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Ethical issues concerning the use of commercially available wearables in children: Informed consent, living in the spotlight, and the right to an open future

SUMMARY

Wearable and mobile technology has advanced in leaps and bounds in the last decade with technological advances creating a role from enhancing healthy living to monitoring and treating disease. However, the discussion about the ethical use of such commercial technology in the community, especially in minors, is lacking behind. In this paper, we first summarize the major ethical concerns that arise from the usage of commercially available wearable technology in children, with a focus on smart watches, highlighting issues around the consent process, mitigation of risk and potential confidentiality and privacy issues, as well as the potential for therapeutic misconceptions when used without medical advice. Then through a relevant thought experiment we move on to outline some further ethical concerns that are connected to the use of wearables by minors, to wit the issue of informed consent in the case of minors, forcing them to live in the spotlight, and compromising their right to an open future. We conclude with the view that mitigating potential pitfalls and enhancing the benefits of wearable technology especially for minors requires brave and comprehensive moral debates.

Keywords: wearable devices, ethics, children, privacy, large data, informed consent, right to an open future, living in the spotlight.

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1. Introduction

Wearable sensor-based technology, such as smart watches, has now become an integral part of everyday life aiming to help both monitor and improve one's health. These devices can use at minimum global positioning systems (GPS) and accelerometry to provide data on location and physical activity, with additional health data such as heart rate and sleep quality becoming increasingly available commercially. A recent review of relevant datasets counted up to 362 commercially available sensor-based wearable devices (Muzny et al., 2020a). Research into the use of such technology has also advanced rapidly in the past decade, with publications related to “wearable devices AND sensors AND health” demonstrating a geometrical increase between 2010 and 2020 (10 publications vs >300 publications in Scopus respectively, including however only 3 publications in children). The extended use of such devices and the amount of personal data collected have given rise to ethical concerns. However, research about potential ethical issues surrounding their use in non-clinical environments has been lacking behind relevant technological advances, especially in the case of minors, who are increasingly starting to use such devices in the community.

The use of such devices for research purposes and ethical concerns and suggestions have been discussed before (Breslin, Shareck & Fuller, 2019; Ulrich et al., 2020) and are not the focus of this paper. Additionally, another very recent publication discusses the ethical challenges in using ambient sensors in healthcare settings (Martinez-Martin et al., 2021). We will review and discuss the use of commercially available devices by minors in the community, with a focus on the ethical aspects arising from such everyday use, and more specifically the consent process, mitigation of risk, and potential confidentiality and privacy issues, as well as the potential for therapeutic misconceptions when used by children without medical advice. These will be additionally highlighted through a relevant thought experiment.

2. Ethical issues in the use of wearable devices

a. Informed Consent

Informed consent is not restricted to the use of data in research but is rather pertinent to any circumstance where personal and/or sensitive data are collected. It is both an ethical and legal requirement, especially under the current European General Data Protection Regulation (GDPR). However, the consent documents for wearable devices and their corresponding mobile or web applications are still very lengthy and more often than not, include terminology or context that is not easily understood

by everyone. As a result, most consumers do not read terms of agreement or privacy policies, which leads to the routinization of consent, where the act of agreeing to the use of technology becomes unreflective and uninformed (Ploug & Holm, 2013). An additional limitation is the availability of such information in the user's native language, which further hinders the "informed" part of the consent process. A very recent experimental survey using a fictitious social networking service demonstrated that 74% of participants skipped the privacy policy altogether, whereas 97% and 93% agreed to the privacy policy and terms of service respectively, without reading them. The authors report information overload as a significant negative predictor of reading the terms of service, with serious possible implications, as demonstrated by the fact that 98 % missed the included clause about data sharing with the NSA and employers and giving their first-born as payment for service (Obar & Oeldorf-Hirsch, 2020). Such findings highlight the issues of consent in commercial settings as well as the potential implications of accepting all terms and conditions without actually reading or understanding them, even more so when consent is given on behalf of a minor and even further information on additional permissions/setups/verifications is needed. In the case of devices that are targeted directly at minors, a second consent option by the wearer – especially in the case of adolescents – might be pertinent, as adolescents over the age of 16 have the right to assent in certain countries. However, this age distinction might present further technical issues with regard to age verification. Whether relevant applications even require age verification for use or the means by which they verify age has been discussed by Pasquale et al. (2020), reporting that, at least in the case of social media applications many of them do not provide robust mechanisms for age verification.

