Working with patients, citizens and carers – getting it right

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Oxford AHSN

Working Together: Training and Development Programme 2018

For healthcare professionals, researchers, patients, carers and the public

30 April

Working Together: approaches and techniques
For people with some experience of PPI
The Gateway Aylesbury, 12pm-5pm

05 June

Writing for lay audiences
For people with some experience of PPI
Oxford Academic Health Science Network, 10am-12.30pm

11 September

Lay partners on staff interview panels
For people with some experience of PPI
The University of Reading, 10am-1pm

06 November

Working Together: an introduction
For people new to patient and public involvement
Unipart Oxford, 10am-12.30pm

For more information or if you are interested in taking part:

email: PPIEE@oxfordahsn.org
web: bit.ly/workingtogetherprogramme

What do you need, to go away feeling that this was a worthwhile couple of hours?

See Post-it-notes attached

What we are planning to cover

- What
- Why
- How

5
"If I'd asked my customers
what they wanted, they'd have said
a faster horse"

What do we mean?

involve
unite
join
participate
engage

Definitions

Involvement: improving everyone's care

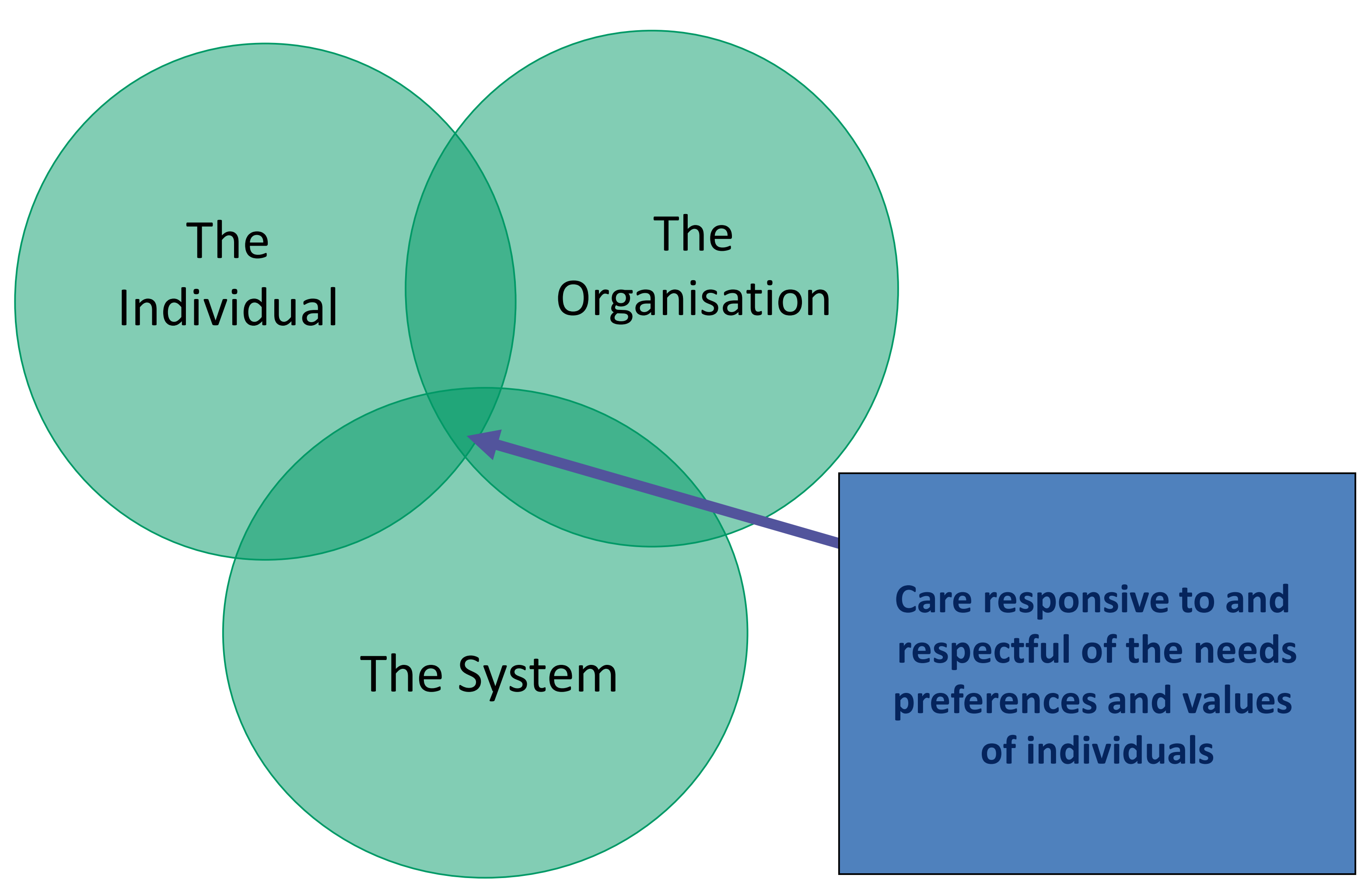
Working with patients, carers and the public to improve care delivery, research, innovation and education on behalf of the whole population

