



# The role of patients in healthcare

Chris Graham, 5<sup>th</sup> November 2021

 @ChrisGrahamUK

## Our vision

The highest  
quality person  
centred care for  
all, always

## Our mission

### We are here to:

- **Influence** policy and practice so that health and social care systems are always centred around people's needs and preferences;
- **Inspire** the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood; and
- **Empower** those working in health and social care to improve experiences by effectively measuring and acting upon people's feedback.



# Examples of our partners



What is the role of patients in  
healthcare in 2021?

# Contents

- The medical model
- Person centred care
- The different and developing roles of patients

# Key messages

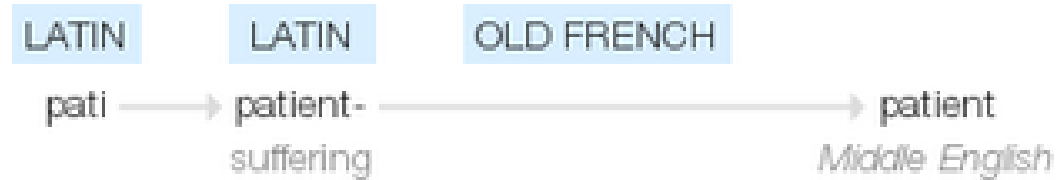
- Person centred care is intended to put people at the heart of how services are designed and delivered
- To achieve this, we need to recognise and welcome patients in multiple roles:
  - As *beneficiaries* of care
  - As *informants* on quality in practice
  - As *partners* in service design

# The medical model



# patient

Origin



- Passive
- Vulnerable
- Dependent
- Deferential

# doctor

Origin



- Active
- Knowledgeable
- Authoritative
- Powerful

“The passive patient will do what he or she is told, and will then wait patiently to recover. The healthcare professional is the healer, while the recipient of healthcare services is the healed, and does not need to take a part in any decision making or in any thinking about alternatives.”



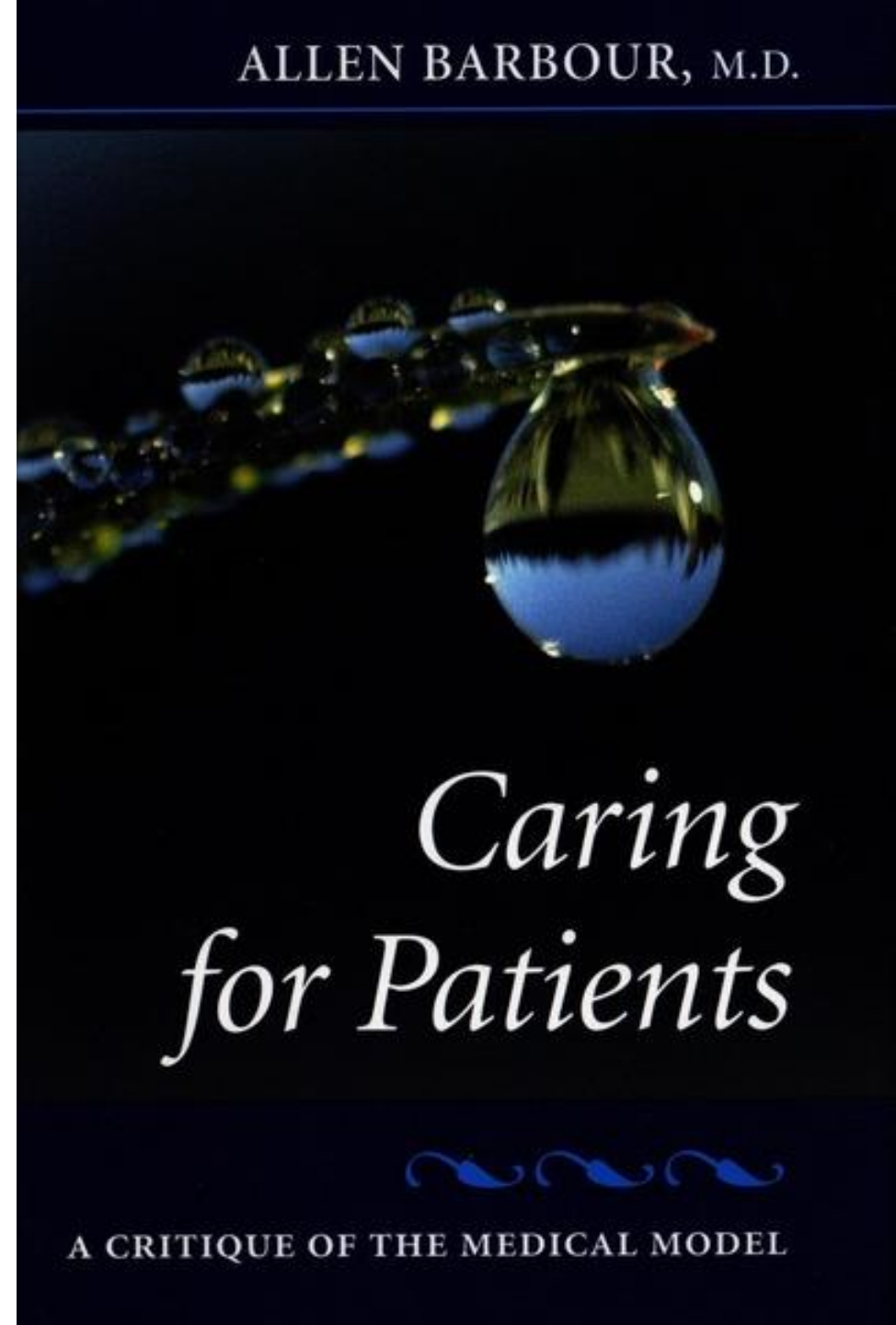


## Criticism of the medical model (1)

- Ignores non-medical factors

“we were trained for seven straight years... to think disease, diagnosis, and treatment as the sole means of managing illness. The model is embedded in our very bones, and... **We focus far more on the “disease” or the “psychopathology” than we do on the person who has it.**

Even when the illness is caused primarily by human situations, we reduce it to names and nostrums.”



