



PATIENT ENGAGEMENT: EVIDENCE ON SUCCESSFUL STRATEGIES

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Research supported by the Canadian Health Services
Research Foundation and Max Bell Foundation

PATIENT ENGAGEMENT RESEARCH


5 components

- Systematic review of the literature
- Review of Web strategies
- Longitudinal assessment of CHSRF/MBF funded demonstration project teams
- Case studies of successful engagement in other jurisdictions, including
- Detailed case study of King's Fund work on The Point of Care program





QUALITY CARE AND PATIENT ENGAGEMENT

- Extending the idea of “patient-centredness”, patient engagement has become a key element in definitions of quality of care and an increasingly frequent stated goal for healthcare organizations.
 - This is due in part to an increased recognition that potential users of health services have a rightful role and an important contribution in determining the design of service development and delivery.
 - Some leading organizations have found increased patient engagement in their quality activities result in a major boost in energy and insight
 - Yet many organizations struggle to realize this goal.
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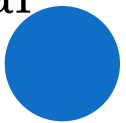


SYSTEMATIC REVIEW RESEARCH QUESTIONS

1. What are the strategies used to engage patients in the design, delivery and evaluation of health services?
2. What is the impact of patient engagement strategies on the design, delivery and evaluation of health services?
3. What are patients' experiences with these engagement strategies?

