



## Outcomes that matter to patients and the public Workshop 6th December

### Report

January 2017

#### Contents:

<b>1. Introduction to workshop and introductions exercise</b>	<b>2</b>
<b>2. Context for the workshop</b>	<b>3</b>
<b>3. Morning case studies and key themes</b>	<b>5</b>
<b>4. Reflections on case studies</b>	<b>7</b>
<b>5. Afternoon group work and themes</b>	
<b>6. Feedback and evaluation</b>	<b>11</b>
<b>Appendices:</b>	<b>14</b>
• <b>Workshop programme</b>	
• <b>Links to slide sets</b>	
• <b>Information about outcomes and helpful resources</b>	

Report written by Sally Crowe, Crowe Associates Ltd January 2017

## 1. Introduction to workshop

This exploratory workshop was designed to bring together a wide range of people working in the Oxford Academic Science Network Region to;

1. Consider and discuss examples of where outcomes that are important to patients/public have been incorporated into health care services, health research, and health commissioning.
2. Reflect on where you/your organization is regarding outcomes that matter to patients and the public.
3. Discuss and agree planning for including patient important outcomes in services, research and commissioning; including practical considerations, value, risk, and methods

## Organizations represented

A wide range of organizations included in the Oxford Academic Health Science Network (AHSN) region were invited and attended. There was a mix of staff and lay members from most of the organizations represented.

4 NIHR Biomedical Research Centre  
1 NIHR Botnar Research Centre, Oxford University  
2 NHS England  
4 NHS Trusts  
1 Oxford University Hospitals Research Development Service  
7 Academic Health Science Network  
4 NIHR Clinical Research Networks  
2 NIHR Nuffield Dept of Surgical Sciences Oxford  
5 NIHR Collaborations for Leadership in Applied Health Research and Care



## Introductions exercise

To facilitate networking participants were asked to discuss and then record what they thought outcomes were. Some were more general observations about outcomes such as; they change over time and over a person's journey with their condition and can be difficult to define. They need to be functional, and measurable and could be positive, negative, or neutral change following a treatment or intervention. There are many perspectives on outcomes including; community, service development, patient, clinician, and organizational. Table 1 summarizes people's descriptions of outcomes.



**Table 1: different interpretations of outcomes**

Personal perspective	Research/evaluation perspective	Organizational perspective
Getting to do what I want despite disease Convenience and access for me as a patient Impact on quality of life (which varies from day to day) Living right to avoid disease Active participation in my own health Being cured The results that matter to people Able to manage condition yourself & continue to live your chosen lifestyle (normal and active lifestyle, 100% back to normal) Practical help when needed Best care best treatment for me Shared decision making Ease of treatments and options	Clinical Economic Patient reported outcome Quality of life measures e.g. days off work Things that matter to patients and carers An outcome is what you choose to measure and support Optimize QOL Levels of outcomes - stratified for research and where the personal parameters are Aspects of an intervention that can be evaluated Result of an end of a treatment, an action or an intervention Umbrella outcomes as well as personal more flexible ones	Result of intervention Tangible, visible, can be shared with staff, patients and carers Good patient care at every level Cost effective quality care Positively changing the result with action Achieving the desired result with treatment and care

of dealing with illness Personal outcomes e.g. feeling part of society What's important to me Taking what I struggle with seriously		
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## 2. Context for the workshop - some background

Sian Rees shared her values and how she saw outcomes being a reflection of understanding what we each value, whether it is personal, clinical, social, environmental or other. She also asked for feedback from the first exercise which showed the diversity of perceptions of outcomes. She used an example in breast cancer decision making to illustrate the importance of considering personal and clinical concerns/goals from different perspectives, see Table 2 below.

### Top Three Goals and Concerns for Breast Cancer Decisions

Condition: Goal	Patient	Clinician	Significance
Keep your breast?	7%	71%	P<0.01
Live as long as possible?	59%	96%	P=0.01
Look natural without clothes	33%	80%	P=0.05
Avoid using prosthesis	33%	0%	P<0.01

Sepucha 2008

**Table 2: Top Three Goals and Concerns for Breast Cancer Decisions**

Sian also used the example in musculoskeletal conditions to illustrate how shared working on outcomes can identify areas for exploration that were previously unidentified (OMERACT <http://www.omeract.org/>). She concluded that the way forward was to approach outcomes development and debate together by 'co defining, creating, designing, producing, delivering, evaluating and disseminating' in partnership.

