System enablers and barriers to continuity of care for First Nations people living with chronic conditions: A rapid qualitative review protocol

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Abstract

Objective: This rapid review aims to evaluate qualitative literature on the health system enablers and barriers to continuity of care for Aboriginal and Torres Strait Islander people in Australia and comparable Indigenous populations and countries (i.e., Māori people of New Zealand and First Nations people of Canada) (collectively referred to as First Nations people).

Introduction: The First Nations people of Australia, New Zealand, and Canada experience lower life expectancy than their non-Indigenous counterparts, with chronic conditions contributing to approximately 70% of this disparity. Reduced access to health services and poorer care outcomes attributed to chronic diseases account for a significant proportion of this gap. The sub-optimal management of ongoing care when living with chronic conditions contributes to health disparities in these countries.

The South Australian Aboriginal Chronic Disease Consortium identified a critical need to create a protocol, evidence-informed on continuity of care for Aboriginal and Torres Strait Islander people hospitalised for chronic disease. Reduced access to health services contributes to delayed detection of risk factors and disease, limited ongoing disease management, increased risk of potentially preventable hospitalisation, and complex care needs, often unmet following a hospitalisation. An investigation of qualitative literature on system enablers and barriers to continuity of care for First Nations populations with shared histories of colonisation will help inform evidence-based approaches to continuity of care.

Inclusion criteria: This review will be focused on the qualitative and mixed-method studies that qualify enablers and barriers to continuity of care. It will consider frameworks, protocols, and designs concerning specific chronic conditions, which are the major contributors to health disparities, and the focus of the South Australian Aboriginal Chronic Disease Consortium: cancer, cardiovascular disease, chronic kidney disease, and diabetes and its associated complications. An emphasis will be placed on the health system, healthcare providers, and other professionals related to continuity of care services or integration of care.

Exclusion criteria: The work will exclude research that does not consider enablers and/or barriers to continuity of care or its integration. Quantitative studies and those considering chronic conditions outside this scope will be excluded.

Methods: This rapid qualitative review will consider relevant primary qualitative and mixed-methods studies published in English between 2010 and June 2022. Key information sources to be searched for publications will be databases Medline, Embase, PsycINFO, and Cochrane Central. Two reviewers will independently review titles and abstracts; relevant sources will be retrieved in full and reviewed. Any disagreements will be resolved through discussion or with one or more additional reviewers. Two independent reviewers will assess papers selected for retrieval for methodological quality using the Aboriginal and Torres Strait Islander quality appraisal tool before inclusion in the review. Relevant articles will be charted to summarise the extracted data. Findings will be explained inductively, in narrative and graphical forms, using the latest frameworks from The World Health Organisation as a lens but allowing themes to emerge from the data. Any deviations from this protocol will be justified and reported in the final review.

Review registration number: PROSPERO ID=CRD42022339990

Keywords: Continuity of care; integration of care; chronic diseases; Aboriginal; Indigenous; First Nations People

System enablers and barriers to continuity of care for First Nations people living with chronic conditions: A rapid qualitative review protocol

Introduction

The South Australian Aboriginal Chronic Disease Consortium identified a critical need to create an evidence-informed protocol on continuity of care for Aboriginal and Torres Strait Islander people hospitalised with a chronic disease.[1,2] The latest Australian data (2022) indicates that chronic conditions were responsible for more than two-thirds (70%) of the gap in disease burden between Aboriginal and Torres Strait Islander people and non-Indigenous Australians.[3] The gap in health-adjusted life expectancy at birth between Aboriginal and Torres Strait Islander people and non-Indigenous Australians was 15.2 years for males and 13.9 years for females.[3]

Between 2017 and 2018, Aboriginal and Torres Strait Islander people waited longer to be admitted for elective surgery than non-Indigenous Australians (median waiting time of 48 days and 40 days, respectively). Additional data from the same period indicates that breast screen participation rates of Aboriginal and Torres Strait Islander women (40 years old and over) were 25% compared with 34% for non-Indigenous women.[4] These numbers demonstrate that Aboriginal and Torres Strait Islander people do not benefit equitably from integrated care services and/or its continuity compared to their non-Indigenous counterparts.[5]