Further, it can be easily forgotten by consumers that continual data collection is occurring and periodic re-consenting may be necessary with the use of sensor technology, as has been suggested for the use of wearable devices for research purposes (Ulrich et al., 2020). In the case of minors, where parents/guardians are required to provide consent, it is even more imperative that both the type of data and the amount of data are explicitly explained as well as issues pertaining to data ownership and third-party usage, as discussed further below. If such data are to be transferred to the user's physician for example, as a way of monitoring health issues, then the process should be clearly described and consent provided for each individual use of the data with clear opt-in options, whereby opting-out from a specific use should by no means make the service completely unavailable, as is usually the case with "blanket" consent.

b. Confidentiality and loss of privacy

As users of wearable devices become increasingly aware of data ownership the pressure is rightly on the manufacturers to clarify secondary and third-party use of data. Data usage should include the option of using a device, such as a smartwatch, without the need to go through a cloud-based storage service, by allowing to opt out from such services and access the data directly. The adoption of the Privacy by Design framework which incorporates privacy in all steps of the engineering cycle of a device or software has been suggested by the Federal Trade Commission (FTC) as a way to help protect the privacy of users (Perez & Zeadally, 2018). The introduction of GDPR in Europe and the Health Insurance Portability and Accountability Act (HIPAA) regulations provide an enforcement tool for the obligation that manufacturers have in clarifying both the type and amount of data collected by their device and its use. However, it is important to note that different legislations and regulations apply in various countries, with several devices allowing for the transfer of data between parties that are legally bound by a different set of regulations. One example is the US HIPAA Privacy rules for sensitive mobile Health (mHealth) data that do not apply to wearable devices as they are directly bought by consumers and not prescribed by a doctor. Furthermore, commonly collected physiological health and derived parameters, such as the number of steps and heart rate, are not considered to be personal health information (Muzny et al., 2020b), although data collected from minors are further regulated under the Children's Data Protection Act (COPPA) in the USA and covered by the GDPR in Europe.

With the ever-increasing number of people, including children, using wearable sensor-based technology, the potential for research-based secondary use of such commercially derived data is tremendous. Whereas research studies are faced with limitations in participant numbers, time of follow-up, and generalizability, real-world evidence (RWE) can help researchers access large and generalizable population cohorts in order to be able to look at specific behavioural patterns and outcomes. This is especially important for minors as they are generally underrepresented in research. This potential for research use of real-world data from commercial sources, however, has to be regulated following an open and public discussion about the use and accessibility of such data, highlighting the need to preserve the user's autonomy while ensuring their safety. This is also important as data mining for marketing purposes is another potential secondary use of such data and it should be further regulated by including all stakeholders in the discussion, especially minors, as they are the end-users and more often than not, may have a better grasp of technology than their parents, i.e. the people giving consent on their behalf.

Following the concept of citizen science, ownership of wearable-based sensor data obtained outside of the framework of research studies requires a regulatory approach where the data remain with the user, and technical solutions are provided to allow the user to opt-out, or even better opt-in, of any reuse proposed to them. A review of attitudes towards the reuse of health data in the European Union reports that while the majority holds positive attitudes towards the use of health data for multiple purposes, these are usually conditional on the expectation that data will be used to further the common good, stating concerns around potential commercialization of data, data security and the use of data against the interests of the people providing it (Skovgaard, 2019). In line with this approach, calls from public sponsors for new sensor-based data platforms for the collection of real-world evidence may require regulated access, i.e. a formal procedure to speed up the validation process. This has been previously suggested for the potential use of such data in cognitive performance research of a similarly vulnerable population of people with cognitive decline and Alzheimer's disease (Teipel et al., 2018).

However, in order to both inform the discussion over data ownership and privacy and enable potential safe secondary usage of data, it is important to understand how consumers feel about their data. One study on home and wearable sensors concluded that when data pertained more to their person (wearable sensors) rather than to their home (home sensors), people were more cautious. Such data could trigger anxiety about their health status and/or overall wellbeing. Overall, participants stressed the need to control the interpretation and flow of their own data (Burrows, Coyle & Gooberman-Hill, 2018). This could be even more important in the case of data from users who are minors as parents are more concerned about the information collected from their children (Desimpelaere, Hudders & Van de Sompel, 2020). A recent study on the perceived risks and willingness to participate in environmental health studies with personal exposure data from the USA reported that in contrast to their own data, female participants preferred a more controlled access to their children's data. They were also more reluctant to share their location or participate if the study involved electronic medical records, expressing concerns over privacy (Udesky et al., 2020). In a qualitative study looking at both children's and parents' perceptions of online commercial data practices, authors report that children often do not have a full understanding of how data collection practices work, but they do have a degree of privacy consciousness, i.e. they can distinguish between identifiable and non-identifiable data. Children also expressed a positive attitude toward the use of personal data, unlike their parents (Desimpelaere, Hudders & Van de Sompel, 2020). What's also interesting is the reported adoption of protected measures from parents for data that is collected explicitly but not implicitly, for instance the use of cookies or GPS location in the case of wearable devices, with some reporting a

lacking sense of control. However, as mentioned above, when using commercially available wearable devices, the consent process is more likely to be a routine one, with most users not even reading the terms and conditions (Obar & Oeldorf-Hirsch, 2020), which makes the need for improving the consent process and making it more explicit and transparent even more imperative.