### Context for workshop - where are we now?

Participants worked together to draw where they were (individually, organizationally or other) on the bridge of outcomes....the land to the right of the bridge we called the 'land of outcomes that matter to patients and public' and workshop organizers were interested in where people placed themselves in terms of reaching the 'promised land'. There was a complete diversity of responses, Picture 1 being typical.

Many felt that they were on the bridge, engaged and interested in outcomes that matter to patients and the public, but needed direction and support (methodological, organizational, leadership, cultural) and were keen to learn more.

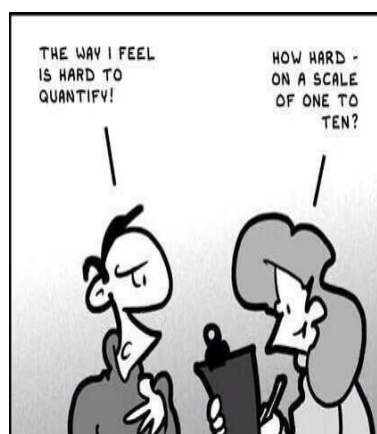


**Picture 1** One group's version of the bridge exercise

A lively discussion followed this session; some anxieties expressed that outcomes development work could get 'bogged' down in detail, politics and people using their influence inappropriately - despite the best of intentions and getting stuck on the bridge! Participants described the value of stepping back from a process to review, and also involving a variety of people to get diverse views and perspectives. We covered the value of building relationships in outcomes development and the issue of cultural 'push back' from people that have fixed ideas about outcomes should be.

### 3. Morning case studies

**Kirstie Haywood, Royal College of Nursing Research Institute (RCNRI), Warwick Medical School, Warwick University.**



- ▶ Key points; Developing a Core Outcome Set for Cardiac Arrest Clinical Trials: the COSCA initiative involved; defining health outcomes, assessing the current state of health outcome assessment in cardiac arrest trials, establishing what matters to patients and health professionals and finally working towards consensus for a core set of outcomes that could be used in all future trials.
- ▶ Methods used included a multi partner steering group, interviews with survivors of cardiac arrest, and a large survey to assess the most important outcomes to measure from a wide range of people. Participants in a consensus workshop finalised the core set of outcomes.
- ▶ Outcomes included; survival, health related neurological function and health related quality of life (which has been rarely measured previously).

**Rosamund Snow; Expert Patient, service-user-researcher and BMJ Patient Editor**

- ▶ Key points; how can patients and the public change what doctors learn as part of their medical education? Using examples in vaginal examination, miscarriage and communicating with people who are deaf or hard of hearing in clinics Rosamund showed how outcomes that matter to patients and the public could be addressed.
- ▶ Methods used included; Medical Students working with Clinical Teaching Associates (real women who are examined and teach concurrently) the difference in examination is described in the table below. In the case of miscarriage real women's experiences of miscarriage were integrated into role play exercises in communication.

**• Clinical Teaching Associates**

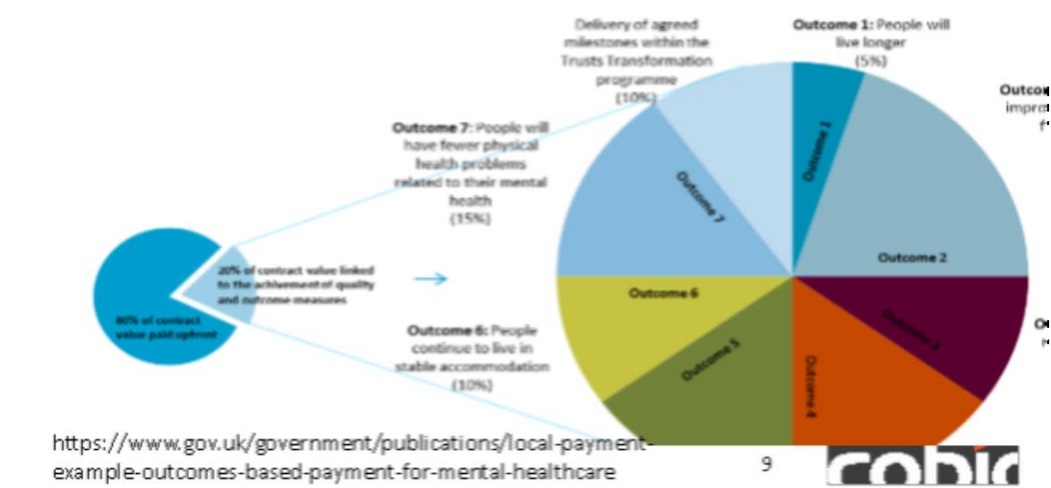
TRADITIONAL EXAMINATION	CTA EXAMINATION
Obtain consent	Makes clear that the patient can say "stop" at any point; obtains explicit verbal consent
Clean hands, plan to use gloves	Offers to lock door Clean hands & use gloves; ongoing hygiene awareness
Insert speculum correctly	Hold speculum closed for insertion Warns patient before first touch
Remove speculum correctly	Shows sensitivity & responsiveness to patient: checking in, looking at face Insert and manoeuvre speculum correctly & comfortably
Cover patient with sheet	Remove speculum gently & fully closed, checking cervix is not trapped Prompts patient to cover up immediately & offers reassurance

