

PHIRI

Population Health Information
Research Infrastructure

Trust in health information systems

Nienke Schutte & Miriam Saso

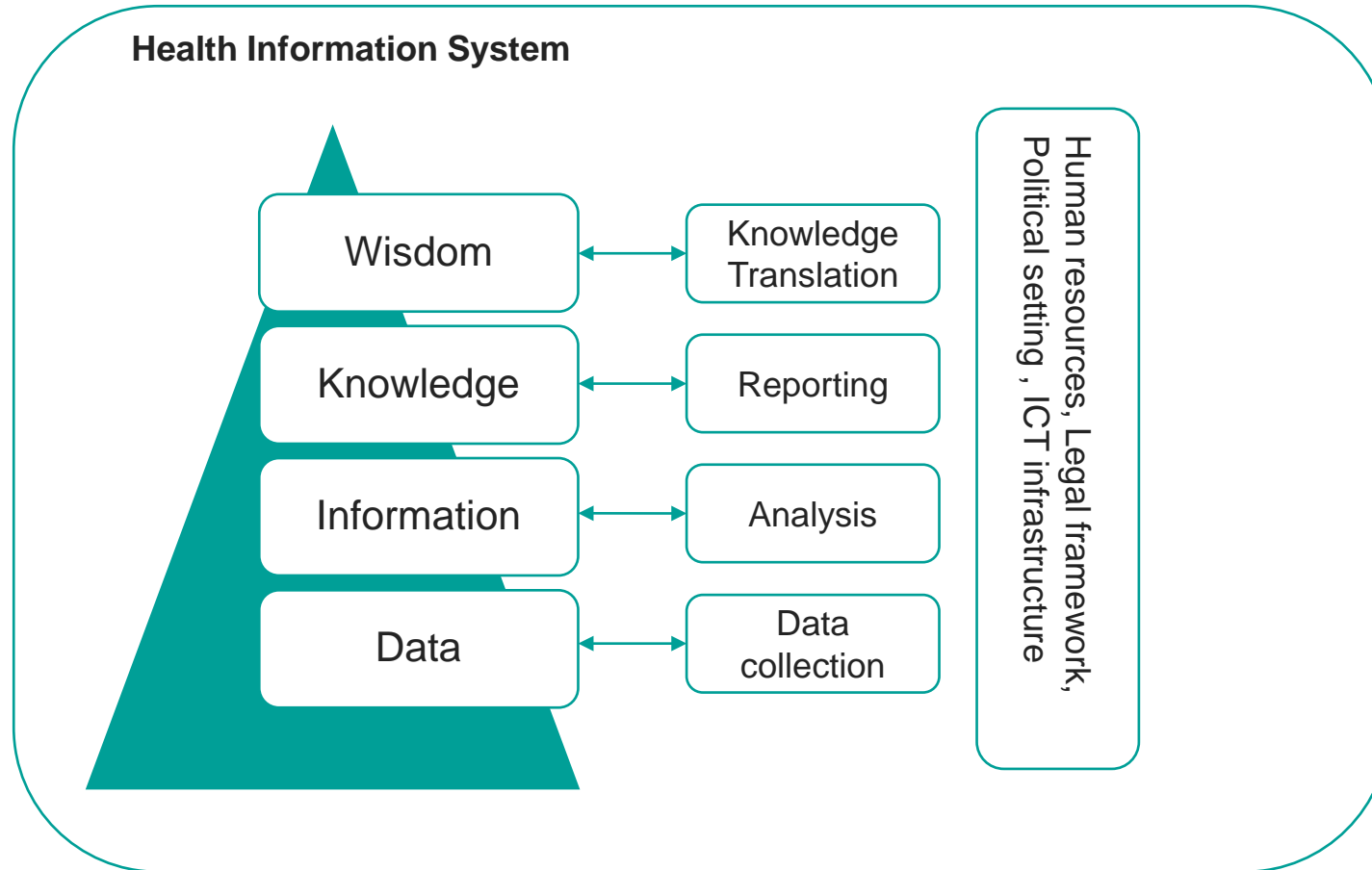
Rapid Exchange Forum

11/03/2024



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What is a health information system?

