Health - Conventions - Digitization

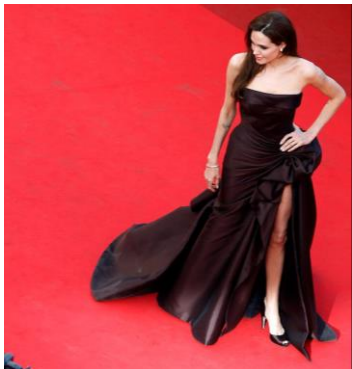The trap between market and civic solutions for health data

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We are producing day-to-day data traces…

➢ Expansion of calculation practices

➢ Change in the form of calculation – "calculating the social" (Vormbusch 2012)

➢ Development of modern observation formats (Heintz 2021)

We are living in uncertain times…

➢ Uncertainty about concepts such as – health, well-being, health data

➢ People react differently in the face of uncertainty

"I know that my children will never have to say, 'Mom died of ovarian cancer'... It's not possible to remove any risk, and the fact is that I remain vulnerable to cancer." (Zeit 2015)

Managing uncertainty through knowledge sharing…

„ The pandemic is an accelerator for many innovative ideas that will save lives, but without Corona would never have received such attention and would have required much more time in their implementation.

The willingness to share and discuss knowledge, experiences, even mistakes, has thankfully increased greatly in recent months."

Source: https://hih-2025.de/die-bereitschaft-wissen-zu-teilen-hat-zugenommen/

Professor Gernot Marx, Director of the Department of Operative Intensive Care Medicine and Intermediate Care at Aachen University Hospital, president of German Interdisciplinary Association for Intensive Care and Emergency Medicine (DIVI)..

So what is the problem? What is at risk?

Deleting Your Period Tracker Won't Protect You

Tweets telling women to do that went viral after Roe v. Wade was overturned, but experts say other digital data are more likely to reveal an illegal abortion.
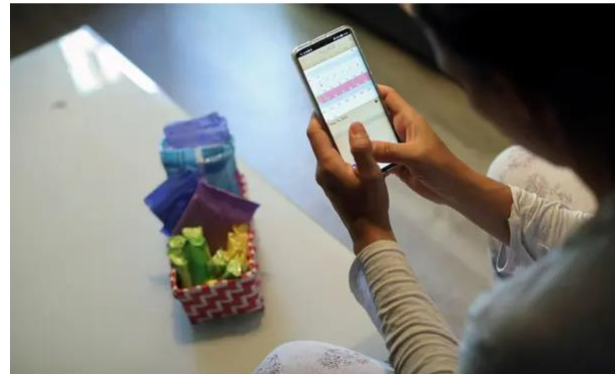
Give this article   663

How period tracking apps and data privacy fit into a post-Roe v. Wade climate

How private is your period-tracking app? Not very, study reveals

Research on more than 20 apps found that the majority collected large amounts of personal data and shared it with third parties

A study of more than 20 pregnancy and period tracking apps found only seven with safe user data and privacy practices. Photograph: Isabel Infantes/Reuters

Sources: https://www.npr.org/2022/05/10/1097482967/roe-v-wade-supreme-court-abortion-period-apps; https://www.nytimes.com/2022/06/30/technology/period-tracker-privacy-abortion.html; https://www.theguardian.com/world/2022/aug/17/pregnancy-period-tracking-apps-privacy

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How can ethical and moral issues be explored in the field of health (data)?

➢ Introduce new theoretical perspective to ask moral and ethical questions around health data differently.

➢ Focus on potential lines of conflict in the development, adoption, and diffusion of health data and technologies.

AGENDA

Short introduction to the Economics/Sociology of Conventions (EC/SC)

Conflicting conventions

Different data worlds

Conclusion

Studying practices of comparing, evaluating, categorizing, quantifying…

➢ Adopting the perspective of the Economics/Sociology of Conventions (EC/SC)

  ➢ Plurality of normative orders oriented towards a common good

  ➢ Heterogeneity of actors in the field of health (data)

  ➢ Plurality of normative orders as a challenge for coordination in health and data situations

The EC/SC considers data as…

➢ resulting from a complex interplay of conventions, actors, and technologies.

➢ based on conventions of measurement, interrelated with political and normative orders.

→ What counts as a relevant, acceptable, and fair process of quantification depends on social and political contexts.

→ Categories and concepts that inform statistical measurement are anchored in public and political discourses and are always linked to specific forms of defining and understanding uncertain and tension ridden situations.

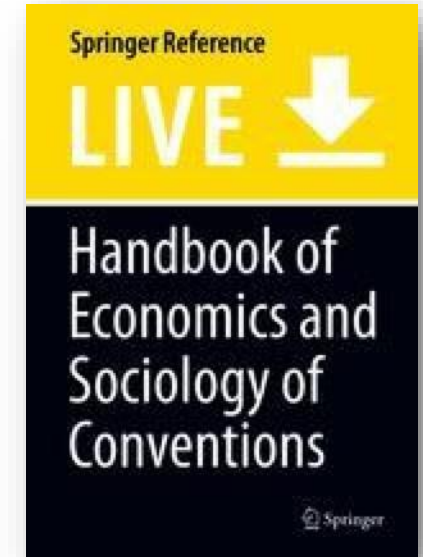„*Quantification means to introduce a convention and then to measure*.“ (Desrosières 2008: 10)

"Raw Data" is an Oxymoron (Gitleman 2013)

"…data is anything but "raw," that we shouldn't think of data as a natural resource but as a cultural one that needs to be generated, protected, and interpreted." (Gitleman 2013)

→ Data are "cooked" in the processes of their collection and use.