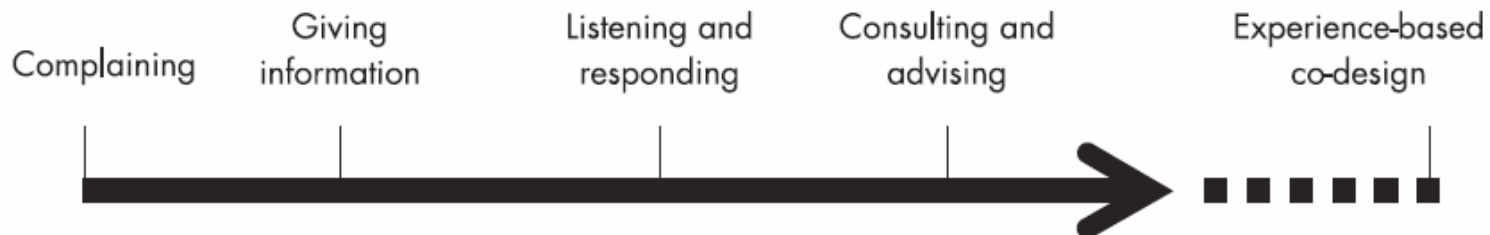


METHODS

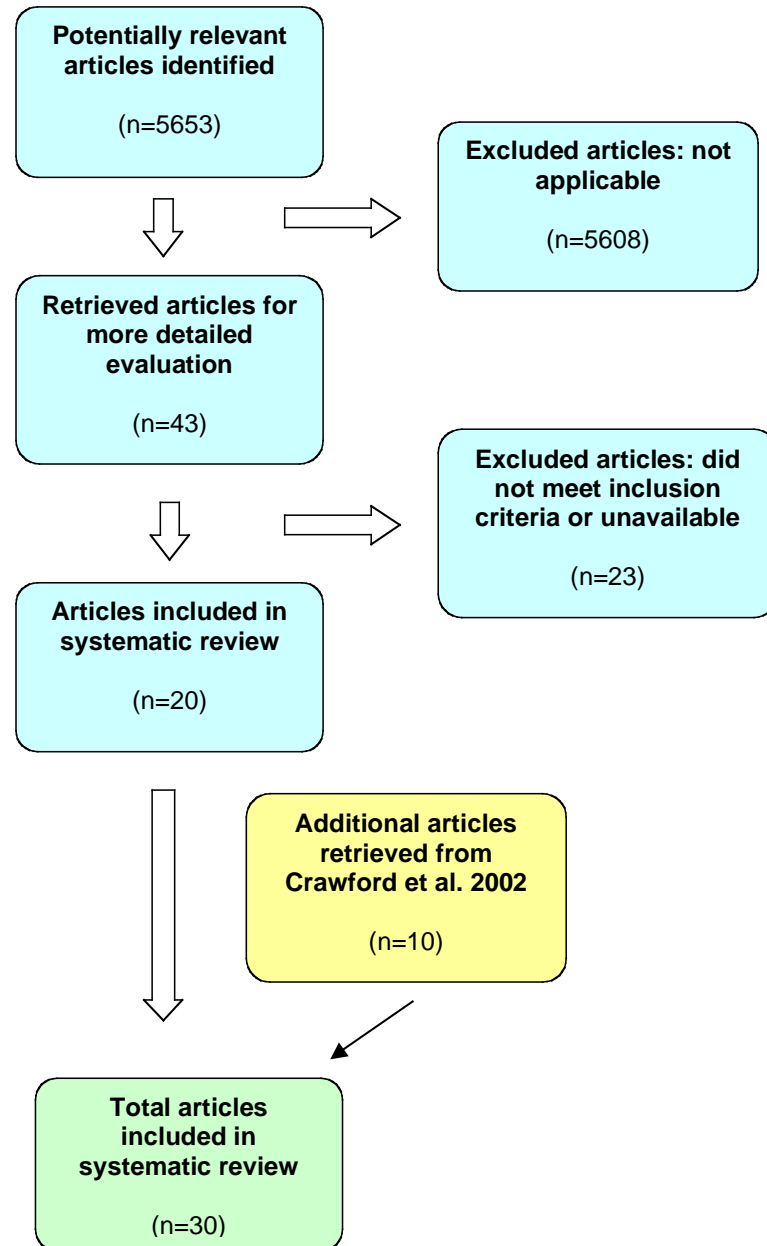
- Databases:
 - Medline Ovid, Embase Ovid, AbiInform Business Source Premier (EBSCO) and ISI Web of Science
 - Search terms:
 - patient (or) user (or) client (or) caregiver (or) family (and) engage* (or) participat* (or) involve* (or) consult* (and) design (or) deliver* (or) evaluat* (or) outcome (or) develop* (or) plan* (and) health services (or) health care (or) health (or) service.
 - Criteria:
 - Inclusion: empirical articles published between 1990-2010
 - Exclusion: theoretical/conceptual articles and those focused on guidelines, instrument development or organizational issues
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DATA EXTRACTION & SYNTHESIS

- Population/ type of service
- Location (i.e., country)
- Strategies for engagement (i.e., methodology and methods used)
- Barriers and facilitators of engagement
- Outcomes of engagement
- Patients' experience with the engagement strategies
- Evaluation of engagement strategies
- Level of engagement:



SEARCH & SELECTION PROCESS:

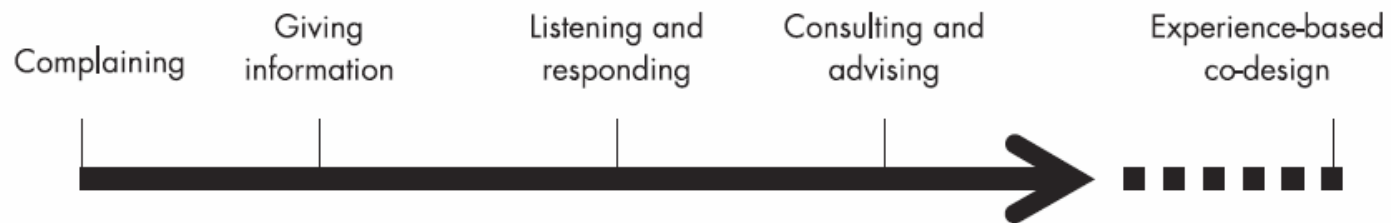


RESULTS

- 30 studies on patient engagement strategies:
 - 16 qualitative studies
 - 14 mixed methods studies
 - Interviews and focus groups were the most frequently used strategies.
 - Some studies employed novel techniques of mapping of a ‘patient journey’, a postal Delphi consultation, advocacy projects, councils and online forums.