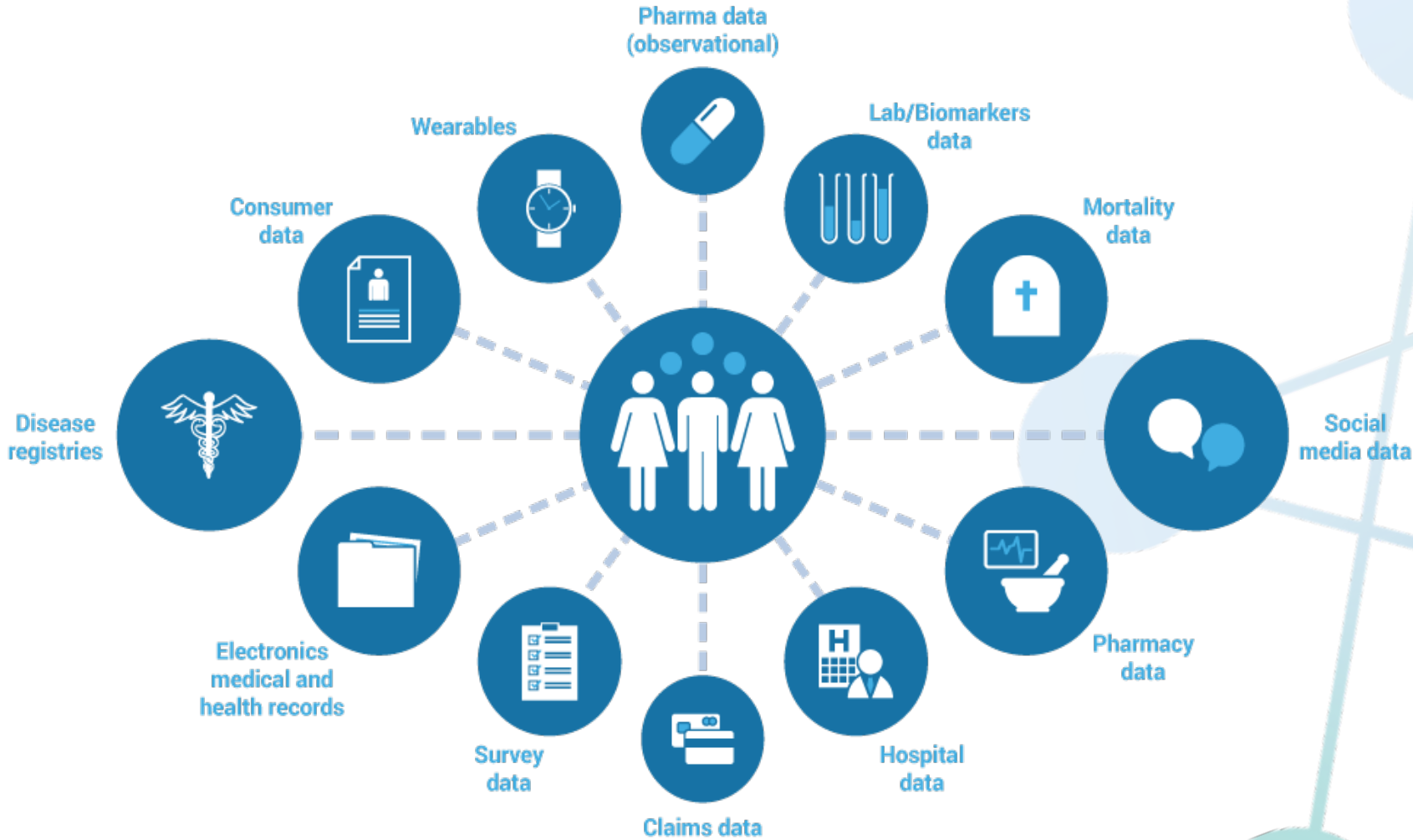


Bogaert (2023) – adapted from Verschuuren and van Oers (2019)

What is a health information system?

