

Evolution of Patient Engagement

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 @acpatient

Overview

- Brief history of patient engagement
- Involvement in individual care
- Feedback for quality improvement
- Co-production and co-design

A Brief History (1)

1960s

- Early critiques
- Campaigning groups

1970s

- Feminism and self-care
- Biopsychosocial models

1980s

- Patient-centredness
- Patient experience and PRO measurement

A Brief History (2)

1990s

- Patient rights and charters
- Competition and choice

2000s

- Shared decision-making
- Chronic care model

2010s

- Coordination and integration
- Co-production

Shared Decision Making

- Clinicians and patients working together to select treatments, based on clinical evidence and the patient's informed preferences.



Sharing Expertise

Clinician

- Diagnosis
- Disease aetiology
- Prognosis
- Treatment options
- Outcome probabilities

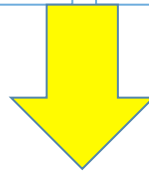
Patient

- Experience of illness
- Social circumstances
- Attitude to risk
- Goals, values, preferences
- Support needs

The Silent Misdiagnosis

Patients:
unaware of treatment or
management options and
outcomes

Clinicians:
unaware of patients'
circumstances and
preferences



Poor decision quality

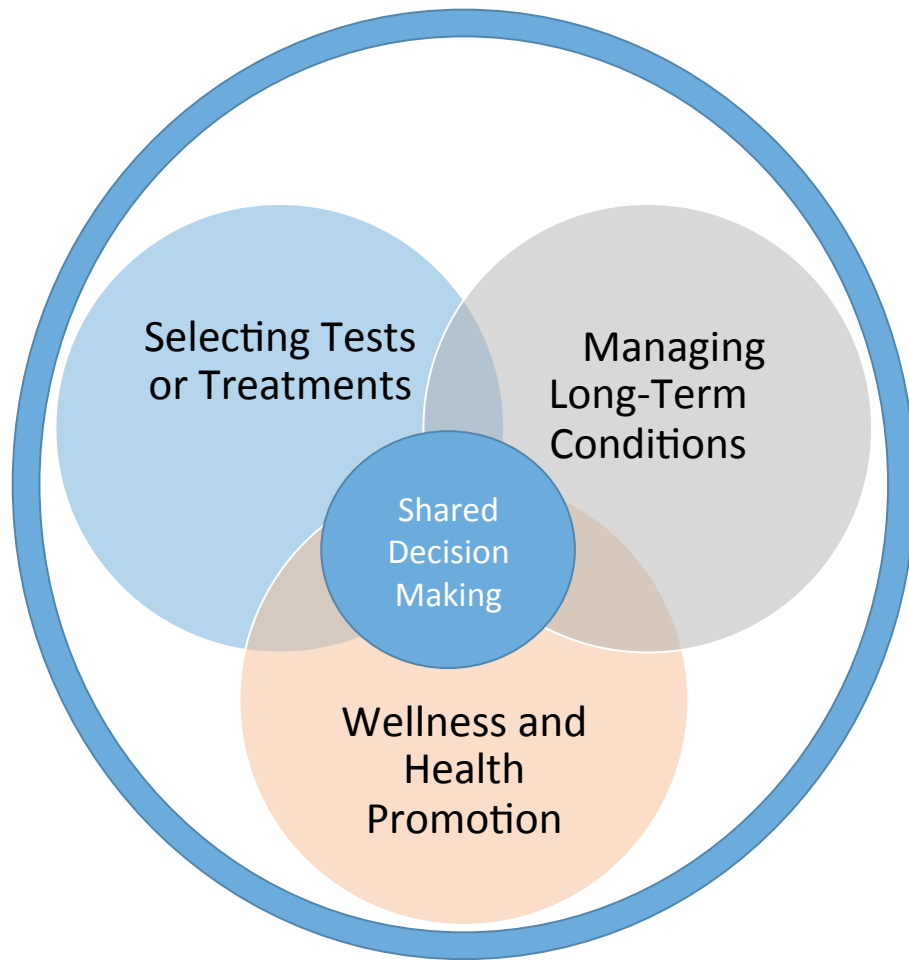
The Passive Patient





I want to:
Know my options
Understand the tradeoffs
Make a choice that's right for me

