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STATI GENERALI ITINERANTI PER L'UMANIZZAZIONE DELLE CURE E IL BENESSERE ORGANIZZATIVO

Congresso scientifico

Umanizzazione delle cure: come ri-costruire la filiera della salute

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Umanizzazione delle cure: come ri-costruire la filiera della salute

Innovazione dei modelli di cura a fianco dei pazienti

Ornella Gonzato

Patient

Activation

Patient-Centered Care

Patient

Participation

Person-Centered Care

Patient

Compliance

Patient
Adherence

Patient Involvement

Patient Engagement

Patient

Empowerment

Patient

Patient

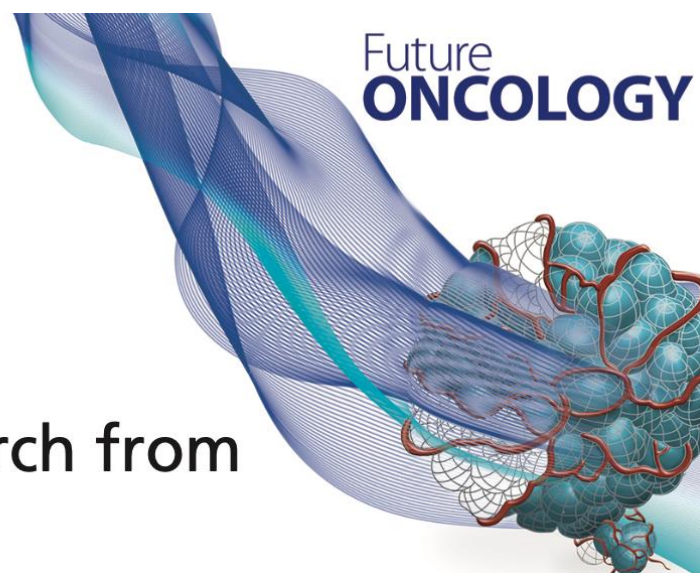
Value

Partnership

SPECIAL FOCUS ISSUE | Patient Engagement in Cancer Research

Review

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Patient engagement in cancer research from the patient's perspective

Domecq et al. *BMC Health Services Research* 2014, **14**:89
<http://www.biomedcentral.com/1472-6963/14/89>



RESEARCH ARTICLE

Open Access

Patient engagement in research: a systematic review

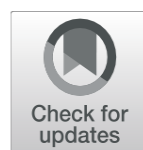
Kaisler and Missbach *Research Involvement and Engagement* (2020) 6:32
<https://doi.org/10.1186/s40900-020-00208-3>



COMMENTARY

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Co-creating a patient and public involvement and engagement 'how to' guide for researchers



Hickmann et al. *BMC Health Services Research* (2022) 22:1116
<https://doi.org/10.1186/s12913-022-08501-5>

BMC Health Services Research

RESEARCH

Open Access



All together now – patient engagement, patient empowerment, and associated terms in personal healthcare

Research Article

Impact of Patient Engagement on Healthcare Quality: A Scoping Review

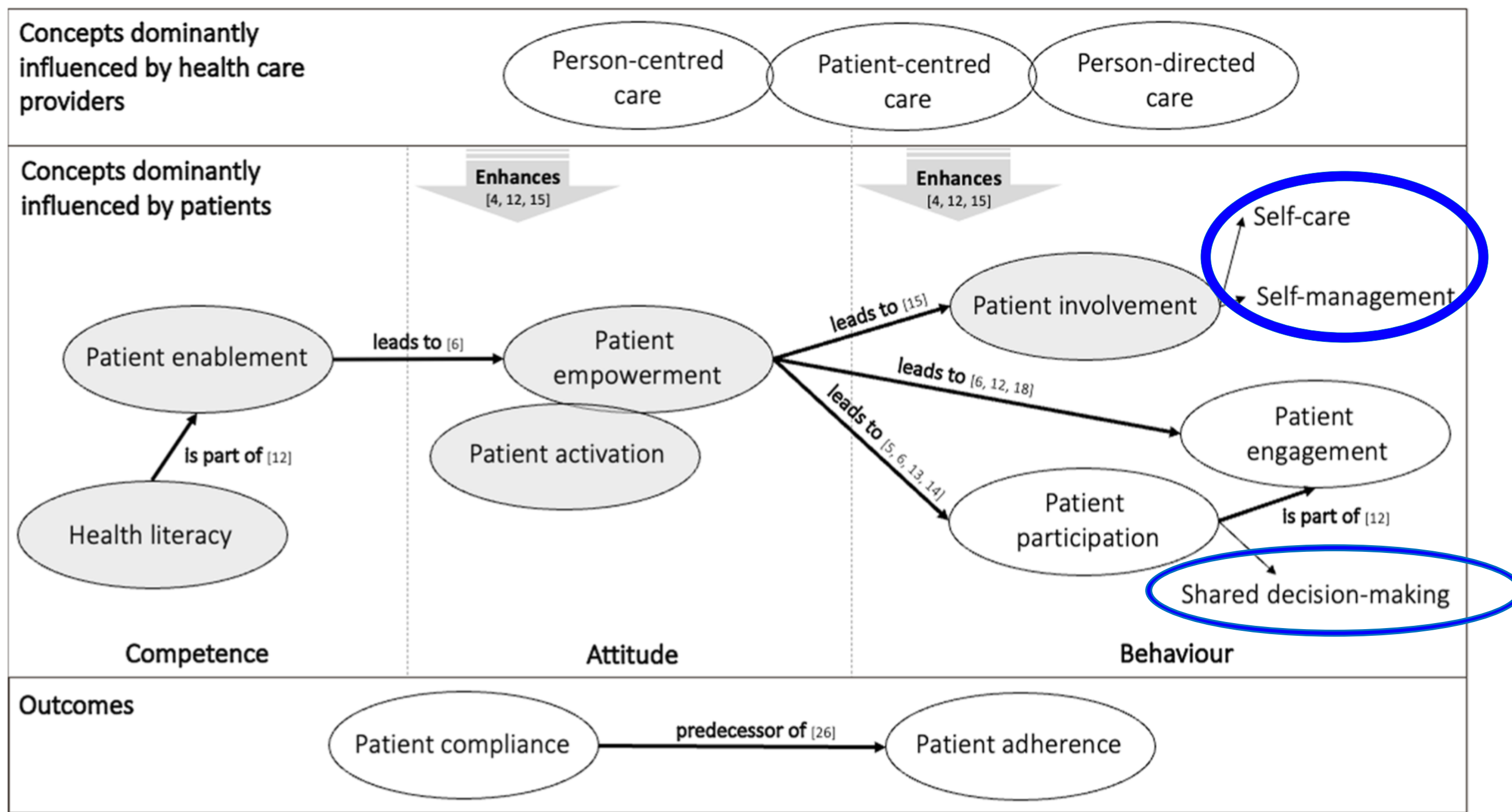
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Rassegna

