


BMJ Open Linkages between health systems and communities for chronic care: a scoping review protocol

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ABSTRACT

Introduction Linkages between health systems and communities may leverage community assets to address unmet needs and provide services for improved continuity and coordination of care. However, there are limited examples of specific strategies for such linkages for chronic disease management. Guided by a local need from stakeholders, this scoping review aims to clarify and map methods and strategies for linkages between communities and health systems across chronic diseases, to inform future implementation efforts.

Methods and analysis The scoping review will be conducted following Arksey and O'Malley's methodological framework and latest Joanna Briggs Institute (JBI) guidelines, with continuous stakeholder engagement throughout. A structured literature search of records from January 2001 to April 2022 will be completed in MEDLINE/PubMed, CINAHL, EMBASE, PsycINFO, in addition to grey literature. Two reviewers will independently complete study selection following inclusion criteria reflecting population (chronic disease), concept (integrated care) and context (health systems and communities) and will chart the data. Data will be analysed using descriptive qualitative and quantitative methods, to map and operationalise the linkages between health systems and communities.

Ethics and dissemination The scoping review does not require ethics approval as it will examine and collect data from publicly available materials, and all stakeholder engagement will follow guidelines for patient and public involvement. Findings will be reported through a summarising list of considerations for different linkage strategies between health systems and community resources and implications for future research, practice and policy will be discussed and presented. The results will also be used to inform an integrated knowledge translation project to implement community-health system linkages to support chronic pain management.

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INTRODUCTION

The increasing cost and social burden of chronic disease, on both healthcare systems and individuals with complex care needs, is one of the most substantial healthcare challenges.¹ Despite this, health systems continue to be organised around an acute, reactive and episodic model of care that does not meet

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This scoping review follows a rigorous methodological framework, transparently reported through the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) reporting guidelines.
- ⇒ The comprehensive search strategy, built in collaboration with a health research librarian, involves multiple electronic databases with peer-reviewed literature, as well as a structured search of grey literature to increase the breadth and scope of the review.
- ⇒ Stakeholders (patients, healthcare providers, decision makers and community organisers) will be consulted and engaged throughout the review process, reported through the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist.
- ⇒ No quality appraisal or risk of bias assessment will be conducted, consistent with scoping review guidelines.

the needs of individuals living with chronic conditions.² Several resultant challenges exist, including fragmented, uncoordinated care that limits both patient experiences and outcomes as well as the efficiency of resource use and delivery of services.^{2,3}

Proposed approaches to improve chronic care have focused on ways to redesign the management of chronic conditions to better equip healthcare systems to handle this immense burden and improve patient outcomes.²⁻⁶ Broadly, this involves the reorganisation of components for effective disease management to allow for interactions between informed, activated patients and prepared, proactive care teams.^{4,5} One example is the creation of linkages between the health system and community resources, proposed to add to the continuum of care by filling gaps in services that are not provided by healthcare organisations.^{4,5} The scope and depth of community resources is emphasised in the Expanded Chronic Care Model

(ECCM), through the integration of population health promotion elements.⁶ This recognises social determinants of health, the non-medical factors (such as forces and systems that shape individual's lives) that influence health outcomes.⁶ Similarly, integrated care frameworks have long highlighted the importance of person-centred population-based care to prevent care fragmentation and healthcare inequities.^{7,8}

Beyond reorganisation, community integration reflects a shift towards a partnership-based approach to care.²⁹ In the context of chronic disease, a systems approach that addresses social determinants of health through cross-sectoral integration can support individuals to become empowered, engaged partners in the co-management of their chronic condition.¹⁰⁻¹² This framing also reflects recent calls to incorporate network theory in integrated care, moving beyond a structural approach to integration and incorporating a processual, relational perspective that recognises integration as a social process.¹³

Health networks worldwide have highlighted the need for chronic care integration between communities and health systems. WHO recently described continuity and coordination of care grounded in engaging and empowering communities as global priorities to support integrated, people-centred health services for complex care needs.³ Community-based approaches have also been recently emphasised for the development of learning health systems that reflect the values and needs of people and communities.^{14,15} The resultant shift to a Learning Healthcare Community model promotes a bidirectional relationship between the health system and the community to co-create continuous learning and improvement cycles that support population health.¹⁵ The creation of community-health system linkages has recently been identified and prioritised by local stakeholders in chronic pain health networks in Montreal to reduce care fragmentation, and our research group is building on this to develop a person-centred learning health community. Determining how, when and which community components to be integrated into care pathways can be aided by previously established linkage strategies used across chronic disease management.

