YOUR DATA! YOUR HEALTH?

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This is a personal record of the Crosstalks workshop held on 14 June 2022 at deSingel in Antwerp. This took place in the context of the long-term *Shake the Disease* project begun in 2018, which maintains an open dialogue on the future of health and healthcare. After a short introduction by **Marc Noppen**, CEO of UZ Brussel (Brussels University Hospital), in which he presented his personal view on the digitization of healthcare, **Tom Coolen**, ICT director at UZ Brussel, led the speakers in and out.
Sebastien Deletaille is the founder of Riaktr and the brains behind the brand-new Rosa digital tool for healthcare providers. He gave an introduction into recent innovations in the collection and use of health data. **Brecht Devleesschauwer**, epidemiologist and head of the Lifestyle and Chronic Diseases Department at Sciensano (Belgium's national public health institute) , presented the opportunities and limitations of using secondary data to support Belgian health policy.

The collecting of (digitized) data on health and quality of life, consultable via interactive and clear instrument panels, is set to play an increasingly important role in prevention, diagnosis and care. That this will happen there is no doubt, but whether it will contribute to the achievement of health goals and better, personalized care remains to be seen.

Between techno-optimism and digi-pessimism

Thinking on the digitization of healthcare covers a broad spectrum, as Marc Noppen pointed out in his introduction. Digital often continues to means: analogue plus computer. The files on the hard disk are the file bins of the past, only much fuller and requiring more input and search time, packed as they are with information that is not always either uniform or relevant. (Think of the billions of photos or documents stored in the cloud that no one will ever see again.) The 'revenge of afterthoughts' as Atul Gawandeas called it in his November 2018 essay in *The New Yorker* titled 'Why doctors hate computers'. The software dictates the what, where and how and in so doing encourages unwanted bureaucracy. Not only do the chances of burnout increase with the number of hours a person spends in front of a computer but also, many times the screens stand between doctor and patient. Technology strives for greater precision, but in the process has made everything more complicated and time-consuming. It is hardly surprising that medicine as a culture adopts a conservative stance. An average medical training lasts twelve years. During this that time, the digital world changes in an almost unrecognizable way, while in the meantime the trainee doctor learns from experience, which he integrates into clinical routines. Changing those ingrained habits takes seven to ten years.

Yet everyone knows that machine intelligence can be a help. A radiologist needs an average of four seconds to view medical images. Artificial intelligence can help select only the images with abnormalities, leaving the doctor more time to

examine them thoroughly. But having logarithms interpret static images is quite different from looking living patients in the eye. Much artificial intelligence (AI) is still looking for more intelligence.

Perhaps unsurprisingly, about half of all physicians fear that technological skills will outweigh clinical knowledge. A majority believe that hybrid care, partly in remote mode, will become increasingly important, but that this distance will negatively affect empathy and quality.

At the same time, everyone also sees the number of doctors and nurses declining in the near future (owing to an ageing population and career choices), which will make AI assistance inevitable. In some medical disciplines, the use of technology will be much more self-evident than in others. The first virtual hospitals (where patients no longer visit, such as the Mercy Virtual Care Center in Chesterfield, US) are already operational. The patient too is involved. The app store already offers more than 300,000 health applications. More than 40 percent of users of those apps (in the US) use them almost every day. In other words: digitization is in full swing, will only increase and will contribute to the development of 'health in all policies' in which care for the sick must make more space for care for healthy people.

The Covid pandemic has shown how, for example in monitoring diabetics, remote care (because there was no other choice) improves control. Systems that are able to make all relevant information from and for the various parties transparent and operable can make a major contribution to the care of the future. And certainly also in hospitals, where the patient's trajectory can be better managed in this way.

However, the big promises about rapidly evolving technological capabilities are tempered by concerns about the tsunami of data generated in this way. How do we maintain the balance between the system (which may end up leading its own life) and the patient (who wants to live a good life). How do we integrate all this information into effective platforms for the benefit of patients? In a complexly structured country such as Belgium, it will be no easy task to form regions, networks and other levels around the patient as the central pivot.

Being innovative with data

What can we expect, hope or fear from innovation in the collecting and use of health data? Sébastien Deletaille argues that what is important is not so much the technology itself, but rather the approach taken towards data management. Priority items are i) the accessibility of the files and ii) the persons to whom this data belongs.

