Revista Crítica de Ciências Sociais, 136, Maio 2025: 45-68

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The value of experience: A historical sociology of data-driven health care systems

One of the key expectations associated with health data is their potential ability to make health systems more reactive, adaptable ("smart") and efficient by integrating patient generated information into the digital infrastructure of these systems. One of the key technologies to bring this expectation to bear are Patient Reported Outcomes Measures (PROMs). PROMs are metrics of how patients feel and function from their own perspective. Focusing on the emergence of PROMs, this article draws on the social studies of quantification to understand how "subjective data" came to be the driving force behind change in contemporary health systems. It suggests that a co-productive interaction between efficiency-focused models of healthcare organisation and an epistemic framing of health as a computational problem is the sociotechnical core of data-driven health care systems.

Keywords: digital technologies; health systems; healthcare; psychometrics; sources of information.

1. Funny questions

A few years ago, a friend of mine had to have an operation on his knee. He had been complaining of pains in the joint for several months, which then became more acute with any minor exertion, such as going out on his inflatable boat in the North Sea, which he loved to do on weekends in the summer. It was this disability that prompted him to go to the doctor. The subsequent letter confirming the date of the operation also included a request to fill in an online questionnaire about his health, which he obviously ignored. He ultimately ended up having to answer the questionnaire at the hospital Admission Desk, under the watchful eye of the head nurse. The operation went well, and when he went back out on the boat he told us that at the follow-up appointment he was asked to fill in the same questionnaire again, to "track recovery". He mentioned in passing how he had found it "funny" to have to repeat the same answers to questions that he had already given to the doctor and nurse moments before in the

consultation room. My friend answered both questionnaires voluntarily but without giving it much thought, and unbeknownst to him, he had just taken part of one of the largest systematic health data collection initiatives in the world, underway since 2009 in the United Kingdom's National Health Service (NHS).[1]

This initiative involves the collection of information on the quality of care on orthopaedic interventions in the form of what is known as Patient Reported Outcome Measures or PROMs. The United States Food and Drug Administration defines PROMs as a report of the status of a patient's health condition "that comes *directly from the patient* (i.e., without the interpretation of the patient's responses by a physician or anyone else)" (U.S. Department of Health and Human Services, 2006, p. 1; emphasis added). In essence, they are, as my friend's story illustrates, short, self-completed questionnaires, which normally combine general and condition-specific health questions (see Figure 1). These data are used to monitor the evolution of the impact of such procedures on the health of a population, across the health system as a whole, and to compare performance and value delivered by providers within the system. In this, the source of the information is key to the importance the NHS and other health care systems put on PROMs as tools to "assess the quality of care delivered to NHS patients from the *patient perspective*" (NHS England, n.d.; emphasis added).

Around the time my friend was undergoing the knee replacement and nonchalantly answering those "funny" questions, a committee of health ministers of the Organisation for Economic Co-operation and Development (OECD), in coordination with the World Health Organization (WHO), the World Bank, and the Council of Europe, issued a statement on how to design and implement what they labelled "people-centred health systems", stressing that such reforms should be driven by "measures of patients' own experience of medical care and health care outcomes" rather than just their processes and costs (OECD Health Ministers, 2017, p. 5). Such measures would, the Ministers suggested, "better equip countries with data that reflects what matters to patients" (OECD Health Ministers, 2017, p. 15), building the foundations learning, adaptive, data-driven health care systems (Wachter, 2016).[2]

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[1] Cf. https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/patient-reported-outcome-measures-proms

[2] There is an important difference between PROMs, which focus on the outcomes of care, and Patient-Reported Experience Measures (PREMs) which assess the process of care (e.g. the information they were provided with or waiting time). Given the emphasis on PROMs of policy agencies such as the OECD, the article focuses on them.