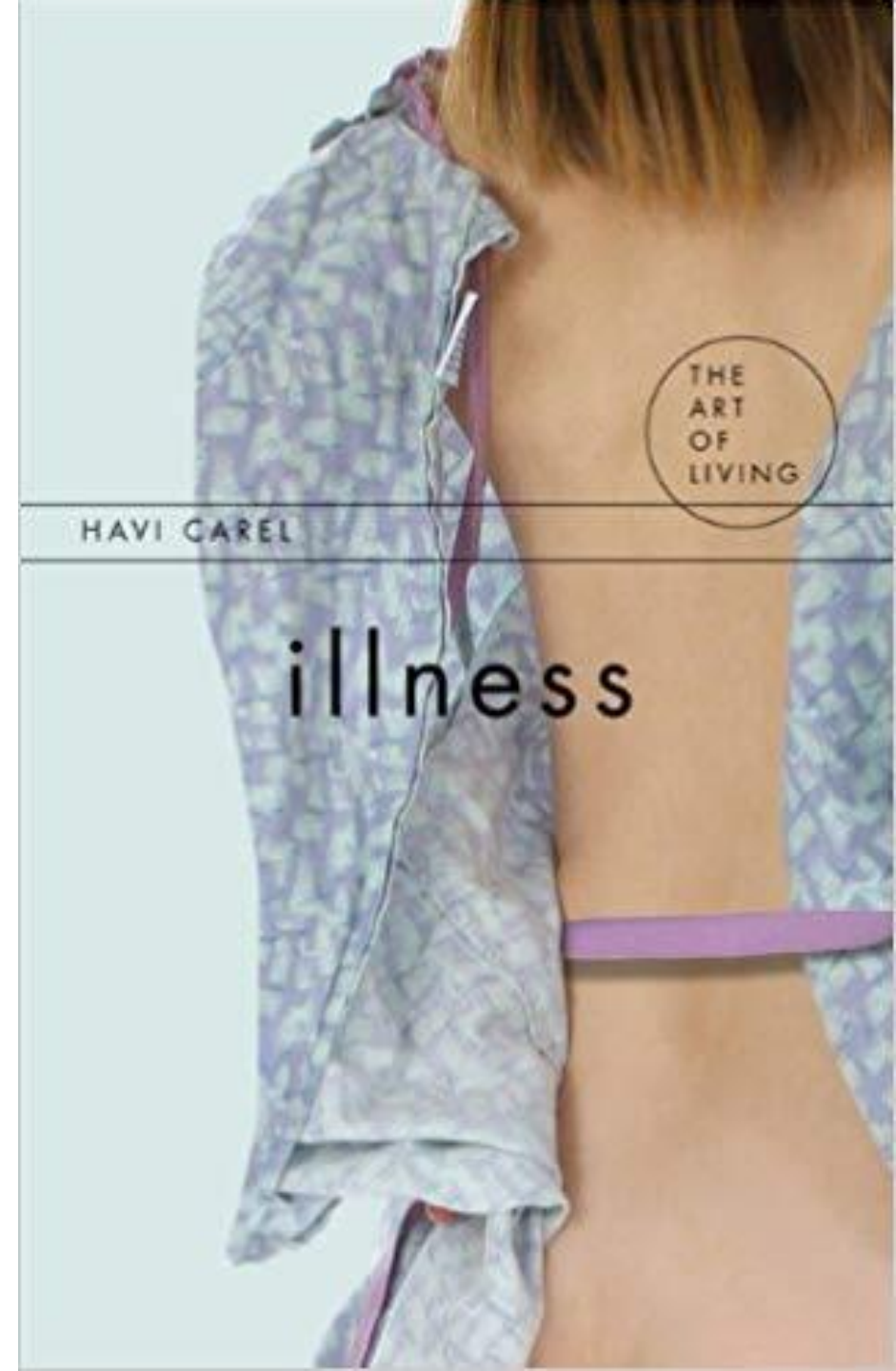
# *Caring for Patients*

A CRITIQUE OF THE MEDICAL MODEL



## Criticism of the medical model (2)

- The expertise of the physician is seen as being inherently more valuable than that of the patient
- Carel (2008) describes this as an “epistemic injustice”:  
  
“In certain extreme cases of paternalistic medicine patients might simply not be regarded as epistemic contributors to their case in anything except the thinnest manner (eg confirming their name or ‘where it hurts’)”



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**Medical Degree**



## Criticism of the medical model (3)

- Privileging of technical knowledge permits secrecy about performance and encourages 'blind trust' – patients have no way of understanding quality
- Coulter (1999):  
“**paternalism** is endemic in the [national health service]. Benign and well intentioned it may be, but it **has the effect of creating and maintaining an unhealthy dependency** which is out of step with other currents in society”