However, methods to create linkages between health systems and communities for chronic disease management are largely unclear, as beyond theoretical support for community integration into chronic care,^{2,4-6} there are limited examples of specific mechanisms for action or strategies for success. Previous systematic reviews and meta-analyses that evaluate the effectiveness of the implementation of chronic care models have largely focused on the health system (eg, clinical decision support), and have consistently demonstrated limited reports of the community resource aspect of the models.¹⁶⁻¹⁹ Previous scoping reviews and environmental scans that examined linkages between community/public health interventions and clinical sectors are limited in their scope and application to the management of chronic disease as they have been specific to preventative care (eg, low birth weight

prevention,²⁰ tobacco cessation²¹) and reflect a different experience than actively managing a chronic condition. The described linkage interventions for preventative service delivery (eg, collocating or coordinating services, referral to prevention resources) provides a foundation to expand on for chronic disease management, as well as the opportunity for further investigation into the characteristics of strategies used within linkage interventions.²¹ Additionally, grassroots efforts for linkages established by community groups are potentially under-reported in published literature and require an expanded review of grey literature.

There is a distinct need for further examination of how community integration occurs in the context of chronic disease, including the types of community assets used to address unmet needs, and linkage strategies reported in both published and grey literature. A greater understanding of specific ways to link community resources to chronic care may lead to further implementation and integration of community-health system linkages with the potential to improve system and patient outcomes for chronic disease management.

Objective

To clarify and map methods and strategies for linkages between communities and health systems for chronic disease management.

METHODS

Type of knowledge synthesis

A scoping review was selected as the type of knowledge synthesis, given the broad, exploratory nature of the research question. This synthesis type is well suited to this review as it aims to synthesise the relevant body of literature to clarify and map key concepts/strategies related to linkages between communities and health systems, for the purpose of summarising and disseminating findings for future research and implementation.²² As the topic is heterogeneous and has not been extensively reviewed previously, a scoping review is the appropriate choice.^{22,23}

The scoping review will be guided by the latest JBI guidelines for scoping reviews,^{24,25} building on the earlier methodological framework of Arksey and O'Malley,²⁶ as well as additional recommendations by Levac *et al.*²³ The workflow of the review will follow the reporting guidelines of the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension checklist for Scoping Reviews (PRISMA-ScR),²⁴ provided in the online supplemental materials, and will be depicted by a PRISMA-ScR flow chart.²⁷ This scoping review was registered on Open Science Framework (10.17605/OSF.IO/UTSN9).

This scoping review will be further guided by the PRECEDE-PROCEED model,²⁸ a public health planning model that has been shown to be useful in developing targeted healthcare improvement strategies for complex chronic care environments.²⁸⁻³⁰ PRECEDE stands for Predisposing, Reinforcing and Enabling Constructs in

Table 1 Stakeholders to be invited to Executive Stakeholder Committee

Role	Description	Setting
Healthcare practitioner (n=2)	Individual with clinical experience with chronic pain management or primary care in Montreal	Integrated University Health and Social Services Center (CIUSSS) West-Central Montreal
Decision maker (n=1)	Individual with administrative experience and decision-making role in Quebec chronic pain management	CIUSSS West-Central Montreal
Health policy expert (n=1)	Individual with experience with public policy, public health or health promotion in Quebec	Quebec Ministry of Health and Social Services Quebec National Institute of Public Health McGill University CIUSSS West-Central Montreal
Community leader (n=2)	Individual with knowledge and experience of local community resources, structures and organisations in Montreal	YMCA Quebec Chronic Pain Association CIUSSS West-Central Montreal
Patient partner (n=3)	Individual living in Montreal with chronic pain, defined as persistent pain lasting >3 months	CIUSSS West-Central Montreal Centre of Excellence on Partnership with Patients and the Public
Researcher (n=1)	Individual trained in health research	Person-Centred Health Informatics Lab, McGill University

Educational Diagnosis and Evaluation. It involves assessing multidimensional community influences by considering social, epidemiological, ecological and administrative policy factors that influence the planning and implementation of an intervention. PROCEED refers to Policy, Regulatory and Organisational Constructs in Educational and Environmental Development. It involves identifying desired outcomes for process, impact and outcome evaluation of implementation, and evaluating the change.^{28–30}

Patient and public involvement

This scoping review will be conducted through a collaborative, co-design approach with adult stakeholders involved with chronic pain management in Montreal (table 1).³¹ Stakeholders will be invited to join an Executive Stakeholder Committee as research partners and will complete a Terms of Reference agreement that clearly outlines expectations for their involvement, different engagement tasks, compensation and the time commitment of at least 1 year. Stakeholder skills, experiences, preferences, values and availabilities will be taken into consideration during the research process.³² Stakeholders will be invited to be actively involved with each step of the research process, detailed in the methodological steps 1-6 .

