

**OUTCOMES THAT
MATTER TO PATIENTS
AND THE PUBLIC**

**WORKSHOP 12TH
DECEMBER 2017**



MEETING PURPOSE

Consider and discuss examples of where outcomes that are important to patients/public have been incorporated into health care services, research, education and commissioning.

Reflect on where you/your organization is regarding outcomes that matter to patients and the public.

Discuss and agree plans to include patient important outcomes in your work



HOUSEKEEPING

Timings



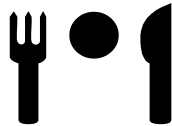
Phones



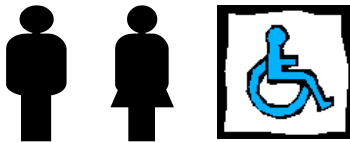
Refreshments



Lunch



Facilities



Expenses



WORKING WELL TOGETHER

Equity of voice – *all* participants have something of value to contribute to this meeting

Respectful & active listening throughout and jargon free.....

Please mute your phones, if you need to check your emails, don't do it whilst people are contributing.....



GETTING TO KNOW EACH OTHER

- Introductions on the table
- Using the post-its provided – write your answer (s) to the question.....
- What is a health outcome?



SOME CONTEXT

SIÂN REES

Director Patient & Public Involvement, Engagement & Experience at Oxford Academic Health Science Network



OUTCOMES THAT MATTER – SOME CONTEXT



Sian Rees

Oxford Academic Health Science Network

WHAT DO WE MEAN?



OUTCOMES THAT MATTER WHERE?