I want to:
Present the options
Communicate risks and benefits
Provide good care (and)
Not get swamped by it

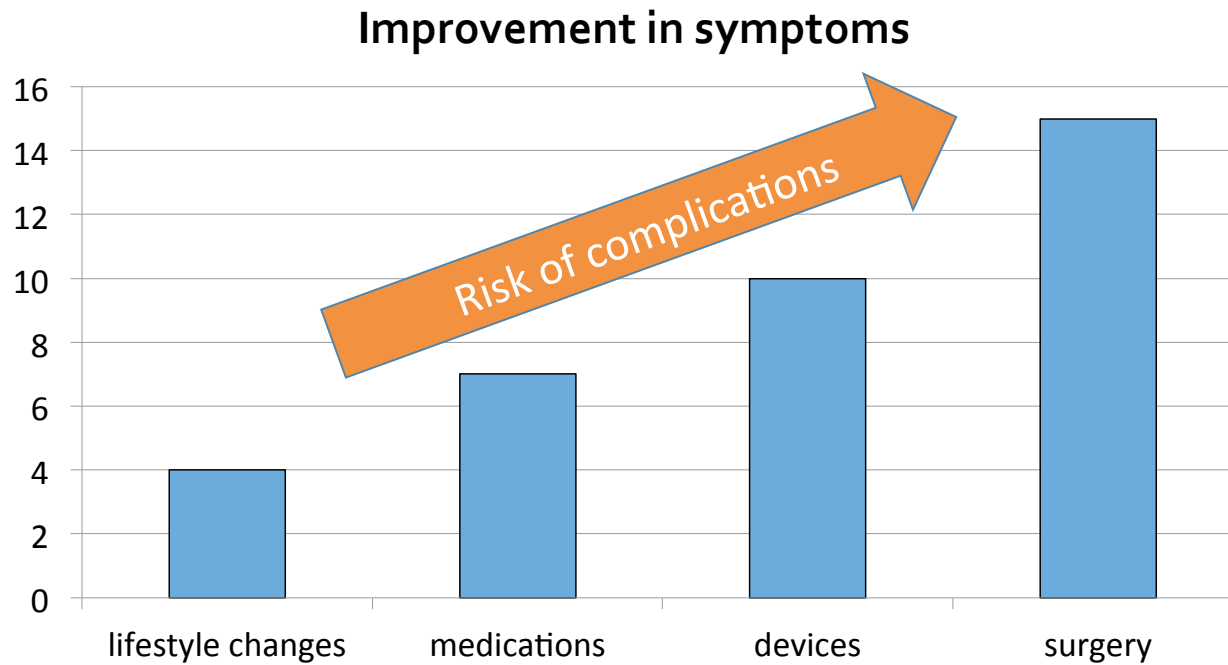


What Patients Need to Know

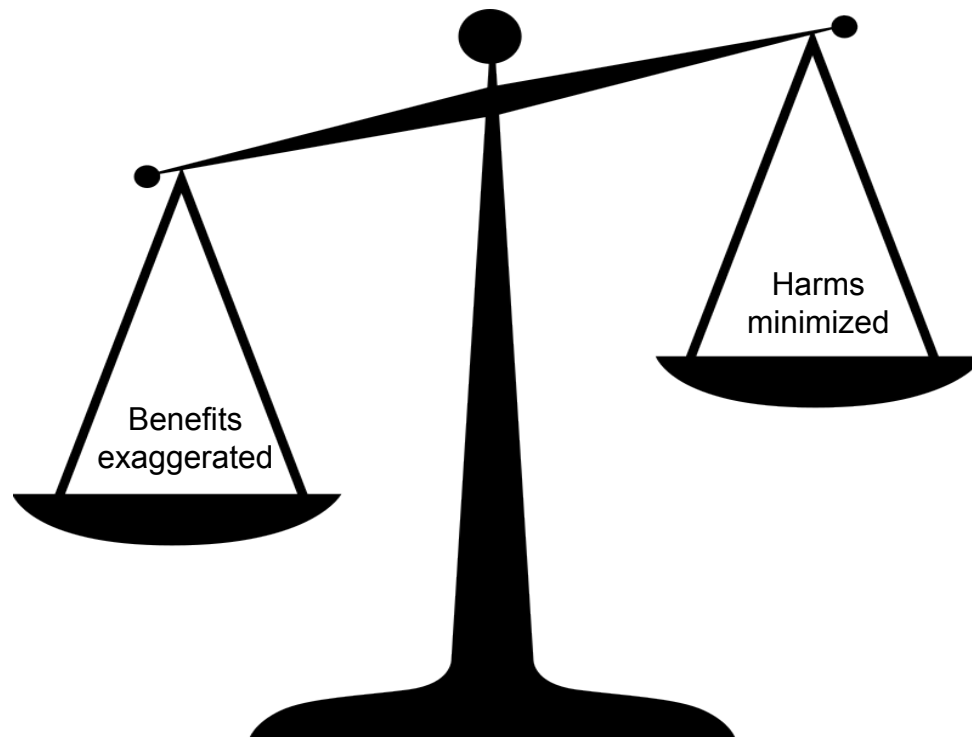
- What are my options?
- What are the benefits and possible harms?
- How likely are these benefits and harms?
- What can I do to help myself?
- What can you do to support me?



Appraising Options and Trade-Offs



Health Information is Often Unbalanced



Arthritis: Should I Have Knee Replacement Surgery?



1
Get the
Facts



2
Compare
Options

3
Your
Feelings

4
Your
Decision

5
Quiz
Yourself

6
Your Summary

What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and show how you feel about the following statements.

Reasons to have knee replacement surgery

Reasons not to have knee replacement surgery

