When evidence meets real-world limitations

Katharina Kieslich
PPRI Secretariat, Pharmacoeconomics Department
Austrian National Public Health Institute (Gesundheit Österreich GmbH / GÖG)

PPRI Network Meeting Lisbon
9 April 2025

1. When evidence meets real-world limitations
2. Evidence-based policymaking: Why is it so difficult?
3. Reflections & questions

When evidence meets real-world limitations

- In pricing & reimbursement we rely on scientific evidence, technical expertise and (ideally) good-quality data

Yet, evidence frequently meets real-world limitations such as…

…What are some of the real-world limitations of evidence that you come across in your daily work?

When evidence meets real-world limitations

In pricing & reimbursement we rely on scientific evidence, technical expertise and (ideally) good-quality data

Yet, evidence frequently meets real-world limitations such as…

- Uncertainty
- Unexpected crises, knowledge not yet available
- Lengthy timelines for assessment of evidence
- Unexpected or unpopular results
- Difficulty of communicating complex information to policymakers/public
- Unfavourable policy/political environment
- Role of the media
- Financial constraints
- Judicialization of decisions
- Public opinion
- Misinterpretation or misrepresentation
- Mistrust of experts and science

This is what you are up against!
Not just scientific limitations!

When evidence meets real-world limitations

Trump administration to cut billions from biomedical research funding

9 February 2025

Share Save

Madeline Halpert
BBC News

Britain has had enough of experts, says Gove

Brexit campaigner offers to have disputed EU contribution figure audited

Justice Secretary Michael Gove takes part in a live Sky News Q&A on Brexit © PA

Henry Mance, Political correspondent

Published JUN 3 2016

544

POLITICAL RESEARCH EXCHANGE
PRX

Political Research Exchange
An ECPR Journal

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/prxx20

Populist attitudes towards politics and science: how do they differ?

Jakob-Moritz Eberl, Robert A. Huber, Niels G. Mede & Esther Greussing

To cite this article: Jakob-Moritz Eberl, Robert A. Huber, Niels G. Mede & Esther Greussing (2023) Populist attitudes towards politics and science: how do they differ?, Political Research Exchange, 5:1, 2159847, DOI: 10.1080/2474736X.2022.2159847

To link to this article: https://doi.org/10.1080/2474736X.2022.2159847

When (non-)evidence meets real-world limitations

"Nikolausurteil" Germany (Federal Constitutional Court 06.12.2005, Az.: 1 BvR 347/98)

- Reimbursement of costs for a therapy treating Duchen
- Doctors treated a young patient with
  homeopathic drugs + other "conven
  treatment
- Sickness insuranc
  insufficien
- Federal Con
  life and duty
- The **payer** (in
  the treatmen

Raises difficult questions about the judicialization of medicine and the right to health!

When evidence meets real-world expectations

Example – England (2017)

- Campaign against the closure of the A&E facilities and maternity wards in a local hospital in Southeast London (Lewisham)
- Department of Health argued that this would create efficiency savings and higher quality care in more specialised hospitals in neighbouring London boroughs
- Campaign received national, not just local support
- Appeals court rules in favour of the „Save Lewisham Hospital" campaign

Thousands of people from around the country took part in a demonstration and rally in Lewisham on 26 January 2013 in protest against Government proposals to close vital services at the hospital. (Photo by Peter Macdiarmid/Getty Images)

Example – Austria (2023/2024)

- Opposition against the establishment of a Federal Appraisal Board for highly-specialised, high-priced medicines → E.g. an 'attack' on cancer patient care


INLAND

Mediziner warnt vor "Anschlag auf Versorgung der Krebspatienten"

Kritik am Bewertungsboard für teure Arzneien reißt nicht ab. Patientenvertreter fühlen sich übergangen. Ministerium kalmiert

Von Josef Gebhard 02.12.23, 06:00

Evidence-based policymaking: Why is it so difficult?