**Nick Hicks, COBIC (Capitated Outcomes-Based Incentivised Care)**

- ▶ Commissioning health services for outcomes that matter to patients and the public was the focus of Nick's presentation. COBIC works on the model of a triangle of effort to lead to outcomes for people and populations. The triangle is comprised of reform in the way services are delivered (led by professionals), the commissioning contracts for achieving outcomes (incentive reform) and reviewing how the health structures work. Nick described several examples of this new way of thinking about outcomes in mental health and musculoskeletal conditions. Outcomes derived in mental health are described in the slide on page 7.

## Oxfordshire Mental Health Case Study

Figure 1: Seven outcome measures and corresponding proportions that is linked to



### Kath Evans Experience of Care Lead, NHS ENGLAND

- ▶ Kath wanted to share with participants how gathering and using public insights to drive improvement in children & young people's outcomes was achievable.
- ▶ Examples of effective approaches include;

17 Best Practice Case Studies of CYP Engagement <http://www.myapt.org.uk/year-4/gift-launches-ebook-with-nhs-england/>

Tools & resources to improve communication between CYP & Health Care Professionals 'CYP Me First' <http://www.mefirst.org.uk/>

The role of Key Workers in Improving CYP care as a route to capturing narrative to improve CYP Experience/Participation with CYP with Complex Conditions <http://www.clicsargent.org.uk/content/nurses>

NHS England's Guide to establishing a youth forum  
<https://www.england.nhs.uk/?s=youth+forum+guide>

Building Health Literacy with Children and Young People  
<http://primarycarekeele.blogspot.co.uk/2015/10/addressing-health-literacy-needs-of.html?m=1>

Picture: Top tips for involving young people in the NHS.



#### 4. Reflections on case studies

Before small groups started to reflect on the pre-lunch presentations Sally shared some thoughts about how the case studies were connected. The case studies addressed issues of power, knowledge and experience, finding and sustaining connections with people with relevant experiences to share, were prepared to work across boundaries and organisations to achieve their aims and were taking sometimes small but determined steps towards progress. Participants discussed and agreed what they thought were elements of success in developing outcomes that matter to patients and the public. These have been loosely analyzed into People, Process, Planning and Purpose factors.

##### People

- Identifying a 'go to' person
- People being open to different views about outcomes



- Identifying and target people who can champion and influence the objective of reaching outcomes that matter to patients and the public
- Identify and engage with all stakeholder groups that might have an interest in the outcomes area being developed
- Engage with leads at different levels of organizations that you want to work with
- Identify who benefits from achieving the 'right' outcomes

### Process

- Start small and grow success, show and tell progress
- Conversations are key to success - these can be informal or formal or both
- Ask open questions and listen to what you get back
- Have the courage to step back and review regularly, checking in - are we on the same page regarding outcomes are we talking about the same thing?
- Ask service users what they think - you can do this face to face, via survey or online in communities e.g. mumsnet, Face book groups etc
- Look for or gather patient stories about experiences of outcomes
- Be bold and try something different!
- Immerse yourself - walk in the shoes of someone experiencing the outcomes
- Don't create artificial barriers to engagement - power games etc

### Planning

- Know and understand the context in which outcomes are being developed
- Involved patients and the public need to be enabled and empowered to contribute effectively
- Think about the resources around you - are there people or organizations that are naturally inclined to be interested in your work? Map these out, examples may include; third sector and voluntary, patient support groups and networks, community groups and networks
- Think about your resources such as funding, in kind contribution, partnerships etc before you start - know what you have to work with
- Learn from mistakes

### Purpose

- Identify the key drivers for the work e.g. patient values
- Don't let perfection or over thinking get in the way of progress
- You may need dogged determination!

