The meta-governance of quality registries for public health

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Introduction

Healthcare-related planning and policy requires evidence, which in turn requires data. Generating sensitive, high-quality data is expensive. Given the constraints of routine or study-related data for quality monitoring, quality registries are commonly used. But when is it adequate, from a public health meta-governance point of view, to establish dedicated quality registries?

Description of the problem

Many countries have established public patient registries over time. The lack of a meta-governance framework complicates decision-making for establishing and funding dedicated quality registries. Simultaneously, legal advancements like the European Health Data Space may enhance the use of routine data in healthcare policy, potentially transforming both registry and meta-governance practices.

Results

We identified key meta-governance challenges, such as setting criteria for the creation, modification, or closure of registries, deciding on public funding and choosing between routine and specially collected data. We argue against using absolute thresholds like disease prevalence, advocating for a scorecard approach that evaluates epidemiologic reasoning, policy relevance, healthcare impact and factors like data availability and registry synergies.

Lessons

The EHDS will enable enhanced secondary data use, necessitating decisions on when to use routine versus specifically collected data. Decision-makers must consider sustainability, ethics, practicability and data linkability, while recognizing risks such as data quality limitations and potential bias from original data collection purposes.

Key messages

The necessity for quality registries varies by case, serving specific policy questions. Optimizing funds and avoiding arbitrary decisions require a strategy based on a meta-governance framework. With the introduction of EHDS, the focus may shift more toward data curation and quality control, making it critical to align registry efforts with the broader health information system.
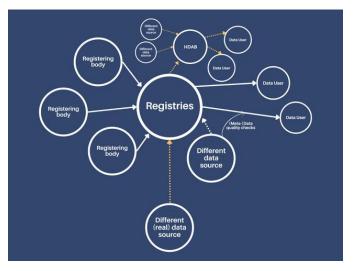

Figure 1: Data Flows in the Register Landscape (solid white lines represent current data flows, while dashed orange lines indicate potential data flows in the context of the European Health Data Space (EHDS))

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