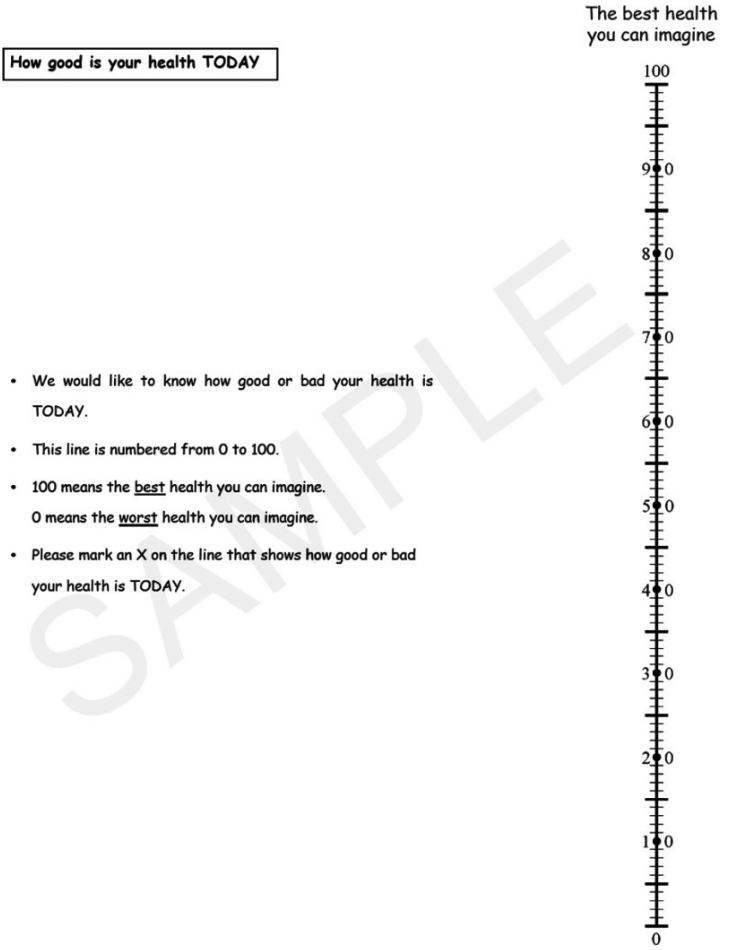

FIGURE 1 – One of the items my friend completed, the EQ VAS

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These transformative visions of health systems around the world contrast with the mundane quality of the "funny questions" my friend had to answer before and after his operation. This disparity prompts the following question: How is it possible that his answers to simple questions asked on a computer in the waiting room of a hospital in the north of England can be part of such a broad and profound transformation of health system policies from a global perspective? This question is all the more pertinent when we consider that

information about subjective states or experience/living is not necessarily, or by definition, the most reliable basis for either building a health system or transforming it. The values that we normally associate with subjectivity, such as individuality, emotivity, unpredictability or bias, or with experiential data – personal, embedded, situated, unique – are at the opposite pole to what we think should be the legitimate epistemic bases for public policies (Porter, 1995). So, how can subjective data be the driving force behind change in health systems? How is it possible to explain, from a sociological point of view, that a patient's experience can have the power to transform the institutions of healthcare organisation?

This article brings together the social studies of quantification (e.g. Mennicken & Espeland, 2019) and "valography" – i.e. the empirical study of practices that support certain values or versions of value (Dussauge et al., 2015) – to propose a historical sociology of data-driven health systems. From this point of view, I investigate the set of pragmatic operations and transactions necessary to transform experience into actionable data: how is health transformed into a thing in itself, a cognitively distinct object that can be mobilised in action? How is it measured in specific institutional and material contexts, and how does it enable forms of health practice and disease management? To answer these questions, the article explores how practices of quantification harness specific values in health data infrastructures, diachronically shaping the way we think and act in the socio-technical worlds in which we live (Desrosières, 1990, p. 215).

Based on documentary data analysis, the paper deploys a genealogical approach to disentangle the heterogeneous threads contributing to the emergence of new ways of thinking and acting (Foucault, 2000). Drawing on a 8000-plus references bibliographic database on PROMs that was used for a computational analysis of the research literature (Greenhalgh et al., 2023) I applied a "reverse snowballing" sampling strategy to identify the process and timeline of the documents involved in the creation of PROMs fields. The analysis focused on the conditions of existence of a specific form – that of the PROMs – thus highlighting the processes by which experience data came to acquire value-meaning or usefulness – in health systems from the mid-20th century to the present. In the next section of the article, I describe how, until the turn of the 1980s, the usefulness of subjective health data was very unclear, with one of the most influential experts in the field of public health, demography and health statistics declaring that this type of data "may be completely irrelevant to any objective criteria of health status or the need for health care" (Sullivan, 1966, p. 10). In order to understand how, years later, subjective data on patient experience has come to be considered a key

foundation of responsive, data-driven health systems, I will explore the co-productive interaction between models of healthcare organisation, which I will do in the third section of the article, and forms of health measurement on the other (section 4).

2. The transformation of experience

One of the key expectations associated with health data is its potential ability to make health systems more reactive, adaptable ("smart") and efficient, by integrating the "voice of the patient" into the digital infrastructure of these systems. Worldwide, digital health data is associated with expectations of greater efficiency ("value for money") and safety, better access and more reactive and personalised care, often using the predictive capabilities of algorithms. However, the growing dependence on digital health data also brings to light the challenges of creating sustainable socio-technical infrastructures that support the creation, collection, analysis and execution of this information.

In fact, the driving vision of data-driven healthcare systems is to facilitate the collection and use of patient-created data in the "real world" by collating information collected "via surveys, sensors, wearables [handheld devices], patient-reported outcome measures, and data from other apps" (Wachter, 2016, p. 30). Here, as in other expositions of this imaginary (Goldacre et al., 2022), the emphasis is on the robustness and solidity of this data, qualities without which the programmes and actions they support cannot be based on "facts", "objective reality" or the "real world". Thus, in the presentation of the strategic orientation of global health policies published by the OECD Health Ministers, as previously mentioned, they suggest that the move towards "more knowledge-based" health systems will be established on the "development of statistical tools specifically designed to assess [...] the experience and outcomes from the patient's point of view" (OECD Health Ministers, 2017, p. 15). For example, in the report of the OECD expert group on health statistics, on which the ministers' statement is based, it is proposed that PROMs programmes represent the best way for

> countries [to] become well equipped to face the challenge of ageing populations and the consequent increase in chronic diseases and multiple morbidities, [making it] essential that the data collected is relevant and actionable and corresponds to what matters most to patients. (OECD, 2017, p. 13)

The proposal is for health systems to focus on producing relevant data by "asking patients themselves" what their subjective assessment is, through PROMs instruments, similar to the one my friend answered.

