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Ethnographic study on open-source closed-loop systems in type 1 diabetes care

An ethnographic-empirical study on the #WeAreNotWaiting movement in Germany.

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Digital behavioral technology, vulnerability and justice

A public health ethical analysis of mobile health technologies and social justice and population vulnerabilities.

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Mobile health technologies, social justice and population-related vulnerabilities

A public health ethical analysis of mobile health technologies and social justice and population vulnerabilities.

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Contact tracing for Covid-19 and Reversibility

An ethical analysis of contact tracing apps for Covid-19 infections.

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Feminist perspective on mHealth

A feminist analysis of the development of mobile health technologies.

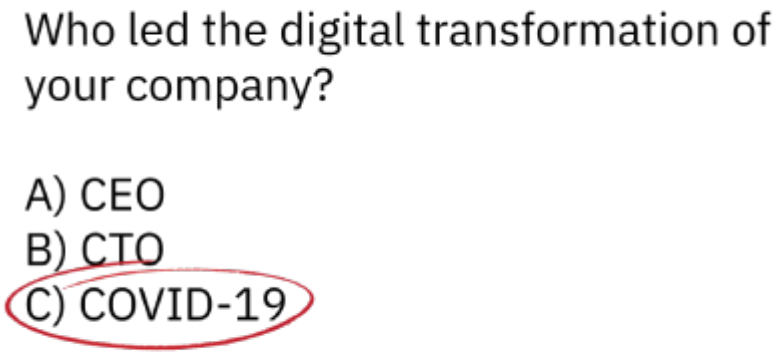
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Mobile applications addressing violence against women

The article is the first systematic review of apps that address violence against women.

Guest post – Public Health's Digitization-Boost (- this is no "thank you corona")



With the outbreak of the pandemic, digitization took up speed rapidly. Just as fast, the question on the drivers of this digital transformation was omnipresent. Implicitly, explicitly, often in a much more serious tone than in the viral tweet I quoted above. It asks for – and suggests – the processes responsible for a paradigm shift towards digitization that so many have been calling for, for a very long time: schools, working moms and dads, companies, hospitals, universities, and above all public administration. All of a sudden, with the precursors of the pandemic, the need for this shift was discussed almost as much as the virus itself. Some even started to see a positive correlation between the ability to survive the crisis and being state of the art digitized, with IT-infrastructure, tools and knowledge.

And rightfully so. Obviously, digital infrastructure and equipment enabled home office and other new-work arrangements and thus have created the possibility to continue working under pandemic conditions. Furthermore, in hospitals and care facilities digital technology prevents death quite visibly: indispensable med-tech, like digital patient monitors, patient records, workflow-planning or other medical devices, aid healthcare professionals in establishing a diagnosis or even surgery. And, additionally, a great share of healthcare digitization happens outside clinics. Society-facing mHealth applications increase effectiveness and efficiency of various processes. A famous example these days is the real time outbreak and epidemic surveillance software, SORMAS. Once built to control Ebola outbreaks in Nigeria, the system now helps track-and-trace corona infection chains in (among others) German, French and Swiss health authorities' offices, thus speeding up paper-based processes with smart, digital data management and worklist management for the staff.

However, compared to other sectors, and globally, the German healthcare sector still falls behind in digitization in many ways. The existing tools could be much more interoperable, much more digital process oriented, much more user-friendly. In some cases, their mere existence would be an improvement. For example, drinking water quality management or school enrollment examinations don't have any digital processes, yet. And we're still only talking about public health.

But, as it usually is, a crisis makes you consider what counts. Hence, it was not very surprising that in response to the pandemic the mHealth services landscape exploded. Countless new tools have been

developed to support health authorities as well as individuals to fight the virus. Health authorities' offices introduced infection chain tracking software, like SORMAS, with – metaphorically speaking – speed of light. Companies, research consortiums, non-for-profits and individuals with civic engagement created a high double-digit number of digital contact tracing tools, that beckon potential with reports about measurable benefits for their users and against the virus. They are great, often altruistic, contributions to our society. They are timely attempts to digitize a sector that has been neglected far too long.

