Attending to the Problem of Uncertainty in Current and Future Health Wearables

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1 INTRODUCTION

There is demonstrable appeal in consumer wearable devices, such as activity trackers, which have been used by approximately 10% of American adults [4] to track measures of their fitness or wellbeing. Because activity trackers are commonly used for motivating behavior change towards accomplishment of modest personal fitness goals or maintaining healthy activity levels over time [8], it is easy to forget that they are also used to inform more critical decision making and serious investigations of self. Examples of this include individuals tracking ongoing health conditions and disease progression [24]; tracking their mood, with potential implications for seeking mental health treatment [4]; and self-diagnosing problems (health or otherwise) [22].

These current uses expose the potential variability of uncertainty tolerance between different users [12]. Those undertaking a serious investigation of self require a certain level of precision and data accuracy, and also need details regarding correlations between variables; whereas salient information for those with a casual interest in their fitness may simply be whether they met some target or whether they are generally improving over time. Technological advances, both recent and on the horizon for health wearables, are predicted to enable breakthroughs in disease prevention, prediction and management—areas for which uncertainty tolerance levels differ significantly from that of the wearable consumer [10]. In addition to existing health wearables that claim to measure blood pressure, breathing rate and mood (i.e. emotions and stress, via galvanic skin response), wearables may soon be able to measure or infer health indicators such as blood glucose, calories consumed, hydration, and heart strain (see: https://www.wareable.com/fitness-trackers).

In this paper we explore the implications of, and difficulties in designing for, uncertainties regarding health wearables. We begin by discussing the relatively minimal impact of uncertainty for current consumer uses of these gadgets as a way of demonstrating the known but as-yet-unresolved challenges in communicating health data to users. Next, we argue that seemingly innocuous uncertainties emerging in the present use of wearables need attending to, because they are likely to have greater consequences in the future. We raise three concerns in particular. First, advances in wearable technology will enable measurement of physiological data of which the user has little or no access to verifiable evidence (see Section 4.1: Emergency Medical Intervention and Disease Prevention). Secondly, low-level uncertainties are compounded by the interdependency between various data systems and their implications (e.g. for disease prevention, prediction and management) (see Section 4.2: Life Coaching). And thirdly, near future scenarios of external use of personal health data introduce new stakeholders whose tolerance for and ability to understand uncertainties will vary, requiring multi-pronged research into strategies for dealing with uncertainties (see Section 4.3: Patient Compliance Monitoring).

2 KNOWN UNCERTAINTIES OF COMMON CONSUMER WEARABLES

For the purposes of this discussion, we use the term “uncertainty” to mean a lack of understanding about the reliability of a particular input, output, or function of a system that may affect its trustworthiness. With wearable activity trackers, uncertainties arise in various forms and affect users’ trust to varying degrees. The consequences of these uncertainties, while not always apparent to the user, also differ. Below we provide a general summary of some of the salient uncertainties that will be relevant to discussions later in the paper.

The saying goes, “garbage in, garbage out;” but it can be difficult to know whether the data coming into a system is sufficiently accurate to produce meaningful outputs—where “meaningful” is defined in relation to the user’s needs. We consider this *input uncertainty*. Inaccuracies in data can be introduced by wearable users in various ways. Diagnostic tracking [20], for example, may require users to manually record instances of symptoms, food that they have eaten, or medications they have taken. In these cases, the reliability of system outputs depends on the user's ability to correctly infer what data their tracker is capable of automatically collecting [23] and their vigilance in manually collecting the rest, as well as the degree to which users are able to understand the standards for entering data and the importance of precision of their input. Users often lack knowledge of how the algorithms process their data, and therefore may fail to appreciate the ways that imprecision in a single input may affect the system's ability to make appropriate recommendations. Supporting users' understanding of these impacts is difficult [18] as few people have the requisite knowledge or interest to interrogate an algorithm. However, we suggest that supporting understanding and reducing input inaccuracies may be helped by a) enabling users to engage in a trial interaction phase, where they can play around with different inputs to see the effects on calculated outputs; b) providing simple tooltips on the inputs that explain the data collection standards and the importance of precision; and/or c) providing some window onto the underlying model and calculations.

Input uncertainties also arise through onboard sensors. Notably, while guidelines for effective sensor placement are typically provided to users, estimations of sensor accuracy are not. The reliability of fitness tracker data has been a source of concern in Human-Computer Interaction (HCI), and comparative evaluations of activity tracker brands reveals minimal though potentially significant differences in reliability [3]. While users of these tools are highly cognizant of their unreliability (e.g. in the case of step counting [6] and sleep monitoring [16]), attempts to test devices for inaccuracies and calibrate use accordingly often fail [18]. Prevailing design advice to address this problem is to enable users to annotate or amend their data if deemed inaccurate [6,20], but users' ability to correct sensor errors is limited to readings they can independently verify. As wearables begin to measure physiological data, such as heart strain, which is not otherwise accessible to the user, new design solutions will be needed to address input uncertainties.