PROMs play a decisive role because they articulate what I propose are the three main epistemic and normative modes of coordination deployed in contemporary health care: economic efficiency, clinical effectiveness and patient involvement (Moreira, 2012). In this, their power seems to reside in being able to balance this unstable triangle by emphasising economic value. This is most visible in how the renowned economist Michael Porter, in partnership with the then Secretary-General of the OECD in a commentary on the report accompanying the ministers' statement, proposed that this change "requires asking patients themselves" for their assessment of health status and quality of life "in order to make results comparable across providers and countries" (Gurría & Porter, 2017). Porter himself is one of the founders of the International Consortium for Outcomes Measurement (ICHOM), an organisation dedicated to providing "standardised" health data for all countries and systems. Aiming to put patients' views and experiences at the centre of commissioning and delivering services, PROMs are seen to enable healthcare payers to hold providers accountable for the care delivered, with a view to inciting providers to improve their practice and create value. In this way, PROMs programmes can legitimately be seen as the realisation of Porter's highly influential work on value-based healthcare, where value is defined as "the results achieved in terms of patient health, for every dollar spent" (Porter, 2010, p. 2477). For example, in Portugal this concept is particularly visible in the management of Luz Saúde, one of the largest healthcare groups in the Portuguese market with a network of 14 hospitals and 15 private clinics, which has the explicit mission of "achiev[ing] the best healthcare outcomes from [the] patients' perspective" (Luz Saúde, n.d.; see also Ribeiro, 2022).

However, from a sociological point of view, it is necessary to question the correspondence between the processing of subjective data and the quality of health care that this imaginary subsumes. The contingent or historically contextualised nature of this equivalence becomes clear when we explore the history of health statistics. Indeed, as suggested above, the collection, processing and calculation of subjective health data is not new or recent phenomenon. Subjective health items have been used at least since the 1940s in settings such as the British General Household Survey, the US National Health Interview Survey and in health surveys in most OECD countries.

For example, in the British Surveys of Sickness, a series of inquiries carried out by the Government Social Survey Department between 1943 and 1952, citizens were asked about their evaluation of their own health and the impact of illness on work. Although the aims of this, then "new", social epidemiology aimed to turn the "the private inner states of individuals into public

objects of government" (Oakley & Barker, 2004, pp. 5–6), such operation was fraught with difficulties:

> Foremost amongst the features for which the Survey of Sickness has been adversely criticised has been that the information it produced was obtained from patients themselves and not from medical sources. As every doctor knows, the accounts which many patients give of their present and past illnesses are often unreliable, and not to be taken at face value; and, while such information can be immediately interpreted and used by the doctor as he [*sic*] interrogates and examines his patient, no such medical editing of the patients' diagnostic statements had a place in the methodology of the Survey of Sickness. […] Though the validity of non-medical information about diagnosis is less than that from medical sources, and though this necessarily imposes a limitation on the validity of the Survey of Sickness, it would be wrong to regard the Survey as lacking in all value simply because the diagnostic information was imperfect. (Logan & Brooke, 1957, p. 34)

The passage is noteworthy for being at the opposite pole of the vision proposed by the OECD of the role of subjective data in health management. In 1957, as part of the creation of one of the first population databases on health and illness, we have a world where the data obtained from the "patients themselves" are seen as vague and imprecise; where, at best, subjective data are conceived as complementary to the more accurate information produced by their doctors. The subjective data were neither accurate nor rigorous; they had neither internal validity, due to a lack of conceptual basis, nor external validity, due to a lack of validation in relation to objective medical authority. These methodological problems called into question whether the data collected by the Illness Survey could actually represent the health of the British public or guide national health policies.

The British Sickness Survey was not unique in seeking validation in professional authority. In the famous American Soldier Study, conducted by the Research Section of the US Army's Education and Information Division during and immediately after the Second World War, researchers used the "independent" assessment of psychiatrists to ratify self-administered instruments for screening responses to combat stress (Stouffer et al., 1949). On the basis of these instruments, the sociologist Louis Gutttman and his collaborators were able to demonstrate that there was a scalar pattern in the subjective manifestations of fear, making it possible to predict the responses of individuals at the front, and to make military decisions regarding the selection of personnel for war missions. This "epistemology of the bunker" (Lutz, 1997) was fundamental in beginning to establish the credibility of

instruments for measuring subjective data in the decision-making cadres of the US Armed Forces, just as other statisticians, sociologists and psychologists did in other institutions in the same period (e.g. Carson, 2007). However, these methodological devices continued to be fragile in the area of health, where controversies often arose over the validity and objectivity of subjective data.

An example of this dates to 1960, when two social scientists from Emory University, James W. Wiggins and Helmut Schoek, using survey data on subjective assessments of health, claimed that Americans tended to relatively underrate their health – that is to say, they felt their health was worse than what Wiggins and Schoek claimed it actually, objectively was (*Science*, 1960). The American Medical Association (AMA) seized upon this issue in its criticism of the Democrats' early 1960s plans to create a health care system for older citizens – subsequently Medicare – as it showed that citizens had most of their health needs met by the existing system, *if only adjusted for their own skewed assessment* (*Science*, 1960). Senator Eugene McCarthy, the Democrat Senator from Minnesota, in turn, reacted publicly in Congress to the AMA's use of the study by questioning "the ability of an individual in an interview with sociologists to determine the actual state of his physical or mental condition" (McCarthy, 1960, p. 3). "Asking people themselves" about their health was not, it appears, a solid basis to underpin the reforming of the health system or to evaluate its quality in terms of outcomes.

