White Rose Research Online

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk
Universities of Leeds, Sheffield and York

Deposited via The University of Sheffield.

White Rose Research Online URL for this paper:
https://eprints.whiterose.ac.uk/id/eprint/118840/

Version: Accepted Version

Article:
Cowdell, F., Booth, A. and Appleby, B. (2017) Knowledge mobilisation in bridging patient-practitioner-researcher boundaries: a systematic integrative review protocol. Journal Of Advanced Nursing, 73 (11). pp. 2757-2764. ISSN: 0309-2402

https://doi.org/10.1111/jan.13378

Reuse
Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown
If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

PROFESSOR FIONA COWDELL (Orcid ID : 0000-0002-9355-8059)

Accepted Article

Article type : Protocol

Full title: Knowledge mobilisation in bridging patient-practitioner-researcher boundaries: a systematic integrative review protocol

Running head: Knowledge mobilisation: bridging boundaries

Corresponding author details

Fiona COWDELL
RN, MA, DProf
Professor of Nursing and Health Research
Faculty of Health Education and Life Sciences
223 Ravensbury House
City South Campus
Birmingham City University
Edgbaston
Birmingham
B15 3TN
Fiona.cowdell@bcu.ac.uk
+44(0) 121 300 4345

Author details

Andrew BOOTH

BA, MCLIP, PhD

Reader in Evidence Based Information Practice and Director of Information
Information Resources Group, HEDS, ScHARR
The University of Sheffield

Ben APPLEBY
RN, MSc, PhD
Senior Lecturer and Research Coordinator
Faculty of Health Education and Life Sciences
Birmingham City University

Acknowledgement
With thanks to Amy Foster for her help with formatting this manuscript

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/jan.13378
This article is protected by copyright. All rights reserved.

Conflict of interest statement
No conflict of interest has been declared by the authors

Funding statement
This report is independent research arising from a Knowledge Mobilisation Research Fellowship, Professor Fiona Cowdell, KMRF-2014-04-004 supported by the National Institute for Health Research. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the National Institute for Health Research, Health Education England or the Department of Health.

Accepted Article

ABSTRACT

Aim

To review published literature to identify when and how patients and health care practitioners have been involved in knowledge mobilisation activity and the impact this may have had on their care.

Background

Improving patient outcomes, satisfaction and quality of care is increasingly reliant on shared decision-making between health professionals and patients. Knowledge mobilisation, at its simplest "moving knowledge to where it can be most useful" is a growing field of academic study. To date it appears that much effort has focused on moving knowledge from researchers to health care practitioners. Knowledge mobilisation to patients is currently under-researched.

Design

Integrative review

Review Methods

Methods of integrative review will be used to address the review problem. PRISMA guidelines were used as a general framework to guide structuring and reporting the review. Elements of method-specific reporting guidelines for specific streams of evidence will be used as required.

This article is protected by copyright. All rights reserved.

Discussion

This review will aim to provide a broad and deep understanding of patient-practitioner-researcher engagement in knowledge mobilisation activity. This synthesis of the extant literature should offer insights into the optimum characteristics of methods for bridging patient-practitioner-researcher boundaries in knowledge mobilisation action.

Keywords: Knowledge mobilisation, translation, transfer, exchange, patient, integrative, systematic review, bridging boundaries, nursing

Systematic review registration:

This protocol will be registered with PROSPERO

Why is this review needed?

- With an increased emphasis on empowerment and shared decision-making more investigation into knowledge mobilisation across patient-practitioner-research boundaries is needed
- To understand more about how and to what extent patients are involved in knowledge mobilisation
- To evaluate the evidence-base of knowledge mobilisation activity and patient outcomes

This article is protected by copyright. All rights reserved.

Accepted Article

Accepted Article

INTRODUCTION

Current policy dictates that patients should be empowered and engaged partners in their health care. There is much rhetoric around shared-decision making and the importance of patients being able to manage their own health care as effectively as possible. The extent to which these concepts are espoused in healthcare differs across the world (Härter et al 2011). Given the increasing number of people throughout the world who need to self-manage these issues are of international relevance.