# BMJ

No 7212 18 September 1999

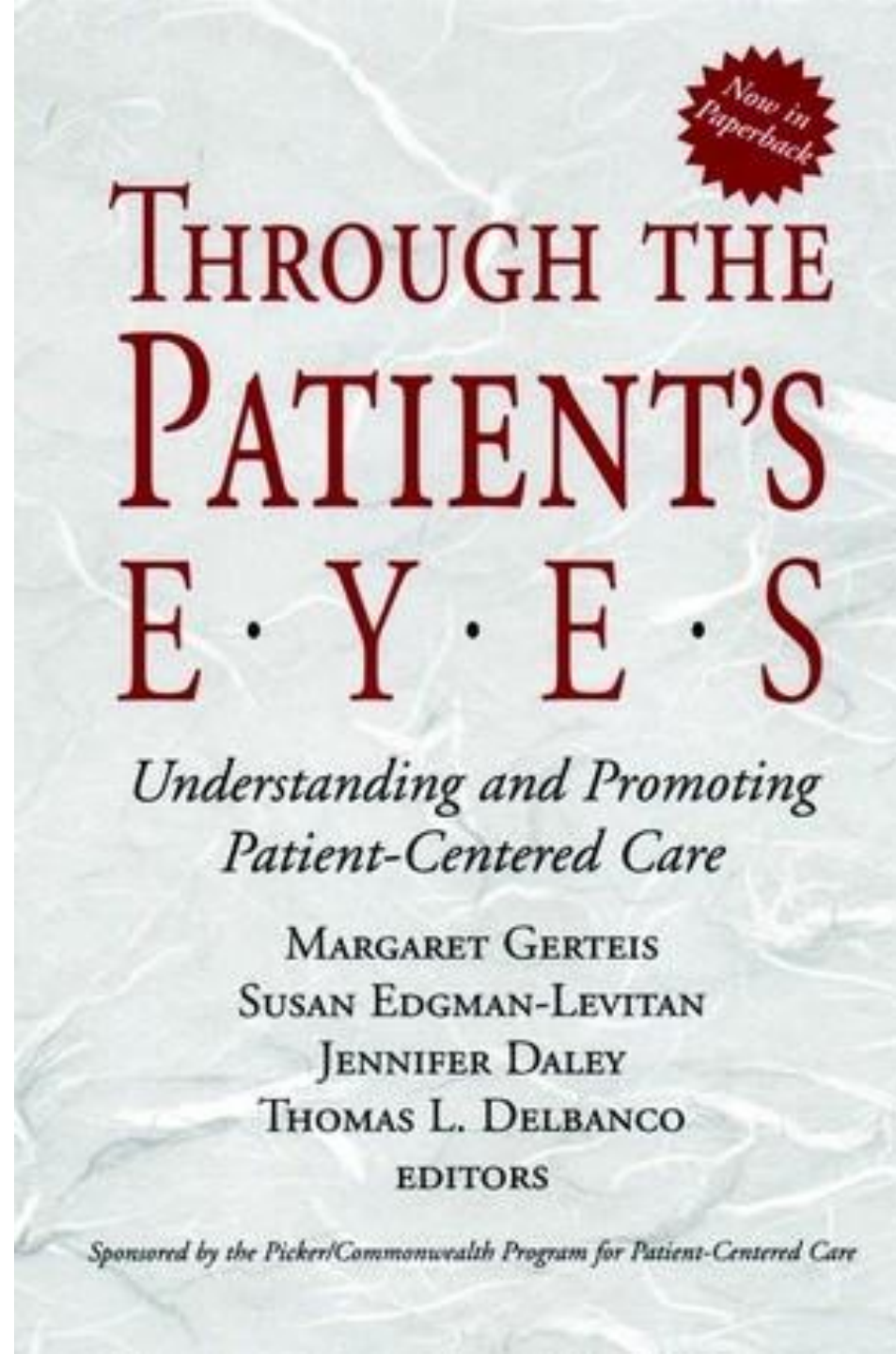


Embracing  
patient  
partnership



# Person centred care

- Puts users 'at the heart of services'
- Encourages view of patients as:
  - *Participants*, not *recipients*
  - *Active*, not *passive*
- Seeks to empower users to be involved...
- ...and services to be built around patients' needs and preferences



**Patient  
experience**

**Quality**

**Safety**

**Clinical  
effectiveness**

## The IHI Triple Aim

**Population Health**

**Experience of Care**

**Per Capita Cost**

*“If quality is to be at the heart of everything we do, it must be understood from the perspective of patients.”*

Lord Darzi, NHS Next Stage Review



# The changing role of patients





# Patients as beneficiaries of care



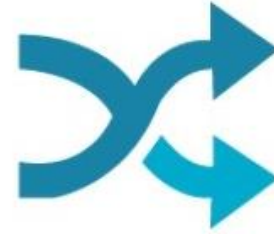
# Picker Principles of Person Centred Care