In this critique of social scientists' ability of measure health, political reformers were not alone. In a seminal paper published a just few years later (1966), Daniel Sullivan, a senior data analyst at the US National Centre for Health Statistics, argued that, in the face of decreasing overall mortality and increased chronic illness prevalence in the population, it was necessary to devise "a more sensitive and informative measure of levels of health […] based on health characteristics of the living as well as" the dead (Sullivan, 1966, p. 1). This aim however presented challenges to the health statistician, used as they were to working with the "hard measure" of mortality. Sullivan suggested that there were three sources of data that could aid the construction of this new health index: clinical evidence, produced and organised by physicians; behavioural data, such as absenteeism or impairment, normally administratively collected and certified; and what he called "subjective indicants". Sullivan was reluctant to advise reliance on the latter to "allocate resources and evaluate health programmes" because,

> [in] an individual's report of symptoms or feelings of illness or his opinion of his health status. […] The major determinants of verbal descriptions of health status have yet to be identified and – more important – may be completely

> irrelevant to any objective criteria of health status or the need for health care. Use of subjective evidence of morbidity would require a complex and uncertain process of inference wherever measures of morbidity varied between groups or over time. The implications for utilization of health resources would be doubtful, at best, until the relations of verbal responses to more objective indicators are more firmly established. (Sullivan, 1966, pp. 9–10)

Sullivan's concern was framed by what he saw as the uncertain standing of information on "feelings" or "opinion", particularly as these were inextricably linked to "verbal" aspects of the question and answer process, such as the order of the words or emphasis within sentences. But it was not only that the validity and sensitivity of subjective health items was difficult to establish; it was also that, in the event of these being methodologically ratified as a measure of feeling, their relation to "more objective indicators" pertaining to health status or health care utilisation was still in doubt. From his perspective, then, subjective health data could only be thought of as a "proxy" to more robust forms of data, whereupon planning and expenditure decision making could be made.

In the same year as the Sullivan's seminal paper, Avedis Donabedian – a public health physician – focusing more specifically on the "urgent need to evaluate and control the quality of care in organized programs of medical care" (2005, p. 691), proposed that assessments of health services should be underpinned by three dimensions: structure, process and outcome (Donabedian, 2005). Normally cited as one of the foundational papers for what later was to be known as "health services research", the paper reviewed the existing literature to suggest that data for such evaluations could be gathered from three main sources: clinical records, direct observation of medical care, and behaviours and opinions. Using a similar categorisation to Sullivan's, for Donabedian, however, the latter form of data was thought to be the exclusive responsibility of "managerial, professional and technical persons" (Donabedian, 2005, p. 699), and explicitly excluded *patients themselves* in its generation.

This was not an oversight or failure on Donabedian's part. As we have seen, there was expert agreement that patients' views on their health were unreliable, that their relevance for the appraisal of health care was unclear at best, and importantly, that the methodology to establish the validity of experience measures was incipient. As was written in a paper addressing this issue at the time: "More is known about the consumption of macaroni or corsets than the health status of the population" (Fanshel & Bush, 1970, p. 1022).

Since the post-war period, data on the health of the population has been considered fundamental to the functioning and management of health

systems. However, as we saw, these data were scarce and, if existing, of questionable quality, methodologically speaking. This means that the transition in the dominant form of epidemiological thinking identified by Wahlberg and Rose (2015) – from a focus on life and death to one on calculating aggregate states of disability and health at a global level – was not linear, and required several levels of articulation between the different approaches to measuring the health of populations, the socio-technical expectations that these measures entail, and the health and social security policies associated with these expectations (Moreira, 2019). In the rest of this article, I will analyse this complex interaction between health measurement methodology and population health policy, starting with the regulatory framework for producing, collecting and analysing health data. What should be the values, aim and collective goals that such data should support and enhance? In other words, what was the data being collected for?

3. Framing measurement

Clues to the collective answer to the question posed at the end of last section can be found in the paper where the quote above was taken from: "A health--status index and its application to health-services outcomes" (Fanshel & Bush, 1970). As with similar attempts to devise a health index at this time, Fanshel and Bush approached the issue of health measurement from the perspective of "system science" and operations research. Authored by an electrical engineer and a public health physician, the paper proposed to develop an indicator that could be used to measure the performance of the "health system". In so doing, it drew on operations research forms of reasoning and handling of data. This was a new take on the issue of health and health measurement that would have significant consequences.

Operations research had been established primarily through addressing the problems of planning military operations in the Second World War, particularly in Britain and the US. Under such conditions, operations researchers devised methods of ascertaining the relationship between conditions and outcomes (e.g. number of casualties) of particular courses of action. The methods were particularly focused on the effectiveness and efficiency of operations, and in producing simple visual and graphic representations that could summarise the alternatives, for the use of military commanders. This combination of mathematical skill, data visualisation and line of command allowed operations researchers to devise forms of programming and calculating probabilities between alternatives states of military battle.

