Exploring users' willingness to share their health and personal data under the prism of the new GDPR: implications in healthcare

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Abstract— At the same time healthcare undergoes a digital transformation, the implementation of the new General Data Protection Regulation (GDPR) introduces changes to internet users. Understanding users' data-sharing attitudes for four type of personal data in regards to the new GDPR can facilitate stakeholders and policy-makers in healthcare to make sense of the current landscape. Authors analyzed the results of a questionnaire survey to explore the willingness of 8.004 people across four European countries to share four types of data: health; perceived values or beliefs; consumption habits and purchases; and wealth. Our results suggest that participants are more willing to share health data and data about beliefs and values than wealth information and that GDPR has impacted the data-sharing behavior of the participants.

I. INTRODUCTION

A vision of future healthcare systems is to enable personalized care, while reducing expenditures, without jeopardizing quality of services [1]. To achieve this the role of data is essential [2]. The exponential amount of personal health contributes on that, as people have adopted wearables, mobile sensors and living space sensors in their daily life [3], [4], [5]. According to the International Data Corporation (IDC), 344.3 million smartphones were sold globally in the first 3 months of 2017 [6], with the number of smartphone users projected to reach 2.1 billion in 2020 [7], while the number of IoT sensors connected to network are forecasted to be between 30 to 50 billion devices [8], [9].

The potential benefits of utilizing the large volume of personal health data are numerous. For example, to identify risks and costs in healthcare delivery, to improve the efficiency of services, to manage life-style related diseases, or to explore new treatments for cancer [3], [10]. Applications for disease prevention like the Flu Near You to map flu symptoms across the US in real time [11], or the HealthMap for infectious disease outbreaks are examples of commercial data-sharing potential [12]. These paradigms have not only increased users' expectations, but also accelerated healthcare professionals and practitioners' efforts towards the creation of more agile systems to share health data [2], [13].

Data protection is related to data access and share [14]. The implementation of the new General Data Protection Regulation (GDPR) on May 2018 introduced European citizens to a new era: the era of individuals' empowerment and shared-decision making. The new legal framework aims to bridge the legal gap that emerged from the evolution of new technologies, as well as to harmonize data protection frameworks across Europe [15]. On a worldwide level according to the World Health Organization (WHO), only 34% of the Member states reported data-sharing legal frameworks for data exchange within the same country, and only 22% for international data-sharing exchange [16]. Therefore, harmonization of legislation in a global level is still in development stage. In the EU it has been less than a year since GDPR implementation, so the empirical research around GDPR and personal data is not yet extensive, while the need for better understanding of users' attitudes is an essential step for future healthcare services.

Technology adoption and users' behavior has been discussed by a number of theories, for example the technology acceptance model or the theory of reasoned action [17], [18]. Both theories argue that users develop specific attitudes towards technology, but also that there is a positive relationship between attitudes and behavioral control [17], [19], [18], [20], [21]. In the context of our study users' intentions to perform actions "are assumed to capture the motivational factors that influence a behavior; they are indications of how hard people are willing to try, of how much of an effort they are planning to exert, in order to perform the behavior." [19] pp.181. Based on that, willingness to share personal data can be indicative of users' intention to perform an action in a given context. In this study we will explore and discuss how data-sharing willingness of users changes in relation to the type of personal data under the prism of the new GDPR, focusing on the implications of these attitudes to future healthcare services.

II. BACKGROUND

Users' incentives to share personal health data has been the subject of previous studies. Weitzman et al. (2012) concluded that willingness is dependent on expectations for care improvements [22], while others related incentives with exchange of health information [23], provision of personalized services [24], or in support of research endeavours [24]. Sharing de-identifiable clinical data for research found to be the preferable mode [25]. Users are in favour of controlling their data, while opt-in models, control options over sharing settings and patients-centered models have been seen to have positive effects on users' willingness [26], [27], [28].

The type of personal data users choose to share has influence on their attitudes. While sharing other types of data, such as demographics, lifestyle habits, and purchase behavior have been seen to entail lower privacy concerns, the case of sharing health data, financial information and personal

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identifiable data, acknowledged to provoke higher concerns which is likely to have impact on users' willingness [29], [30], [31], [32], [33]. Information sensitivity is closely related to privacy risks and attitudes, and relates to discomfort to disclose personal information to service providers [34]. Malhotra et al. (2004) related the perceived sensitivity of the information with users' willingness; the more sensitive information considered to be the more reluctant is one to disclose it to service providers [34]. The study of Whiddett et al. (2006) reached similar conclusions in a health context [35]. In the same vein, Pickard found that 81% of the consumers would be willing to share data about their diseases and conditions for research purposes, but less about their electronic medical records (72%), suggesting that the type of medical information differentiates attitudes [24].

