

Final Position/Research Paper

Ethical Considerations for Smart Wearables

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Abstract

Healthy lifestyle is a happening trend nowadays and it comes with wearables to help us make smart choices. Let's look at a bigger picture behind the scenes to see what data these devices collect, how they process it, who all have access to it and how it is used. Let's see if there are any risk indicator red flags that could help identify & avoid ethical misuse of the devices and their data before it gets too late. How far do current regulations or public health policies go in controlling use of these devices, or their data in particular circumstances, or is it too late to define an ethical boundary?

The main objective of this paper is to help identify an ethical boundary to avoid the smart wearables industry going down the same slippery slope as social networking technology misusing personal data with artificial intelligence (AI) without end users consent. (Lapowsky, 2019) as reviewed in Cambridge Analytica Scandal, which forced users to change their decisions unethically misusing the data without the end user knowing about it.

Introduction

Wearables have become a way of life for encouraging healthy living. For years together fitness and a healthy lifestyle was a regular part of life and it was monitored by usual checks of weight at home or clinics or vitals checks during annual or quarterly doctor visits. There was never a need to monitor heart rate, blood pressure, steps or sleep cycles frequently for living a healthy lifestyle. But then any major issues or illnesses were also identified in later stages. Like gradually increasing weight or sudden changes in heart rate providing early signs of possible heart disease, increase in blood sugar levels from normal thresholds indicating possible diabetic incline etc. With advent of wearables the doctors manual pulse checker went electronic to give more accurate readings and become more convenient and affordable with mass availability for the common man. Blood glucose checkers provide early signs of sugar levels to switch to healthy eating habits. Being able to measure your steps and calorie burn provides daily goals for fitness. These checks for numbers, goals and visualization for the data in

various health interpretations has given a different perspective making us more informed and conscious about our health. Wearable devices have become an inseparable important need for having a healthy lifestyle. In some cases the manufacturers have support from the doctors to promote these too. (Vogler & Schwab, 2019, p1) the author states “One has to note that the idea of ”Quantified Self” is therefore marketed by the firms selling those wearable medical and (mainly) fitness devices.” Would we be able to live healthy lives if these wearables are taken away? Think about the data that these devices collect about us, who has access to it, how is it being used, is feedback provided to us unbiased?

Methodology

The two main methods used for collecting data and evidence for this research paper were:

- Literature reviews
- Anonymous Survey

Literature reviews

In order to get a perspective of existing considerations on reviewing wearable devices from various areas a literature review of available research material in articles was performed. The review was used to draw an outline of device types, their classification, data transfer technologies and cybersecurity considerations for analyzing relevant information towards the objective of this paper. The reviews were broadened beyond just wearables to look at use of AI to analyze medical data and its advantages and concerns. The other extreme end that was considered was looking at pros and cons of using exoskeleton robots as wearables as a possible extension of wearable devices in future. The content from these articles is cited in this research paper and details available in the references section for further reading.

Survey

A casual multiple choice survey in a social group of friends working in the IT industry was conducted with specific questions and selecting from multiple choice of answers to review the end user perspective of using smart wearable data and its sharing in various industries like healthcare providers, insurance, food shopping apps etc. Survey responses are presented in the appendix. Analysis of the survey results is discussed in the “Ethical Issues and Legal Considerations” section of this paper.

Wearables and ethical boundaries exploratory anonymous survey

Survey question:

Do you feel it's ethically correct, if wearables are made mandatory by insurance providers where "all" objective data trends collected by the device are used by your healthcare provider to track your fitness and health to:

1. decide the premium/risk bracket of the coverage
2. help predict and prevent any major health risks
3. recommend healthy lifestyle changes
4. suggest alternative healthier foods in your shopping cart in supporting stores

Select from possible answers:

- A. Yes ethical - I support it and trust sharing wearable objective data for statistical analysis by healthcare provider/insurance
- B. Yes partially ethical - I support it but do not trust sharing wearable objective data, I would prefer statistically analyzing data myself with selective sharing
- C. Meh unethical - I don't support it - but I would like to get statistical analysis of my wearable objective data and not share it with anyone
- D. No way totally unethical - I don't support it and dont trust anyone seeing or analyzing my wearable objective data
- E. Other perspective - provide short explanation

