

Inspiring tomorrow's professionals

Decision Making Within The Consent Process Understanding Patients' Perspectives

Professor Felicity Astin FESC
Effective Consent Practice
9th Feb 2016



No declarations of interest

Inspiring tomorrow's professionals



f.astin@hud.ac.uk

Session Overview

1. Informed Consent: Wider Context

- What is a person centred health system?
- Informed consent and shared decision making
- Barriers and enablers to shared decision making.

2. Informed Consent: The example of coronary angioplasty

- Patients' and cardiologists' views of informed consent

3. How to optimise informed consent?

- What interventions work?
- Other factors to consider



Part 1: Informed Consent: The Wider Context



A 'Person Centred' Health System

*'Supports people to make informed decisions about, and to successfully manage, their own health and care,
To make informed decisions and choose when to invite others to act on their behalf'*

1. Principles that guide the NHS

4. The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and

You have the right to accept or refuse treatment that is offered to you, and not to be given any physical examination or treatment unless you have given valid consent. If you do not have the capacity to do so, consent must be obtained from a person legally able to act on your behalf, or the treatment must be in your best interests.⁷



What is Informed Consent?

Multiple perspectives and influences

- Legal view
- Ethical view
- Policy view
- Academic view
- Patient & family view
- Health professional view



Shared Decision Making Process

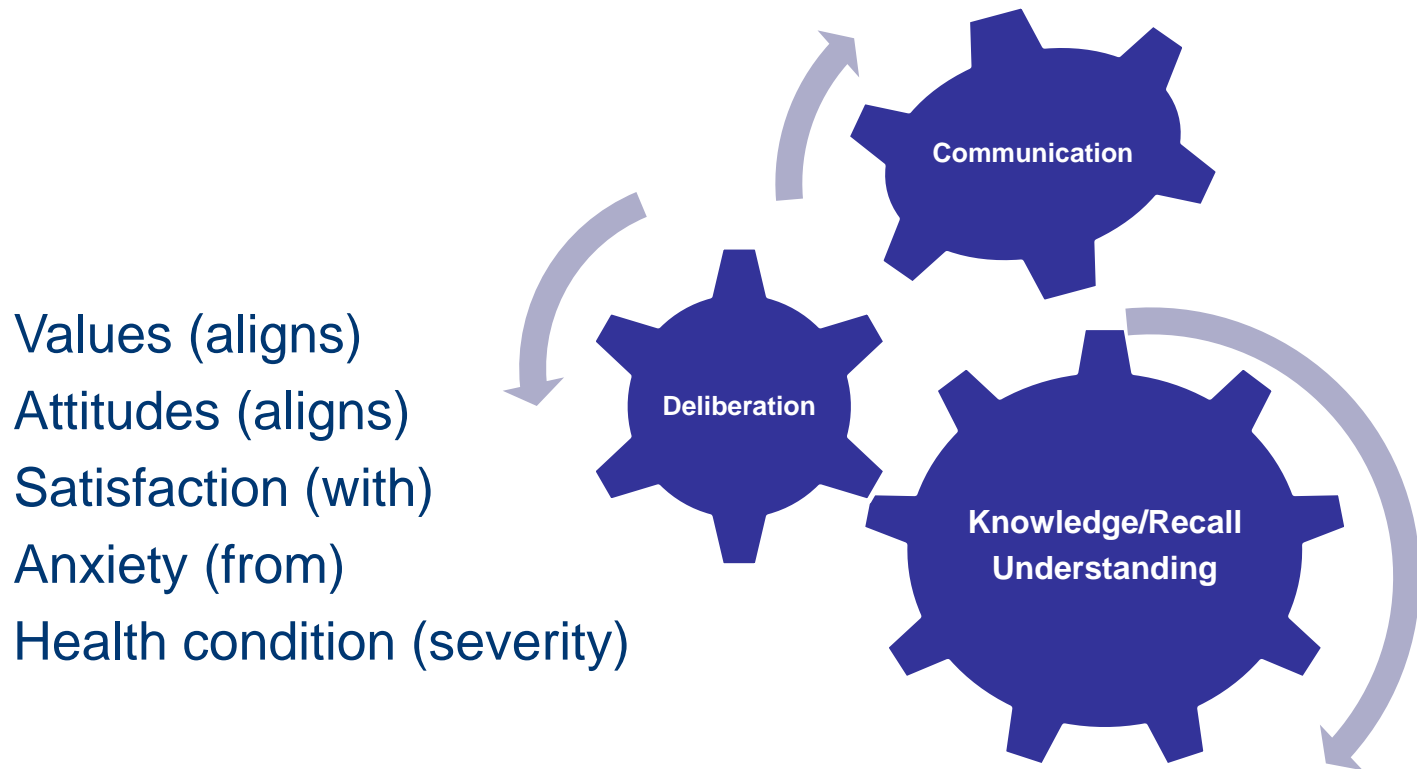
Process in which patients are encouraged to participate in selecting appropriate treatment or management options