Another type of uncertainty, which we call *output uncertainty*, arises when users are unable to determine the meaningfulness of the inferences or recommendations produced by a system (see Section 3: Sidebar: Understanding Health Wearables Data). For example, many users of activity trackers struggle to understand how they compare with others—e.g. understanding whether their readings are normal, exceptional, or worrying [16]; or whether they can claim to be "fit" [14]. Even if users are able to determine that their readings are outside what would be considered by doctors to be the normal range, they ask for clear guidance about what to do with that information [14,15]. In short, current tools do not provide the level of support users need to interpret the significance of their data [3], and without this, they cannot determine the significance of uncertainties in that data.

While there is some evidence to suggest that providing users information about why a system behaved a certain way can increase trust [17], and that not doing so, e.g. not providing uncertainty information, can lead to reduced trust [11], a recent study found that algorithm and system transparency does not necessarily lead to higher trust [21] and greater intelligibility tends to reduce trust when there are significant output uncertainties [17]. These points suggest questions that deserve further research: when—or indeed, for what users—is it appropriate to communicate how the systems are working and how confident the systems are in their outputs? And then, how should these uncertainties be communicated to maximize trust?

A final concern of note is what we call *functional uncertainty*, which arises when users are unable to understand how, why and by whom their data is being used. Concerns about privacy and security are manifestations of this uncertainty. It is not always apparent to users exactly what data is being collected from their devices, as well as the duration, location, or security level of their storage. For example, Epstein et al. [7] found that nearly half of the participants in their study turned off location tracking, fearing that friends might be able to see where they were at all times or that their location information might be sold to companies to better target ads. In certain contexts, a lack of location information might reduce the precision of other calculated metrics which depend on it. Further, consent terms and conditions being notoriously verbose and inaccessible, consumers may not fully understand the implications of the consent given when signing up with their devices [1]. This, in turn, can affect user compliance with recommended usage, introducing additional input uncertainties.

We argue that for general fitness and wellbeing needs, the impacts of the uncertainties described above are limited. They may contribute to loss of trust and high rates of device abandonment [5], but while this may be of concern to companies producing these gadgets, it is not especially problematic otherwise. Our interest for the remainder of the paper, however, is how the effect of these uncertainties may intensify in more ambitious uses of health wearables data.

3 SIDEBAR: Understanding Health Wearables Data

The virtually limitless opportunities for passive data collection with wearables means that average users now have large amounts of multidimensional data with which to make decisions. To do so effectively, they must make sense of patterns within this data. This challenge is endemic to personal informatics (or "lived informatics" [22]) more generally, the goal of which is to "help people collect personally relevant information for the purpose of selfreflection and gaining self-knowledge" [15]. In the context of health wearables specifically, systems are typically designed to help users understand the impact of a range of contextual factors on a desired health outcome, such as wellbeing [2].

Enabling user health revelations poses a significant information presentation challenge. Users demonstrate poor graph literacy [2], yet commercial brand wearables interfaces are predominantly graph-based. These interfaces also tend to prioritize time-based views of data, smoothing out peaks and troughs and obscuring the most salient contexts around which they occur—information that would ostensibly lead to the greatest user insight [2,15]. It is also often not readily apparent to users how the complexities of interactions between factors is negotiated by the system's algorithms [2], nor whether such decision making is rooted in robust science. Complicating matters even more, users have poor conceptual grounding for concepts such as "health", "wellbeing" and "fitness". For example, Kay et al. [11] show that users are poorly equipped to determine the clinical relevance of weight fluctuation data.

A growing body of work in HCI explores strategies for supporting intelligibility of data collected by health wearables (e.g. [2,6,11,12,15,16]). This work is fundamental to attending to the challenges of uncertainty for health wearables, as it is key to providing users insight into both a) when inaccuracies occur, and b) the impact of inaccuracies in a reading or output relative to their intended use of the device.

4 UNCERTAINTIES IN FUTURE USES OF HEALTH WEARABLES

In what follows, we introduce three areas where we anticipate growing use of commercial activity tracker data and explore how these contexts may further affect uncertainty tolerance and, therefore, affect implications in designing for uncertainty. We focus on these three scenarios in particular as a way of drawing out three distinct concerns that require attending to in future research in this space.

4.1 Emergency Medical Intervention and Disease Prevention

As yet, health wearables enable users to make sense of past events—what activities they have done and what impact those activities are likely to have on their wellbeing—to prompt positive behavior change (cf. [8]). The next stage of development might be for health wearables to predict health crises. Examples include alerting a hospital of early signs of a heart attack[1] or warning users of their likeliness to develop breast cancer.

