



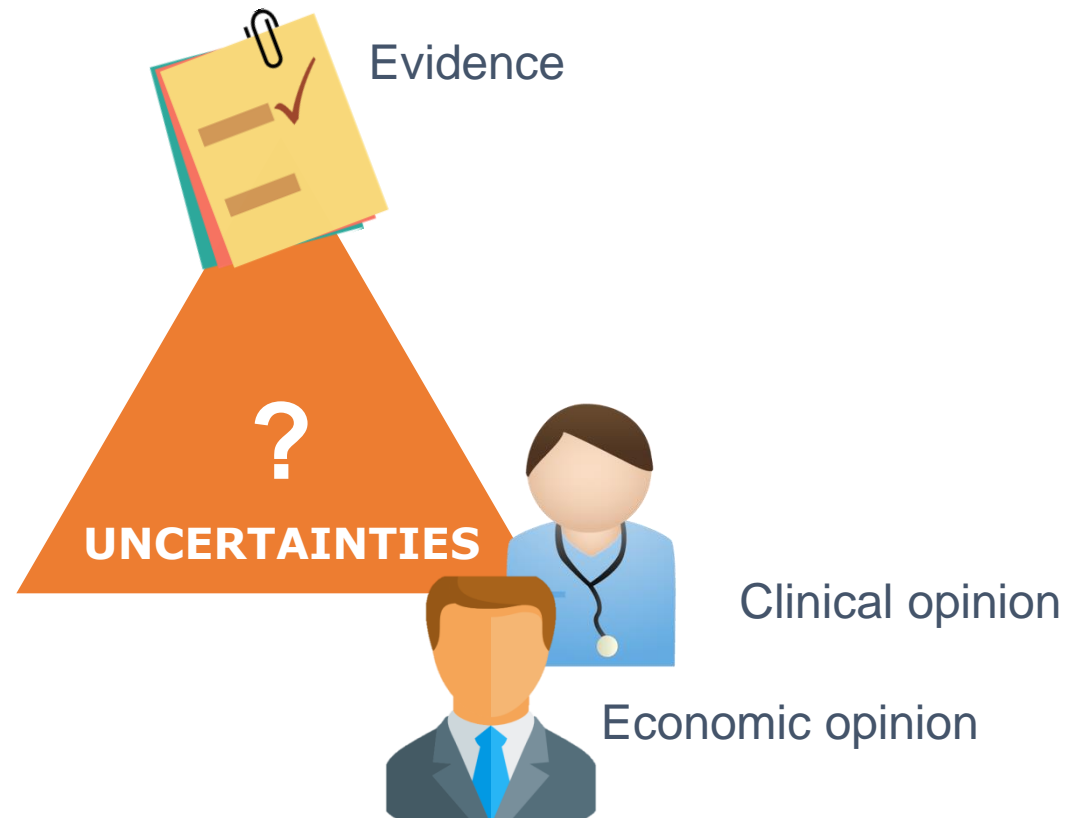
Principles of advocate involvement in access decisions



The old days: Decisions considered the clinical and economic expert opinion



But the evidence never answers all the questions



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That's why decision makers are increasingly turning to us

It is the patient involvement in bringing their perspectives and experience that help to illuminate the uncertainties inherent in value determinations



Principles of access advocacy



Sharing access advocacy experience

“We are experienced access advocates.
We know how to do this.
Yes, it is hard and takes a lot of patience.
But it is also extremely rewarding”

How can we package up all the experience
and knowledge that we have in a way that
others can use in a way that motivates, gives
confidence, and shares our passion?