Recenti Prog Med 2017; 108: 455-475

Promozione del patient engagement in ambito clinico-assistenziale per le malattie croniche: raccomandazioni dalla prima conferenza di consenso italiana



Hickmann et al. BMC Health Services Research (2022) 22:1116 <https://doi.org/10.1186/s12913-022-08501-5>

« The concept map presents a basis for a uniform understanding and application of the concepts leading to better acceptance and utilisation of concepts in healthcare services... **Patient engagement is presented to be the most conclusive and furthest developed concept in the subject area** »

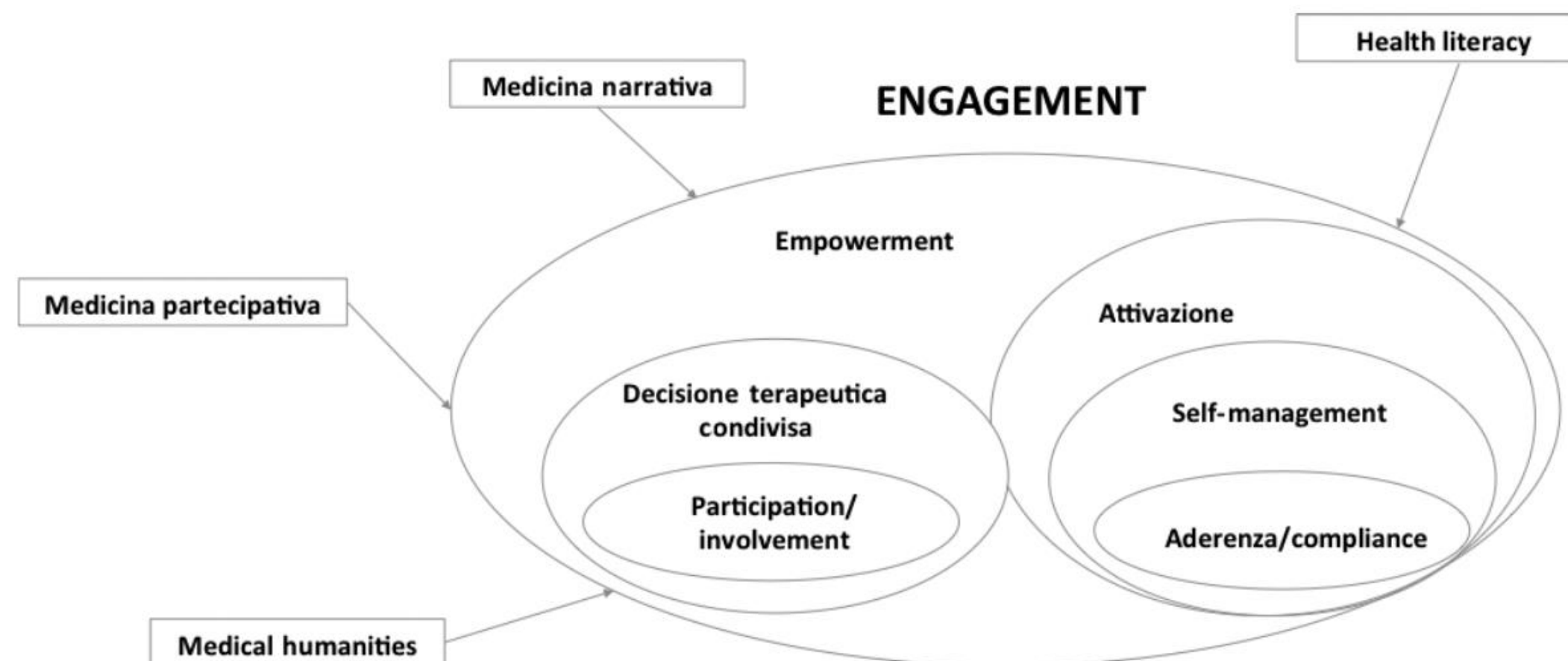
Qual è la definizione di engagement?

