

Are you transparent? – Calling for a citizen-centred public debate on healthcare-related data

Authors¹:

Bouwsma Jasper, ETH Zurich, Switzerland

Odero Michael, Midan health nutrition and wellness center, Kenya

Rockenschaub Patrick, University College London, United Kingdom

von Arx Martina, University of Geneva, Switzerland

Wamunga Daniel Owino, Midan health nutrition and wellness center, Kenya

1. Introduction

The following paper was elaborated as a teamwork during Autumn Academy 2019, a gathering of young scientists, organised in the context of “Engelberg Dialogues” by Academia Engelberg taking place at the cloister Engelberg, Switzerland. The topic of this interdisciplinary workshop was “The transparent patient”. Based on abstracts submitted earlier for admission to this Autumn Academy, participants were grouped in order to condense their knowledge and apply what they had learned when discussing openly the challenges around the transparency of patients. Besides the abstracts of above-mentioned group members, we have greatly benefited from the abstracts and presentations of our colleagues as well as the many discussions we could learn and benefit from.

Although the authors of this paper have different disciplinary backgrounds, different origins and different experiences as patients, we had one major common ground: the need for a citizen-centred public debate. This claim arose against the background, that all issues related to the transparent patient are depending on the context, meaning the personal attitudes of citizens, the healthcare system, as well as other societal and cultural dimensions.

Hence, the aim of our paper is to offer three broad questions on the topic of the transparent patient of which we think citizen must consider, discuss, and/or even debate to decide upon how their personal health data should be treated. We suggest using these questions as a guideline for public events and/or debates. We deliberately formulated the questions very openly to stimulate further discussion and as well as continuous questioning. Our objective is to have a debate going beyond emotionally laden arguing. Each of the authors is convinced about the necessity of and many opportunities of electronic patient files and analysis of such data. We are aware that our suggested questions can neither be answered with a simple yes or no, nor with a definitive statement. Our aim is to organize formats for public dialogue on the topic of patient transparency. In addition, we expect answers to these questions to change with age, with medical history (e.g. new diagnosis), social relations (e.g. new diagnosis of a relative), and/or over time (e.g. after birth of a child). Furthermore, the restriction to these three basic questions will allow to adjust it to country-specific contexts. The choice and the formulation of

¹ *all authors contributed equally to the paper and are therefore listed alphabetically*

the questions is the result of two brainstorming processes within the group, which was enriched by one phase of individual reflexion in between.

In the following chapter, each of the three questions is further elaborated in a separate paragraph. The objective of these sections is not to provide answers, but to suggest related sub-questions and give some examples of how the main question could be illustrated in order to stimulate the debate. In chapter three, the authors have each described tangible but hypothetical cases from the eyes of the citizen-patients (a.k.a. persona's in Design Thinking methodologies). Each case is based upon the personal and scientific experience of the authors and can as such be expanded to an endless list of patient-citizens with different opinions. As such we recognize that there will not be a single answer or solution, but instead a significant variance between citizens and their current and future use and usage health related data. We end this paper by providing some concluding remarks.

2. Three important questions guiding public debate about healthcare-related data

The following paragraphs will further elaborate the three core questions we have chosen. Figure 1 shows potential outcomes of imaginary patients dealing with these questions. It is a visualization of the patient's decisions regarding their personal medical history. Figure 1 just relates to examples we invented. Details on the patients' personal stories can be found in chapter three.

2.1. What type of health-related data about you do you want to be collected, stored and shared?

The world is quickly digitizing, technology might rob us of some very crucial information about us knowingly or unknowingly. This information might be taken out of our excitement or out of our own curiosity, for example with the excitement of making new friends through social media like Facebook, twitter or WhatsApp we could give information, also out of our own curiosity to know more about the world we could make people extract a lot of information about us (a sample case of curiosity is a case of face transformation android application used in China to connect members of a family which were separated many years back). All this information we give might not necessarily impact directly on our health but our social life.

In the context of our question, we want the public to be clear and give a directive on exact information one can give willingly in relation to their health or illness. Therefore, we see a need for an open discussion about the type of health-related data that should be collected, stored and shared. It is important to note that the perception and attitude on the sensitivity of information related to health and illness is grounded in cultural background, social upbringing, level of education and exposure. We would also like to underline the fact that a lot of health-related data is already collected in clinical settings or through our use of applications and search engines. This first question also aims to draw attention to the way health-related data might be fused into one dossier in the future.

2.2. Who do you want to have access to your health-related data?

In order to make meaningful contributions to our existing health system as citizens of this country, we believe that your participation and involvement is key in designing a framework upon which vital health-related data can be collected, stored and who can be given access to it. Important decisions from clinical assessments, diagnosis and possible forms of treatment are

usually made based on data collected from different health professionals who handle you as a citizen when you are sick. Often such data may not be accessible to everyone though in cases of multiple conditions /cases like in H.I.V /AIDS, coupled with Acute Kidney Injury or even Liver cirrhosis, certain content of one's data may be needed to be accessed by more than one Health Profession (Nurse, Doctor, Pharmacist and Nutritionists).

