HEALTH DATA TALK SERIES:

The need for (real-time) outcomes data from a patient perspective

VISION

In an ideal world we would have **a plan for every disease**, with a list of desired and (most) important **health outcomes** that patients truly value[1]. Some outcomes, such as survival, slowing down the progression of a disease and physical consequences of the treatment are obvious indicators and can easily be captured in such a plan. However, other outcomes, such as quality of life, subjective wellbeing, mental health, comfort, avoidance of complications, or ability to work, are less apparent and can only be understood through the **perspective of the patients** themselves.

To develop a plan that reflects these desired outcomes, we have to identify the information and data needed to measure and evaluate them. Specialists, health care professionals, policy-makers and health care users should **collaborate** to determine which health outcomes and their corresponding **key performance indicators** (KPI's) are absolutely critical to track the progress of the plan. These KPI's can then be consolidated into a **dashboard** that can be used annually, or more frequently, to evaluate whether the plan is making progress or not, or whether it should be course-corrected. Such dashboards also allow to assess where (and by whom) the best results are achieved, compared to the average or worst outcomes based on patient needs.

THE CRITICAL ROLE OF DATA IN TRACKING PATIENT OUTCOMES

In this context, it is clear that **aggregated high-quality data** are essential to understand patients outcomes based on factors such as the severity of their disease, their treatment, the hospital they went to, their active involvement in their treatment plan or any other aspect that may have influenced health outcomes. Many of the data needed for the dashboards can likely be captured from **existing (administrative) databases**: hospital databases (e.g. data on how often people are rehospitalized due to e.g. infections, or length of stay), databases of the family doctors or the pharmacists (e.g. data on which medication is delivered), national registries (e.g. data on cause of death) or reimbursement data from health insurance funds (e.g. data on how often people use healthcare services). However, efforts will be needed to ensure the **quality and timeliness** of these data sources. For example, many of the disease statistics that we currently have are limited to a few major diseases such as cancer, diabetes and cardiovascular diseases, and these are usually only available after a few years, once the registries have integrated all the data from the hospitals in a harmonised way.

In order to obtain the other necessary information[2] to track and evaluate the desired outcomes, **additional data systems** will need to be set up, such as opinion surveys among patients, aggregating patient diaries, or the use of innovative digital technologies. We are reaching a stage in medical science in which many patient data are also captured through digital technologies such as remote patient monitoring, wearables, and other AI-driven technologies. These data are available in **real time**. Obviously these data contain important information for the individual patient, because it allows for a fast or even immediate response by the medical team if some alarms are set off (primary use of these data). But these digital health technologies also enable the aggregation of real time patient data offering **more detailed and up-to-date insights** than those currently available in administrative databases. With due regard to legal, privacy, and security regulations (as described in more detail in other Health Data Talk Series papers[3]), these real-time data should be made available for **secondary use** in areas such as public health policy, quality improvement, research, and innovation. In this way, patient population data can also keep track with the launch of new technologies and treatments and ensure that patient insights can inform and improve medical practices and policies.

1 These outcomes should ideally be in line with, but more ambitious and specific than, the actual federal health objectives, see https://www.health.belgium.be/nl/news/persmededeling-van-de-interministeriele-conferentie-volksgezondheid-1

2 Information such as quality of life, patient involvement in treatment plans, patient reported outcome measures (PROMS), patient reported experience measures (PREMS)

3 See for example: Health Data Talk Series: Secondary use of data leading to innovation in health (from an industry perspective) available on HDA Academy website.

INTEGRATING DATA FOR CONTINUOUS EVALUATION AND INNOVATION

Furthermore, digital technologies and computer science will make it possible to **integrate different data sources** much faster and much better: administrative data sources could be linked to the data from the clinician, to those of the psychologist or physiotherapist, the lifestyle of the patient and his/her adherence to treatment, the real time data from digital technologies, and many more. In this way it will not only be possible to **evaluate the disease plans** continuously based on recent data, but also to assess the **impact of recent innovations** to treat the disease (diagnostics, medication, surgery, radiotherapy, ...). The integrated data could also generate new insights into living with and managing the disease such as lifestyle choice, physical activity, etc. All in the advantage of better patient outcomes.

CONCLUSION

We recommend **prioritizing the integration and collection of more data**, specifically more precise, real-time and disease-specific data, with a higher level of granularity than the often crude data available today. These data should be captured in dashboards with KPI's that are continously evaluated. If all patients are closely monitored, we will have better and more representative insights from smaller subpopulations, such as patients with a rare disease or with rare mutations. It will be possible to identify sudden issues, to compare treatment options, to track patient adherence and to evaluate outcomes. Insights that require specific and often elaborate and time-consuming research now, will be instantly available. Due to the sensitivity of the data, all this should ofcourse be realized within legal frameworks and under correct conditions, as described in the other Health Data Talk Series papers[3]. This approach will **improve health care outcomes (at population level) and enable more tailored and effective treatments (at individual level) for all patient groups.**

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