I want to be able to do low-impact activities, such as swimming and golf, as well as chores and housework.

My knee doesn't really get in the way of the physical activities I like or need to do.



Six Elements of Shared Decision Making



1

Invite patient
to participate



2

Present options



3

Provide
information on
benefits and risks



4

Weigh options
based on patient
goals and concerns



5

Facilitate
deliberation and
decision making



6

Assist with
implementation

Patient Decision Aids: the Evidence

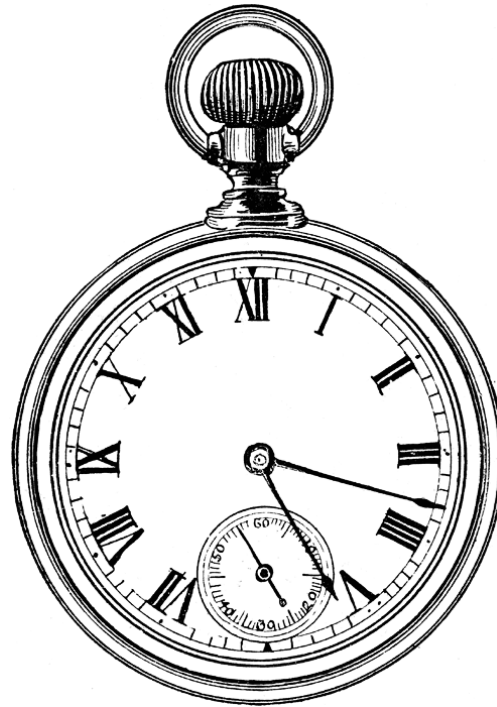
- In 115 trials involving 34,444 participants, use has led to:
 - Greater knowledge
 - More accurate risk perceptions
 - Greater comfort with decisions
 - Increased participation in decision-making
 - Better agreement between values and choice
 - Fewer patients choosing major surgery



