Dynamic Consent for Sensor-Driven Research

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Dynamic Consent for Sensor-Driven Research

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***Abstract*—Dynamic consent is a term initially emerged in biomedical research that involves a large-scale, long-term participant engagement for continuous data collection (e.g., biosamples, health records). Dynamic consent is a wider concept of informed consent that enables granular consent in dealing with personal data. Dynamic consent is typically incorporated into a personalized digital platform that allows participants to tailor and manage their own consent preferences. This feature leads to improved transparency and proactive privacy management. Due to such benefits, dynamic consent offers potential applications in other domains that collect diverse data that require multiple consents over time. One possible testbed is *digital health*, where there have been several attempts to track symptoms and diagnose mental illnesses (e.g., depression) with data collected from mobile and wearable devices (i.e., digital phenotyping). As these sensors continuously collect personal data, users may feel uncomfortable in certain private contexts. However, the current status of the studies only provides one-off informed consent without consideration of specific user contexts, which calls for context-aware fine-grained control. Thus, this paper explores the feasibility of dynamic consent in sensor-driven research and suggests a future outlook of dynamic consent usage in mobile and ubiquitous computing.**

***Index Terms*—Mobile and Wearable Sensing, Digital Phenotyping, Dynamic Consent, Sensor-Driven Research**

I. Introduction

Informed consent is a process in which a healthcare provider informs a patient about the risks, benefits, and alternatives of a given treatment [1]. Acquiring informed consent from participants prior to a research has been a fundamental step in biomedical research, which involves a large-scale clinical studies for pharmaceutical purposes with human subjects [2]. This process is known to form the basis of data protection and privacy management.

However, recent technological advances in biomedical research raise questions on the appropriateness of traditional informed consent (e.g., paper-based, face-to-face interaction). As information technology enables much richer and comprehensive collection of personalized datasets and increases the possibility of linking collected datasets via genetic databases, registries or online digital databases, traditional informed consent faces a few challenges (e.g., re-consent, data privacy) in reflecting such changes in the nature of biomedical research.

Naturally, there is a transitional movement that calls for a flexible form of consent. Dynamic consent is a wider concept of informed consent that provides participant-centered decision making in managing consent preferences via digital interface. It allows researchers and participants to see in real-time what permissions are associated with the data and enables participants to review and update their consent decisions over time. This new way of doing research was initially developed in the field of biobanks, a type of biorepository that stores human biological samples (e.g., genomics data) and data derived from such samples for research [2]. Biobanks offer access to samples and data derived from these samples, which can be used by multiple researchers for cross-purpose research studies [3].

Although its current usage is confined to biomedical research, dynamic consent has the potential to be applied more broadly to research domains that utilize health data. Since health data requires constant monitoring and may require different consent over the phases, one possible domain worth exploring is digital health that deploys mobile and wearable devices. There is a growing body of digital health study that has been focusing on detecting and intervening mental illness with mobile and wearable devices [4], [5]. This kind of sensor-driven research requires continuous multi-data stream collection, and thus, dynamic consent can be used to deal with data management and privacy concerns.

With such background, we provide an overview of dynamic consent and explain the need of context-aware dynamic consent in digital health (Section 2). We then conduct an exploratory study that implements a preliminary version of context-aware dynamic consent in sensor-driven research (Section 3). Then, we further provide an outlook on its potential in the mobile and ubiquitous computing community (Section 4). The key contributions of this work are as follows:

- First, we introduce the concept of context-aware fine-grained dynamic consent into the research community by extending the existing concept in the field of biomedical research.
- Second, we provide an empirical exploration of dynamic consent in sensor-driven research and share our insights on its feasibility and challenges.
- Third, we offer implications for future research directions in managing data collection and participant privacy protection in the context of sensor-driven research.