Distinction between evidence-based policymaking and evidence-based decision-making?

Rationales for evidence-based policymaking

- Decision-making more rational = better?
- De-politicisation of difficult decisions → Delegation of governmental decisions to others, e.g. quasi-governmental scientific or other bodies
- Basing decisions on 'what works', seeking input from experts
- More support from the public

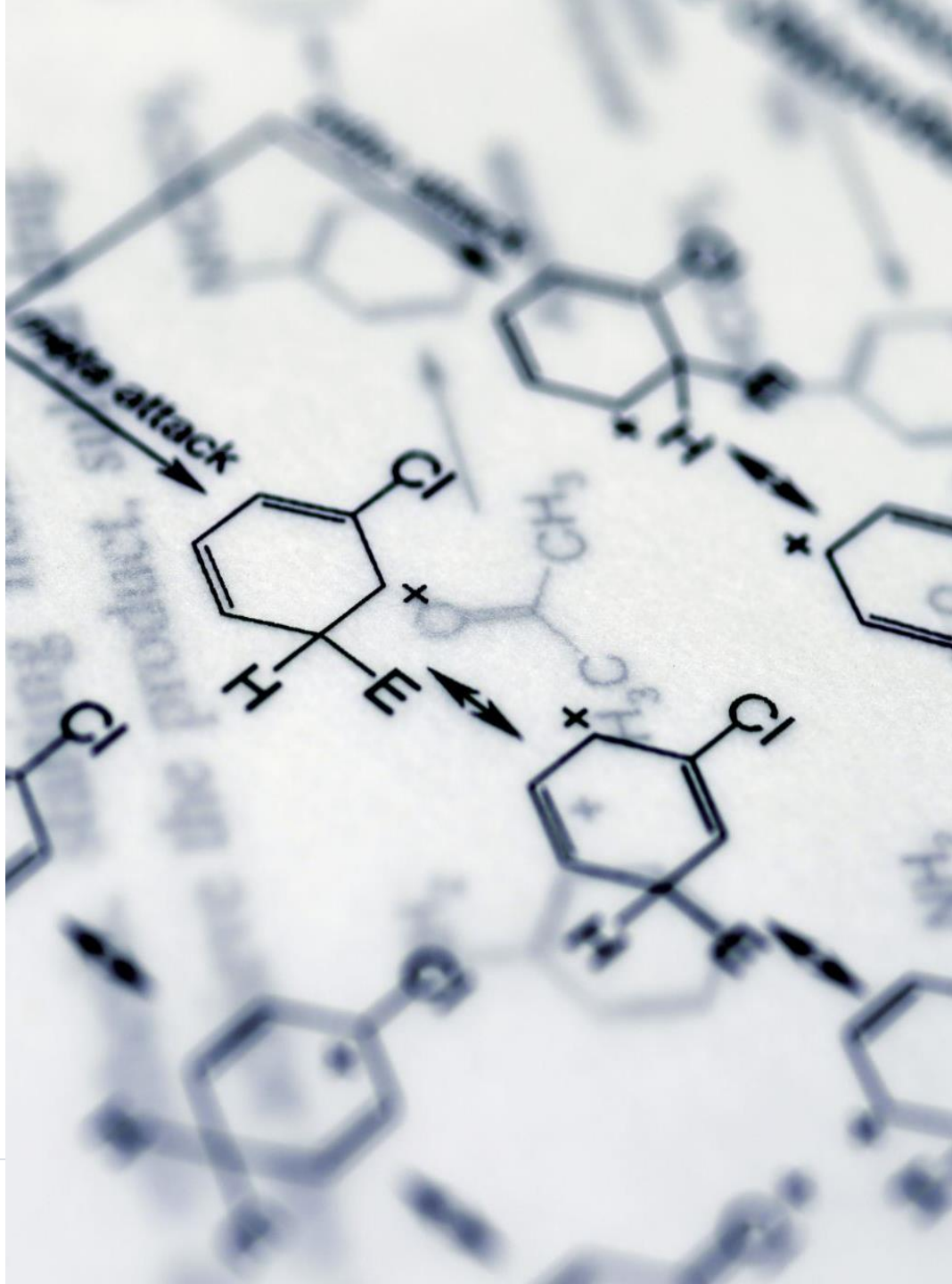
Risks

- Politicisation of evidence (example US and British intervention in Iraq in 2003)
- Manipulation of evidence; selective use for political purposes
- Intransparency: Interests, groups and money behind the evidence?

Evidence-based policymaking: Why is it so difficult?

According to Weiss et al. (2008) there are:

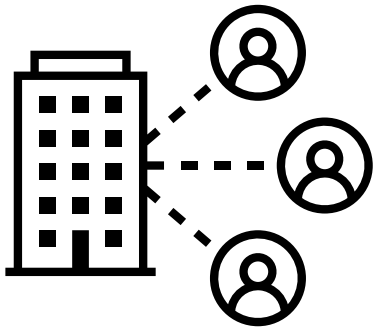
- Shortcomings on the **research side** (too much or too little evidence; not conclusive; not addressing the right questions; too complex; too slow) → Scientific uncertainty
- Shortcomings on the **policymaking side** (not interested; opportunistic; goals not ideologically aligned)
- Insufficient links between policymakers, researchers, professional associations and bureaucrats → Different frames and understandings of problems lead to complicated **(mis)communication**



Evidence-based decision-making: Why is it so difficult?

Many institutions such as HTA organisations were established as institutions to whom certain (difficult) policy decisions (which medicines to pay for?) were delegated → **Evidence-based decision-making enshrined** in institutions

- Institution with a direct decision-making mandate
- Institution with mandate to make recommendations / input into the decision-making process (i.e. other people or organisations make the final decisions)



How and why is this distinction relevant when it comes to de-funding scenarios?

Evidence-based decision-making: Why is it so difficult?

Challenges for institutions in pricing and reimbursement

The "cost or clinically effective but unaffordable" challenge