Fast access to reliable health advice



Effective treatment delivered by trusted professionals



Continuity of care and smooth transitions



Involvement in decisions and respect for preferences



Clear, comprehensible information and support for self-care



Involvement of, and support for, family and carers



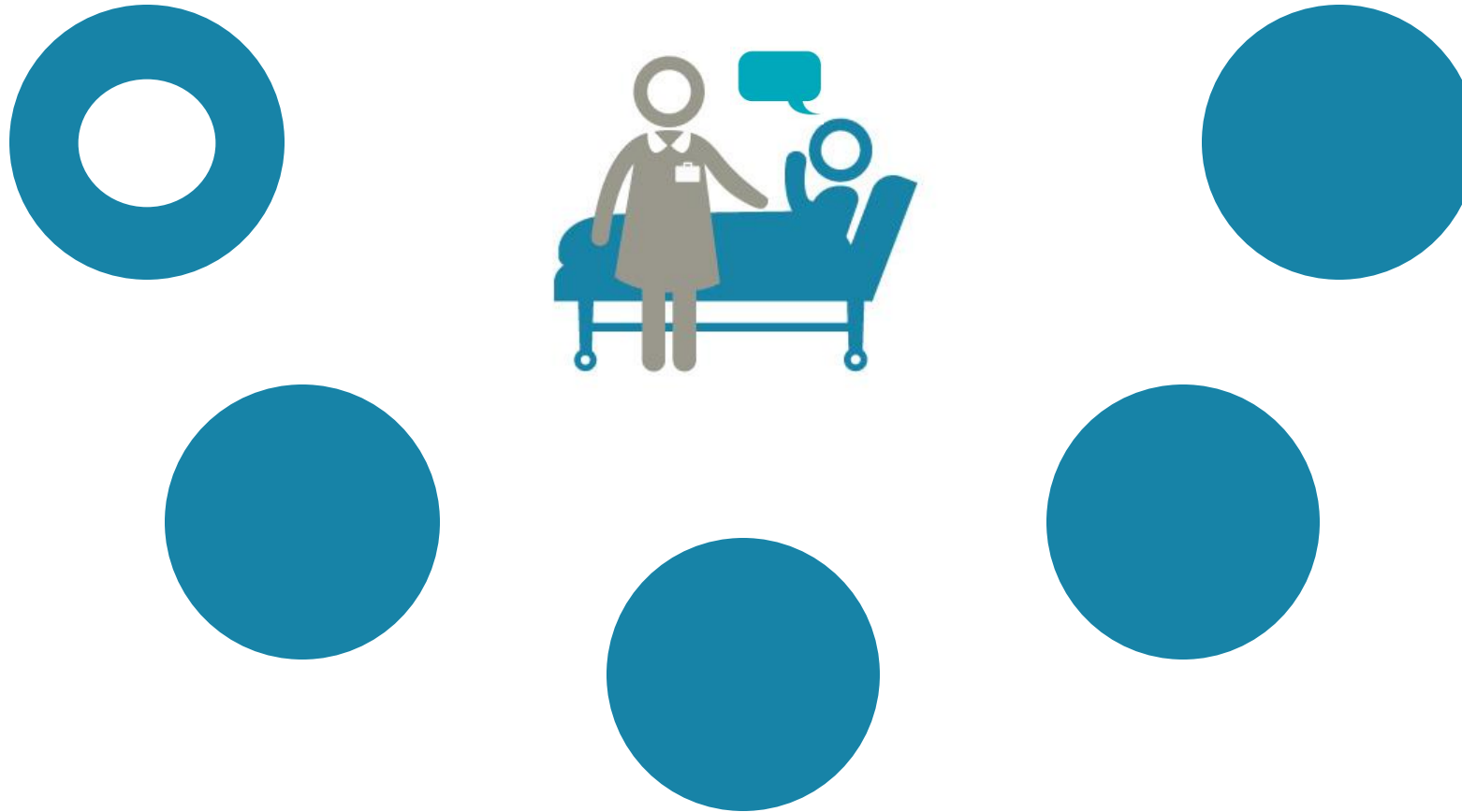
Emotional support, empathy and respect



Attention to physical and environmental needs

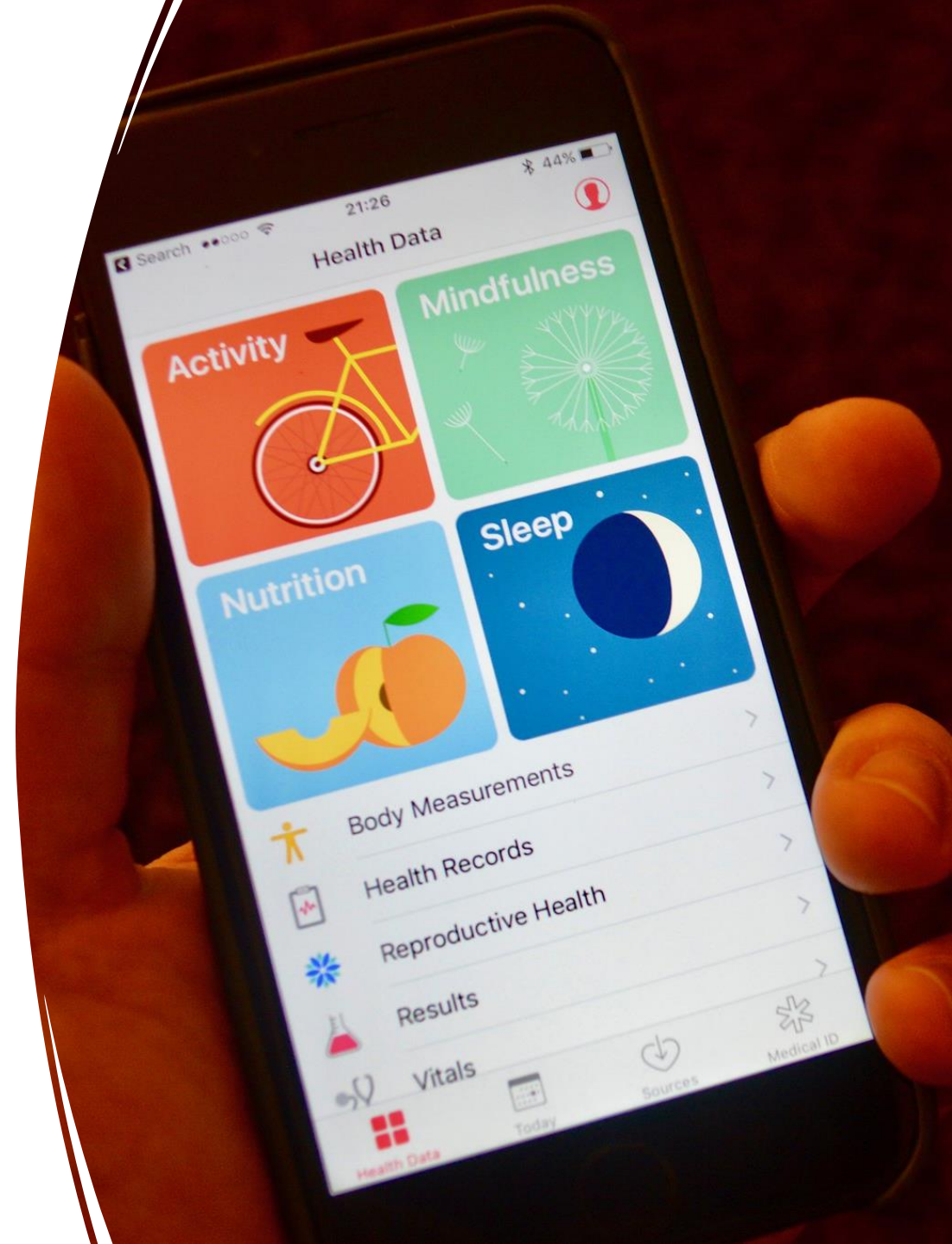


# Respecting people's individual needs



# Active, involved patients

- Technology is – arguably – helping to democratise health and care
- Wearables, apps, and the internet of things all place ever more health insight in the hands of patients
- Does this create a new role – that of the ‘*expert patient*’?







# Patients as informants



# A brief history of patient experience

- 1950s: first patient satisfaction surveys<sup>1</sup>