Step 1: identifying the research question

The following research question will guide the scope of inquiry for the review: What methods and strategies have been used to integrate community resources into health systems for the continuation of care for adults with chronic conditions? Accordingly, the purpose of the review is to comprehensively identify and map different linking strategies used across the chronic disease literature, to inform future implementation efforts. Both the research question and purpose are aligned with

established priorities from stakeholders within the local health networks and were further reviewed and refined by the Executive Stakeholder Committee. The different concepts of the above research question are operationally defined as the following:

- ▶ *Population*: adults with chronic disease, consistent with the umbrella definition proposed by Bernell and Howard, involving one or more persistent conditions that last >3 months, including those that transition from acute to chronic.³³
- ▶ *Concept*: integrated care, that aims to overcome care fragmentations through improved continuity and coordination and is grounded in engaging and empowering people and communities.³⁴ Integration reflects a set of methods aimed at creating connectivity, alignment and collaboration within and between the cure and care sectors, cutting across multiple services, providers and settings.^{34 35} Linkage strategies and methods can be further operationalised as the *who*, *why* and *how* of integration.
- ▶ *Context*: the context for integration will be between health systems and communities. The health system, consistent with WHO, is defined as ‘all organisations, institutions and resources that produce actions whose primary purpose is to improve health’.³⁶ It can be further defined by the function of the system, as the direct provision of medical services. This reflects the treatment of medical conditions by healthcare workers in healthcare settings.³⁷ Community assets are defined as the collective resources available to individuals and communities that can be leveraged to support health and well-being.³⁸ Community assets may be described as formal resources, including structures (eg, place of worship, gyms, libraries, museums,

parks), or community organisations providing paid or free services (eg, food banks, transportation).³⁹ Community assets may also be described as informal resources, including individuals (eg, volunteers, neighbours), and associations (eg, civic groups or informal clubs).³⁹ This was reflected in the stakeholder engagement, which emphasised informal community resources including peer support and volunteer opportunities.

Step 2: identifying relevant sources of evidence

A structured electronic search will be conducted in the following databases: MEDLINE/PubMed, CINAHL, EMBASE and PsycINFO, limited to works published in English from January 2001 to April 2022. Search terms related to the following main concepts were combined using the Boolean operator AND: integrated care coordination; health system; community and chronic disease. The search terms associated with each concept were developed through an iterative process, using the mapping functions in each database to build a comprehensive search strategy of subject headings and keywords. The proposed search was reviewed and approved by a health research librarian. A preliminary search was conducted in all included databases, provided in online supplemental materials. The list of generated references will be imported to EndNote software, and reference duplicates between the databases will be identified and removed. The database searches will be followed by a hand search of reference lists from the included articles, and further article recommendations by identified content experts.

Grey literature will be searched following a grey literature checklist.⁴⁰ A grey literature search plan will be developed around the following search strategies: customised Google search engines; target websites and consultation with identified content experts.⁴¹ Internal website searches will be limited to the first 10 pages. The grey literature search will involve clear documentation of each search strategy, including date and terms searched, number of items retrieved/search results and number of items screened.

This step of identifying relevant sources of evidence will also be treated as an iterative process.^{23–26} The research team and key stakeholders will meet to refine the search strategies across information sources, through a targeted iterative searching technique of examining the keywords of included studies.⁴²

Step 3: selecting sources of evidence

Two independent reviewers will screen the retrieved literature for inclusion per the agreed upon eligibility criteria, detailed below.^{23–26} First, the two reviewers will perform a pilot selection to ensure a mutual understanding of the eligibility criteria and identify areas where further clarification is needed. Following the pilot, the two reviewers will independently select studies based on the title and abstract (providing codes of ‘include’, ‘exclude’ or ‘unclear’). All studies coded as ‘include’ or ‘unclear’

will be further reviewed for selection by full text by both independent reviewers. Reasons for study exclusion will be documented. Any disagreements on inclusion will be resolved by consensus or mediated by a third reviewer. The corresponding or first authors of any studies coded as ‘unclear’ will be contacted to clarify unclear or missing information. The inclusion criteria for study selection, consistent with the operational definitions of the research question population, concept and context, includes the following:

- i. Literature will be considered if it is published in the English language. There will be no limits related to study design.
- ii. Literature will be considered if it concerns integrated care, as defined above,^{34 35} connecting health systems and communities.^{36–39}
- iii. Literature will be considered if it describes strategies, methods or frameworks for creating or sustaining linkages between health systems and community resources.
- iv. Literature will be considered if it concerns chronic disease, as defined above,³³ in adult patients (>18 years of age).