Concerns are also usually raised regarding potential data breaches. Although data breaches are rare, they do happen, and when they occur they can cause harm to both the user and the public's trust in the technology. There have been instances of anonymized spatial data being shared from commercial devices and applications that had the potential to identify sensitive locations and user habits (de Montjoye et al., 2013). Such data can be used to reveal spatial and mobility data of minors and other vulnerable groups, as well as to reconstruct social networks in adults and children; and users themselves tend to consider them as "private" (de Montjoye et al., 2018). Major breaches of individuals' privacy with social media tools such as Facebook have occurred in the past, and citizens are rightfully worried about the use of their data (Pagoto & Nebeker, 2019), especially in the case of data collected from children. To mitigate and minimize such risks, manufacturers must utilize all available technological measures and the process regulated by data protection legislation.

c. Therapeutic misconceptions

Wearable devices with sensor technology are advertised as tools used to help individuals monitor and improve their health and health-related behavior, such as physical activity, diet, and sleep. However, a review of the effectiveness of behavior change applications associated with such devices, reported that only 6 out of 23 devices were developed based on a theoretical model of behavioural change and that those that were theory-based were more effective in influencing outcomes (Zhao, Freeman & Li, 2016). This is again problematic in devices targeted toward children, as these are even less likely to be theory-based. Any claims made by manufacturers should be supported by theoretical models and research; but these may not be the only ethical considerations that should be taken into account.

3. Further ethical considerations: A thought experiment

A thought experiment for the use of wearable sensor-based devices in children, especially smartwatches, could provide a much clearer insight into the issues discussed above, and even outline further concerns that are usually overlooked, such as forcing minors to live in the spotlight, and compromising their right to an open future.

Consider the case of John, a 12-year-old, healthy boy in every aspect, save for the fact that John is obese. His body mass index (BMI) exceeds 35, which compared to the average BMI of children John's age places him in the 99th percentile and gives his parents good reason for concern. Their concern is increased because both John's father and mother have an alarming family history of type 2 diabetes and essential hypertension, respectively. Given that children John's age are usually reluctant or unable to commit to a healthy lifestyle, i.e. be physically active and adopt a healthy diet, John's parents, after having discussed their options with John thoroughly, decided that John should be equipped with a wearable device that will track his position on a permanent basis, and also monitor his blood pressure and levels of physical activity. The collected data would be constantly available to John through a specialized application on his smartphone, and also reported to his parents on a real-time basis, so that they could take action in case something were to happen.

John's parents hope that this will motivate him to become more physically active, more aware of his physical condition, and more committed to a proper dietary schedule. John, on the other hand, feels a lot safer since his condition will be constantly monitored not only by himself but also by his parents. He also hopes that the device will help him lose weight soon so that he can participate in more activities and become more accepted by his peers, i.e. he is as eager to give his consent as his parents. However, mutual satisfaction itself doesn't make any decision ethically unproblematic, especially when the autonomy and the rights of the moral agent are at stake.

a. Informed consent by minors

The use of wearable tracking and monitoring devices in minors normally gives raises autonomy-related ethical issues and concerns (Chang-Tek Tai, 2019), since minors are generally considered not to be in the position to give informed consent, at least not to the extent or degree any normal adult agent typically is. As stated above, a 12-year-old boy can hardly be expected to fully grasp what he needs to consent to, as reading and understanding the terms and conditions that are typically listed in consent documents is challenging for adults. Concerns like these fuel the less controversial part of the debate, that could be easily resolved: it would suffice if wearable devices that are equally available to minors without parental consent came with consent documents that would be easily comprehensible by minors. Apart from this specific example, however, entertaining consent-related concerns in the case of minors is perfectly justified.