Managing Long Term Conditions

Professional care –
3 hours per year (1 x 15 mins
month)

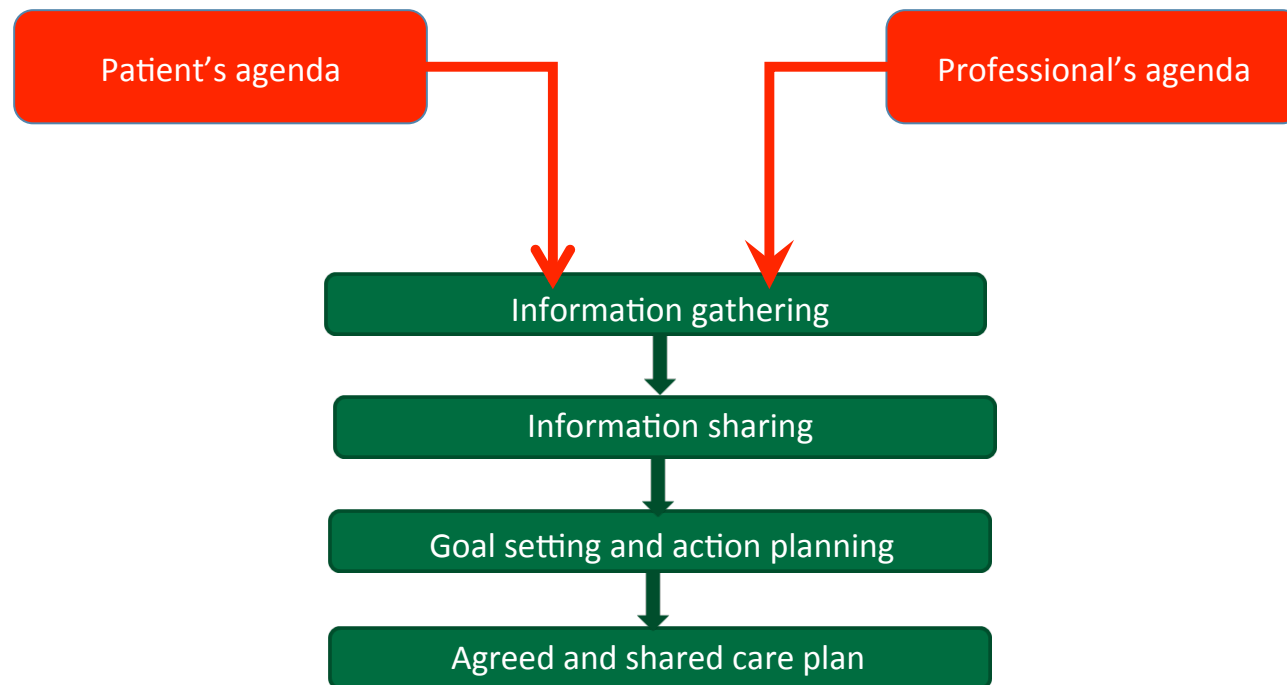
Self-care –
8,757 hours per year



The Chronic Care Model



Care Planning Conversations



**Care
planning
cycle**

Care Planning: the Evidence

- In 19 trials involving 10,856 participants, personalised care planning led to:
 - Better physical health (blood glucose, blood pressure)
 - Better emotional health (depression)
 - Better capabilities for self-management (self-efficacy)



Coulter et al. Personalised care planning for adults with chronic or long-term health conditions. Cochrane Database of Systematic Reviews, 2015

The four principles of person-centred care



Why Patient Experience Matters



People who report better healthcare experiences.....

- Are more satisfied with their care
- Are more likely to adhere to treatment/ prevention recommendations
- Are less likely to die from acute myocardial infarction
- Have fewer consultations and admissions
- Have safer care and fewer adverse events

Price et al. Medical Care Research and Review 2014

What are we measuring?