Continuity of care is defined by the World Health Organisation (WHO) as the degree to which people experience a series of discrete health care events as coherent and interconnected over time and consistent with their health needs and preferences.[6] WHO investigates the continuity of care issues around care coordination, focusing on the conditions and ongoing relationships needed to support harmonious interactions among multiple providers within interdisciplinary teams and across care settings and sectors.[6]

WHO's approach considers the priority practices and actions that enable care integration at different levels and the equal distribution of the functional and normative integration of care across its coordination. These considerations follow the Rainbow model of integrated care, which refers to a framework for integrated care used to identify the point or level at which specific practices and actions operate).[6,7] These points in a health system at which continuity and care coordination exert an influence are distributed within three levels and their respective activities, as per Table 1 (adapted from WHO).[6]

Table 1. Points in a health system at which continuity and care coordination exert an influence[6]

Levels	Points in a health system	Activities
Micro	Clinical integration	Interpersonal continuity
		Holistic assessment and care planning
		Coaching and peer support
		Patient-centred medical home
		Family health unit
		Case management
Meso	Professional integration	Interdisciplinary teams
		Transitional care services
		Clinical pathways
	Functional integration	Continuity of information
		Technology-enabled care
		Decision support
	Organisational integration	Collocation of services
		Single point of access
		Community initiatives
Macro	System integration	Comprehensive managed care
		Health and social care pathways
		Health and social care networks

Understanding these points of the WHO approach to integrating people-centred health services is relevant for identifying the enablers and barriers to continuity of care for First Nations peoples living with chronic conditions. WHO has found that having a high level of continuity of care

translates into health benefits, including fewer hospital admissions, fewer visits to emergency departments, and lower care costs.[6]

First Nations populations in Australia, Canada, and New Zealand share similar histories of colonisation, engage with a health system centred on universal healthcare, and share comparable drivers of health inequities.[1,8] Across all three countries, the effects of ongoing colonisation result in First Nations populations experiencing earlier onset and higher rates of disease across these chronic conditions compared to non-Indigenous counterparts.[1,2,8,9] Therefore, exploring continuity of care experiences (as defined by WHO) across the described populations can provide insights into how systems and services can be improved.[6]

The range of approaches and interventions of continuity of care presented in Figure 2 can bring a practical lens to comprehend current inequities and gaps for First Nations people. Analyses of such aspects are necessary to prevent the current sub-optimal management of ongoing care and associated disparities experienced by First Nations people.[1,2]