Experience: listening to, and acting on, what patients, carers and the public say

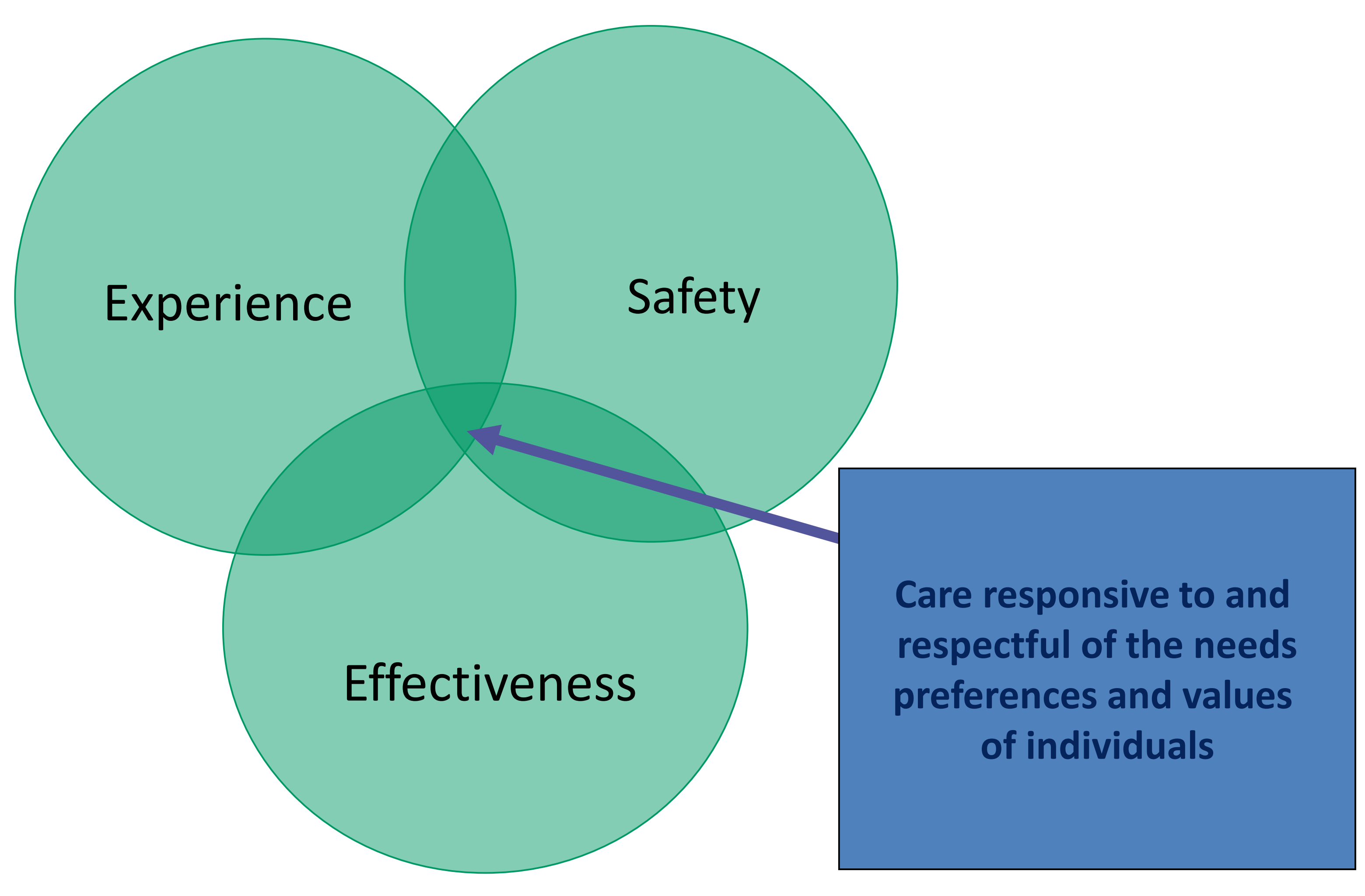
Collecting, understanding and using patients' , carers' and the public's (and staff's) feelings about their involvement in care, research, education and innovation