Gawande wrote already back in 2018: technology makes it possible to make more diagnoses, go deeper into the body or brain and offer more treatments. At the same time, technology will also generate more noise and uncertainties. Medical care will be better documented, but understanding the significance of this documentation may not necessarily be facilitated. The larger the collection of data, the more you can find in it, including even meaningless connections. In other words, what does it mean – for the person in question?

That position is almost self-evident for Deletaille, a *digital health entrepreneur* for whom patients are customers, consumers of information. He has developed medical software for general practitioners at Medispring, co-founded Riaktr, a successful telecom startup, and recently launched a digital instrument, Rosa, for healthcare providers. With this tool, he wants to enable patients to manage their health and health care from their phones. The reason behind it lies in his experience of just how difficult it is to find your own health data, let alone manage it.

Thanks to wearable measuring devices, miniaturized and hidden in smartphones and smartwatches, data is now permanently collected. New data series are being created providing continuous pictures of numerous measuring points. We don't know yet what all this will teach us. What we do know is that it is the first time that humanity has collected this kind of information on this scale. Data availability takes many forms, from continuous temperature measurements during a Covid infection to reading personal DNA sequences. Right now it is a question of looking for correlations, and certainly for causal connections. In complex and chronic conditions such as MS, this mobile, portable data collection does indeed provide new information. For example, the patient platform 'Patients like me' offers information on patients' habits, their well-being and the (side) effects of their treatments.

Major strides are also being made in the use of this data. Using *natural language processing*, hospital files can be made usable for research. AI's strongest programs are even taking the lead in this. While analysing pictures in diabetic retinopathy, DeepMind picked up on phenomena that doctors didn't notice, such as biomarkers for cardiovascular risk. The artificial intelligence technology was trained on the basis of 15,000 eye scans by 18 Indian ophthalmologists, which marked all the features. Based on these data sets, the system was able to make reliable predictions about age, smoking and drinking behaviour, gender and the likelihood of cardiovascular disease within five years. Not only do we learn a lot from this, we also learn faster. The scientific article on this application was

published nine months later in *Nature*, and in another nine months the technology was being applied clinically.

The same method is now being applied to breast cancer screenings and to the reading and understanding of doctors' written notes, making it possible to search entire medical records for keywords. A learning computer system like Corti.AI is now able to analyse emergency calls. Based on dozens of parameters (including background noises or voice intonations independent of the content of the message), the system knows within seconds whether the victim is still conscious and whether an ambulance needs to be dispatched. This intelligent support can advance the final decision by a minute and increase the chances of survival. Six thousand lives have already been saved in Denmark in this way.

In practice

How data collection can help in making the right decisions became clear during the Covid crisis. The question came from the Prime Minister and the Minister of Health whether the decisions taken by the government had had a real impact and whether the population had indeed changed its behaviour and reduced travel. A follow-up question was whether statisticians could predict, based on new cases, where the epidemic would spread further.

A similar exercise had already been conducted in West Africa to curb the spread of Ebola by combining health and telecom data. This provided an instrument panel for the UNICEF teams to limit the mobility of the population, by isolating cities and closing roads.

When Covid struck, the government was able to map the movements of the Belgian population on the basis of anonymized, aggregated data from telecom companies. Linked to the locations of new sources of infection, the shifting frontline of the epidemic could be mapped. Based on those findings, the government was able to decide to continue the lockdown, knowing that halving mobility had already yielded very good results. The message 'stay in your room' was indeed proving effective.

Using data to combat corona worked well because Sciensano, the telecom companies and the government cooperated well, under the supervision of an ethics committee, in complete transparency and with a clear view of the bottlenecks and of the advantages to all parties involved. It was also a world first that all telecom companies cooperated.

A story of data

An important point of attention is how to bring this data flow to the general public in the right way. Not everyone can be convinced with figures and dry facts, and graphs often have the opposite effect. A good story that incorporates those figures and statistics has greater impact. Thus the *NY Times* published on its website the spread of the coronavirus from Wuhan in a multi-dimensional story that provided insight into the dry numbers: how it happened, what was going on and how did it evolve. The figures played a supporting role in this. Medor is doing something similar in Brussels. Take a look at https://bxl-malade.medor.coop/ to see how data on socio-economic status, health and environment are combined. You will learn interactively about the differences that exist within the Brussels metropolitan area in terms of income, mobility, well-being, rents, population density, etc. The site shows and gives you a feeling for how health is intertwined with the context in which people live.