Empowerment and engagement strategies, when well executed, can improve patient outcomes and satisfaction and bring about cost-savings. Knowledge is one element of empowering patients. Knowledge mobilisation, at its simplest "moving knowledge to where it can be most useful" is a growing field of academic study. To date it appears that much effort has focused on moving knowledge from researchers to health care practitioners. Knowledge mobilisation to patients is currently under-researched. The move towards empowerment and shared-decision making suggests a need for more investigation into knowledge mobilisation across patient-practitioner-researcher boundaries.

BACKGROUND

Current policy dictates that patients should be empowered and engaged partners in their health care (Department of Health (DH) 2010, DH 2012, HM Government 2014). Empowerment is a complex and much debated notion. In the health care arena empowerment over one's health is often viewed as a positive both in and of itself, as it tends to lead to better patient outcomes (Muir & Quilter-Pinner 2015). It may save money through reducing consultations and increasing concordance (Ahmad *et al.* 2014). However, the rhetoric of empowerment is often not matched by changes in practice (Wolf & Veintot 2015).

This article is protected by copyright. All rights reserved.

Empowerment is predicated on more equal power relationships between health care providers (HCP) and patients. This requires challenging deeply embedded practices and attitudes in HCPs (Richards 2013). Empowerment cannot be bestowed on people; there is a need for joint action towards this state.

Engagement obliges patients and HCPs to actively participate in health decisions and actions (Gallivan *et al.* 2012); this concept is allied to patient activation (Greene & Hibbard 2013, Hibbard & Greene). Whatever terminology is used the idea necessitates a cultural change in the way that autonomy and personal responsibility of patients is viewed (Henry 2006). There is evidence that when patients are engaged in their healthcare, outcomes improve (Edgman-Levitan & Brady 2013) and higher levels of satisfaction are reported (Burns *et al.* 2014).

A diverse literature proposes ways patient empowerment and engagement may be achieved, although it is recognised that there are many challenges. Ultimately all those involved in health care need to use a common language (Bellows *et al.* 2015), achieve shared understandings and mutual respect (Entwistle *et al.* 2010). Knowledge is one of the key elements in achieving empowerment and partnership working between patients and HCPs. Although it is recognised that knowledge alone will not bring about the desired change in current practice and relationships, it is undoubtedly an important influence. At present consultations tend to be characterised by "informational inequality" (Kashaf & McGill 2015) with HCPs holding the balance of power through possession of empirical knowledge. Some HCPs express concerns about patients' expert knowledge and beliefs about themselves and their condition (Shaw & Baker 2004). In some instances, the view persists that patients are empty repositories waiting to be filled with knowledge or people who need to have their misunderstandings corrected (Wolf & Veintot 2015). It is true that practitioners will often

This article is protected by copyright. All rights reserved.

Accepted Article

possess more clinical information than patients but equally patients are experts in their lives and their conditions (National Voices undated). Patients typically possess far greater insight into how potential treatments may affect their lives and be congruent with their own values, beliefs and preferences (Coulter 1999). Patients need information, power and control to stay healthy. Many new models promote patient empowerment and engagement but these tend to be confined by geographical area or particular condition (Muir & Quilter-Pinner 2015).

One practical approach to getting patients and HCPs to work together is the use of shared decision-making (SDM) (Elwyn *et al.* 2006, Momumjid *et al.* 2016). The popularity of the concept has been growing since the 1990s and, although there is still no absolute definition (Bouniols *et al.* 2016), shared decision-making is generally agreed to be based on the principles of respect for patient autonomy and solidarity between HCP and patients (Chewning *et al.* 2012). Variation in shared-decision making is illustrated in a dedicated issue of Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen which includes perspectives from 13 different countries and showcases the Salzburg Statement on Shared Decision Making (Härter et al 2011). Evidence suggests that most patients want to be involved in decision-making (Charles *et al.* 2006). An authentic shared approach requires both patient and HCP to be involved in information exchange, both expressing treatment preferences and both agreeing on treatment decisions (Montori *et al.* 2006, Hyde *et al.* 2016). The idea that patients need to have sufficient knowledge on which to base their decisions is, unsurprisingly, widely supported (Pollard *et al*. 2015). Some limited evidence suggests that SDM can improve patient outcomes (Shay & Lafata 2015). Many benefits are reported: agreed plans of care are likely to be consistent with the patient's lifestyle, living situation, goals and personal preferences and it may increase patient satisfaction, reduce healthcare cost and use and increase treatment adherence (Légaré & Witteman 2013, Joseph-Williams *et al.*

This article is protected by copyright. All rights reserved.