Person centred care?

Person-centred:
the individual, the organisation and the system



Person-centred:
central to the quality of care



Why do it?

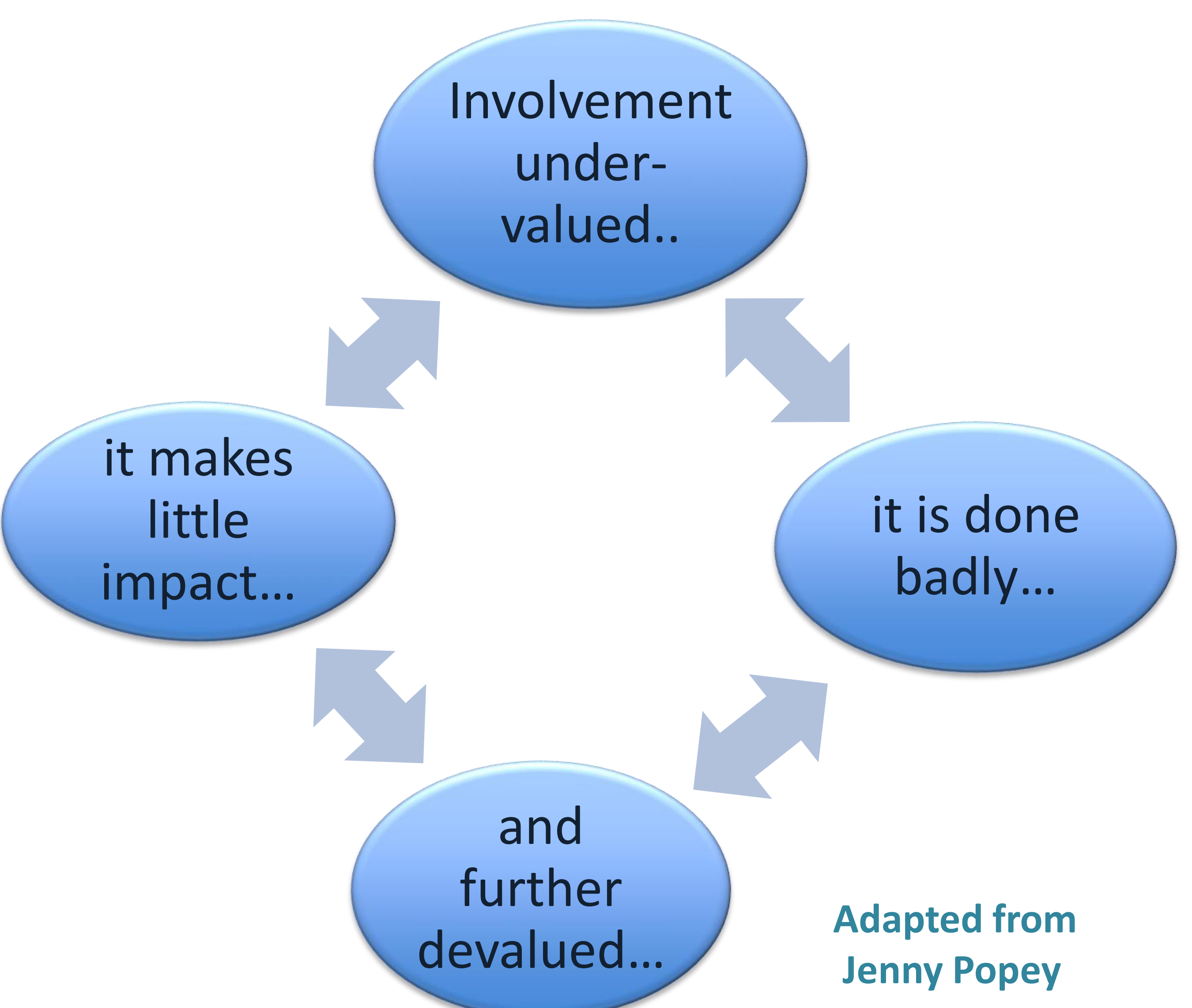
- Told to
- It’s the right thing to do
- It makes a difference