- Recognise problem
- Identify potential solutions
- Discuss options and uncertainties
- Provide information
- Check understanding and reaction
- Agree a course of action
- Implement chosen treatment
- Arrange follow up
- Evaluate outcome

(Health Foundation 2012)



Informed Consent



Recognising Different 'Types' of Expertise

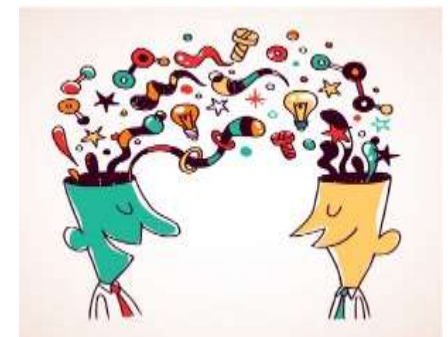


Partners need to;

- Share information
- Accept responsibility for joint decision making

Barriers & Facilitators to Shared Decision Making

- Culture & attitude
- Resources and time pressures
- Systems & incentives
- Provider motivation
- Positive impact on care
- Patient perspective?



Mini-review

Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions

France Légaré^{a,b,*}, Stéphane Ratté^a, Karine Gravel^a, Ian D. Graham^{c,d}

^a Research Centre of the Centre Hospitalier Universitaire de Québec, Québec, Canada