But – plot twist – the perpetually lively debate around digitization and the Covid pandemic comes with an implicit criticism: That digitization is never fast enough. That an organization – be it a private company or a health authority – might never be digitized enough. And this criticism is perfectly justified in many, many cases – like track-and-trace management, which still includes far too many non-digitized components. We needed – and still need – functioning digital tools to get us out of the corona mess. They were and are absent. And their absence has cost lives, and still does. The tricky detail here is that criticism about missing digitization and slow progress was, throughout the crisis, loudest in the public health sector. The very sector whose job it is to help us survive the corona crisis, through public health prevention.

Sure. Public health is one of the least digitalized sectors in Germany, as I've argued above. And looking at and working with many health offices throughout the pandemic I have seen them noting down patients' data on paper, fill them, at the end of their office day, manually into a spreadsheet that gets imported into a surveillance outbreak response management system, and a second (!) system that transfers the data to the RKI. A process that is not only imperfectly digitized but is, especially in cases of data loss or illegible handwritings, jeopardizing lives. Due to avoidable errors, because people can simply not be warned or put in quarantine. Ironically, if a fully digitized system had been implemented before the pandemic, it would have saved crucial time for cluster detection and patient care.

After all, there is no doubt that change is needed. No one wants a new pandemic under these circumstances. All agree that drinking water quality management or school enrollment examinations would be easier if digitized. But change-management on this scale comes with a price. And when sixty contact tracing apps (and many other digital tools) come running at the nearly four hundred German local health authorities *during a pandemic*, they cannot do otherwise but surrender to digitization. They are caught in a dilemma: they want to do everything in their power to carry out their day-to-day business. And that currently means fighting the pandemic. And they want to do it as efficient as possible. And that means digitizing first.

The pandemic blows up their usual track-and-trace processes, that might work for twenty Hepatitis cases per year, but now require very different approaches. But translating to a digital platform takes time and has potential for failure, thus taking more time, the one resource no one has these days. This creates a tug of war you -macro socially speaking- can only lose. Especially when every one of the nearly four hundred local health authorities in Germany is responsible for their own digitization strategy.

From a certain perspective it does look as if our society is unable to act with foresight, as it is busy reacting to pressing issues. Nevertheless, saddling a horse while it runs at full speed is a challenge. I wish the criticism was framed in a way that appreciates the miracles the people in the health offices are performing. Recalling that we all cheered for them on our balconies earlier in the pandemic. Yes, we're not digitized enough. But thinking about it from the perspective that every given technology can ever only be an interim solution until the latest version is overhauled, we can calmly tick c) and start to value the positive effects the pandemic has on societal digitization.

This is not to say "thank you corona". This is to say that sometimes it doesn't matter who the driver of our transformations is, as long as the transformations are useful. This is to say that we should learn from the experiences we made in extraordinary, extreme times and move forward. This is to say "Corona you suck, but we'll make the best of it."

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via social networks. Since 2021, she is part of the DR-AI research project. For this, her research focuses on ethical and social implications of the development of diagnosis-assisting AI systems for radiology and dermatology, as well as the integration of ethical research into technology projects.

Cyberchondria: the dark side of digital health

A few years ago, one of my friends started having headaches that felt, as per her description, like a sudden electric shock. Of course this was unpleasant because it was painful; but it was rather disquieting as well because the experience was completely new and she had no idea about the cause. Consulting a doctor would be expensive and someone like her (a middle-class resident of one of the least developed countries without health insurance and health security) usually keeps it as a last resort. Consequently, she impatiently searched the internet for information about such headaches and got many search hits based on which she started diagnosing herself. She also kept a list of the potential diagnoses; ranking them as per her symptoms and the most probable causes. Her top three diagnoses were 'occipital neuralgia', 'migraine', and a 'tumor' on the neck. She was very terrified and started getting more anxious, which made the headaches even worse. Finally, she consulted a pharmacist who gave her a medication of paracetamol mixed with a pain reliever. After a day of taking the medications, she started feeling better and never consulted a doctor on this problem again. However, to this day, she frequently describes getting anxious about the cause of that headache and often imagines that in reality, she has a tumor that is just passive right now. When I ponder over her story, I ask myself – could it be that she indeed has a slow but serious medical condition that has gone undiagnosed? For me, it is a testament that the digital media has an influencing power on our health – and how, besides all the advantages that it offers, it has a dark side as well.