II. Context-Aware Dynamic Consent

A. Challenges of Traditional Informed Consent

Informed consent is regarded as central to voluntary participation in biomedical research to notify participants of the risks and benefits of taking part, and to explain what will happen during a study [6]. The requirement for consent is underpinned by ethical principles of respect for persons and individual autonomy, which is supported by the Declaration of Helsinki and its following legal clauses [7].

Along with this legal foundation, there is a shift in the nature of biomedical research infrastructure such as biobanks and data repositories that support open access policies [8]. Thus, researchers are required to endorse adaptive and flexible approaches to accommodate these rapid changes and comply with ethical and regulatory requirements.

One challenge of traditional informed consent lies in its difficulty acquiring re-consent. In the case of biobanks where there are multiple researchers and research projects, it is practically difficult to foresee every future research need and acquire each consent in the process of recruitment or prior to research [2]. Re-consenting can be costly and time-consuming in traditional informed consent that takes paper-based form and requires face-to-face interactions [9].

Second challenge is the limited autonomy and privacy risks of participants. As biomedical research requires continuous collection of biological samples and health-related records over a long period, participants are asked to consent to multiple, emergent research methods. Along the process, participants should be given much choice and control in their personal data management. However, such control is not fully executed due to insufficient information on data protection [2]. Although current guidelines recognize consent as an ongoing interaction between researcher and participants, traditional paper-based tools that have been used to record consent have limited engagement [2]. Such status delimits participants' proactive configuration on specific privacy preferences.

B. Dynamic Consent and its Features

In an attempt to overcome the aforementioned limitations of traditional informed consent, more adaptive and flexible approaches have emerged. One strategy to overcome the static nature of traditional informed consent is *dynamic consent*, which refers to a personalized digital interface to facilitate participants' engagements in clinical research. There are two distinctive features of dynamic consent in terms of consent management [9].

First, participants can configure their consent preferences in real-time. The crux of dynamic consent is that participants can give/revoke consent to the use of their samples and data in response to specific contexts and are able to make fine-grained withdrawal decisions [9]. Second, dynamic consent offers transparency and improves privacy risk management. By providing operational control to participants in terms of data management, participants can track their data usage. This audit process increases public trust and autonomy of a participant by offering them a chance to make proactive decisions [8].

C. Context-Aware Fine-grained Dynamic Consent in Sensor-Driven Research

Thanks to its flexibility in consent management, dynamic consent offers potential applications in other domains that require multiple and varied uses of data. Dynamic consent offers operational control of data collection and sharing to participants by allowing them to selectively collect and share their data depending on their contexts. This context-awareness is essential in living lab research scenarios for smart healthcare where study participants use mobile and wearable devices to continuously collect data from their everyday lives (e.g., GPS and physical activities) and occasionally perform participatory sensing tasks (e.g., emotion or food intake diaries) [10]. Recent mobile and ubiquitous computing studies are probing the potential of living labs by conducting sensor-driven research that uses sensor and interaction data to offer insights into human behavior and function in health and diseases.

This new approach, also known as digital phenotyping is showing how the sensors in our daily lives can be repurposed to provide behavioral biomarkers and build models that can predict the risk of diseases (e.g., depression, heart disease) and tailor digital intervention [11]. The methodological advantages of using these passive/unobtrusive sensors are that the sensors can provide meaningful insights through continuous measurements in real-time, and at scale. For example, the Apple Heart Study app uses data from Apple watch users identify irregular heart rhythms to infer potentially serious heart conditions [12]. Similarly, eHeart project from UCSF collects comprehensive data of a users' wearable device, social and medical records to predict the occurrence of a heart disease [13]. Wang et al's study deployed a continuous sensing app called 'StudentLife' to monitor students' academic performance and mental well-being [4].

Besides its benefits, little work has addressed digital phenotyping's potential privacy concerns. While data collected from biomedical research involves human biological samples and representative data from those samples, the range of data collected from digital phenotyping is more comprehensive than traditional biomedical research [14] (see Table I). As it involves 24/7 continuous sensing of personal data (e.g., biosignals), digital phenotyping poses greater privacy risks (e.g., routine data breaches, unintentional collection of sensitive information) [15].