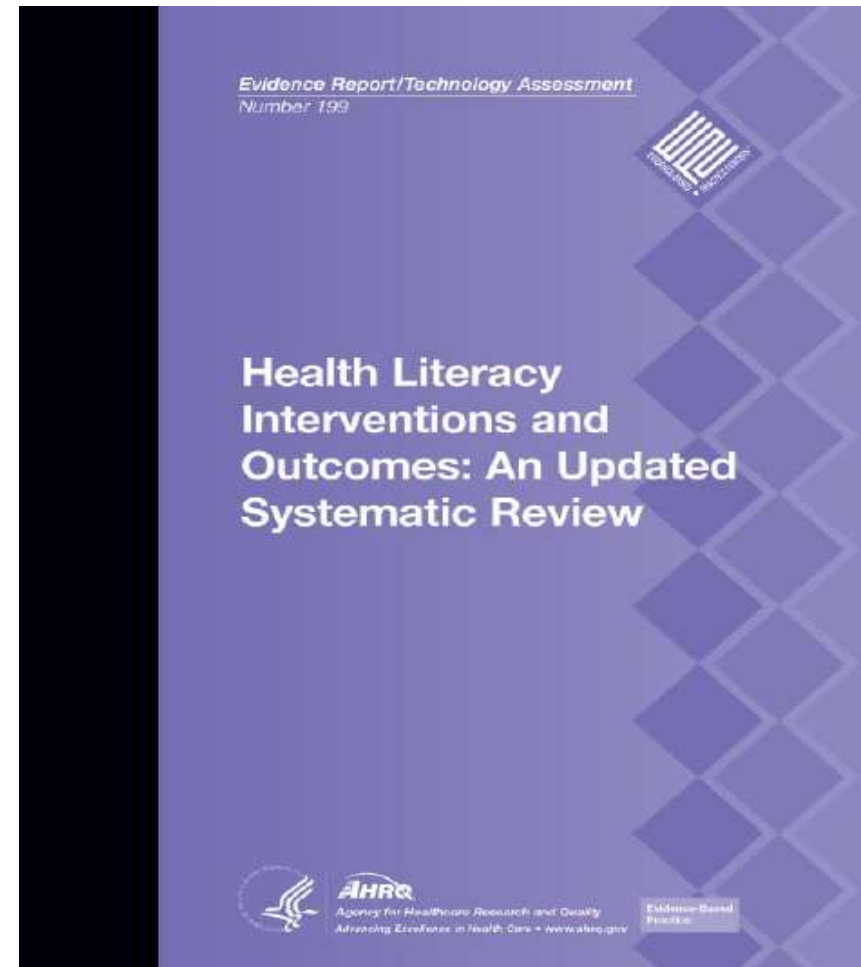
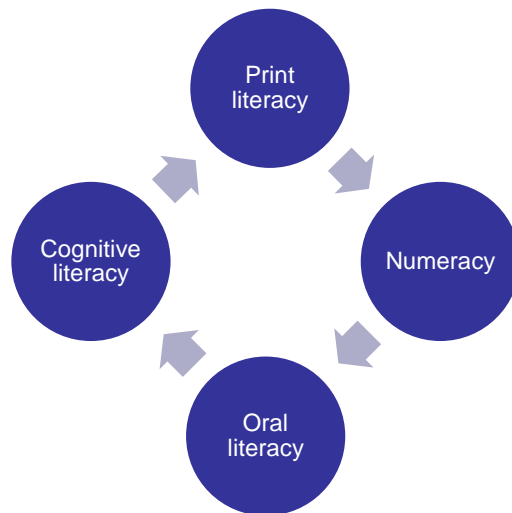
^b Department of Family Medicine, Université Laval, Québec, Canada

^c Faculty of Health Sciences, University of Ottawa, Ottawa, Canada

^d Canadian Institute of Health Research, Canada

Health Literacy Level

- Ability to access, understand and use health information to inform decision about health



Health Literacy, Empowerment & Health Behaviour

- An empowered patient?
- A health literate patient?

		Psychological Empowerment	
		Low	High
Health Literacy	High	Needlessly Dependent Patient	Effective Self-manager
	Low	High-needs Patient	Dangerous Self-manager



Contents lists available at SciVerse ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Review

Health literacy and patient empowerment in health communication:
The importance of separating conjoined twins

Peter J. Schulz^{a,*}, Kent Nakamoto^b

^aInstitute of Communication and Health, Università della Svizzera italiana, Lugano, Switzerland

^bDepartment of Marketing, Virginia Tech (Virginia Polytechnic Institute and State University), Blacksburg, USA

Part 2: Optimising Informed Consent for Percutaneous Coronary Intervention: A Mixed Methods Study



Mixed Methods Study


- Aim
- Design

4 Phases

- Systematic review
- Qualitative study
- Survey study
- Knowledge Transfer

The Mid Yorkshire Hospitals NHS Trust

University of
HUDDERSFIELD
Inspiring tomorrow's professionals



Improving patient care:
Coronary Angioplasty Services

Date: 23 March 2016

Time: 9.30-17.15 Venue: Met Hotel in Leeds, UK

- + Do you work in a catheter laboratory, cardiac ward/unit or related service?
- + Do you commission cardiovascular services?
- + Are you going through revalidation?
- + Are you an interested service user?

Topics will include:

- What will Percutaneous Coronary Intervention (PCI) care look like in the future?
- What are the risks, benefits and complications of elective and urgent coronary angioplasty?
- How do patients make decisions to have PCI treatment?
- Which approaches work best for patient/family education?
- How can we optimise the PCI informed consent process?
- What do health professionals need to know about the legal aspects of informed consent?

You are invited to an exciting one-day conference. The programme will be delivered by practising cardiologists, specialist nurses, researchers, academics and lawyers.

Registration fee is £25 including lunch and refreshments. To book your place please visit: www.store.hud.ac.uk

Closing date for registration is 12 February 2016. Please register soon as places are limited.