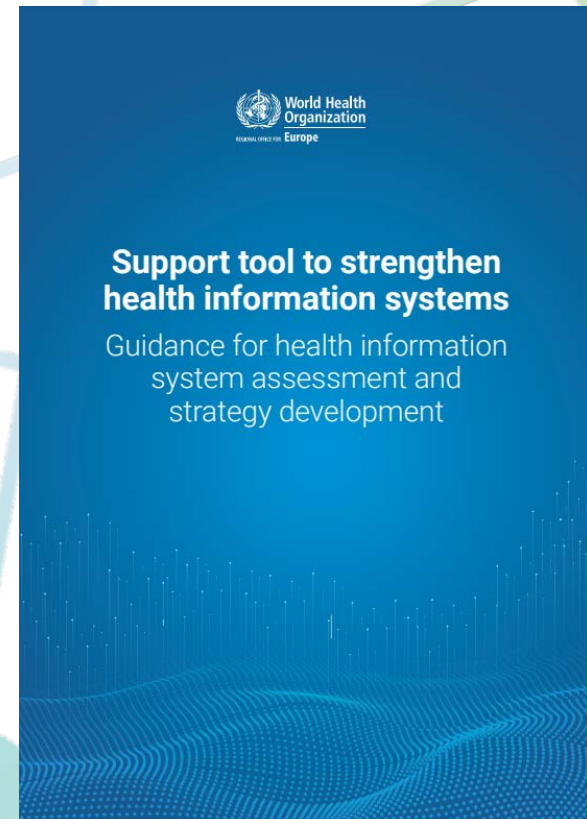
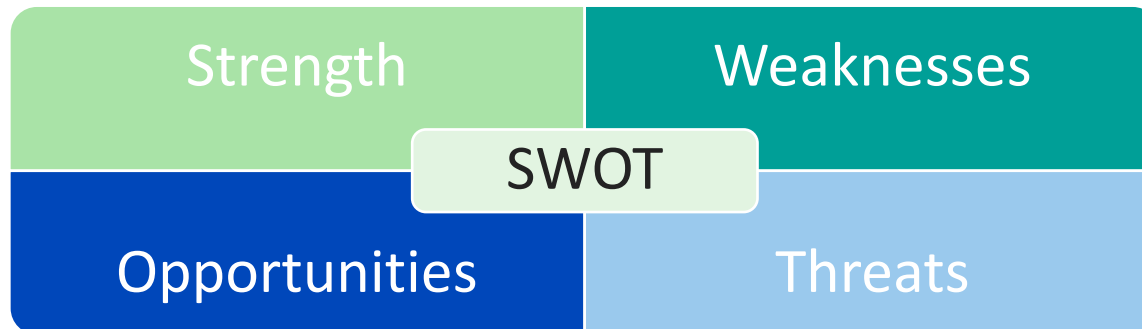
- Health information systems can contribute to
 - individual care
 - public health monitoring and surveillance
 - analysing health trends, develop foresight
 - fostering evidence-informed decision-making.
- Health information systems are **integral to generating knowledge for improving population health**
- European countries possess unique health information systems which are based on historical, cultural and governance contexts → Health information systems vary across Europe
- **European countries** hold primary responsibility for organising and delivering health services and medical care → **EU** level health policy therefore serves to complement national policies

Health data in a Health Information System



Tool to assess Health Information Systems

- Developed in 2015; revised in 2021 to reflect the current HIS context in the WHO European Region
- Two parts:
 1. Performing an assessment
 2. Development of an HIS strategy