Smart Wearable Devices

There are various types of smart wearable devices based on the types of sensors and the data that they collect to analyze it. They can be classified based on various factors based on how they are connected to the body, types of sensors, types of data they collect, how they transmit the data and how the data is used. The classification helps explore the breadth of wearable devices available in the market for a focussed review ranging from strapped wrist or arm bands to the future of wearable robots. In general a wearable device most commonly used today consists of a set of sensors, firmware for data conversion, data transmission and display. In some cases the sensors could be separated from the data collection/transmission unit. But to classify devices on sensors would be based on bioelectronics using heat, light, body fluid chemical sensors, sound and movement or acceleration. The simplest ones are acceleration sensors that sense movement like in pedometers or sleep trackers. (Chang et al., 2019, p2-4) authors state that the same acceleration sensor can be used for multiple purposes based on data algorithms for tracking steps as a pedometer and monitoring movements as a sleeptracker. Further elaborating “L'Oreal has introduced a new wearable “My Skin Track UV” recently and it can measure the exposure data of UVA and UVB on users” which uses sensing of light. (Vogler & Schwab, 2019, p2) neuroprosthetic sensors using tiny neural in body chemistry in cochlear implants or hearing aids using sound, nanosensors on the skin mounted using tape. The authors further elaborate on use of sound sensors “Using the smartphone’s microphone, diseases like asthma, chronic obstructive pulmonary disease (COPD) and cystic fibrosis can be diagnosed, analyzing various factors like the integration of airflow rate, replacing a portable spirometer, which can cost up to 4000\$.” Some body fluids sensors monitor composition of blood by banadid type glucose readers stuck on the body with a tiny needle pierced in the skin. All of the most common wearable devices today have a feature to be configured and controlled using an app installed on a computer or a phone to transmit data for further analysis.

Connectivity and Data Analytics

The data collected from the sensors is processed by the firmware to provide it for further transmission and data analytics by apps that statistically track the data over a period of time. The first stage of data connectivity involves the sensor and firmware which is closely attached to the body. (Vogler & Schwab, 2019, p2) "The network of the devices which are worn by a person on their body is called "body area network" (BAN), or sometimes "wireless body area network (WBAN)". Further as part of this network protocols like bluetooth or WiFi are used to connect the device to an app on a computer or a phone. The app further processes this data to communicate with device providers for analytics and tracking via the users home or cellular network. (Chang et al., 2019, p3) "In addition to Bluetooth, NFC is short-range radio technology based on RFID and interconnection technology and supports data exchange with compatible devices." Furthermore there are multiple pathways and options that the devices can communicate to transmit collected data. This race for providing multifunction ability has at times caused the providers to overlook security aspects of protecting the data from intentional theft or accidental leakage due to vulnerabilities.

Once the data is available to the analytics service provider which could very much be the same as the device manufacturer it is in most cases processed by AI algorithms to assess it against various samples and trends over a period of time. (Chang et al., 2019, p3) "Every wearer becomes a creator of big data and big data are collected from different areas of wearer's daily life." In addition the data analytics provider has large volumes of data trends to compare and contrast the users data statistically. (Vogler & Schwab, 2019, p1) "To find patterns in the collected data, people either need assisting software, which is mostly provided by the producer of the wearable device or they need sound statistical skills themselves." Not all the data that is transmitted from the device to the provider is tagged as user data. For example some of the data is just used for trending against other samples to correct and provide feedback to the AI systems reducing error rate and increasing efficiency. (Pesapane et al., 2018, p5) "Once a clinical decision based on AI is integrated into clinical care, withholding information from electronic records will become increasingly difficult, since patients whose

data are not recorded cannot benefit from AI analyses.” This is one of the key uses of the data to train the system with as many genuine samples as possible. There is definite advantage for the provider but also for the user to have their data compared against large dataset to identify possible health risks at an earlier stage. From a healthcare provider or doctors perspective this data helps them track their patients through a period of time than over only during visits.

