Workshop: Democracy and Health

Mapping the Field & Developing Design Principles for Democratizing Healthcare Governance

World Congress of Bioethics 2026

Johannesburg, 09.07.2026

Institute of Biomedical Ethics and History of Medicine

Giovanni Spitale, PhD
Prof. Dr. Nikola Biller-Andorno
Anna Naishtat

CC BY NC SA

Introduction

Introduction | Search strategy | Search results | Assessment

Institute of Biomedical Ethics
and History of Medicine

Nikola Biller-Andorno

Prof. Dr. med. Dr. phil.
Director, Institute of Biomedical Ethics and History of Medicine

Giovanni Spitale

PhD
Postdoc, IBME

Anna Naishtat

Research Assistant, IBME

CC BY NC SA

Democracy and Health – why now?

In many countries, healthcare is entering a period of profound transformation

- AI and digitalisation are reshaping healthcare.
- Demographic change and rising costs are increasing pressure.
- Societal expectations continue to grow.
- Choices made now will shape health systems for decades.
- Authoritarian drift in many countries challenges role of democratic governance in healthcare and beyond.

→ This is a timely opportunity to ask how health systems should be governed.

Spitale and Naishtat 2025 - https://doi.org/10.17605/OSF.IO/JHDMP

Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

Democracy and Health – why now?

Many health systems already have democratic foundations

- They are shaped by law, public institutions, rights, professional standards, and political accountability.

- But many strategic choices remain highly technical, fragmented, or weakly visible to the public.

- In Switzerland, healthcare expenditure is around 12% of GDP and over CHF 90 billion annually.

- Citizens have a legitimate interest in how priorities are set and futures imagined.

→ Our focus is not on whether health systems are democratic or undemocratic, but on how democratic principles can be made more explicit, systematic, and useful.

Spitale and Naishtat 2025 - https://doi.org/10.17605/OSF.IO/JHDMP

Democracy and Health – why now?

An undertheorized opportunity

- Bioethics has helped transform the clinician–patient relationship.
- Much less attention has been paid to democratic agency at the level of health systems.
- "Democratic health governance" is increasingly invoked.
- But its meaning, scope, and design principles (such as inclusiveness, accountability, responsiveness, transparency, epistemic justice, ...) remain underdeveloped.

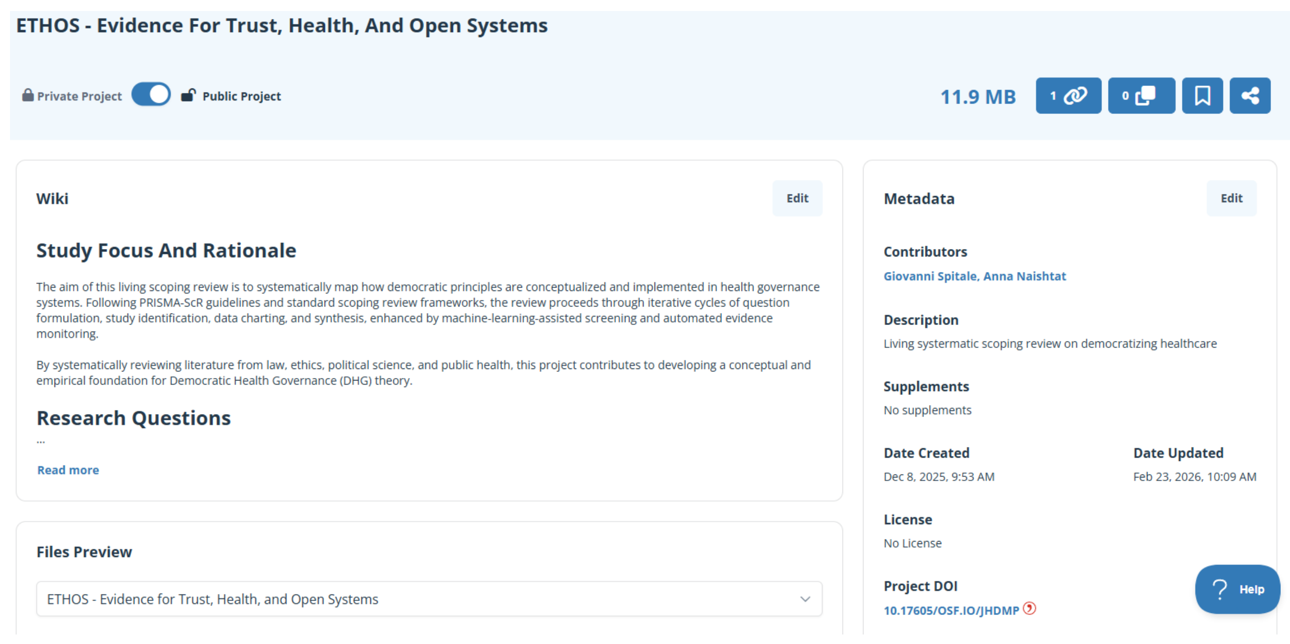
→ We may be missing opportunities to shape health-system transformation more deliberately and democratically.

