HAUTE AUTORITÉ DE SANTÉ

Colloque HAS

La dynamique patient innover & mesurer

16 novembre 2016 PARIS

Traduction / *Translation*

Channel 1 English

Canal 3 Français

Please, switch off during the lunch

Merci d'éteindre votre casque durant le déjeuner

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Le point de vue des patients dans l’évaluation des technologies de santé

Animatrice

Maud GUILLAUMIN, journaliste

Grand témoin

Angela COULTER, directrice des initiatives mondiales, Informed Medical Decisions Foundation, États-Unis

Colloque **HAS**
La dynamique patient
innover & mesurer
16 novembre 2016 PARIS

Intervenants

Karen FACEY, consultante internationale en politique de santé

Laura WEEKS, conseillère scientifique, Agence canadienne des médicaments et des technologies de santé, Canada (vidéo)

Irina CLEEMPUT, économiste de la santé, Centre fédéral d'expertise des soins de santé, KCE, Belgique

Marion DANNER, chercheure associée, Institute for Health Economics and Clinical Epidemiology, Hôpital universitaire de Cologne, Allemagne

Angela COULTER, directrice des initiatives mondiales, Informed Medical Decisions Foundation, États-Unis

Catherine RUMEAU-PICHON, adjointe à la directrice de l'évaluation médicale, économique et santé publique, HAS

Christophe DUGUET, directeur des affaires publiques, AFM-Téléthon – membre de la commission évaluation économique et santé publique, HAS

Contributions de patients

Karen FACEY

Consultante internationale
en politique de santé

Health Technology Assessment

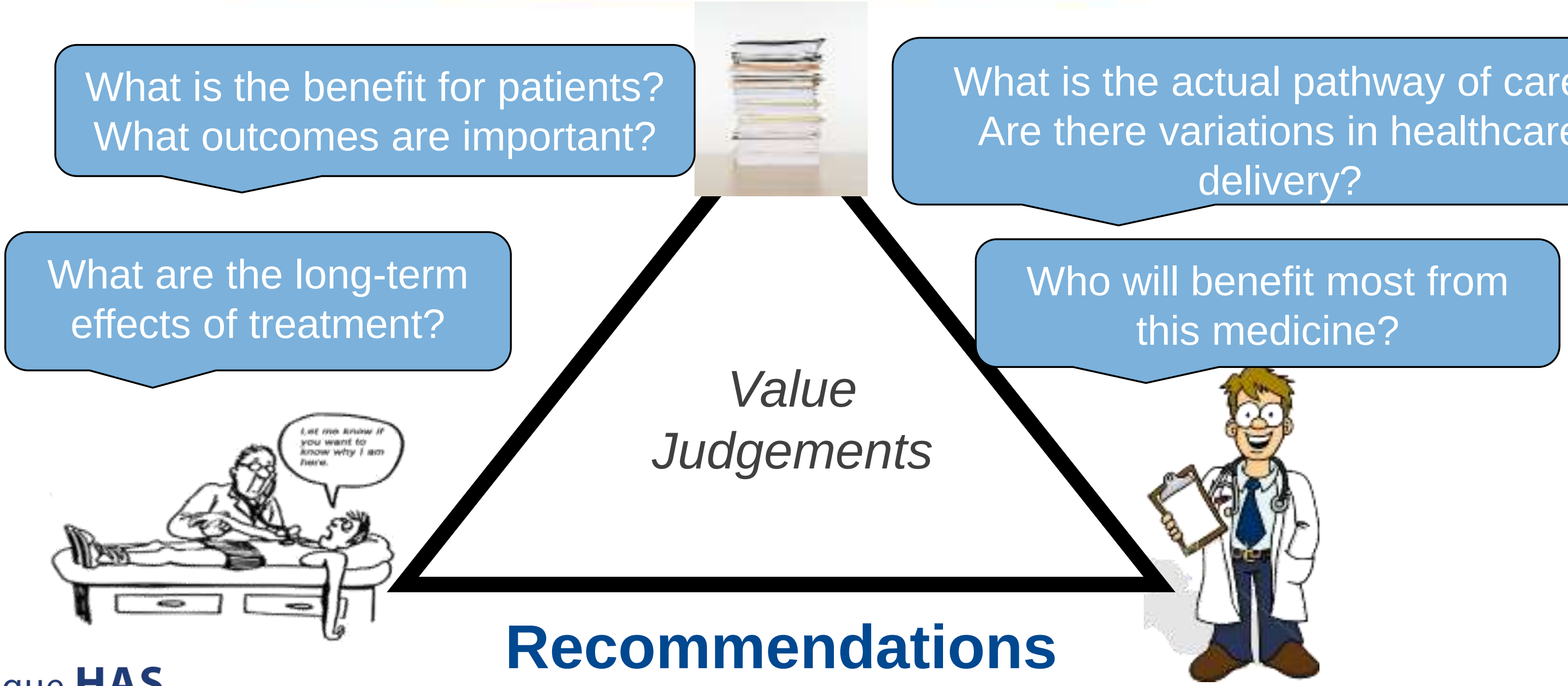
(www.eunethta.net)

HTA is a multidisciplinary process that summarises information about the medical, social, economic and ethical issues related to use of a health technology* in a systematic, transparent, unbiased, robust manner

It aims to inform policy at national, regional or hospital level.

***A "health technology" is any intervention that may be used to promote health, to prevent, diagnose or treat disease, or for rehabilitation or long-term care**

HTA and Decision Uncertainty



What is the benefit for patients?
What outcomes are important?

What is the actual pathway of care?
Are there variations in healthcare delivery?

What are the long-term effects of treatment?

Who will benefit most from this medicine?

Value Judgements

Recommendations

Democratic

More informed, transparent, accountable, and legitimate decisions

Scientific

More robust and comprehensive approach to HTA that incorporates social values and ethics, as well as patients' problems, lived experiences, outcomes, and preferences

Instrumental

Making better-quality decisions across all stages of HTA

Developmental

Increasing public understanding of HT and HTA, & strengthening public/patient capacity to contribute to HT policy issues

Theorized Goals of Public and Patient Involvement in HTA

Final Report from the OHTAC Public Engagement Subcommittee. April 2015

How can patients' perspectives influence policy?

A patient's view is an individual's subjective experience

- Is it representative?
- Is it biased by industry influence?

How can patients' and informal care-givers' perspectives be combined with evidence from controlled clinical trials or complicated economic models of cost and benefit?

Patients' perspectives in HTA: a route to robust evidence and fair deliberation'

(Int. J. Tech Assess Health Care, 2010, 334-340)

Karen Facey,
Scotland

Javier Gracia,
Spain

Helle Ploug Hansen, Denmark

Alessandra Lo Scalzo, Italy

Jean Mossman,
Health Equality Europe

Antoine Boivin,
Canada

Ann Single,
Australia

Patient involvement in HTA

Patients’ views and preferences contributing to HTA:

- *In the form of robust research about patients’ perspectives and experiences*

- Through participation in the HTA process

Participation in the HTA process

At every stage:

- Study design to produce evidence relevant for HTA
- HTA topic proposals
- Scoping
- Patient Group Submission
- Presentation of patient experience to expert committee
- Sitting on an HTA decision-making committee
- Consultation on recommendations
- Patient friendly summaries
- Dissemination/communication
- Designing & reviewing patient engagement processes
- Use HTA to inform charity investments
- Contributing to governmental review of HTA

Ways patients can participate in HTA

- Completing a form on a website
- Public consultation response – open or structured
- Workshops
- Individual informal discussions with patients
- Participation in a committee
- Development of materials for patients
- Structured submission of information from patient groups
- Letters of protest or appeal
- Public petition
- Media appeal

Patients Group Submissions

- What it is like to live with the illness
- Experience with current therapies
- Expectations or experience of new therapy
- 3 most important items


<HTA committee name>

Health Technology Assessment (HTA) on
<Name of Medicine in Condition X>

1. Purpose of this form

COMPLETING A PATIENT GROUP SUBMISSION TEMPLATE: GUIDANCE FOR PATIENT ORGANISATIONS

for Health Technology Assessment and Appraisal of Medicines


Health Technology Assessment International

Key ethical considerations for patient groups collecting and reporting information for HTA submissions

