

Mental Health Online

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Valorization addendum

VALORIZATION ADDENDUM

Work on this dissertation has unfolded in a context where the internet has been used more and more for health-related purposes by citizens, governmental agencies, and by medical institutions. The number of mobile health applications available as well as the number of people using them have increased tremendously; electronic patient records have been introduced in many countries; and numerous online platforms have been developed to bring together patients, health activists, caregivers, medical professionals, and researchers. The findings presented in this dissertation show that making (medical) expertise available, recognizable, and useful for online audiences is no easy feat. On the contrary, it involves numerous adaptations and transformations of various offline approaches, tools, and practices; and it requires the collaboration of many different types of stakeholders, numerous skills, and complex negotiations.

Many enthusiasts hoped that the internet would be a medium through which health-related information could be successfully provided to large audiences. Yet, one of the main merits of the study I conducted is to have drawn attention to the significant influence the type of online platforms, their affordances, and architecture have in regard to how knowledge can be shaped and made available to specific audiences. At the same time, it has highlighted the important role new stakeholders play in such a context and has identified some of the values that shape how knowledge is made available as well as how new insights are produced online. This dissertation also shows that far from being a cheap, easy, unproblematic solution, the internet is a medium that requires a lot of work in order to be made to benefit people with health concerns and society overall. This is an important sobering call at a time when governments continue to expect that the internet would: broaden the availability of healthcare in remote areas; help improve the quality of healthcare; reduce the tremendous financial burden that expensive medical interventions and an ageing population are claimed to place on national budgets.

In discussing the overall societal benefits of my study, this addendum is organized in three parts. First, I highlight several reasons that make me rather skeptical about such a 'valorization' exercise. Second, I discuss some of the efforts made to disseminate the findings of this research beyond the academic community. Third, a set of recommendations is developed for scholars interested to study online practices as well as for important stakeholders identified while conducting this study. These include: people diagnosed and caregivers who consider using or who use the internet for health-related information, mental health professionals, policy makers, and governmental agencies that want to use their online platforms to more successfully communicate with the public.

1. VALORIZATION AND MY DISCONTENTS

It would be naïve to believe that there has ever been a time when scientists, researchers, or public intellectuals have not had to step out of their laboratories, ivory towers or ‘margins’ to engage with broader audiences. However, over the last three decades, initiatives by which scholars are called to account for the relevance of their work outside of academia have grown. Reflecting this trend, Maastricht University has introduced a requirement whereby doctoral candidates must include a valorization addendum in their dissertation. In it, knowledge valorization is defined as “the process of creating value from knowledge, by making knowledge suitable and/or available for social (and/or economic) use and by making knowledge suitable for translation into competitive products, services, processes and new commercial activities” (Regulation governing the attainment of doctoral degrees at Maastricht University, 2018, art. 23: 47). I am rather skeptical about such an approach, because it implies that there may be forms or types of knowledge that are not valuable. The regulation assumes, despite historical evidence to the contrary, that the relevance of any given piece of knowledge can be accurately known or assessed relatively close to the moment when it has been produced. Furthermore, even though this definition of valorization seems to focus on the social implication of research, in practice its economic uses are prioritized, which can also be inferred from the “competitive products” mentioned in the last part of the quote provided. This understanding of valorization prioritizes thus a for-profit logic to the detriment of perspectives that could promote other values, such as social justice, equality, solidarity.

Yet, there is a certain alignment between the valorization ethos that has rendered this addendum necessary and the “democratization” of knowledge that I studied. Many of the online practices discussed in my dissertation and this addendum are the (side) effects of a growing trend towards individual responsabilization and commodification. In it, individuals are approached as autonomous producers and consumers, who are responsible for the choices they make and need to account for them, particularly when they involve the use of public funds. While the general population is increasingly called to answer for the costs their un/healthy lifestyles place on national budgets, researchers need to account for the public funds they receive, and increasingly to defend the *raison d’être* of their discipline, particularly when the insights it can contribute to are less palpable and hard to quantify (Nussbaum, 2010). Commodification tendencies are present in both situations as well. Many of the online insights provided by people diagnosed with bipolar disorder discussed in this dissertation can and are commodified into a variety of data products, that pharmaceutical companies may purchase for targeted marketing, or that hospitals, insurance companies, credit controllers or research institutes acquire

for other purposes. Similarly, researchers are increasingly prompted to consider the applicability of the findings they may arrive at, and how they may contribute to the accumulation of capital (Halffman & Radder, 2015). This is obvious also from the definition of valorization presented above.