→ Even when evidence is favourable, a medicine might not be reimbursed, or access might be restricted due to funding challenges

The "Don't take anything away from patients" challenge ("Not-out-of-my-backyard")
→ Even when evidence is favourable, it is difficult to stop funding a treatment or medicine because patients, doctors and others do not like change

Can lead to **implicit or arbitrary forms of rationing or access restrictions**, which can have negative **consequences on health equity**

Reflections

- (Scientific) **evidence alone is rarely enough** to convince the public, patients or policymakers that something should be de-funded
- **Evidence is always contextualised** (Science & Technology studies show that evidence is rarely 'neutral' but involved value judgements with regard to methods, hierarchies of evidence etc.)
- **De-funding should not happen arbitrarily**, but be based on **transparent decision-making processes and consider the ethics of setting priorities in health** (effects on different patient populations, socio-economic groups, regional spread of the effects etc.)
  - More or better patient and public involvement/participation
  - Open and honest societal conversation about priorities in healthcare
  - More or better cross-national and regional cooperation such as EU-HTA regulation (Joint Clinical Assessments)

Reflections

Questions

- Do we need to adapt our understanding of evidence in light of challenges?
- How do we communicate the need and evidence for stopping something?
- How do we build (institutional) resilience and expertise to deal with opposition?
- How do we build capacity to build alliances for necessary changes or tough decisions?

How can the PPRI network help you navigate these challenges?

Thank you for your attention

Katharina Kieslich

PPRI Secretariat

Pharmaceutical Pricing and Reimbursement Information (PPRI)

katharina.kieslich@goeg.at

ppri@goeg.at

Gesundheit Österreich GmbH (GÖG / Austrian National Public Health Institute)

Stubenring 6, 1010 Wien

goeg.at | ppri.goeg.at