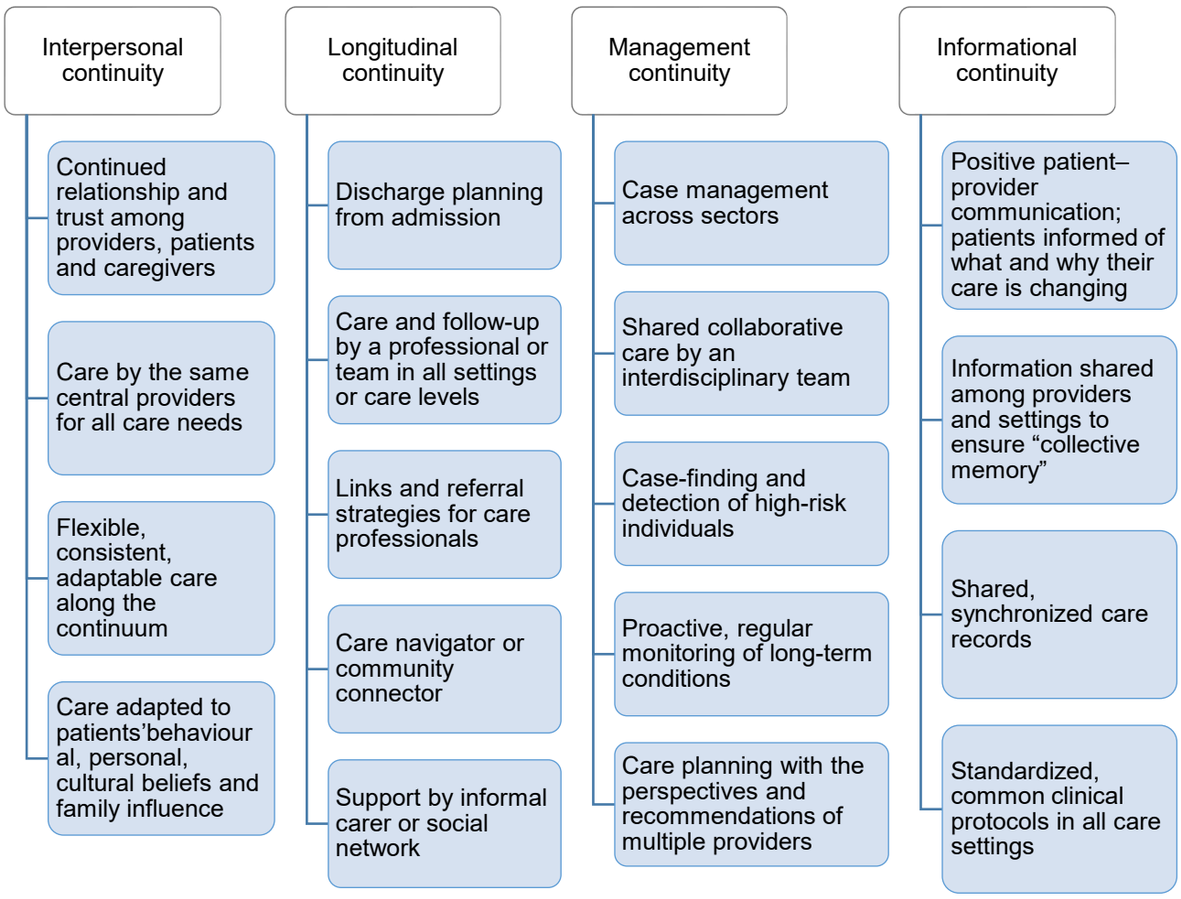

Figure 1. The range of approaches and interventions for achieving continuity of care (adapted from WHO).[6]

This study will look for the barriers and facilitators for better health for Indigenous and First Nations people to bring insight into the patterns and lessons learned.[9,10] This approach considers similarities across First Nations people, qualifying the typical patterns of experiences and learnings across larger groups while simultaneously considering several chronic diseases.[9,10] In summary, we will consider in this review the qualitative and mixed-method investigations around:

1. Aboriginal, Torres Strait Islander, Indigenous, and First Nations people.
2. Chronic disease within the scope of the South Australian Aboriginal Chronic Disease Consortium.
3. Health systems and their continuity of care.
4. Barriers and enablers to continuity of care.

Creating this rapid review as a qualitative evidence synthesis will provide meaningful evidence and insights to ensure appropriate, accessible, acceptable, culturally safe, and high-quality

coordinated care for Aboriginal and Torres Strait Islander people in South Australia and similar groups across the globe. Our preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews, and the *JBI Evidence Synthesis* was conducted. No reviews were identified on health system enablers and barriers to continuity of care for First Nations people living with chronic conditions.

Review question

What are the health system enablers and barriers to continuity of care for First Nations people living with chronic conditions?

Methods

This rapid review will be conducted following the JBI methodology for systematic reviews of qualitative evidence, adapted to be a rapid review that considers principles of the Cochrane rapid review method,[11] and has been registered in PROSPERO ID=CRD42022339990.

Inclusion criteria

Participants

The participant scope includes First Nations people from Australia, Canada, and New Zealand living with these chronic conditions: cancer, cardiovascular disease, chronic kidney disease, diabetes, and associated complications. The work will exclude participants with nationalities, ethnicities, and disorders outside the scope. We will not seek to redefine definitions around 'First Nations' terminologies and accept each study author's description of their population.

Phenomena of interest

This review will consider studies that qualitatively explore the continuity of care and/or its integration (as defined by WHO) specific to our participants.[6,7]

Context

Barriers and enablers to continuity of care will be considered in understanding participants' similar characteristics (e.g., colonisation history, universal healthcare systems, and social determinants of health).

Types of studies

This review will consider studies that focus on qualitative data, including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and feminist research. We will also consider the qualitative component of mixed methods studies. It will consider interpretive studies that draw on the experiences of enablers and/or barriers to continuity of care or its integration.

