Fostering Dialogue to Explore the Ethics of Sharing Personal Information on Leisure and Fitness Applications: Towards Better Informed Consent
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Workshop Report\(^1\) Written by Josan Pineau\(^2\)

The international workshop, *Fostering Dialogue to Explore the Ethics of Sharing Personal Information on Leisure and Fitness Applications: Towards Better Informed Consent*, held at the University of Ottawa, with financial support from the Faculty of Arts and the Diversity and Equity Research Group (DERG), was organized by Dr. Rukhsana Ahmed, Associate Professor, Department of Communication, University of Ottawa, in collaboration with Dr. Devjani Sen, Postdoctoral Fellow, Department of Communication, University of Ottawa. The workshop brought together prominent scholars in the legal, privacy, and communication fields, as well as creators of leisure and fitness apps and practitioners from across Canada and the United States. The aim was to discuss the ethics behind sharing personal information collected from leisure and fitness apps and create guidelines for ‘best practices’ for designing more effective informed consent and privacy policies to ultimately protect the rights of end-users to safeguard their personal data. The intersection of ethics and information sharing is vastly understudied. This workshop broke new ground as it was the first of its kind to address privacy issues in relation to the creation of health and fitness applications and the collection of personal and private data.

The workshop began with a welcome address by Dr. Rukhsana Ahmed, who emphasized the importance of unrestricted and stimulating dialogue between both the speakers and participants in the room to ensure that the conversation was constructive and thus innovative. Vice-Dean Research, Faculty of Arts, Dr. Juana Muñoz-Liceras was invited to share some opening remarks and stated that this workshop is extremely important as it brought together developers of health applications, scholars, and other professionals to discuss together cutting-edge and new ways to think about rights of privacy. Afterwards, Dr. Ahmed showed a brief introductory video explaining the importance of privacy in the context of mobile devices to set the stage for the workshop. As the workshop was ultimately designed to benefit end-users, Dr. Devjani Sen concluded the opening remarks with a

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\(^1\) For any queries about this report, please contact Rukhsana Ahmed ([rahmed@uottawa.ca](mailto:rahmed@uottawa.ca)) or Devjani Sen at ([d sen@uottawa.ca](mailto:d sen@uottawa.ca)).

\(^2\) Josan Pineau is a student graduating from the Univeristy of Ottawa with an Honours Bachelor in History and Religious Studies. Moving forward, Ms. Pineau plans on exploring academic professions and broadening her horizons in relation to law and policy in Canada.
short presentation articulating the varying definitions of what privacy really means for a sample of end-users from diverse backgrounds.

The first panel was on the topic of legal and privacy issues regarding the sharing of personal information on mobile applications with specific focus on health and wellness applications. Dr. Teresa Scassa, Canada Research Chair in Information Law at the University of Ottawa, brought the foundational legal perspective on privacy issues raised by wearable technologies. In her talk, Dr. Scassa addressed the issues with wearable technologies and the accumulation of personal data such as exercise, food, weight, sleep, etc., and the added problem that the networking of the user’s data between various devices causes. Examining applicable Canadian laws, Dr. Scassa identified three major privacy consent aspects for concern in contemporary society: the ubiquitous collection of personal information, the collapsing boundaries between public and private contexts, and lastly the very idea that we live in a data society which is constantly getting all the information possible and creating data profiles of everyone. All of this begs the questions of what is consent, what is a reasonable collection of personal data, are individual persons secure, who is receiving the collected data (third party access), and the necessary transparency of companies with information collected on the individual.

The second speaker was Dr. Andrew Patrick, IT Research Analyst at the Office of the Privacy Commissioner of Canada. His presentation, entitled “Forms of Consent,” gave a review of the guidelines of consent developed by the Office of the Privacy Commissioner of Canada when considering Canada’s federal and private-sector privacy law PIPEDA. Dr. Patrick began his presentation by discussing the new amendment to PIPEDA which added that full consent is only attainable when there are reasonable expectations that users understand what exactly they are consenting to: ‘what is reasonable?’ Further, express consent must be used when dealing with sensitive data. Dr. Patrick asserted that health and fitness information (medical data) is always sensitive and therefore always requires express consent. In this way, the classic consent model, which bases the consent on the idea of only using the collected information for a specific purpose, is out of date. The challenge here lies in the ubiquitous collection of valuable information for multiple purposes and multiple third-parties. This presentation questioned the appropriateness of old consent models by applying them to contemporary examples. Finally, Dr. Patrick introduced ways in which the engineering of products and applications can play a major role in improving the informed consent process.
Dr. Benjamin Bates, Barbara Gerals Schoonover Professor of Health Communication at Ohio University, presented “The Belmont Report and the Digital Age: Updating Ethical Principle for Mobile and Wearable Research.” He asserted that privacy policies and forms of consent should use the model of ethical research laid out in the Belmont Report which emerged in 1979. The Belmont Report offered ethical principles and guidelines for the collection of human data that is still prevalent in current society. Specifically, the three principals of respect for persons, justice, and beneficence outlined in the Report should be relied upon at present to ensure informed consent. Consideration has to be taken not only for relevant research outcomes but also for the harm or benefit to the participants. In some cases, health and wellness applications have put people at emotional, employment, and financial risk. Overall, informed consent must be present with the ability to opt-out of specific clauses, beneficence must be paid attention to and lastly justice must always be present.