Advantages and Health Awareness

The key advantages of wearables is self awareness and control of health for the users. This further reduces dependency on healthcare providers for tracking your own metrics. Wearables also provide very affordable means to monitor a wide range data making users more knowledgeable about their health. Early signs of risk like changes in heart rate or sugar levels help users be aware of possible diabetic tendencies and take control of the situation way before its done during annual checkups.

(Vogler & Schwab, 2019, p1) “ However, revealing patterns is not the only reason that wearable medical and fitness devices are used. Another reason is that it is possible to obtain objective data, so that it is not possible to have incorrect self-perception, and therefore to achieve one’s goals without the help of a neutral second party.” This greatly helps users monitor their own data against other samples for keeping track of their trends motivating a healthier lifestyle and setting milestones for achieving better health. Additionally the positive trends help drive these habits in social circles motivating the community of users to keep up with the healthy trends in a connected environment.

Other advantages that have been seen are in forms of driving improvement and maintaining routines taking control of your own health. The users have the feeling of empowerment to track symptoms and trends to better respond to upcoming health issues that can be avoided by rigor and discipline. The availability of data with ease and simplicity makes this discipline building process more easy, efficient and highly effective.

Another factor is where early diagnosis helps drive down treatment costs also assisting insurance trends. Furthermore the function of expensive medical equipment can be easily performed by wearable

devices for single user for an ongoing diagnosis trending at a much cheaper cost. (Vogler & Schwab, 2019, p4) "Using the smartphones accelerometer or a video-feed recorded by the camera of the smartphone, even classic medical devices for heart rate detection, blood pressure and blood oxygen saturation like the ECG or EKG (up to 5000\$) can be replaced by a much cheaper alternative that is already available to the patient." Photoplethysmography helps track reflected light from the blood in certain body parts like fingers or earlobes to monitor intensity of reflected light with systolic and diastolic pulse cycles.

Proactive monitoring of data trends provides early detection and timely intervention saving the user a lot of time in doctors visits and diagnosis. In general the user would have to make several different lab tests first to diagnose the condition and then have them reviewed by one or several doctors or specialists at specific intervals to get the condition checked. The device in this case not only saves the user time but also helps the doctor to focus on treatment rather than analyzing diagnosis reports and allows them to spend more time with additional patients that need focussed attention in critical cases.

From a security point of view mobile devices and cell phones have already become the preferred handy device with most of the users critical apps, data and social life. The cellphone OS and app providers have been trying to keep up with securing the rising number apps and functionality packed on these devices. A security flaw or vulnerability would not go unnoticed with the scale of impact it would cause demanding immediate attention for fixing the issue and possible risk remediation to avoid similar exposures in future. So in short the wearable apps being in this environment would be equally safer as other critical apps as long as the wearable apps themselves do not fall victim to the attacks providing a backdoor to security threats. (Vogler & Schwab, 2019, p4-5) "wearable devices use already existing technology and the same protocols that are being used to transfer all kinds of personal data, like mobile or online payment, where the users bank information is transmitted the same way medical data is transmitted with wearable health devices, these benefits can clearly be regarded as a good and valuable improvement in the users life and health."

Ethical Issues and Legal Considerations

While there are significant advantages of generating and monitoring data from wearables for empowering the user, several ethical issues and legal considerations lurk in this space. Listed are the ones that have been prominently called out in the articles reviewed. Further followed by analysis of the survey results to understand the mindset of an end user.

Enhanced capability of the devices to empower humans has always been looked at from a moral perspective where defining a boundary is essential. (Vogler & Schwab, 2019, p6) As the author highlights “Assistive technology was often quickly normalized in culture. Examples are glasses, vaccines, and prosthetics. People tend to draw a moral line where technology grants super-human possibilities.” This becomes very sensitive when there are no frameworks established to define the ethical boundaries. In some cases challenging the wearable robots for converting normal human beings into humanoids. (Kapeller et al., 2020, p9) “In the industry domain, ‘turning workers into machines’ has been connected to the dehumanisation of work and the possible exploitation of workers.”