Accepted Article

2014). Despite all these potential gains SDM remains a subject that is relatively high in academic and policy agendas but possibly less evident in everyday practice. The most frequently cited barriers from the health care provider perspective are: time; concern that inappropriate decisions may be made and a perception that patients may be unable or unwilling to participate (Pollard *et al.* 2015). This last point is challenged in the conclusion of a comprehensive review that suggests that patients can't, rather than won't, participate in decision making (Joseph-Williams *et al.* 2014). These authors argue powerfully that knowledge is *not* power for patients, for engagement in SDM they need both knowledge *and* power - a point reinforced by Hyde *et al.* (2016) in their call for practitioners and patients to *share* information. A common theme in all this literature is that patients need *both* knowledge *and* power to exercise control over their own health care. Essentialy, both patients and HCPs need sufficient knowledge and to be willing and able to share this, to make decisions about an individual's health care. It may be argued that there is a need to develop knowledge mobilisation techniques that bridge the patient-practitioner-researcher boundary to promote use of shared knowledge to inform decision making.

Knowledge mobilisation (KM) is an emerging and much debated discipline. It can be defined as "the reciprocal and complementary flow and uptake of research between researchers, knowledge brokers and knowledge users" (Social Sciences and Humanities Research Council 2016). Some would contest the idea that KM is purely concerned with research knowledge, supporting a much wider inclusion of available information and expertise (Ward 2016). For clarity we define KM and associated variants at the simplest level of "moving knowledge to where it can be most useful" (Ward 2016).

This article is protected by copyright. All rights reserved.

Accepted Article

Accepted Article

Knowledge mobilisation and associated terms are becoming more prevalent in the health literature although, at present, most attention is given to moving research knowledge to practitioners. Despite a substantive literature there is a notable lack of investigation into the extent to which KM and allied work has included patients in healthcare and, specifically, into strategies which are designed to bridge the patient-practitioner-researcher boundary. This will be the focus of our review. Our review begins with the philosophical standpoint that patient empowerment and engagement are desirable and necessary in today's healthcare climate. To gain a comprehensive understanding we will include a wide range of literature.

AIM

Our aim is to review published literature to identify when and how patients and practitioners have been involved in knowledge mobilisation activity and the impact this may have had.

Objectives

Specific objectives are to:

1. Review the ways patients have been engaged in KM activity (how)
2. Assess the extent to which patients are involved in KM activity (how much)
3. Examine the extent to which patients and HCP have been explicitly engaged in shared KM activity (how)
4. Assess the extent to which patients and HCP are involved in shared KM activity (how much)
5. Evaluate the impact of patient involvement KM activity (so what)
6. Evaluate the impact of shared patient and HCP involvement KM activity (so what)

This article is protected by copyright. All rights reserved.

Accepted Article

Inclusion criteria will capture the patient / KM dyad literature. If, in this wider body of literature we find examples of the patient / KM / HCP triad we will conduct a subgroup analysis using the methods outlined below.

For clarity and precision we will use the following definitions:

- *Knowledge mobilisation:* an umbrella term for four key terms most commonly used in seminal papers in this field namely; knowledge translation, knowledge transfer, knowledge exchange and knowledge mobilisation (Ward 2016)
- *Patient:* any recipient of health services
- *Health care practitioner:* a person who provides preventive, curative, promotional or rehabilitation health care

Our review question is 'What are the optimum characteristics of strategies to bridge patient-practitioner-researcher boundaries in knowledge mobilisation activity?'