The focus on competition and commodification at the heart of valorization is deeply worrying. In a world where universities are allocated funds based on quantified markers that grossly oversimplify the activities and societal contribution of such institutions, researchers must compete for scarce research funds, with limited time to allow themselves to be inspired, to give their thoughts a chance to ‘brew’, and to explore multiple options or new areas of interest. At the same time, while collaborations with industry and other partners are encouraged, little money is allocated for collaborative research, so that researchers from the same or similar disciplines could actually work together rather than compete against each other. To be clear, there is nothing wrong with a bit of healthy competition, nor with trying to assess activities and output using a great variety of metrics in an attempt to acquire a better or more complex understanding of a given phenomenon. What I believe is wrong is reducing the societal benefits of research and education mainly to elements that can be quantified, and, to make matters worse, approaching such markers as if they had a direct relation to the actual benefits rather than seeing them as the result of negotiations, as the product of specific values, measurement instruments, power and epistemic relations at this specific time in Western countries. Thus, such an approach does not actually have the ‘truth’ value that it is often ascribed, and it also distracts from aspects that may be more important or which may have more lasting effects. Using quantified metrics, institutions can keep track of the number of public events researchers have attended and of the number of non-academic publications they have written. Yet, despite so-called advances in psychometrics, such an approach can still not account for how such encounters or texts may inspire or motivate people, or how they may change their perspective on a given topic. Nevertheless, I do believe that researchers have a responsibility to make their knowledge available to large audiences, that they should be involved members of the communities and societies they live in, and that the knowledge they produce should benefit as many people as possible. This is what has made writing this valorization addendum truly meaningful for me.

2. DISSEMINATION OF RESULTS

From the very beginning, I imagined the key audiences of this study to consist not only of academics, but to include people diagnosed with bipolar disorder and other (mental) health conditions, caregivers, interested citizens, medical professionals,

activists, and policy makers. To ensure that the insights acquired spoke to the interests of such broad audiences, I attended several events at different stages of my research. In so doing, I have used these activities as opportunities for me as a scholar to speak *with* rather than merely *to* non-academic audiences.

In 2015, I presented some preliminary findings at the international conference “Patients in the Health Ecosystem: Information Challenges and Communication Issues” that was held in Paris, and which brought together scholars, patients, health activists, and governmental officials. In the talk I gave, I highlighted several similarities and differences regarding the ways in which knowledge on bipolar disorder was made available on French and American online platforms. The questions and insights acquired from the other participants were used to guide my analysis in the later stages of this study. Having thus acquired a better understanding of the difficulties people diagnosed encountered when using the internet for health-related purposes, I paid more attention to the type of audience that was addressed on the online platforms I studied and to the level of education and (good) health required for it to be easily and correctly processed. In order to answer some of the concerns raised by the people diagnosed and patient activists I met, I subsequently focused more on the regulations available in France and the U.S. and how they shaped how governmental agencies shared their insights online.