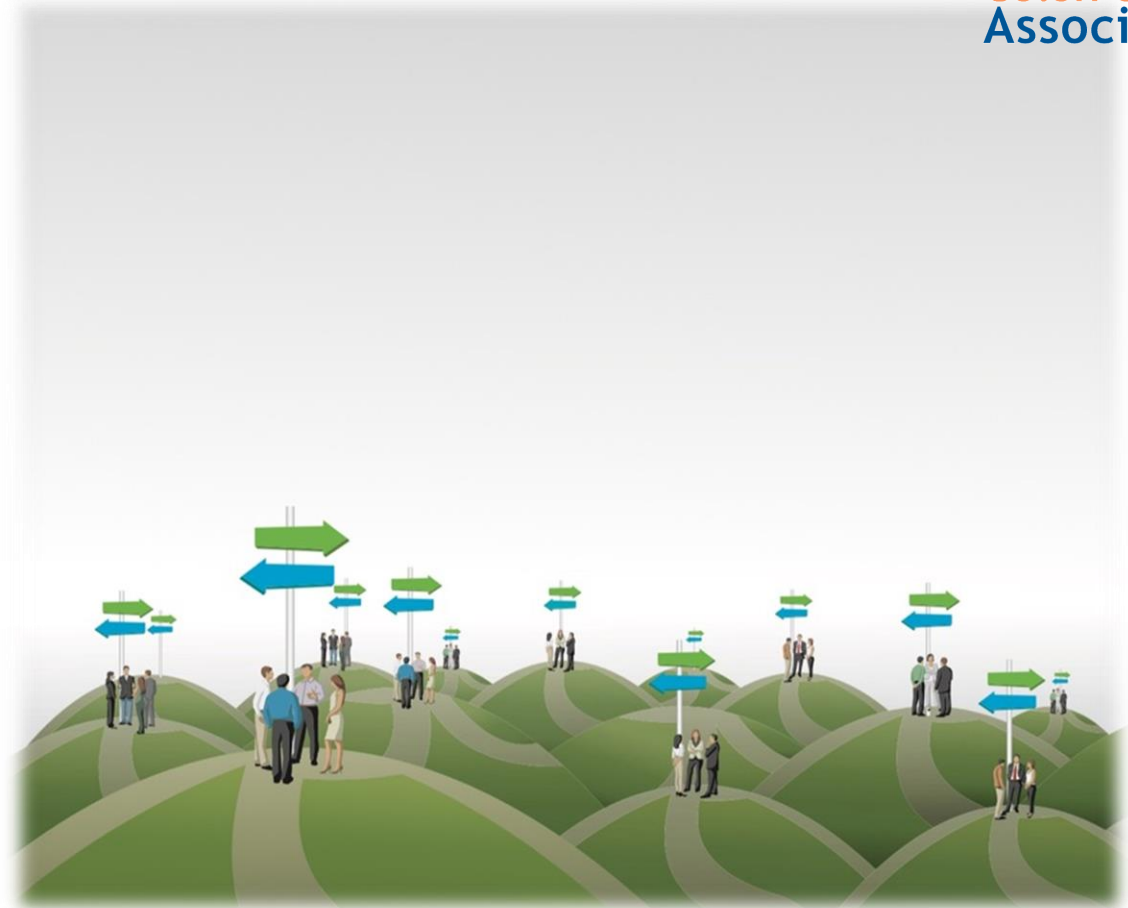


We all have our own ways of doing this...

To us, what we do seems obvious, and we have learnt how to do it over many years

Yet, how we each 'do' access advocacy is unique, it is personal and it is built as a consequence of our experiences

So how do we reach people who are not yet ready to take the plunge into access advocacy, and give them the encouragement they need



Resource list



- NICE (UK) public involvement factsheet
- NICE (UK) Patient/Carer Submission Template
- NICE (UK) Hints and tips for patient experts
- CADTH (Canada) Patient engagement guide
- Save Your Skin Foundation (Canada) Patient input webinar
- Save Your Skin Foundation (Canada) Library of submission
- Save Your Skin Foundation (Canada) Pharmacoeconomics guide
- The Lung Cancer Registry (Global)
- The registry of patient registries (Global)
- Faster Cures (US) Building smarter patient registries report
- ESMO Benefit Scale Background (EU)
- CSC Access to Care in Cancer 2016 (US)
- EUPATI Toolbox (EU / Global)
- IAPO Working with stakeholders – toolkit (Global)



IAPO toolkit



Working with partners and stakeholders Patients' organisation toolkit

A comprehensive toolkit on working with stakeholders

Explores the rationale and approach of working with many other healthcare stakeholders (including with other advocacy groups)

Contains sample material that can help advocacy organizations get started

Overview of content

- Framework for interaction
- Collaborating with other patients' organisations
- Examples of how patients' organisations can work together
- Collaborating with healthcare professional associations
- Collaborating with government
- Collaborating with industry
- Top tips for working with industry
- Working with pharmaceutical companies
- 'How to...' guides
- Templates
- Case study examples





Global
Colon Cancer
Association