L'engagement, nell'ambito clinico assistenziale della cronicità, è un **concetto sistemico** che identifica e qualifica le possibili modalità di relazione che una persona con una domanda di salute/prevenzione, assistenza e/o cura può intrattenere con la sua condizione clinica, il suo caregiver informale (in particolare la famiglia), il professionista sanitario e il team assistenziale nel suo complesso, il contesto organizzativo, il sistema socio-sanitario e il sistema sociale allargato, durante il proprio percorso clinico-assistenziale.

L'engagement è funzione della capacità, della volontà e della scelta graduale delle persone di assumere un **ruolo proattivo** nella gestione della propria salute.

L'engagement nell'ambito clinico assistenziale della cronicità è un **concetto-ombrello** che ne articola, sistematizza e include altri, quali **adherence, compliance, empowerment, activation, health literacy, shared decision making, activation** (in Appendice 2 il glossario dei concetti chiave della medicina partecipativa).

L'engagement è un **processo complesso** che risulta dalla combinazione di diverse dimensioni e fattori di natura individuale, relazionale, organizzativa, sociale, economica e politica che connotano il contesto di vita della persona.



Opzioni di traduzione come “coinvolgimento attivo”, “protagonismo della persona nel percorso di assistenza e cura”, “co-autorialità nel percorso socio-sanitario” e metafore come “diventare co-piloti e non soltanto passeggeri nel percorso sanitario” sembrano potenzialmente ben esprimere la complessità del concetto di engagement.

Documento di consenso «Promozione del patient engagement in ambito clinico-assistenziale per le malattie croniche»

Alla luce di questo scenario, il concetto di *patient engagement* (o coinvolgimento attivo del malato – di qui in poi si manterrà la dicitura anglosassone) ha assunto crescente attenzione in sanità³. La letteratura scientifica internazionale addita il patient engagement quale *conditio sine qua non* per l'innovazione sanitaria. Gli ultimi decenni, infatti, hanno visto un viraggio profondo dei modelli di cura verso una crescente e sempre maggiore valorizzazione del ruolo della persona, vista come soggetto attivo ed “esperto” all'interno del processo clinico-assistenziale. D'altro canto, i sistemi sanitari si trovano a interloquire con persone

G. Graffigna et al.: Promozione del patient engagement in ambito clinico-assistenziale per le malattie croniche

PATIENT-CENTERED CARE

«An approach to service which embraces a philosophy of respect for, and a partnership with people receiving services «(Dow et al., 2006).

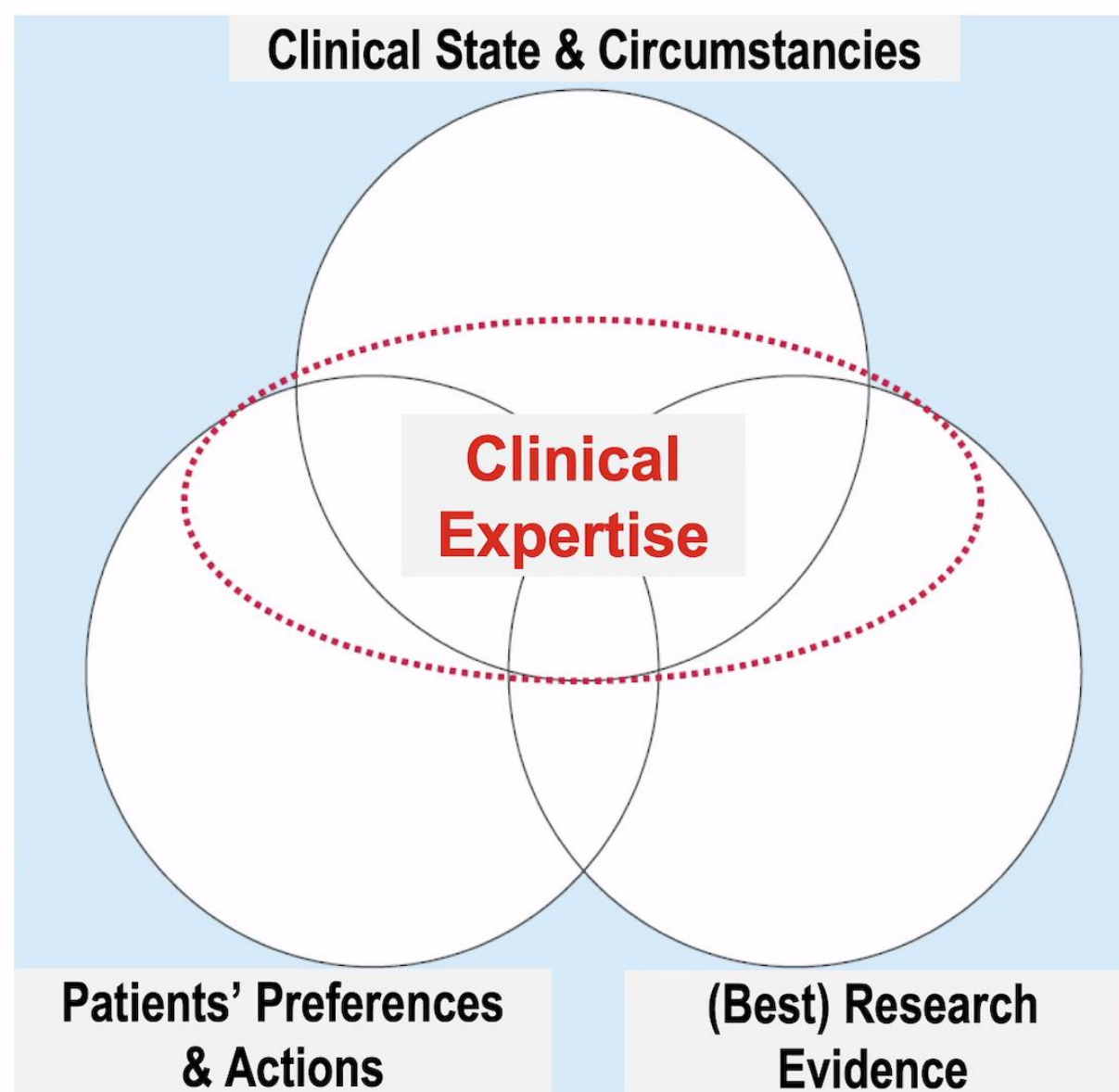
«Health care that is closely congruent with and responsive to patients' wants, needs and preferences» (Bowers, 2000).

«Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions» (Institute of Medicine, IOM, 2001).

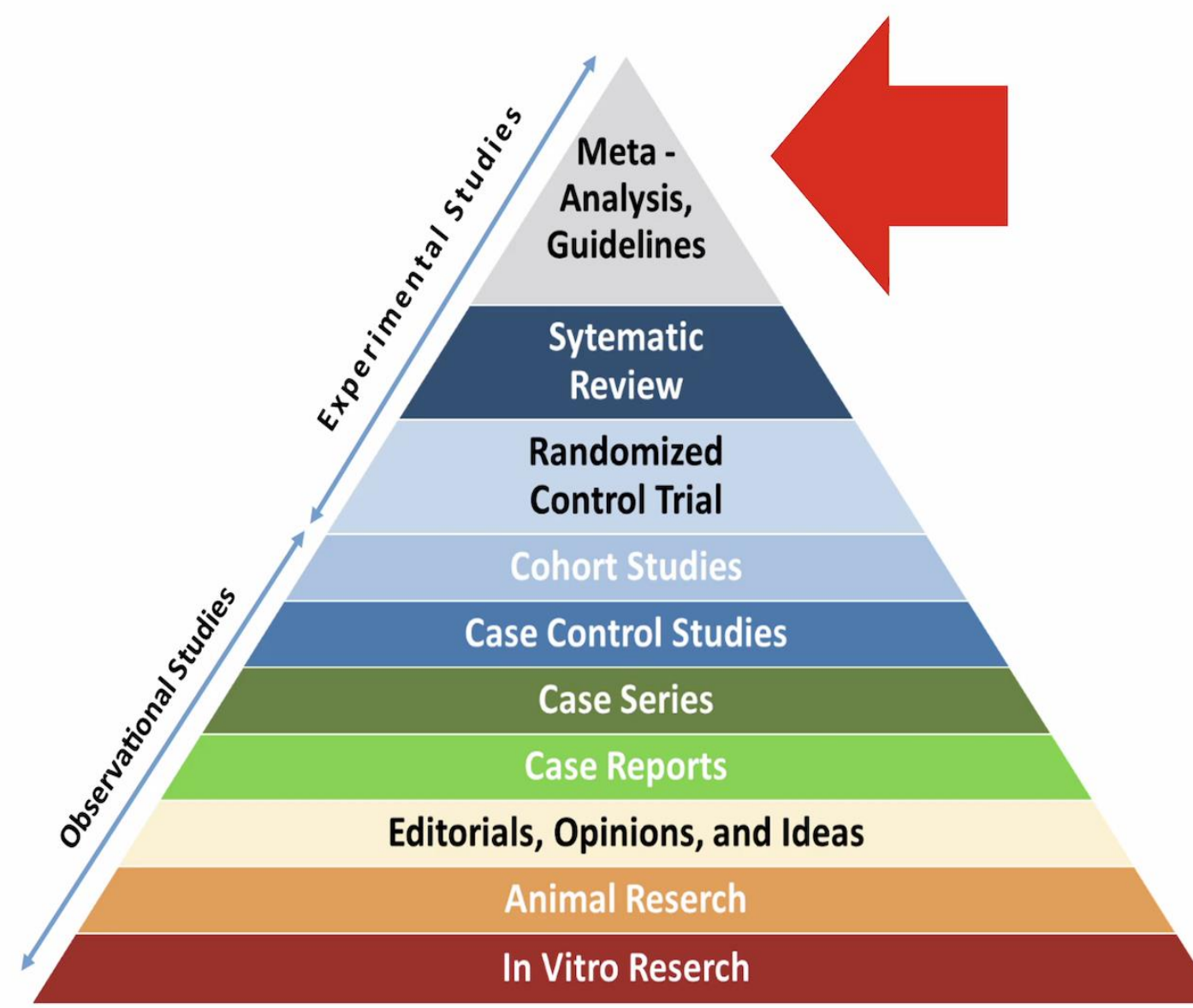
«Focusing care delivery on patient needs and preferences is a useful way to define patient-centered care» (Luxford et al., 2011).