Furthermore, participants may feel uncomfortable about data collection in certain private contexts (e.g., wearable data collection in the bed or restroom; or GPS data collection at privacy-sensitive locations such as hospital visits). Despite these concerns, the current status of digital phenotyping research allows only one-off consent prior to research, making participants difficult to change their consent preferences.

These limitations suggest further exploration of how participants perceive and facilitate dynamic consent in sensor-driven research. Although Kumar et al's study [16] proposed a similar concept that explores context-aware dynamic permissions model for Android applications, our study differs in the sense

	Traditional Bio-Research	Digital Phenotype Research
Data types	• Biological samples • Data from samples	• Data collected from mobile/wearable devices (e.g., biosignals, social media usage)
Data collection environment	• Controlled environments	• Everyday life (i.e., living lab)
Data collection interval	• Periodic	• Always-on

TABLE I: Comparing traditional bio-research and digital phenotype research

that it attempted to grant user autonomy in data collection and sharing in the context of 24/7 sensing. According to a recent study of students' perspective of privacy concerns in digital phenotyping, students' primary concerns were loss of autonomy and control over the collected data [5]. These observations in sensor-driven research clearly show the need for context-aware dynamic consent to enhance user autonomy by enabling selective sharing of collected data for contextualized privacy protection and by satisfying information needs of data processing and handling

III. Exploratory Study

A. Design Space Exploration

We build upon our research by providing an extended definition of dynamic consent and envision context-based fine-grained control that grants user autonomy in sensor data collection research. In this section, we explore how we realize dynamic consent in mobile and ubiquitous computing scenarios. As shown earlier, dynamic consent differs from dynamic consent in existing biomedical research studies in terms of collected data (e.g., types, format), data collection environments, and data collection interval (see Table I).

As a representative case study, we consider a sensor-driven research study where we designed a sensing platform to collect sensor data across mobile (i.e., smartphone) and wearable devices (i.e., FitBit Inspire HR, Polar H10) (Figure 1). This research attempts to collect a vast array of sensor data such as physical activity, app usage, battery, Bluetooth, call/text logs, keylog meta-data, location, media (e.g., camera events), notifications, and Wi-Fi fingerprint data. In addition, users are asked to periodically answer their current moods via experience sampling methods (ESM). A user's own smartphone was used for mobile data collection, and we distributed both FitBit Inspire HR and Polar H10 devices to the participants. During the introduction of the data collection, we explained that these collected data were intended to develop affective computing algorithms (e.g., personalized mood inference).

As the first step, we simply implement a fine-grained dynamic consent feature that allows participants to turn on/off specific data item collection at any context as they wished (Figure 2). This initial exploration will help us to further explore how to design and implement various context-aware features to automate dynamic consent in mobile environments.

B. In-Situ Field User Study

To explore the feasibility of dynamic consent in sensor-driven research, we conducted a small-scale user study spanning four weeks in the wild (n = 23). Participants were university students recruited via a university's online community. As to eligibility, Android phones with operating system below version 7.0.0 were excluded. Prior to the research, participants were informed to install the designed sensing platform and instructed of a general overview of the research (e.g., research purpose). Participants were also informed of the definition of dynamic consent and how it operates on the sensing platform. To enable fine-grained control of data collection, we allowed participants to change their consent on each data item whenever they perceived their current status to be privacy-sensitive.

To ensure participant privacy and transparency, we created an additional document aside from IRB. Given the large amount and sensitive nature of data being collected, we provided participants with a document that offers high-level descriptions of each data sensing stream and what each device (i.e., smartphone, FitBit HR Inspire, Polar H10) was capturing. As to data collection, our research includes a vast array of sensor data. We collected nine sensor data categories from smartphones, which are: Location, Network, Device status, Battery, Calls/Text log meta-data (e.g., call frequency), Keylog meta-data (e.g., keyboard type, character types), Media (e.g., camera events), App usage (e.g., notifications), Activity types. Here, note that we informed our participants that we do not collect any content data from call/text logs or camera events. We also collected heart rate and physical activity types (e.g., calorie, steps, sleep) from FitBit and Polar H10. Upon participation, these data were collected via 24/7 sensing.