After the war, a number of operational researchers were employed by corporations such as RAND[3] and transposed the methods and approaches used in the war operations room – the "bunker" that Lutz (1997) conceptualised – to the management of business and large policy programme budgeting in government. As historians of economics have long realised, this transference of models and forms of reasoning from military engineering to management was fundamental to the development of information-based economic theories in the post-war years (e.g. Mirowski, 2002). In the process, economics' utility--maximisation assumption was converted into a computational problem – an operation of information processing. For health care, this meant that it was necessary to find ways of calculating the "gain", the difference obtained from investing in specific medical programmes, for individuals and for the populations involved. Thus, economists' key metric of cost-effectiveness came to be established as the central criteria on which to compare an alternative course of action, to the detriment of other aims of public policy such as human flourishing, empowerment or equity (Berman, 2022).

This reliance on operations research, in turn, shaped the range of possible programmes that could be endorsed by governments. As Robert A. Levine, a Harvard-trained economist and staff researcher at RAND Corporation in the 1950s and 1960s, put it, taking this approach meant not only using different techniques but also rethinking "*the operation* of the Great Society" (Levine, 1968, p. 86; emphasis added), a set of domestic programs in the United States launched by Democratic President Lyndon B. Johnson in 1964-1965. Levine's proposal was that instead of relying on centralised planning, this common good could be achieved through "the design of a system in which people make decisions for themselves in their own best interests, but in which the sum total comes out as a *net increment* to the social good – something like Adam Smith's 'invisible hand'" (Levine, 1968, p. 87; emphasis added). In other words, such a system would convert the behaviours of its parts – individuals' utility maximisation actions – in a collective *gain* – as value.

To be clear, the application of such thinking to health care was famously a thorny problem, as it was thought that people did not have the knowledge about the nature and quality of health care to decide what were their own best interests – i.e. to be able to maximise their utility. Indeed, the economist Kenneth Arrow had notably proposed a few years prior that because it was

[3] RAND Corporation (Santa Monica, CA) was established in 1945 as Project RAND, contracted to the Douglas Aircraft Company, and tasked with military-related research. Three years later, the company became an independent not-for-profit private sector research organization, concerned with studying public welfare and security-related issues. More information can be found here: http://www.rand.org/about/history/

difficult to obtain accurate information in relation to illness and care, and because this knowledge was asymmetrically distributed between providers and consumers, health care had relied on professional trust to respond to market failure (Arrow, 1963). This suggested that, as there were no health care consumers in the proper sense of the word, their utility maximisation could not be assumed, and thus health care markets were difficult to establish. As Levine's piece indicated, however, there was the possibility – at least theoretical – that people might be able to act as consumers if the *system* was designed so as to make possible and incentivise that type of behaviour.

The likelihood of such system being implemented increased with the election of Richard Nixon in 1968 (Nixon, 1969), and came to be focused in three years of rhetoric, hearings, and negotiations that led eventually to the Health Maintenance Organization (HMO) Act of 1973 (U.S. Congress, 1974).[4] As one of the key proponents of HMOs, Paul Ellwood, a physician turned reformer working for the Kayser Foundation, explained during the public controversy about their function, the key feature of the health maintenance strategy was the design of a system that encouraged competition and the evolution of organizations that manage themselves with minimal intervention or regulation (Ellwood et al., 1971). An admirer of Levine and the group of New York conservative intellectuals he belonged to – including Daniel Bell, Samuel Huntington and Seymour Martin Lipset –, Ellwood (2011) contrasted this with the two existing models of organisation of health care: the professional model, exemplified by most US health services, with individual payments and doctors playing a decisive role in defining the structure of healthcare and its evaluation; and the central planning model, exemplified by Great Britain or Sweden (and after 1974, Portugal), in which control of budgetary resources is held by regional or national administrative bodies (Ellwood, 1972). Both models were at the time subject to intense criticism, the first because it created what sociologist Elliot Freidson called a "market shelter" (1970), and protecting providers against the scrutiny of clients/users; and the second because it was potentially capable of "sacrific[ing] certain potential interests of an individual patient [in order] to satisfy organizational needs" (Mechanic, 1977, p. 75).

A competitive system, on the other hand, was imagined to rely on market forces to incentivise providers to organise health care delivery in a more responsive manner, integrating services and emphasising prevention and

[4] By the 2010s, HMOs were seen as a failed solution to health care organisation and did not have much popular appeal (see Gallup, n.d.). Presently, only Kayser Permanente has enjoyed success being structured as physician-led HMO.

health maintenance. In order to create such a competitive system, proponents argued that it was necessary to create a database, an infrastructure that would "provide both individual consumers and quantity buyers with accurate information on the comparative performance of alternate sources of health care" (Ellwood et al., 1971, p. 296). This was to offset the scarcity of information that undermined the creation of health care markets, with the aim of establishing a "calculative device" (Callon & Muniesa, 2005) that would equip actors with the cognitive capacities to behave rationally in the demand for and supply of healthcare. One important and decisive feature of this proposed data system (e.g. Bunker et al., 1978) was that it should rely neither on information provided solely by clinicians – like in the professional model – nor on data certified by bureaucrats – like in the central planning model. This meant, effectively, that the two sources of information that both Sullivan and Donebedian (previously mentioned) thought were the most reliable for the creation of a health measurement apparatus were not fit for the purpose of the new, proposed competitive system. The system had thus to rely on the third, fickle source of data identified by Sullivan: "subjective indicants" of feelings or opinions. This was the data that would enable individuals to act, as RAND health economist Joseph Newhouse (1977) put it, as "informed consumers". The problem, as we know, was that this data did not exist. What would it take for these data to come alive?