EBM: “the conscientious, explicit and judicious integration of **best available scientific evidence** with **clinical expertise** and **patient values** to facilitate clinical decision making» Sackett D.L. et alii. BMJ 312, 7023, 71,1996

Evidence Based Medicine

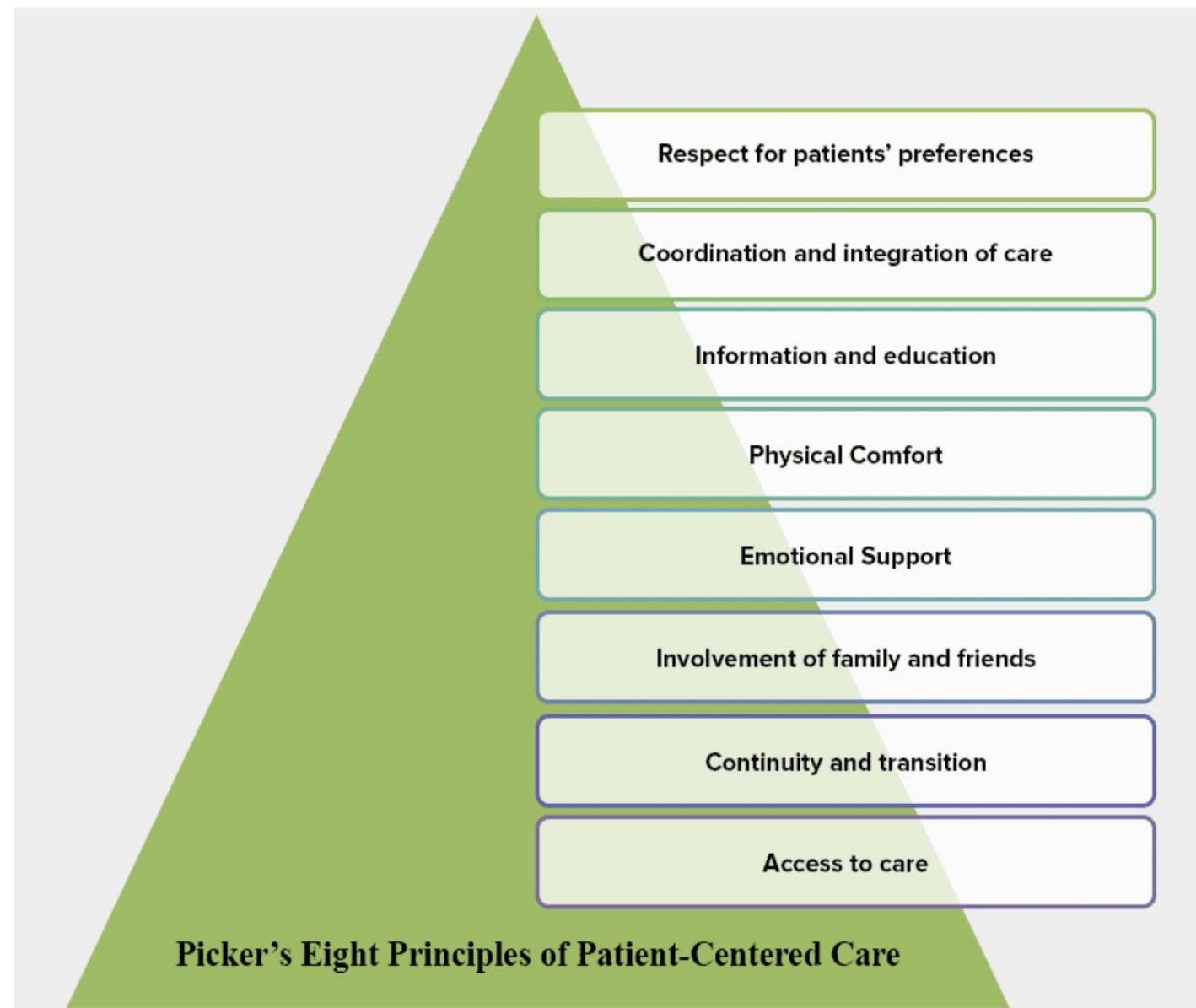


Modified from Haynes RB et al, BMJ 2002; 324: 1350



NCI Web Site, 2004

Primary dimensions of Patient-Centered Care (PCC)



- **Respect for patients' values, preferences and expressed needs**
- **Coordination and integration of care**
 - Coordination of clinical care
 - Coordination of ancillary and support services
 - Coordination of front-line patient care
- **Information and education**
 - Information on clinical status, progress and prognosis
 - Information on processes of care
 - Information to facilitate autonomy, self-care and health promotion
- **Physical comfort:**
 - Pain management
 - Assistance with activities and daily living needs
 - Hospital surroundings and environment
- **Emotional support and alleviation of fear and anxiety:**
 - Anxiety over physical status, treatment and prognosis
 - Anxiety over the impact of the illness on themselves and family
 - Anxiety over the financial impact of illness
- **Involvement of family and friends**
- **Continuity and transition**
- **Access to care**

Measuring the quality of patient-centered care: why patient-reported measures are critical to reliable assessment

Conclusion: Patient-reported measures are arguably the best way to measure patient-centeredness. For instance, patients are best positioned to determine whether care aligns with patient values, preferences, and needs and the Measure of Patient Preferences is an example of a patient-reported measure that does so. Furthermore, only the patient knows whether they received the level of information desired, and if information was understood and can be recalled. Patient-reported measures that examine information provision include the Lung Information Needs Questionnaire and the EORTC QLQ-INFO25. In relation to physical comfort, only patients can report the severity of physical symptoms and whether medications provide adequate relief. Patient-reported measures that investigate physical comfort include the Pain Care Quality Survey and the Brief Pain Inventory. Using patient-reported measures to regularly measure patient-centered care is critical to identifying areas of health care where improvements are needed.