In June 2017, I was invited to give a workshop in Maastricht on “The digitalization of healthcare” by the German Academic Scholarship Foundation. This gave me the opportunity to present my findings to a group of students and young professionals from various disciplines, including medicine, psychology, mathematics. On this occasion, I also prepared materials and exercises for the workshop participants to engage in a critical discussion on the advantages and disadvantages of using the internet in the provision of healthcare. In so doing, I helped future professionals and scholars to better understand some of the reasons that prompt people to search for health-related information online, and to better grasp the advantages and disadvantages of using the health-related services that big technological companies, such as Google or Facebook, make available. Sharing my findings with future medical professionals made them more aware of the different needs and expectations people diagnosed often have from their medical encounters. It also helped them realize that people sharing the information they acquire online with medical professionals is generally not meant as a challenge to their authority, but is often intended to improve the quality and outcome of their interactions. The exercises and discussions I had with students from non-medical disciplines helped them contextualize the use of the internet for health-related purposes, and prompted them to think more critically about the online provision of health-related information, and how online contributions could be used by third parties. Talking about the challenges people with mental health diagnoses encounter online and offline also rendered the students

more aware of how stigma continues to affect people diagnosed with mental health conditions. I also encouraged them to consider more carefully the role social, economic, and cultural factors can play in the onset and trajectory of such conditions.

As the analysis presented in this dissertation had been completed and as my doctoral study was drawing to an end, I engaged in several other activities in order to disseminate the most important findings. In March 2018, I participated in a roundtable discussion and gave a poster presentation at the British Academy European Research Council Workshop “Mental Health Policy and Social Science Practice: Enhancing Engagement and Expertise”, that was held in Edinburgh. The workshop brought together academics, politicians, patients, and caregivers. In October 2018, I gave a presentation titled “*Digitale biogemeenschappen: Gemeenschap vormen en gewoontes delen op blogs en fora door mensen met een bipolaire stoornis*” (Digital biocommunities: community-building and sharing practices on blogs and fora among people diagnosed with bipolar disorder) at one of the EuroScience Open Forum (ESOF) Lectures organized for members of the public by the *Universitair Centrum Sint-Ignatius* in Antwerp. This enabled me to engage in a fruitful exchange with caregivers and medical professionals, including psychiatrists, psychologists, and general practitioners, on how the use of the internet could foster solidarity among people diagnosed with bipolar disorder. It also allowed me to better understand that the internet had come to be perceived as posing an important threat to the professional authority of some of these people and to have a dialogue about the types of patient and professional forms of online engagement they would support. On April 23, 2019 I attended a consultation of the Dutch Youth Health Council, where young researchers were invited to engage in an open discussion and to make recommendations on the ethical and responsible use of online applications and wearable technologies for health-related purposes at the initiative of Bruno Bruins, the Dutch Minister of Medical Care. The findings presented in this dissertation enabled me to make fruitful contributions to the discussion, some of which were taken up in the final report (forthcoming).

Apart from talks and presentations, I have shared the insights I acquired while conducting my research by writing for non-academic audiences. In December 2017, I wrote an essay titled “Digital morning, or manic by design”, in which I explored the risks and benefits of an increased use of online applications and wearable technologies. It won the Visionary Essay Competition (2018) at the inauguration of the Institute of Data Science at Maastricht University and was made available for broader audiences to read on the website of this institute. I also wrote a column on the use of the internet for health-related purposes in the popular philosophy magazine *Wijzgerig Perspectief* (2019).

3. RECOMMENDATIONS

3.I Recommendations for scholars studying online practices

Work on this dissertation has made me aware of several important difficulties that one can encounter when planning to study online practices. Acquiring permission to conduct virtual ethnography has not been possible in my study, as the online platforms owners- be they private businesses or public institutions- were not willing to support third-party research. Furthermore, while my research project was unfolding, it became more and more necessary for scholars to ask permission from platform owners to use online data, even when such data are publicly and openly available, and when they consist of the online contributions of platform users. To prevent such problems, the following may help:

- Contact with the online platforms of interest should be established and permission to collect data should be obtained as early as possible, to make it less difficult to bring changes to the overall project, should such permission not be granted. Having already developed personal contacts with people affiliated with the platform may facilitate such negotiations. Since the first point of access are often call center employees, who may not have the authority to engage in such negotiations, it may be more effective to send a letter written by the legal department of the university or research institute to the company that owns the online platform, in which general information about the study, its ethical approval status, and the type of data that will be collected from the platform are described.
- The Terms of Use of the platforms studied should be checked frequently and recorded or captured for future reference. Ideally the agreement with the online platform should also stipulate that no future changes may affect the research activities agreed upon or, at least, that information about any such changes will be timely provided.
- Legal counsel should be pre-emptively sought when such data are collected, analyzed, and intended for publication across multiple countries, to avoid any legal hassle due to differences in national legislation and regulatory practices.