Consenting to data collection and sharing also raises ethical concerns when it comes to minors because it requires technical and legal knowledge that is usually neither

available to nor comprehensible by children John's age. Additionally, safeguarding the security, anonymity, and irrevocability of personal data related to one's health condition, lifestyle or habits is especially crucial in the case of minors like John, since in case of failure, this type of data will normally follow a minor for a long time, and it could potentially affect their chances in life. In our view, sensitive personal data, health-related data included, becomes even more sensitive in the case of minors, since they are much more vulnerable to any breach. This makes it even more imperative to secure informed consent on behalf of minors regarding the future use of their data as in John's case.

b. Living in the spotlight

A much more profound moral concern is related to the psychological impact the constant monitoring of one's physical condition and activity is expected to have on minors John's age. John's physical condition makes the use of such a device necessary and potentially beneficial. To a certain extent, he will not lead a perfectly ordinary life like his peers. John might be susceptible to developing an introspective outlook on himself, one that is neither usual nor even desirable for children of this age. Unlike other children, John will live in the spotlight of his parents, and more importantly – himself. This may affect John's psyche, and character, which in some cases might even outweigh the anticipated benefits to his physical health. He might develop hypochondriac tendencies, an overdependence, or even addiction to his intelligent wearable device (Mani & Chouk, 2017), he may become overly introspective and reserved, lose autonomy (Rauschnabel, He & Ro, 2018), and the spontaneity typical for his age. He may even become egotistic. In short, the use of a wearable sensor-based device may result in John experiencing a certain degree of disproportionate psychological harm, which he could not foresee, and has never provided his consent to, nor have his parents.

c. Privacy and the right to an open future

While health monitoring devices equipped with tracking sensors that report one's location on a regular basis may be a huge reassurance for both parents and children, especially in cases such as John's, they are also a radical breach of a minor's privacy. John's parents will be informed of his whereabouts on a real-time basis, while John will be aware of the fact that his parents can always find out where he is and what he is doing, which may result in him feeling that he has to always answer to his parents for even the smallest things. This, however, would severely compromise John's right to an open future, in the sense that he would be deprived of something that is common and typical for children his age, i.e. privacy and the uncompromised chance

to explore what he is capable of, as well as the world around him. Always answering to others, and being under constant surveillance, John runs the risk of being deprived of a future with a reasonable range of various opportunities (Protopapadakis, 2019).

Joel Feinberg introduced the principle of children's right to an open future to advocate the view that parents should not proceed with actions that would restrict the future possibilities for their children, but rather leave them with the greatest permissible scope for developing their own (life) choices when they reach adulthood (Feinberg, 1980). Gradually developing into the adult John wishes and chooses to be, however, requires a certain degree of privacy. As is the case with most children his age, John should be able to decide whether he will attend or skip class, go to a poolroom or diner, drive a bike or skate to school, etc. In other words, he should have the chance to occasionally distance himself from the person he is expected to be and just do silly things. Having his activity and location monitored on a real-time basis, though, hardly leaves any place for spontaneity and nonconformity which certainly narrows down John's access to an open future. This also comes with a certain amount of injustice: being obese is no reason for John to be completely deprived of privacy.

4. Conclusions

With the increasing use of smart technology in everyday life, it is imperative that we openly discuss both the benefits and the potential downfalls of such technologies, especially in the context of vulnerable groups such as children. Including the very people who use, or consent to the use, of such technologies in the discussion is deemed necessary. For one, people are more likely to use such technology if they are better informed about it and are more likely to use it safely and to their benefit, if they are aware of the type of data might be shared, with whom, and why. One recent ethnographic study reported that people's openness to sharing data from their smart devices varied according to their individual circumstances and views on the reasons why data might be shared (Burrows, Coyle & Gooberman-Hill, 2018).

In addition to these, we believe that the discussion concerning the use of wearables by minors ought to be much more ethically nuanced and even go beyond the trodden track. We believe that it should also address concerns regarding the potential psychological effects of wearables on minors, as well as take into consideration the fragility and fluidity of their moral character and overall mental constitution. In this paper, we discuss only three issues we believe usually don't get the attention they deserve, to wit a) the possibility of acquiring fully informed consent from minors – and what it would mean to fail in doing so, b) the possible negative consequences on their psychological development if the use of wearables forces minors to be living in

the spotlight, and c) whether the use of wearables holds the risk of compromising a minors' right to an open future. The remedies we suggest below mostly aim to outline these concerns and fuel the debate.

As far as informed consent in the case of minors is concerned, we believe that it is urgent to render the inclusion of minor-friendly consent documents mandatory for wearable devices that are either exclusively, or equally intended for minors. Alternative forms of permission requests such as comic-based designs might provide a more effective medium than text (Watson, Just & Berg, 2021), especially for minors. As long as such regulations are not implemented, however, acquiring informed consent from minors may only be contingent.