Increasing trust in each part of the system

Wisdom

Trust that decision-making is evidence-informed

Knowledge

Trust that knowledge translation products target the right stakeholders

Information

Trust in robust methodologies and proper contextualization

Data

Trust that high quality data is reused in a GDPR compliant manner

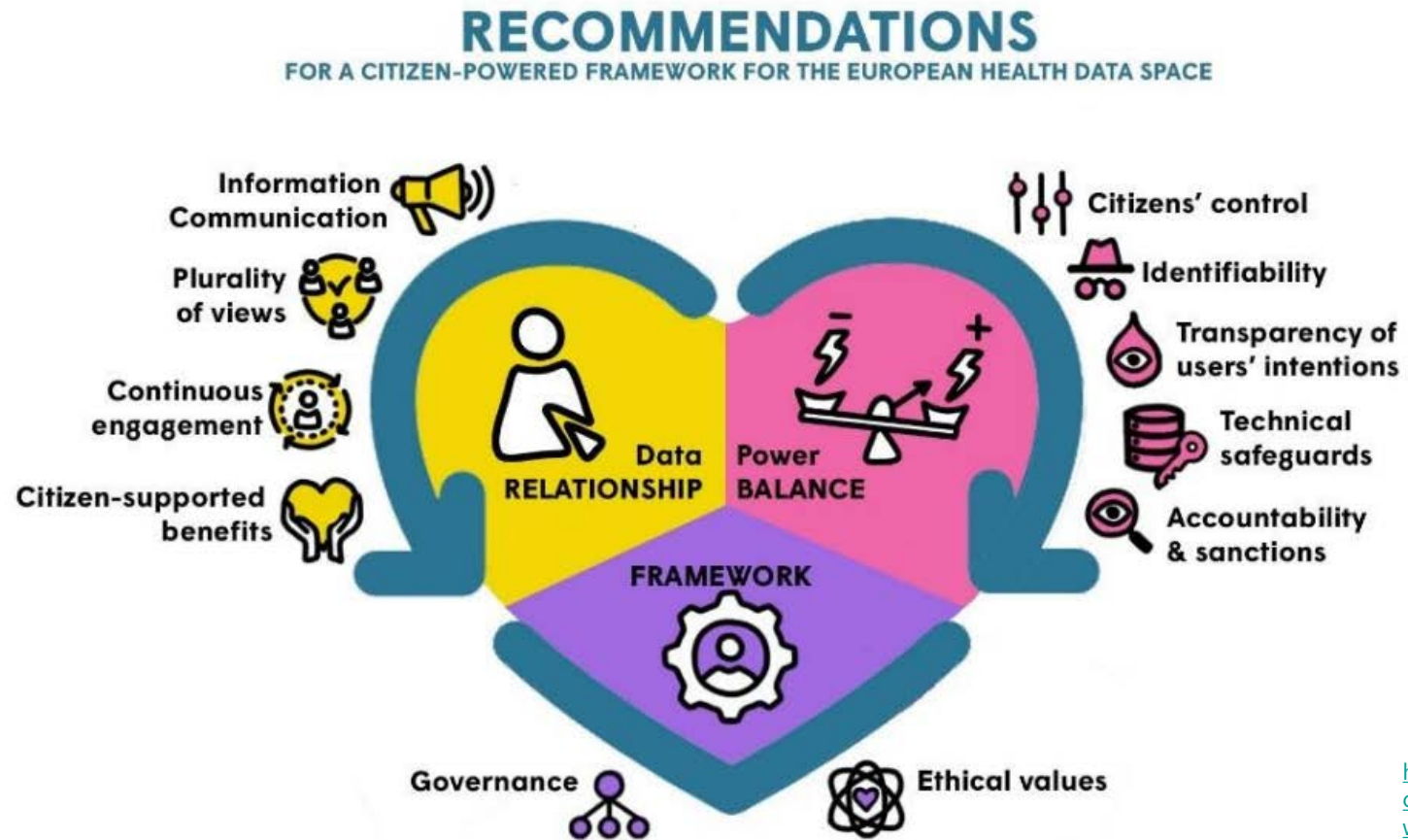
An example: consultation European citizens

Joint Action Towards the European Health Data Space (TEHDAS):

public consultation to collect citizens' perceptions on secondary use of health data

- Online consultation December 2021 - May 2022
- Mainly in France, Belgium and the UK
- Close to 6,000 suggestions were contributed

An example: public consultation European citizens



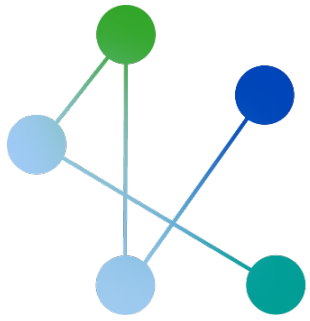
<https://tehdas.eu/results/tehdas-consultation-citizens-support-the-secondary-use-of-health-data-when-it-matches-their-ethical-values/>

An example: public consultation European citizens

Highlights:

- Data to be powerful!
 - Can be harnessed for good, but also to cause harm
 - Important to respect the rights of the people behind the data
- Citizens support health data reuse to support the common good (they mention: improve public health, healthcare, research and policy).
 - Conversely, many contributors were against reuse for commercial purpose
- There is a need to protect the privacy and to acknowledge the technological limits of data security
 - Participants divided on whether data should be anonymized or not
- Broad range of preferences given by citizens about what they want from their communication methods:
 - Varying from being informed on a f2f basis (by, for example, a GP) to remote and impersonal methods of communication including social media campaigns, web pages and annual reporting

<https://tehdas.eu/results/tehdas-consultation-citizens-support-the-secondary-use-of-health-data-when-it-matches-their-ethical-values/>



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Thank you!

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