The scenario of predictive emergency medical intervention raises the question of who ought to have access to personal health data. While it would be quite helpful to link one's health data directly to the closest hospital in order to set the long chain of care in motion as early as possible in an emergency, there would be highly sensible consumer pushback around the access various parties might want to have to personal health data (i.e. functional uncertainty in this arena would not likely be tolerated). Alternatively, if a wearable device alerted the user to get to a hospital at the start of a possible medical crisis, how certain should that device be required to be? Should gadgets err on the side of caution, possibly provoking false alarm? While not alerting a user due to insufficient certainty may lead to preventable deaths, so might causing alarm when not necessary, which may lead to users ignoring subsequent alerts like "The Boy Who Cried Wolf."

The very notion of a health wearable alerting a user to an otherwise imperceptible impending crisis demonstrates the insufficiency of solutions for addressing uncertainty that rely on manual data correction by the user (cf. [6,20]). Explaining the data collected and the ways that data is processed by the algorithm may be more appropriate for assisting a user in determining whether the device output is certain enough to warrant seeking medical attention. At the same time, this information must be delivered in ways that can be rationally evaluated by a person who has just received an anxiety provoking output (see Section 5: Sidebar: Communicating Uncertainty). Both parts of this solution are non-trivial and require further research.

4.2 Life Coaching

Tracking data points through history is of limited value for individuals seeking improvements in and maintenance of wellbeing in contrast to information about dependencies and correlations between variables [5], such as the effect of certain foods on an individual's blood sugars. Given that users are often not rational data scientists [22], and that they are consistent in asking for greater analytic capabilities than their devices are currently capable of, it seems inevitable that the industry will introduce systems that purport to provide more definitive answers for users. The danger would be doing so without properly attending to the uncertainties we highlighted above.

This is made particularly clear in the case of wearables that claim to identify correlations between mood and activities (e.g. ZENTA: https://www.indiegogo.com/projects/zenta-stress-emotion-management-on-your-wrist). It is conceivable that wearable life coaches may soon draw from other pervasive technologies to provide indications of, for example, toxic relationships between the user and other individuals and encouraging them to cut unhealthy social ties. While such revelations could have clear benefits, the implications of inaccuracies of one's data, or of the data that is being drawn from other sources to determine correlations, would begin to extend beyond the individual user, affecting others in their social circle who have not necessarily consented to such analysis. Additionally, the consequences to the individual of

[1] There are already non-consumer wearable technologies that are currently in use for these purposes, though they lack the portability and accessibility of mass market wearables.

making a decision to cut a person out of their life are not necessarily knowable to a system, e.g. would cutting ties introduce undue financial instability into their lives? How certain would one have to be of the toxicity of a relationship to be willing to end it? It may indeed be the case that people would more readily accept diagnoses of their problems in the form of a scapegoat than accept that their unhappiness is a result of a number of their behaviors they find difficult to change, which is all the more reason that tools that claim deep insights into users' lives be very clear about the uncertainties they are juggling in their algorithms.

For advanced diagnostic tracking in the form of life coaching, new techniques are needed to identify potential triggers from relevant contextual information; and to the extent that doing so entails drawing data from other pervasive devices, this may introduce further uncertainties that need to be reflected in overall measures of uncertainty. Additional work is needed to understand how best to communicate these uncertainties to users. In particular, tools should be developed for capturing users' cognitive and affective responses to these uncertainties (see Section 5: Sidebar: Communicating Uncertainty) and the subsequent actions taken by users to improve uncertainty feedback visualizations and interfaces (e.g. [11,12]).

4.3 Patient Compliance Monitoring

It has been argued that the commercial appeal of activity trackers for relatively affluent and active individuals has obscured the true potential of these devices to help manage chronic illnesses [10]—particularly given that those with a true health need are significantly less likely to abandon their gadget when the novelty has worn off [10]. If the degree of certainty in the reliability of activity tracking data were to become better understood, it might be more readily accepted into the doctor's office as a way of inferring compliance with exercise plans and dietary advice (see [24]). With this end in mind, we anticipate that commercial wearables will advance to the point of being able to determine a) whether/when a patient is taking prescribed medication and at what dosage,[2] b) what the effects of that medication are on their physiologies, and c) what other behavioral factors are affecting symptoms.