Services

Commissioning

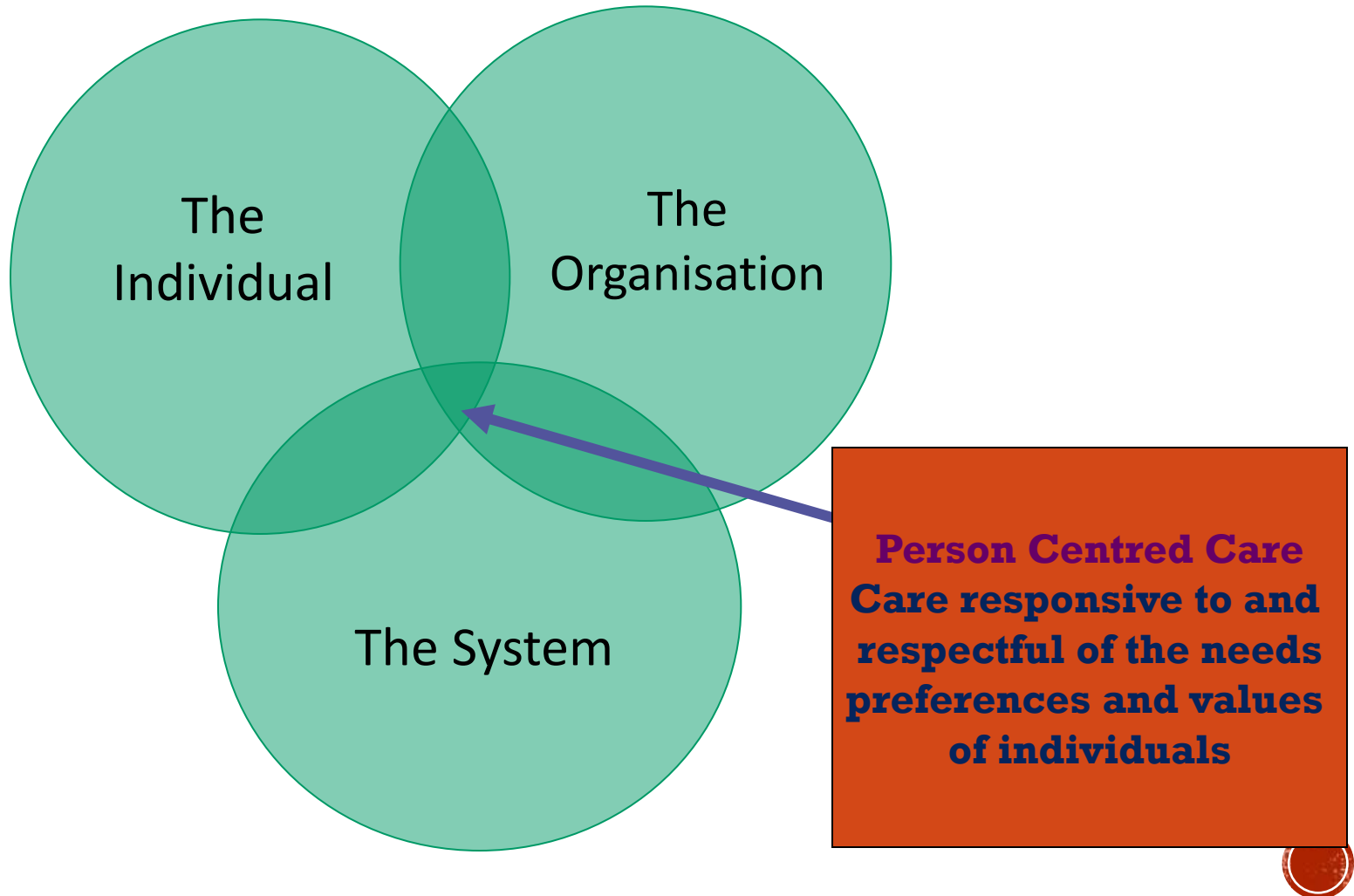
Research

Education

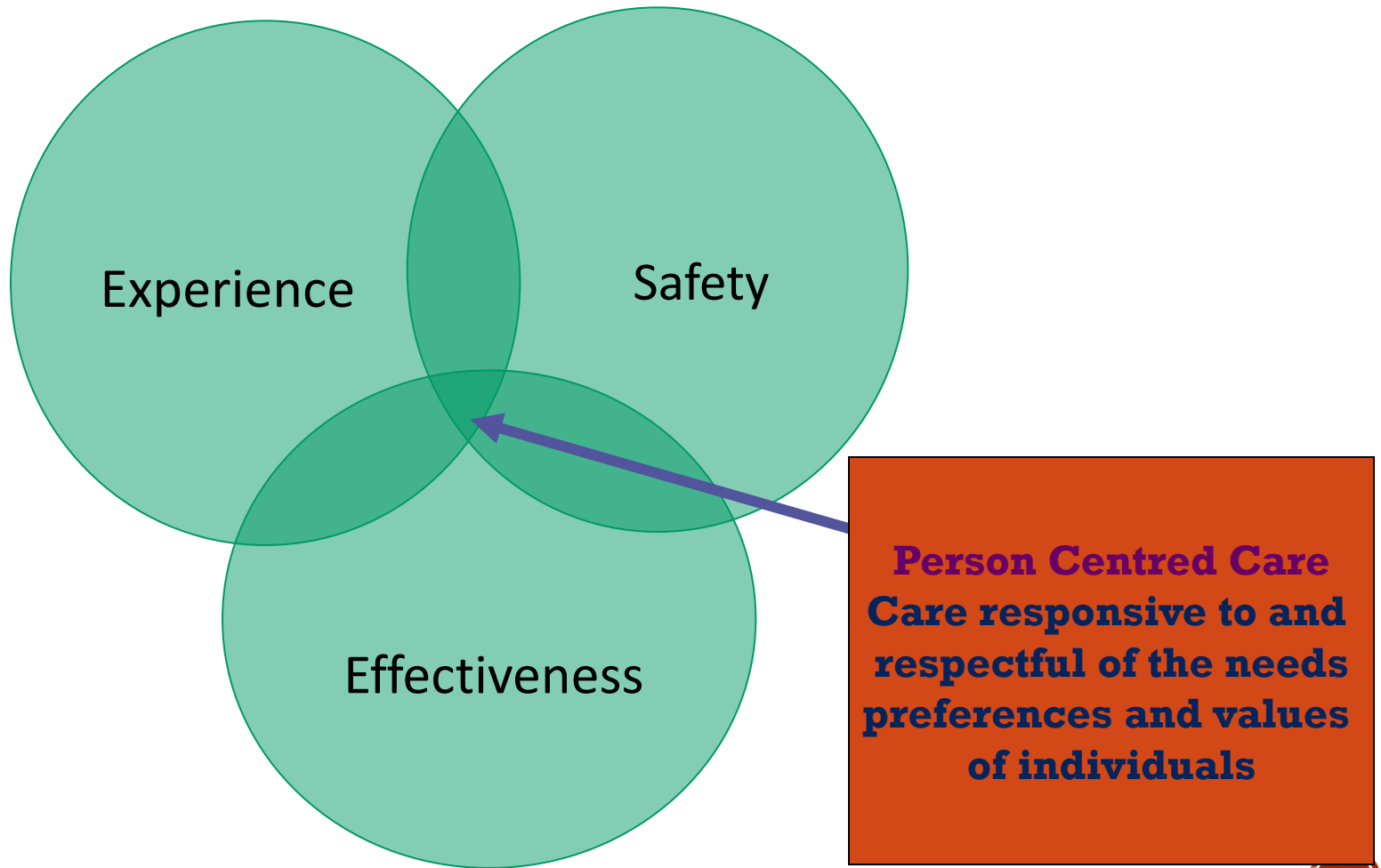
Innovation



OUTCOMES THAT MATTER: WHO?



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 – in practice