- **Patient-centered care**
 - **Patient-centredness**
 - **Dimensione della qualità dell'assistenza**



Co-funded by
the Health Programme
of the European Union



Title: A framework of systems-based quality standards applicable to all networks and centres for rare cancers adding to ERN requirements

Quality standards and Indicators - main domains:

- Governance and coordination
- **Patient-centredness**
- Multidisciplinary approach
- Quality Assurance
- Research
- Training, development and education
- Networking and collaboration
- Infrastructure and data

2. Patient-centredness

Patients and patients' representatives are actively involved in planning and monitoring of the strategic activities of the RCN

Examples are: involvement in the Board to define policies, strategies and improvement plans (e.g. reviewing research outputs), reviewing pathways, improving referral procedures, communication.

The RCN has established patient pathways based on the needs of patients, clinical evidence, and best use of resources.

The RCN ensures that patients' experiences and satisfaction are to be regularly collected by HCPs; the information is used by the network to take strategic decisions.

The RCN ensures that HCPs have processes that ensure that at all times in the pathway it is clear which physician and which HCP has the responsibility for the care of the patient, and contact details are provided to patients.

The RCN HCP members actively involve patients in shared decision-making concerning their own treatment plans.

The RCN ensures that its HCP members have policies and procedures for ensuring the holistic care of patients (including paediatric patients) and their care providers from the beginning of the diagnostic process throughout the whole survivorship span, including rehabilitation or End of Life.

Information about the members of the Network and all relevant clinical pathways is sufficient to enable patient access to the Network.

Accreditation
and Designation
Programme

Appendix II

OECl
Qualitative Standards

1. Governance of the cancer centre/institute	5
2. Organisation of quality systems	7
3. Patient involvement and empowerment	10
4. Multidisciplinarity	13
5. Prevention and early detection	15
6. Diagnosis	16
7. Treatment	18
8. Research	24
9. Education and training	28

OECl: Organization of European Cancer Institutes

Patient satisfaction/experience	
Standard 26	
Patients' experience of cancer care is an integrated part of the quality improvement system of the cancer centre/institute.	
1.	CORE The cancer centre/institute has methods to regularly gather patients' experiences during outpatient and inpatient care.
2.	CORE Satisfaction surveys are analysed, reported and acted upon through the line management of the centre.
3.	The cancer centre/institute uses questionnaires to ascertain the perceptions of the patients' health status, level of impairment, disability and health-related quality of life (e.g. Patient-Reported Outcome Measures (PROM)).
4.	The cancer centre/institute uses questionnaires to assess the impact of the process of care on patient experience, e.g. communication and timelines of assistance (e.g. Patient-Reported Outcome Measures (PREM)).

Chapter 3: Patient involvement and empowerment (standards 19 to 28)

Patient involvement	
Standard 19	
It is the mission of the cancer centre/institute to encourage patient involvement in services.	
1.	CORE The cancer centre/institute involves patients and patients' voluntary organisations and support groups in the planning and organisation of services.
2.	The standard process of introducing new practices in clinical care ensures that patients are involved.
3.	There is a committee representing patients and serving as a link between the cancer centre/institute and the patients for advice and consultation.

Bombard et al. *Implementation Science* (2018) 13:98
https://doi.org/10.1186/s13012-018-0784-z