- Processes observable by patients
 - Subjective (e.g. pain was controlled)
 - Objective (e.g. length of time waited)
 - Observations of others' behaviour (e.g. doctor, nurse, other staff)
- Outcomes observable by patients
 - Physical (e.g. climbing stairs)
 - Psychological (e.g. mood)
 - Subjective (e.g. knowledge)
 - Self-management capabilities (e.g. self-efficacy)
 - Health-related behaviours (e.g. diet, exercise)
 - Use of health services (e.g. number of admissions)

How are we measuring these things?

➤ Quantitative methods

- Structured surveys (postal, face-to-face, phone, online)
- Routine data (e.g. HES)

➤ Qualitative methods

- Focus groups
- Narrative interviews
- Observations
- Secondary sources (e.g. social media)

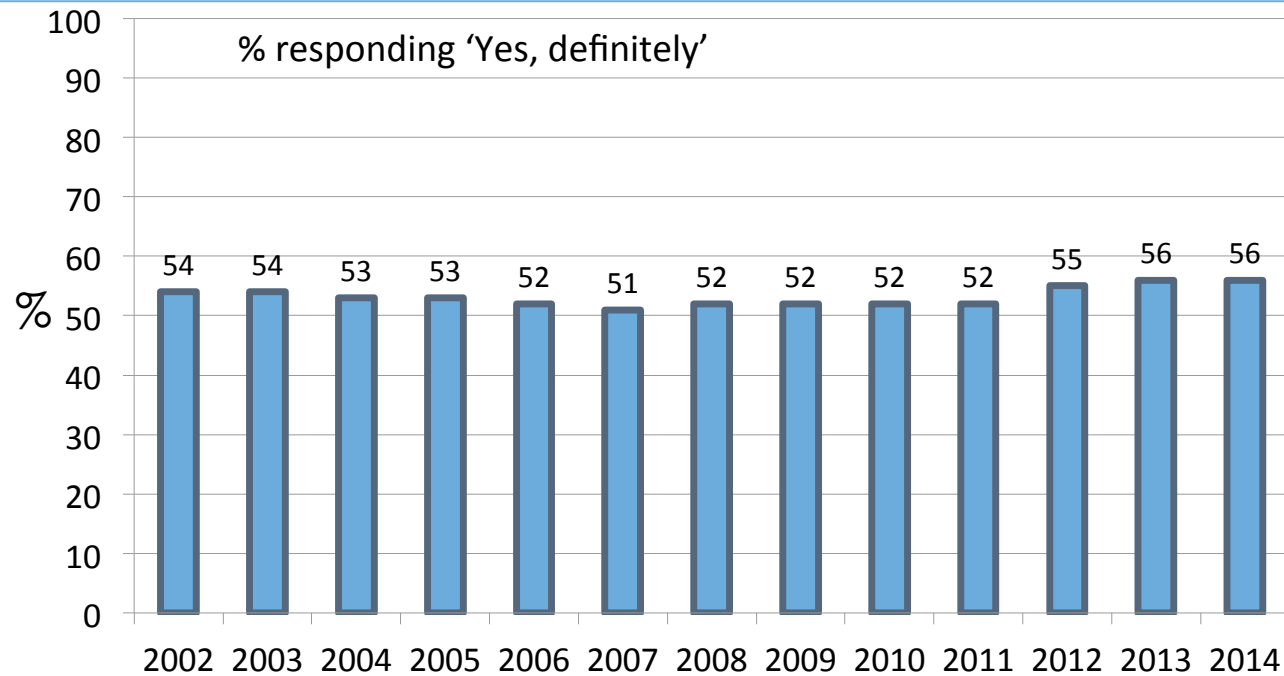
Patients' Ratings of Hospitals

The screenshot shows a web browser window displaying the NHS Choices website. The address bar shows the URL <http://www.nhs.uk/Services/hospitals/ReviewsAndRatings/De>. The page header includes navigation links: Home, About, Contact, Tools, Video, Choose and Book, Communities, and IPS. There are also links for Translate and Log in or create an account. The NHS