Exclusion criteria will consist of the following:

- i. Literature will be excluded if it is not published in the English language.
- ii. Literature will be excluded if it does not concern coordination across health systems and community resources (such as independent community interventions not integrated or connected to health systems).
- iii. Literature will be excluded if it only concerns formal community health structures (eg, community-based primary care clinics) that do not have any additional integration with community resources.
- iv. Literature will be excluded if it only describes the need for future clinical-community integration, rather than current practices.
- v. Literature will be excluded if it concerns acute care (ie, non-persistent conditions, treated within a timeframe of 3 months).
- vi. Published conference abstracts or study protocols will be excluded.

The selection stage will also be considered an iterative process, allowing the eligibility criteria to be refined by stakeholders as the understanding of the breadth and scope of the literature advances.^{23–26}

Step 4: charting data

Two independent reviewers will extract the data. The data to be extracted will include details about the population, context, concept (outlined in table 2). Data extraction forms were developed based on the research question and review purpose, informed by the PRECEDE-PROCEED model.^{28–30} The fields were further refined following stakeholder engagement to reflect relevant needs and priorities. Following an iterative approach, data extraction fields may be further updated and finalised throughout the selection process.^{23–26}

Table 2 Overview of data to be extracted

Domain/Subdomain	Description
General document characteristics	
Authors	Name of authors
Year	Year of publication
Country	Country of publication
Publication type	Peer-reviewed, grey literature
Document type	Empirical study, commentary, review, report, guideline
Study design	For empirical studies, observational, experimental or descriptive
Population	
Demographics of study participants	For empirical studies, listed details for categories of age, sex, gender, ethnicity
Target population	Identified chronic disease targeted by linkage
Social determinants of health	Social determinants of health addressed (economic stability, education, health and healthcare, neighbourhood and built environment, social and community) ⁴⁹
Health context	
Health system	Identified components of health system ^{36 37}
Clinical setting	Identified setting (primary care, rehabilitation, long-term care)
Care providers	Identified healthcare professionals involved in health-oriented context of linkage
Continuum	Timing in patient care continuum (prevention, intake, transition, discharge, maintenance)
Community context	
Sectors	Identified areas of community sector (transportation, housing, health and social services, civic participation and employment, environment, recreation)
Location	Rural, urban, suburban
Types of assets	Formal, informal ³⁹
Resources	Name and mission/mandate of the identified community assets (eg, institutions, organisations, services, activities, groups) ^{38 39}
Actors	Identified key individuals involved with the community context of linkage (eg, navigator)
Linkage strategy	
Name	Name of intervention/programme linking health system and community (if applicable)
Aim	Described purpose of linkage

Continued

Table 2 Continued

Domain/Subdomain	Description
Frameworks	Name of frameworks/models used
Stage	Developing, maintaining, sustaining linkage
Directionality	Direction of linkage (from health system to community, from community to health system, bidirectional)
Actions	Type of actions involved in linkage (awareness, coordination, communication, sharing, referral) ⁴³
Mechanism	Description of linkage mechanisms for intersectoral integration
Network properties	Listed details of network size, centrality, tie strength, embeddedness, structural holes ¹³
Influencing factors	
Relational	Listed components of organisational culture related to relational coordination (shared goals, shared knowledge, mutual respect) ^{13 50}
Behavioural	Listed activities targeting behavioural influences (eg, knowledge, attitudes beliefs) to support intersectoral integration (training, information, local champion) ²⁸⁻³⁰
Structural	Listed structural level components supporting intersectoral integration (governance, available funding, policy/regulatory procedures) ²⁸⁻³⁰
Evaluation	Listed outcomes if evaluation of linkage occurred

The extraction form will be piloted on a minimal number of articles (~5–10), after which the two reviewers will meet to assess consistency. A third reviewer will be included to resolve any disagreements between the two reviewers. As this is a scoping review, the quality of the included studies will not be appraised.^{23–26}

