

Core Outcome Sets  
Why are they  
important to us?  
A Patient Perspective

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# HOME

- ▶ Patient involvement from the beginning–initial Delphi study
- ▶ Various nationalities
- ▶ Some through patient groups, others through individual clinicians or research initiatives

# What do patients think about research initiatives?

- ▶ Cochrane?

Patients think that medicine IS evidence-based.

- ▶ Core Outcome Sets?

Patients assume that researchers must know what's important to them and COS would have been sorted out a long time ago.

**What are clinical effectiveness trials for?**

**Patient Benefit**

**What are Core Outcome Sets for?**

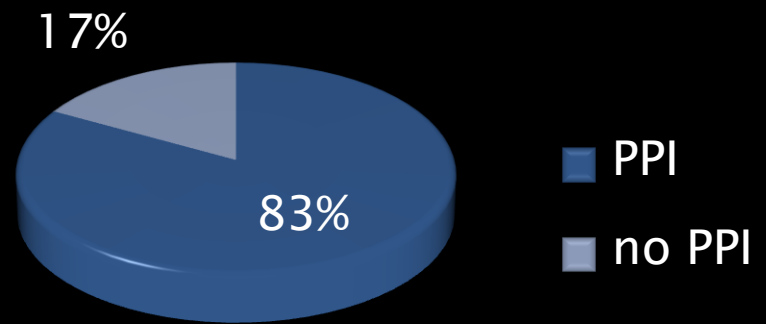
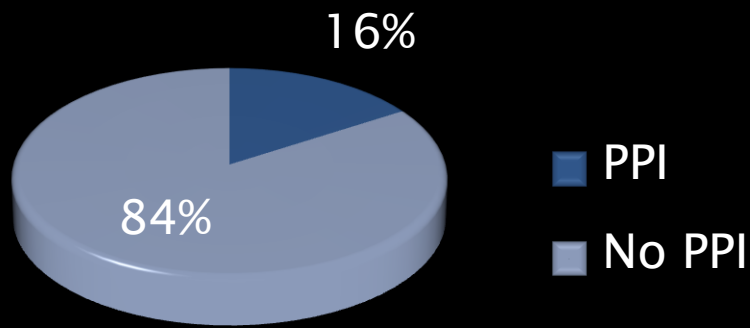
**Patient Benefit**



# Involve Patients!

Most advice on PPI (Patient and Public Involvement) and that of the Cochrane Collaboration point to the fact that patients can contribute positively to defining outcomes and may well contribute new outcomes that researchers had not considered.

# Current PPI activity from the COMET database



# Why are COS important for patients?

Patients want to research their own conditions on the internet and elsewhere

It is difficult enough for them to discover information without having to look at trials which are not comparing the same outcomes

*Why didn't the researchers think about X, Y and Z???*



# Why are COS important for patients?

Doctors know about the condition but patients know about the impact –

- ❖ On their daily lives – how the condition restricts what they can do
- ❖ On their families
- ❖ On their employment prospects
- ❖ On their relationships

If they contribute to the COS for their condition the result will be more relevant outcomes better quality research and – hopefully – better health for patients.

# When to involve patients?

Start before the beginning!

If patients are included in designing a COS, not just invited to comment on a finished document, the COS will be more accessible and understandable. This will make it easier to promote to people with an interest in getting involved.

# What are the challenges for patients?

Language –

medical terminology

acronyms and jargon

A condition-specific glossary will help

Delphi studies! HOME Delphi study was crucial but difficult

# COMET

INITIATIVE