Misuse of generated data is another issue where the data could be used beyond its predefined purposes to track users history or disease tendencies to sell this data unethically to care or service providers. Regulations like Health Insurance Portability and Accountability Act (HIPAA) and General Data Protection Regulation (GDPR) provide privacy or cybersecurity controls guidance but completely lack an ethical perspective. (Pesapane et al., 2018, p6) “This sets out a number of requirements for EU member states which aim to prevent cyberattacks and keep their consequences under control.” Where as HIPAA mainly concentrates on privacy of health information (Pesapane et al., 2018, p6) “in the U.S. government regulation is less strict, cases like Cambridge Analytica/Facebook should remind the government that actions should be taken, and that the behaviour of companies needs changes.” AI learning from samples poses an ethical dilemma when the limitation of availability of data or an ethnic perspective induces a bias inadvertently manipulating the outcomes. (Pesapane et al., 2018, #) “an algorithm designed to predict outcomes from genetic findings may be biased if there are no genetic studies in certain populations.” Another extreme example where the core purpose of an AI feature could

be questionable, where Google maps learning the data to predict the presence of a trooper on a certain route, questioning its ethical purpose.

Peer or society imposed pressure around wearable usage or as a mandatory requirement by providers is a red flag, where in extreme cases leading to insurance scams and fraud for mandating wearables.

Even in cases where healthcare providers favor certain device manufacturers could be ethically concerning. (Vogler & Schwab, 2019, p6) "The German health insurer AOK grants a bonus to people who have good enough data in their fitness record (Apple Health or Google Fit). The US insurer Aetna reportedly collaborates with Apple to give users personalized health advice based on the data of the apple watch."

Also possible exposure of users behaviors and habits making them vulnerable, especially in cases when GPS tracking collects location data of children is another area of concern. In some cases it could be viewed as beneficial for parents to monitor their child's location for safety. But in other cases it could be misused by device manufacturers or vulnerabilities exposing this information to the hackers. (Chang et al., 2019, p1) "In 2017, Germany announced a ban on sales of children's smart watches. The main reasons for the ban is that the smart watch can be monitored by hackers, since the smart watch can be a tool for threatening children's safety"

Also GDPR regulation covers protecting data where users themselves could expose their own data or do not completely understand the cybersecurity aspect of using a device safely. Despite the exposure risks or resulting long term consequences of sharing their data some users are willing to take that path risk to get more features or promotions. This actually brings us to the critical review of the results for the survey shown in methodology. The actual responses and results of the survey are presented in the Methodology section.

Critical analysis for the survey results

The graphical screen shot of the survey results is shown in the appendix. This is the critical analysis and the inference drawn from the results -

- Audience & population: 8 users who work in IT, and are gadget surfers

- 12.5% - 1 user denied the data sharing mandate as absolutely unethical with possibility of fraud
- 12.5% - 1 user found no mandates ethical and ok to selectively share data for recommendations
- 25% - 2 users found it unethical and did not favor sharing but wanted statistical analysis from AI
- 25% - 2 users found it partially ethical to process and share data selectively
- 25% - 2 users found data sharing mandates with insurance and healthcare providers as ethical

Overall only 12.5% of the users were totally against data sharing and 25% of the users had no issues sharing their data. Rest were in the middle for selectively sharing their data for health recommendations or statistical analysis. This in a way reflects a possible another concern of self sharing data by users for marketing gimmicks.

Conclusion and considerations

The wearables devices are going to be an inseparable part of our gadget filled lives and also our bodies going forward. These will be in near future attached to our bodies externally, (Kapeller et al., 2020, p1) "Wearable robots (WRs), including robotic exoskeletons and orthoses, are an emerging technology designed to augment, train, or supplement motor functions." Some even would be operationally embedded inside our bodies as nanodevices or implants (Vogler & Schwab, 2019, p2) "others use a combination of methods (e.g. a passive nanosensor under the skin, transmitter outside the body)" In either case our bodies will be a quantified source of rich data with statistical trends and predictions.

