Toward Dynamic Consent for Privacy-Aware Pervasive Health and Well-being: A Scoping Review and Research Directions

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Recent advances in sensor-enabled services have facilitated the use of mobile, wearable, and IoT devices; for example, an extensive range of sensor data are used to automatically track symptoms and diagnose health and well-being status of an individual (e.g., depression). As personal data are being continuously and unobtrusively sensed and collected at large scale, this raises privacy concerns in certain contexts (e.g., GPS data collection at privacy-sensitive places). Current one-off informed consent in such pervasive sensing scenarios does not offer context-awareness support that enables selective data disclosure based on a user's needs or preferences (e.g., disabling GPS data collection when visiting hospitals). A lack of context-awareness support in informed consent would be a critical barrier to user acceptance of data-intensive pervasive computing for health and well-being. As an alternative method, we introduce the concept of "dynamic consent," a type of informed consent that enables granular data consent and management, initially introduced in biomedical research for patient data management. We explore how this consent practice within biomedical research might inform usable privacy designs in pervasive computing by conducting a scoping review of dynamic consent literature and discussing future research directions.

Privacy concerns in pervasive sensing for health and well-being. There is a growing interest in leveraging user-generated health data with mobile and wearable devices (e.g., step count and heart rate data)[1] for pervasive services that promote physical and mental healthcare.[2,3] Such a sensor data-driven approach, also known as digital phenotyping, demonstrates how the passive and unobtrusive sensors embedded in our daily lives can be used to extract behavioral biomarkers from digital footprints and build machine learning models that can automatically predict the risk of problematic behaviors or disease onset.[2] For example, the StudentLife project used passive sensor data (e.g., location, physical and social activities) to identify how such passive sensor data are related to mental well-being and academic performance.[4] The Apple Heart Study used large-scale data collected from Apple watch users to detect irregular heart rhythms and potentially serious heart conditions.[2]

Along with mobile and wearable technology, leveraging IoT devices can open up new research potentials in living lab scenarios as well. For example, a smart home equipped with mobile and wearable sensors and IoT devices can create a data-intensive environment that helps to track inhabitants' health states and offer personalized healthcare (e.g., long-term/remote monitoring for chronic disease or older adults[5]). Recent digital healthcare research performed pervasive clinical assessments on diverse cohorts of older adults through in-home monitoring.[5] Here, ecologically valid sensor data acquisition will be a stepping stone for enabling timely personalized healthcare services.[6] Furthermore, a holistic view of personalized healthcare is envisioned in an emerging concept of "deep digital phenotyping" that integrates an individual's clinical and biomedical data with real-world mobile, wearable, and IoT data.[7]

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Although such sensor-driven research undeniably provides novel opportunities for promoting health and well-being, it can also put the privacy of the participants at stake. This is because collecting such naturalistic data as personal digital footprints become the sensitive and authentic sources of an individual;[1] e.g., biometric data (e.g., heart rate and gait patterns), behavioral data (e.g., mobility), contexts (e.g., GPS location and time-stamps), and extra user data (e.g., self-reports about mood and stress). Ubiquitous nature of pervasive sensing makes it challenging to protect user privacy because data could be constantly collected without the users being aware of. Furthermore, interweaving diverse digital footprints are likely to cause behavior profiling or potential identification of an individual.[8]

With growing concerns on data privacy, we also observe growing emphasis on users' data ownership and user-driven data control in forthcoming legal regulations and ethical paradigms. For example, one of the central principles underpinning the EU's General Data Protection Regulation[9] is to increase people's awareness surrounding consent for data processing and usage. It places a legal responsibility to protect participant data ownership and requires specific descriptions of collected data and their purposes. The MyData movement[10] is a personal data management paradigm being discussed in healthcare and financial contexts. According to the notion, it allows a data subject's direct access, control and ownership over their data, and aims for individuals to make active decisions on the scope and usage of their personal information.