### Other

- Permissive culture is helpful
- What about if we asked patients to write their own outcomes at the start - what would we get??

Some groups identified challenges in doing this sort of work, for example what do we do when there is disagreement between parties about outcomes? This is where consensus

working comes in whereby you agree what you can agree on. Different approaches have different ways of funneling people into agreement (e.g. forced ranking, voting etc). There is no real consensus on which of these methods are the best for the NHS. One group wanted to know how to identify the best people to work with? Many of the points in the People section of elements of success are useful here but ultimately it will be a mixture of factors including identifying pre-existing agendas of involved people in outcomes work, and looking for collaborators who are open to ideas and solutions. Finally one group suggested that this work may deliver outcomes for research that researchers don't like or don't think are important and how could you deal with that? This may be a cultural issue or a technical one.

## 5. Afternoon group work and themes

Five groups convened to work on five different ideas for developing outcomes important to patients and the public. They were asked to describe a plan to develop their outcomes using what their experience and what they had learnt throughout the day.

### 1. Self-harm in adolescents - an early intervention

**Context:** Patients can be secretive and don't trust adults or the system; they tend to communicate predominantly through social media and online fora.

**Developing outcomes:** Need to engage with specialist workers such as school nurses, youth leaders, as well as friends and family of others who self-harm. Specialist charities and support organisations also need approaching. Favoured method would be 1:1 interactions initially and using previous research and narratives (e.g. healthtalk). Have an open mind about what outcomes might emerge and follow this up with awareness for schools, parents and peers

### 2. Increasing clinical research in \*\*\*\* surgery using outcomes that matter to patients as a driver

**Context:** want to improve patient care and treatment in the surgery experience, some resistance to embracing what might be important to patients - focus tends to be on clinical issues.

**Developing outcomes:** undertake a prioritization approach that includes important outcomes from clinical and patient perspectives. Methods include searching the literature for existing work on developing outcomes in this area, and conducting a survey. Work with a small group of patients to generate some stories about their experiences to engage the attention of the surgeons (who are disengaged). Connect with the relevant charities (there are two the group knew about) and have a conversation about issues they see coming into the advice lines etc. Frame the work as having an impact on patient experience of surgery and the service and also that this will drive up quality.

### 3. Deep Mind App

**Context:** to improve 'in patient' care and reduce inefficiencies (and potentially save on costs). App will aim to ensure that patient care is optimized in real time as the data

collection is 'near patient' and in real time. All info held in app will be held by both patients and health professionals (inpatient clinicians especially the 'nay sayers'!

**Developing outcomes:** early involvement of end users in process and with next of kin (patients). Information needs include patient biography, joined up patient clinical data, and comparative information e.g. drugs

#### **4. Improving patient outcomes in bone marrow biopsy process**

**Context:** To improve the patient experience and outcomes in bone marrow biopsy services.

**Developing outcomes:** basic research on how other depts are doing it. Convene a patient discussion group (inc regular patients, occasional and once off's) similar group for clinicians and admin/staff. Draft proposed changes and present to joint patient and staff group for discussion and refinement. Distinguish between outcomes clinical and experience (PROMS and PREMS). Trial the changes and then evaluate the outcomes again and compare.

Groups fed back 2 or 3 key elements of their plans and received additional comments and feedback from other groups. The workshop concluded.

#### **7. Feedback and evaluation of meeting**

##### **Summary of feedback from evaluations**

What did you enjoy and/or find most useful about the workshop?

##### **People related:**

- Networking x 8
- Patient representatives participating x 9
- Meeting and hearing new people's experiences and perspectives x 4
- Variety of people and case studies x 3

##### **Content related:**

- Presentations and variety of case studies x 8
- Morning exercises
- Talking about range of projects that people were working on
- Problem based discussions and broader outcomes in healthcare x 6
- Hearing about the gradual development of PPI across the NHS and in research
- Seeing the commonalities across the case studies, barriers and success
- Picking up great ideas
- Like the idea of blue sky thinking so often focused on particular projects and don't look up!
- Discussion about

##### **Structure etc:**

- Good mix of presentations and discussion
- Well structured and thoughtful
- Atmosphere
- Good venue

Any changes or improvements that would you recommend? (E.g. regarding the venue/materials/facilitator/content etc.)

