

A Mixed Methods Review of Person and Family Engagement in the context of Multiple Chronic Conditions

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What are we talking about when we talk about engagement?



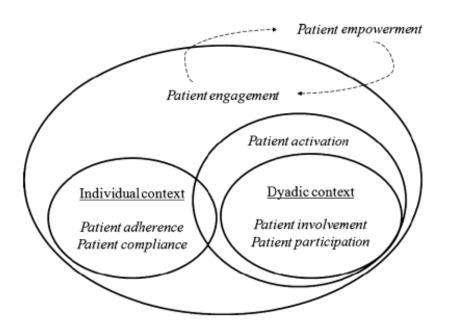


Figure 3 A framework to understand relationships among terms.

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Giving patients a starring role in their own care: a bibliometric analysis of the on-going literature debate

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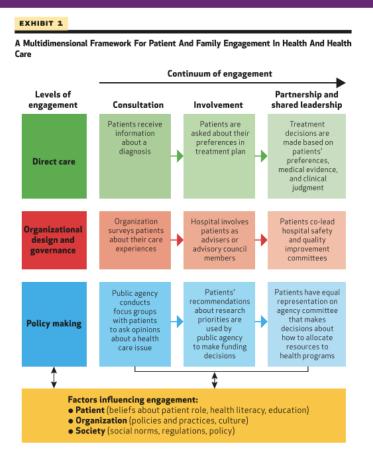
Defining Engagement



"A **set of behaviors** by individuals, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of individuals and family members as active members of the health care team and collaborative partnerships with providers and provider organizations."

Conceptualizing Engagement





Definition of engagement: "Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system – direct care, organizational design and governance, and policy making – to improve health and healthcare."

Purposes of engagement:

- 1) To satisfy desires and expectations of patients and families in healthcare
- To improve health outcomes, quality, and safety
- 3) To control costs

We undertook a scoping review of reviews that addressed engagement in the context of multiple chronic conditions.





"engagement"





Self-management



Involvement in decisionmaking

Interventions aimed to promote engagement among those with MCC vary widely.



Goal setting
Agenda setting
Question-prompt lists
Provision of feedback
Educational
interventions

Patient navigators
Individual coaches
Case managers
Community Health
Workers
Peer leaders

Telehealth Web-based tools Shared health records

Longer appointment times

Preparation

Personnel

Technology

Practicelevel changes

Building the science of engagement in the context of MCC is limited by heterogeneity.



Tremendous heterogeneity in:

- the concept and measurement of engagement
- the population of interest (those with multiple chronic conditions)
- the design of complex interventions
- outcomes

#1: Goals of engagement and outcomes that matter most for persons with MCC



- How can we best ensure that study goals and outcomes align with the goals and desired outcomes of persons with MCC?
- How do we measure these goals and outcomes in a way that allows comparisons among different interventions and studies?



#2: Infrastructure









- How do system-level and community-level structural factors relate to engagement in direct care for those with MCC?
- How do system- and community-level factors interfere with or support engagement, and how do we design a system that makes it easy?

#3: Tradeoffs between benefits and costs of engagement



- What safeguards need to be put in place to ensure that a focus on engagement doesn't unintentionally further marginalize vulnerable populations, including those with multiple chronic conditions?
- How do we engage vulnerable or hardto-engage populations in research about engagement and to guide implementation of engagement interventions?



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