Implementation Science

SYSTEMATIC REVIEW

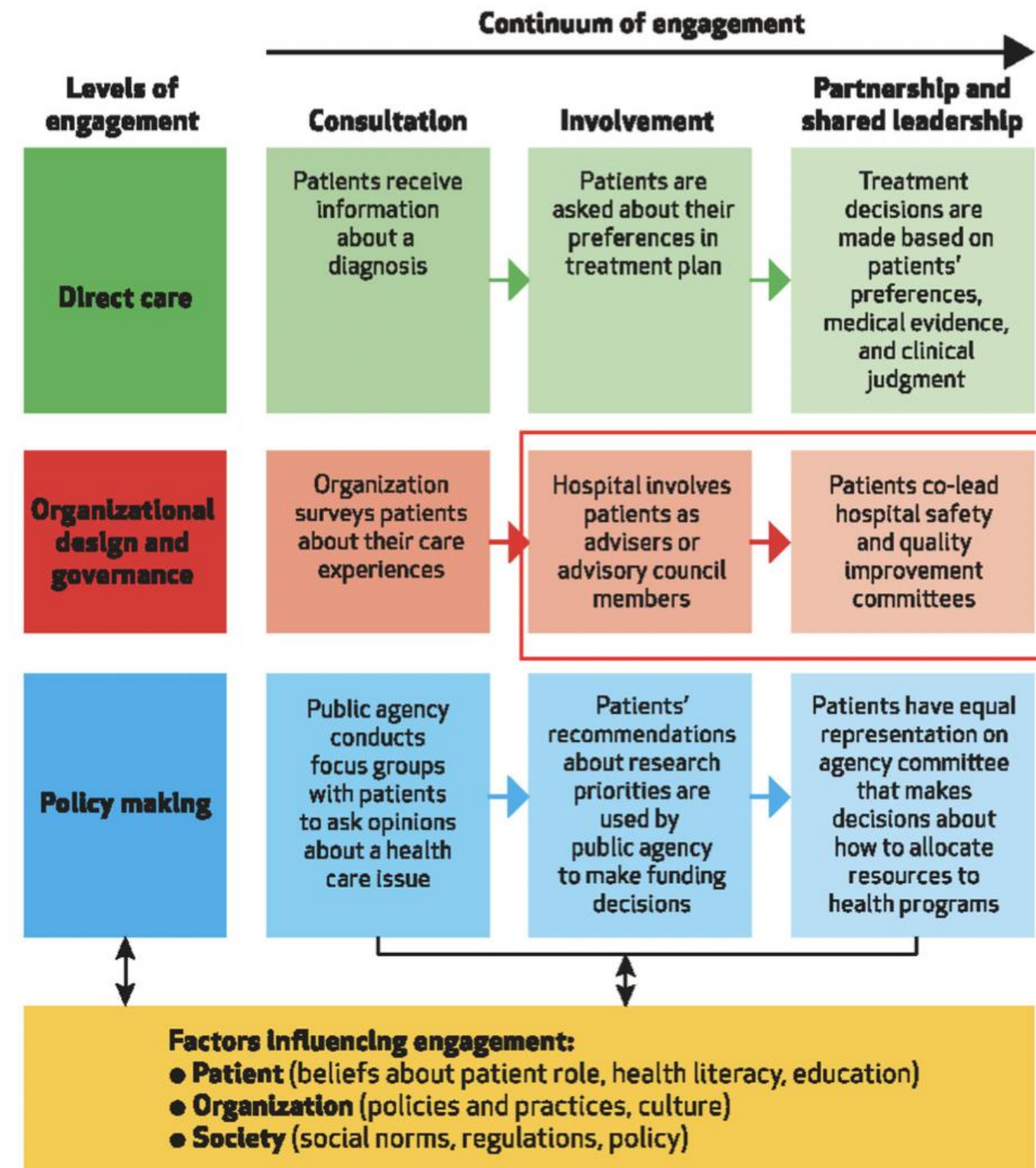
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Engaging patients to improve quality of care: a systematic review



Patient engagement has become a cornerstone of quality of care [1–6] and is a frequently stated goal for healthcare organizations. Traditionally, and most commonly, this engagement has focused on the relationship between patients and providers in making care decisions or how to improve patient efforts to manage their own care [7]. However, there are growing efforts to integrate patients in broader ways, including efforts to improve or redesign service delivery by incorporating patient experiences [8–12]. These efforts are due in part to an increased recognition and acceptance that users of health services have a rightful role, the requisite expertise, and an important contribution in the design and delivery of services [4]. While the

A Multidimensional Framework For Patient And Family Engagement In Health And Health Care



Few people would argue against person-centred care, but what does it really stand for, and why do we need it today?



PROMs / PREM_s/PSM_s

Impatto del trattamento sulla salute	Impatto del servizio sull'esperienza	Soddisfazione
Patient Reported Outcome Measures (PROMs)	Patient Reported Experience Measures (PREMs)	Patient's Satisfaction Measures
self-report sulla salute e qualita' della vita	esperienza oggettiva sull'utilizzo del sistema sanitario durante	esperienza soggettiva del servizio/trattamento

Value-based healthcare

How to define value in “value-based healthcare (VBHC)”?

There is no single agreed definition of value-based healthcare or even of what value means (for whom) in the health context.

- **Sistemi di Misurazione della Performance -PMS**

Let's play the patients music

A new generation of performance measurement systems in healthcare

Sabina Nuti, Guido Noto, Federico Vola and Milena Vainieri
Institute of Management, Scuola Superiore Sant'Anna, Pisa, Italy

Abstract

Purpose – Current performance measurement systems (PMSs) are mainly designed to measure performance at the organizational level. They tend not to assess the value created by the collaboration of multiple organizations and by the involvement of users in the value creation process, such as in healthcare. The purpose of this paper is to investigate the development of PMSs that can assess the population-based value creation process across multiple healthcare organizations while adopting a patient-based perspective.