Choices logo is prominently displayed with the tagline "Your health, your choices". A search bar is present with the placeholder text "Enter a search term". Below the search bar are navigation buttons for Health A-Z, Live Well, Care and support, Health news, and Services near you. The main content area features a section for John Radcliffe Hospital, including its name, telephone number (01865 741166), address (Headley Way, Headington, Oxford, Oxfordshire, OX3 9DU), and website (<http://www.ouh.nhs.uk/hospitals/jr/default.aspx>). A rating section shows a 4-star rating (4 out of 5 stars) and a "Leave review" button. Below this, a detailed rating section shows "4 Stars" with 4 yellow stars and 1 white star, and the text "NHS Choices users' overall rating Based on 213 ratings for this hospital". A navigation bar at the bottom of the hospital section includes links for Overview, Departments and services, Facilities, Contact details, map and directions, Reviews and ratings, and Leave review.

Patients' Ratings of Senior Doctors



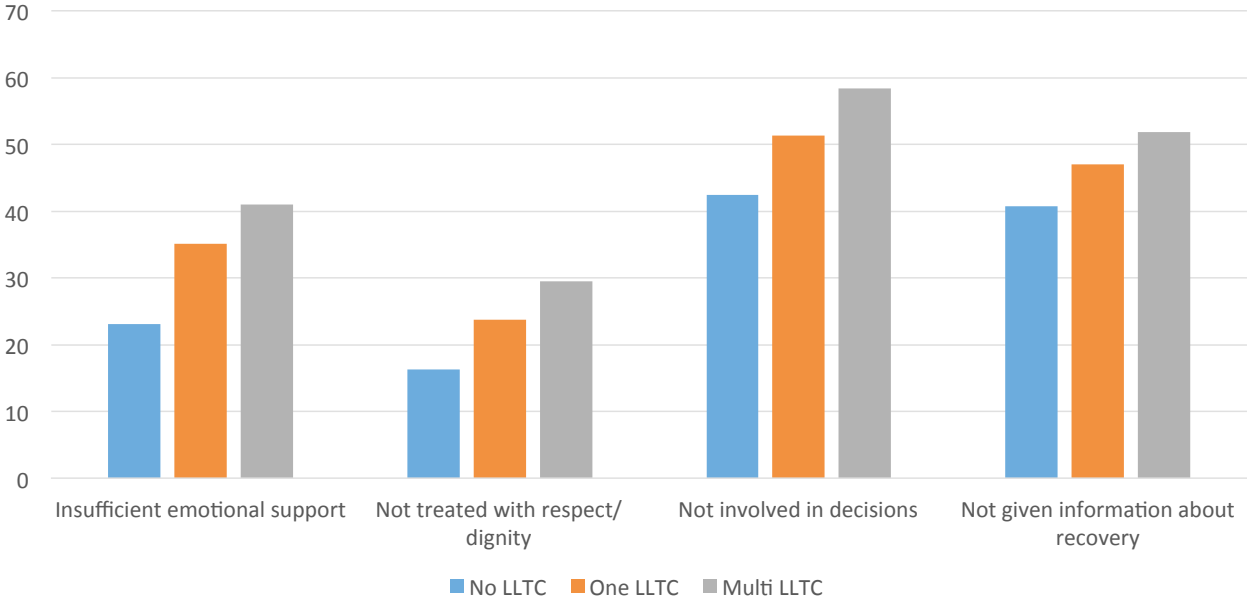
Were you involved as much as you wanted to be in decisions about your care and treatment?