Search strategy

An initial limited search of Medline will be undertaken, followed by an analysis of the text words in the title and abstract and the index terms used to describe each article. The identified keywords and index terms will be used to develop a full search strategy for Medline (see Appendix #1). The full search strategy, including all specified keywords and index terms, will be adapted for Embase, PsycINFO, and Cochrane CENTRAL. The search will be limited to studies published in English since 2010, considering Medical Subject Headings (MeSH): Medline Chronic disease AND Continuity of care AND Indigenous AND Qual.

Study selection

Following the search, all identified citations will be collated and uploaded into EndNote (Clarivate Analytics, PA, USA), and duplicates removed. Two or more independent reviewers will screen titles and abstracts for assessment against the inclusion criteria. Potentially relevant studies will be retrieved in full, and their citation details imported into the JBI System for the Unified

Management, Assessment and Review of Information (JBI SUMARI) (JBI, Adelaide, Australia). This full review will record and report reasons for excluding papers that do not meet the inclusion criteria. Any disagreements between the reviewers (at each stage of the selection process) will be resolved through discussion or with an additional reviewer/s. The results of the search and the study inclusion process will be reported in full in the final systematic review and explained inductively, in narrative and graphical forms (e.g., PRISMA flow diagram). Any deviations from this protocol will be justified and reported in the final review.

Assessment of methodological quality

All included studies will be assessed for methodological quality by a set of two independent reviewers from this team (JW, RC, SH, LG, SB, MAPP). They will critically appraise the studies using the Aboriginal and Torres Strait Islander quality appraisal tool.[12] Using only this tool will facilitate the rapid critical appraisal considering the Aboriginal and Torres Strait Islander peoples' values and ethics around achieving appropriate, high quality and relevant health research. Results will be reported in narrative and table forms summarising the number of "Yes", "No", "Partial", and "Unclear" answers to the fourteen assessment areas of the tool.[12]

Data extraction

The data extracted will include specific details about the populations, context, culture, geographical location, study methods, chronic conditions and the health system enablers and barriers to continuity of care for First Nations peoples living with those chronic conditions. Findings will be extracted in Excel by two independent reviewers from the team. Any reviewer disagreements will be resolved through discussion or with a third reviewer.

Data synthesis

Qualitative research findings will, where possible, be pooled using table 1 and Figure 2 themes as lenses, allowing other themes to emerge from the data. This process will involve the aggregation or synthesis of results to generate a set of statements representing that aggregation, assembling the findings, and categorising them based on similarity in meaning. These procedures will produce a comprehensive set of synthesised results that can be used as a basis for evidence-based practice. The findings will be presented in narrative and/or graphical forms. Any deviations from this protocol will be justified and reported in the final review.

Funding

This project is funded by the South Australian Department for Health and Wellbeing. The funders will not be involved in any aspects of the review process.

Declarations

The authors like to highlight the contributions of The South Australian Aboriginal Chronic Disease Consortium in the problem identification of this research. The authors want to acknowledge the importance of the experience and expertise that Odette Pearson brings to the study as a Kuku Yalanji/Torres Strait Islander woman, co-Theme Leader of the Wardliparingga Aboriginal Health Equity Theme at South Australian Health and Medical Research Institute, and affiliate Associate Professor at the Adelaide Medical School, University of Adelaide. The authors also acknowledge the 25 years of experience in service and systems design in Aboriginal health and community services and the family connections that Kim Morey brings as an Anmatyerre/Eastern Arrernte descent. She leads Health Systems Research and co-Theme Leader of Wardliparingga Aboriginal Health Equity Theme at the South Australian Health and Medical Research Institute. She has extensive knowledge of public sector systems, policy development, strategic advice, and monitoring.

Author contributions

Dr Maria Alejandra Pinero de Plaza, Prof Robyn Clark, A/Prof Odette Pearson, Katharine McBride, A/Prof C-J Wu, and Kim Morey are the study guarantors and conceived the study and its characteristics. They have also revised and agreed on the current protocol manuscript. Mrs Shannon Brown co-created the search strategy, performed the search and its translations, and assisted in the review process and manuscript revisions. All authors read and approved the final Protocol manuscript.

Conflicts of interest

The authors declare no conflict of interest.