LEVELS OF ENGAGEMENT



n=1
(3%)

n=14
(47%)

n=8
(27%)

n=7
(23%)

Bate & Robert 2006



FACILITATORS AND BARRIERS

Facilitators	Barriers
<p data-bbox="112 354 763 392"><i>Design of engagement strategies:</i></p> <ul data-bbox="183 399 937 1370" style="list-style-type: none"><li data-bbox="183 399 937 492">• Enable patients or carers to set the agenda ('user-led models')<li data-bbox="183 492 937 628">• Enable patients or carers to participate in the research ('action research approach')<li data-bbox="183 628 937 856">• Enhance patient voices by:<ul data-bbox="318 678 937 856" style="list-style-type: none"><li data-bbox="318 678 937 771">○ Including higher proportions of patients versus providers<li data-bbox="318 771 937 856">○ Engaging providers from a distance<li data-bbox="183 856 937 949">• Use of democratic deliberation to build consensus<li data-bbox="183 949 937 999">• Use of external facilitation<li data-bbox="183 999 937 1142">• Conduct education/training sessions prior to engagements to clarify roles and objectives<li data-bbox="183 1142 937 1235">• Conduct debriefing exercises to enhance representation and quality<li data-bbox="183 1235 937 1285">• Secure executive level sponsorship<li data-bbox="183 1285 937 1370">• Conduct engagements before decision has been made	<ul data-bbox="1081 399 1777 856" style="list-style-type: none"><li data-bbox="1081 399 1777 449">• Complex discussions<li data-bbox="1081 449 1777 628">• Lack of clarity on:<ul data-bbox="1217 492 1777 628" style="list-style-type: none"><li data-bbox="1217 492 1777 542">○ Roles<li data-bbox="1217 542 1777 592">○ Objectives<li data-bbox="1217 592 1777 628">○ Responsibilities<li data-bbox="1081 628 1777 721">• Issues or topics with limited capacity to change<li data-bbox="1081 721 1777 856">• Engagements conducted by consultative groups, not decision makers

FACILITATORS AND BARRIERS, 2

Sampling Strategies:

- | | |
|---|---|
| <ul style="list-style-type: none">• Ensure wide representation• Include remote or marginalized populations<ul style="list-style-type: none">○ Use online media○ Travel to rural/remote areas• Offer honorariums, reimbursement of expenses | <ul style="list-style-type: none">• Inclusion of:<ul style="list-style-type: none">○ A disproportionate number of providers compared to patients○ Providers who previously cared for patients involved |
|---|---|

FACILITATORS AND BARRIERS, 3

Facilitators	Barriers
<p data-bbox="94 325 324 361"><i>Participants:</i></p> <ul data-bbox="94 372 788 715" style="list-style-type: none"><li data-bbox="94 372 710 458">● Offer flexibility in the level of involvement<li data-bbox="94 472 788 558">● Have users conduct interviews, at homes, when possible<li data-bbox="94 572 788 715">● Emphasize that there is executive level support of the engagement to participants	<ul data-bbox="823 372 1792 1322" style="list-style-type: none"><li data-bbox="823 372 1586 408">● Inclusion of self-selected participants:<ul data-bbox="919 422 1769 658" style="list-style-type: none"><li data-bbox="919 422 1315 458">○ Confident patients<li data-bbox="919 472 1769 558">○ Those comfortable with influencing service delivery<li data-bbox="919 572 1769 658">○ Those who have fewer symptoms or family care duties<li data-bbox="823 672 1373 708">● Inclusion of proxy groups:<ul data-bbox="919 722 1508 815" style="list-style-type: none"><li data-bbox="919 722 1508 758">○ Parents to represent children<li data-bbox="919 772 1489 815">○ Carers to represent patients<li data-bbox="823 829 1306 865">● Inclusion of providers:<ul data-bbox="919 879 1789 1122" style="list-style-type: none"><li data-bbox="919 879 1789 915">○ Who are poorly trained in engaging patients<li data-bbox="919 929 1489 965">○ Who are resistant to change<li data-bbox="919 979 1789 1065">○ Who perceive that patients are unwilling to participate<li data-bbox="919 1079 1721 1122">○ Who feel threatened by devolving power<li data-bbox="823 1136 1489 1172">● Lack of participant commitment<li data-bbox="823 1186 1450 1222">● Lack of participant confidence<li data-bbox="823 1236 1789 1322">● Lack of interest (e.g., immediate threat to service delivery)