This event is funded by a National Institute for Health Research, Research for Patient Benefit Grant. For more information contact Professor Felicity Aastin f.aastin@hud.ac.uk or follow us on twitter @areyouinformed

Sheffield Teaching Hospitals NHS Foundation Trust

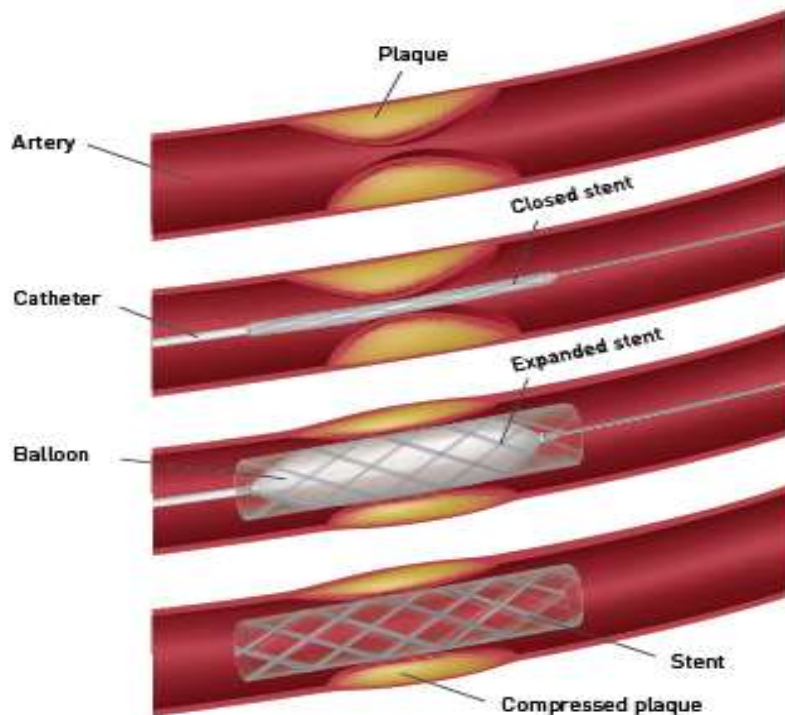
University of Salford MANCHESTER

UNIVERSITY OF LEEDS

NHS National Institute for Health Research

Percutaneous Coronary Intervention (PCI): An Exemplar

- What is PCI



- Emergency
- Urgent
- Elective (PCI or OMT?)

Why choose PCI?

Qualitative studies: PCI

- Lidz et al. (1983) Ethnographic study
- Lin et al. (2007) Focus group with cardiologists/physicians
- Whittle et al. (2007)
- Goff et al.(2014) Analysis of discussions patients & cardiologists
- Several barriers to patient participation
- Mismatch in clinical knowledge and beliefs
- Patients are over optimistic in their expectations
- Overstatement of benefits



Two Models of Implementing Informed Consent

Charles W. Lidz, PhD; Paul S. Appelbaum, MD; Alan Meisel, JD

Consent as a process

Not improving clients comprehension

Creating a more bureaucratic and less humane interaction

Client sensing participation in process not desired

Consent as an event

Promotes ongoing communication regarding expectations

Ensures client able to integrate their information into a well organised understanding

Shift from passive to active participation

Our study

We often only interact with the patient on the day of the procedure

The surgeon came and gave me booklets...I said 'Look do you know what you are doing? If you do just get on with it!

What am I going to feel like after it is done? I need to get back to work

What's it like? Is it uncomfortable?

Some people just say I don't want to know anything about risks.

I'm a firm believer in if the medical profession give me a decent reason then I'm quite happy to go along with it. I'll do a bit of research but I'm prepared to be guided by what Dr's say



Survey Studies

- Neary et al. (2008)
- Janssen et al. (2008)
- Rothberg et al. (2014)
- Signing consent form protects Dr & hospital
- Information preferences varied by age, mood and coping style
- In the setting of mild, stable angina, most people assume PCI prevents MI and are likely to choose it.