- Less time for plenary sessions - more time for discussion
- More time for questions from participants for presenters (from a presenter)
- Some pre reading?
- Sharing of learning from afternoon sessions (not clear if they didn't like it or wanted more!)
- Make commissioning and policy more involvement led e.g. DOH!
- Venue for difficult to get to from Headington on public transport
- Talk from a patient
- 'Ask the Expert' session

Overall scoring of the workshop

Score	1	2	3	4	5	6
<b>Did the workshop meet its stated aims?</b>	1	2	3	2	9	12
<b>How useful has the workshop been to you, and/or your organization?</b>	1	2	3	5	8	10
<b>Please indicate your overall rating</b>	1	2	3	3	10	9

If you have scored 3 or less, please tell us why: None

**Please tell us what you take away from today and any action you will be taking following the workshop:**

**I take away:**

- Commonalities across outcomes work in barriers and elements of success
- How silent we are about the projects we do!! How do we amplify more?
- Need a more bottom up approach to outcomes development in service delivery
- Do we actually discuss treatment goals or outcomes with patients?
- We might be optimizing the system for the wrong things

- Involvement and engagement (in outcomes development) is a movement and needs to be promoted, supported and driven
- I've changed my thinking about outcomes from just research to care delivery as well
- What amazing people and minds are working on innovative ways!
- We must all talk more and really engage on involve at the right time
- Work outside your boundaries - you learn more!

### **What I will do after the workshop**

- Investigating patient groups already existing x 2
- Getting PPI into the medical agenda
- Asking BMJ if they will support a case study PPI series
- Making contact with people, set up some community meetings, following up networks x 6
- Using knowledge gained from today to further outcomes work
- Following up contracts made and getting clinicians and patients to work together
- Think about what we are trying to optimise services against, and find ways to influence significant partners to place value on what outcomes patients really want
- Reflecting and reporting on the things that don't work so well as those that do!
- Better ways for helping people achieve their aims (outcomes)
- More support for PPI generally (in research and health) x 3
- Develop a more bottom up approach for involvement strategy at my Trust and develop relationships with GP practices
- Writing something for the BMJ!
- Discuss with health watch Bucks to take forward ideas
- Hold an open patient event to get research ideas for our work within our areas of expertise
- Following up some of the case study ideas
- Wider conversations about surgical treatments
- Feeding back to my Department about considering patient outcomes chosen by patients to improve bone marrow biopsy service
- Looking for outcomes that are more meaningful for patient populations I'm working with, do they differ from more traditional ones we have been working with?
- Keep advocating for the value of engagement and sharing stories
- I will try and assess one of the procedures we do in bone marrow biopsy to make it a better patient experience!
- Use social media more to connect with people
- Ask more questions and challenge more - why not??!!

## **Appendices**

- **Programme**

9.30 am Registration and refreshments

10.00 Welcome, overview, introductions exercise Sally Crowe - Crowe Associates Ltd  
10.15 Background and Context for this workshop Sian Rees - Lead Patient & Public  
Involvement, Engagement & Experience Oxford AHSN  
10.30 Where are we now? Small group work and feedback

11.15 Refreshment break

11.45 Case Studies

- Kirstie Haywood, Royal College of Nursing Research Institute (RCNRI), Warwick Medical School, Warwick University. Public involvement in Patient Reported Outcome Measures (PROMs)
- Rosamund Snow; Expert Patient, service-user-researcher and BMJ Patient Editor: how patients and the public have changed how and what doctors learn
- Nick Hicks, COBIC (Capitated Outcomes-Based Incentivised Care) Commissioning for outcomes and public involvement
- Kath Evans Experience of Care Lead, NHS ENGLAND, gathering and using public insights to drive improvement in children & young people's outcomes

13.00 Lunch break

14.00 Reflections on case studies Small group work and discussion with case study presenters

15.00 Refreshment break

15.20 Applying the shared learning Task based group work  
16.15 Next steps, including most useful way to report this workshop Sian Rees  
16.30 Workshop ends