There is a plurality of (health) conventions and data worlds …

➢ Healthcare and health policy are strongly normative issues.

➢ EC/SC approach in healthcare highlights the omnipresence of values in the field of healthcare.

Soziologie der Konventionen

Valeska Cappel
Karolin Eva Kappler *Hrsg.*

Gesundheit – Konventionen – Digitalisierung

Eine politische Ökonomie der (digitalen) Transformationsprozesse von und um Gesundheit

OPEN ACCESS   Springer VS

Springer Reference
LIVE

Handbook of Economics and Sociology of Conventions

Springer

Sources:
Kappler K. (2022) E-Health and the Digitization of Health. In: Diaz Bone R., de Larquier G. (eds) Handbook of Economics and Sociology of Conventions. Springer, Cham. https://doi.org/10.1007/978-3-030-52130-1_42-1
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Plurality of conventions in healthcare

Order of worth	Higher common principle	Political Philosophy	Qualified good doctor (justification)	Disqualified doctor (critique)
Market	Competition, self interest	Smith	Market competitiveness Good price Value for money	Business Profit
Civic	General will, collective action	Rousseau	Welfare policy, Solidarity	Irresponsibility wasting resources
Industrial	Efficiency performance	Saint Simon	Expert Scientist Technical efficiency	Protocolization Standardization
Domestic	Proximity, neighborhood, tradition	Bossuet	Family doctor Regular physician	Personal dependencies Routinization
Opinion Fame	Popularity, audience, public recognition	Hobbes	Notoriety, celebrity (charismatic)	Expensive Not available
Inspired	Imagination, inspiration	Saint Augustin	Researcher Innovation Creativity	Publish or perish cutting off from reality

Adapted from Boltanski and Thévenot (2006), Batifoulier (2009) and Duchesne (2021)

Batifoulier 2022, p. 10

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Developments in French health policy (Batifoulier et al. 2021)

➤ erosion of solidarity

➤ central role of private health insurance for making the patient feel responsible.

  ➤ Commodification of healthcare
  ➤ Industrialization of healthcare

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Evidence-based medicine as an industrialization of healthcare (Da Silva 2022)

Spread of evidence-based medicine leads to…

→ Inspiration fades.

→ Source of legitimacy shifts from the health professional to the producers of standards.

→ Link of proximity fades.

→ Statistical analysis of large numbers gains importance. What counts is not that a treatment can work on a singular patient, but that it works on average.

Table 1 The two conventions of quality of medical work

	Inspired/Domestic Convention	Industrial Convention
Definition of disease	Qualitative break with normal state	Quantitative break with normal state
Subject of the activity	Patient/disease pair	Disease
Problem of healthcare to be solved	Singularity and complexity	Heterogeneity of practices
Subject of healthcare	Individual patient	Average patient
Specificity of knowledge	Based on experience	Based on standards
Professional's task	Adapt to the case	Assign cases
Definition of quality	Professional	Evidence based medicine
Professional ethics	Act on behalf of the patient	Act in accordance with standards
Institution of trust	Professional ethics	Certification agencies

Source: Adapted from Da Silva (2021: 101)

'Googlization of health': the growing role of tech companies in health and medical research (Sharon 2018)

Table 1. Moral repertoires present in GHR.

Repertoire	Common good	Values	Example	Health(care) as
Civic	Collective well-being	Inclusivity, solidarity, equality	'Becoming part of something bigger' (tech firm)	A human right
Market	Economic growth	Competition, consumer choice, profit	'Competition is awesome; it forces people to up their game' (director, health coalition)	A market good
Industrial	Increased efficiency	Functionality, expertise, optimization	'Transforming health and care through technology' (public health provider)	A (data) system to streamline
Project	Innovation and the network	Activity, experimentation, connection	'Healthcare is ripe for disruption' (practitioner)	A project requiring innovation
Vitality	Greater health	Good health, life, vitality	'Help them lead healthier lives' (executive, tech firm)	Intrinsically worthy

GHR: Googlization of health research.

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Four major health conventions/orders (Hanrieder/Montt Maray 2021)

Providing a moral grammar of global health

➢ order of survival interprets health as the collective defense against infectious threats

➢ order of production considers health as an investment in order to provide the maximum possible amount of health per dollar

➢ order of fairness demands global health to try to eliminate discrimination and inequity in access to healthcare

➢ order of spirit interprets health as "the integrity of the individual in the face of medical or economic intrusion" (Hanrieder and Montt Maray 2021).