Design: Cross sectional survey

Sample: 10 NHS Trusts

159 acute PCI (48.8%)

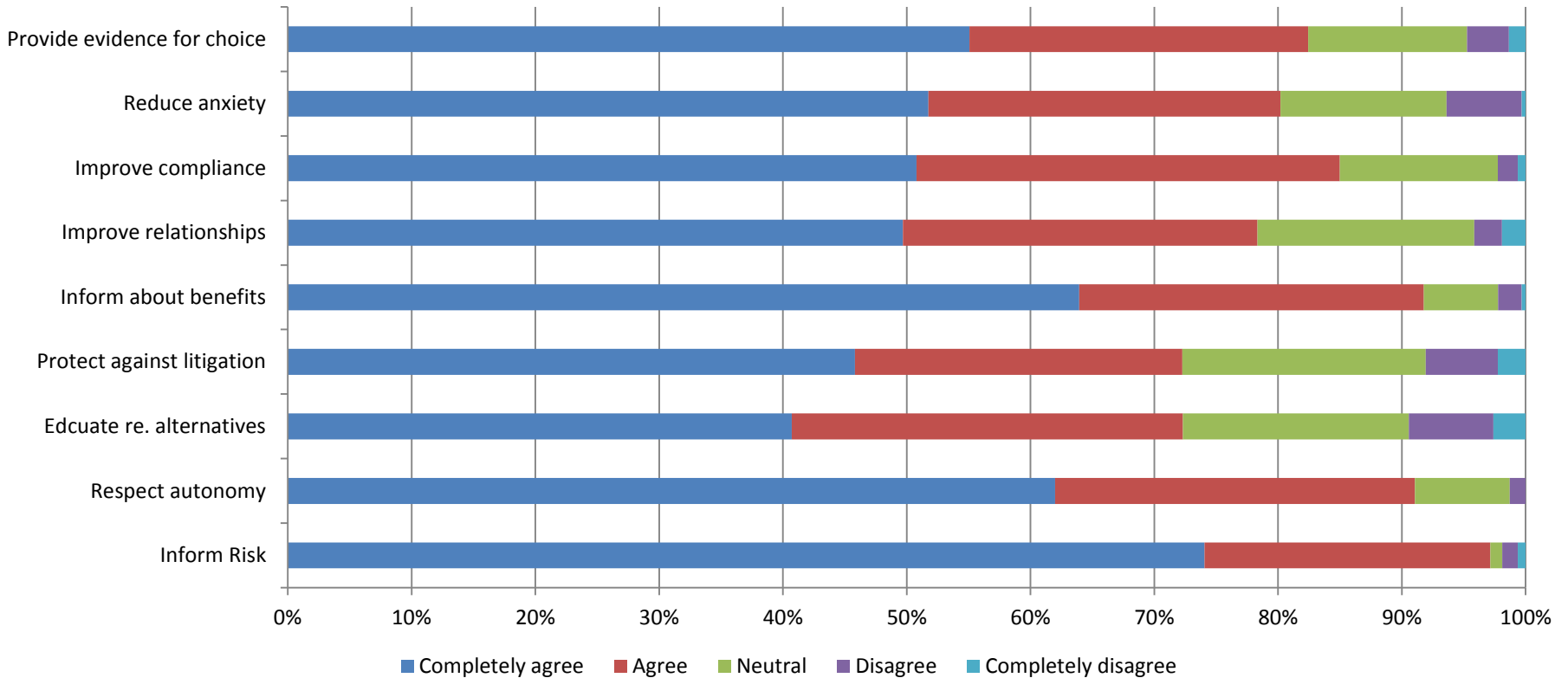
167 elective PCI patients (51.2%)

- 75% male (245)
- Age mean 66.5 (27 to 91)