FIVE YEAR
FORWARD VIEW

General
Medical
Council

Regulating doctors
Ensuring good medical practice

The Tokenism Cycle



Why do it?
It's the right thing to do

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

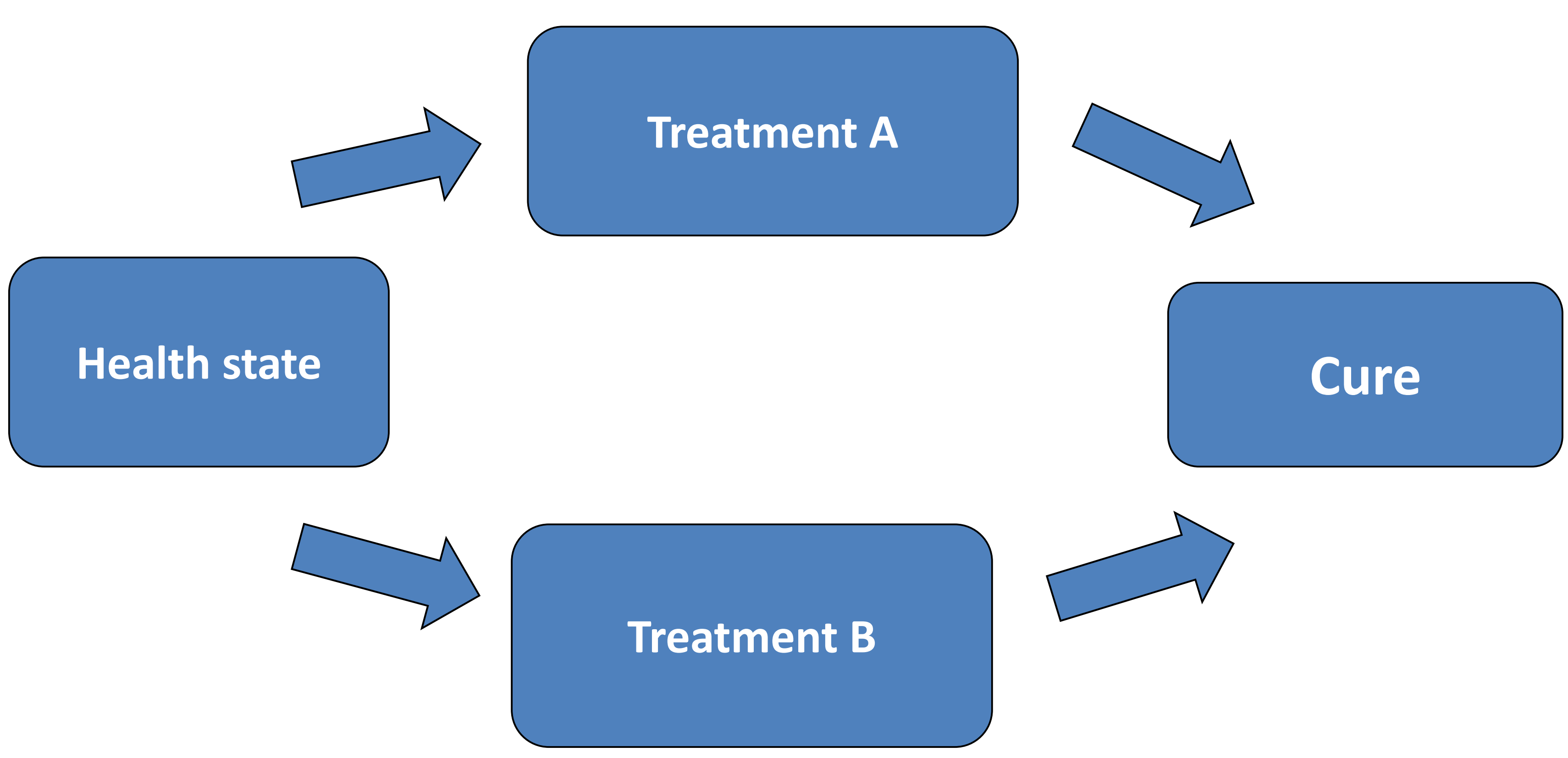
- Different treatments

Is there a problem?

Incorrect treatment

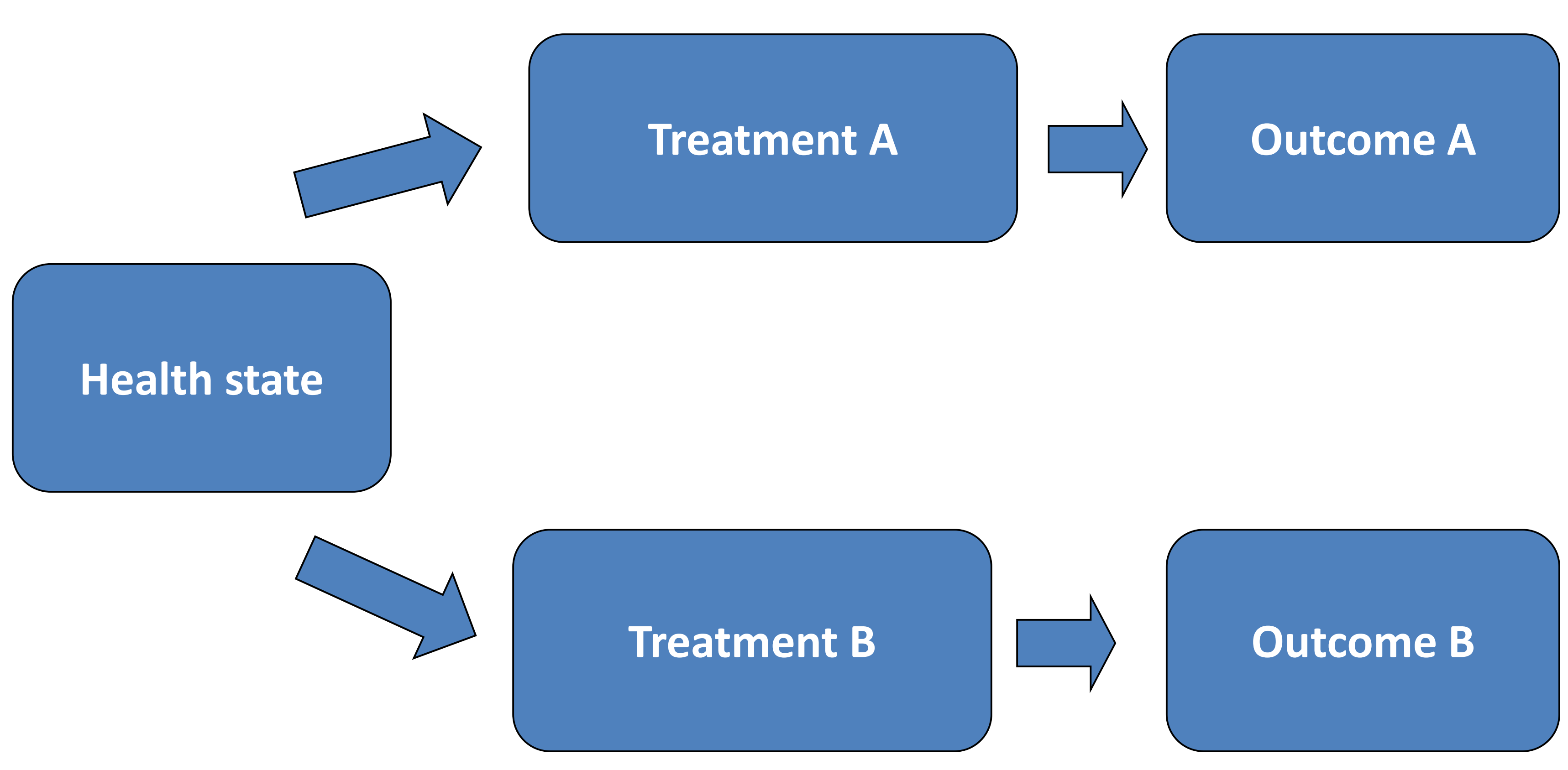
Patients' Preferences Matter - Mulley, Trimble and Elwyn

