

Engaging Patients in Generation
and Use of Evidence:
how are we doing?

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THE NHS
CONSTITUTION
the NHS belongs to us all

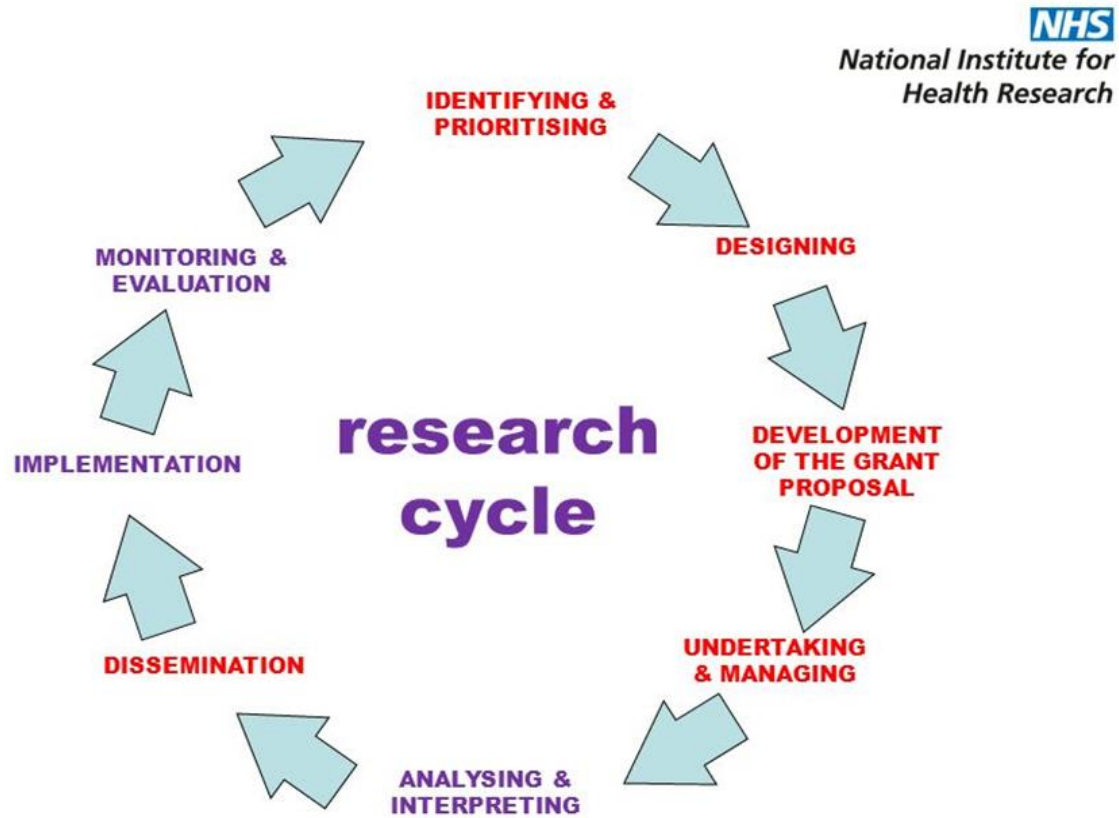
Research for all?

- Asking the right questions?
- Funding the best studies?
- Measuring outcomes that matter?
- Making research accessible?
- Encouraging use of evidence?

Patient and public involvement in research

Funding	Participating	Prioritising	Designing and delivering	Disseminating	Using
Taxpayer contributions Donations to medical charities	Clinical trials HSR Epidemiology Feedback on experiences	Consultations Priority-setting partnerships Funding bodies	Study design Selecting outcome measures Ethical approval Recruiting participants Gathering data Analysing data Writing up results	Publishing articles Peer review Systematic reviews Developing clinical guidance	Understanding disease and prevention Improving quality and safety Reducing waste Making decisions

National Institute for Health Research (NIHR)



James
Lind
Alliance

Priority Setting Partnerships

INVOLVE



SPIRE
VOLVE
FLUENCE
NOVATE

Involvement in commissioning research



Fig. 1. Examples of how public contributors worked with CCF in 2016/17

Involvement in study design and implementation

- Helps with funding and ethics approval
- Better recruitment, study information, data collection instruments
- BUT lack of evidence on impact

Evans D et al. *Health Services and Delivery Research* (2014)