Along with context-sensing spanning four-weeks, participants were also given ESM questionnaires that aimed to collect psychological states. Questionnaires included mood, attention level, stress level, mood duration, disturbance level, mental load and emotional changes. The questionnaires were given to participants 8 times a day. At the end of each day, participants received daily surveys that inform them about dynamic consent and ask their decisions on data collection setting change (yes/no). In the survey, if participants answered *yes*, we further asked the type of data and a specific context. In the case of *no*, we asked why they kept their original decision (i.e., default setting). After four-weeks of the experiment, a semi-structured interview (n = 17) was conducted to explore the overall experience of dynamic consent in mobile computing context.

C. Results

Our daily survey results show that participants would generally stick to default settings without making any changes in data collection decisions. Except for deliberate turn-off cases

Fig. 1: Mobile and wearable devices used in the field study

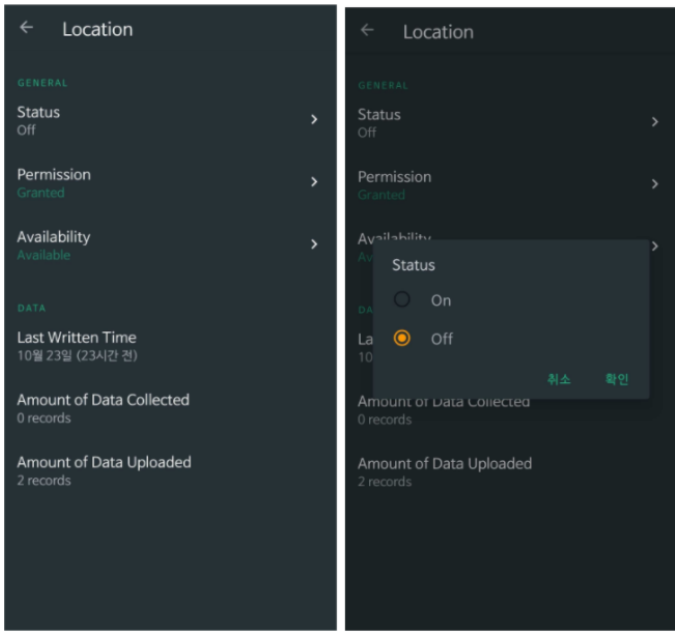

Fig. 2: Fine-grained dynamic consent: e.g., turning off GPS data collection setting

due to technical issues (e.g., battery/data volume issues), there were four data types that participants would decide not to share in certain contexts – *Bluetooth, survey, physical activity, and FitBit*–, which were turned-off due to exams and battery issues.

Interview items covered participants' motives for data collection experiment, general perception on data collection/sharing for research purposes, perceived privacy risks, overall user experience in dynamic consent, and design recommendations. From the interview data, we extracted key determinants that lead to such few changes in making data collection decisions.

To implement this, two researchers used the approach proposed by Braun and Clarke [17], which consists of six phases: familiarization with the data, generating codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Following the approach, we performed the analysis in a bottom-up, iterative fashion and came up with the following four determinants.