TOWARD PRIVACY-AWARE CONSENT FOR PERVASIVE HEALTH AND WELL-BEING

With rising privacy concerns in terms of personal data collection and its usage, there is dispute concerning the appropriateness of the current informed consent practice. Informed consent is a fundamental step in biomedical research that indicates that an individual is fully informed of the nature and purpose of a research project, what data will be collected, how the data will be handled and used upon their agreement to participation.[11] The process is critically important because research in the biomedical field generally requires a large-scale and long-term participant engagement for continuous data collection (e.g., biosamples and patient health records).[12] Also, participants cannot receive assistance without disclosing their intimate physical and behavioral data.

Current informed consent practice in pervasive computing for health and well-being scenarios typically assumes participant consent for data collection only at the initial stage. However, given the range of personal data accessible from mobile, wearable and IoT devices for health and well-being research, current informed consent seems to fall short of providing granular control based on users' privacy preferences (e.g., disabling GPS data collection when visiting hospitals). Thus, the appropriateness of the current informed consent practice in pervasive computing should be re-evaluated. In this article, we explore the applicability of "dynamic consent" for usable privacy designs in pervasive computing for health and well-being. Dynamic consent is a type of consent that has been actively facilitated in the field of biomedical research. The concept is being discussed as an alternative to traditional consent practice due to its features that overcome the limitations of original consent.[13] Since this concept is foreign to the pervasive computing community, we conduct a scoping review to introduce the core concept and its application, and have a discourse on whether this approach has the potential to scale to naturalistic data collection in a living lab environment and address the stakeholders' needs in pervasive health and well-being domains. Our scoping review consists of the following: 1) a review of dynamic consent in biomedical research to introduce the concept and its core features, and 2) a review of recent attempts to explore the feasibility of dynamic consent in pervasive computing research. Furthermore, we discuss possible design opportunities of leveraging the concept of dynamic consent within pervasive computing for health and well-being research.

TABLE 1. Broad consent versus dynamic consent.

	Broad consent	Dynamic consent
Timing	• Asked to consent once (at the beginning)	• Asked to consent continuously (at each data collection events)
Advantages	• Simplicity	• Greater control, flexibility and transparency
Disadvantages	• No granular control over data	• User burden due to many consent choices

INFORMED CONSENT: BROAD CONSENT VERSUS DYNAMIC CONSENT

Generally, there are two types of informed consent being widely discussed in biomedical fields (see Table 1). The first is "broad consent," which is the de facto standard that presumes participants' consent to reuse

collected data for future research in a similar area.[14] Broad consent typically takes the "one-off" approach, which provides informed consent at the beginning of a study when participants are recruited.[12,15] Considering that biomedical research requires the continuous collection of biological samples and health-related records over a long period, participants could be also 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, participants are asked to reconsent only when there may exist an ethically relevant difference from previous research,[16] which makes it difficult for participants to change their initial data collection settings and manage their data privacy. Due to this characteristic, broad consent is often deemed as lacking in transparency and autonomy in spite of its simplicity.

Compared with broad consent, "dynamic consent" entails narrower and more specific consent, putting more emphasis on "user participation" and "power to users."[12,16,17] The concept was first introduced in a genetics study conducted in 2001 to assure participant privacy in collecting personal genetics data.[18] "Unlike broad consent, dynamic consent offers bidirectional, continuous, and interactive communication between researchers and participants". Through a digital platform,[12] it asks participants to reconsent to every new experiment or data collection. Participants can alter consent choices, such as engage/withdraw from new research, give/revoke access to a certain data item in certain research,[12,16] and agree to renew the uses of the data collection. Since dynamic consent enables participant interaction through a platform, participants' data collection preferences can be modified on an ongoing basis.

BRIEF REVIEW OF DYNAMIC CONSENT

Case Reviews

To deepen our understanding, we provide brief reviews of several major use cases of dynamic consent from biomedical research. The following cases are the representative examples because of the scale and duration of health data collection.

Early references to the dynamic consent can be traced back to 2001 when an online proprietary genetic banking system was proposed by First Genetic Trust (FGT).[18] In FGT, people expressed their concern over their personal genetic data being collected and shared. Back then, such concern was pointed as a potential barrier to the development of personalized medicine. To provide greater assurance for individuals that their privacy will be strongly protected, FGT proposed a dynamic informed consent mechanism that would protect individual's medical and genetic information, allowing access to select and use the DNA information only when given a specific consent.