- 1960s/1970s: limited interest; <10 published papers per year looking at patient satisfaction
- 1980s: 'satisfaction' becomes a priority in UK and US<sup>2-3</sup>
- 1990s: Picker/Commonwealth work seeks to define 'patient-centred care'<sup>4</sup>
- 1990s: criticism of 'satisfaction'<sup>5</sup>; focus begins to move to patient experience<sup>6</sup>

1: Abdellah & Levine, 1957.

2: NHS Management Inquiry, 1983, c.f. BMJ, 1983, pp.1393.

3: Cleary & McNeil, 1988.

4: Gerteis et al., eds, 1993.

5: Williams, 1994.

6: Cleary, 1998.

# Experience vs satisfaction

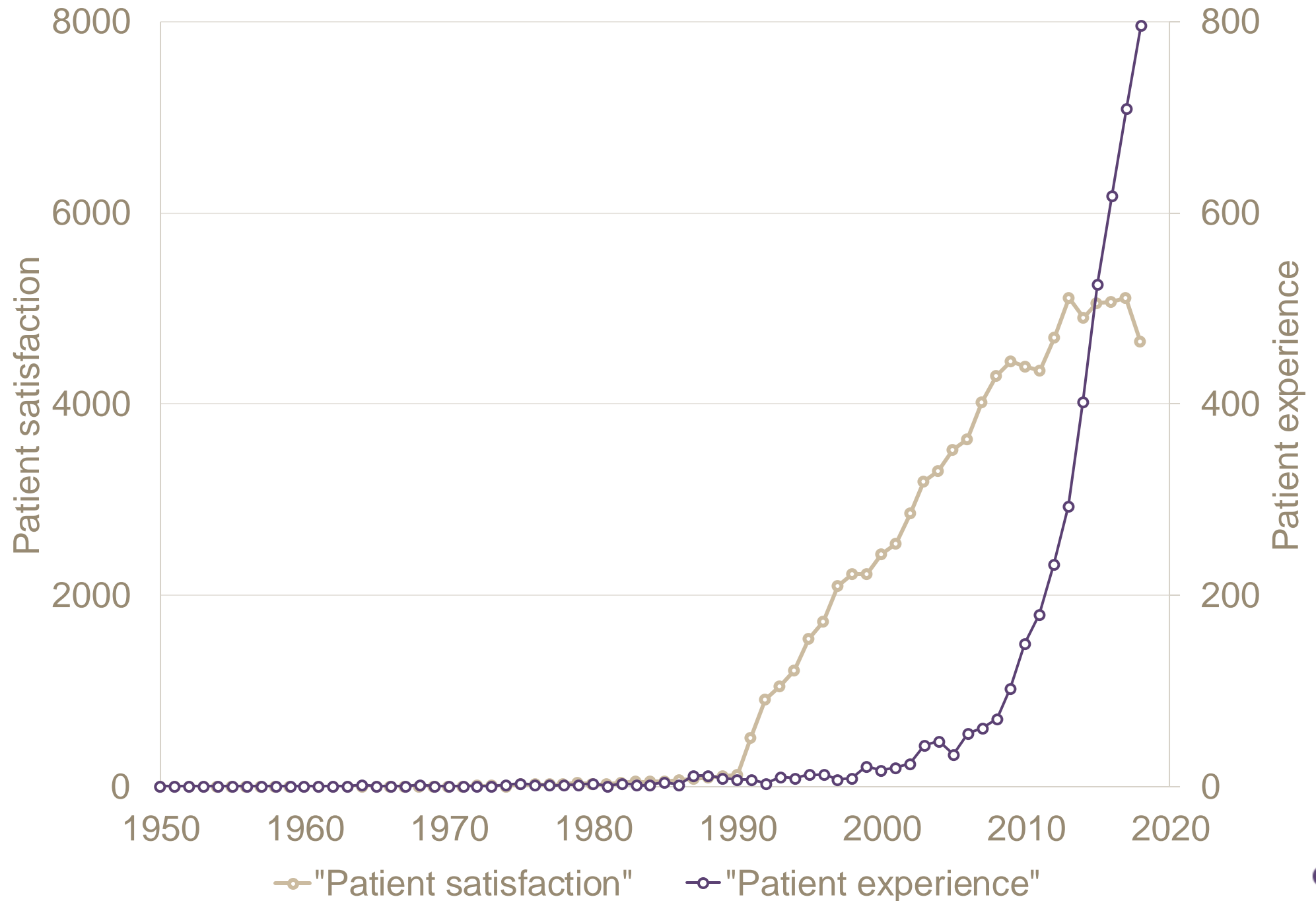
- Satisfaction...
  - “Implies only that expectations have been met”<sup>1</sup>
  - Is highly subjective
  - Represents “a complex function of expectations that may vary greatly among patients”<sup>2</sup>
  - Is generally not actionable
  - “Tends to endorse the status quo”<sup>3</sup>
- Good user experience is *both* related to clinical effectiveness *and* an end in its own right