In the face of concerns related to the effect of wearables on the psychological development of minors, we believe that the use of wearable devices in minors should be backed up with conclusive evidence from further psychological research. Our search for relevant literature –although not systematic- produced very poor results that mostly focus on short-term effects such as obtrusiveness and anxiety (Ryan, Edney & Maher, 2019), and only with regard to the general population, not children in particular. Research in user perceptions and preferences has provided some evidence that evoking the emotions of “delight” and “comfort” can help users connect with a device and enhance purchase intention and use (Liao, Tanner & MacDonald, 2020), which could be further problematic in children and adolescents. While global standards on the use of such devices are being established (Ash et al., 2020), and are a necessary step in their widespread use, potential benefits in physical activity, weight control, sleep, and diet have not been consistently validated. A recent systematic review has shown little benefit on chronic disease health outcomes in adults (Jo et al., 2019). Similarly, a systematic review on the benefit of wearable devices for long-term physical activity and weight loss in overweight and obese adults did not show enough evidence to support wearables over the comparator methods, while issues with consistency in study methods were additionally highlighted (Fawcett, Van Velthoven & Meinert, 2020). Although challenges in device accuracy and validity are being tackled, it is important that the discussion around the ethical challenges also continues and that it includes children and adolescents, who are increasingly beginning to use such technology in the context of their everyday lives.

Whatever the case may be, we believe that the inclusion of short, comprehensive statements on the suggested use by minors and the potential issues for one's psychological constitution and development would be a remedy against potential negative effects on underage children's mental health.

In light of the potential harms of privacy breaches, technology developers – much like clinical researchers – should consider the moral complexity of using tracking or

sensory devices in potentially vulnerable populations (such as minors) as well as the possible measures they could and should take to safeguard them, like allowing full and easily accessible opt-in options, and/or also including the limited possibility of fake or coded spatial monitoring, especially for teenagers.

Finally, educating consumers on the benefits and potential downfalls of technology, how data is collected and shared, and by whom, is an essential step in increasing privacy-enhancing behavior. There is some recent evidence, showing that smartwatch privacy-enhancing games can increase privacy-protective actions with longer-lasting effects, influenced primarily by convenience, privacy salience, and data sensitivity (Williams, Nurse & Creese, 2019).

Through digital literacy, alongside improved consent and data sharing processes, we can empower the current and future generations of consumers to be able to fully enjoy the benefits of wearable devices while at the same time contributing to the common good through citizen-based research and mitigating potential real or perceived pitfalls, especially in vulnerable groups such as children. For this purpose, all stakeholders – especially minors – should be taken into consideration, and all potential risks and benefits – however small they may be – ought to be thoroughly discussed and balanced by means of broad and comprehensive moral debates.

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Etički problemi vezani uz korištenje komercijalno dostupnih nosivih uređaja kod djece: Informirani pristanak, život u centru pažnje i pravo na otvorenu budućnost

SAŽETAK

Nosiva i mobilna tehnologija značajno su napredovale tijekom proteklog desetljeća i dobile su novu ulogu - više ne unaprjeđuju zdrave životne navike, već nadgledavaju i liječe bolesti. S druge strane, rasprava o etičkom korištenju takvih komercijalnih tehnologija među populacijom, posebice maloljetnicima, značajno kaska. U ovom ćemo radu najprije sažeti glavna etička pitanja koja se pojavljuju kad djeca koriste komercijalno dostupnu nosivu tehnologiju s naglaskom na pametne satove. Istaknut ćemo probleme vezane uz proces davanja pristanka, smanjivanje rizika te moguće probleme vezane uz povjerljivost i privatnost, kao i moguće terapijske zablude kad se uređaji koriste bez liječničkog savjetovanja. Zatim ćemo kroz značajan misaoni pokus navesti daljnja etička pitanja vezana uz maloljetničko korištenje nosivih uređaja. Primarno se to odnosi na pitanje informiranog pristanka kod maloljetnika,

toga da ih se prisiljava da žive u centru pažnje, i ugrožavanje njihova prava na otvorenu budućnost. Zaključit ćemo rad mišljenjem da ublažavanje mogućih zamki i unaprjeđivanje prednosti nosive tehnologije, posebno za maloljetnike, zahtijeva hrabre i iscrpne moralne rasprave.

Ključne riječi: nosivi uređaji, etika, djeca, privatnost, veliki podaci, informirani pristanak, pravo na otvorenu budućnost, život u centru pažnje.