This is of course just one example of how digital technology impacts our lives. Thanks to the low cost and easy accessibility of digital platforms, people all over the world are in constant interaction with technical devices and online applications, and this affects us in both ways, positively and negatively. Digitalization has changed the way we work, the way we use to entertain ourselves, the way we access and process information, and the way we communicate with our family, friends, companies, and state institutions. Without digital devices, many of us would perhaps even feel incomplete and less competent. No wonder, therefore, that digital technology is also affecting our healthcare practices. Concepts such as digital health, mHealth, telehealth have become commonplace in the healthcare context. There are clear advantages of the emergence of mobile technology in healthcare, research, and development – it reduces costs, enhances effectiveness and even saves lives. The story of the friend, however, depicts one of the potential downsides of the digital revolutionization of healthcare – 'Cyberchondria'. It can be defined in layman's terms as the habit of excess internet search for medical information related to health conditions and symptoms. Cyberchondria is a clear example of how information technology may negatively affect the minds and well-being of the public.

Nowadays, many people with concerns and questions regarding their health issues are tempted to search the internet about their symptoms. They can self-diagnose and even treat and medicate themselves. In itself, that is a good thing. But, as mentioned earlier, this is not always the case. Although some people will come to understand their conditions better and feel informed by digital health information, others might increasingly become more confused and anxious. Those in the former category may benefit from feeling empowered by the information. For those in the latter category, the excess information may have a negative impact on health-related behaviour and decisions. Moreover, in some

countries, people can get access to and take medicines without proper prescriptions. In these countries, pharmacists often sell drugs in an unregulated system. Such over-the-counter transactions are obviously riskier, especially in the context of cyberchondria. People might be driven by biases and distortions based on the information gathered digitally. They might also be much more likely to end up with misleading ideas regarding their diagnosis, and the applicable drugs and treatment methods. In some cases, the practice of one's self health management through 'Dr. Google' leads to medical complications. There is research evidence which states "the false security and often unsubstantiated know-better attitude stemming from gathering health information from various online sources is driven by the practice of cyberchondria and influences the decision to (not) visit doctors". This attitude renders alarming concerns about the health risks. Even more, it might not just be the individual patients who could suffer the consequences.

Zooming out further, ranging from the individual level to the community level, and to the national level, cyberchondria may even have an adverse effect on the implementation and monitoring of the United Nations' Sustainable Development Goals (SDGs). There are 17 SDGs, involving for example hunger, poverty, and sustainable energy. In particular the third SDG, "Good health and well-being", is relevant to the context of digital health. The SDGs are aspirational, but monitoring and measuring their impact and progress is a complex task, especially in an environment in which continuous data collection is a challenge amidst socio-cultural, political, and geographical difficulties. As mentioned, false security and know-better attitudes are driven by the practice of cyberchondria and influence cyberchondriacs' choices to avoid visits and consultations with medical professionals. While the accessibility of the Internet has fuelled self-diagnosis and self-treatment practices, it has also created problems for proper health monitoring. In particular, patients' diagnoses, underlying diseases, and other important health parameters are not recorded in appropriate health databases, which would serve for the monitoring of patients' health developments. The plans and policies of the healthcare system, based on the feedback mechanism driven by such databases, thus, inherently face an issue of bias – privileging some groups while unfavoring others. Failure to record continuous and comprehensive data may then create recursive biases in every process of the healthcare system, research, national data registry, and the SDGs implementation and monitoring: specific demographic categories may be overlooked in the monitoring process, which could lead to inefficiently or unfairly allocated funds, and that would then exacerbate the inequalities which caused the discrepancies.

The above illustration of interlinkage between cyberchondria and SDGs reflects the necessity of an integral and systemic approach to address the global challenge of SDGs implementation and monitoring. Such an approach requires expertises from a wide range of domains, not just digital health. Consider for an example how the problem of cyberchondria relates to one of the other crucial challenges of the recent time – the Antimicrobial Resistance (AMR). AMR is the phenomenon that, due to exposure to antibiotics, strains of bacteria adapt, which reduces the efficacy of these drugs. Bacteria that have become resistant to a wide range of antibiotics have been described as 'superbugs', and these are increasingly common. The emergence of AMR endangers health care practice around the globe, as sometimes even simple infections are no longer treatable. This phenomenon is simple enough, but both the pathways leading to resistance and its possible solutions are incredibly complex. The World Health Organization (WHO) recognises issues of missing data during tracking and monitoring superbugs. Further, the WHO argues that AMR shall be an important part of a lot of health-related indicators in the SDGs. Precisely in this regard, cyberchondria is problematic. When people self-medicate on the basis of insufficiently founded fears, they are much more likely to use drugs in inappropriate ways: to use them when they don't actually need them, to use them too long, or too short. In the case of antimicrobials, such inappropriate use drives AMR. Further, the online search of medication and diagnoses may not only be limited to human symptoms but also involve the unregulated use of antimicrobial drugs in animals. All of these increase the chance of misuse of antimicrobial drugs which in turn increases the risks of AMR.