OUTCOMES OF ENGAGEMENT

- A majority of the engagement studies (n=22; 73%) assessed the outcomes of the engagements.
- Outcomes were generally classified as:
 1. Educational or tool development
 2. Improved care or service delivery
 3. Informing policy or planning initiatives



EXAMPLES OF OUTCOMES & LEVEL OF ENGAGEMENT

Type of Outcomes	Level of Engagement
<i>Education or Tool development</i>	
Information packages for patients	Consultative to co-design, co-design
Information sheets to work with families	Consultative
Educational programs for patients	Consultative
Assessments of physician communication skills	Consultative
Personal health record-type booklet	Consultative
Patient referral form	Consultative
Volunteer contract	Consultative
Improvement questionnaire	Co-design

EXAMPLES OF OUTCOMES & LEVEL OF ENGAGEMENT, 2

Type of Outcomes	Level of Engagement
<i>Improved Care or Service Delivery</i>	
Extended opening hours	Co-design
Employment of a dedicated mental health advocate	Co-design
Improved pain management	Informative to consultative
New discharge initiative	Informative to consultative
Improvement of the activities & environment of a day centre	Consultative
Creation of an employment unit to improve opportunities	Co-design
Improved disease control	Consultative to co-design

EXAMPLES OF OUTCOMES & LEVEL OF ENGAGEMENT, 3

<i>Informed Policy or Planning Initiatives</i>	
National care strategies	Consultative, co-design
Clinical care models	Consultative, co-design
User –carer strategy	Consultative to co-design
User involvement models	Consultative to co-design
Mental health policy implementation guide	Consultative to co-design
Plan to improve aspects of service delivery	Consultative to co-design
Plan for regional planning priorities	Consultative
Patient representation on Board	Co-design
Auditing policy and frameworks	Co-design

EVALUATION OF ENGAGEMENTS

- Most studies (n=20; 67%) evaluated their engagement strategies.
 - However, this was typically limited to assessing the rigour and validity of the studies' sample, instruments, or results.
- A few studies (n=8; 27%) evaluated the effectiveness or quality of their engagement methods or processes.
 - Only one incorporated a formal process evaluation to assess the quality of the groups' dynamics and made changes to their design based on these results during the course of the study



DISCUSSION

- A substantial amount of insight was gleaned about successful designs, sampling and implementation of patient engagement strategies.
- There was a low level of evaluation among these engagement studies, which was generally gained through authors' reflections on the strengths and limitations of their studies, and not specifically evaluating the engagement process or its outcomes on care.
 - This might reflect the infancy of the field, lack of developed evaluation metrics and the heterogeneity of concept (“conceptual muddle”: patient engagement, user involvement, etc).



DISCUSSION, 2

- Few studies formally evaluated **patients' experiences** with the engagement activities.
 - This is particularly ironic given its intent to be patient-centred.
 - Since most studies were **consultative** this may explain the lack of evaluations of patient experiences with engagements.
 - Since patients were not fully *engaged* (but *consulted*), there is little motivating an assessment of patients' experience in activities that were not intended to engage them.
- While a majority of studies in our review found that **engagement had positive outcomes**, few of these studies set improved quality of care as an objective of their engagements.
 - Whether and how patient engagement translates into quality care remains unclear.



DISCUSSION, 3

- Future research:
 - Develop consistent conceptualizations for patient engagement
 - Develop evaluation measures on:
 - Patients' experience with engagement
 - Procedural and substantive evaluations
 - Group composition, cohesion, collaboration
 - Equality of participation, respect for opinions
 - Level of deliberation or reasoning
 - Impact on quality care
- Practice implications - Critical elements for success:
 - Organizational and managerial endorsement
 - Resources, external facilitation, and participant education and training
 - Deliberative, participatory and long-term approaches



ACKNOWLEDGEMENTS

Pooja Bhatia, B.A.

Research team:

Ross Baker (PI)

Marie-Pascal Pomey

Neil Seeman

Jocelyn Cornwell

Jean-Louis Denis

Anu-MacIntosh Murray

Carol Fancott

Yvonne Bombard

Financial Support:



CHSRF Grant

CIHR Postdoctoral Fellowship (to Y. Bombard)

CIHR Strategic Research Training Programs of:
'HCTP' & 'Public Health Policy'