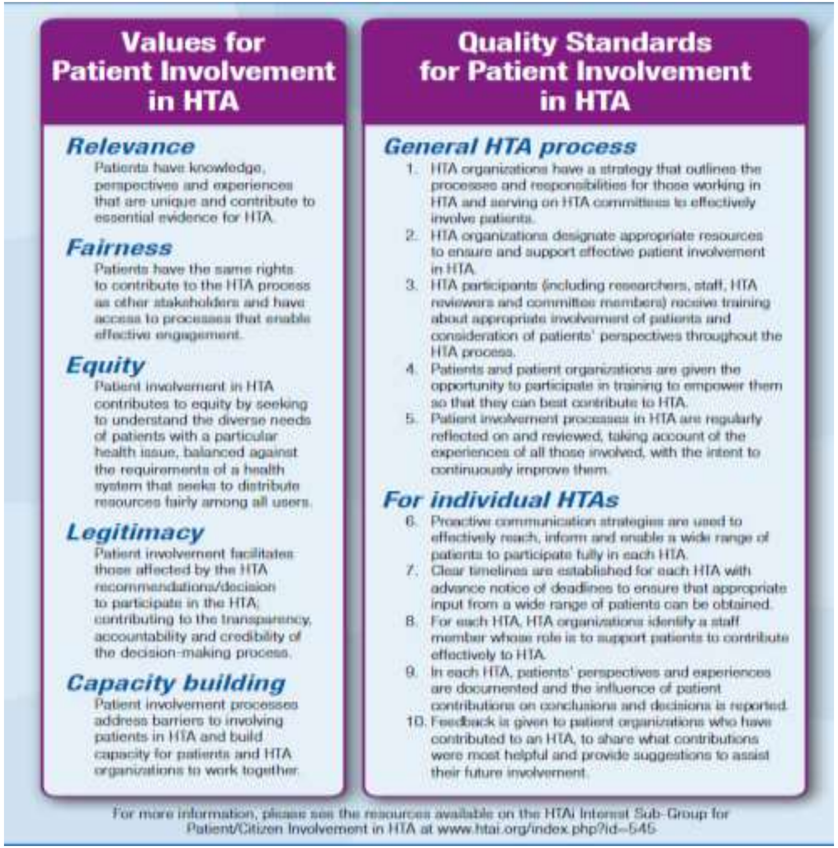
Short guide

Patient insights – focus, outcomes and value

Guiding principles for Patient Involvement Activities

Final Report from the OHTAC Public Engagement Subcommittee. April 2015

Purposeful	Aligned with clearly stated goals and rationales
Fair and equitable	Designed to ensure inclusion of a broad range of perspectives determined by those most affected or potentially affected by the condition or technology
Transparent	Processes and decisions clearly described and communicated to ensure a broad understanding and facilitate involvement
Proportional	Degree of patient involvement is proportional to nature and purpose of the technology, size and demographics of targeted patient population, and disease incidence and prevalence
Pragmatic	Will take account of level of rigour, time, resources and effort required
Evidence-informed	Will be informed by the best available evidence



Values for Patient Involvement in HTA

Relevance
Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA.

Fairness
Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.

Equity
Patient involvement in HTA contributes to equity by seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.

Legitimacy
Patient involvement facilitates those affected by the HTA recommendations/decision to participate in the HTA; contributing to the transparency, accountability and credibility of the decision-making process.

Capacity building
Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.

Quality Standards for Patient Involvement in HTA

General HTA process

1. HTA organizations have a strategy that outlines the processes and responsibilities for those working in HTA and serving on HTA committees to effectively involve patients.
2. HTA organizations designate appropriate resources to ensure and support effective patient involvement in HTA.
3. HTA participants (including researchers, staff, HTA reviewers and committee members) receive training about appropriate involvement of patients and consideration of patients' perspectives throughout the HTA process.
4. Patients and patient organizations are given the opportunity to participate in training to empower them so that they can best contribute to HTA.
5. Patient involvement processes in HTA are regularly reflected on and reviewed, taking account of the experiences of all those involved, with the intent to continuously improve them.

For individual HTAs

6. Proactive communication strategies are used to effectively reach, inform and enable a wide range of patients to participate fully in each HTA.
7. Clear timelines are established for each HTA with advance notice of deadlines to ensure that appropriate input from a wide range of patients can be obtained.
8. For each HTA, HTA organizations identify a staff member whose role is to support patients to contribute effectively to HTA.
9. In each HTA, patients' perspectives and experiences are documented and the influence of patient contributions on conclusions and decisions is reported.
10. Feedback is given to patient organizations who have contributed to an HTA, to share what contributions were most helpful and provide suggestions to assist their future involvement.

For more information, please see the resources available on the HTAi Interest Sub-Group for Patient/Citizen Involvement in HTA at www.htai.org/index.php?id=545

Patient Involvement in HTA
June 2017

I:Conceptualization
II: Methods
III: Country experiences

HTA and decision making

HTA can be considered as a bridge between scientific evidence and decision making

Patients' perspectives can illuminate the HTA bridge by :

- Clarifying burden - illness,
  health service organisation and treatment
- Identifying important outcomes –
  benefits and disbenefits
- Highlighting areas of unmet need
- Describing real added value

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16 novembre 2016 PARIS

Exemple d'une agence cherchant à intégrer diverses formes du point de vue patient

Laura WEEKS

Conseillère scientifique,
Agence canadienne des médicaments
et des technologies de santé, Canada

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Travaux pilotes sur la mesure des préférences

Irina CLEEMPUT

KCE
Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

Économiste de la santé, Centre fédéral d'expertise des soins de santé, KCE, Belgique

Reconciling public and patient preferences in healthcare decision making

Belgium pilots new model


KCE

Drug reimbursement systems: international comparison and policy recommendations

KCE reports 147C


KCE

INCORPORATING SOCIETAL PREFERENCES IN REIMBURSEMENT DECISIONS

RELATIVE IMPORTANCE OF DECISION CRITERIA ACCORDING TO BELGIAN CITIZENS

2008 ➜ 2010 ➜ 2012 ➜ 2014 ➜ 2016


KCE

Threshold values for cost-effectiveness in health care

KCE reports 100 C


KCE

MODELS FOR CITIZEN AND PATIENT INVOLVEMENT IN HEALTH CARE POLICY

PART I: EXPLORATION OF THEIR FEASIBILITY AND ACCEPTABILITY


KCE

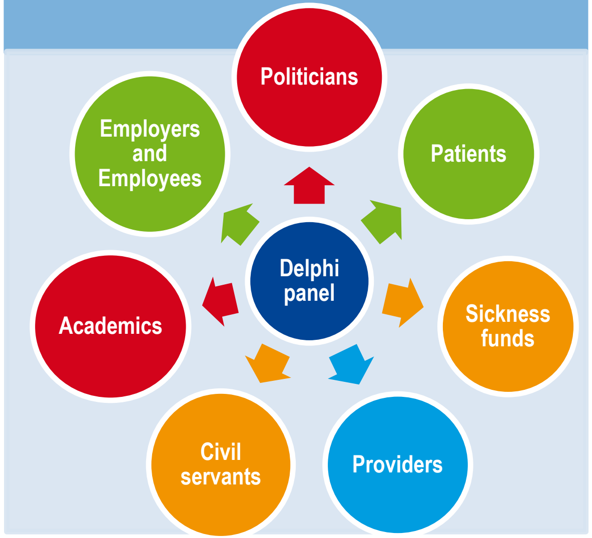
MULTI-CRITERIA DECISION ANALYSIS FOR THE APPRAISAL OF MEDICAL NEED: A PILOT STUDY

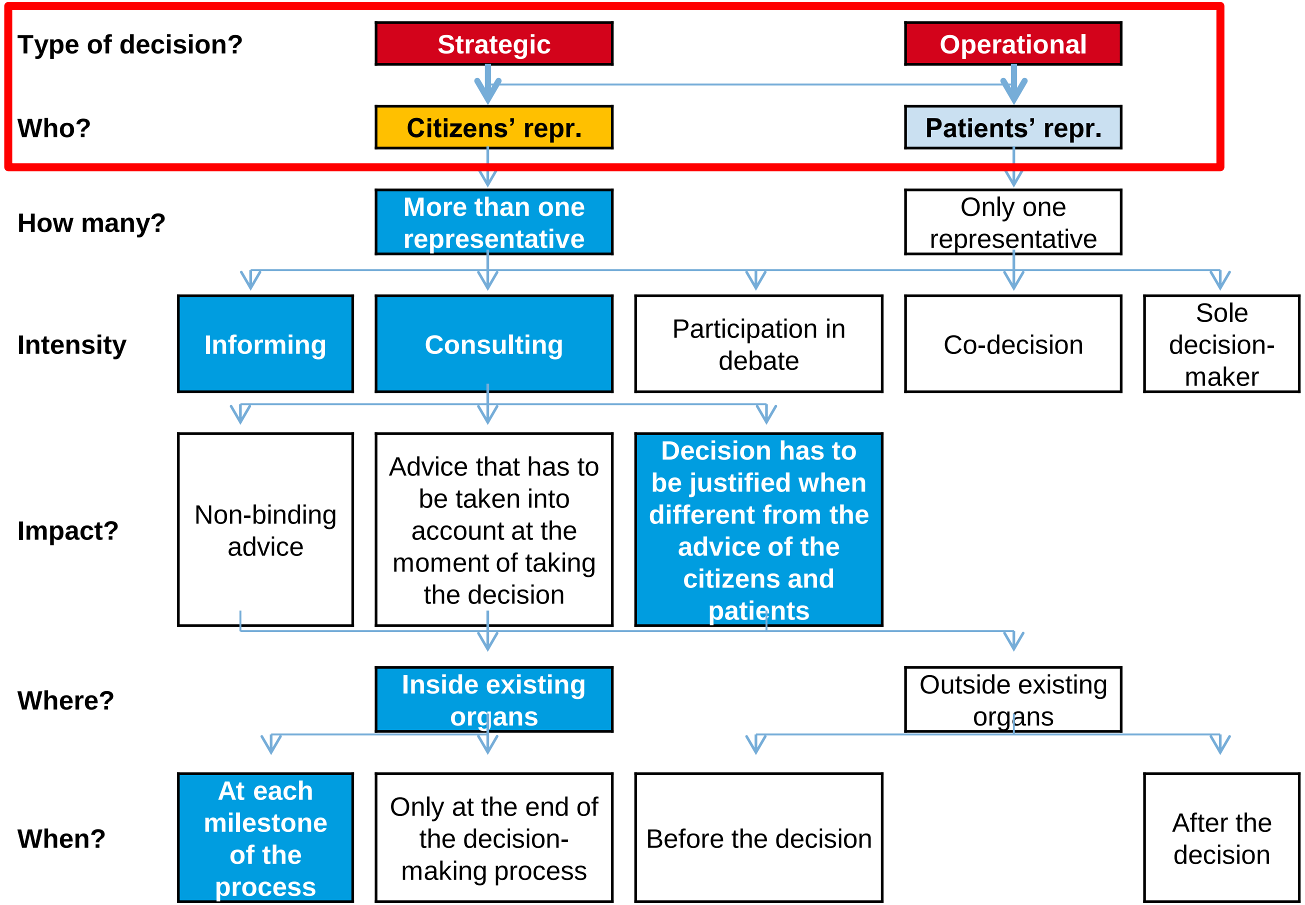
2012: Patient and citizen involvement

Research questions

- **Possible models** for public & patient involvement in HC decision making processes?
- **Acceptability** of these models to stakeholders?
- Perceived **risks and benefits**?
- **Preferred** model?