1 Cleary, P.D. (1998). Satisfaction may not suffice! A commentary on ‘a Patient’s Perspective’. *International Journal of Technology Assessment in Health Care* 14 (1) 35-37.

2 Cleary, P. D. (1999). The increasing importance of patient surveys. *BMJ*, 319(7212), 720–721.

3 Williams, B. (1994). Patient satisfaction: A valid concept? *Social Science & Medicine*, 38(4), 509–516. [http://doi.org/10.1016/0277-9536\(94\)90247-X](http://doi.org/10.1016/0277-9536(94)90247-X)

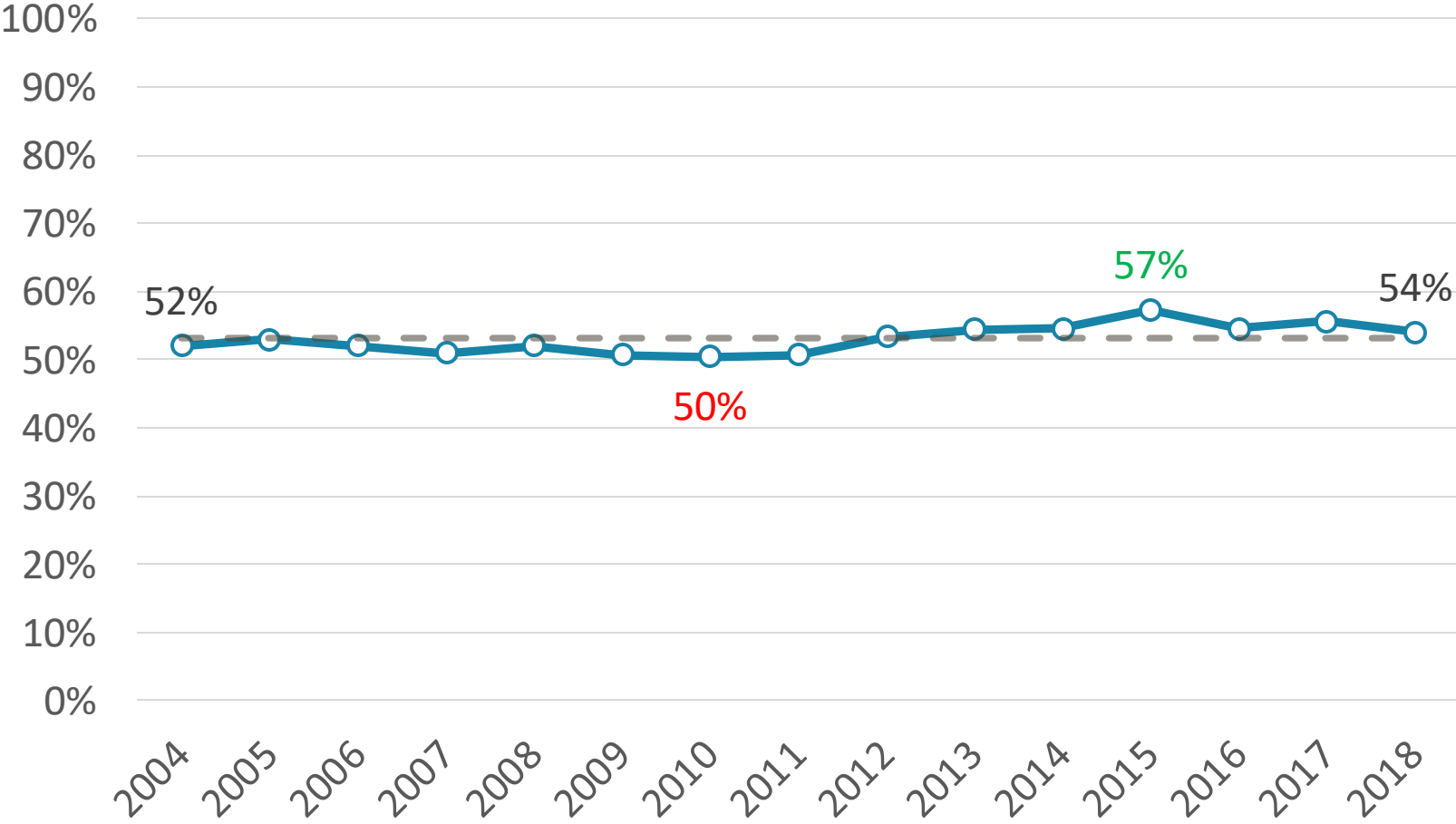




# Inpatients: “Were you involved as much as you wanted to be in decisions about your care and treatment?”



Involvement in decisions and respect for preferences