4. Scaling health

In the previous section, we explored how data on patient experience came to be seen as an essential component of a specific institutional format of health care organisation that relied on competition. As we also examined, however, the problematic status of this data from a methodological point of view continued from its earlier uses in 1940s to the 1970s. As a review of state of the art in outcome assessment put it, at the end of the 1970s,

> there exist[ed] a paradoxical situation in which policy demands that operational quality assurance systems use the outcome method to assess quality of care, while there is a dearth of valid and reliable outcome criteria and standards and no method of proven feasibility by which they can be applied. (Brook et al., 1977, p. 3)

It had been in part to address this state of affairs that, in the US, the National Centre for Health Services Research and Development had been created in 1968 to "contribute to health and select the critical points which […] will result in more effective medical treatment, greater efficiency, and greater availability of services to all our people" (Huntley, 1969, p. 86). With

a special focus on assessing research methods and techniques in the social sciences that could assist decision making at programme level, the Centre was responsible for funding a variety of studies specifically concerned with the question of measuring outcomes within an overall aim of cost containment, as identified by the Nixon Administration (see footnote no. 4). This also intended to overcome what was recognised as "the temptation to measure what appears to be objective and reproducible rather than what is really relevant" (Huntley, 1969, p. 89) and to focus on what was seen as pertinent areas such as functional status and "consumer" satisfaction.

To reiterate, this initiative provided the funds to a variety of research projects that focused on developing such pertinent outcome measures, such as the ones developed by G. W. Torrance and colleagues (1972), or by S. Fanshel and J. W. Bush as previously referred, or the Sickness Impact Profile, a behaviour--based index of dysfunction (Bergner et al., 1976). But nowhere is the cojoining of the data requirements to support an economics-defined efficient deployment of health care, on the one hand, and the focus on methodological rigour to develop such data so clear as in the RAND Health Insurance Experiment (HIE).

Originally funded by the Office of Economic Opportunity during Donald Rumsfeld's directorship to study the effects of the pricing of health care on its demand, as originally imagined by economists Joseph Newhouse and his colleagues (e.g. Newhouse & Taylor, 1970), the study came to also include the evaluation of different health insurance schemes (fee-for-service, practice co-payment, etc.) due to its public importance in light of the HMO debate. One key methodological problem that became rapidly apparent was that it was necessary to measure the quality of the services provided across and within different health insurance systems if the experiment was to be valid: i.e. it was necessary to control for the influence of what economists would define as "externalities" that could not be eliminated in the experimental design alone. This brought the study into alignment with the policy aims to develop better measurements of quality of health care within health services research described above, but required a set of expertise that was not included in that which was brought together by the economics-focused original HIE study design.

As we have seen, there was uncertainty about which expertise this should be, and in the original design of the HIE the focus was on the identification of morbidities through a medical history and the expert-led screening of health conditions and habits (Kisch & Torrens, 1974) in much the same way Donabedian would have proposed a decade earlier. Moving beyond this approach represented another set of epistemic risks but, viewed from the perspective of methodological specialists that came to be involved in the study,

it also represented the "opportunity of a large social experiment [which] should be used as much as possible to improve the reliability and validity of health measures" (Ware, 1976, p. 11). This large social experiment gave the HIE methodologists room for manoeuvre to use the abundant financial resources and expertise available at RAND to realise what Anne Bowling (2017, p. 71) described as "one of the most profound applications of psychometric theory and methods in the field of health measurement".

Psychometrics is the set of methods and techniques originally used to study "intelligence", but which was later extended to other psychological characteristics, such as facets of personality or motivation. Historical studies on psychometrics have described in detail how, from its creation by Francis Galton at the end of the 19th century to its stabilisation as a routine procedure in organisations such as schools or workplaces between the two world wars, the discipline has established itself as a fundamental technology for managing modern populations (e.g. Carson, 2007). By making it possible to determine the relative distribution of individual attributes in a structured way, psychometrics facilitates the elaboration of what Bruno Latour and Steve Woogar (1986) defined as "inscriptions" that can be easily manipulated, readily compared, recombined, correlated, or subsumed. The power of inscriptions was indeed so important in consolidating psychometrics as an applied discipline that Kurt Danziger, in his historical survey of psychology, suggested that, at the turn of the 1940s, "researchers had such an exclusive reliance on the use of tests that they seemed to want to replace science with techniques" (1990, p. 165). In this process, Louis Thurstone's work on the "measurement of subjective qualities" between the late 1920s and the 1950s was of fundamental importance (Thurstone, 1959).

Thurstone, originally trained as a mechanical engineer, focused on measurement as a key operation to deploy knowledge of psychological processes. In a series of papers focusing on what he labelled the "law of comparative judgement" (Thurstone, 1927), he proposed that the magnitude of the subjective difference in relation to key psychological characteristics can be ascertained by the relative frequency with which stimuli can be discriminated. The method proposed that to measure something as "value" or a political attitude it was necessary to obtain a series of responses to questions on disputed issues, so as to ascertain how they qualify in relation to the attitude in question ("race" or divorce, for example). Given a sufficient number of discriminating comparative questions, it should be possible, Thurstone argued, to build a spread of opinions – a curve – on that issue and to locate, with some certainty, individuals' position within that range. The idea was impressively elegant as it advanced the practical proposition that by using simple, minimal,

qualitative human judgment – by asking simple questions like the ones my friend had been asked –, one could obtain an ordering of the preference of the objects – a quantitative scale – that could provide the reference point for public discussion and decision making on that issue.