These examples prove that the technology works, and with good results (at least for these applications). However, in the mind of the naturally suspicious citizen the question arises: "Who asked me for this information?" Or: "These applications may be interesting, but what will the government do with all that data in the future?" Health data is one of the most personal things there is. Many people are somewhat reluctant to share it even with their loved ones.

Deletaille notes that health care lags behind other sectors by a decade here. In the past, you could withdraw money from an ATM only if you were a customer at that particular bank. Nowadays you can withdraw money with any bank card at any bank. In the past, if you wanted to change telecom provider, you also had to change your mobile number. Something that is unthinkable today. In the healthcare sector, too, we are faced with a process in which our personal data needs to become usable for various health service providers, albeit without infringing privacy (ownership of the data) or losing transparency (who uses which data for what).

However, there is still a long way to go before that we get that far. To be usable in various applications, data must first be standardized. Ways also need to be developed to anonymize relevant clinical data without compromising its usefulness. Finally, there must be a legally protected culture of trust in which patients can give permission in a clear and pragmatic way to have their data used. Citizens must be able to make that data available with confidence, knowing that sound regulations offer protection against misuse.

From measuring to knowing

Medor's story shows how data can be reused for purposes it was not originally intended for. No one has ever authorized the use of that data, but it does lead to insights at a higher level of complexity than the collectors could have imagined when collecting it. It also highlights the tension between scientists studying it now and entrepreneurs already thinking about the future. Are these scientists therefore more realistic than the entrepreneurs, more reserved or perhaps even more pessimistic?

These were the first thoughts of Brecht Devleesschauwer, a researcher at Sciensano, where he heads one of the institute's five scientific directorates, responsible for Epidemiology and Public Health. The institute supports and strengthens the Belgian and European health information system by providing a contextual view of public health, with proactive policy support and evaluation.

Sciensano seeks to transform raw data into ordered information that can only become knowledge through coherent and contextual insight, which in turn can lead to wisdom through evaluation and action. Instrument panels need to make data transparent and legible, translated into knowledge that can be used for action.

The primary data is collected through the Belgian Health Survey, first organized in 1997. Five surveys have now been completed, with the next one planned for 2023. This survey has resulted in by-products such as local health surveys, Covid-related surveys, and surveys to measure the mental well-being of the Belgian population. The results are (to a limited extent) interactively searchable via the website, but only in English, and after registration, via https://www.sciensano.be/en/projects/health-interview-survey/hisia. It does not look modern, because it is attached to old software.

Alongside this, the third edition of a food consumption survey is underway, NutriTrach is monitoring the composition of the Belgian menu, the Treatment Demand Indicators are being monitored and there is the Early Warning System Drugs.

Sciensano is just one of the dozens of organizations that collect information in Belgium, such as StatBel, Fedris, IBZ or famhp. The information landscape is therefore very diverse. From this very diverse network, www.Gezondbelgie.be is attempting to bring together the many partners' varied reports on health and healthcare into a manageable and coherent whole. Interested parties will find legible information about all important disorders and determinants of our health, and about the functioning, quality and effectiveness of our health system. Under 'disease burden' we find comparisons of var-

ious disorders and their effects on quality of life. In this way the impact of different disorders can be compared with each other. A simple graph shows that mental health problems are by far the largest disease burden at 21% (with depression being the most important), followed by 19% for cancer and 14% for musculoskeletal disorders. Presented in this way, such information should be able to provide direction and guidelines for policy measures. Sciensano is well aware that many times it arrives with this data after the facts (or the minister's questions) and does not weigh pro-actively enough on policy. One factor here is that statisticians are often not skilled in making the necessary translation of this dry matter into policy.

Opportunities and limits

Both at home and in Europe, there is a great willingness to open data vaults and share information. It is clear to everyone that a legal framework is indispensable and that the rights and interests of the individual must come first. A distinction is made here between the primary use of data, in which the highest standards for privacy and security must be applied, and its secondary use for research and policy, in which less stringent criteria can be used.