01| BITE-SIZE GUIDE TO PATIENT INSIGHT

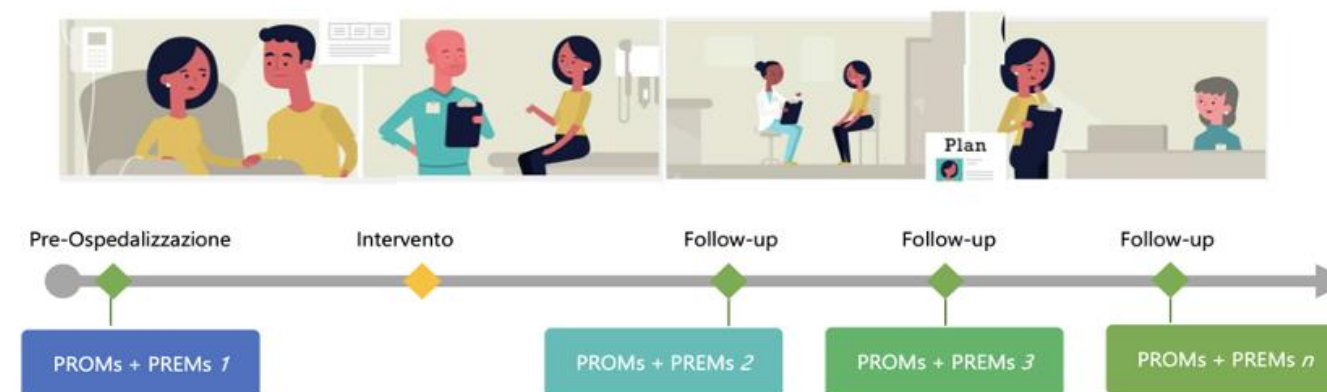


THE NATIONAL PATIENT REPORTED OUTCOME MEASURES (PROMS) PROGRAMME

Publications gateway reference: 07307



PROMs & PREM s

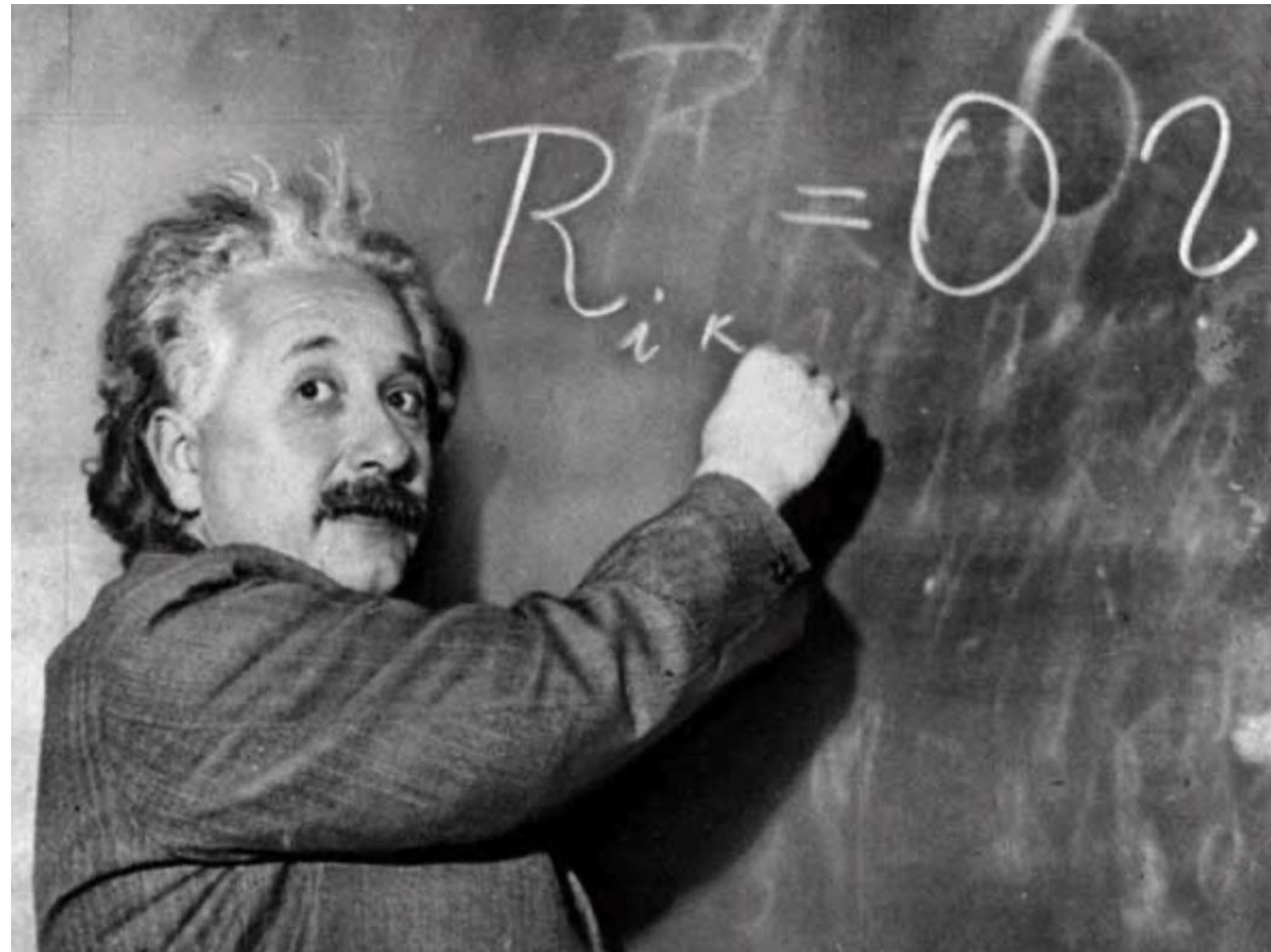


PROMs Patient Reported Outcome Measure

PREM s Patient Reported Experience Measure

In conclusione...

**“We cannot solve our problems with the same thinking we used
when we created them.” A. Einstein**



GRAZIE!