Methods





Type of decision? Strategic | Operational

Who? Citizens’ repr. | Patients’ repr.

How many? More than one representative | Only one representative

Intensity Informing | Consulting | Participation in debate | Co-decision | Sole decision-maker

Impact? Non-binding advice | Advice that has to be taken into account at the moment of taking the decision | Decision has to be justified when different from the advice of the citizens and patients

Where? Inside existing organs | Outside existing organs

When? At each milestone of the process | Only at the end of the decision-making process | Before the decision | After the decision

2010: Decision framework

Question	Possible criteria
Does the product target a therapeutic and societal need?	Disease severity, prevalence, availability of alternative treatments
Are we, as a society, prepared to pay for *a* treatment that will improve this indication out of public resources?	Own financial responsibility, life-style
Are we, as a society, prepared to pay for *this* particular treatment?	Relative effectiveness, Significance of health gains
Are we prepared to pay *more* for this treatment than for the best alternative?	Added therapeutic value, savings elsewhere in the HC sector, quality of evidence, uncertainty
How much more are we willing to pay out of public resources for this treatment (P&R)?	Added therapeutic value, BI, ICER, disease severity, savings elsewhere, limits to cost sharing, quality of evidence

2014: Defining relevant criteria and determining their relative importance according to the general public

Question
Does the product target a therapeutic and/or societal need?
Are we, as a society, prep o pay for *a* trea t that will i
A
A a
How much more are we willing to pay out of public resources for this treatment (P&R)?

Impact of the disease from the ***patient perspective***

- Inconvenience of current treatment
- Impact of disease on life expectancy
- Impact of disease on quality of life

given current treatment

Impact of the disease from the ***societal perspective***

- Disease-related public expenditure
- Prevalence

given current treatment

Public preferences/weights of decision criteria defining “needs”

Therapeutic need

- **Inconvenience** of current treatment 0,43
- **Quality of life** with current treatment 0,43
- **Life expectancy** with current treatment 0,14

Societal need

- **Prevalence** 0,35
- **Disease-related societal cost** 0,65

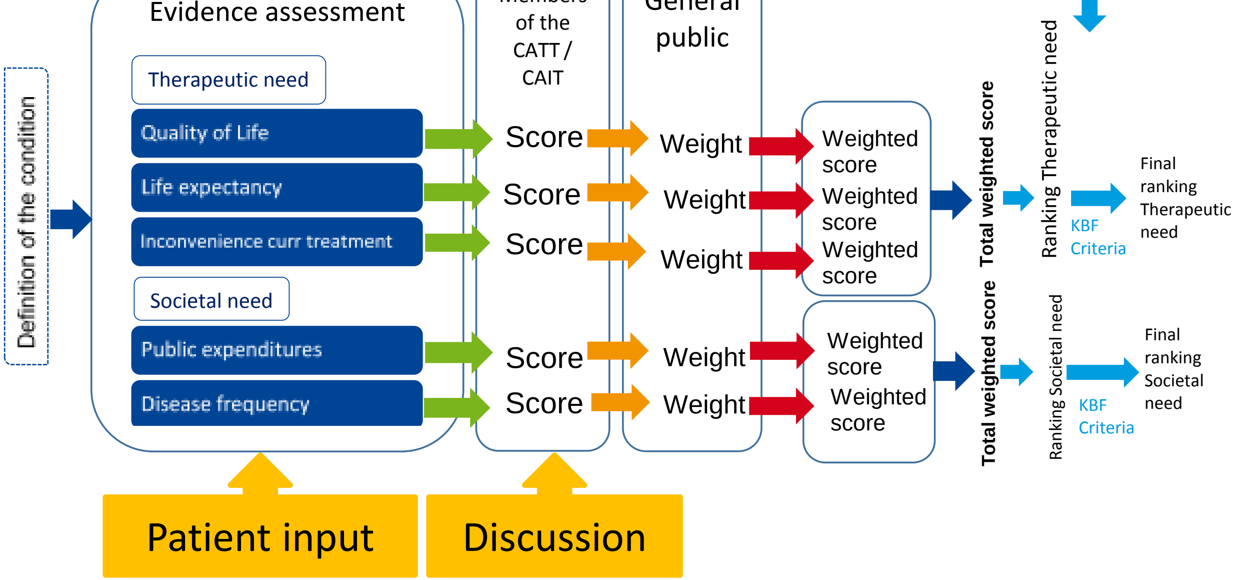
2016: Unmet needs assessment MCDA Pilot test


KCE

INCORPORATING SOCIETAL PREFERENCES IN REIMBURSEMENT DECISIONS

RELATIVE IMPORTANCE OF DECISION CRITERIA ACCORDING TO BELGIAN CITIZENS


Burgers als leidraad bij terugbetalingen in de gezondheidszorg


Definition of the condition

Evidence assessment

Therapeutic need

- Quality of Life
- Life expectancy
- Inconvenience curr treatment

Societal need

- Public expenditures
- Disease frequency

Members of the CATT / CAIT

Score

Score

Score

Score

Score

General public

Weight

Weight

Weight

Weight

Weight

Weighted score

Weighted score

Weighted score

Weighted score

Weighted score

Total weighted score

Ranking Therapeutic need

KBF Criteria

Final ranking Therapeutic need

Total weighted score

Ranking Societal need

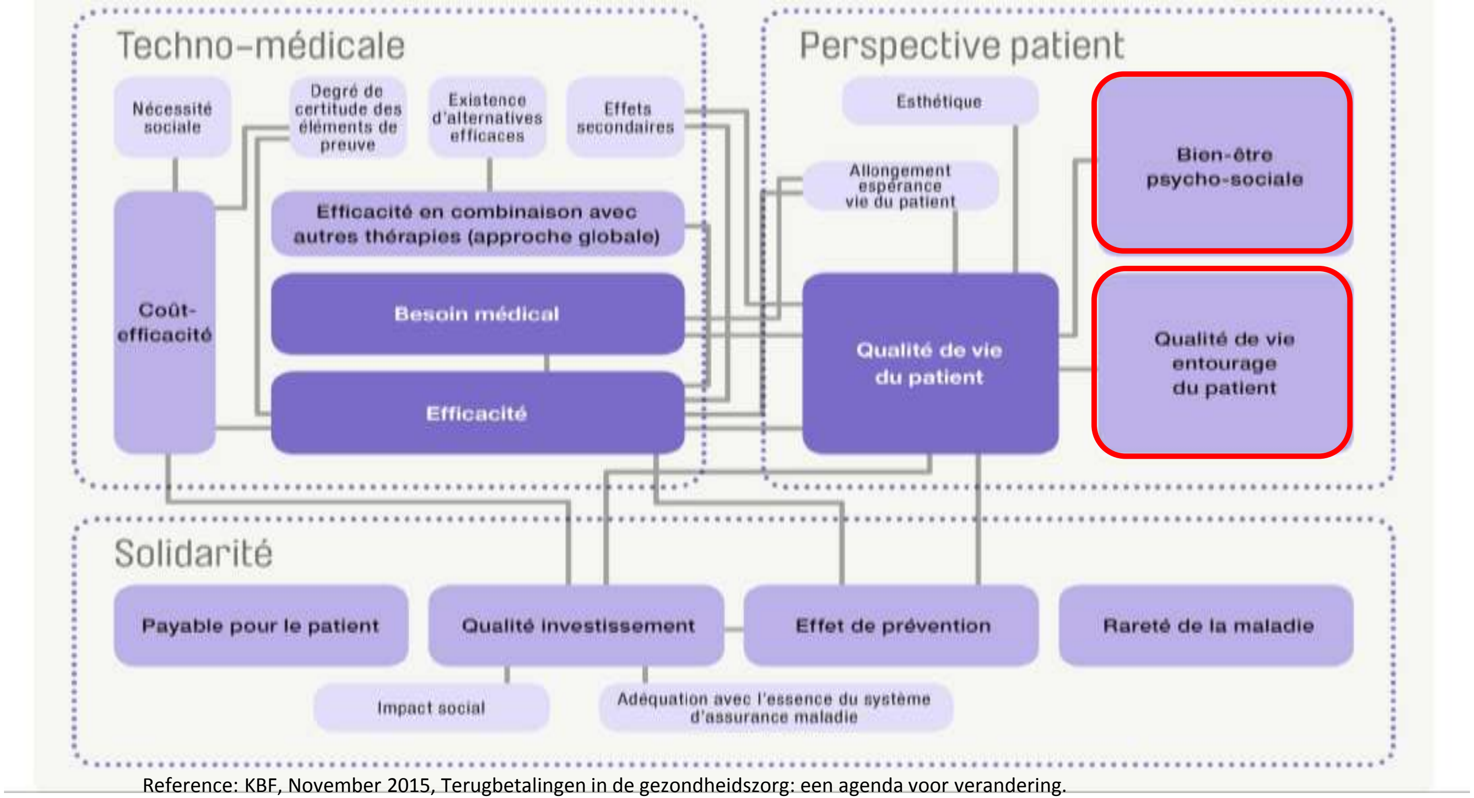
KBF Criteria

Final ranking Societal need

Patient input

Discussion

Critères



Techno-médicale

Nécessité sociale

Degré de certitude des éléments de preuve

Existence d'alternatives efficaces

Effets secondaires

Coût-efficacité

Efficacité en combinaison avec autres thérapies (approche globale)

Besoin médical

Efficacité

Perspective patient

Esthétique

Allongement espérance vie du patient

Bien-être psycho-sociale

Qualité de vie du patient

Qualité de vie entourage du patient

Solidarité

Payable pour le patient

Qualité investissement

Effet de prévention

Rareté de la maladie

Impact social

Adéquation avec l'essence du système d'assurance maladie

Reference: KBF, November 2015, Terugbetalingen in de gezondheidszorg: een agenda voor verandering.

