Identifying and safeguarding ethics in eHealth services is thus important to promote the development of an ethical eHealth [3], because it is also not ethical to not offer eHealth services benefits to all.

Beneficence, non-maleficence, justice, and autonomy are important overall ethical principles enshrined in the Hippocratic Oath. When crossed with digital health technology, these ethical principles essentially cover issues related to privacy, protection,

¹ Corresponding author, Brigitte Séroussi; E-mail: brigitte.seroussi@aphp.fr

defence of rights, advocacy, equality and equity, and trust [4]. Trust relies on data processing transparency (citizens should find out who accessed their health data, when and for which purpose) that may reassure citizens about their data being processed properly. However, though guaranteed by the GDPR, these rights may not be fully respected leading citizens to mistrust eHealth and discard digital health services.

Prior to the launching of a new national French digital health service, My Health Space, a digital health record system accessible to patients and authorized healthcare professionals, and the expected concomitant deployment of digital uses in health, the French Ministry of health wanted to assess the interest of setting up a national platform for reporting digital health ethical issues. The objectives of this work are to assess the extent of ethical issues arising by the use of digital health services, identify the populations that are most likely to experience these issues (patients? health professionals?), understand the efforts that citizens would be willing to accept to report an ethical issue, and evaluate the expectations of citizens following this reporting.

2. Material and Methods

2.1. Conclusions of prior national citizen workshops

In 2020, the French Ministerial Delegation for Digital Health organized citizen workshops that concluded on four major areas of concern about digital health: (i) exclusion of a portion of the population (digital divide), (ii) fragmentation of health information (the silos of a fragmented health system lead to a lack of fluidity in an often hyperspecialized medicine, which involves a large number of medical and administrative actors in different temporalities, (iii) deprivation of patient information and lack of transparency of data processing, (iv) complexity of digital health services.

2.2. Analysis of citizens' need of a tool to report digital health ethical issues

We first organized face-to-face semi-structured interviews of a sample of digital health users, including citizens and healthcare professionals. The interview script addressed questions on the participant's actual use of digital health services, the ethical issues he/she encountered, and how he/she reacted (did he/she try to find solutions on internet? did he/she try to report the issue (e.g., through customer service), what reporting services did he/she use?). Each interview was recorded in a report. All reports were transcribed for manual thematic analysis [5].

In a second step, we conducted an online anonymous survey targeting patient-citizens experiencing a daily use of digital health tools in the follow-up of their chronic disease. The questionnaire was published on social media, relayed by *France Asso Santé* (the French National Union of registered associations of users of the health system). The survey asked about (i) digital health services most frequently used (prevention and wellness tools such as calorie tracking, step count calculation, pulse tracking; websites to consult and download laboratory or medical imaging results; online appointment scheduling; online pre-admission/file submission for medical or medico-social clinical facilities; monitoring of chronic diseases, e.g., diabetes, asthma, or of drug side effects, e.g. oral chemotherapy; monitoring of biological constants as part of a medical follow-up, e.g., blood sugar, blood pressure; personal medical record, such as the French DMP, or EHRs), (ii) ethical issues encountered by citizens concerning their health data (I didn't

understand where my health data were going; I didn't understand if my health data were shared and with whom; I didn't understand if my health data were reused to be sold by the digital solution provider; I tried to delete information but could not; I was asked for personal information that was not relevant to my condition or the purpose of the digital health service), (iii) technical difficulties experienced by citizens when using a digital service (I could not find my information in the application; I couldn't use the tool or the website because it was too complicated; I read the terms and conditions (T&C), but I did not understand what kind of data processing was performed and whether data were shared with third parties), (iv) feelings of citizens when faced to digital health ethical issues (Lonely; Stressed/worried; Dependent; Upset, all items being graded on a 5-point Likert scale, with 1: not at all, and 5: very), (v) citizen reactions (I did nothing, but I did not use the digital solution anymore; I did nothing and deleted the application; I talked about the issue with a health care professional; I searched the internet to find where I could describe my problem; I reported the issue on social media (forums) to see if other people encountered the same issue and how they solved it).

The last question was to test if there was a portal (developed by the government) where one could report digital health ethical issues with the aim of contributing to their resolution, one would use it or not and why.

3. Results

3.1. Face to face interviews

Individual interviews were conducted between September and October 2021 on a sample of 32 people selected to represent the diversity of digital health users and that accepted to participate: health professionals, citizens, experts from medico-social and health sectors (including a director of a long-term care facility), someone from a healthcare technology company (Doctolib), from CNIL (*Commission nationale de l'informatique et des libertés* is the French regulator of personal data), representatives of patient associations (France Asso Santé and the French Diabetes Federation), and representatives of hospital patients. Each interview lasted between 30 and 90 minutes.

Digital health services mostly used were mainly online appointment booking and laboratory results retrieval sites, with a high level of confidence in these sites. Citizens did not raise any ethical issues. Despite they agree that how things are working is "opaque", their suspicion was compensated by their trust towards health professionals (for the management of EHRs) and the value of the service provided (health or well-being websites and applications). The most confident were those who work in the digital sector, because they felt that they have a better understanding and control of the process. Fears were finally distant threats/disagreements as compared to the service provided and the health issues raised by digital tools.

3.2. Online survey

Between October 22, 2021 and November 5, 2021, 400 responses were collected, but we excluded the first 200 from our statistics because of some inconsistencies in the questionnaire. In both the interviews and the online survey, the majority trend was the use of online appointment booking and laboratory results retrieval sites. Figure 1 displays the distribution of mostly used digital health services.