- **Links to slides**

### Context for the workshop

Rees <http://www.oxfordahsn.org/wp-content/uploads/2017/01/S-Rees-Outcomes-that-matter-slides.pdf>

### Case studies

**Kirstie Haywood**

<http://www.oxfordahsn.org/wp-content/uploads/2017/01/K-Haywood-Outcomes-that-matter-slides.pdf>

**Rosamund Snow**

<http://www.oxfordahsn.org/wp-content/uploads/2017/01/R-Snow-Outcomes-that-matter-slides.pdf>

Nick Hicks

<http://www.oxfordahsn.org/wp-content/uploads/2017/01/N-Hicks-Outcomes-that-matter-slides.pdf>

Kath Evans

<http://www.oxfordahsn.org/wp-content/uploads/2017/01/K-Evans-Outcomes-workshop-AHSN.pdf>

- **Outcomes handout**

### What is a health outcome?

Health outcomes are changes in health that result from measures or specific health care investments or interventions. Achieving good patient health outcomes is the fundamental purpose of health care. This can be applied for individuals as well as populations. Examples could include;

- preventing death after a heart attack through hospital care
- improving a patient's quality of life through improved eyesight following cataract surgery
- improving waiting times in A & E
- helping someone die at home who wants to do so
- reducing stigma associated with mental health

In research (that contributes to our understanding of effective health and social care) outcomes are what we expect to see change, improve or get worse during or after research. Examples could include changes in symptoms, side effects of treatments and/or changes in general quality of life, or trends in populations.

### Are there different types of health outcomes?

Yes, below are some examples;

- Economic (e.g. does the intervention offer good value for money?)
- Therapeutic (e.g. does the intervention work from a patient and clinical perspective?)
- Organisational (does the intervention have contextual/service delivery impacts?)
- Safety and adverse effects (does the intervention have implications for the well being of the recipient?)

### In research why is it important to choose/develop the 'right' outcome?

An outcome measure is used to assess the effectiveness or safety of an intervention (e.g. treatment) being studied in research (e.g. a trial). An outcome might be fatigue - choosing the "right" outcome measure can:

- help patients/clinicians measure fatigue in a meaningful, appropriate, easy, and accurate way
- guide the development and evaluation of treatments (interventions) care for fatigue
- help shared decision making about treatments and care for fatigue (i.e. based on results)

## In healthcare why is it important to choose/monitor the 'right' outcomes?

Measuring, monitoring, reporting, and comparing outcomes in healthcare is an important step towards better, more effective and efficient healthcare. Outcomes are also used to compare health service providers and practitioners and for assessing improvement (or not) over time.

## Random historical fact about health outcomes!!

E A Codman (a pioneering Boston surgeon) in 1900 defined the idea as 'the common sense notion that every hospital should follow every patient it treats, long enough to determine whether or not the treatment has been successful, and then to inquire, "If not, why not?" with a view to preventing similar failures in the future'.

## Is there health outcomes jargon I should know about?

**Patient Reported Outcome Measures (PROMs):** Reports coming directly from patients about how they feel or function in relation to a health condition and its therapy without interpretation by healthcare professionals or anyone else.

**Patient Reported Experience Measures (PREMs):** Typically these are validated questionnaires or surveys and provide an objective way of enabling patients to describe their experiences of the (quality of) care received from their own perspective.

**Commissioning for Quality and Innovation (CQUIN):** The system was introduced (2009) to make a proportion of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of patient care.

**Core Outcomes Sets (COS):** These sets represent the minimum that should be measured and reported in all clinical trials of a specific condition, and are also suitable for use in clinical audit or research other than randomized trials.

How do we establish health outcomes that matter to patients and the public?

Well.....essentially we need to engage and ask them! For example;

- Reviewing the literature, sources of patient experiences and views
- Asking people in an open way (focus group, workshop) asking people in a structured way (survey, questionnaire) these can be face to face or online
- Testing suggestions out with more people (piloting) and checking that the outcomes perform as expected (cognitive testing)

*Developed by Sally Crowe for 'outcomes that matter to patients and the public' workshop December 2016*

## Additional Resources

- <http://www.health.org.uk/sites/health/files/MeasuringWhatReallyMatters.pdf>
- [www.choosingwisely.co.uk](http://www.choosingwisely.co.uk)