Conclusion

- Needs-driven system → patient involvement!
- Mix of quantitative and qualitative approaches
- CAVE diseases without patient organisation
- 2017-2018: Development of ways / approaches to elicit patient needs in diverse areas
- Diverse projects ongoing (e.g. PREFER)

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Travaux pilotes sur la mesure des préférences

Patient preference elicitation: quantitative methods and pilot projects in Germany

HAS
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Marion DANNER

UNIKLINIK KÖLN
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Chercheure associée, Institute for Health Economics and Clinical Epidemiology, Hôpital universitaire de Cologne, Allemagne

01

Quantitative methods for patient preference elicitation:

Analytic Hierarchy Process
Discrete Choice Experiments

Why to elicit patient preferences?

⇨ **Decisions in health care are taken every day, usually by more than one person**

⇨ **Preferences are part of every decision, but can not be ‘observed’**

in shared desion-making…

…or group decisions

⇨ **the (potential) patient is the primary ‘consumer’ and ‘payer’ of health care**

How to elicit patient preferences?

Preferences → collect → **Stated preferences** → measure → **Relative importance of treatment attributes and levels to patients**

Methods:

- **qualitative:** focus groups, personal interviews, think-alouds
- **quantitative:** multi-criteria decision analysis, e.g.

  Analytic Hierarchy Process (AHP);

  Discrete choice experiment (DCE);

How can quantitative preference elicitation help?

Outcome-specific results of HTAs or cost-effectiveness assessments, e.g.:

- effectiveness
- side effects
- quality of life
- other outcome-specific findings

⇨ **prioritize outcome-specific** results?

⇨ **aggregate** results?

⇨ **weigh benefits against risks**? How much risk is a patient willing to take for a certain benefit?

How do quantitative methods work?

AHP / DCE:

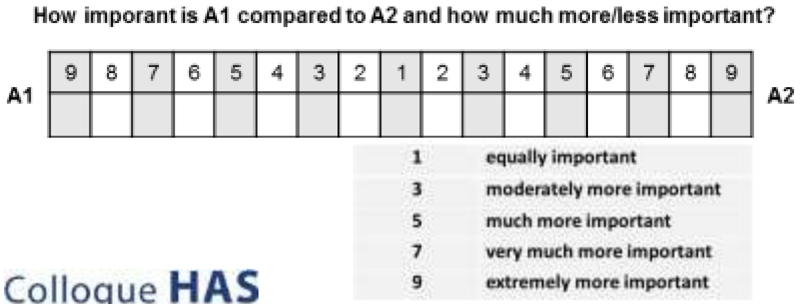
Several treatment alternatives: Which treatment characteristics (attributes / levels) are import to patients?

A1 (effectiveness)
- L1: improvement by 10 %
- L2: improvement by 20 %
- L3: improvement by 40 %

A2 (potential side effects)
- L1: risk of nausea
- L2: risk of allergic reaction
- L3: risk of increased fatique

A3 (administration of intervention)
L1: oral, once daily
L2: injection, every week

AHP: pairwise comparison of attibutes and levels

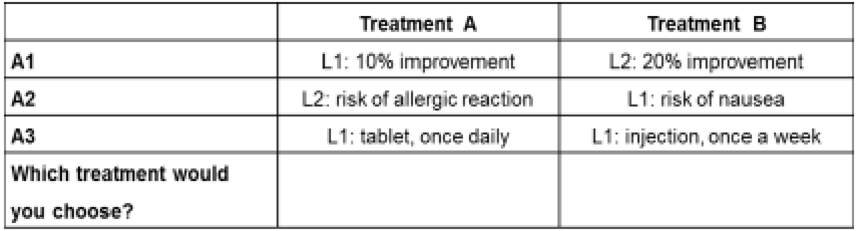


How imporant is A1 compared to A2 and how much more/less important?

A1	9	8	7	6	5	4	3	2	1	2	3	4	5	6	7	8	9	A2

1	equally important
3	moderately more important
5	much more important
7	very much more important
9	extremely more important

DCE: comparing treatment options



	Treatment A	Treatment B
A1	L1: 10% improvement	L2: 20% improvement
A2	L2: risk of allergic reaction	L1: risk of nausea
A3	L1: tablet, once daily	L1: injection, once a week
Which treatment would you choose?		

AHP / DCE pilots

AHP (IQWiG):

- treatment of major depression
- group setting (qualitative element: group discussion)
- patients versus treating physicians / experts

DCE (IQWiG):

- treatment of hepatitis C
- individual paper-pencil questionnaires
- patients versus treating physicians / experts

AHP&DCE (IGKE):

- treatments in age-related macular degeneration, comparison of methods

DCE (IQWiG):

- treatments in periodontal diseases

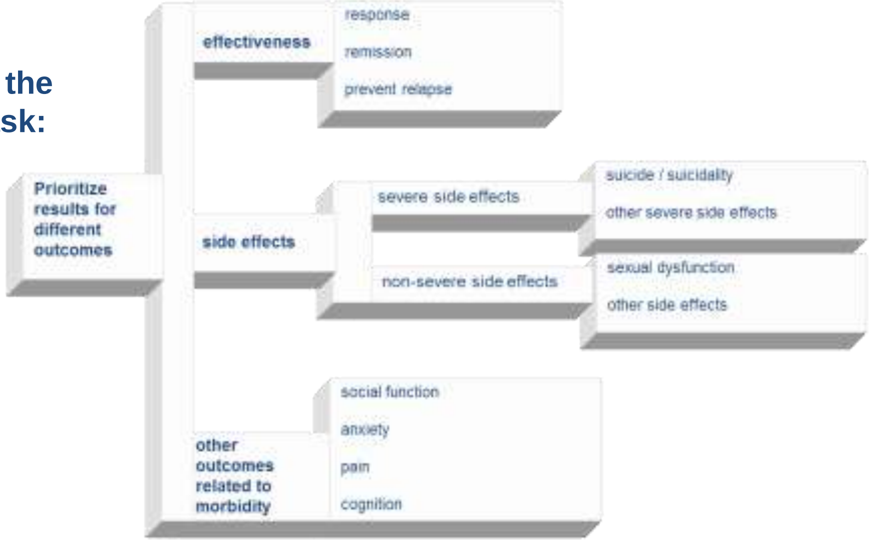
Results of AHP pilot in depression

Study objective: Feasability of AHP in measuring patient preferences

Structure the decision:

Objective of the elicitation task:

Attributes **Levels**



Prioritize results for different outcomes

- **effectiveness**
  - response
  - remission
  - prevent relapse
- **side effects**
  - severe side effects
    - suicide / suicidality
    - other severe side effects
  - non-severe side effects
    - sexual dysfunction
    - other side effects
- **other outcomes related to morbidity**
  - social function
  - anxiety
  - pain
  - cognition

Results of AHP pilot in depression

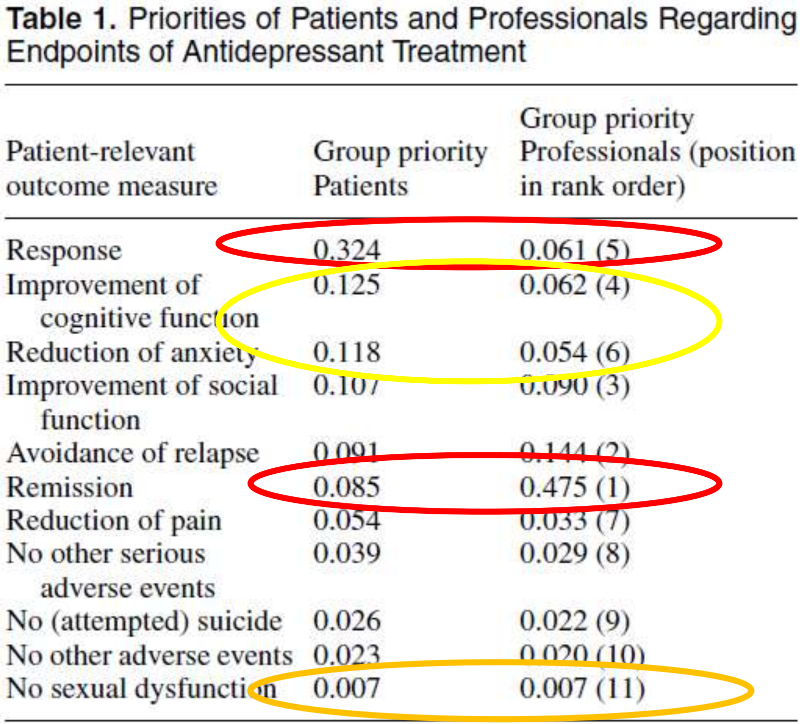


Table 1. Priorities of Patients and Professionals Regarding Endpoints of Antidepressant Treatment