This question therefore seeks to augment possible issues surrounding access to your health-related data as well as how it will impact in improving service delivery through the transparency patient model.

2.3. For what purpose do you want your health-related data to be used?

The third question automatically follows the former two and focus on the purpose the patient explicitly or implicitly expects from sharing her or his data. We distinguish between value for i. me (i.e. individual), ii. for my family, iii. for society (e.g. patient group). Naturally, there can only be value if the citizen in question is willing and able to share her or his personal health data. Hence, if citizen participants of our public have answered the first question with no, we ask them if they also understand that by definition no value can be created. It is not our objective to pose this question as a confrontation, but to clarify and/or discuss their understanding of the de facto consequence.

3. Five imaginary patient examples illustrating potential citizen-centred answers to our questions

The following paragraphs illustrate five imaginary patient cases (i.e. personas). We invented them to give the reader an idea what potential challenges patients can face when having to find their proper answer on the transparency of themselves. Any resemblance to a living person is purely coincidental.

3.1. Bettina: diagnosed with multiple sclerosis (MS) five years ago

Bettina is a 36-old Dutch mother of two. She was diagnosed with MS just after weaning her first child, Lars. Together with her husband Thomas she decided to have a second child, Eline, and decided not to start MS therapy until after breastfeeding. Bettina's ultimate objective is to take care of Lars and Eline.

As soon as the therapy started, Bettina's medical file started exploding. Regular check-ups resulted in piles of paperwork that detailed her journey through the health system. Numerous health measurements were regularly taken by as many different healthcare professionals. Her only constant during that time was her neurologist, who also advised her to start Ocrevus as her treatment of choice. Instead of doing a daily injection, she had to go to hospital twice a year for an intravenous treatment. Somehow that seemed easier to combined with a family!

She was incredibly happy for her neurologist Dr Jansen, who helped her and supported her when she couldn't even discuss something with Thomas. Bettina even communicated via email and WhatsApp when she was on holiday in Italy and needed health advice. Dr Jansen was also sympathetic when Bettina expressed reservations about some very sensitive information in her patient record and ensured her that only she and clinical colleagues directly involved in Bettina's MS care would have access to the files. In particular, she dispelled Bettina's worries that her long-time gynaecologist would also be able to see her files.

	What type of health-related data about you do you want to be collected?			Who do you want to have access to your health-related data?			For what purpose do you want your health-related data to be used?		
	medical records	lifestyle data	genetic data	collection	storage	access	me / patient	family	society
Bettina (multiple sclerosis)				doctors	hospital home telecom	doctors researcher			
Cédric (pacemaker)				doctors patient app	hospital app	researcher			
David (HIV)				doctors patient	practice hospital telecom	doctors			
Elizabeth (Alzheimer's)				doctors	hospital	researcher			
Jane (cancer)				doctors patient app	practice hospital company	doctors company			
...									

Degree of agreement

Figure 1: Hypothetical patient examples regarding our three suggested core questions to be discussed in public debate

Bettina consented to the collection of her data only for the explicit purposes of her care. She wants to keep people outside her immediate family from knowing about her disease if she can, and she is always very careful to not let any correspondence with her hospital lying around in the house in case someone would visit unexpectedly. However, recently she read about a research initiative on MS in the newspaper and she wondered whether her data might help. She would have to ask Dr Jansen if she could anonymously donate her data.

3.2. Cédric: recently received a pacemaker

The days immediately before and after his surgery were very hectic. Cédric lost track of the many investigations performed and felt overwhelmed when he was discharged from hospital. In addition to medication that should ensure that his body didn't reject the pacemaker, he also received dietary advice and an exercise plan. Some weeks after the incident, the computer club in which he is volunteering, organizes a public event on prevention of heart disease by means of smart tracking devices. Convinced that using such a device would improve his health he starts measuring his physical activity, daily calorie intake and sleep patterns.

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As soon as Cédric went back home, he immersed himself in his professional and private obligations again. He did not want anyone to know about his condition because he feared being labelled as weak and unable to fulfil his duties. He told everyone that he had been away that week because a relative of his had died abroad and that he had to attend the funeral to explain his absence. Although his health app regularly alerts him to irregularities in his sleep patterns, he does not share this information with his doctor out of fear of being sent on sick leave. Instead, Cédric tells his doctor that he is sleeping well.

Half a year later the computer club launches a citizen-initiated study to evaluate the impact of self-tracking on patients. Cédric happily supports the project on the condition of anonymity and consents to share his tracked data, even though his fellow club members know nothing about his pacemaker.