DESIGN AND METHODOLOGY

We will use integrative review methodology (IRM) to undertake a comprehensive review and synthesis of a wide range of literature (Whittemore & Knafl 2005). IRM is effective in synthesising existing knowledge from a diverse range of sources to deepen understanding. In this systematic integrative review similar studies will be grouped together and quality assessment tools and analytical methods relevant to each publication will be used (Kirkevold 1997). We will provide rich contextual data which captures both the breadth and depth in

This article is protected by copyright. All rights reserved.

the literature (Kastner *et al.* 2016). We plan to identify exemplars of good practice, gaps in extant literature and future research needs. In keeping with IRM philosophy our intention is that this review will, if possible, be used to inform policy and practice (Tricco *et al*. 2016). To ensure rigour we will follow the 5 IRM stages of Whittemore & Knafl: i) problem identification; ii) literature search; iii) data evaluation; iv) data analysis and v) presentation. Depending on the quantity and quality of the evidence base we will add a sixth step of making recommendations for practice and/or further research, as appropriate. IRM can be applied using a spectrum of systematic to non-systematic methods of data processing. Our intention is to use a high level of systematic processing incorporating a similar level of data processing as a systematic review. A PRISMA- P (Shamseer *et al.* 2015) checklist is included, however, in recognition that this is an integrative review completion has focused on directly relevant items. Our team comprises two nurses with expertise in knowledge mobilisation and an expert in evidence based information practice.

Stage 1: Problem identification

High quality knowledge is one of several elements that are required to achieve genuine patient empowerment and engagement. Knowledge mobilisation, put simply "moving knowledge to where it can be most useful" (Ward 2016) is becoming embedded in health care practice. However to date most work has focused on effective movement of research to practitioners. Despite the acknowledged need for both informed patients *and* HCPs relatively little attention has been paid to how KM and associated strategies can be used to bridge patient-practitioner-researcher boundaries. Our focus is on the extent to which patients have been involved in KM; how this has been achieved; the extent to which such work has also involved HCPs and evaluation of impact. Our research question is: 'What are the optimum characteristics of strategies to bridge patient-practitioner-researcher boundaries in knowledge mobilisation activity?'

This article is protected by copyright. All rights reserved.

Accepted Article

Accepted Article

Stage 2: Literature search

Identifying literature for the review

We will search for and synthesise two types of evidence:

1. Peer-reviewed academic literature identified through systematic database searching and complementary search techniques such as review of reference lists (backward chaining) and citation searching (forward chaining).
2. Grey literature, including non-peer-reviewed articles and online reports located through a structured online web search

Systematic search of academic literature

A comprehensive electronic search will be conducted guided by an information expert (AB), details are summarised in table 1. Databases include: CINAHL, MEDLINE, EMBASE, Web of Science (all databases), ASSIA, PsycINFO, British Nursing Index, DH-Data and King's Fund Library Catalogue. Search terms are summarised in table 1, these terms and associated synonyms will be used in various combinations. The focus is on English language papers acknowledging that culturally-specific differences might complicate the interpretation of findings from our review. We will search from 2006 to date, given that the last decade has seen an exponential rise in literature concerning KM. A copy of the search strategy as developed and executed on MEDLINE is included as Appendix 1.

Structured search of the grey literature

The term grey literature tends to refer to unpublished research. To identify documents of interest we will search: Electronic Theses Online Service (EthOS), Index to Theses, Zetoc conference proceedings, King's Fund Library, DH Data, British Library Catalogue, COPAC (Combined UK Universities Catalogue), INVOLVE and the Patients Association. We will

This article is protected by copyright. All rights reserved.

search Google and Google Scholar using key terms and phrases. Reference list of all included items will be reviewed to identify further potentially relevant references.

Inclusion and exclusion criteria

Inclusion and exclusion criteria have been developed on the basis of a scoping review and are presented in table 2. Our criteria for inclusion are purposely broad as, following a scoping review and given the nature of our question, we are unlikely to identify a significant body of empirical studies. In addition to empirical studies, either qualitative, quantitative or mixed methods, we will include descriptive papers and policy documents. Opinion papers and editorials (i.e. not detailing a specific example of KM) will be excluded. Inclusion and exclusion will be determined in a three phase process of title screening, abstract screening and full text review.