Perceived values have been seen to be to some extent personal preferences that reflect socialization [36]. Values are culturally shared, but people have different hierarchical structures and rank them in different positions based on their perceived importance. However, this hierarchy is unstable and can change depending on different factors, for example materialism [37]. Over the last years researchers explored the effects of different data types on users' willingness to share personal data [30], [31], [33]. Nevertheless, our knowledge about data-sharing attitudes after the implementation of the new GDPR is limited.

III. METHODOLOGY

The study was distributed by Kantar TNS Oy, a global market research company, on behalf of Sitra. Sitra is a Finnish Innovation fund that through its research aims to influence policy makers towards a more sustainable well-being in social, financial and ecological levels. The data used in this paper is a subset of a larger research that conducted within the frame of IHAN project [38]. The scope of IHAN project is to provide society with the foundations for trust data economy and to influence policy-makers towards a human-driven data economy. Data collection was carried out from 6th to 18th of December 2018 in four European countries: Finland, Netherlands, Germany and France. An average completion time of the online survey was twelve minutes.

The survey was composed of 27 questions to collect data pertinent to background characteristics of respondents, attitudes toward services, trust towards services and data management. Participants were asked open-ended and closed-ended questions. For the purpose of this study authors considered only two closed-ended questions to address the main research question (RQ) of this study: *How has the EU's GDPR affected users online sharing behaviour in regards to four types of personal data?* To answer the main RQ, the following RQs were investigated:

RQ1. Are users willing to share health data more than other types of data?

RQ2. How the new GDPR affected users online behaviour?

In this study, personal data refers to four types of data pertinent to: health or heredity; perceived values or beliefs;

consumption habits or purchases; and wealth. In RQ1 users where asked about their willingness to share the aforementioned types of data with service providers. In RQ2, users were given three options to answer: "I have contacted the service provider for actions and informations"; "It has not affected my behaviour in any way" or "I don't know". In addition to RQ1 and RQ2, several socio-demographic backgrounds questions were given to the participants to capture factors that might influence users' willingness and where taken into consideration in the analysis of results.

The questionnaire of this study was delivered in the official language of each country. Results were translated to English to ensure consistency and common understanding of results. The inclusion criteria were consent for participation to the survey and self-declaration to be at least 18 years old. In total, 8,004 replied to the questionnaire: 2,000 from Finland, 2,000 from Netherlands, 2,004 from Germany and 2,000 from France. The survey was conducted anonymously in compliance with the EU GDPR legal framework. The calculation of data was performed using IBM SPSS software.

IV. RESULTS

TABLE I
PARTICIPANTS DEMOGRAPHICS.

Demographics	Average of percent of all countries (n=8004)
Gender	
Male	49%
Female	50%
Other	1%
Age	
18-34	32%
34-44	19%
45-65	49%

Table I presents the participants demographics, while Table II presents the results of RQs. The most common response supported sharing data, with the exception of participants in Germany regarding wealth data. Gender has slight impact on the results, males are slightly more willing to share their data than females. Younger people tend the share their data more than older participants. GDPR seems to have impacted the behavior of the majority of respondents (all genders and age ranges included).

V. DISCUSSION

In line with previous literature [30], [34], we found that users would be willing to share data about consumption and purchases, however they were very reluctant to disclose data about wealth. Approximately two out of three users were willing to share information about their values and beliefs, and health and heredity data. The ease of sharing values and believes is not perhaps a surprising finding, if we consider that people often share personal values on social media [39]. An interesting finding is that wealth data considered to be more sensitive type of data than the other three types.

The idea of data altruism could possibly explain the participants' willingness to share their health data, as users often believe that by sharing their health data could contribute to

