

# **Outcomes that matter**

**Sian Rees**  
**Oxford Academic Health Science**  
**Network**

# What do we mean?



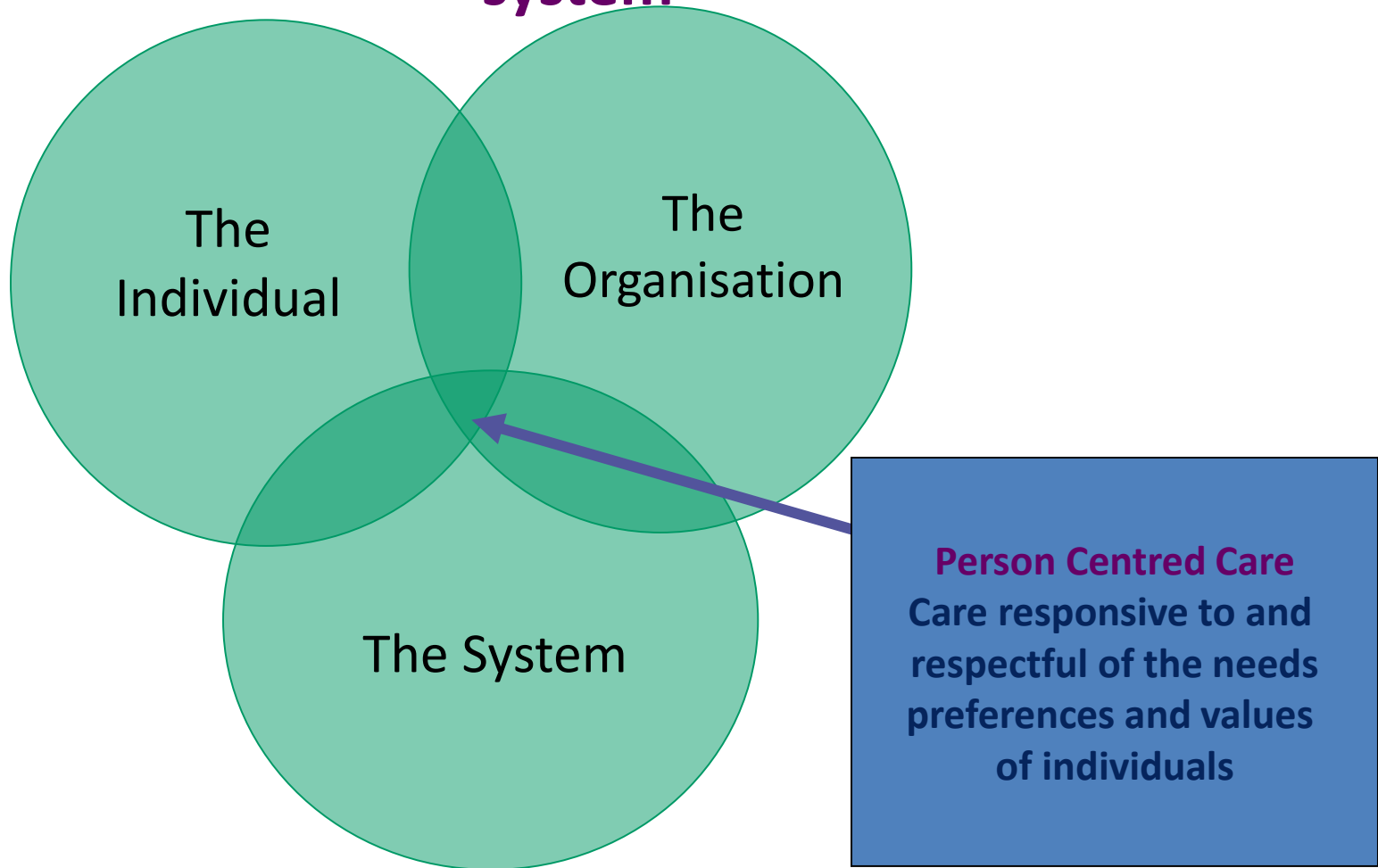
# Outcomes that matter in health Where?