Two patients, medically identical

- Identical health state
- Identical diagnosis

Different doctors

- Different treatments

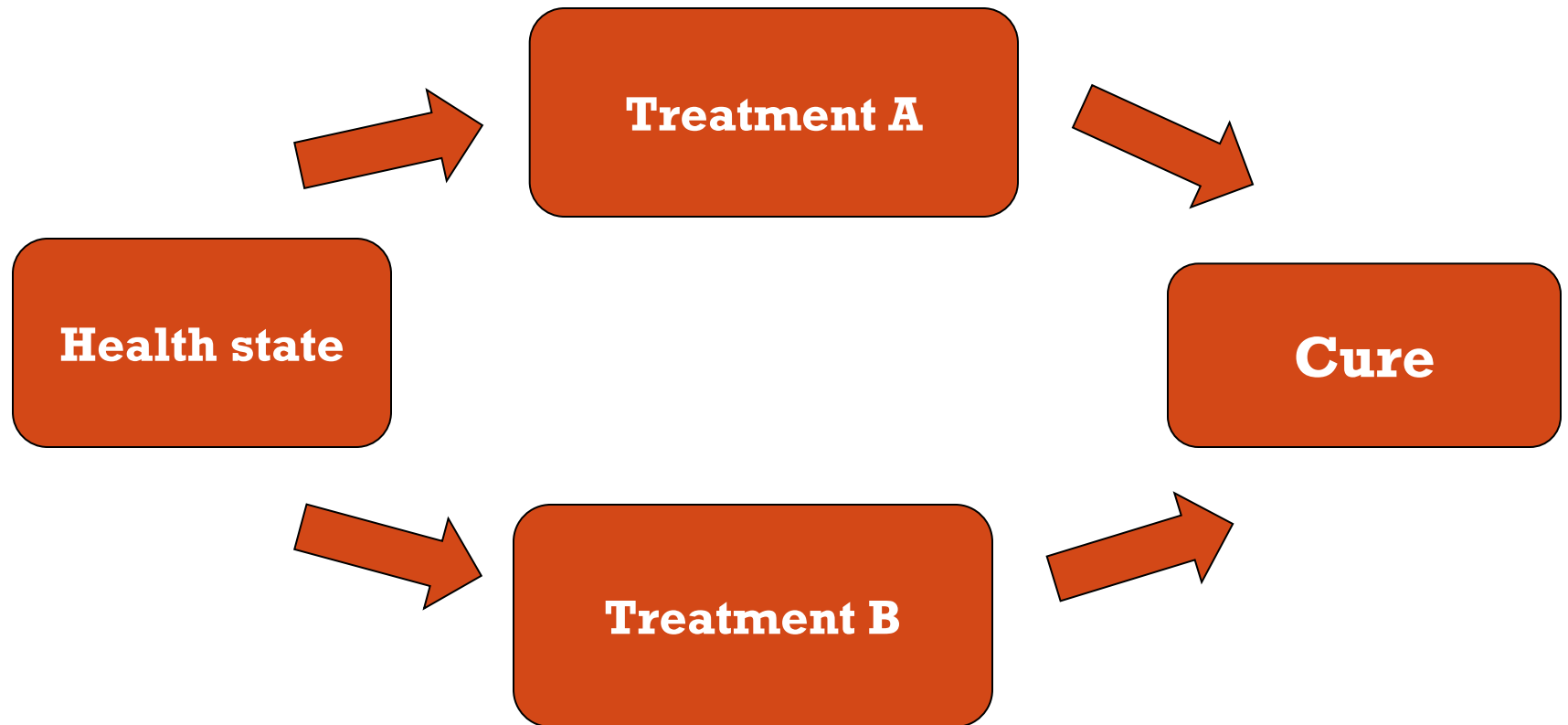
Is there a problem?