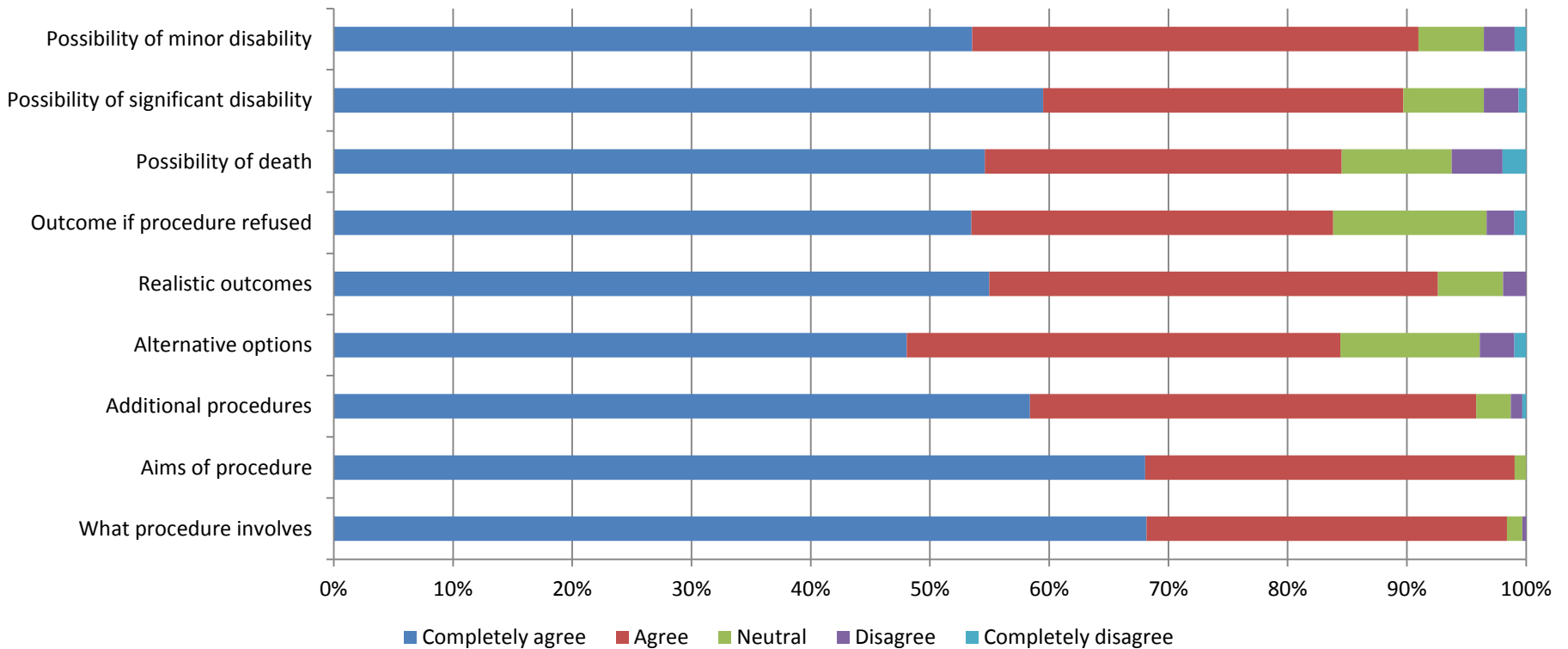
Researcher generated survey

- Attitudes to consent
- Preferences about information
- Understanding about PCI

Findings: What is informed consent for?