UNLIKE BROAD CONSENT, DYNAMIC CONSENT OFFERS BIDIRECTIONAL, CONTINUOUS, AND INTERACTIVE COMMUNICATION BETWEEN RESEARCHERS AND PARTICIPANTS.

Ensuring Consent and Revocation (EnCoRe) project is also a well-known information and communications technology research project that examines the design and development of dynamic consent mechanisms.[19] The project was conducted between the computing department and three biobanks from Oxford. Biobank is a type of biorepository that stores biosamples (e.g., genomic data) and data derived from the samples for contemporary research, such as genomics or personalized medicines.[20] These banks offer access to samples and data derived from these samples, which can be used by multiple researchers for cross-purpose research studies. EnCoRe offers a "patient-centric" web-based system that enables participants to exercise the choice of granting and revoking consent over the use of their information in an easy and intuitive manner. The system also allowed participants to track and audit any changes they made.

Another example is the Cooperative Health Research in South Tyrol study,[21] which provided participants with detailed description of study-related materials and updated information on the webpage. Collected data were subjective data (e.g., fat intake, physical activity, and smoking) and bio data (e.g., blood and urine) that were necessary for extracting biomarkers for cardiovascular-related chronic disease. For better understanding of research purposes and contexts, the webpage provided a 9-minute information movie that systematically explains the research project. As to data sharing, participants were given an option to choose data access levels, data sharing types (e.g., international or public repositories), and data reuse options (e.g., complete withdrawal after the research).

Similarly, the Rare U.K. Diseases Study (RUDY) is another well-known example.[22] The research team was interested in collecting data (e.g., physical function,

TABLE 2. Traditional biomedical research versus pervasive sensing research.

	Traditional biomedical research	Pervasive sensing 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

blood and urine tests, bone density test, and skin biopsies) from a large number of patients (n = 3467) who were going through rare diseases that happen under one in 2000 people (e.g., giant cell arteritis). The RUDY platform offers an Internet-based consent form specific to a type of disease. Furthermore, participants were asked to report disease-related information (e.g., self-assessed level of fatigue) via the online forum.

Aside from the aforementioned three representative case studies, a recent trial on dynamic consent developed a web-based application called control (CTRL), which was used in the Australian genomics study.[23] A multidisciplinary team was involved in the development of an application to consider user experience, privacy and security, international standards in data sharing, and ethical issues. The application is known to recruit 5000 patients for genomic testing through 18 different rare diseases and cancer-related projects.

FEASIBILITY OF DYNAMIC CONSENT IN PERVASIVE COMPUTING FOR HEALTH AND WELL-BEING

Based on our previous review of dynamic consent in biomedical studies, we have identified three key distinctions of pervasive sensing that are different from data collection in traditional biomedical research (see Table 2). Particularly, unlike other research domains in pervasive computing that generally focus on a single sensor-based data collection (e.g., location tracking via GPS), pervasive health and well-being domain entails collecting a wider range of personal data via diverse sources, which leads to following three key distinctions.

- Data types—While the data sources of traditional biomedical research are limited—specific biological samples or data derived from these samples from a patient cohort—pervasive health studies involve more comprehensive range of data (e.g., biosignals and social media usage) from diverse sources (e.g., mobile and wearable devices, IoT, and social media).
- Data collection environment—Traditional biomedical research usually collects target data in a controlled lab environment, whereas pervasive health studies collect data from daily lives.
- Data collection interval—Traditional biomedical research takes a certain interval for new data collection events, whereas data collection in pervasive computing occurs 24/7 due to passive sensors.

Such identified three key distinctions call for adopting dynamic consent in pervasive sensing scenarios that involve the collection of extensive user-generated health data. Thus, we conducted a scoping review to better understand and evaluate the feasibility of dynamic consent in pervasive computing for health and well-being. For a review, we referred to well-known scholarly literature search engines: Google Scholar, ACM Digital Library, and IEEE Xplore. The keywords used for the search were "informed consent," "dynamic consent," and "pervasive computing." Through the search process, we observed that the application of dynamic consent that matched the pervasive computing scenario is rarely studied, resulting in only four studies after manual screening.

