Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Real-World Data: How To Improve Data Collection and Use in Irish Healthcare

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Context and perspective

What is health technology assessment?

Health technology assessment is:

> “a multidisciplinary process that summarises information about the medical, social, economic and ethical issues related to the use of a health technology in a systematic, transparent, unbiased, robust manner.”

Its aim is to inform the formulation of safe, effective, health policies that are patient focused and seek to achieve best value.

What is a health technology?

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We can evaluate anything that involves a change to the delivery of health services, but we generally think of a health technology as:

- drugs, including vaccines
- medical devices, including equipment such as surgical robots and implantable devices
- diagnostic tests, for example, tests to detect colorectal cancer
- surgical procedures, such as coronary artery bypass
- public health interventions, for example, a colorectal cancer screening programme
- support systems, such as electronic patient records
- organisational features, for example, the establishment of centres of excellence.

What does a HTA involve?

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A HTA can address all or some of the following domains:

- Health problem and current use of technology (AKA burden of disease).
- Description and technical characteristics
- Clinical effectiveness & safety
- Costs and economic evaluation
- Organisational aspects
- Ethical analysis
- Social aspects
- Legal aspects

Real-world data

Best available evidence versus *available best evidence*

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Best available evidence

Look at what is available and determine the validity and applicability to the research question. Select the data that is most relevant and appropriate in the context, with the caveat that if no usable data are available, we can't answer the question.

Available best evidence

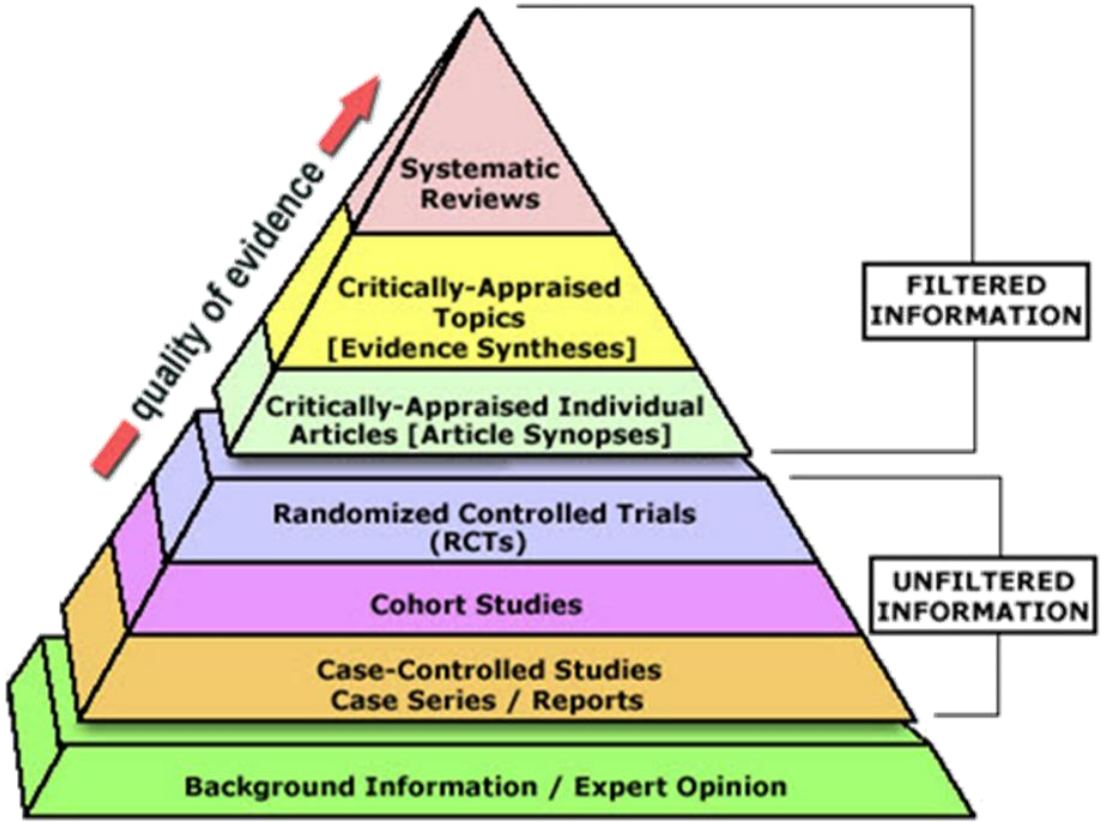
Set out the minimum standard of evidence that is considered acceptable and do not consider anything of a 'lower standard'. You may say, for example, that anything less than RCT evidence is unacceptable.