In a nutshell, cyberchondria can have immensely negative implications and hamper the quality of health of the public on an individual level; the health care system on a community and national levels; and the health initiatives such as SDGs and AMR on a global level. Current literature seems to have a gap in terms of academic research linking these three layers of health issues triggered by cyberchondria. As AMR is one of the potential repercussions of cyberchondria, especially in medically underprivileged communities, it may also be worthwhile to explore the linkage between cyberchondria and the AMR and its impact on the global SDGs implementation and monitoring.

LITERATURE

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YouTube as a health app? How reliable is health-related content?



Image source: Blog post by Tom Allingham
https://www.savethestudent.org/make-money/how-to-make-money-youtube.html

Today, digital technology seems to provide the answer to all health concerns. You name a health problem and there’s someone who claims to have an answer to it on the internet. In 2009, YouTube, an online platform that supports the uploading and streaming of video content, became mainstream. In the past few years, YouTube has become increasingly famous, to the extent of being considered a new digital “necessity.” Nowadays, it comes as a built-in app in all android phones. In addition, practically everyone who uploads content on YouTube (from here on ‘YouTubers’) also has their presence on other social media like Instagram, Pinterest, Tik Tok, Facebook, etc. Many of these YouTubers, and the channels that they deliver, make a variety of health claims. For example, there are a multitude of videos on the health benefits of asparagus, on lacing one’s running shoes in case of bunions, on managing eye health in aged care facilities and on the dangers of oil consumption for Vegans. I will return to the latter example shortly.

All in all, it is fair to describe YouTube as one of the most influential health apps in the world today. However, as the arachnid wisdom goes, “with great power, comes great responsibility”.

Although a lot of the most popular videos on YouTube are uploaded by trusted sources, such as research

institutes, public health agencies and reputable media, a lot of it clearly isn't. Apart from some basic rules on hate speech, slander and some of the worst misinformation (for example on the Covid-19 pandemic) there are no substantive requirements made on YouTubers. As a result, these videos generally don't follow any established research methodology which in turn makes many of their claims questionable and their lack of scientific rigour creates a huge bias in the message that they convey. How? There are four answers to this;

- The selection of articles may be biased. Scientific methodology involves incorporating information that does not necessarily fit your perspective. Scientists are of course only humans, and some may try to discard or downplay inconvenient sources. However, they can be and – in many cases are held accountable for providing a balanced overview of the relevant literature. YouTubers, of course, are held to no such standards. Many of them select references to match their preconceptions and select only those articles that support their claims.

- Alternatively, YouTubers may just leave out references altogether, i.e. not provide sources for the claims conveyed through their channels.

- The third reason is the possible involvement of subjectivity in the interpretation of research papers. YouTubers may simply lack the expertise to properly assess the available data. After all, not every health channel on YouTube is run by an epidemiologist or a health practitioner. This may lead to unintentional misinterpretation of results.

- Some YouTubers may have their followers' best interests at heart but some may also be motivated by commercial incentives, specifically marketing and advertising products, in the trending space of health and wellness. Some of them might end up passing on wrong or medically unjustified information to the audience. In fact, wellness is a word often used by YouTubers in such a manner that it blurs the line between health and beauty, thereby persuading people, especially the younger generation, to purchase things that may only benefit the YouTubers and not the audience.

In today's world where many people are connected to and via social media, such influencers with their iffy research may influence their followers to take actions that may not be in their best interest. For instance, in the video about oil consumption for vegans mentioned above, the YouTuber makes a very strong claim that vegans are at high risk of cardiovascular disease if they consume oil but fails to back this up by providing sources that clearly support this claim. Upon careful reading of recent publications online on this topic (for example this) and careful inspection of his videos, it may be deduced that the YouTuber misrepresents and even apparently wilfully manipulates the information. Let us zoom in on this specific example.