It's the future we cannot deny in the digitally connected world. There is a need for identifying the right review mechanisms and regulations to expand the controls to cover ethical contexts. The past incidents of privacy violations have provided a boundary line we don't want to cross and also use similar precautions to implement ethically sensitive regulations with soft and hard thresholds for ethical assessments and penalties. It won't come as a surprise to get fitted with a digital contact lens as you age to proactively monitor your body fluids and display your metrics right in our eyes.

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Appendix

Anonymous survey

Wearables and ethical boundaries - exploratory

This is a short one question anonymous survey exploring the ethical boundaries around use of wearable devices and its data.

The question:

Do you feel it's ethically correct, if wearables are made mandatory by insurance providers where "all" objective data trends collected by the device are used by your healthcare provider to track your fitness and health to:

1. decide the premium/risk bracket of the coverage
2. help predict and prevent any major health risks
3. recommend healthy lifestyle changes
4. suggest alternative healthier foods in your shopping cart in supporting stores

Select the answer from the choices below that best suits your perspective. If any of the provided options do not suit you, please select "other" and provide a short explanation.

Thank You for your participation!

Note: Please provide only one response to keep the data clean, as this is an anonymous survey is not collecting or tracking info for survey respondents.

Do you feel it's ethically correct, if wearables are made mandatory by insurance providers where "all" objective data trends collected by the device are used by your healthcare provider to track your fitness and health to: 1. decide the premium/risk bracket of the coverage 2. help predict and prevent any major health risks 3. recommend healthy lifestyle changes 4. suggest alternative healthier foods in your shopping cart in supporting stores

- ☐ A. Yes ethical - I support it and trust sharing wearable objective data for statistical analysis by healthcare provider/insurance
- ☐ B. Yes partially ethical - I support it but do not trust sharing wearable objective data, I would prefer statistically analyzing data myself with selective sharing
- ☐ C. Meh unethical - I don't support it - but I would like to get statistical analysis of my wearable objective data and not share it with anyone
- ☐ D. No way totally unethical - I don't support it and don't trust anyone seeing or analyzing my wearable objective data
- ☐ Other: _____

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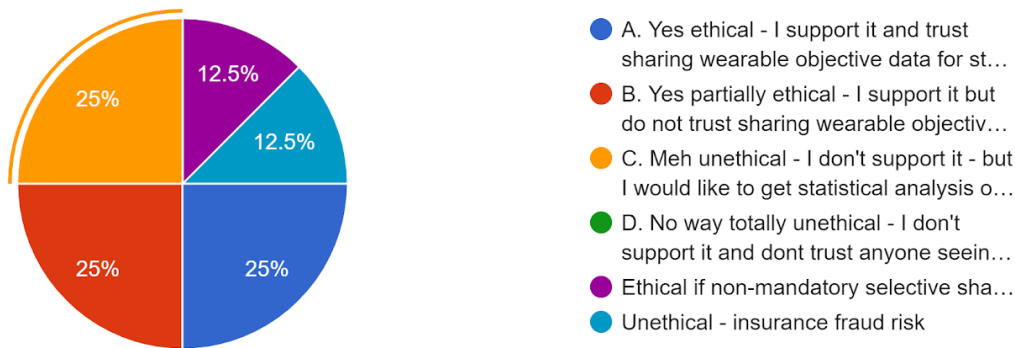
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Survey results Pie Chart

Do you feel it's ethically correct, if wearables are made mandatory by insurance providers where "all" objective data trends collected by the device ...er foods in your shopping cart in supporting stores

8 responses



Survey responses

B. Yes partially ethical - I support it but do not trust sharing wearable objective data, I would prefer statistically analyzing data myself with selective sharing
A. Yes ethical - I support it and trust sharing wearable objective data for statistical analysis by healthcare provider/insurance
C. Meh unethical - I don't support it - but I would like to get statistical analysis of my wearable objective data and not share it with anyone
B. Yes partially ethical - I support it but do not trust sharing wearable objective data, I would prefer statistically analyzing data myself with selective sharing
C. Meh unethical - I don't support it - but I would like to get statistical analysis of my wearable objective data and not share it with anyone
Ethical if non-mandatory selective sharing
A. Yes ethical - I support it and trust sharing wearable objective data for statistical analysis by healthcare provider/insurance
Unethical - insurance fraud risk