To be exact, building such a scale was by no means easy: it required an enormous amount of work because a large number of judgements were required to enable experimenters to determine the reliability of the scale so generated. Thus what came to be known as the Thurstonian method of scale construction consisted of a series of procedures for generating, selecting and weighting statements "on the issue in question", then asking a sample of individuals ("judges") to agree/disagree with the resulting 20 statements, the final "score for each person [being] the average scale value of all the statements that he [*sic*] has indorsed" (Thurstone, 1928, p. 553). The resulting scales need then to be statistically analysed in terms of variance, and correlated to one another to test validity, sensitivity and reliability of the measures. But this labour-intensive process was worthwhile because it brought stability, solidity and universality to qualities that were until then considered fuzzy, deeply subjective things, such as attitudes. Using Alain Desrosières' powerful expression, the generation and validations of scales turned those vague objects into "things which hold together", enabling particular forms of "thinking about the social world and acting on it" (Desrosières, 1990, p. 215).

In this transformation lies, I argue, the powerful capacity of psychometric scaling procedures, developed by or responding to Thurstonian techniques, such as Likert's technique of summated ratings (Igo, 2007; Young, 2017). A personal opinion in relation to divorce, for example, is no longer evaluated in relation to a "conventional" moral standard but in relation to a statistical distribution of public attitudes, a "public" that is brought to bear in the same operation. By becoming transferrable, combinable, and routinised, such standard measurements become performative, as practices, norms, and organisational arrangements shift to take them into account. Through this process, attitudes, values or "experience" become tractable objects, supporting organisational procedures to identify and change patterns of behaviour. As a result, the embedding of such applied psychology techniques within modern, bureaucratic institutions in the interwar period, particularly in the US, facilitated and guided the adjustment of individuals to specific social and technological environments such as schools, family, work or retirement.

This transformative capacity also drove psychometricians' confidence in tackling unfamiliar objects such as health. In the same way that Thurstone had, in the late 1920s, asserted that "attitudes can be measured" in so far as they are "like practically all other measurable attributes in the nature of

an abstract continuum" (Thurstone, 1928, p. 533), psychometricians in the HIE aimed at investigating whether and how a single measurement device for health could be established "in order to place persons along the *health continuum*" (Ware, 1976, p. 3; emphasis added). The support provided by the US Department of Health, Education and Welfare, and by the research infrastructure of RAND itself, was key to keeping this empirical focus open, and allowing for what John Ware, the lead investigator for health measurement in the HIE, labelled an "omnibus approach" for the team to gather and analyse data on over 100 scale items gained mostly by self-administered questionnaires of the participants of the study over more than 5 years.

Drawing on the WHO 1948 definition of health as a means to adequately capture the positive aspects of health that, in their view, "mark[ed] the transition from a quantity to a quality of life measurement strategy" (Ware, 1976, p. 3; see also Larsen, 2022; Moreira, 2019), their model of health included discrete functional, mental and social components. Their further hypothesis was that rather than attempting to subsume the relationship between these components in one single health scale, drawing on the correlations between variables (above), this could be more adequately captured through the measurement of "general health perceptions" such as self-rated health. These, in their view, lay at the intersection between aspects of health as way to "take into account the cognitive processes underlying the evaluation" (Ware et al., 1980, p. 12) that participants made of the information they have about their health. This more "subjective" aspect of health provided construct validation on the impact of the other dimensions of health on the person (Davies & Ware, 1981), and promised to uncover the evaluative process whereby persons transform health information into what health economists might conceive as a utility (value). Imagining this evaluation as a "cognitive process" – a mental operation, or computation – made this aspect of health especially amenable to be investigated through psychometric methods, and provided a distinctive power to the battery proposed by the RAND investigators.

Taking the HIE further, some of the RAND investigators became involved in a new study – the Medical Outcomes Study – funded by charitable foundations directly invested in the problem of access and management of health care, such as the Kayser Foundation. One of the key objectives of the study was to find a compromise between the more precise, reliable and valid multi--item measures of health – such as the 108 item questionnaire used in the HIE – and the single-item scales of health often used in national surveys (Stewart et al., 1988). In this, their main objective was to make it possible to use such scales in a clinical environment, reducing respondent burden (time to fill in the survey and cognitive effort involved), and interpretative uncertainty.

These pragmatic concerns were of primary importance in bringing to bear the competitive, market-driven health care organisation that reformers such as Ellwood were proposing.

Indeed, Ellwood, in his Shattuck lecture on "Outcomes management: A technology of patient experience" suggested that researchers at the Medical Outcomes Study were at the forefront of "developing and testing increasingly practical instruments for measuring outcomes" (1988, p. 1552). His vision was that those instruments should become "a new universal language of hurting, functioning, working, interacting, and living" (Ellwood, 1988, p. 1552). Market rankings and preferences could hence rely on this "universal language", encoding a stable qualification of wellbeing and function across individuals and health care context. Through this process, "patient experience" could be made equivalent across conditions, specialities, and organisations through the complex operations of psychometric measurement, that is to say, from the enactment health as a psychological "evaluation" of information.