3.2 Recommendations for people diagnosed and caregivers

My study has shown that there are important differences among online platforms regarding the type of content on mental health they make available as well as about the level of engagement and the forms of interaction they enable among users. Furthermore, the findings presented in my dissertation have also revealed that interactions on different online platforms are shaped by specific values, with solidarity often being enacted by online contributors on specific fora. The following may help people diagnosed and their caregivers in their online quests:

- Individuals diagnosed or caregivers require patience and perseverance when searching for online platforms that provide (mental) health-related information in ways that speak to their needs and preferences. Depending on how the algorithm of the search engine they use is optimized, they may need to search past the first few pages of results to find online spaces where they feel comfortable or which provide the insights they are looking for.
- Information about medical and other therapeutic approaches should be collected from multiple online platforms and the accounts of multiple people diagnosed should be read to acquire a better understanding of the ways in which they are prescribed and of the various side-effects they may have.
- Even though it may be difficult at times, online (mental) health-related insights should be consumed with a critical attitude. Information about the source of these insights, the methods by which they were arrived at, when, and by whom should be minimal criteria to bear in mind.
- The lack of online accounts about certain physical experiences, mental states or behaviors when undergoing a particular mood episode or when taking a certain medication should not automatically disqualify or cast doubt about them. For instance, the fact that no online testimonies are found that attest to an increase in alcohol consumption when taking a particular antidepressant does not necessarily mean that one is not telling the truth or that this is an invalid inference. Rather, it should lead to a more careful observation of this experience and to open and elaborate consultations with different medical professionals. At the same time, the description of mental states and of the effects and side-effects of medications should be done in a responsible manner and after careful consideration, knowing that people experiencing different moods, having access to different types of healthcare, and in different socio-economic positions may have access to them.
- Caution should be used when providing (mental) health-related information online. Since some of this information may also affect others in one's family or social circle, talking to them about it in advance may provide some clarity

or some sort of a communal agreement as to what information is seen as belonging strictly to the individual and which insights are understood to be collectively owned by that specific group. When such consultations are not desired or possible and when online engagement is intended to be private, people should first devote some time and effort to finding out how they can increase the chance of protecting their privacy rather than immediately conducting online searches, reading, watching, or describing their difficulties and dilemmas.

- The Terms of Use rubric of each platform should be carefully read before sharing information online. Even though some online platforms may seem safe places, sanctuaries where one can find refuge, understanding, and respite, only detailed information about the data collection processes on these platforms and their subsequent use can indicate to what extent this is truly the case. Furthermore, such policies can change, particularly in the case of mergers or acquisition by other companies, so remaining alert to any modifications would be an appropriate, albeit time-consuming attitude.

3.3 Recommendations for medical professionals

My dissertation has shown that people diagnosed can make important contributions in areas where the currently available medical knowledge is uncertain or insufficient. Such contributions are often the result of detailed self-monitoring practices and of the avid consumption of relevant medical information. These practices are undertaken out of a desire to improve one's self-knowledge and ability to manage one's condition, but are also informed by the need to convince medical professionals about the side-effects they experience and about the advantages of a desired change of medication. Furthermore, the findings of my study have shown that people diagnosed have a broad understanding of what constitutes treatment effectiveness, whereby the ability to continue to engage in various activities, ranging from fulfilling one's familial and professional duties, to participating in one's favorite hobbies, play an important role. From this point of view, their online search for mental health-related information is often motivated by the limited time they have at their disposal to discuss such matters with medical professionals or is due to the latter's unwillingness or inability to engage in such talks in an empathetic manner. Certain measures could be taken by medical professionals to address and redress some of these issues:

- Appointments with people (to be) diagnosed should be approached as encounters with individuals who are knowledgeable about their condition and who actively seek solutions to better manage their health. Whereas the

time for such appointments is limited, they should therefore be listened to with attention and care.