Patient-relevant outcome measure	Group priority Patients	Group priority Professionals (position in rank order)
Response	0.324	0.061 (5)
Improvement of cognitive function	0.125	0.062 (4)
Reduction of anxiety	0.118	0.054 (6)
Improvement of social function	0.107	0.090 (3)
Avoidance of relapse	0.091	0.144 (2)
Remission	0.085	0.475 (1)
Reduction of pain	0.054	0.033 (7)
No other serious adverse events	0.039	0.029 (8)
No (attempted) suicide	0.026	0.022 (9)
No other adverse events	0.023	0.020 (10)
No sexual dysfunction	0.007	0.007 (11)

Danner et al. 2011

Insights from pilot & other projects

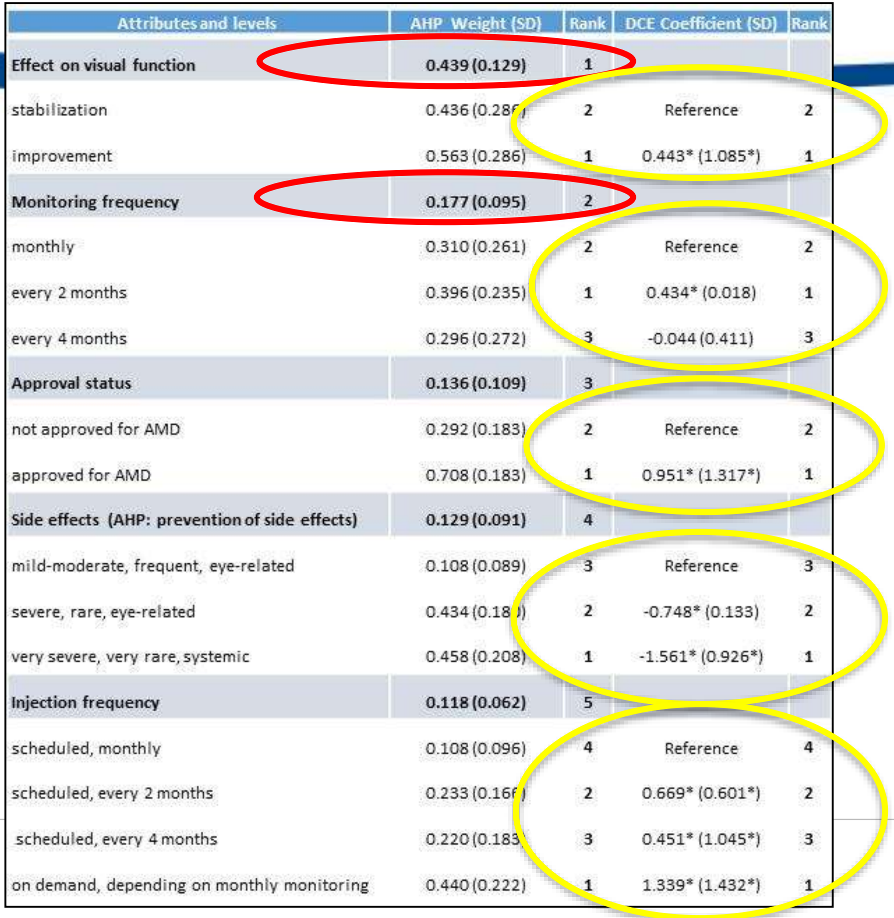
- Discrepancies between patients’ & treating physicians’ preferences / views

- **Methods are feasible**, but questions regarding **instrument validity**: comparison of different methods for quantitative preference elicitation (convergent validity)

- **Reliability** (interpersonal, intrapersonal): repeat surveys, sample size (?), different settings, patient subgroups (?)

- Methodological drawbacks, other methods (e.g. Best-Worst scaling, Swing weighting)

Insights from AMD project comparing AHP and DCE



Attributes and levels	AHP Weight (SD)	Rank	DCE Coefficient (SD)	Rank
Effect on visual function	**0.439 (0.129)**	**1**		
stabilization	0.436 (0.286)	2	Reference	2
improvement	0.563 (0.286)	1	0.443* (1.085*)	1
Monitoring frequency	**0.177 (0.095)**	**2**		
monthly	0.310 (0.261)	2	Reference	2
every 2 months	0.396 (0.235)	1	0.434* (0.018)	1
every 4 months	0.296 (0.272)	3	-0.044 (0.411)	3
Approval status	**0.136 (0.109)**	**3**		
not approved for AMD	0.292 (0.183)	2	Reference	2
approved for AMD	0.708 (0.183)	1	0.951* (1.317*)	1
Side effects (AHP: prevention of side effects)	**0.129 (0.091)**	**4**		
mild-moderate, frequent, eye-related	0.108 (0.089)	3	Reference	3
severe, rare, eye-related	0.434 (0.18[illegible])	2	-0.748* (0.133)	2
very severe, very rare, systemic	0.458 (0.208)	1	-1.561* (0.926*)	1
Injection frequency	**0.118 (0.062)**	**5**		
scheduled, monthly	0.108 (0.096)	4	Reference	4
scheduled, every 2 months	0.233 (0.166)	2	0.669* (0.601*)	2
scheduled, every 4 months	0.220 (0.183)	3	0.451* (1.045*)	3
on demand, depending on monthly monitoring	0.440 (0.222)	1	1.339* (1.432*)	1

Ranking of relative level importance identical for AHP & DCE

No direct information on attribute importance from DCE available

May be calculated based on level importance

Insights

Best if quantitative combined with qualitative preference data

Needed to generate ’evidence’ on patient preferences

Get patients involved in decisions, take preferences into account

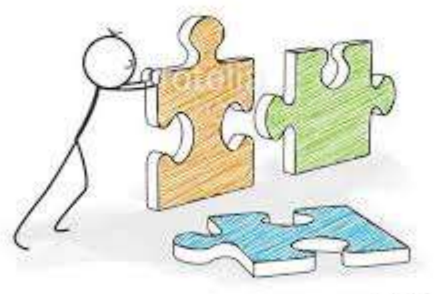
Support approval / submission decisions:

- AHP helpful if a prioritization / ranking of outcome-specific HTA results is needed (e.g. evidence tables)
- DCE: attribute importance always dependent on choice of levels (e.g. AMD, periodontal project)
- DCE helpful if benefit-risk exchange rate is needed (e.g. FDA obesity device project: for an increase in effectiveness by x%, patients are willing to accept an increase in the risk of side effects of y %)
- Other methods: « active and evolving area of research » (FDA 2016), methodological challenges!

Conclusions

More research into methods is needed

Preference information is one piece of information to add to the value of HTAs…



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Marion DANNER, chercheure associée, Institute for Health Economics and Clinical Epidemiology, Hôpital universitaire de Cologne, Allemagne

Christophe DUGUET, directeur des affaires publiques, AFM-Téléthon – membre de la commission évaluation économique et santé publique, HAS

Karen FACEY, consultante internationale en politique de santé

Catherine RUMEAU-PICHON, adjointe à la directrice de l'évaluation médicale, économique et santé publique, HAS

Conclusion

Angela COULTER
Directrice des initiatives mondiales,
Informed Medical Decisions
Foundation, États-Unis

Engaging Patients:
What We Have Learnt

The four principles of person-centred care

01

What problems are we trying to solve?

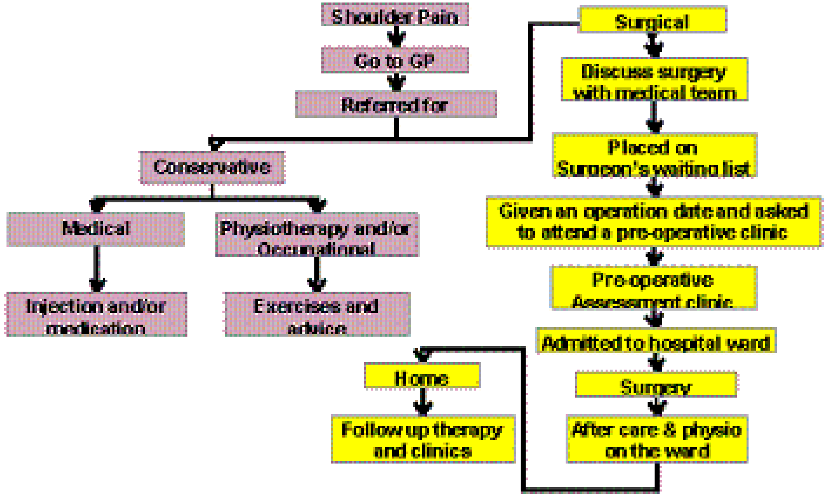
Today’s Healthcare Through Patients’ Eyes