Title screening

Two authors (FC & BA) will independently review the title of each publication identified in the search. Those that are clearly not relevant, for example those not focusing on KM or patients, will be excluded. Any titles considered ambiguous or where reviewers disagree will progress to abstract screen.

Abstract screening

Two authors (AB & FC) will independently review the abstracts of articles included from title screening. Any disagreements will be resolved by discussion between the two reviewers and if agreement cannot be reached a third author will be involved. Discussion will continue until consensus is achieved. Publications will proceed to full text review if it is clearly relevant or the abstract suggests it may be relevant but contains insufficient detail to make a decision.

This article is protected by copyright. All rights reserved.

Accepted Article

Full text review

Two authors (FC & BA) will independently review publications to ensure inclusion criteria are met. Disagreements will be discussed and, if not resolved, will be escalated to the third author with a casting vote. Data extraction forms will be developed according to the resources identified. These will include a summary which will be used to inform categorising papers by type and focus.

Bibliographic management

Our searching and screening process will be recorded using the bibliographic data management system (RefWorks™). This will provide an audit trail of decision making at each stage of screening.

Stage 3: Data evaluation

Given a deliberately inclusive sampling frame, we will use an appropriate evaluation tool for each included item. Empirical quantitative and qualitative studies will be evaluated using the appropriate Critical Appraisal Skills Programme (CASP) checklist (CASP 2016). Theoretical sources and reports will be assessed against the criteria of: authenticity; methodological quality; informational value and representativeness of available primary sources (Whittemore & Knafl 2005). Different types of study or reports will be classified by study type and/or publication type and further sub-divided if appropriate. Quality assessment will consider issues such as the clarity of study aims and whether the findings are valid and /or credible. Two authors (FC, BA) will undertake quality appraisal of included literature and the third author will be involved in cases of discrepancy. The critical appraisal process will underpin assessment of the strength of evidence from individual and grouped studies.

This article is protected by copyright. All rights reserved.

Accepted Article

Accepted Article

Stage 4 Data analysis

Data analysis with diverse data is challenging and needs to be transparent (Kastner *et al.* 2016). Depending on the included literature we will perform analysis within and across groupings. Potential groupings include:

- Populations
- Type of KM strategy
- Evaluation methods
- Theoretical basis

In the event that we are able to undertake meta-analysis, meta-synthesis or meta-summary and sub-group analysis we will use review methods designed for specific synthesis purposes (for example Cochrane review methodology for meta-analysis (Higgins and Green 2011).

To synthesise the findings we will follow the five-stage process proposed by Miles and Huberman (1994) namely: i) data reduction; ii) data display; iii) data comparison; iv) conclusion drawing and v) verification. Each of these steps is explained in more detail in table 3. This approach will facilitate the production of an integrative summary of all results and underpin conclusions, generalisations and recommendation from this review.

Stage 5 Presentation

The integrative summary will form the basis of our report. Our output will include a transparent explanation of our review process with a logical chain of evidence that readers can be confident of our conclusions and their grounding in the data. Given the likely

This article is protected by copyright. All rights reserved.

heterogeneity of the included studies, study characteristics will be summarised through narrative summary and summary tables of study characteristics. Thematic synthesis will be used for qualitative studies and where quantitative findings or results of surveys map to the qualitative thematic framework. Dissemination of results will be through local, national and international conferences and publications using a range of media for groups including the public, patients, health care professional, knowledge mobilisers and researchers.

Ethical considerations

There are no specific ethical considerations for this review.

Validity and reliability

Methods of integrative review (Whittemore & Knafl 2005) will provide a focus for the integrative review of available evidence. It is acknowledged that there is no specific reporting guideline for integrative or mixed-method reviews. The use of review methods and a clear report of decision-making will ensure a transparent review process. The use of the PRISMA framework (Shamseer *et al.* 2015) will provide a systematic process for reporting the review of evidence and enhance reliability. Elements of method-specific reporting guidelines for specific streams of evidence will be used as required to enhance rigour.