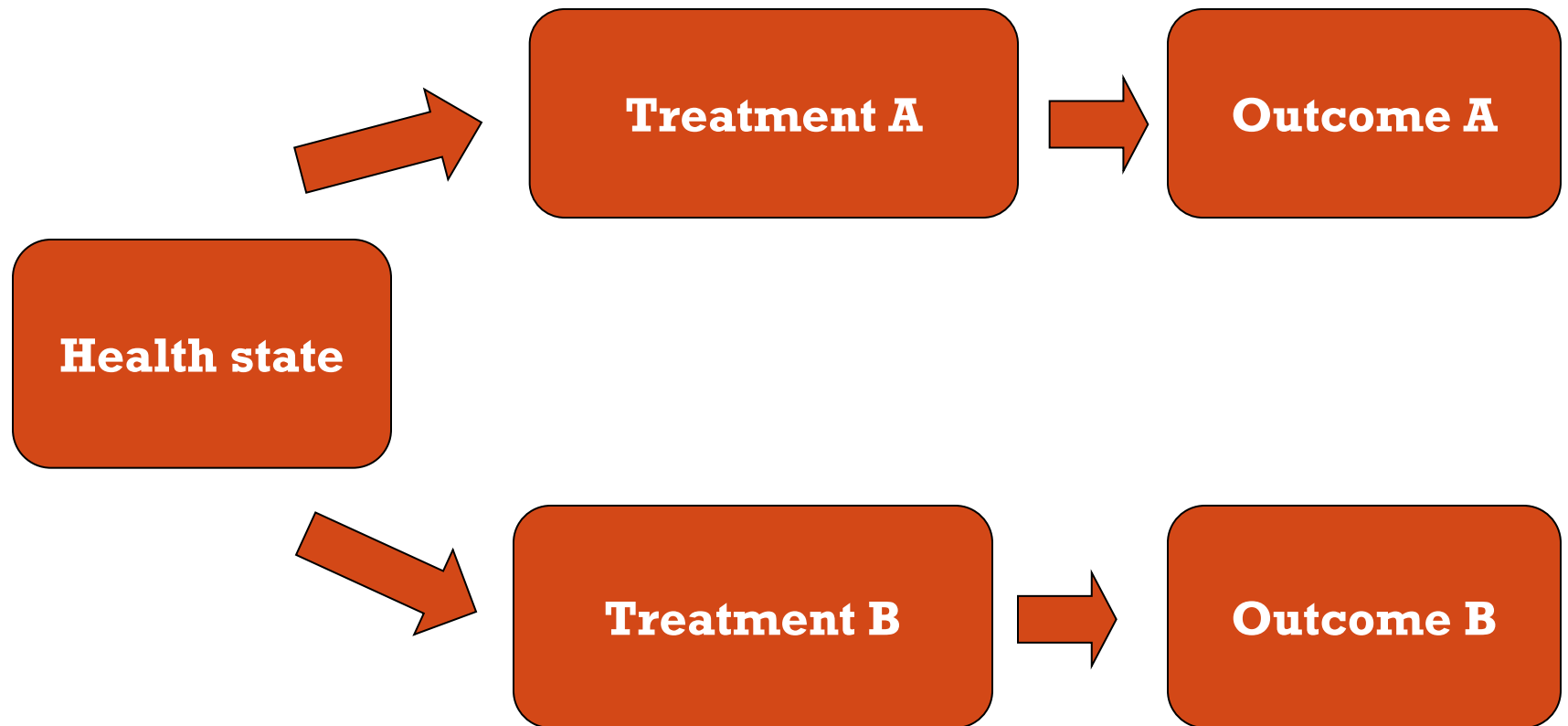
INCORRECT TREATMENT



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



HOME **ABOUT** **OMERACT10** **PUBLICATIONS** **CONTACT**

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’.



Outcomes that matter