First, the most frequently cited reason was '*consent fatigue or burden.*' Participants expressed a sense of cognitive burden as they had to go through the whole list of data items to select a specific data type they wished to turn off. Thus, participants reported difficulty changing consent preferences in real-time, which made users feel the consent process burdensome. P1 reported, "*You see, the list is too long and it takes forever to find this one data I want to turn off! I was in a hurry to turn off my GPS data, but just gave up soon.*"

Second, this consent burden was further exacerbated by our participants' low-level privacy concerns and their good sense of data ownership as they were given an option to selectively share their data collection. P11 reported, "*Honestly I wasn't concerned at all. You gave me an option to switch off whenever I wanted. So, I guess that's why I never changed the setting. I trusted you and the research.*"

Third, participants responded that it was unnecessary to change their decision because they signed up for the experiment. In other words, they consented to data collection and were informed of the importance of data collection in the research. This obligation or a lack of autonomy discouraged them to actively engage in the consent process. For example, P3 reported, "*Anyway I signed up for this study and I think that means I agree with the whole process. I just didn't care at all about the data collection for four weeks.*"

Fourth, participants assumed that frequent turn-offs for certain data items may lead to some loss to themselves (e.g., monetary loss due to low levels of participation) and research data collectors (e.g., failure to collect quality data). This contrasts with the researchers' explanations that dynamic consent is encouraged and does not cause any financial penalties. P9 said, "*Actually I was kind of concerned with my GPS data and there were certain times that I wished to turn it off. But I was also kind of worried whether it would affect the research itself and my compensation as well.*"

IV. Discussion

The purpose of our investigation was to explore the feasibility of dynamic consent and user perception in the field of mobile and ubiquitous computing. We found that cognitive load and participants' low-level privacy concerns along with lack of perceived autonomy led to passive usage of dynamic consent feature. We discuss how our empirical observations can inform future research directions on dynamic consent.

Cognitive burden was one of the major hurdle on dynamic consent usage. We can lower the user burden by providing persuasive mechanisms that possibly automate laborious user interactions. For example, we can bundle a list of sensor data items by categorizing data; this helps users to enable or disable specific categories at once. This kind of bundling lowers a user's cognitive burden on decision making as well [18].

A dedicated user interface can be built to systematically help users to dynamically manage a user's consent. Different

projects may require different sets of sensors, and a user may have difficulties tracking how the user's data are collected. A unified interface may help users to track what data are collected under what projects. Furthermore, categorized selection may lower the burden of enabling or disabling data collection. A more sophisticated feature can be offered by implementing programmable user interfaces by end-users (known as end-user programming). Trigger-action programming is one of the widely used methods; for example, IFTTT (if this then that) allows users to specific conditions and actions for dynamic consent [19]. A user's contexts can be specified in the conditions to dynamically change a user's consent (e.g., "disable heart rate data tracking when I arrive at home"). This kind of trigger-action programming will enable context-aware dynamic consent.

Our participants lacked privacy concerns and yet they perceived higher levels of autonomy in terms of data collection. It would be important to offer nudging features (e.g., daily reminder) to inform users of their right to consent change. In addition, we can provide intuitive summary information of privacy risks [20]. As an important design consideration to boost participants' autonomy, such features will promote participants' proactive management of consent preferences.

V. Limitation

One caveat of our results is that there may be potential biases in participant responses as the dataset is collected only from university students. It would have been better to recruit a wide range of subjects with equal attributes such as age, gender, and IT skills to reflect multifaceted aspects of dynamic consent. Considering the diverse backgrounds of participants in the recruitment stage should be taken into account for future research. There were a few technical challenges in which participants (n = 3) had to turn off all data sharing options due to background applications consuming battery. Further studies that address these issues are required to identify potential factors that might hinder user acceptance in dynamic consent.

VI. Conclusion

Dynamic consent offers the potential to help individuals to tailor and manage their own consent decision-making and protect their personal data. As the use of health data will continue to be supported by digital technologies that enable collection, processing, and sharing on a large scale, we build upon prior biomedical studies to offer insights on further adoption of dynamic consent in the field of mobile and ubiquitous computing. Our findings suggest the need for context-aware dynamic consent that allows users to dynamically change their consent on data collection based on their contextual privacy needs.

Several questions remain to be addressed, however, including how to design more persuasive dynamic consent to induce proactive user decision-making and how context-aware features can be refined to the research endeavor and expectations of participants. We call for further studies that cement the role of dynamic consent in sensor-driven research to ensure data privacy of participants.

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