- Online platforms where people diagnosed share their experiences and insights should be consulted, as they highlight the issues people diagnosed find important, and can provide helpful indicators as to their expectations from medical encounters.
- The establishment of diagnosis and decisions about the best therapeutic approach should be arrived at in collaboration with the person diagnosed and, if s/he so prefers it, with a family member or another person who will be involved in the care process. In so doing, more attention should be paid to the realities of the life of the person, and to how they may render certain forms of treatment more acceptable than others.
- More time should be devoted to the provision of clear and detailed information about the effects and side-effects of medications that people are prescribed, to ensure that these are well understood.
- Whereas many medical professionals welcome their patients' efforts to become informed about their health, a great number thereof remain skeptical about such practices. Rather than perceiving those diagnosed who bring information acquired online to medical appointments as troublemakers or as "difficult patients", they should be recognized as individuals who try hard to improve their (mental) health. An open discussion about the benefits and disadvantages of such practices and a common selection of online platforms where the mental health-related information provided is of good quality could strengthen the relationship between people diagnosed and medical professionals. This may require, however, the creation of a new type of medical professional, someone who is knowledgeable both about mental health and about digital practices. This dissertation has shown that some very knowledgeable and skilled people diagnosed, that I have termed "online expert mediators", have managed to position themselves as mediators between people diagnosed, caregivers, and medical professionals, thereby becoming highly influential and popular online as well as offline. An alternative to creating such a new profession would be the development of closer collaborations between medical institutions and online expert mediators. This may lead to a more effective engagement with online information among people diagnosed and their caregivers, and may improve the quality of interactions between medical professionals and people diagnosed.
- Even though talk of datafication and personalization make it sometimes easy to forget, not all people diagnosed with mental conditions and their carers have access to mobile mental health applications and online resources, nor do all of them want to engage in digital practices. Medical professionals should

therefore experiment with different approaches and forms of collaboration to reach common treatment decisions together with people diagnosed, which are also based on the latter's willingness to engage with online resources. Furthermore, measures need to be taken to ensure that the nonusers of digital technologies are provided with accurate and sufficient information to adequately manage their condition.

3.4 Recommendations for policy makers

This dissertation has shown that enacting expertise on a (mental) health condition online is a complex endeavor, which is shaped by the stakeholders involved, their position and the resources they can call upon, by the architecture of the online platform used, as well as by the socio-economic and cultural climate in which such activities take place. Importantly, it has shown that expertise is a practical achievement, arrived at through negotiations among multiple stakeholders within a broader ecosystem. This has several implications for policy-makers:

- Consultations in view of the development of new policies on a given topic should be preceded by inquiries into relevant stakeholders and into the types of expertise they can each bring to the table. Simply relying on the insights provided by people endowed with credential expertise may skew the recommendations or render them less effective and useful than would otherwise be the case. The recognition of relevant stakeholders could be facilitated through the development of future scenarios and through other futuring exercises, as they can contribute to a better understanding of the effects and ramifications these policies can have upon groups that may remain invisible when only the current state of affairs is considered.
- Those entrusted with conducting the prior inquiries mentioned above should be carefully selected, as they should be sufficiently knowledgeable, open, and communicative, to recognize the substantial knowledge of stakeholders who may be lacking official accreditations.
- Attention should be paid to ensure that each stakeholder group includes individuals from different cultural backgrounds, as different values and ideals importantly shape behaviors, the use of technologies and services, as well as how certain rights are understood and made manifest.
- Such consultations should also include, from the very early stages, also representatives of the government, ethicists, legal and economic advisors, given that the effectiveness of new policies depends on the broad context in which they are deployed.