Source: Care Quality Commission/ Picker – NHS Adult Inpatient Survey 2018



# Patients as partners



# Understanding co-production

- Many and varied definitions
  - Can include individual and/or collective action
  - Can be about ‘influence’ or ‘power’
- It is **not** engagement, consultation, feedback, or even co-design – it is *all* of these and more
- The idea of coproduction has developed gradually and has its roots in theories of citizen participation

# Arnstein (1969): “A Ladder of Citizen Participation”

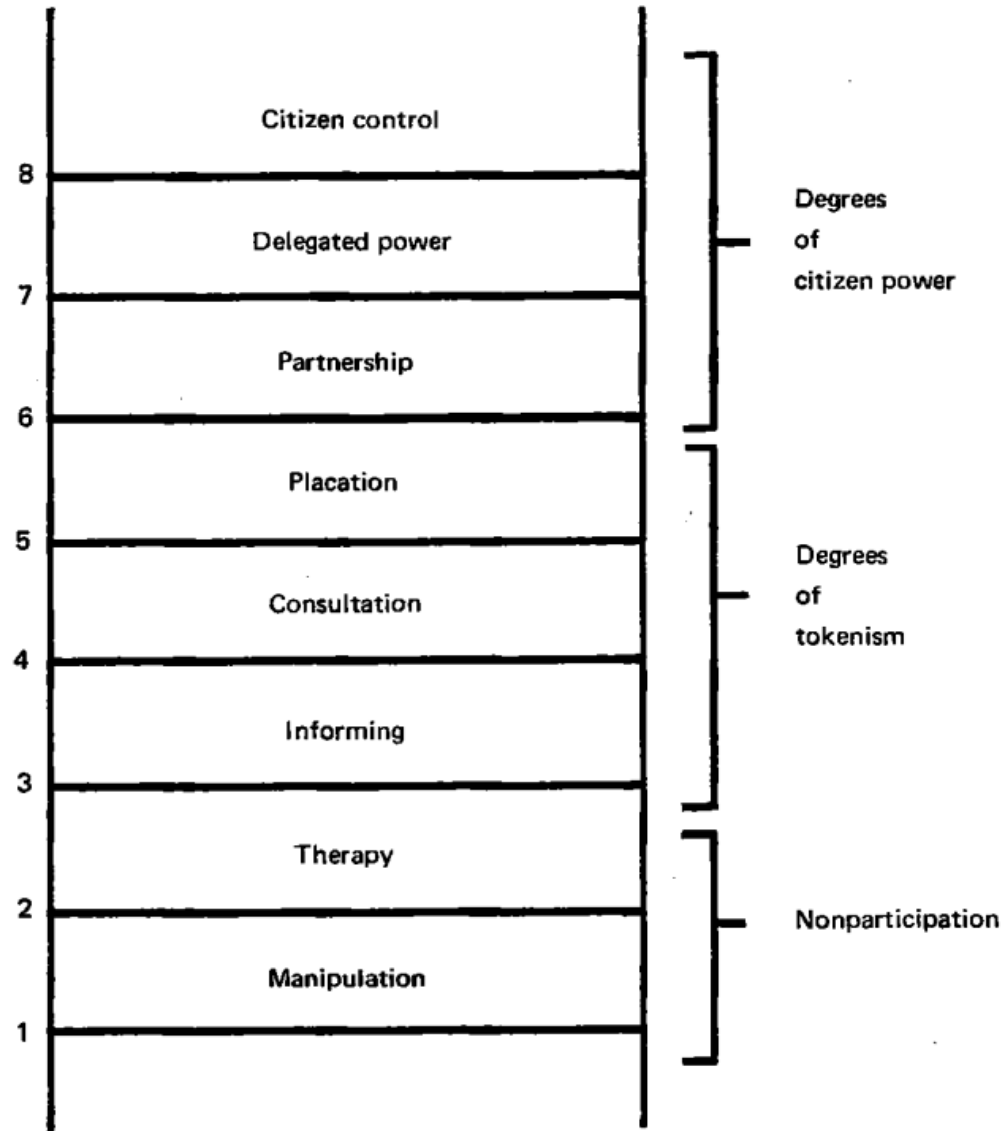
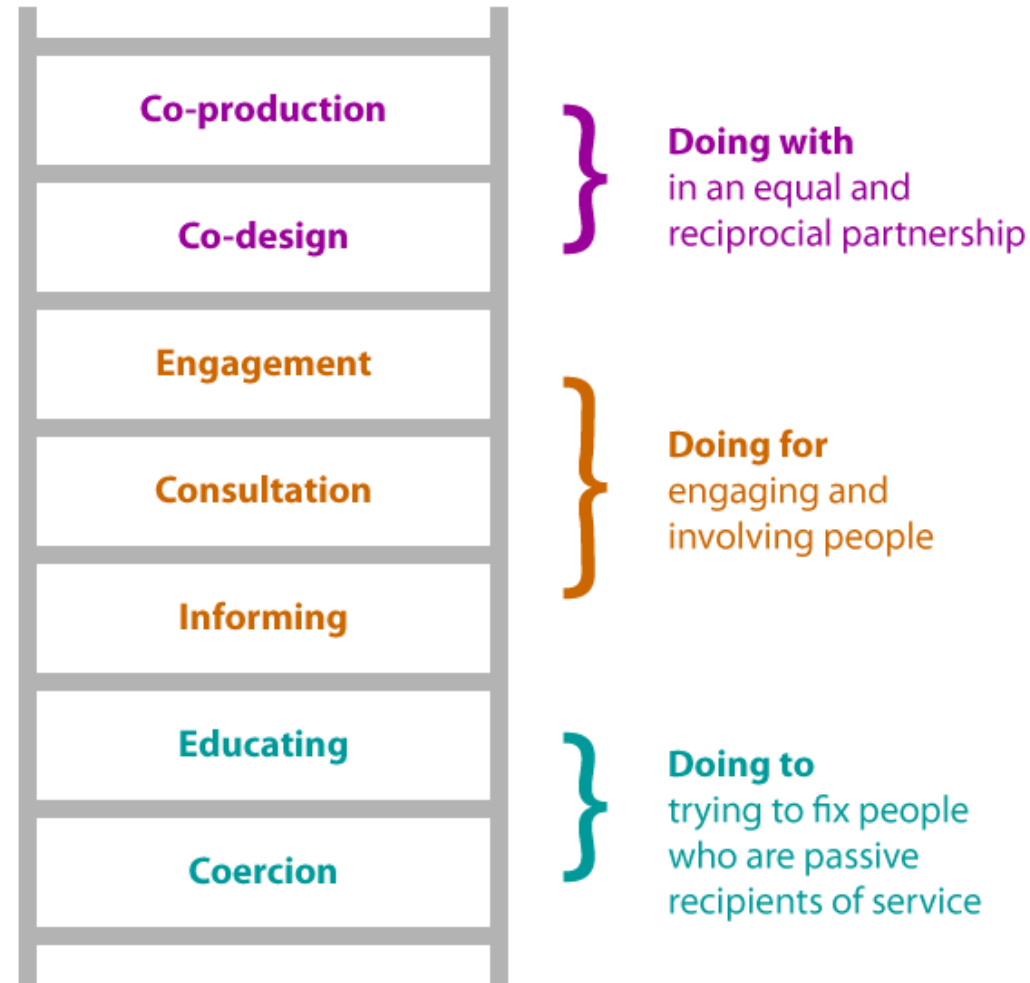