Our results revealed that the use of dynamic consent is in the very initial stage of expansion to various computing domains. We deem these initial studies to be important ground works for charting the requirements for applying dynamic consent in the pervasive computing domain. Here, note that only one study was directly related to healthcare context, whereas the other studies were rather related to probing dynamic consent's potentials in pervasive computing on a more general level. As pervasive sensing scenarios that use user-generated health data from mobile/wearable sensors increase, we expect to see a more volume of relevant studies in forthcoming years. In the following, we elaborate on our findings.

Case 1. Consent Design Guidelines for Pervasive Computing

Luger and Rodden's work[24] discussed challenges in informed consent for pervasive computing and suggested design considerations for future consent. Some of the key challenges were the static nature of traditional consent, a lack of consideration of user contexts, delivering privacy notices to users, and difficulties in implementing fully informed consent in pervasive computing contexts. The work suggested the following design considerations: 1) consent must allow real-time interactions and negotiations for data sharing and 2) consent must be designed to provide greater user autonomy and control over collected data. It is interesting to note that calls for such designs are the main features embedded in dynamic consent.

In their follow-up work, Luger and Rodden[25] conducted a focus group interview with pervasive computing systems/service designers to evaluate the utility of informed consent design guidelines proposed by the research team. The guidelines were 1) review/withdrawal data, 2) embedding visualization, and 3) allowing real-time interaction with the system and interrogation of data collection (e.g., users are able to search what types of data are being collected). Designers evaluated that these guidelines have the limited utility to be adopted in real-world applications, but would be of most interest to the research community.

Case 2. Fine-Grained Data Collection and Sharing

Enabling fine-grained control on data collection and sharing is one key approach of enabling dynamic consent. In a recent in-the-wild data collection study, Lee et al.[26] incorporated a fine-grained dynamic consent feature to a mobile/wearable sensing platform and conducted a qualitative analysis to explore participants' privacy concerns and usage behaviors of fine-grained controlling. The sensing platform deployed in the study aimed to collect a vast array of sensor data across multiple devices (e.g., smartphones, smartwatch, and chest band) for building an affective computing algorithm (e.g., personalized mood inference). In the study, participants were allowed to browse all types of collected data items. Researchers reminded that they can freely change data collection settings by informing that they can turn on/off specific data item collection at any time that they deemed privacy-sensitive or inappropriate. The results showed that participants rarely changed the data collection setting, mainly due to consent fatigue or burden.[26] Participants needed to review a long list of data items to selectively enable and disable them, which was considered burdensome. Another interesting finding was that participants had relatively low-level privacy concerns for data collection research, because they already agreed upon selectively sharing their data, leading to a low-level of data autonomy.

Case 3. Predictive Model for Participant Consent

Social media as a data source of social sensing have been widely used for health and well-being research (e.g., predicting depression symptoms using social media interaction data). Norval and Henderson[27] explored the feasibility of automatically predicting whether users agree to share the social media profile data from Facebook (e.g., location check-ins, photos, status updates, and liked Facebook pages) to different stakeholders, such as researchers and clinicians for health related purposes. In their study,[27] researchers collected 4660 contested decisions from 67 participants' social data. Multilevel regression analyses revealed the predictors of sharing decisions, such as data type (e.g., check-ins and photos), education background, the number of friends, and share proportion (i.e., an individual's overall tendency of sharing). Since false positives are a serious issue (i.e., falsely sharing sensitive data), cost sensitive machine learning using a Naive Bayes model was used to automatically classify consent decisions. The results showed that 97.0% of the cases that should not be shared were correctly classified, but only 32.7% of the cases that should be shared were correctly predicted, which leads to the accuracy of 65.3%. This work can be extended to typical pervasive computing scenarios where users will continuously generate sensor data streams (e.g., mobile usage, activity data, and physiological data) in everyday life contexts and consent decision making would dynamically change over different users' contexts. Overall, this study highlights the importance of the contextual and complex nature of consent prediction, and offers technical considerations (e.g., cost sensitive learning) that should be taken into account for future dynamic consent to better predict participant consent decisions in different contexts.

LOOKING FORWARD: BUILDING CONSENTFUL PERVASIVE TECHNOLOGIES

In this section, we discuss the future design considerations of dynamic consent for pervasive health and well-being scenarios based on previously discussed the three key distinctions of pervasive sensing and lessons learned from case studies.