What do we mean by real world data?

Real-world data are ostensibly observational data as distinct from data collected in an experimental setting, such as a randomised controlled trial.

That really encompasses a lot of data, although the traditional hierarchy of evidence might leave you thinking otherwise because the focus is very much on RCT or pooled RCT evidence.

The reality for HTA of non-pharmaceuticals is that we are heavily reliant on observational evidence.



What question are we addressing?

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It’s worth noting that a HTA is often trying to address a variety of questions, including:

- Can the intervention work?
- Does the intervention work in practice?
- Is it an efficient use of resources?
- Is there anything else we need to worry about?

Using data in practice

HTA is data-hungry

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A HTA is very greedy for data at every turn. We typically do the following:

- Analyse the epidemiology of the disease (incidence, prevalence, morbidity and mortality)
- Conduct a systematic review of clinical effectiveness and safety
- Construct an economic model with parameters for
  - Costs
  - Epidemiology
  - Clinical effectiveness
- Analyse the logistical issues associated with delivering the intervention

Where do we run into problems?

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Everywhere.

Where do we run into problems?

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Most typically:

- Issues with estimating disease incidence and prevalence, which are essential to determining the target population for an intervention.
- Very limited data for primary care.
- Health-related quality of life data of questionable applicability.
- Data for specific patient subgroups.
- Few comprehensive datasets with national coverage or that are nationally representative.
- Challenges in accessing the national datasets that do exist.
- Inability to link across datasets.

Why do we run into these problems?

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Remember:

- Most data are collected for billing purposes. The content and coverage reflect the flow of money and minimum set of information needed to pay for services.
- In general, data collection is expensive and should only be to carried out inform or support the delivery of care. Superfluous data collection on the off-chance it might one day be useful for research is poor practice.
- Data linkage is fraught with problems and subject to tight control for good reasons.
- Access to sensitive personal health data needs to be very tightly managed to ensure no abuse or misuse.
- We don’t have a unique patient identifier in Ireland.

How do we deal with these problems?

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We do our best to wrangle usable data:

- We generally resort to combining data from a wide variety of sources, coupling Irish with international data, and mixing trial and observational data.
- We rely on expert opinion to help us understand how the data may fail to reflect the lived reality for patients and providers.
- That approach is susceptible to all sorts of issues, like combining incompatible data or failing to recognise important correlations, so we use extensive sensitivity and scenario analyses to figure out the implications of biased data.

How do we move forward?

Can we do better?