Given this data, doctors could disambiguate factors that are impacting a patient's health. This is important information, further, for determining the accuracy of patient self-reports, which can be flawed for a number of reasons, ranging from innocuous memory failings to subjective interpretation of one's experiences to intentional misrepresentation or deception. To the extent that patients understand that noncompliance is detectable by their doctor, this may promote greater compliance. On the other hand, the use of wearables as an objective (certain) measure may result in greater emphasis being placed on quantitative data than the patient's own anecdotal reports. If inconsistencies between the two accounts arise as a result of uncertainties surrounding the wearable data (i.e. input uncertainties relating to sensor error rates and the device having been used incorrectly by the patient), this could have negative implications for the patient-doctor trust dynamic if the uncertainties are not clarified to both parties.

Just as it is not clear how to communicate uncertainties to the average consumer, it is also not clear how to communicate uncertainties to doctors. Effective communication of uncertainties may take different forms between these two groups. Doctors may, for example, be more comfortable interpreting raw data or graphs or may need data in a certain form to be comparable with their existing patient records. It may take new training to be able to interpret results from commercial wearables within the standard assessment frameworks—indeed, these practices may need to evolve—as well as further training for dealing with patients who may have drawn their own (possibly false or irrelevant [11]) conclusions from their personal devices.

Entering into this space also raises potential ethical questions such as, whether we want our doctor to know everything we do. If not, research is needed to find a balance in data certainty that supports serious medical decision making, while preserving plausible deniability for the patient.

5 SIDEBAR: Communicating Uncertainty

Experimental psychology studies, such as those undertaken by Susan Joslyn and others at the University of Washington (http://depts.washington.edu/forecast/), have shown that the provision of information about uncertainty can lead to greater trust in system models and better decision making. These benefits are far from assured, however, as studies have also shown that non-expert end users have great difficulty interpreting uncertainty information [12].

One of the presumed reasons for this difficulty is that uncertainty increases the cognitive load individuals need to manage while making a decision. It requires that individuals engage in slow and methodical thinking, as opposed to more quick and heuristic thinking. Verbal and numerical expressions of uncertainty both create potential complications for decision makers—the former being open to more subjective interpretative variability; the latter often being more difficult to decipher [9]. Both forms are potentially subject to framing effects, which influence people's processing of the information. Research has also uncovered deterministic construal errors [9], i.e. the tendency to interpret uncertain information as deterministic. For example, individuals frequently incorrectly interpret the "cone of uncertainty" in hurricane forecasts as the extent of the wind field, while it in fact represents the extent of all possible hurricane

[2] Given that wearables are currently in development that can measure glucose in the blood, we do not see it being a great leap to imagine that they will soon be able to measure the prevalence of other compound chemicals in the blood.

trajectories. All of these factors require careful consideration when designing representations of uncertainty information.

6 Conclusion

Based on the scenarios above, we present three areas in which future work ought to be conducted to attend to the issues they raise:

- *Providing access to confirmatory evidence of reliability.* An inherent problem of many pervasive sensor technologies is that the data recipient has little or no way of verifying the data's accuracy [13]. In the case of health wearables, while users might have some general sense of whether they are dehydrated or have low blood sugar, for example, they are unlikely to be able to put an exact number to these measurements. So how might health wearables of the future provide access to confirmatory evidence of its precision? Doing so would seem especially useful for enabling the user to help with device calibration (as discussed in [18]) to help mitigate some potential input uncertainties.
- *Preserving provenance of uncertainties.* Due to the trend toward greater interdependence between data systems, with outputs from one system being churned through the algorithms of another [13], it is conceivable that data from individuals' self-tracking devices be used as bedrock data in other systems from which a whole range of inferences are made. Ensuring that uncertainties are preserved and communicated throughout a long chain of systems, whose developers and interpreters might have different readings of these uncertainties and tolerances for them, is challenging but necessary if these systems are to be interpretable at scale (as discussed in [19]). This requires the development of mechanisms for ensuring that important context is not lost—including, for example, both the uncertainties and uncertainty tolerances at different points in the chain.
- *Tailoring communication of uncertainties.* Designs must be flexible and/or customizable, presenting uncertainty information in ways that are understandable by the full range of end users, who have differing needs in data granularity and information presentation.[3] Given that much of the value of health wearables for lay consumers comes from data being available at-a-glance, there is a need to balance important nuance with the interface usability (as discussed in [16]). Still, there are moments when even lay consumers may require access to uncertainty information, with systems perhaps allowing users to delve deeper as required. Contextual information, such as users' intended and ongoing use of their wearable data, might also be useful for determining what kinds of uncertainty information the system ought to responsibly communicate. At the same time, designers must be cognizant of users' variability in cognitive and affective responses to uncertainty information, to design systems that can identify, learn from, and adapt to these responses to inform most effectively.

At this time, we present these design implications as open challenges to the community without suggesting precise mechanisms for realizing these through design.

[3] This includes making uncertainty information accessible to developers of external systems in cases when data is integrated into other systems, as raised in the previous bullet.

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