Spitale and Naishtat 2025 - https://doi.org/10.17605/OSF.IO/JHDMP

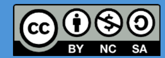
Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

Study focus and rationale

- Systematically map how democratic principles are conceptualized and implemented in health governance systems
- Through iterative cycles of question formulation, study identification, data charting, and synthesis, enhanced by ML-assisted screening and automated evidence monitoring
- This project contributes to developing a conceptual and empirical foundation for Democratic Health Governance (DHG) theory

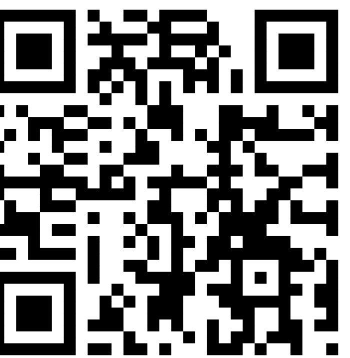


Spitale and Naishtat 2025 - https://doi.org/10.17605/OSF.IO/JHDMP



https://roompulse.borant.eu

Code: 67891



Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

CC BY NC SA

Search Strategy

Introduction | Search strategy | Search results | Assessment

Institute of Biomedical Ethics
and History of Medicine

Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

Query definitions

Evolution across versions:

- Core logic throughout: democracy/democratic governance terms AND health governance/policy terms
- Iterative broadening of the participation side: added “citizen engagement”, “public participation”, "community participation"
- Added MeSH controlled vocabulary to catch indexed literature not using exact search terms
- Added date range (2000-2025) and English-language filter
- Final query (V7) run across three databases: PubMed, Scopus, Web of Science

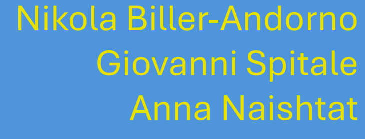
Final version:

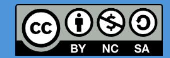
Three concept blocks combined with AND:

1. Democracy terms: “Democracy [MeSH] + free-text: “democracy”, “democratic”, "public participation", "citizen engagement", "community participation"
2. Health governance terms: “health governance”, “health system governance”, public health decision-making”
3. Filters: 2000-2025, English, title/abstract

→1191 results on PubMed. Adapted for Scopus (1973) and Web of Science (771). 2358 total after deduplication.

Spitale and Naishtat 2025 - https://doi.org/10.17605/OSF.IO/JHDMP





Search results

Introduction | Search strategy | Search results | Assessment

Institute of Biomedical Ethics
and History of Medicine

Prisma scheme

1501 papers screened for full-text assessment; 1/3 assessed

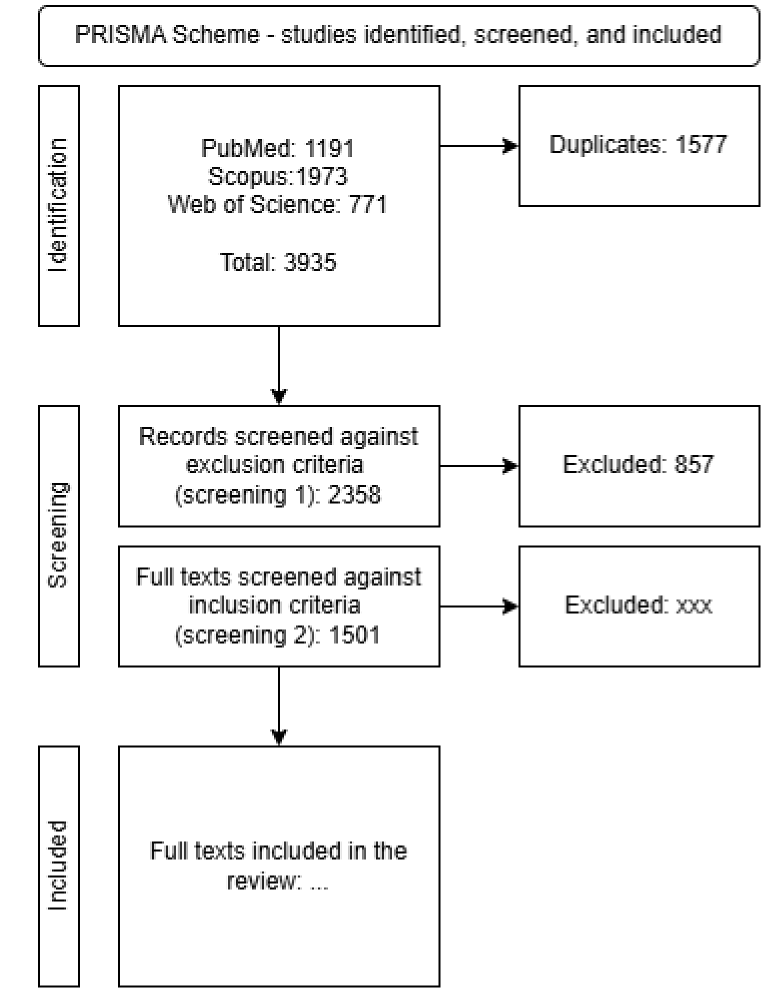
Abstracts screened against exclusion criteria:

- 2358

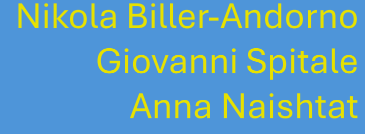
Abstracts excluded:

- 857

Status today:
347 included
62 excluded
534 to be screened



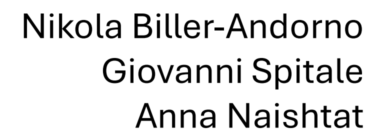
Spitale and Naishtat 2025 - https://doi.org/10.17605/OSF.IO/JHDMP



Assessment

Introduction | Search strategy | Search results | Assessment

Institute of Biomedical Ethics
and History of Medicine


Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

The corpus so far

Assessment based on 80 papers included after both screening rounds

Geography:

- Anglophone countries (Australia, Canada, UK, US) dominate together with other high-income countries – more than half of all papers
- Non-Western contexts under-represented

Study types:

- Empirical qualitative papers make up the majority
- Notable share of theoretical and viewpoint/commentary papers arguing *for* participation rather than analyzing how it works → risks skewing the evidence base toward justification

Governance level:

- Predominantly national-level

Spitale and Naishtat 2025 - https://doi.org/10.17605/OSF.IO/JHDMP

Two logics of participation

Invited participation:

- Deliberative forums, citizens' panels, community consultations
- Designed and convened by institutions
- Citizens participate on the institution's terms
- Most papers fall here

Claimed (extra-institutional) participation:

- Social movements, protests, electoral pressure, grassroots organizing
- Citizen-initiated, often in response to feeling excluded from formal channels
- Participation happens on the public's terms
- Smaller but distinct cluster

Abimbola (2019) describes collective governance as emerging either "as a bottom-up phenomenon with a coalition of users coming together on their own" or being "constituted top-down as an intervention."

These two logics carry different assumptions about power, legitimacy, and who initiates democratic engagement.

Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

CC BY NC SA

Tokenism & superficial participation

- Most consistent risk flagged across the literature
- Participation exists in form but not in substance
- Papers repeatedly describe governance structures where citizens are formally included but have little real power over decisions
- Citizen recommendations frequently non-binding: participation provides input but rarely binding direction

Barrett et al. (2013), quoting Carcasson: “The public is invited to respond to decisions that have already been made or perhaps to express their opinion right before the decision is made. At that point, the role of the public is reduced … to an extremely limited scope of potential action.

Deng & Wu (2010), a participant said: “I felt that we were invited only to endorse their conclusion. The agenda had been set before the discussion.”

“The population remains at the margin of the decision process […], unable to contribute to the transformation of the social reality.” (Campos, 2017)

Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

CC BY NC SA

Who gets to participate? Access, power, and context

Access barriers: Financial costs, time demands, lack of compensation

- Disproportionately affects vulnerable populations: "For some vulnerable women, [...] lack of education deterred them from attending meetings. These women were concerned about their lack of English language skills or the usefulness of their contributions compared to those with higher education" (Razavi et al., 2020)
- Australian deliberative forum (Molster et al., 2011) compensated participants $100 AUD/day for four days → difficult in resource-constrained settings

"Elite" participation: Better-organized, more educated groups dominate

- Social hierarchies shape who gets heard: in Nepal, "local elites are [...] 'capturing' the process and excluding lower caste people and women," with only 8% of committee members female (George et al., 2015)

Context-dependence: Participatory models may not transfer across settings

- "Recruitment of participants would be much easier in countries where serving as a juror in court has been a norm, but in Thailand — where there is no jury system and people were not familiar with the concept — the decision to participate was often made reluctantly and cautiously." (Chuengsatiansup et al., 2019)
- LMICs face additional structural obstacles: low awareness, weak institutional capacity, resource constraints

Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

CC BY NC SA

Absence of technology

- Digital tools as participation mechanisms are almost entirely absent from the literature
- Vast majority of mechanisms are face-to-face and analogue
- “There is a limited use of digital tools in ensuring that community members irrespective of place and time do have consistent access to health information” (Assan et al., 2019)
- Where technology does appear: social media for mobilization, not structured participation

Why it matters:

- The field has not seriously engaged with how technology mediates democratic participation in health governance
- Significant gap for DHG theory?

Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

CC BY NC SA

The risk of populism in participatory governance

The risk:

- Giving the public more say in health policy assumes the public will make fair, evidence-based decisions
- This is not guaranteed: More participation does not automatically mean more just or equitable outcomes
- Democratic health governance must balance citizen voice with rights-based and ethical constraints

Gap in the literature

- This tension is unaddressed in the assessed literature (so far)
- Papers advocating for more participation don't engage with the risk that participation could produce discriminatory or harmful outcomes

A critical gap for DHG theory: Under what conditions should citizen preferences be constrained?

Institute of Biomedical Ethics and History of Medicine

Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

CC BY NC SA

Theory vs. evidence

What theoretical papers claim:

- Participation improves legitimacy, accountability, social justice
- Outcomes stated as expected/desirable results (optimistic)
- Heavy on advocacy; argues for participation rather than analyzing it
- “[…] participation in health programmes has been based on a number of unproven assumptions. […] The money which the [World] Bank invested in participation, over $85 billion over the period 2003-2013, was ‘arguably still driven by ideology and optimism more than by systematic analysis, either theoretical or empirical’” (Rifkin, 2018)

What empirical papers find:

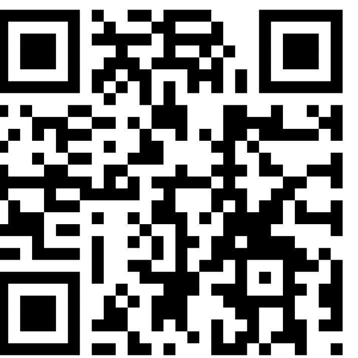
- Mixed and conditional picture
- Positive outcomes do occur: policy change, improved legitimacy, community empowerment
- But largely conditional: well-resourced processes, explicit strong institutional commitment, or extra-institutional pressure
- Several cases: recommendations non-binding or outcomes coincidental (policy was already underway)
- "Despite this evidence of policy update, in truth many of the processes were already underway before the jury's recommendations were released.” (Ritter & McLauchlan, 2023)

Suggests the field may be ahead of its evidence base and raises the question of under what conditions participation actually influences governance rather than legitimizing decisions already made.

CC BY NC SA

https://roompulse.borant.eu

Code: 67891



Institute of Biomedical Ethics
and History of Medicine

Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

CC BY NC SA

References

- Abimbola 2019, "Beyond positive a priori bias: Reframing community engagement in LMICs" – DOI: 10.1093/heapro/daz023
- Assan et al. 2019, "Challenges to achieving universal health coverage through community-based health planning and services delivery approach: a qualitative study in Ghana" – DOI: 10.1136/bmjopen-2018-024845
- Barrett et al. 2013, "Assessing the Policy Impacts of Deliberative Civic Engagement" – DOI: https://doi.org/10.1093/acprof:oso/9780199899265.001.0001
- Campos 2017, "Citizen participation and the health policies of Unasur" – DOI: 10.1590/1413-81232017227.03212017
- Chuengsatiansup et al. 2019, "Citizens' Jury and Elder Care: Public Participation and Deliberation in Long-Term Care Policy in Thailand" – DOI: 10.1080/08959420.2018.1442110
- Deng & Wu 2010, "An innovative participatory method for newly democratic societies" – DOI: 10.1016/j.socscimed.2009.10.053
- George et al. 2015, "Anchoring contextual analysis in health policy and systems research" – DOI: 10.1016/j.socscimed.2015.03.049
- Molster et al. 2011, "Blueprint for a deliberative public forum on biobanking policy" – DOI: 10.1111/j.1369-7625.2011.00701.x
- Razavi et al. 2020, "Barriers to Equitable Public Participation in Health-System Priority Setting Within the Context of Decentralization: The Case of Vulnerable Women in a Ugandan District" – DOI: 10.34172/ijhpm.2020.256
- Rifkin 2018, "Alma Ata after 40 years" – DOI: 10.1136/bmjgh-2018-001188
- Ritter & McLauchlan 2023, "Citizens' juries and their role in improved alcohol policy" – DOI: 10.1080/09687637.2022.2050185

University of Zurich[UZH]
Institute of Biomedical Ethics and History of Medicine

Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat

CC BY NC SA

Let’s keep talking

Download the slides

biller-andorno@ibme.uzh.ch
giovanni.spitale@ibme.uzh.ch
anna.naishtat@ibme.uzh.ch

Some guiding questions for further discussion

Questions for discussion

- What should distinguish democratic health governance from good governance more generally?

- How can participation inform health governance without becoming tokenistic?

Spitale and Naishtat 2025 - https://doi.org/10.17605/OSF.IO/JHDMP

Institute of Biomedical Ethics
and History of Medicine

Nikola Biller-Andorno
Giovanni Spitale
Anna Naishtat