OMERACT - Outcome Measures for Arthritis Clinical Trials

OMERACT 5

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OMERACT 8

-Symptom included



Fatigue



Outcomes that matter – how?

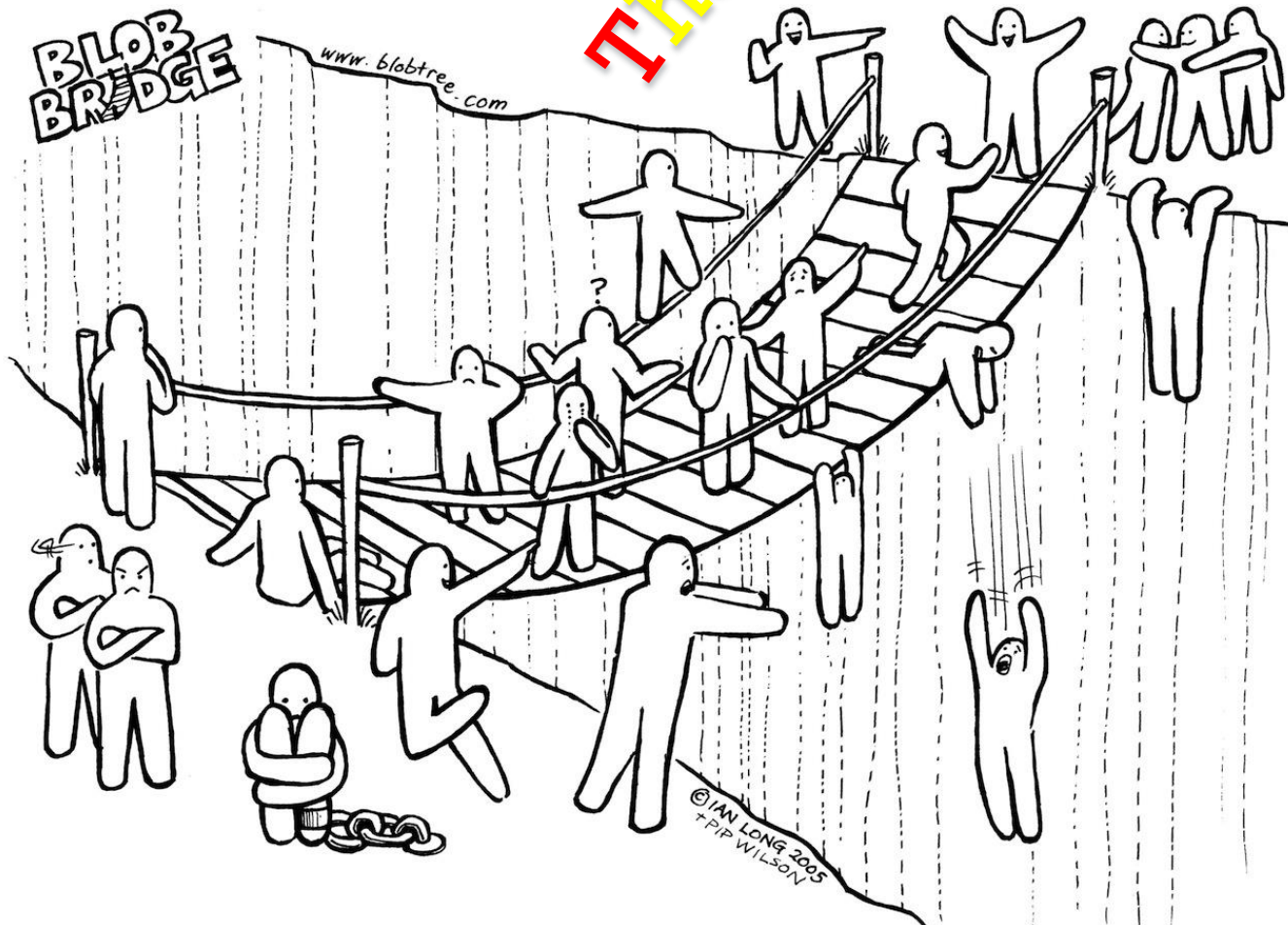
Co...