FIGURE 2 *Eight Rungs on a Ladder of Citizen Participation*

# Think Local Act Personal: “Ladder of Co-production”



# Always Events<sup>®</sup>

- Defined as:
  - “those aspects of the patient and family experience that should always occur when patients interact with healthcare professionals and the delivery system.”
- Piloted and evaluated in the NHS
- Four phases completed – more than 100 organisations involved to date



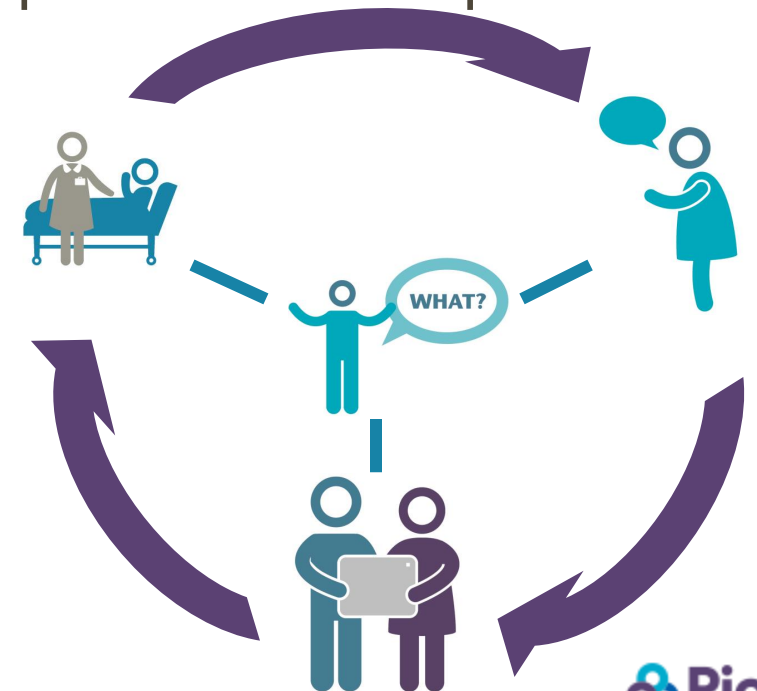


## Conclusions



# Key messages

- Person centred care is intended to put people at the heart of how services are designed and delivered
- To achieve this, we need to recognise and welcome patients in multiple roles:
  - As *beneficiaries* of care
  - As *informants* on quality in practice
  - As *partners* in service design
- These roles can be part of an improvement cycle



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