Source: NHS inpatient surveys

Problems by Health Status (LTCs)

NHS Adult Inpatient Survey 2011



Hewitson et al. BMC HSR 2014

Measurement is Not Enough



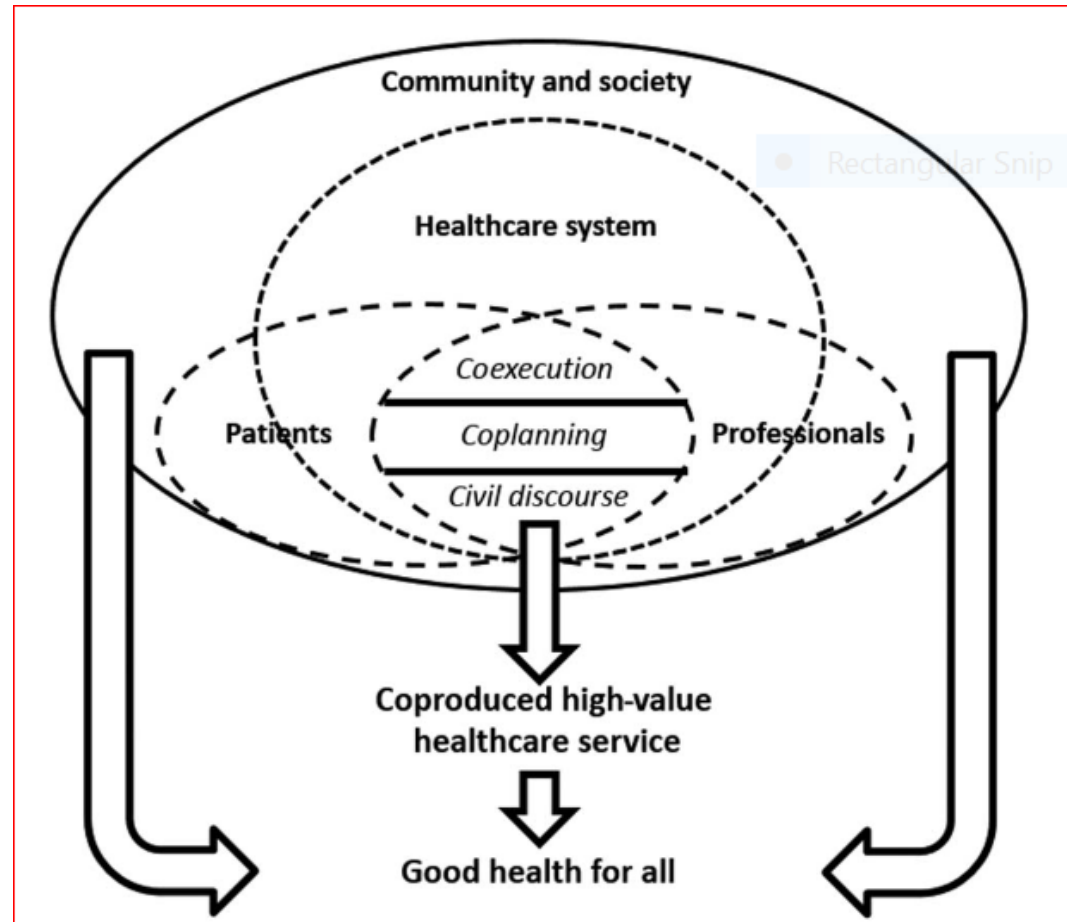
Co-Production = promoting productive partnerships to tackle difficult problems together



Co-production

- Healthcare is a service, not a product
- Services are co-produced by service professionals and service users
- Health outcomes are a product of the dispositions, capacities and behaviours of both parties

Batelden et al BMJ Qual Saf 2015



Experience-Based Co-Design



- Uses all available knowledge, expertise, networks and influence
- Enables new thinking about old problems
- Increases responsiveness and relevance
- Reduces waste and cost

Barriers and Challenges



- Time/resources
- Inflexible systems
- Clinical culture

Essential Elements of a Change Strategy

- ✓ Strong, committed senior leadership
- ✓ Dedicated champions
- ✓ Active engagement of patients and families
- ✓ Clear goals
- ✓ Focus on the workforce
- ✓ Building staff capacity
- ✓ Adequate resourcing
- ✓ Performance measurement and feedback