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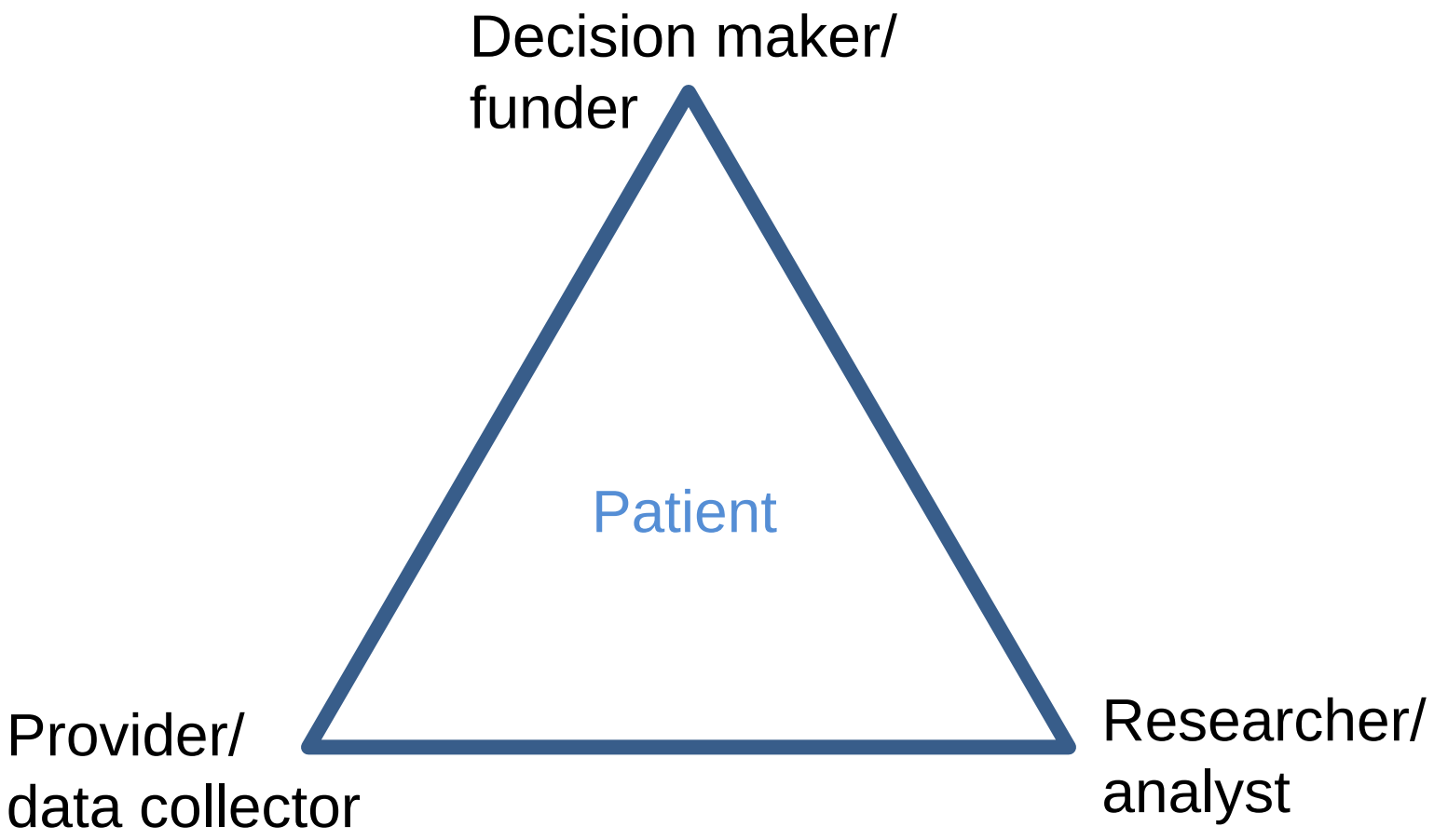
The last two years of the COVID epidemic have shown us that better is possible:

- Key datasets were brought together and housed in a data hub managed by the Central Statistics Office.
- The data were accessible remotely but could not be downloaded.
- Analysis outputs were reviewed for statistical disclosure control before being provided to researchers.
- An encrypted unique identifier was incorporated to allow linkage of data from testing, contact tracing, and hospital care.
- New data were uploaded daily, allowing for near real-time analysis of trends and activity.

Who are the stakeholders?



What can we do?

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We need better collaboration between providers, researchers, patients and decision makers:

- There are many instances where data are being collected, but often limited to what is needed directly for billing and service provision. In some cases, a small amount of additional data may vastly increase the richness and utility of the dataset overall.
- Distinguish between *have to have*, *should have* and *would like to have*.
- Determining what information is needed for decision making and ensuring that the relevant data are collected.
- Data collection has to be planned in advance to ensure it is available to inform decision making.
- The cost of data collection needs to be explicitly considered.

Summary

Summary

- From the perspective of health technology assessment, supporting decisions about major investments in healthcare relies heavily in real-world evidence.
- The available data are rarely entirely fit for purpose, and we tend to be heavily reliant in international data.
- Data collection in Ireland could be improved, but it has to be recognised that it is at a cost.
- Better collaboration between providers, researchers, patients and decision makers would support better design of data collection to ensure that decisions for Irish patients are based on relevant Irish data.
- Better data are only beneficial if ultimately used to improve service delivery and patient outcomes.

Thank You

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