- **define**
- **design**
- **deliver**
- **disseminate**



WHERE ARE WE NOW?

The land of outcomes



- Start in pairs, using the bridge cartoon on your table



WHERE ARE YOU ON THE BRIDGE?

Discuss and colour in the image that most represents where you are right now.....

Discuss what it means to reach the '*land of outcomes that matter to patients and the public*'

For the journey - what is stopping you

Reaching the promised land, does the bridge need to change?

If you are already there – how did you get there?
How does it feel? What has changed?



FEEDBACK FROM THE BRIDGE

- We will ask each table for some feedback so please make some notes
- Use the post-its to record your ideas, reflections etc



OUTCOMES THAT MATTER TO PATIENTS AND THE PUBLIC

Case studies



REFLECTING ON CASE STUDIES....



REFLECTING ON CASE STUDIES

- Are there particular approaches in the case studies that you liked or disliked?
- Want more information on? Wanted to clarify?
- If you have experience of being involved in public engagement or debate in outcomes for services, research or commissioning?

.....What worked or was positive?

.....Were there problems or issues? What are these and how do we overcome them?

.....If you were doing it again what would you do or want done differently?

.....How did these compare to the case studies?

Reflecting



METHODS, APPROACHES, CONSIDERATIONS

- Many ways to make a cuppa.....

HOW TO MAKE
A "PROPER"
CUP OF TEA



HOW TO MAKE
A "PROPER"
CUP OF TEA



- We want to capture all the methods, approaches and considerations discussed today.....



OUTCOMES THAT MATTER TO PATIENTS AND THE PUBLIC; **WHAT ARE IMPORTANT ELEMENTS OF SUCCESS** IN METHODS, APPROACHES, CONSIDERATIONS?



APPLYING THE SHARED LEARNING

- Take 5 - 10 mins to develop a scenario/context for developing outcomes that matter to patients and the public – suggest that you use something real from the group.....
- If this is too difficult ask us for an example

APPLY NOW



TASK: A SHORT PLAN TO DEVELOP OUTCOMES THAT MATTER TO PATIENTS & THE PUBLIC FOR YOUR CHOSEN SCENARIO. PLAN SHOULD ADDRESS;

Context: healthcare/service - what do you want to improve?

Context: research - what do you want to capture and measure?

For both:

Sources of existing useful & relevant information? Someone done this before?

People involved?

How to work together and engage?

How to use the outcomes? Get others interested?