Step 5: collating, summarising and reporting results

Extracted quantitative data will be analysed using counts (number and percentage) and synthesised using a narrative form. We will consider in these analyses the characteristics of records, of which results will be reported in tabular form to show the breadth and depth of included literature. Additionally, we will perform a qualitative content analysis on extracted qualitative data through descriptive qualitative techniques.²⁴ Data coding will be guided by the WHO Framework for Integrated People-Centred Health Services.³ Identified linkages between health systems and communities will be mapped to the Continuum of Community-Clinical Linkages,⁴³ to describe the complexity of the linkage (networking, coordinating,

cooperating, collaborating or merging). The linkages will be further operationalised through mapping to the PRECEDE-PROCEED model,^{28–30} to describe enabling factors and administrative capacity associated with the varying levels of complexity in linkages.

The findings on integrated community and health system linkages will be reported through a summarising list of considerations and strategies for developing and maintaining different types of linkages between health systems and community resources, as a guide for future research and implementation on the continuation of chronic disease management. As such, implications of the review findings for future research, practice and policy will be discussed and presented.

Step 6: consultation

The goals of stakeholder engagement include the following: to identify priorities and goals of the review, identify potential linkage strategies that may not be captured by the search strategy and suggest key informants to address these gaps, discuss practice and policy implications and knowledge translation strategies. Rather than a single consultation phase, engagement with the Executive Stakeholder Committee will occur continuously throughout the scoping review,^{23–26} to allow for ongoing and deliberate stakeholder input and exchange and to ensure the scoping review considers what is important to individuals with chronic pain, clinicians, healthcare decision makers and community partners. The design and structure of the Executive Stakeholder Committee will assist to reconcile perspectives from different stakeholders, as the group will aim to come to a consensus, when possible. A facilitator will lead the online consultations to minimise perceived power imbalances and establish group norms. Stakeholders will also be able to provide anonymous comments to the facilitator through the direct messaging function of the platform.

Stakeholder input will be presented as separate from other review findings, guided by GRIPP2 reporting checklist for patient and public involvement in research.⁴⁴ When appropriate, input from different stakeholders will be delineated to show perspectives specific to the different groups, based on the information shared during stakeholder engagement.

Following the completion of the review, the results be used to inform the first stage of a related integrated knowledge translation project,^{45–47} to tailor the linkage strategies identified across chronic diseases to the context of chronic pain management. Guided by the PRECEDE-PROCEED model,^{28–30} stakeholders will collaboratively identify and select priority areas and linkage strategies that are relevant to the local clinical context and the strengths of the community.

ETHICS AND DISSEMINATION

The project does not require ethics approval, as the scoping review methodology involves reviewing and

collecting data from publicly available materials. All stakeholder engagement for the scoping review will follow guidelines for patient and public involvement.^{32 48}

Critically, the consultation described above reflects stakeholder engagement, not data collection, an important distinction as the stakeholders are not study participants. Therefore, ethical review and approval is not required.

This scoping review seeks to comprehensively identify, map and operationalise what has been done across chronic disease management, for the purpose of summarising and disseminating findings for future research and implementation. Results will be presented through a list of considerations and strategies, with potential to be developed as a policy brief. Results will be disseminated to relevant audiences, including patients, healthcare providers, healthcare system decision makers, community leaders and researchers, with assistance from the Executive Stakeholder Committee to adapt the message to the target audience. Results will be submitted to an open-access journal for publication and will be further disseminated through academic and non-academic conference presentations/workshops focused on strategies for establishing linkages between health systems and community resources for chronic disease management. As described above, this scoping review is part of a larger research programme to develop linkages to community resources to support local chronic pain management. This will involve further active dissemination efforts, such as creating partnerships with identified community organisations or groups, to inform the implementation of integrated community-health system linkages for person-centred chronic pain care.

This scoping review has the potential to extend health services literature related to community integration for chronic disease management, building on previous work related to preventative service delivery.²¹ Furthermore, the findings are applicable to the wider field of integrated care, contributing to the literature on intersectoral integration with the opportunity to inform areas of inquiry related to network theory and systems approaches.¹³ This scoping review may potentially contribute to practice by guiding future implementation efforts. A greater understanding of how health systems can connect with community resources may lead to structured strategies that can be implemented across chronic care continuums with the potential to improve system and patient outcomes for chronic disease management.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the 'Methods' section for further details.

Patient consent for publication Not applicable.

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Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data sharing not applicable as no datasets generated and/or analysed for this study.

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