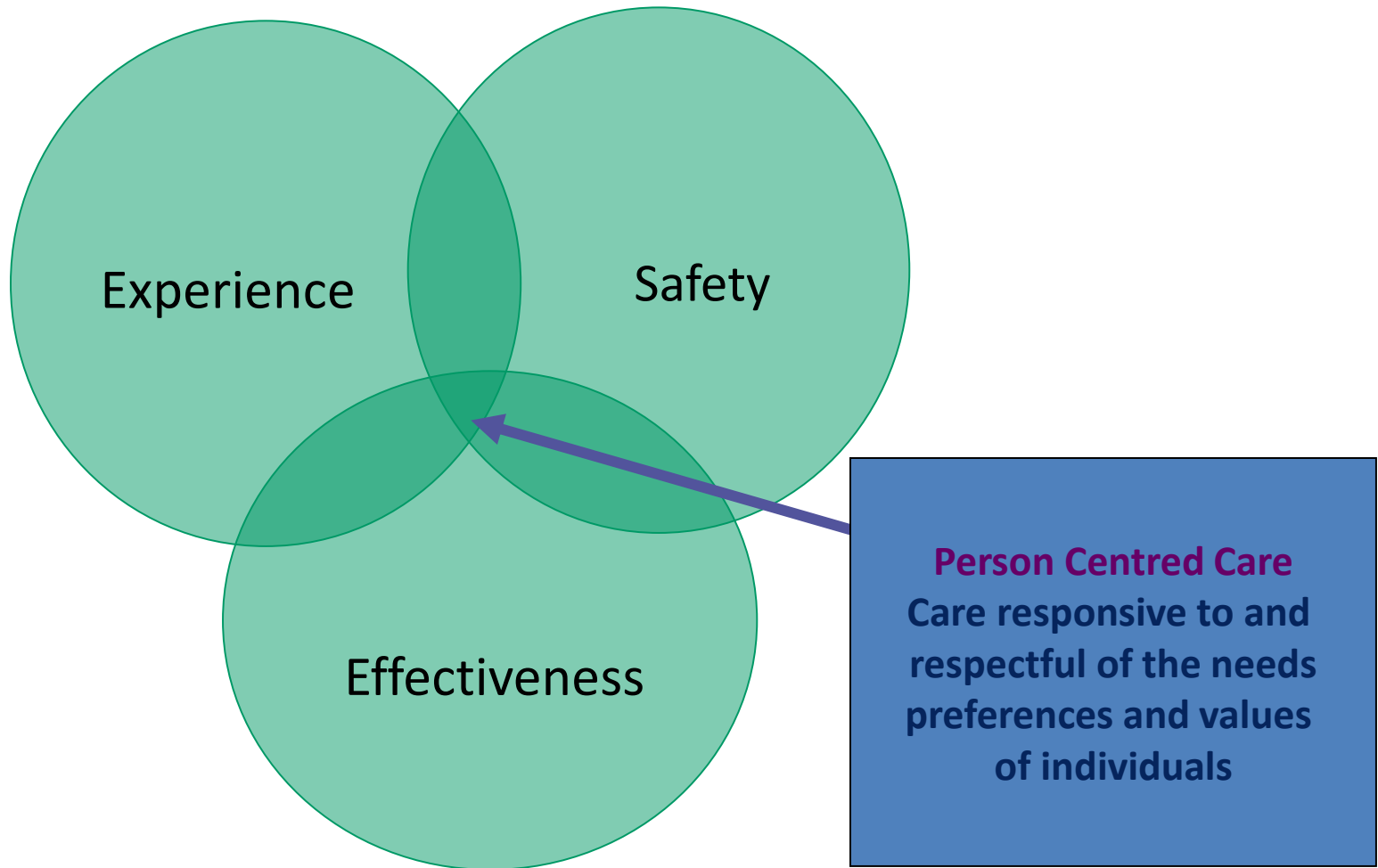
**Services**  
**Commissioning**  
**Research**  
**Education**  
**Innovation**

# Outcomes that matter:

**Who** - the individual, the organisation and the system



# Outcomes that matter: what



**What outcomes?**



**What matters?**

**What do you  
value?**

# Value Values

merit, worth, usefulness, use, utility,  
practicality, advantage, desirability,  
benefit, gain, profit, good, service,  
help, effectiveness, efficacy, avail,  
importance, significance, point, sense