TABLE II

RESULTS OF RQS. (N = 8,004). *Acronym. DN: I don't know*

			Country				Gender		Age		
			Finland	Germany	Netherlands	France	Male	Female	18-34 y	35-44 y	45-65 y
RQ1	**Health or heredity**	Yes	60.31%	51.54%	60.19%	54.30%	56.96%	55.95%	65.55%	57.18%	49.92%
		No	32.54%	35.67%	25.37%	25.54%	30.41%	29.68%	22.06%	26.86%	36.55%
		DN	7.15%	12.79%	14.45%	20.16%	12.63%	14.37%	12.40%	15.96%	13.53%
	Values or belief	Yes	62.92%	52.70%	61.32%	46.19%	56.92%	54.43%	66.53%	58.57%	46.92%
		No	24.85%	32.00%	21.62%	30.10%	32.69%	36.74%	26.60%	31.42%	41.52%
		DN	12.23%	15.30%	17.06%	23.71%	14.46%	17.89%	15.21%	18.00%	16.38%
	Consumption habits	Yes	77.83%	67.88%	67.24%	64.37%	69.98%	68.77%	76.88%	69.92%	63.68%
		No	13.21%	19.45%	17.71%	15.96%	17.13%	16.24%	10.33%	15.33%	21.58%
		DN	8.96%	12.68%	15.06%	19.67%	12.89%	14.99%	12.79%	14.75%	14.74%
	Wealth	Yes	48.23%	38.81%	44.85%	47.18%	48.65%	40.57%	58.50%	47.97%	33.60%
		No	41.68%	46.56%	39.12%	30.80%	37.29%	42.37%	26.26%	35.72%	50.66%
		DN	10.09%	14.63%	16.03%	22.02%	14.06%	17.06%	15.25%	16.30%	15.75%
RQ2	There is an impact on behavior		75.82%	77.80%	74.89%	69.80%	82.35%	66.98%	93.52%	77.30%	59.90%
	No impact on behavior		36.14%	37.56%	33.31%	36.30%	35.38%	36.80%	30.61%	33.16%	40.69%
	DN		9.95%	8.22%	17.66%	10.98%	9.59%	13.16%	10.49%	12.82%	12.09%

health improvements for the general population [40]. Another explanation could be attributed to the benefits of data sharing to users. According to IBM Big data & analytics Hub, 4.9 million users globally could have received out-hospital monitoring using sensors in 2016 [41]. Applications such as real-time alerting for asthma monitoring [42], identification of risk factors for opioid abuse [43] and discovery of new medication for lung cancer cure [44], are among the applications that had been seen to have positive impacts on people's life. Health data is already treated as a currency. Blockchain application in healthcare is not a fictitious scenario. CoverUS pays consumers for selling their health data with a cryptocurrency called CoverCoin [45]. Other examples are the US-based company Miinome in which clients can cash-in their DNA in return of recommendations or the Hub of All Things project in which users can store and trade their personal data in exchange of "private analytics and algorithms for insights into their data, their health, their history and their memories" [46], [47]. The updated opt-in model introduced after the implementation of GDPR could have also a positive influence on users willingness. This finding is in line with previous research about users' preference for opt-in and patients-centered models [26], [27], [28]. However, we should consider that the opt-in consent check box is presented so frequently on webpages and mobile apps that it is likely that users do not read the consents and just agree on that, resigning thus their privacy rights.

In the second quarter after the implementation of the new GDPR more than one third of the participants (36% on average) reported that the enforcement of GDPR has had no effect on their behavior. Though the timeframe of this study after the enforcement of the new GDPR is short, we could argue that the fuss on social media networks around the new legislation and the reception of numerous email by companies and organizations about new cookies and consent appears to have effected users' attitudes. From a corporate viewpoint, preparations about the implementation of the new legislation were hectic several months or even years before its implementation. For example, check lists

to prepare for compliance has been prepared to facilitate the transition [48]. Nevertheless, in regards to the level of readiness of companies and organizations to provide access and sharing rights to users some instances prove that they where unprepared to offer these services to users [49]. This also requires that users have knowledge over their rights. Taking into consideration that privacy policies often fail to communicate risks of data linkage and processing rights, knowledge over privacy and data sharing risks should not be considered obvious for everyday users [50].

Before May 2018 voices were stressing a number of fallacy challenges for the new law. Namely the "delusion" that subjects will have control over their data and false expectations about simplification and comprehensiveness of law [51]. Sharing health data is essential for provision of tailor-made services, preventive care and creation of sustainable healthcare systems. A challenge for future healthcare is to support users to understand their own disclosure rights, but also benefits and risks. Simplification of privacy statements could also contribute on that. Our findings suggest that while that users' attitudes are changing, users are willing to share their personal health data. In the light of that, policy-makers and stakeholders should safeguard future endeavours and ensure responsible and ethical use of personal data.

VI. CONCLUSIONS

Our findings suggests that our participants consider health data and data about beliefs and values in a similar manner. However, users were reluctant to share information about wealth. The results of this study suggest also that GDPR has impacted the behavior of participant's in term of sharing data. Future work should include more qualitative research in order to better understand why users adopted these attitudes.

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