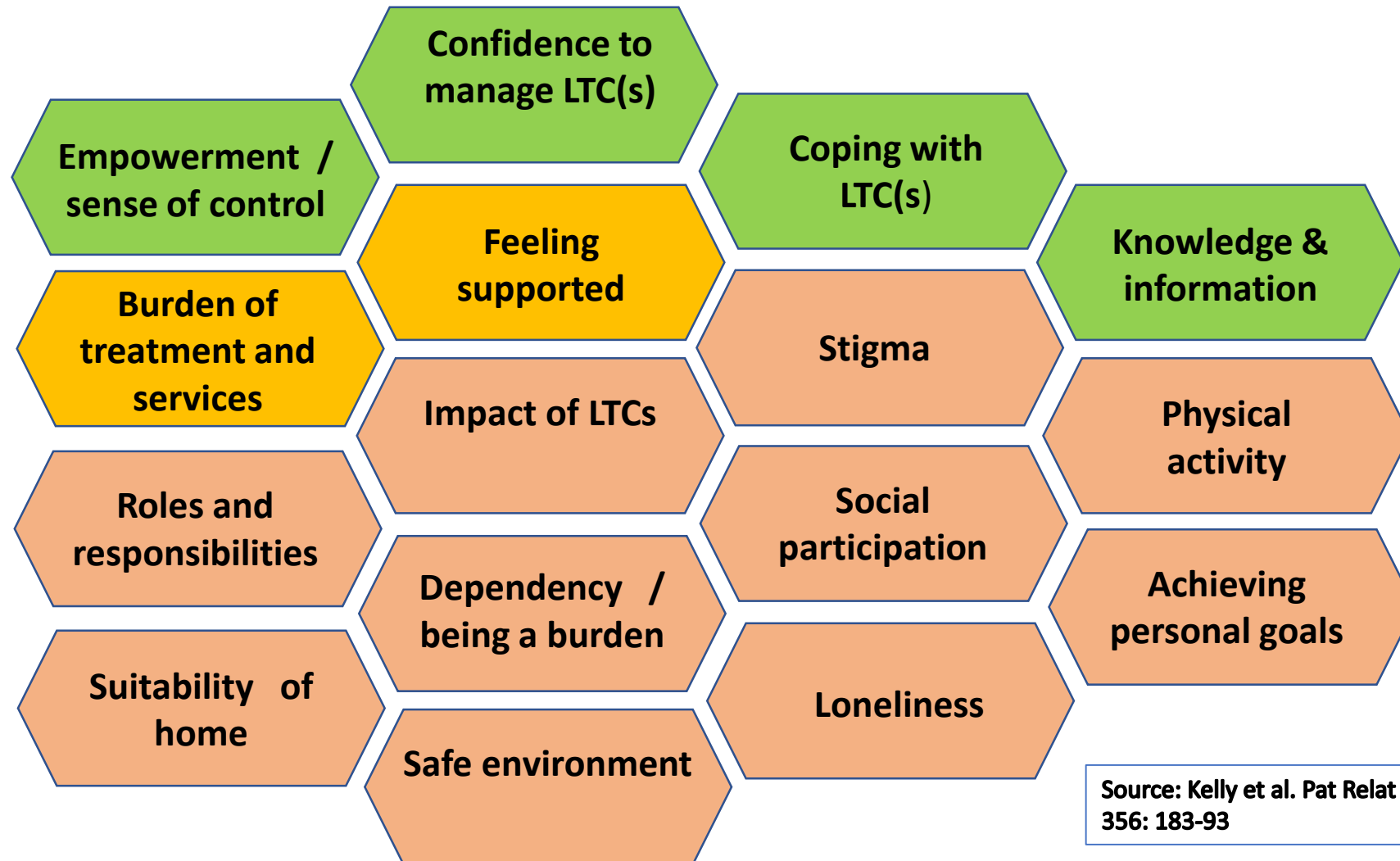
Staley K. *Research Involvement and Engagement* (2015)

Brett J et al. *Health Expectations* (2014)

Domecq J P et al. *BMC Health Services Research* (2014)



Measuring outcomes that matter



Source: Kelly et al. Pat Relat Outcome Meas 2016; 356: 183-93

Involvement in developing PROMs

- Patients were involved in the development of only 11% of 193 patient-reported outcome measures (PROMs)

Wiering B et al. *Health Expectations* 2017;20(1):11-23



Involvement in journals



- Increase relevance and reduce waste in research
 - Patient peer review of articles, mandatory statement on patient involvement in research studies
- Clearer focus on patients' priorities
 - Patients as contributors/co-authors of articles
- Better understanding of what matters to patients
 - Patient editors, patient-led content, BMJ Opinion, Tweet chats

Involvement in clinical guidelines



G-I-N PUBLIC's
Toolkit on
Patient and Public Involvement in Guidelines

UPDATED!