3.3. David: diagnosed HIV-positive

David has been diagnosed with HIV/AIDS when he was 46 years old. David requires comprehensive support by a broader team of clinicians, but he does not have direct access to adequate health services. Even remote supervision is difficult as he is living in a rural part of Kenya, does not own a smartphone to use WhatsApp, and his children moved far away into the city centres.

His clinical team in Nairobi keeps in touch via simple text messages. They require David to send regular updates of his body mass index, blood pressure, and food intake that are taken at the local doctor. They then send him his treatment plan and medication via post. Once a year, he must take the bus to Nairobi to test his viral load as well as general liver and kidney function tests.

Over the last decade, HIV has become more accepted in Kenyan society and has lost much of its stigma. As a result, David isn't worried about sharing his disease status or using unencrypted text messages to communicate with his clinicians.

David suddenly starts to deteriorate one day. His local doctor can't identify the cause and consults the specialists in Nairobi via phone. Together, they diagnose an opportunistic infection and start antibiotic treatment immediately. Both record the incidence in their files, and the nutritionist on David's clinical team adjusts his dietary plan to support him recover from his incidence.

3.4. Elizabeth: widow of an Alzheimer's patient

Elizabeth is the 72-year old widow of the late Frank Gordon, who recently died after gradually losing the fight with Alzheimer's disease. Ever since the diagnosis of his

condition, Elizabeth has taken care of Frank and in the last three years of his life she became his legal guardian under English law. To become Frank's guardian was exceptionally difficult, it was if Frank became a child and no longer her husband.

Since Frank's Alzheimer's diagnosis Frank and Elisabeth had frequent interactions with the NHS (UK health system.). In regular appointments with his radiologist, a series of brain scans were taken. Frank simultaneously visited a memory clinic where he repeatedly took tests to assess his cognitive decline.

All data on Frank was stored on the servers of the local health authority and shared between his primary care physician and his neurologist to coordinate a continuous treatment plan. Elisabeth was involved in the decision making and had access to the records, automatically of course when she became Frank's guardian.

After Frank passed away, Elisabeth noticed how the data collected on Frank helped track the progression of disease and adjust treatment accordingly. She wants to donate Frank's medical record to Alzheimer research in order to enable researchers to better predict the course of Alzheimer's disease in future patients. Frank would have loved that his suffering would somehow benefit others. Other patients as well as carers such as herself.

3.5. Jane: under treatment for oesophageal cancer

Jane is 52 years old Kenyan living in Kisumu City and undergoing treatment for oesophageal cancer. Her treatment consists of a holistic disease management plan.

Such a management plan takes multiple sources of evidence into consideration: tissue analysis, risk factors such as smoking, and even genetic evidence. The information is collected by multiple sources including her primary care physician, the local hospital, the specialist hospital in Nairobi, and herself.

All information is stored within an app designed by a private company who is licensing their product to the Kenyan health system. Access is by default limited to Jane and her treating clinicians but additional log-ins can be given to her family members on request. After confronting her doctor about it, Jane learns that the app's creators also have access the data and that their contract even allows them to use her data for research purposes under certain conditions.

Her doctor ensures her that there is no risk of re-identification but Jane continuous to be uneasy about the potential sharing of her information. Cancer is widely seen as a heavenly punishment in Kenyan culture, so widespread knowledge of Jane's disease could lead to social stigmatisation in her local community. However, Jane does not feel that she has a choice if she wants to continue her treatment and reluctantly continues to provide her data.

4. Concluding remarks

Coming from different backgrounds, the authors of this paper agree that more public discussions on the topic of use and usage of patient health must take place. We have identified three core questions, which we suggest more, or even every, citizen should contemplate. We

suggest informed debates about the virtues and vices of electronic collection, storage and sharing of health-related data. Moreover, we presented citizen-patient cases from our own experience to illustrate the various ways in which these questions can be answered.

What immediately transpires is that the answers to the posed questions will inadvertently vary from country to country and heavily depend on the societal context. Citizen in Kenya will have other values and opinions than those in the UK, and the average citizen in the Netherlands will answer differently than the average Swiss. Even on a national level, large variations remain. Within a single country, there will be those that are open to the collection of medical data, while others have reservations. In fact, we must acknowledge that the same patient will very likely come to different conclusions for different aspects of his or her health or at different times in his or her life.

Any successful system aiming to collect and centralise health-related data will have to anticipate this heterogeneity of views and proactively incorporate patient choice into its design. Ultimately, only a system that allows the citizen to decide about the parameters of his health-related data will lead to better community healthcare. We will have to accept that there are those patients for whom the actual or perceived risks are too great to give away their personal data in good conscience. On the other hand, we should not take this as an excuse to do nothing at all and enable those citizens willing to provide data to contribute to improving clinical practice and medical research. Individual agency should be at the very core of our approach, with the patient retaining full control the access and use of their personal record at any time and for each part of their health. The framework suggested by us might help each citizen to navigate these choices for themselves and move us a step closer to a widespread public debate.