DISCUSSION

In this review we aim to provide an understanding of the breadth and depth of patient engagement in KM. This synthesis of the extant literature should begin to offer insights into the important area of bridging patient-practitioner-researcher boundaries in knowledge

This article is protected by copyright. All rights reserved.

Accepted Article

mobilisation. We anticipate this review will be of interest to patient groups, health care practitioners, policy makers and knowledge mobilisers. We therefore intend to disseminate our work widely.

Limitations

This review will aim to provide a broad and deep understanding of patient-practitioner-researcher engagement in KM activity. This is an ambitious undertaking particularly in terms of setting parameters for inclusion. Although our review is using a systematic and transparent methodology it is possible that we will not capture all relevant data. Our interpretation of data may be open to bias but the involvement of the review team and multiple perspectives, will limit this.

CONCLUSION

This synthesis of the extant literature should offer insights into the optimum characteristics of methods to bridge patient-practitioner-researcher boundaries in knowledge mobilisation activity. We anticipate that the review will be of interest to patient groups, HCPs, policy makers and knowledge mobilisers. We therefore intend to disseminate our work widely in diverse formats. The findings will be used to inform future research studies by identifying and prioritising areas where further research is most needed.

This article is protected by copyright. All rights reserved.

Accepted Article

Accepted Article

Author Contributions:

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;

2) drafting the article or revising it critically for important intellectual content.

* http://www.icmje.org/recommendations/

REFERENCES

Ahmad N., Ellins J., Krelle H. & Lawrie M. (2014) *Person-centred care: from ideas to action. Health Foundation.* Retrieved from http://www.health.org.uk/sites/health/files/PersonCentredCareFromIdeasToAction.pdf

Bellows M., Burns K., Surgeoner B. & Gallivan J. (2015) Meaningful and effective patient engagement: what matters most to stakeholders. *Patient Experience Journal* **2**(1),18-28.

Bouniols N., Leclère B. & Moret L. (2016) Evaluating the quality of shared decisions: A systematic review. *BMC Research Notes* **9**:382

Burns K., Bellows M., Eigenseher C. & Gallivan J. (2014) 'Practical' resources to support patient and family engagement in healthcare decisions: a scoping review *BMC Health Services Research* **14**, 175.

Chewning B., Bylund C., Shah B., Arora A., Gueguen J. & Makoul G. (2012) Patient preferences for shared decisions: A systematic review. *Patient Education and Counseling*. **86**, 9-18

This article is protected by copyright. All rights reserved.

Accepted Article

Charles C., Gafni A., Whelan T. & O'Brien M. (2006) Cultural Influences on the physician-patient encounter: the case of shared treatment decision-making. *Patient Education and Counseling*. **63**,262-267.

Higgins and Green (2011) Cochrane Handbook for Systematic Reviews of Interventions. Retrieved from http://training.cochrane.org/handbook

Coulter A. (1999) Paternalism or partnership? Patients have grown up—and there's no going back. *British Medical Journal.* **319**,719-720

Critical Appraisal Skills Programme (CASP) (2016) *CASP Tool and Checklists*. Retrieved from http://www.casp-uk.net/casp-tools-checklists

Department of Health (2010). Equity and excellence: liberating the NHS. NHS White Paper Retrieved from https://www.gov.uk/government/publications/liberating-the-nhs-white-paper

Department of Health (2012) Liberating the NHS: No decision about me, without me – further consultation on proposals to secure shared decision making. Retrieved from https://consultations.dh.gov.uk/choice/choice-future-proposals/supporting_documents/Choice%20consultation%20%20No%20decison%20about%20me%20without%20me.pdf

Edgman-Levitan S, Brady C. & Howitt P. (2013) Partnering with Patients, Families and Communities for Health: A Global Imperative – Report of the Family Engagement Working Group. Retrieved from http://www.wish-qatar.org/app/media/387 (accessed 17.1.17)

Elwyn G., O'Connor A., Stacey D., Volk R., Edwards A., Coulter A. on behalf of the International Patient Decision Aids Standards (IPDAS) Collaboration. (2006). Developing

This article is protected by copyright. All rights reserved.