- In making public the policies arrived at through such consultations, information should also be provided about the reasons why other popular approaches were not taken up. This would enhance the democratic character of these procedures and would strengthen public trust in policy-makers.

3.5 Recommendations for governmental agencies

In my dissertation, I have argued that governmental agencies need to improve their efforts in order to effectively share information online. One of the problems identified is the rather homogeneous character which such bodies ascribe to their audiences as well as the assumption that the mere availability of information would unproblematically lead to its consumption and to desired subsequent changes in the readers' behaviors. The recommendations provided below are meant as suggestions or possible solutions for official bodies or organizations which are interested in using the internet effectively in order to share their insights:

- Online literacy workshops should be organized and provided both online and offline to ensure that people have a basic understanding of the advantages and disadvantages of using the internet, and that they are aware of their rights and obligations. While searching and sharing health-related insights online has become common practice, many people are still unaware of the multitude of ways in which their online behavior can be recorded and subsequently used for various purposes. Furthermore, they need to be made aware of how they can distinguish between claims and practices they are asked to agree to in order to gain access to an online platform, that are legal, illegal, or for which there is currently no or only incomplete legislation available. Attention should also be paid to cultural differences and to the ways in which different cultural traditions and scientific approaches may “color” the information, recommendations, and testimonies available online.
- Dedicated spaces should be created on online platforms, whereby important controversies regarding the topics discussed on these platforms are addressed and the position of different specialists and groups of experts is explained in clear, intelligible ways. While such an approach would initially require substantial efforts and may involve significant costs, it would help the public better understand the perspective of these official bodies and develop more informed opinions. At the same time, such initiatives may help broad audiences understand how to better distinguish between the social efforts through which scientific facts come into being and mere views and opinions, no matter how popular the latter may be.

- At least basic information should be provided about the development of the insights and recommendations made available on the online platform. At a minimum, the following should be included: the identity of those who author the insights made available online or, at least, the professional make-up of the group; a general description of the approach and resources used, some brief explanation on how the validity and relevance of such information is verified and updated over the years.
- Comprehensive lists of diverse online resources should be made available on specifically designated locations on the online platform, in order to increase the likelihood of readers engaging with health-related information of a certain quality. The selection and actualization of these resources could be achieved through a bottom-up approach, by conducting surveys among people diagnosed, caregivers, and medical professionals, to inquire if they use online platforms for health-related purposes, for how long, what these specific purposes are, and whether they would recommend these platforms to others, what for, and on what grounds. Subsequently a group of professionals, patients, and caregivers could be convened to develop a list of criteria by which the online platforms could be assessed. Thus, the list of online resources could consist of the online platforms most frequently mentioned in the survey which fulfill those criteria.
- Experiments should be conducted whereby information is shared in different ways and at different levels in order to increase the likelihood of readers developing an accurate understanding thereof. Next to written text, vignettes and other pictorial renditions, videos, podcasts or different audio formats would be worth providing online, as they may better respond to the ways in which individuals of different ages, with different levels of education and approaches to learning, prefer to engage with health-related information.
- Different types and amounts of information should be provided in order to address the needs, levels of interest, and familiarity of different readers. For instance, the insights shared could be structured along levels of complexity, such as basic, advanced, proficient, a division which should be clearly indicated to readers on the main page of the platform.

One of the main messages of this dissertation is that the internet cannot be used for health-related purposes unproblematically, that it cannot be a cheap replacement of the scientific, communication, medical, and care work undertaken by so many people. A lot of work is still needed for the internet to fulfill its potential as a medium actively contributing to the provision of better, faster, and cheaper (mental) healthcare. And for this we need experts: experts on the technical aspects concerning this medium, experts on algorithms, experts on the infrastructures required and their maintenance,

experts on scientific communication, experts on disease and care. Hopefully some of the recommendations sketched in this Addendum may contribute to the development of new approaches and collaborations, so that this work can be furthered and (mental) health online platforms may truly benefit a great(er) number of people.

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