Uncertainty in treatment options



Patients' Preferences Matter - Mulley, Trimble and Elwyn

Patient preference



Patients' Preferences Matter - Mulley, Trimble and Elwyn

You don’t know what you don’t know!

Why do it?

It makes a difference

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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Fatigue

It makes a difference: organisational care – BMJ systematic review

- Patient experience is positively associated with self-rated and objectively measured health outcomes; adherence to recommended medication and treatments; preventative care such as use of screening services and immunisations; healthcare resource use such as hospitalisation and primary-care visits; technical quality-of-care delivery and adverse events

- Patient experience consistently positively associated with patient safety and clinical effectiveness across a wide range of disease areas, study designs, settings, population groups and outcome measures

Doyle 2013

Cochrane Review Of Decision Aids

86 trials in 6 countries of 34 different decisions, use has led to:

- Greater knowledge
- More accurate risk perceptions
- Lower decision conflict
- Greater participation in decision-making
- Fewer people remaining undecided

Stacey 2011

Experience based co-design

Range of improvement activities:

- clocks;
- privacy after diagnosis;
- sleep and light/noise;
- hair-washing, belongings following the patient….

48 improvement activities in total:

- 21 small scale changes
- 21 process redesign within teams
- 5 process redesign between services/activities
- 1 process redesign between organisations

What staff said

'So I can see that this person is not only a human being, but he is also a father, he is a son, he is a brother, he is a friend, he is a cousin, he's a plumber or an electrician, he is a sportsman, he has an interest in horse riding, whatever it happens to be. He has a dog, he has a budgie, he has plans, he has expectations, he has regrets, he has feelings.'

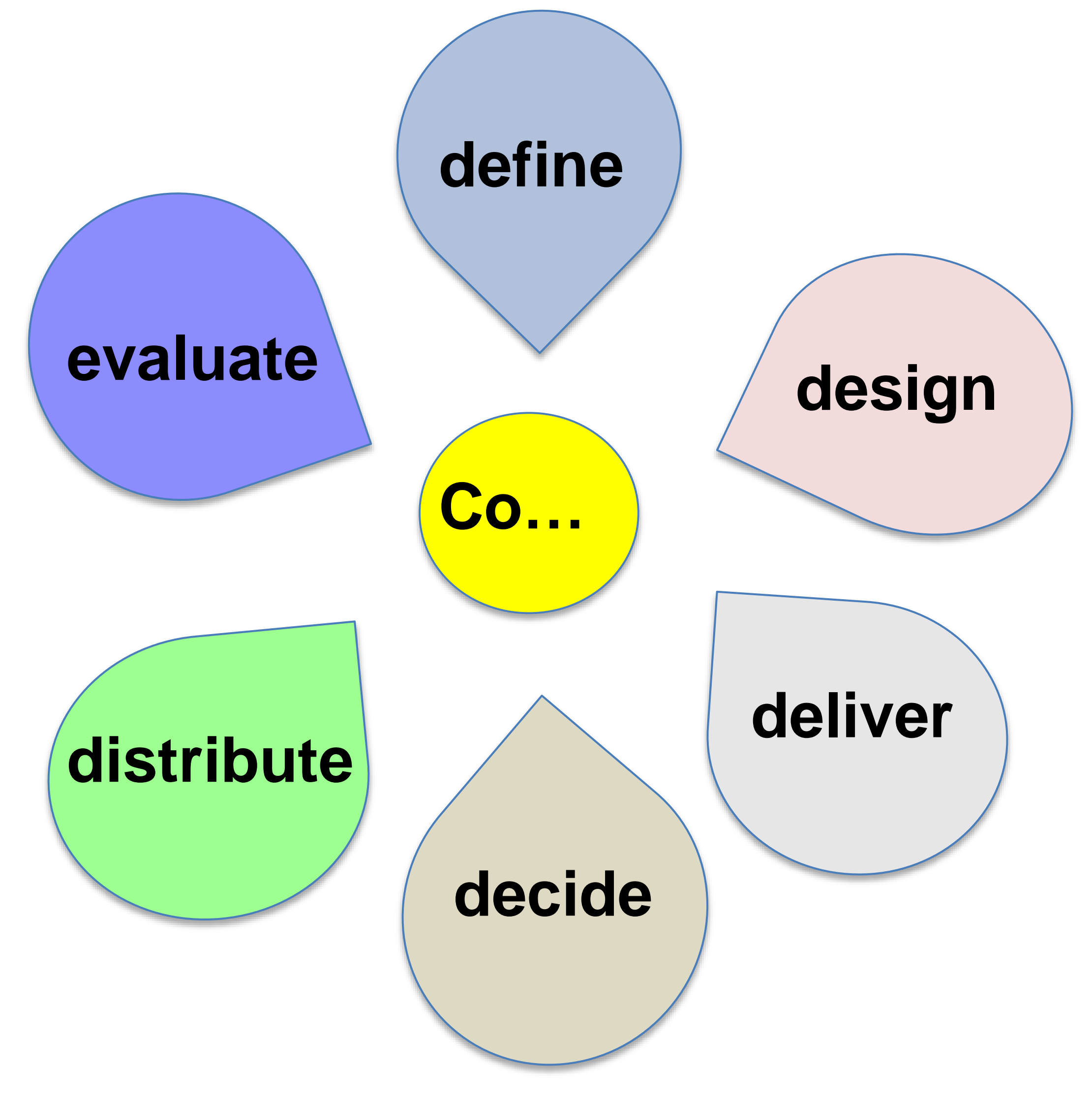
'I have already changed the way I think and care for patients even though we haven't started implementing changes yet. I have a better understanding now of how things are from the patients' perspective.'