There are limits to the use of this data. First and foremost, an ethical boundary: What data do you share with the doctor, with the government, with the private sector? A survey by the King Baudouin Foundation (the report can be downloaded from www.kbs-frb.be/nl/zoom-zorg-voor-je-health-data) shows that a large majority (89%) of a representative sample of Belgians do want to share their personal patient files with professionals who are responsible for their care. They realize to a large extent that they themselves can benefit from this, because without giving this access they may receive a less adapted and therefore worse treatment. More than three-quarters of those surveyed (76%) are ready to share their health data with research centres or hospitals for scientific research. There too the idea plays a role that you can help not only yourself but also others and often the most vulnerable in society. Nevertheless, many people simultaneously realize that this information is potentially open to misuse. Patients are therefore more reluctant to share data with the (pharmaceutical) industry, governments, insurers or private companies. Citizens want to share, but also want to maintain control. Informed consent should therefore ideally be obtained on an ad hoc basis, tailored to the goals and the parties involved. Today, the legislator already maintains that it offers protection to citizens and patients. Yet the individ-

uals to whom the data relates are rarely given real control over their own data. At the same time, however, citizens and patients are asking for greater transparency, traceability, feedback and self-management in order to use their data as leverage for personal and general well-being.

From the perspective of local health consultation or prevention platforms, there is a growing demand for co-creation in which citizens can contribute ideas and work towards healthier living environments. This is preferably done on the basis of reliable health data linked to a network of other social parameters. For this, all those involved, including outside the healthcare sector, need to participate. It is crucial here to realize that the patient is always the weakest party. Anyone lying critically ill in a hospital bed wants to get out of it as soon as possible. Filling out questionnaires in an app or on paper is then the last of a person's worries.

These concerns are echoed in the European Parliament's recent recommendations that emphasize that the use of AI and data processing in the health sector should be anchored in strong ethical requirements concerning privacy, accountability, transparency, reliability and permanent human oversight.

These conditions point forward to the legal and technical limitations that the use of personal health data encounters. Admittedly, the GDPR rules provide a useful framework. It is also important to work on standardization and interoperability between the health data databases in our country. For this, the Health Data Authority comes at the right time. The HDA needs to be the single point of contact and connected to all databases. An efficient exchange of health data via an integrated electronic patient record will be unavoidable in the future. It is therefore to be welcomed that the Belgian government is working on the Belgian Integrated Health Record (BIHR), with everyone curious as to what it will look like.

The individual pieces of the jigsaw are already there, but the overall picture is still far from complete. The entire exercise is not going smoothly right now. This was evident, for example, from the difficulties encountered in following up Covid patients once discharged from hospital. In other words, there is still work to be done, and not just in the technical field. According to a Sciensano survey, 33% of Belgians lack adequate health skills. The King Baudouin Foundation's digital inclusion barometer shows 40% of the Belgian population as having has poor digital skills. In a recent pilot study on reha-

bilitation, 18% of patients dropped out of the project because they could not handle the mobile app. Only a quarter of the Covid patients who left UZ Brussel after eight weeks were able to use the follow-up app. Other research shows that citizens' digital ineptness prevents three-quarters of them from participating in the digital revolution. Their socio-economic status is the heaviest obstacle in this regard.

All this despite the fact that digitization is a major worksites of our healthcare system. Technology in the service of public health and well-being is an enormous opportunity. It is therefore essential that everyone participate in this story, patients as well as providers.

Inequality at every turn

Health in all fields is therefore hampered for the time being by inequality in all areas. This also applies to digitization, with or without apps or forms of AI. Differences in socio-economic status explain many of the major discrepancies in physical and mental health. This is the story that Medor is telling us about Brussels and its population, and it speaks volumes. The sobering thing is that this story has been told for at least 120 years.

In 1889 Charles Booth published his *Poverty maps of London* on which the socio-economic status of the city's inhabitants, linked to income, well-being and health, can be read street-by-street. For analogue bibliophiles there is the beautiful edition by Thames&Hudson, while digophiles can visit the interactive website of London School of Economics www.booth.lse.ac.uk.

The content of the story and even its form have hardly changed over the course of more than a century. It is a distressing finding. What is really needed to tackle the fundamental ill health of and in our society?

All concerns about the financing model that complicates the uploading and management of data are justified. The same applies to privacy, inform(at)isation, anonymization or accessibility, and to the role of patients, who ought to be the central partners at the helm of their own data. But what if the people we see on our digital instrument panels are simply unable to play the game themselves? It would be great if the digital revolution could also represent a step forward for them too.