Accepted Article

a quality criteria framework for patient decision aids: online international Delphi consensus process. *British Medical Journal* Retrieved from http://www.bmj.com/content/bmj/333/7565/417.full.pdf

Entwistle VA, Carter SM, Cribb A. & McCaffery K.(2010) Supporting patient autonomy: the importance of clinician-patient relationships. *Journal of General Internal Medicine*. **25**, 741-745.

Gallivan J., Kovacs Burns K., Bellows M. & Eigenseher C. (2012) The many faces of patient engagement. *Journal of Participatory Medicine*. Retrieved from http://www.jopm.org/evidence/research/2012/12/26/the-many-faces-of-patient-engagement/

Greene J. & Hibbard J. (2011) Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*. **27**(5),520-6.

Härter M, van der Weijden T, Elwyn G. Policy and practice developments in the implementation of shared decision making: an international perspective. Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen. 2011;105(4):229-33. doi: 10.1016/j.zefq.2011.04.018. Epub 2011 May 4.

Henry M. (2006) Uncertainty, responsibility and the evolution of the physician/patient relationship. Journal of Medical Ethics. **32**, 321–323.

Hibbard J. & Greene J. (2013) What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Affairs*. **32**(2),207-214

HM Government (2014) Personalised Health and Care: 2020 Using Data and Technology to Transform Outcomes for Patients and Citizens A Framework for Action. Retrieved from

This article is protected by copyright. All rights reserved.

Accepted Article

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/384650/NIB_Report.pdf

Hyde C., Dunn K.M., Higginbottom A. & Chew-Graham C. (2016) Process and impact of patient involvement in a systematic review of shared decision making in primary care consultations. Health Expectations. Retrieved from http://onlinelibrary.wiley.com/doi/10.1111/hex.12458/references

Joseph-Williams N., Elwyn G. & Edwards A. (2014) Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Education & Counseling. **94**(3), 291-309.

Kashaf M.S. & McGill E. (2015) Does Shared Decision Making in Cancer Treatment Improve Quality of Life? A Systematic Literature Review. *Medical Decision Making* **35**(8), 1037-1048.

Kastner M., Antony J., Soobiah C., Straus S.E. & Tricco A.C. (2016) Conceptual recommendations for selecting the most appropriate knowledge synthesis method to answer research questions related to complex evidence. *Journal of Clinical Epidemiology*. **73**, 43-49.

Kirkevold M. (1997) Integrative nursing research: an important strategy to further the development of nursing science and nursing practice. *Journal of Advanced Nursing*. *25*(5), 997-984.

Légaré F. & Witteman H.O. (2013) Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Affairs*. **32**,276–84.

Miles M.B. & Huberman A.M. (1994) *Qualitative data analysis: An expanded sourcebook*. London: Sage Publications.

This article is protected by copyright. All rights reserved.

Accepted Article

Momumjid M., Gafni A., Brémond A. & Carrère M.O. (2016) Decision Making in the Medical Encounter: Are We All Talking about the Same Thing? *Medical Decision Making*. 27(5), 539-546.

Montori V., Gafni A. & Charles C. A. (2006) Shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expectations*. **9**,25-36

Muir R. & Quilter-Pinner H. (2015) Powerful people: Reinforcing the power of citizens and communities in health and care. Institute for Public and Policy Research. Retrieved from http://ippr.org/read/powerful-people-reinforcing-the-power-of-citizens-and-communities-in-health-and-care#foreword

National Voices. (undated) Prioritising person-centred care supporting shared decision-making: summarising evidence from systematic reviews. Retrieved from http://www.nationalvoices.org.uk/sites/default/files/public/publications/supporting_shared_decision-making.pdf

Pollard S., Bansback N. & Bryan S. (2015) Physician attitudes towards shared decision making: A systematic review. Patient Education and Counseling. **98**(9), 1046-1057

Richards T., Montori V., Godlee F., Lapsley P. & Paul D. (2013) Let the patient revolution begin. *British Media*. **346**(126), 14.

Shamseer L., Moher D., Clarke M., Ghersi D., Liberati A., Petticrew M., Shekelle P. & Stewert L.A. (2015) The PRISMA-P Group Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P): elaboration and explanation. British Medical Journal. Retrieved from http://www.bmj.com/content/349/bmj.g7647

This article is protected by copyright. All rights reserved.