Making research findings accessible to patients

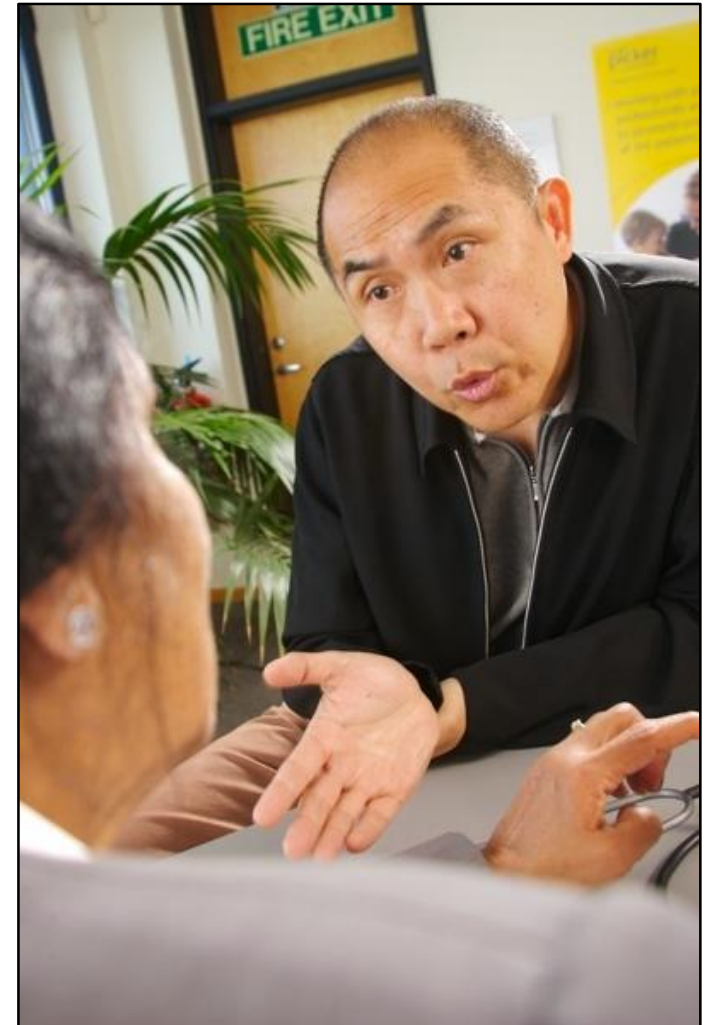


What patients need to know

what are my
options?

what are the possible
benefits and risks of
those options?

how **likely** are the
benefits and risks of
each option to occur?



Shared decision-making

Clinicians and patients working together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences.

Coulter and Collins. Making Shared Decision Making a Reality. King's Fund 2011





Key components of shared decision-making

- 1. Information**
Reliable, balanced, evidence-based information outlining prevention, treatment, or management options, outcomes and uncertainties
- 2. Deliberation**
Decision support with clinician or health coach to clarify goals, options, preferences and actions
- 3. Implementation**
System for recording, communicating and implementing patient's preferences

Patient decision aids



- Information about treatment options and likely outcomes
- Help to determine preferences - what matters most to you?

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.	
		
More important	Equally important	More important
I have more bad days than good.	I have more good days than bad.	
		
More important	Equally important	More important

Risk Communication

- Explain uncertainty
- Numbers are often better than words and graphics are even better
- Use natural frequencies, not percentages or relative risk
- Use specific time frames
- Constant denominators are better than constant numerators
- Use both positive and negative framing where possible
- Give individually-tailored probabilities adjusted for baseline risk where possible
- Make risks relevant with everyday examples