The first interactive panel aimed to discuss the legal ambiguity that exists when discussing the ownership of sensitive data collected on mobile apps. One question asked if a health and fitness app is US based and therefore data is stored on US servers, how do Canadian laws protect the confidentiality of user data? And if not, what are the ethical and legal implications? Dr. Scassa replied that laws like PIPEDA and federal legislation will apply if the collection of data is happening in Canada. However, the ability to monitor the data’s usage in the US is a different story. This all depends on the cooperation between the US and Canadian parties. One participant, Dr. Nigel Cameron, Fulbright Visiting Research Chair in Science and Society, University of Ottawa, President of the Center for Policy on Emerging Technologies, and Research Professor at Chicago-Kent College of Law in the Illinois Institute of Technology (IIT), asked a telling question: “At what stage do we think the privacy question will be sufficient enough to become a public question that our community rallies behind?” Dr. Scassa replied that when data issues start falling into the realm of human rights issues will the privacy issues then start to become apparent in general society. Another question asked about the balancing between transparency and privacy. Dr. Bates replied that there is often a public good that is being served through data transparency. However, that not everything needs to be transparent because it is not for the greater good. Therefore a question must be asked: Is there a larger public good that is being served by making something public that outweighs privacy?

The second panel aimed to discuss the overall challenges of designing leisure and fitness applications for an increasing global base of end-users, who, as studies suggest are believed to only superficially scan privacy policies and not otherwise engage well with them. Starting off, Dr. Neda Faregh, Visiting Scholar at the Centre for Refugee Studies, York University and Program
Coordinator of the Multicultural Mental Health Resource Center, McGill University, and Dr. Devjani Sen, explored psychological and thus cultural considerations from the perspective of the end-user when designing privacy policies for mobile applications. Specifically, the talk considered how cultural identity can affect a person’s perception and interpretation of privacy. The problem is that there is no global definition of privacy. There are clear differences between Western and Eastern understandings of privacy. As a closing note, Dr. Faregh stressed that ultimately conceptions of privacy are culturally and contextually bound and therefore will affect what individuals disclose on mobile health apps.

The last presentation was given by Ms. Lorraine Chapman, current Director of UX Healthcare of Macadamian, who brought a business perspective to the workshop. Her presentation focused on patient engagement and how business and applications ensure the engagement of end-users in clinical and medical applications. As a software consulting firm, her company focuses on designing healthcare applications that appropriately engage patients and doctors alike, whilst also engaging and providing a frictionless experience. A frictionless experience requires there to be minimal barriers. Recent health apps leverage multiple platforms to integrate into a patient’s existing routines and habits. In this way, the sharing of private information is easier and therefore causes privacy issues. The inherent issue is successfully providing an experience that doctors and patients enjoy alike and also ensuring privacy laws and policies are upheld. This balancing is extremely difficult when trying to satisfy the consumer in us all.

Taking a more hands-on approach, the second panel discussed the reality of what end-users actually understand and, taking this into consideration, how best to present the necessary information to users while also considering the diverse cognitive and cultural differences of end-users. One question asked what role, if any, do cultural differences have in influencing people’s inclination to disclose personal information? Dr. Neda Faregh replied that what one cultural background or ethical heritage will disclose about themselves is different from the next. Ethnic and religious backgrounds often have an effect on personal information disclosure. One culture that is extremely patriotic may not have a problem disclosing their ethnic and religious affiliation, but another culture that is perhaps persecuted may be less than willing to provide the same information. Participants posed many questions to Ms. Lorraine Chapman, and one such question wondered if Ms. Chapman’s company had ever considered asking their consumers about what they expect from consent forms. In this way, the software company could gain end-user expectations on reasonable consent. Ms. Chapman replied
that although she sees benefits in asking such a question, her company is hired by business vendors and unfortunately they do not ask her researchers for that service.

To increase participant engagement, the workshop had participants placed into groups with the goal of discussing all that had been learned in the past presentations and previous knowledge, and collaborate to analyze specific case vignettes and explore the ethical implications of sharing personal information with third parties. Among other topics, the group discussions focused on social media and social motivations to share personal information on such platforms. Some participants opined that before using the service, users should be required to take an online tutorial on privacy. Further, some participants felt that a privacy standard with recognizable icons should be used on these social media platforms to notify the user that such platforms and apps coincide with the set privacy standards. Other group discussions focused on the idea of having different levels of permission for different types of information shared. The overwhelming consensus was a concern as to whether the end-user actually understands the question of consent being asked: one is often asked to give permission but are unaware of what one is consenting to. The suggestion to overcome this barrier was to have companies and applications very directly inform the users who exactly has access to their information. Some participants strongly suggested creating ongoing notification boards or popups on applications informing the end-user how their information is being used and giving them the ability to opt-out and say no.

Closing remarks, given by the workshop facilitators, Drs. Rukhsana Ahmed and Devjani Sen, underscored the significance of continuing this exploration into the ethics of information sharing on health and wellness applications by collaborating with healthcare professionals, scholars, lawyers and other professionals from Canada and the United States. They reiterated the importance of better educating users of mobile apps on how personal information may be shared by unknown third parties and in so doing, safeguarding users against sharing private information when using these applications. Ultimately, the goal of this international workshop was to explore the ethics and legality behind data collection and sharing on leisure and fitness apps as well as understanding how to best design privacy policies for the end-user. Accordingly, the workshop did engage participants in fruitful dialogue and collaborative activities on guiding principles for sharing personal information on mobile devices and is expected to extend into a series of workshops in the future to continue to wrestle with these issues.