User-Friendly Intuitive Instruction and Guidance

Dynamic consent claims participants have the control over data and are able to renew their consent every time. This underlying message assumes that the participants are aware of all the information given to them (e.g., data types and collection purposes) and have the competence to make a right decision.[16] Revisiting the study Case 2,[26] however, such assumption may not always be valid considering participants' low level of privacy concerns due to their unwillingness to educate themselves. According to a recent study on participants' privacy concerns in mobile and wearable sensor data collection for building mental health-related services,[28] participants reported difficulty associating diverse sensor data with its potential usage in health-related research due to the diversity of data types. These observations suggest a need for embedding more friendly and easy-to-follow guidelines to educate participants to help them engage in their privacy decision and make full use of dynamic consent.[29]

Following the design considerations suggested from the study Case 1, one possible design opportunity is to embed a feature that instructs participants' potential privacy risks in different data collection environments (e.g., sensitive data collection at specific contexts)[30] with visual assistance (e.g., visualizing data flows).[31] By offering an intuitive review of the collected data and its specific usage in health and well-being research,[32] participants can be more aware of their own data and their rights regarding data privacy. Another possible design consideration is devising context-aware intelligent agents that help users gain a correct mental model of collected data,[33] delivering privacy notice and choice through a two-way dialogue and help users set his/her desired choices in natural language text.[34] Such agents can especially help participants with limited amounts of knowledge (e.g., older adults and less tech-savvy users) make better informed decisions.

Delivering dynamic consent as a form of intelligent agents can be facilitated in healthcare environments, such as smart homes that involve not only mobile and wearable sensors but also IoT devices for chronic disease management or health monitoring. For example, Feng et al.'s study[35] constructed an IoT assistant app for privacy choices based on a user-centered analysis of how people actually exercise privacy choices in smarthome settings. The assistant offered available privacy choices of an IoT system to users in a machine-readable format along with a concise privacy notice, and users were given an option to receive context-aware (i.e., location-based) privacy notice and choice notifications via mobile devices.

Automating Default Setting to Reduce Decision Fatigue

As stated in the study Case 2, "decision fatigue" was another often-cited reason from previous studies that hindered participants' active engagement in their privacy decision and data management.[12,16,26,36] Participants reported that the process of going through the list of all sensor data and associating each data with healthcare context cumbersome (possibly due to the high volume of diverse data types collected in different environments).[26] Given the complexity and repetitive nature of consent preferences, participants preferred default settings over personal management. Thus, security researchers like Yee[37] stressed the importance of choosing the right defaults in interaction design.

Following this statement, one possible design consideration is to design a system that leverages data-driven user privacy profiles to provide recommended settings that match users' diverse privacy preferences, thus adapting a large number of default settings to the users' preferences. Similarly, He et al.'s study developed a smart profile system that helps to configure a personalized setting based on a single user decision, offering users which decision to adopt based on their large-scale data.[38] Ironically, leveraging data-driven user profiles to reduce decision fatigue could cause privacy violations, because behavioral profiling or user identification can be conducted by interweaving diverse data sources.[8,28] Another option is to build a simple rule-based approach, such as using trigger-action programming,[39] that might help users to specify contexts (e.g., time, place, and data types) for proactive consent decisions. Such solution can significantly reduce the number of manual settings and the overall user cognitive load, but leaving the decision to some extent to users. Fully automating consent decisions as in the study Case 3[27] will further lower such manual efforts, based on certain inferences about the user's past privacy behaviors or certain personal characteristics.

CONCLUSION

We provided a scoping review of the dynamic consent in biomedical research and its feasibility in pervasive health and well-being. As the use of health data generated from personal mobile and wearable sensing devices increase, adopting this novel approach will enable flexible and context-aware health data collection and sharing. Yet only a handful of studies have explored the concept and several issues remain to be addressed, we believe that dynamic consent will play a pivotal role in providing context-aware support that provides proactive decision making in terms of data privacy. We call for

further studies that explore the wider applications of dynamic consent in mobile and wearable sensor data collection for pervasive health and well-being research.

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