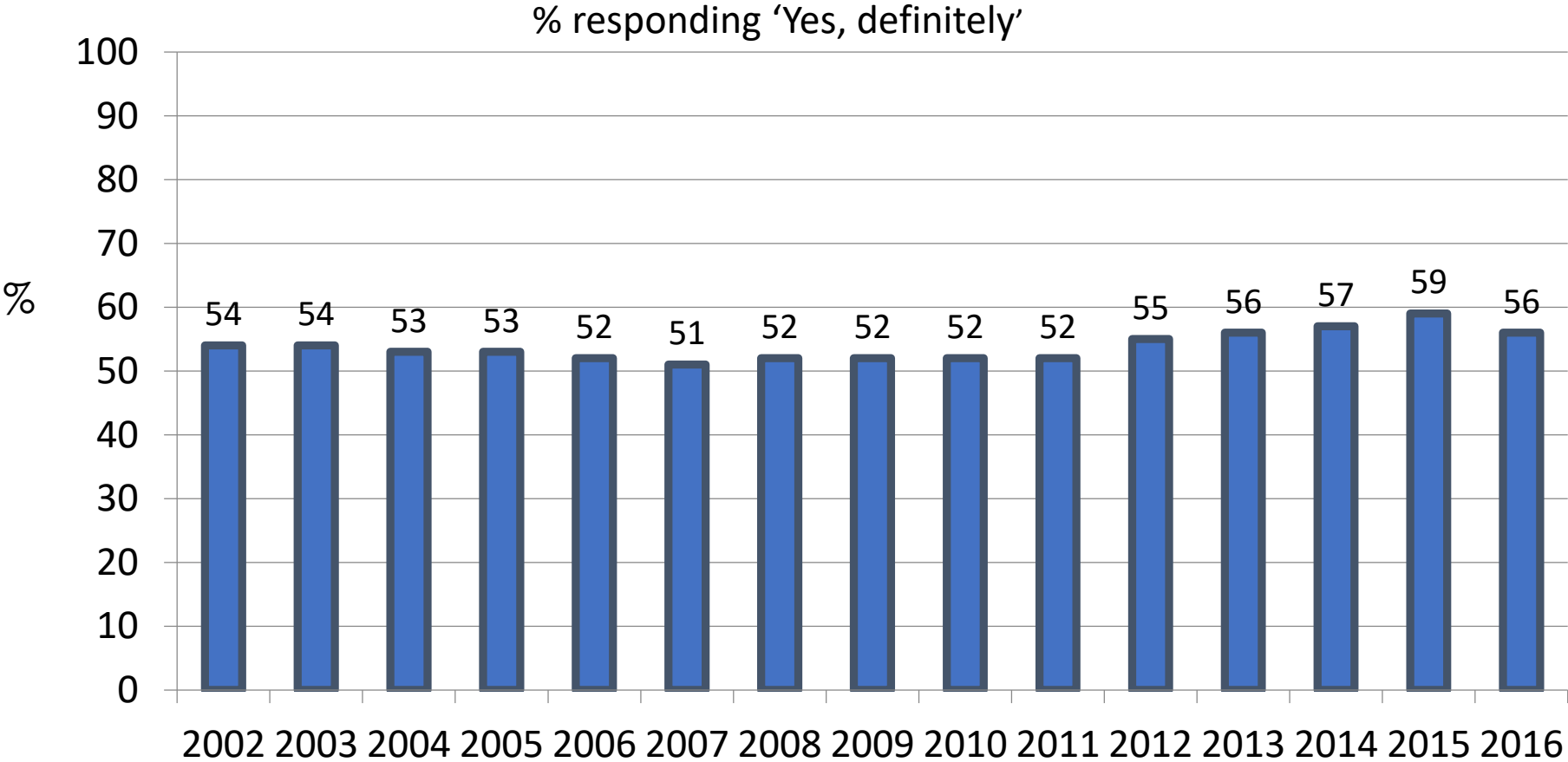


Patient decision aids: the evidence

- In 105 trials involving 31,043 participants, use has led to:
 - Improved knowledge
 - More accurate risk perceptions
 - Greater comfort with decisions
 - Greater participation in decision-making
 - Fewer people remaining undecided
 - Fewer patients choosing major surgery



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



Source: National Inpatient Surveys Care Quality Commission, n=>75,000

Clinicians' and patients' expectations of the benefits and harms of treatments, screening and tests

Clinicians

- Benefits over-estimated, harms under-estimated

Patients

- Benefits over-estimated, harms under-estimated

Types of decision support

Clinical Guidelines

- Assumes doctor makes the decisions
- Primarily for doctor
- Evidence-based
- Describes likelihood of various outcomes
- Outlines uncertainties
- Recommendations based on values of clinical experts

Patient Decision Aids

- Assumes shared decision making
- Primarily for patient
- Evidence-based
- Describes likelihood of various outcomes
- Outlines uncertainties
- Does not make recommendations, describes reasonable options



yes

no

maybe

Summary