'An extremely valuable learning experience. I am a better nurse because of it.'

Patient (and staff) Shadowing

Co-production

Co-production: the components



5 Ds and an E

No More Throw Away People

The parable of the blobs and squares

https://www.youtube.com/watch?v=egav5xjb-lg

Coproduction – your experience

Q: What has been your best experience – when you felt most involved, most alive or most excited about your involvement?

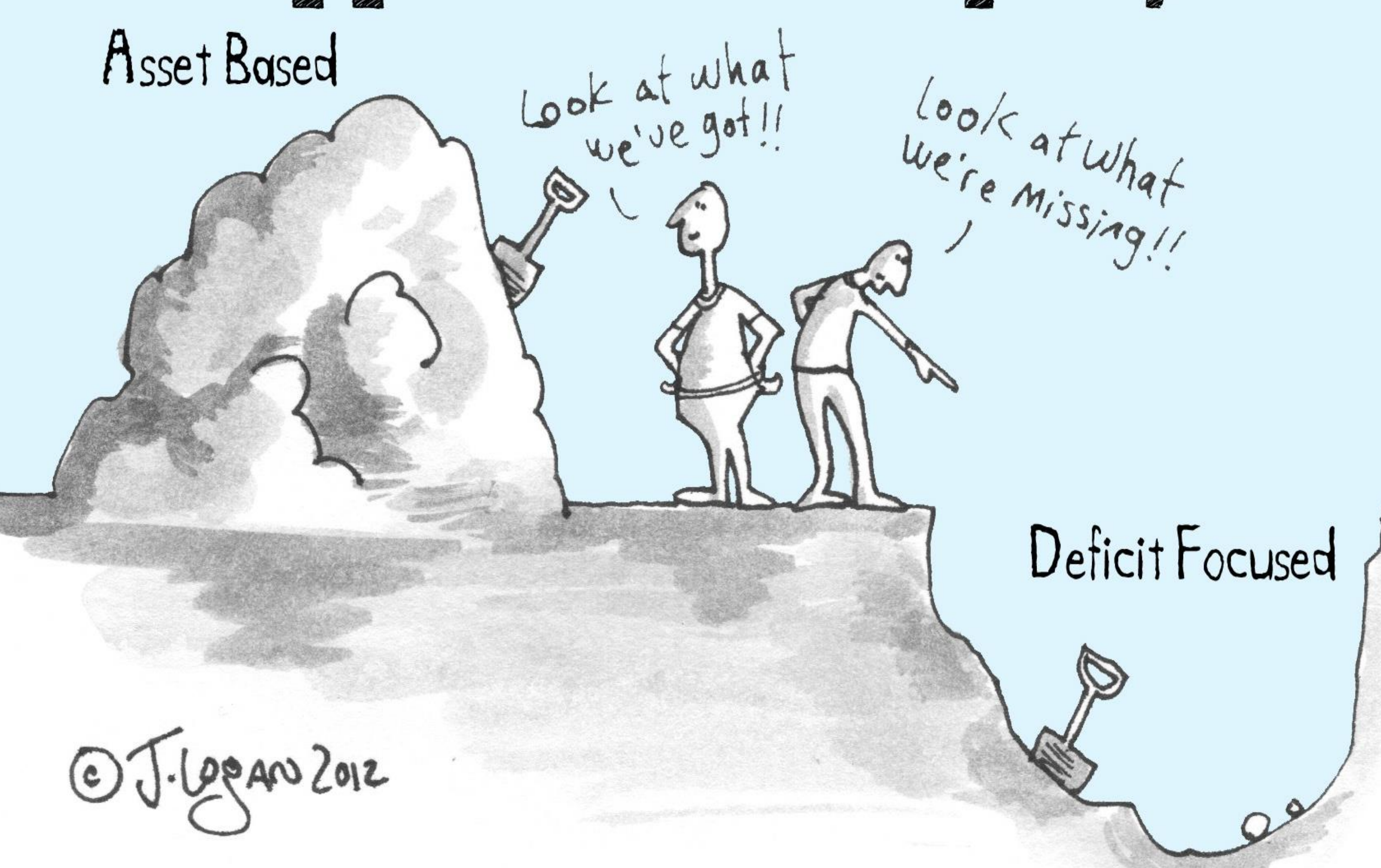
- What made it exciting?
- Who was involved?
- What strengths did you use?

Effective PPI.....

- Improves people's experience
- Supports shared decision making
- Enhances planning
- Increases public and staff understanding
- Builds better relationships
- Makes services more efficient
- Is not just a statutory requirement

There is more than one reality

Appreciative Inquiry



Appreciative Inquiry Core Philosophy

- Whatever you want more of already exists in a group or an organization.

- What is working well around here?

Appreciative Inquiry – the theory

- **Developed by David Cooperrider and Suresh Srivastva at Case Western Reserve University in 1987**
- **An organisation is a 'miracle to be embraced rather than a problem to be solved'**
- **Inquiry into organisational life should have the following characteristics:**
  - **Appreciative** - looks for the positive
  - **Applicable** - practical and grounded in reality
  - **Provocative** - encourages risk taking
  - **Collaborative** - involves everyone

Appreciative Inquiry Assumptions

- In every group or organization, something works
- What we focus on becomes our reality, if we look for problems, we will find them …and make them bigger

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- Search for and amplify solutions that already exist

IMPOSSIBLE

Appreciative Inquiry Assumptions

- **People have more confidence to journey to the future (the unknown) when they carry forward parts of the past (the known)**
- **If we carry forward parts of the past, they should be the best bits**

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- People have more confidence to journey to the future (the unknown) when they carry forward parts of the past (the known)
- If we carry forward parts of the past, they should be the best bits
- It is important to value differences
- And to recognize that reality is created in the moment ….and there are multiple realities

Appreciative Inquiry: the study of what works well

Empirical

- Define the immediate problem
- Fix what is broken
- Focus on decay / on what is missing
- What problems are you having?
- Learning from mistakes
- Who is to blame?

Appreciative

- Search for solutions that already exist
- Amplify what is working
- Focus on life giving forces – growth
- What is working well?
- Learning from what works
- Who to affirm?

What next?

What will you start doing?

What will you stop doing?

What will you carry on doing?

Sign-up!

Involvement Matters

Patients, carers, professionals and the public working together in the Thames Valley and Milton Keynes.