8.N. Citizen and patient access to information and participation

Public participation in health data governance: a scoping review

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Background:
The sheer growth of the health data shared and traded globally holds great promise and menace to public health. Big health data can foster scientific advancements with potential to heal millions across the globe. However, inerasable digital footprints left by the use of apps and digital services challenge people's privacy and autonomy in (un)foreseeable ways that may cause them to stop sharing data. While many argue that public participation in data governance is a right, others view it as a means to increase data subjects' recruitment and amass large quantities of data. Little systematic knowledge exists, however, about the arguments for and impact of public participation on health data policy and management.
Methods:
A descriptive systematic scoping review was performed. Studies indexed in PubMed, WoS and PsycINFO published until March 2019 were searched. Only empirical, original, peer-reviewed studies reporting on public participation on health data governance were included. Eligibility and data extraction were performed by 3 researchers.
Results:
The 21 studies analyzed point to public participation in several governance dimensions including data access, linkage,

dissemination and policy. Involvement of (potential) data subjects in health data governance was substantiated by democratic arguments of legitimacy, transparency and accountability. However, the need to earn public support for data generation and use can override these arguments and foster utilitarian approaches that may transform participatory exercises into a technology of legitimation for a priori made decisions. Furthermore, although public participation in data governance can deliver instrumental benefits (e.g. participant-centred data policy), systematic assessment of participatory exercises' impact is lacking.

Conclusions:

Public participation in health data governance can promote public trust in and thrust for science. Further research is needed to fully assess its impact.

Key messages:

- Democratic-led participatory exercises in health data governance can foster public trust in science.
- Further research is needed to fully assess the impact of public participation in data governance.