Findings: Disclosing risk



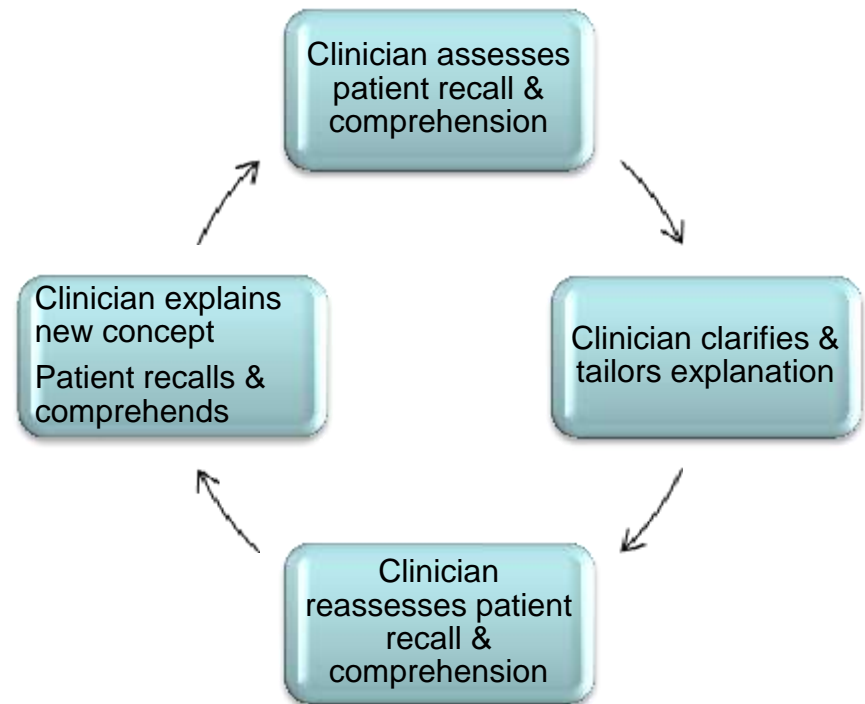
Part 3: How to optimise informed consent?



Approaches to Optimising Consent

1. Patient Education/Communication

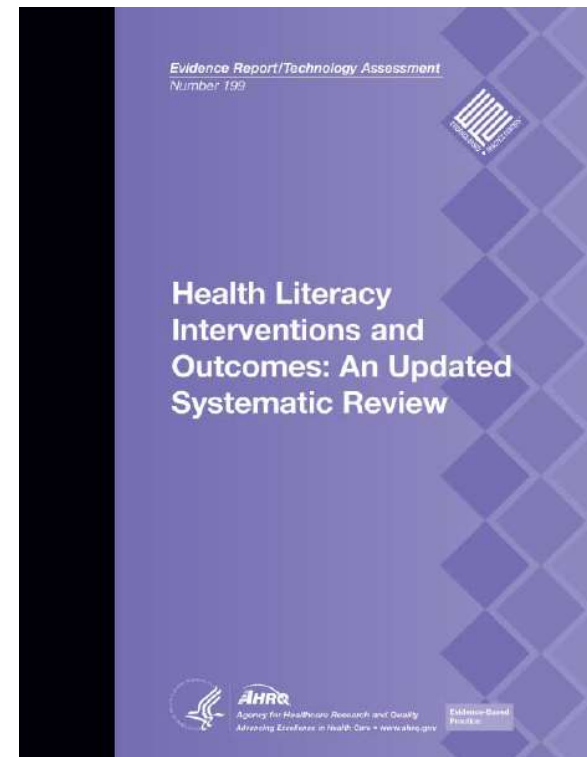
- Use 'Teach-back' technique
- Consider setting & timing
- Value the process
- Health professional education



Approaches to Optimising Consent

2. Information Resources/Aids

- Written information
- Audio-visual
- Multi-media
- Decision making aids



Approaches to Optimising Consent

Which interventions work?

- 65 RCT's from 12 countries
- Interventions written, audio-visual, decision aids
- Improved knowledge
- Satisfaction increased
- Decisional conflict reduced
- Consultation time ? increased

Interventions to promote informed consent for patients undergoing surgical and other invasive healthcare procedures (Review)

Kinnersley P, Phillips K, Savage K, Kelly MJ, Farrell E, Morgan B, Whistance R, Lewis V, Mann MK, Stephens BL, Blazeby J, Elwyn G, Edwards AGK



**THE COCHRANE
COLLABORATION®**

3. Tailor consent forms



- Shorten & simplify
- Require documentation of comprehension
- Model training programme
- Survey national practice

Mid York's NHS Trust
British Cardiovascular Society
British Cardiovascular Intervention
National Institute for Health
Research

F.Astin@hud.ac.uk

Follow at:

MyInformedConsent@
areyouinformed

Dr Dwayne Conway
Dr Joy Probyn
Dr Janet Holt
Dr Joanne Greenhalgh
Mr Keith Marshall
Mrs Judith Wright
Mrs Judith Holliday
Dr Rod Stables