Resulting lines of conflict and ethical perspectives

The institutionalization of contradictory common good orientations leads to permanent conflicts.

Which common good orientation legitimizes decisions and how could and would we decide if we could discuss the different normative logics presented in the table?

The evaluation and acceptance of digital applications is only understandable, when the plurality of this value logics is considered and consulted.

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From spaces of equivalence to data worlds

➢ Different conventions or orders of worth require unified data spaces, also called "spaces of equivalence" (Desrosières 1998)

➢ These different worlds of data production vary in their methodological cultures, their epistemic values, their quality criteria and their collective understanding of and relation to the "common good".

Data worlds (Diaz-Bone and Horwarth 2021)

Data world = data infrastructures (historically formed cognitive and organizational frameworks and resources that structure the production, distribution, and usage of statistical data) are anchored and embedded in social rationalities ("conventions") and for understanding how data are produced, analyzed, evaluated and, eventually, applied as an informational resource for collective action.

→ "Dispute" between statistics in relation to big data and commercial data production on the one hand and civil society actors on the other.

Official Statistics

Big Data

Civil Society

Table 2
Comparing data worlds

	Official statistics	Big data	Civic society
Quality conventions	Industrial convention, civic convention	Market convention, convention of inspiration, industrial convention	Civic convention, industrial convention, domestic and network convention
Infrastructure	State centered, financed by tax payers, but independent (on the basis of law)	Mainly owned by private companies, nontransparent and driven by private interest	Aligned and mobilized by different kinds of actors to generate data fit for public action; conceived as "owned" by the public and accessible for engaged civilians
Engagement for common good	Aiming in a long-time perspective for provision of neutral data, categories are related to interests and tasks of governments and ministries	Aiming in a real-time perspective for profit-generating knowledge and knowledge to influence consumer behavior	Aiming for middle-term knowledge related to social issues, conflicts and problems. and related to public action and empowering civic agencies (as social movements, NGOs)
Common good	Democratizing knowledge about societal "facts", enhance effectiveness and transparency of governance; enhancing voters' political knowledge by providing objective data about society	In most cases no engagement for a common good	Providing numerical representations which empower civic agencies and countervail governmental or entrepreneurial representation of "social facts"; bringing in civic participation into political decisions based on self-generated data
Mode of governing by numbers	As provider of numerical presentation for governmental institutions, media and public actors; in many countries official statistical institutes are independent from political intervention and have an institutional autonomy	Embedded mainly in economic decision making, marketing and consumer behavior analysis; governance effects are mainly invisible; big data infrastructures and big data are also mainly owned by private companies	In alliance with mass media and social media, civic data world mobilizes political support to influence governmental agencies, companies and populations.

Source: Diaz-Bone and Horwarth 2021

Table 3
Mutual critiques between different "data worlds"

	Official statistics	Big data	Civil society
Official statistics		Inefficient, state dependent, applying old-fashioned methodologies, too slow in data proceeding and publication	State centered and not providing data, relevant for contemporary social issues and civic concerns
Big data	Opaque procedures, not relying on methodological standards, not pursuing a common good		Profit-oriented and opaque, not linked to a common good, ignoring the imperative to justify measurement
Civil society	Methodological amateurs, particular and politically biased interests of social movements and specific parties	Naïve, because engaging for a common good and not for profit; limited by lack of access to data generating technologies	

Source: Diaz-Bone and Horwarth 2021

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➢ The development toward the datafication of health through the introduction of new data infrastructures produces an epistemic change (Ruckenstein and Schüll, 2017).

  ➢ Combination of new (individualized) data with old health data

  ➢ Promoting individualized, predictive, and preventive medicine

  ➢ Promoting standardization, industrialization, commodification, and monetarization

  ➢ Improving political control processes in the health system.

➢ Empowerment of patients, who are being made more and more responsible for their health, without considering their orientation toward the common good (Ruckenstein and Schüll, 2017).

➢ Conflicting data worlds - the public sector or official statistics and private (tech) companies play an increasingly important role (Diaz-Bone and Horvath, 2021).

Kappler HB

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Datafication of health leads to…

… health as a commodity

… the introduction of economic policy disguised as patients' empowerment to give them market-power and thus make the field of health accessible as a market through quantitative, predictive, and preventive aspects

… the institutional approach understanding health as a standard and the effort to quantify health outcomes.

→ We observe a shift from welfare-state-organizational principles to market-economic-organizational principles, particularly in European health systems.

To prevent data exploitation…

> **@emilymbender@dair-community.social on Mastodon**
> @emilymbender
>
> "We desperately need smart regulation around the collection and use of data, around automated decision systems, and around accountability for synthetic text and images," -- me to @TonyHoWasHere at @thedailybeast
>
> thedailybeast.com/senator-chris-...
>
> >>
>
> thedailybeast.com
> This Tweet Is Proof Lawmakers Aren't Ready for the AI Boom
> Connecticut Senator Chris Murphy should have kept this one in the drafts.

![katho - Katholische Hochschule Nordrhein-Westfalen / Catholic University of Applied Sciences](logo)

KÖLN

Thank you for your attention!

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