Disempowering

Encourages passivity and dependency

Undermines self-reliance

Inflexible and Rule-Bound



Assumes everyone wants/needs the same type of care

No room for personal goals

Rigid, controlled by professionals/system managers/regulators

Complex and Fragmented

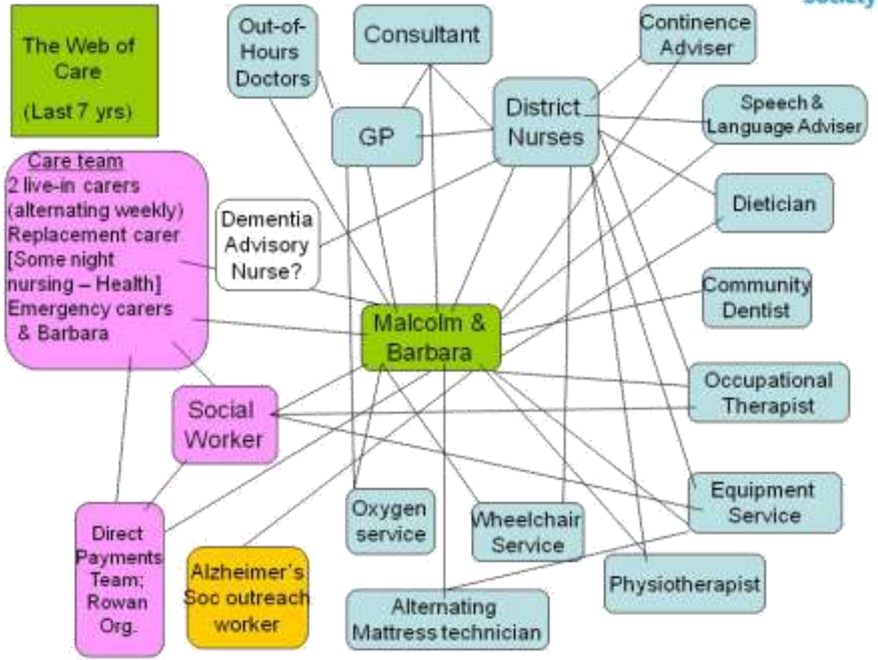
Not integrated

Uncoordinated

Confusing

Burdensome

Alzheimer's Society



The Web of Care

(Last 7 yrs)

Care team
2 live-in carers (alternating weekly)
Replacement carer
[Some night nursing – Health]
Emergency carers & Barbara

Out-of-Hours Doctors

Consultant

Continence Adviser

District Nurses

GP

Speech & Language Adviser

Dietician

Dementia Advisory Nurse?

Malcolm & Barbara

Community Dentist

Occupational Therapist

Social Worker

Equipment Service

Oxygen service

Wheelchair Service

Physiotherapist

Direct Payments Team; Rowan Org.

Alzheimer's Soc outreach worker

Alternating Mattress technician

02

What can patients, families and communities contribute?

Patients, families and communities

The greatest untapped resource!

People’s Contribution to Health (1)

- Understanding the causes of disease
- Diagnosing and self-treating minor illness
- Knowing when to seek professional help
- Choosing appropriate providers
- Selecting appropriate treatments
- Monitoring symptoms and treatment effects
- Coping with chronic conditions and managing care

People’s Contribution to Health (2)

- Being aware of safety issues and preventing errors
- Adopting healthy behaviours to prevent disease
- Ensuring healthcare resources are used efficiently
- Participating in research and health technology assessment
- Articulating views in debates about priorities
- Helping to plan, govern, evaluate and improve services
- Working together to tackle the causes of ill health

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

‘with’, not ‘to’ or ‘for’

‘what matters to you?’, instead of ‘what’s the matter with you?’

03

What works?

Features of a Person-Centred Approach

Listening

Involving

Communicating

Informing

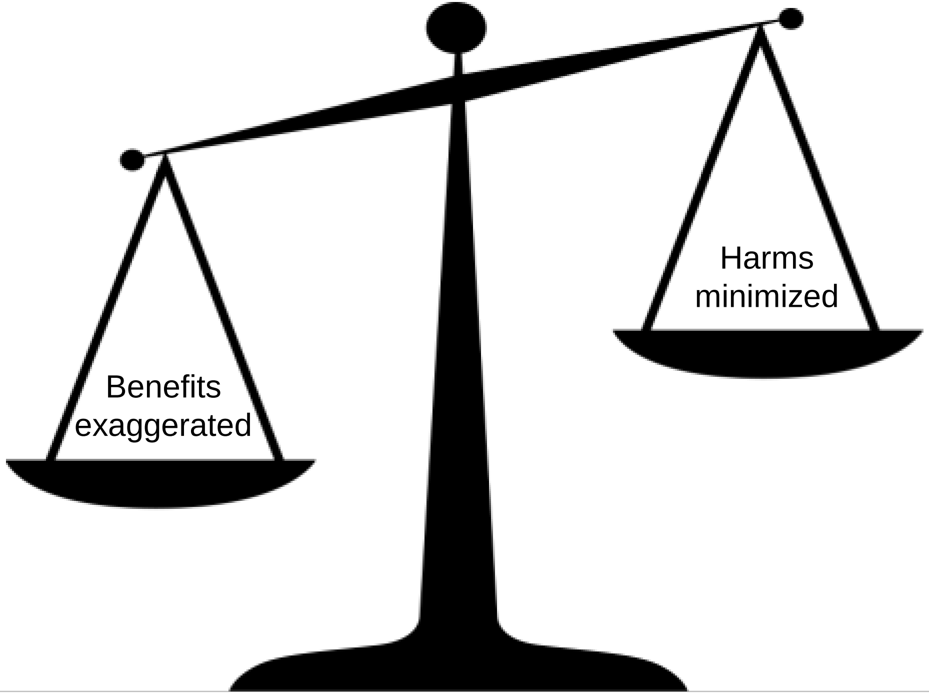
Planning

Supporting

Measuring

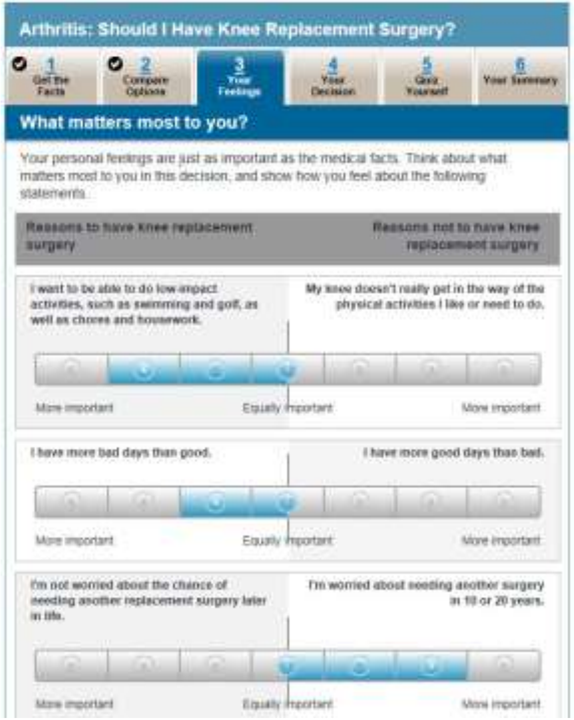
Searching for Health Information

Health Information is Often Unbalanced



Patient decision aids

Reliable, balanced, evidence-based information outlining prevention, treatment, or management options, outcomes and uncertainties



Arthritis: Should I Have Knee Replacement Surgery?

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.
I have more bad days than good.	I have more good days than bad.
I'm not worried about the chance of needing another replacement surgery later in life.	I'm worried about needing another surgery in 10 or 20 years.

Decision Aids: the Evidence

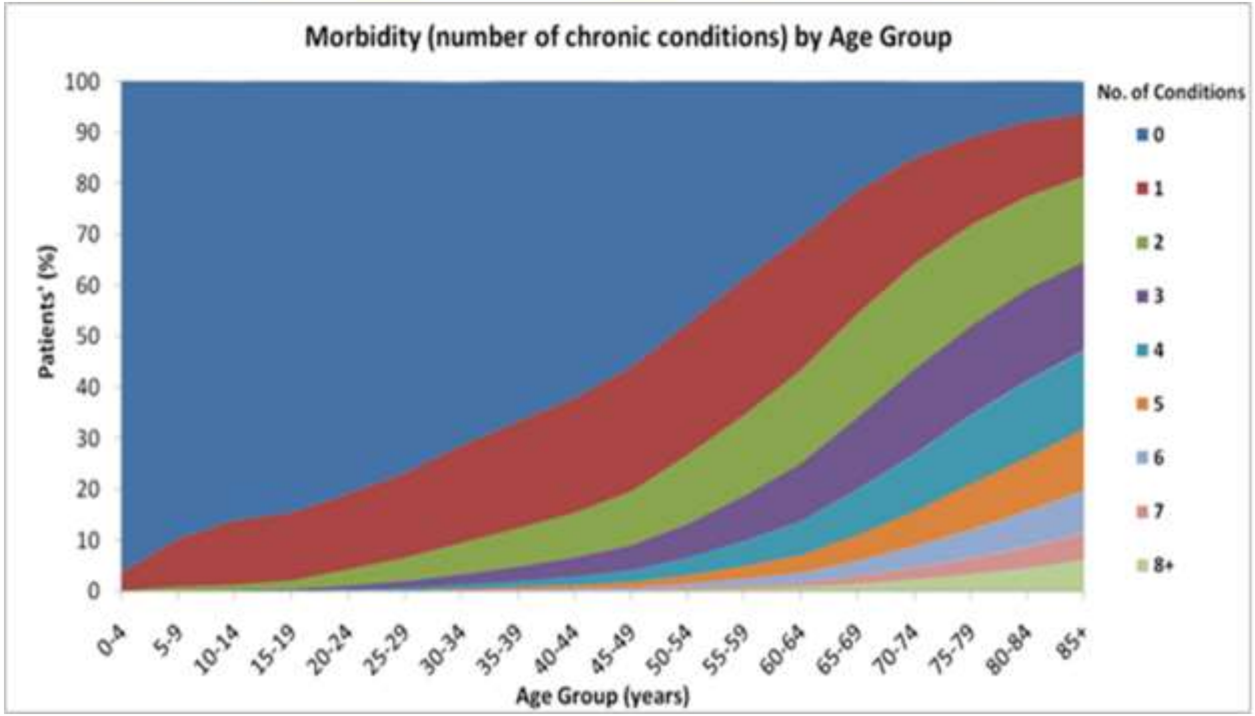
In 115 trials involving 34,444 participants, use has led to:

- Greater knowledge
- More accurate risk perceptions
- Greater comfort with decisions
- Greater participation in decision-making
- Fewer people remaining undecided
- Fewer patients choosing major surgery

THE COCHRANE
COLLABORATION®

Stacey et al. Cochrane Database of Systematic Reviews, 2014

Rise in multi-morbidity



Barnett et al. Lancet 2012; 380: 37-43

Managing Long Term Conditions

Professional care –

3 hours per year
(1 x 15 mins per month)

Self-care –

8,757 hours per year (99.9%)

Personalised care planning

Conversation between a patient and a clinician to jointly agree goals and actions for managing the patient's health problems.

Involving Patients in Personalised Care Planning

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)

Cochrane
Library

Cochrane Database of Systematic Reviews

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

Patient experience, safety and clinical effectiveness

Open Access Research

BMJ open

A systematic review of evidence on the links between patient experience and clinical safety and effectiveness

Cathal Doyle,[1] Laura Lennox,[1,2] Derek Bell[1,2]

To cite: Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013;**3**:e001570. doi:10.1136/bmjopen-2012-001570

► Prepublication history and additional material for this paper are available online. To view these files please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2012-001570).

Received 18 June 2012
Revised 2 November 2012
Accepted 12 November 2012

ABSTRACT

Objective: To explore evidence on the links between patient experience and clinical safety and effectiveness outcomes.

Design: Systematic review.

Setting: A wide range of settings within primary and secondary care including hospitals and primary care centres.

Participants: A wide range of demographic groups and age groups.

Primary and secondary outcome measures: A broad range of patient safety and clinical effectiveness outcomes including mortality, physical symptoms, length of stay and adherence to treatment.

Results: This study, summarising evidence from 55 studies, indicates consistent positive associations between patient experience, patient safety and clinical effectiveness for a wide range of disease areas, settings, outcome measures and study designs. It demonstrates positive associations between patient experience and self-rated and objectively measured health outcomes; adherence to recommended clinical practice and medication; preventive care (such as health-promoting behaviour, use of screening services

ARTICLE SUMMARY

Article focus

- Should patient experience, as advocated by the Institute of Medicine and the NHS Outcomes Framework, be seen as one of the pillars of quality in healthcare alongside patient safety and clinical effectiveness?
- What aspects of patient experience can be linked to clinical effectiveness and patient safety outcomes?
- What evidence is available on the links between patient experience and clinical effectiveness and patient safety outcomes?

Key messages

- The results show that patient experience is consistently positively associated with patient safety and clinical effectiveness across a wide range of disease areas, study designs, settings, population groups and outcome measures.
- Patient experience is positively associated with self-rated and objectively measured health outcomes; adherence to recommended medication and treatments; preventative care such as use of

More positive experiences are associated with:

- better clinical indicators
- fewer complications
- better functional ability and quality-of-life
- greater adherence to treatment recommendations
- lower resource use
- less likelihood of premature death

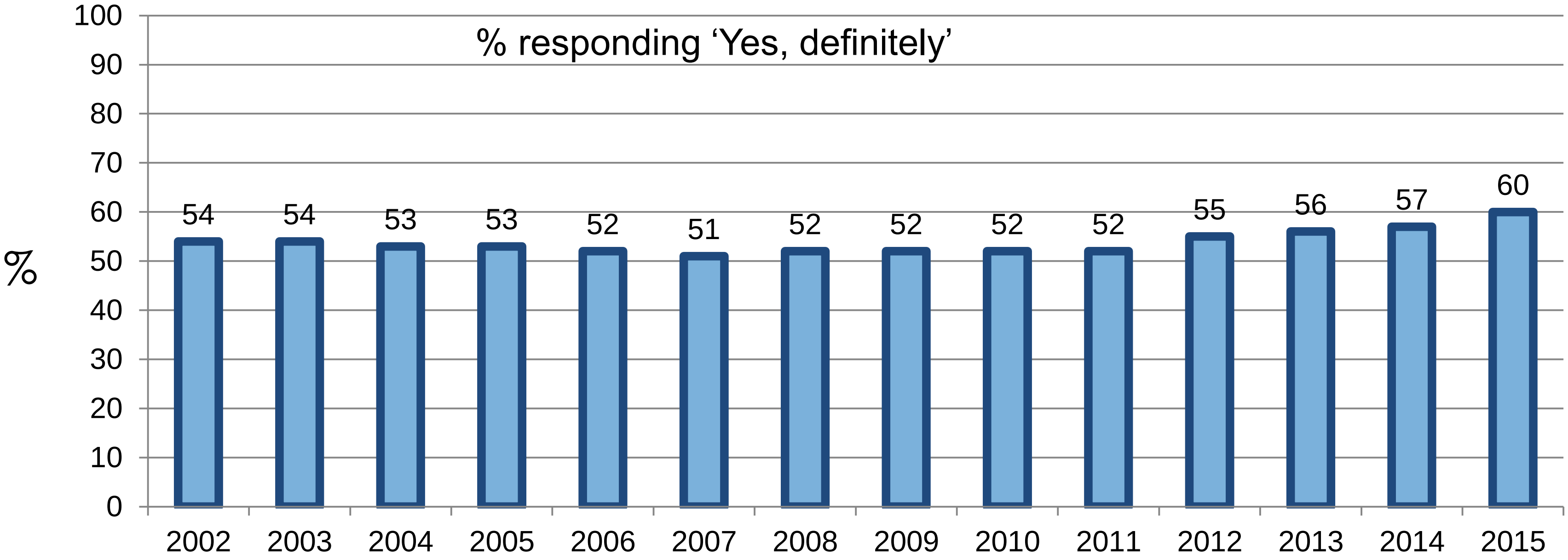
04

Measurement Issues

Why Measure?

- To identify problems in care delivery
- To inform quality improvement and service development
- To help professionals reflect on their own and their team's practice
- To monitor the impact of any changes
- To compare quality and outcomes of care between organisations
- To inform patients and professionals
- To enable public accountability

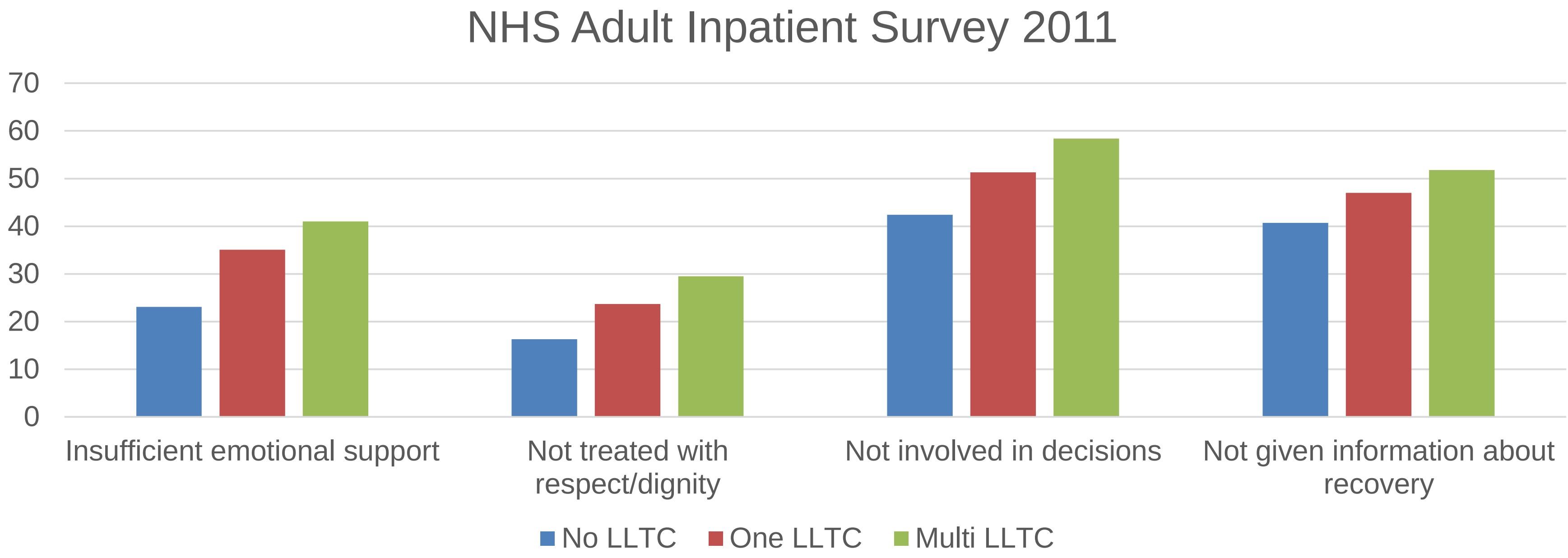
Were you involved as much as you wanted to be in decisions about your care and treatment?