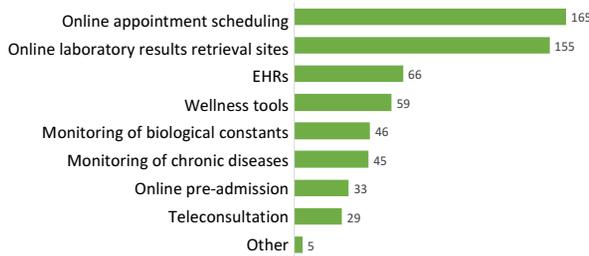


Figure 1. Distribution of mostly used digital health services (n=200).

Of the 200 actual respondents, 63 reported having encountered ethical issues (on health data processing or other topics such as the weak inclusivity of digital health services). Figure 2 displays the distribution of such ethical issues.

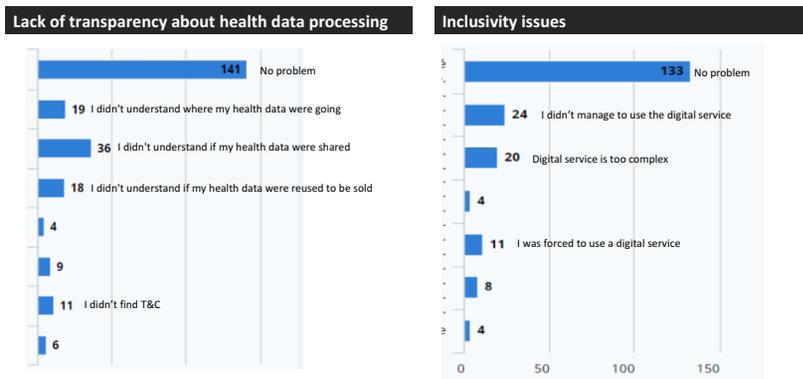


Figure 2. Distribution of ethical issues for health data processing and digital health accessibility (n=200).

Other digital health ethical issues have been reported in the “other” answer:

- Appointment scheduling for people with disabilities: "When I arrived at the appointment in a wheelchair, I had to go back home because I had not specified that I was in a wheelchair, which was impossible when I made the appointment online, and there was no access for disabled persons."
- Forced teleconsultation: among teleconsultation users, more than half complained that they were forced to use the service (n=29).
- Access to online laboratory results: "I gave up on getting my exam reports because of problems accessing the service."
- Forced consultation: "The replacement of my physician called me even though I am not followed for a particular pathology. I discovered afterwards that he billed for a teleconsultation, even though he had not informed me."

The analysis of the answers to how respondents felt when faced to some ethical issues when using a digital health service showed that 49% of the persons were rather or very angry, and that 33% felt rather or very dependent (see Figure 3).

The survey provides answers to how people react when trying to solve ethical issues. Of the people who said they encountered one of the problems listed, 27% (out of 63)

took advantage of the online questionnaire to describe it in the “Specify” window. When questioned about whether they would report digital health ethical issues on a dedicated governmental platform, some respondents give conditions and obstacles: "have a feedback", "reports need to be analyzed", "one more reporting service!"

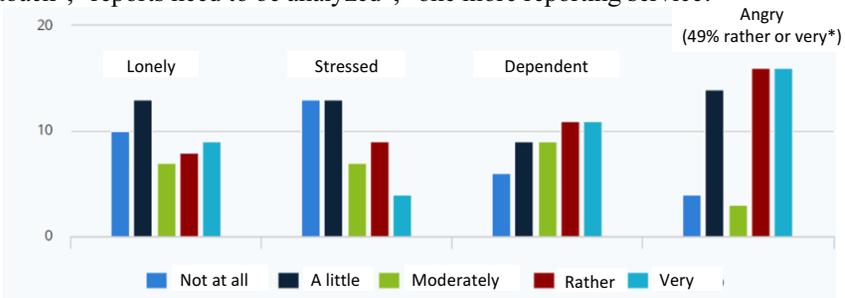


Figure 3. Distribution of users' feelings when faced to digital health ethical issues (n=63)

4. Discussion and Conclusions

Users encounter known digital health ethical problems, but the details for action have yet to be defined. Existing media (*e.g.*, CNIL complaint service) allow citizens to report irritants, but they are little or not treated. A significant part of digital health users was nevertheless ready to report the problems encountered, only if some conditions are checked: there is a feedback for each report; the ethics unit in charge of processing the reports should strongly communicate to encourage compliance with the laws and regulations in force by the actors concerned (professionals, publishers, organization); the reporting service must be visible and easily accessible from the tools concerned: it is necessary to find a high-traffic site that makes the service visible and effortlessly accessible; the implementation of a way of processing reports according to their types is essential for a quality user service which requires a significant work to identify and characterize these types; having a tool for processing reports must be anticipated before getting high volumes (CRM type or other).

References

- [1] Jokinen A, Stolt M, Suhonen R. Ethical issues related to eHealth: An integrative review. *Nurs Ethics*. 2021 Mar;28(2):253-271.
- [2] Althobaiti K. Surveillance in Next-Generation Personalized Healthcare: Science and Ethics of Data Analytics in Healthcare. *New Bioeth*. 2021 Dec;27(4):295-319.
- [3] Skär L and Söderberg S. The importance of ethical aspects when implementing eHealth services in healthcare: A discussion paper. *J Adv Nurs*. 2018 May;74(5):1043-1050.
- [4] De Rosis S and Barsanti, S. Patient satisfaction, E-health and the evolution of the patient-general practitioner relationship: evidence from an Italian survey. *Health Policy* 2016; 120(11): 1279–1292.
- [5] Braun V and Clarke V. Using thematic analysis in psychology, *Qualitative Research in Psychology* 2006,3(2):77-101.