References

1. Brown A, Keech W, McBride K, et al. The South Australian Aboriginal Heart and Stroke Gap Analysis for the South Australian Aboriginal Heart and Stroke Plan 2017-2021. 2016;
2. South Australian Aboriginal Chronic Disease Consortium. *SA Aboriginal Chronic Disease Consortium Road Map for Action 2017-2021*. 2017-2021. http://aboriginalhealthconsortium.org/our-priorities/#action
3. Australian Institute of Health and Welfare. *Australian Burden of Disease Study 2018: Interactive data on risk factor burden among Aboriginal and Torres Strait Islander people*. 2022. https://www.aihw.gov.au/reports/burden-of-disease/abds-2018-interactive-risk-factor-indigenous
4. Australian Institute of Health and Welfare. *Culturally safe health care for Indigenous Australians*. 2020. https://www.aihw.gov.au/reports/australias-health/culturally-safe-healthcare-indigenous-australians
5. Banham D, Chen T, Karnon J, Brown A, Lynch J. Sociodemographic variations in the amount, duration and cost of potentially preventable hospitalisation for chronic conditions among Aboriginal and non-Aboriginal Australians: a period prevalence study of linked public hospital data. *BMJ Open*. 2017;7(10):e017331. doi:10.1136/bmjopen-2017-017331
6. World Health Organization. Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services. 2018;
7. Valentijn PP, Schepman SM, Opheij W, Bruijnzeels MA. Understanding integrated care: a comprehensive conceptual framework based on the integrative functions of primary care. *International journal of integrated care*. 2013;13
8. Redwood S, Gill PS. Under-representation of minority ethnic groups in research — call for action. *British Journal of General Practice*. 2013;63(612):342-343. doi:10.3399/bjgp13x668456
9. Glover M, Kira A, Johnston V, et al. A systematic review of barriers and facilitators to participation in randomized controlled trials by Indigenous people from New Zealand, Australia, Canada and the United States. *Global Health Promotion*. 2015;22(1):21-31.
10. Umaefulam V, Kleissen T, Barnabe C. The representation of Indigenous peoples in chronic disease clinical trials in Australia, Canada, New Zealand, and the United States. *Clinical Trials*. 2022;19(1):22-32. doi:10.1177/17407745211069153
11. Garritty C, Gartlehner G, Nussbaumer-Streit B, et al. Cochrane Rapid Reviews Methods Group offers evidence-informed guidance to conduct rapid reviews. *Journal of clinical epidemiology*. 2021;130:13-22.
12. Harfield S, Pearson O, Morey K, et al. Assessing the quality of health research from an Indigenous perspective: the Aboriginal and Torres Strait Islander quality appraisal tool. *BMC Medical Research Methodology*. 2020;20(1)doi:10.1186/s12874-020-00959-3

Appendices

Appendix I: Medline search strategy

Medline Chronic disease AND Continuity of care AND Indigenous AND Qual 31_05_2022

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to May 27, 2022>		
1	exp Pulmonary Disease, Chronic Obstructive/ or exp Cardiovascular Diseases/ or Hypertension/	2676545
2	(hypertension or "high blood pressure" or "elevated blood pressure").tw,kf.	445816
3	("heart failure" or copd or coad or "chronic obstructive pulmonary disease" or "coronary artery disease" or "cardiovascular disease" or "congestive heart failure").tw,kf.	496073
4	or/1-3	2957126
5	exp Diabetes Mellitus/ or Diabetic Foot/ or Diabetic Neuropathies/ or Diabetic Cardiomyopathies/ or Diabetic Nephropathies/ or Diabetic Ketoacidosis/ or Diabetic Retinopathy/ or diabetic angiopathies/ or diabetes insipidus/ or diabetic nephropathies/	486064
6	(NIDDM or diabetes or diabetic* or IDDM).tw,kf.	724459
7	or/5-6	785902
8	exp Neoplasms/ or exp Medical Oncology/	3699909
9	(cancer* or carcinoma* or neoplas* or tumo#r* or malignan* or oncolog* or leuk#emia* or metasta* or lymphoma* or melanoma*).tw,kf.	3455663
10	or/8-9	4626034
11	kidney diseases/ or exp hypertension, renal/ or exp nephritis/	176960
12	((kidney or renal) adj4 (disease or hypertensi*)).tw,kf.	178768
13	(CKD or ESKD or Nephropath* or Nephritis).tw,kw.	122564
14	or/11-13	358892
15	Chronic Disease/	275718
16	(chronic adj5 (disease* or illness* or condition*)).tw,kf.	413833
17	or/15-16	626850
18	4 or 7 or 10 or 14 or 17	8330035
19	american native continental ancestry group/ or indians, north american/ or alaskan natives/ or indigenous canadians/ or inuits/ or oceanic ancestry group/	29921
20	(first nation or first-nation or first nations or first-nations or indigenous or first people*).tw,kf.	40544
21	(Aboriginal* or Torres Strait Islander or ATSI).tw,kf.	9977