The title of the video is apparently designed to generate clicks, or at least is not very subtle: "Oil: The Vegan Killer". We click. We see a young man, casually dressed, with a well trimmed beard and an unbuttoned shirt, who immediately starts talking, bombarding us with information. He wastes no time on impressing on the viewer a sense of danger associated with fat in general by the fancy graphs and charts making his video to appear edifying. There's little time to assess the claims and the relatively slick visual graphics work to emphasize a sense of alarm: the word "FAT" is slammed on the screen in block letters to convey the message that anything related to lipid substances should be shunned. Moreover, by making suggestive comparisons to consuming large amounts of refined sugar it is claimed – rather vacuously – that "processed foods are processed foods". There is, however, no definition provided, no explanation given beyond the apparent assumption that fat is just unqualifiedly bad, in and of itself. What follows are several minutes of irrelevant information, limping comparisons and some fallacies. Yet, because the narrator seems to rely on scientific insights, it is difficult for even well-informed individuals to sift out the truth of the matter. More specifically, the video suffers from three serious methodological flaws. First, in the entire video, it is explained how oil consumption is detrimental to human health but it wasn't critically commented on how oil consumption is bad for the health of vegans in particular. Second, no links are provided to any paper that supports the claim of oil intake on a *vegan* diet. Third,

the claim seemed to be foggy because it wasn't mentioned what quantity of oil was bad for vegans in particular. To support this, only those excerpts of the presentation/speech of researchers were shown when they mention how oil is bad for health, not particularly mentioning vegans or the quantity of the oil that is bad for health.

Only those who are particularly interested in epidemiological studies may take the pain to critically examine such research, but to a regular consumer of online information, YouTube might be a source of quick, seemingly reliable, and entertaining source of health information.

This is not limited solely to "research videos" but also to other health information content on YouTube, for instance, as we have seen, many YouTubers use 'click baits' in the form of exaggerated or even false titles/images so that people go through their videos. Furthermore, the YouTube recommendation service works to draw users further and further into the disinformation 'rabbit hole'. (Link 1 , Link 2, Link 3)

In the second quarter of 2020 YouTube took down 26% more videos than the videos taken down last year during the same period and 83.5% of these videos were either spams, scams or had misleading content. This was performed by relying more strongly on electronic algorithms – and decreasing human interference in the filtering of videos. Although this was done with the intention of prioritizing responsible information practices over entertainment, the question still remains, how capable is the machine brain in filtering out superficial health related research content that – under the veil of "research" – looks unsuspicious to both the human and machine mind.

Recent bogus videos on the causes, vaccination and treatment of COVID-19 that have been surfacing on YouTube are an apt example of how disinformation is spread. For example, there were YouTube videos circulating on WhatsApp falsely claiming the availability of vaccination of COVID-19 and also regarding baseless treatment and causes of COVID-19. This disinformation was further spiced up by individual WhatsApp users which only added to the pile of disinformation regarding Corona virus.

It is hard to imagine a world without the Internet and smartphones, but cases like this show the fragility of Internet video blogging. There's a lot of health related content on YouTube which can be misleading, have bad influence or even be harmful to the viewers in various ways, including audiences following a certain diet, work out regime or a health lifestyle that celebrities preach about without taking into consideration their individual existing health conditions or needs. It seems hard to overstate just how dangerous this is. These practices may lead to the risk of the development of other diseases or injuries, not just to one or two individuals, but, as videos become more popular, on a near population scale. At the moment of writing this blog, the 'Vegan Killer' video was 'only' watched 683,432 times, but, taken together disinformation on health by way of YouTube is absolutely massive. By contrast, scientifically valid, academic papers may get only 100 citations.

Therefore, it is imperative that people are given access to genuine evidence-based information. This observation raises a number of ethically interesting questions. How to deal with the deluge of misinformation? Of course, we do have the 'right to freedom of expression' but the fact that a baseless, misinterpreted or incomplete information can reach millions of people and influence their health decisions is blood-curdling. Perhaps, YouTube should consider regulating its health related content on humanitarian grounds and people should be more willing to be smart viewers.

Stumbling into Something Very Bad

These are dangerous times. Let us not stumble into Something Very Bad.