Accepted Article

Shaw J. & Baker M (2004) “Expert patient”—dream or nightmare? The concept of a well informed patient is welcome, but a new name is needed. *British Medical Journal*. Retrieved from http://www.bmj.com/content/328/7442/723

Shay L.A. & Lafata J.E. (2015) Where is the evidence? A systematic review of shared decision making and patient outcomes. *Medical Decision Making*. **35**(1), 114-131.

Shea B., Grimshaw J., Wells G., Boers M. andersson N., Hamel C., Porter A., Tugwell P., Moher D. & Bouter L. (2007) Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. *BMC Medical Research Methodology*. Retrieved from http://bmcmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-7-10

Social Sciences and Humanities Research Council. *Knowledge mobilization*. (2016). Retrieved from http://www.sshrc-crsh.gc.ca/funding-financement/programs-programmes/definitions-eng.aspx

Tricco A.C., Antony J., Soobiah C., Kastner M., Macdonald H., Cogo E., Lillie E., Tran J. & Straus S.E. (2016) Knowledge synthesis methods for integrating qualitative and quantitative data: a scoping review reveals poor operationalization of the methodological steps. *Journal of Clinical Epidemiology*. **73**, 29-35

Ward V.L. (2016) Why, whose, what and how? A framework for knowledge mobilisers. Evidence and Policy. Retrieved from http://docserver.ingentaconnect.com/deliver/fasttrack/tpp/17442648/evp_ward_nkl7_uploaded_1464963509052.pdf?expires=1484660328&id=uce&checksum=44C6C05661379D0E71B6FC862532B23A

This article is protected by copyright. All rights reserved.

Whittemore R. & Knafl K. (2005) 1The Integrative review: updated methodology. *Journal of Advanced Nursing*. **52**, 546-553

Wolf C. & Veinot T. (2015) Struggling for space and finding my place: an interactionist perspective on everyday use of biomedical information. *Journal of the Association for Information Science and Technology*. **66**, 282-296

Insert Appendix 1 - Sample Search Strategy on PubMed MEDLINE

Table 1: Summary of search terms

Databases	**Limiters**	**Knowledge terms**	**Patient terms**	**Consumer terms**
CINAHL Medline Web of Science (all databases) ASSIA PsycINFO British Nursing Index, DH-Data and King's Fund Library Catalogue.	English language Published from 2006 onwards	knowledge translation knowledge transfer knowledge exchange knowledge mobilisation	Patient Health consumer Patient participation Patient engagement Patient involvement	Client Co-production Co-creation Co-design Citizen engagement Active engagement Service user

This article is protected by copyright. All rights reserved.

Accepted Article

Table 2: Inclusion and exclusion criteria

Inclusion	**Exclusion**
Empirical studies Theoretical studies Reports Policy documents Descriptive papers Explicit use of KM or associated strategies Patient or patient & HCP	Opinion papers Editorials

Table 3: Five-stage synthesis process of Miles and Huberman (1994)

Stage	**Process**
i) data reduction	A logical classification system will be developed based on type of evidence and our predetermined conceptual classifications of, how, how much and so what (see objectives for further detail). We will code data and if appropriate synthesise codes into broad themes. We will develop a matrix into which we will enter data extracted from each source article. This will provide a manageable framework which summarises pertinent data
ii) data display	Data will be displayed to illustrate patterns and relationships within and across the data. This will be the starting point for our interpretation
iii) data comparison	In an iterative process we will: • Identify patterns and themes • Check for believability • Compare and contrast data • Determine common and unusual patterns • Incorporate parts into wholes

This article is protected by copyright. All rights reserved.

	• Observes for variation and identify related factors • Build a logical chain of evidence
iv) conclusion drawing	We will synthesise the data into a set of robust generalities aiming to be as inclusive as possible
v) verification	We will return to the data in the final stage to ensure accuracy and confirmability of our process and conclusions

Accepted Article

This article is protected by copyright. All rights reserved.