CONFERENCE ABSTRACT

Integrating data for integrated care - a guideline for data linkage in health services research and beyond

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Introduction

The linkage of different types of data in health services research is still a young discipine and not yet widely used, not least due to a wide range of barriers spanning technical, methodological and legal issues. On the other hand, there is an increasing recognition of the added value of linked datasets in terms of generating more in-depth insights.

This can be seen in data linkage being mentioned explicitly in both national [1] and EU level [2] funding instruments, in major health studies such as the German NAKO longitudinal study [3] but also in policy initiatives [4, 5].

Notwithstanding these advances, there is no common set of guidelines to ensure that studies build on data linkage follow common, proven approaches ensuring consistency of methods and outcomes.

Against this background, a group of 23 German researchers from 19 oganisations convened in May 2018 and began the formulation of a common set of guidelines for data linkage (referred to as "good practice data linkage" in German). These guidelines have recently been published in Germany [6] but need now to be transferred to the wider European context.

Targeted population

The guidelines are primarily addressed to researchers using data linkage in health services research studies. But they are also of relevance for data managers in policy and service delivery contexts. The current version of the guidelines is to some extend tuned to the German setting and requires a transfer to the EU level, as outlined below.

Highlights

There is a total of seven guidelines, addressing: 1) research aims and questions, data sources, resources, 2) data infrastructure, data flow, 3) data security, 4) ethics, 5) key variables, linkage methods, 6) validity testing, quality assurance, and 7) long-term data use for yet undefined questions. The guidelines are in turn divided into 24 recommendations. The current version of the guidelines was sent to a number of German academic societies for feedback and consent before publication. It is conceived as a living document that will be updated regularly to reflect new developments.

Transferability

The core of the guidelines can be considered applicable beyond the German context already. But the recommendations in particular will require a dedicated translation process. This process is intended to be launched via the European Innovation Partnership on Active and Healthy Ageing and other bodies (yet to be determined) in the coming two years.

Conclusions

Guidelines for data linkage are needed to ensure good quality in research and other areas of application. A first set was created build on a broad German consensus and now needs to be transferred to the EU level.

References

[1] https://innovationsfonds.g-ba.de/

[2] https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/opportunities/topic-details/sc1-dth-12-2020

[3] https://nako.de/informationen-auf-englisch/

[4] http://www.oecd.org/els/soc/Workshop-Social-Data-16Oct2019.htm

[5] European Commission, Communication on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society [COM(2018) 233 final]. Brussels, 2018.

[6] March, S. et al.. Gute Praxis Datenlinkage (GPD) Gesundheitswesen 2019; 81: 636-650; DOI: 10.1055/a-0962-9933