From this work, one of the most commonly used health outcomes measurement instruments would eventually emerge – the 36-Item Short-Form Health Survey – which remains a point of reference in PROMs questionnaires similar to the one my friend filled in before and after his knee operation (Cella et al., 2019). What for him were no more than "funny questions", was in effect part of an information gathering and processing system that enabled the creation of a "language" through which comparisons, rankings and choices could be made, supporting the operation of a competitive system in health care.

5. Conclusion

We return then to the initial question: how did experience become so central to the management of contemporary healthcare systems? An answer to this sociological question is proposed by my looking at the history of health data and statistics, starting by describing how until the end of the 20th century, health information obtained from the patient was considered an unreliable source of information to guide decision-making at system or organisational level. Next, I described how the measurement of subjective health came to be seen as an essential ingredient in the creation of competitive ways of organising healthcare. I analysed how this was underpinned by an operational research framing of healthcare, and the application of an engineering approach to the analysis and management of healthcare organisations and the construction of markets. This resulted in the creation of powerful models that calculate value through computational mechanisms, helping to establish efficiency or cost-effectiveness as the primary target of organisation strategy and policy-making.

I then analysed the epistemic and technological processes that were able to integrate subjective health into this political framework. I focused specifically on psychometric scales and their ability to create standards of "subjective qualities". Based on their technical expertise in transforming uncertain objects into measurable things, psychometric methodologists approached the problem of measuring health by transforming it into an abstract continuum, an object that can be captured using minimal information that can be collected, stored, combined and calculated. This computational enactment of health was perfectly suited to the political form of coordination proposed in the creation of competitive healthcare.

Together, and in interaction, these political and epistemic structures make it possible to measure health from the "patient's perspective". The focus, of course, is on implementing efficiency as a value in the functioning of the healthcare system. As has been suggested, this focus locates PROMs on the map of alternative social goods that can be sought in policies, such as equity or representation (Moreira, 2012). Recently, PROMs have also been promoted as a way of giving voice to patients' concerns within direct patient care. In the Danish Programme PRO initiative, for example, the main aim is to make the patient a "partner" in the healthcare system. However, this introduces pragmatic tensions and conflicts between the normative factors that underlie data collection and processing (Langstrup & Moreira, 2022). Reconciling efficiency with other health goals perhaps requires a change in the way we think about subjective, experiential data, and not just an increase in the amount or diversity of data collected, or a blind trust in artificial intelligence to identify that so called "universal language of living". Creating data systems where patients are driving agents of meaningful change is reliant upon understanding the social processes by which patient reported data is made meaningful and actionable. It is through this sociological understanding of how specific values become embedded in health data infrastructures, as demonstrated in this article, that we are able to act in the health care worlds in which we live.

Edited by Scott M. Culp

Conflicts of Interest Statement
The author declares that there are no conflicts of interest to disclose.

Funding
The author received no financial support for the research, authorship, and/or publication of this article.

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Received on 04.10.2024
Accepted for publication on 29.01.2025
https://doi.org/10.4000/146ci

O valor da experiência: uma sociologia histórica dos sistemas de saúde baseados em dados

Uma das principais expectativas associadas aos dados de saúde é a sua capacidade de tornar os sistemas de saúde mais reativos, adaptáveis ("inteligentes") e eficientes, integrando a informação gerada pelos pacientes na infraestrutura digital desses sistemas. Uma das principais tecnologias para concretizar essa expectativa são as "Medidas de resultados reportados pelos doentes" (PROM, na sigla em inglês). As PROM são métricas de como os pacientes se sentem e funcionam na sua própria perspetiva. Com um foco empírico na emergência dos PROM, este artigo baseia-se nos estudos sociais de quantificação para explorar como os "dados subjetivos" passaram a ser a força motriz da mudança nos sistemas de saúde contemporâneos. O artigo sugere que uma interação coprodutiva entre modelos de organização de cuidados de saúde centrados na eficiência e um enquadramento epistémico da saúde como um problema computacional é o âmago sociotécnico dos sistemas de cuidados de saúde baseados em dados.

Palavras-chave: cuidados de saúde; fontes de informação; psicometria; sistemas de saúde; tecnologias digitais.

La valeur de l'expérience : une sociologie historique des systèmes de santé fondés sur les données

L'une des principales attentes associées aux données de santé est leur capacité à rendre les systèmes de santé plus réactifs, adaptables (« intelligents ») et efficaces, en intégrant l'information générée par les patients dans l'infrastructure numérique de ces systèmes. L'une des technologies majeures pour concrétiser cette attente est celle des « Mesures des résultats rapportés par les patients » (PROM, selon l'acronyme en anglais). Les PROM sont des indicateurs de la manière dont les patients se sentent et fonctionnent selon leur propre perspective. Avec un focus empirique sur l'émergence des PROM, cet article s'appuie sur les études sociales de la quantification pour explorer comment les « données subjectives » sont devenues le moteur du changement dans les systèmes de santé contemporains. L'article suggère qu'une interaction coproduite entre des modèles d'organisation des soins centrés sur l'efficacité et un cadre épistémique de la santé comme problème computationnel constitue le cœur sociotechnique des systèmes de soins de santé fondés sur les données.

Mots-clés: psychométrie; soins de santé; sources d'information; systèmes de santé; technologies numériques.