22	(Kaurna or Adnyamathanha or Mula or Maralinga or Narungga or Ngaanyatjarra or Ngarrindjeri or Pitjantjatjara or Yolngu or Anangu or Yankunytjatjara or Arrernte or Aranda or Arunta or Arrarnta).tw,kf.	188
23	(Inuit* or Inupiat* or Metis* or Metis* or Kalaallit* or aleut* or eskimo* or Whenua* or Iwi*).tw,kf.	4859
24	(Maori* or Maori).tw,kf.	3968
25	Health Services, Indigenous/	3825
26	or/19-25	72484
27	delivery of health care/ or exp "delivery of health care, integrated"/ or health services accessibility/ or practice patterns, nurses'/ or practice patterns, physicians'/ or patient care team/ or nursing, team/	329851
28	exp patient care planning/ or primary health care/ or exp "continuity of patient care"/ or exp patient-centered care/ or case management/	439595
29	aftercare/ or hospital to home transition/ or patient discharge/ or patient handoff/ or patient transfer/ or retention in care/ or transition to adult care/ or transitional care/ or exp Rehabilitation/	392749
30	((Care* or service or healthcare or treatment or healthcare or Nurse* or physician or provider* or doctor* or nursing) adj5 (delivery or deliver* or continuity or continuum or transition* or retention or collaborative or intergrat* or team* or interdisciplinary or shared or transmural or transitional or seamless or manage* or follow-up or follow up or liaison or navigator or barrier* or obstacle* or challenge* or perspective* or perception* or facilitat* or enable* or access or implement* or collocation)).tw,kf.	687447
31	((patient* or hospital) adj2 (discharge* or hand off or hand-off or handoff or transition*)).tw,kf.	83885
32	((patient-center or patient-centre* or technolog*) adj2 (care* or health or healthcare or treatment)).tw,kf.	29368
33	(aftercare or rehababilitat* or prehababilitat* or pre-hababilitat* or Patient-held record* or shared notes or decision support*).tw,kf.	23693
34	((Multi agency or multi-agency or interagency or inter-agency or inter agency or multi professional or multi-professional or Interprofessional) adj5 (care* or health or healthcare or treatment)).tw,kf.	5381
35	((care* or case or clinical or clinic* or professional or functional or organisation* or organisation* or system* or interpersonal) adj2 (plan* or manage* or pathway* or network* or intergrat* or continuity or continuum or intergrat*)).tw,kf.	269934
36	or/27-35	1627166
37	18 and 26 and 36	2334

38	interviews as topic/ or focus groups/ or narration/ or exp qualitative research/	154576
39	((semi-structured or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide* or group*) adj3 (discussion* or questionnaire*)).tw,kf.	60168
40	(Interview* or focus group* or diary or diaries or transcrib* or verbatim or field not* or memo or memos or memoing).tw,kf.	529923
41	(audiotap* or audio-tap* or audio record* or audiorecord* or tape record* or taperecord* or video*).tw,kf.	169824
42	((context* or semantic or content) adj2 analys*).tw,kf.	44794
43	(narrat* or qualitative* or ethnograph* or fieldwork or field work or field research* or informant* or phenomenolog* or hermeneutic* or grounded or interpretive* or participant observ* or background observ* or reflective* or reflection* or textual* or open-ended or theme? or thematic* or triangulat*).tw,kf.	650133
44	px.fs.	1151827
45	((personal* or patient* or participant* or lived) adj2 (experience or experiences or perception* or perceptive or perspective*)).tw,kf.	113286
46	(mixed method* or mixed-method*).tw,kf.	33558
47	or/38-46	2206018
48	37 and 47	835
49	limit 48 to yr="2010 -Current"	657