# Personal

belonging to or affecting a particular person rather than anyone else



**What do you value?**



**Relationship**

# What Matters? What is valued?

**No decision about me without me**

**Who knows best?**



# Right care for the right patient at the right time

Two patients, medically identical

- Identical health state
- Identical diagnosis

Different doctors

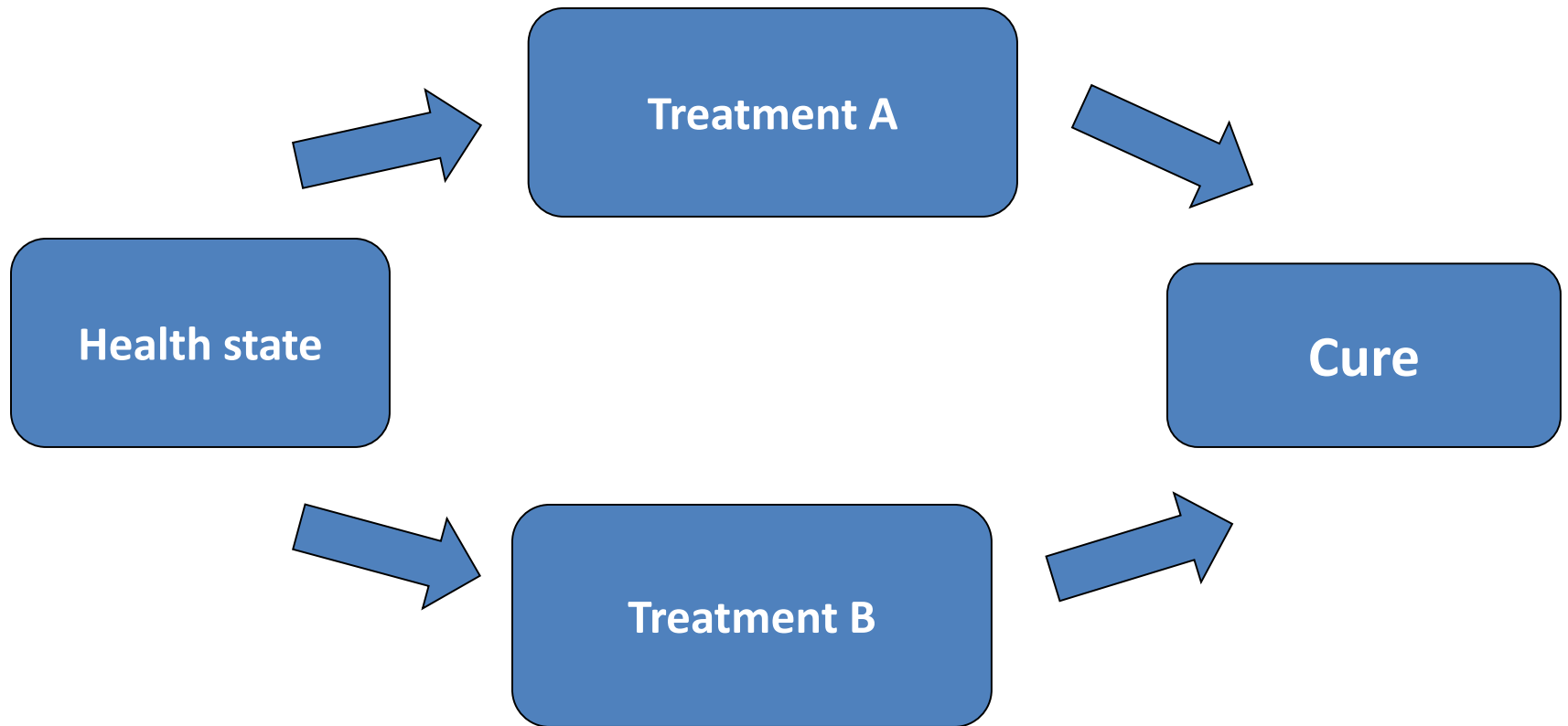
- Different treatments

**Is there a problem?**

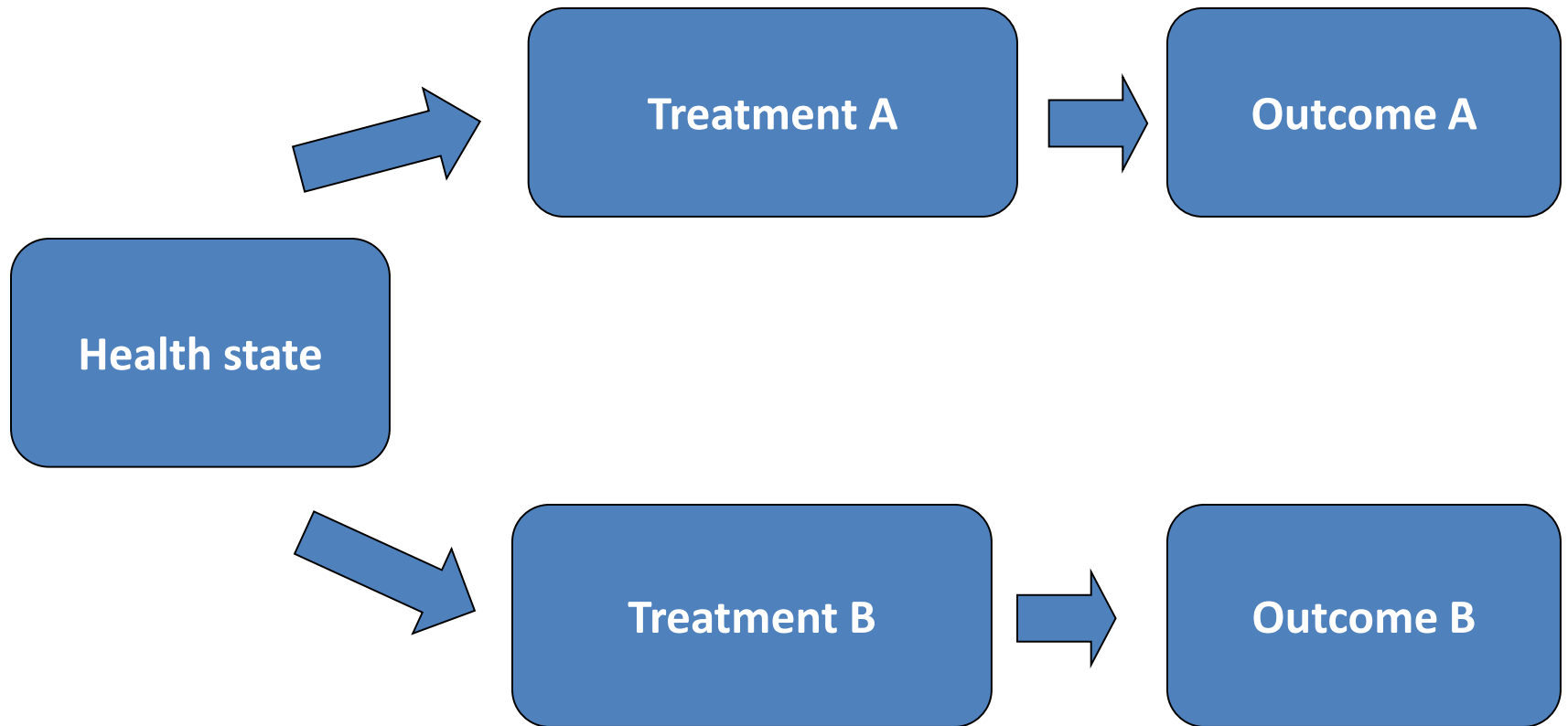
# Incorrect treatment



# Uncertainty in treatment options



# Patient preference



# Top Three Goals and Concerns for Breast Cancer Decisions

Condition: Goal	Patient	Clinician	Significance
Keep your breast?		71%	
Live as long as possible?		96%	
Look natural without clothes		80%	
Avoid using prosthesis		0%	



# Top Three Goals and Concerns for Breast Cancer Decisions

Condition: Goal	Patient	Clinician	Significance
Keep your breast?	7%	71%	P<0.01
Live as long as possible?	59%	96%	P=0.01
Look natural without clothes	33%	80%	P=0.05
Avoid using prosthesis	33%	0%	P<0.01

**Uncertainty in healthcare requires  
choices and trade offs for both  
treatment and outcomes**

**Understanding personal value is  
central to getting this right**

**What do patients  
value?**

# What do patients value?

- **Relational aspects of care:**  
**dignity, empathy, privacy**
- **Functional aspects of care:**  
**access, food, noise**

# Outcomes that matter

## OMERACT - Outcome Measures for Arthritis Clinical Trials

### OMERACT 5

- include patients

### OMERACT 6

- initiate research on patient perspective

### OMERACT 7

- 'new' symptom identified

### OMERACT 8

- Symptom included



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EXECUTIVE HISTORY RESEARCH PATIENTS EVENTS

*Outcome Measures in Rheumatology*

### ABOUT OMERACT

**What is OMERACT?**  
OMERACT strives to improve endpoint outcome measurement through a data driven, iterative consensus process involving relevant stakeholder groups. The term OMERACT was originally established in 1992 to mean "Outcome Measures in Rheumatoid Arthritis Clinical Trials". Since then the OMERACT initiative has turned into an international informal network, with working groups and gatherings interested in outcome measurement across the spectrum of rheumatology intervention studies. The acronym has therefore been broadened to now stand for 'Outcome Measures in Rheumatology'.



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### OMERACT 7

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### OMERACT 8

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Fatigue

# Outcomes that matter – how?

- **Co**
- - define
- - create
- - design
- - produce
- - deliver
- - evaluate
- - dissemination