Source: NHS inpatient surveys

Care Quality Commission June 2016

Problems by Health Status (LTCs)



Hewitson et al. BMC HSR 2014

Patient Reported Outcome Measure (PROM) - EQ-5D-5L

Mobility

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

Self-care

- washing, dressing

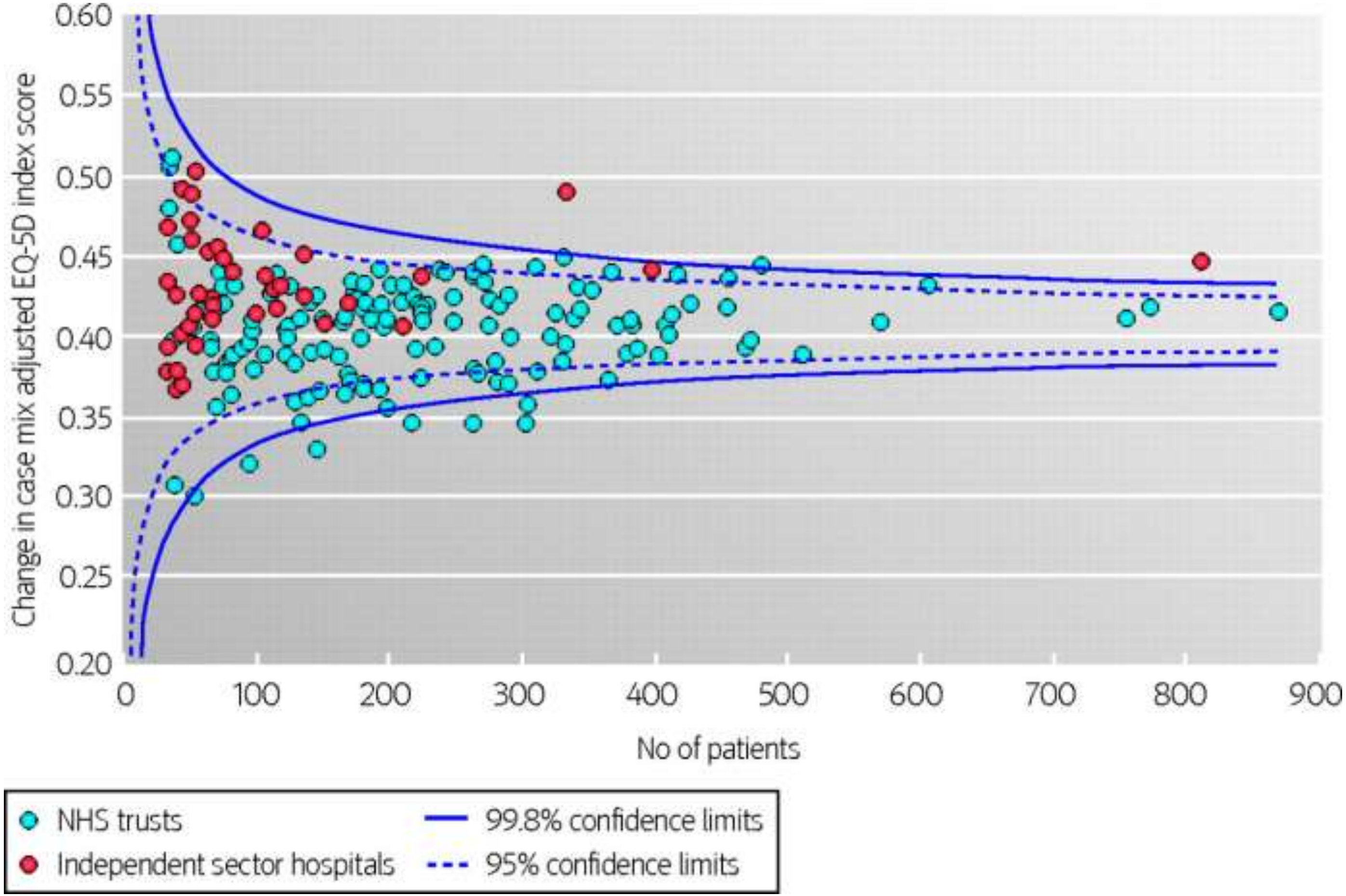
Usual activities

- work, study, housework, family or leisure

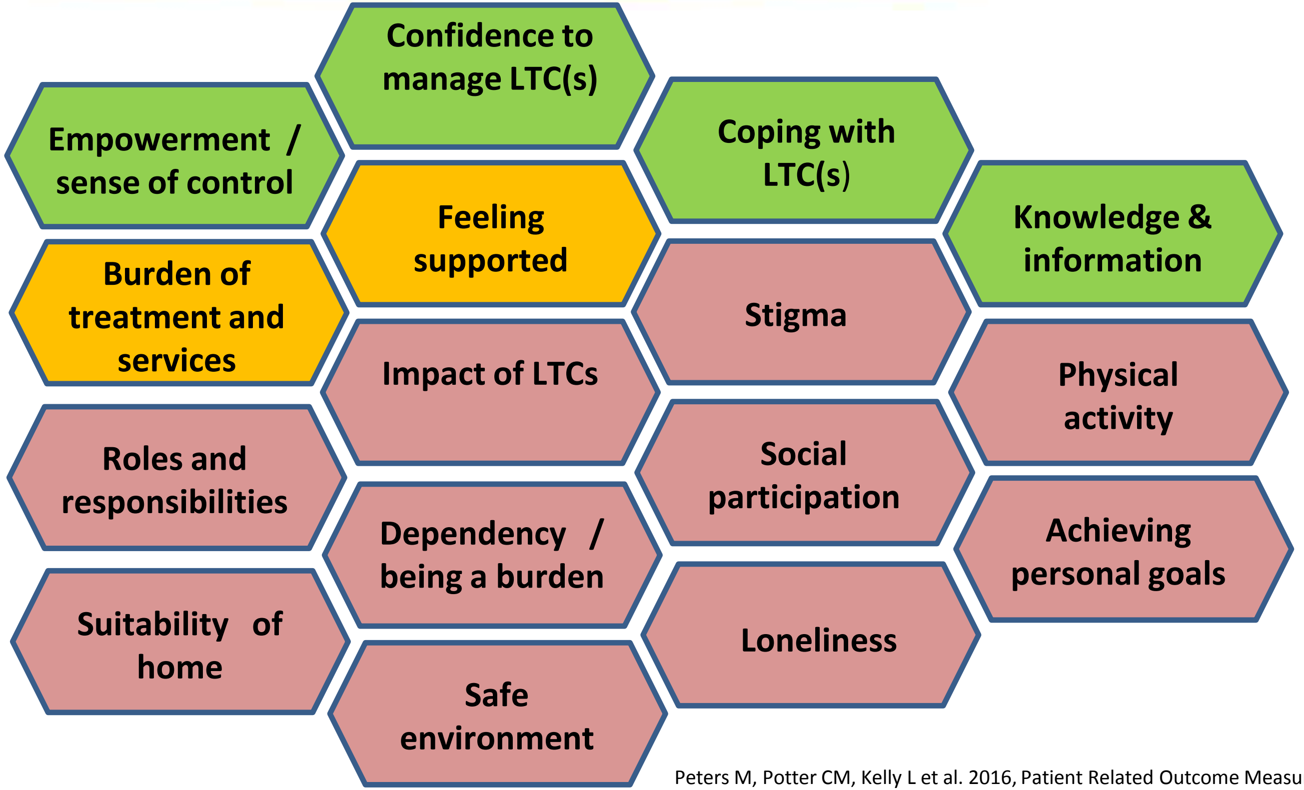
Pain/discomfort

- anxiety / depression

+ visual analogue scale


0.60
0.55
0.50
0.45
0.40
0.35
0.30
0.25
0.20
Change in case mix adjusted EQ-5D index score
0
100
200
300
400
500
600
700
800
900
No of patients
NHS trusts
Independent sector hospitals
99.8% confidence limits
95% confidence limits

Outcomes that Matter



Empowerment / sense of control

Burden of treatment and services

Roles and responsibilities

Suitability of home

Confidence to manage LTC(s)

Feeling supported

Impact of LTCs

Dependency / being a burden

Safe environment

Coping with LTC(s)

Stigma

Social participation

Loneliness

Knowledge & information

Physical activity

Achieving personal goals

Peters M, Potter CM, Kelly L et al. 2016, Patient Related Outcome Measures 7:109-125

Measurement is Not Enough

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

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

Coulter et al. BMJ 2014; 348:g2225

HAUTE AUTORITÉ DE SANTÉ

Colloque HAS

La dynamique patient
innover & mesurer

16 novembre 2016 PARIS

Clôture

Dominique MAIGNE
Directeur, HAS

Chacun des intervenants a déclaré ses liens d'intérêt avec les industries de santé en rapport avec le thème de la présentation (loi du 4 mars 2002)

Retrouvez ces déclarations sur le site Internet de la HAS, espace Colloque HAS

www.has-sante.fr

La Haute Autorité de Santé vous remercie d'avoir participé à cette séance

www.has-sante.fr