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Quantification and visualization methods of data-driven chronic care delivery pathways: protocol for a systematic review

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Title

Quantification and visualization methods of data-driven chronic care delivery pathways: protocol for a systematic review

Corresponding author

Luiza Siqueira do Prado

luiza.siqueira-do-prado@univ-lyon1.fr

EA 7425 HESPER

Health Services and Performance Research

Université Claude Bernard Lyon 1

Domaine Rockefeller- 2eme étage (aile CD)

8 avenue Rockefeller

69373 Lyon 8

+33 (0) 7 83 45 23 66

Authors

Luiza Siqueira do Prado (luiza.siqueira-do-prado@univ-lyon1.fr)¹,

Samuel Allemann (s.allemann@unibas.ch)^{1,2},

Marie Viprey (marie.viprey@chu-lyon.fr)^{1,3},

Anne-Marie Schott (anne-marie.schott-pethelaz@chu-lyon.fr)^{1,3},

Dan Dediu (dan.dediu@univ-lyon2.fr)⁴,

Alexandra Dima (alexandra.dima@univ-lyon1.fr)¹

Affiliations

¹ EA 7425 Health Services and Performance Research HeSPeR – Université Claude Bernard Lyon 1, Lyon, France

² Pharmaceutical Care Research Group, Department of Pharmaceutical Sciences, University of Basel, Basel, Switzerland

³ Pôle de Santé Publique, Hospices Civils de Lyon, Lyon, France

⁴ Laboratoire Dynamique du Langage UMR 5596, Université Lumière Lyon 2, Lyon, France

Abstract

Introduction Chronic conditions require long periods of care and often involve repeated interactions with multiple healthcare providers. Faced with increasing illness burden and costs, healthcare systems are currently working towards integrated care to streamline these interactions and improve efficiency. To support this, one promising resource is the information on routine care delivery stored in various electronic healthcare databases (EHD). In chronic conditions, care delivery pathways (CDPs) can be constructed by linking multiple data sources and extracting time-stamped healthcare utilization events and other medical data related to individual or groups of patients over specific time periods; CDPs may provide insights into current practice and ways of improving it. Several methods

1
2
3 have been proposed in recent years to quantify and visualize CDPs. We present the protocol for a
4 systematic review aiming to describe the content and development of CDP methods, to derive
5 common recommendations for CDP construction.
6

7 **Methods and analysis** This protocol followed the Preferred Reporting Items for Systematic review
8 and Meta-Analysis Protocols (PRISMA-P). A literature search will be performed in PubMed
9 (MEDLINE), Scopus, IEEE, CINAHL and EMBASE, without date restrictions, to review published papers
10 reporting data-driven chronic CDPs quantification and visualization methods. We will describe them
11 using several characteristics relevant for EHD use in long-term care, grouped into three domains: 1)
12 clinical (what health-related events it includes and for what clinical aims?), 2) data science (how is
13 the method developed and what data infrastructure it relies on?), and 3) behavioral (what behaviors
14 and interactions does it promote in users and through what methods?). Data extraction will be
15 performed via deductive content analysis using previously defined characteristics and accompanied
16 by an inductive analysis to identify and code additional relevant features. Results will be presented in
17 descriptive format and used to compare current CDPs and generate recommendations for future CDP
18 development initiatives.
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20
21

22 **Ethics and dissemination** Ethical approval is not required for this review. Results will be disseminated
23 in peer-reviewed journals and conference presentations.
24

25 **PROSPERO registration** pending approval
26

27 **Keywords** clinical decision support systems; medical informatics application; data visualization;
28 clinical pathway; delivery of health care, integrated; electronic healthcare databases.
29

30 **Word count** 2612
31

32 **Strengths and Limitations**

- 33 • While most reviews of health technology tools focus on clinical objectives and technical
34 characteristics, we will also consider behaviours of and interactions between users to
35 describe the selected methods.
- 36 • We will perform both deductive and inductive content analysis to fully describe the methods.
- 37 • We will focus on methods described in peer-reviewed papers and exclude conference
38 proceedings and other types of reports, to obtain detailed validated descriptions; this may
39 limit our access to more recent studies due to the fast-paced development in the field.
- 40 • Lack of completeness in methods descriptions may limit our ability to assess all
41 characteristics, such as the stages of development, the involvement of stakeholders or
42 experts prior to data acquisition and analysis.
- 43 • As this is a relatively new field of health technology, there are no guidelines for reporting and
44 no consensus on quality criteria for the studies we will evaluate; our work will also contribute
45 to the development of such recommendations.
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51 **Introduction**

52 Effective delivery of integrated care is a priority for healthcare systems worldwide and has been the
53 focus of considerable efforts in recent years, particularly in response to the increasing demands of
54 chronic care^{1,2}. Long-term conditions may require lifetime care, which may consist of multiple
55 interactions with a variety of healthcare providers at variable time intervals^{3,4}. When service delivery
56 is fragmented, the overall effectiveness of these interactions in terms of long-term quality of life and
57 health-related outcomes is reduced, and risk of harm is increased^{5,6}. Centralizing patient information
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3 produced by different providers in electronic healthcare databases (EHD) has the potential to help
4 implementing new ways of service delivery to improve outcomes⁷. Several attempts have been made
5 to link multiple data sources to generate comprehensive descriptions of patients' healthcare
6 journeys in long-term conditions. These descriptions are produced by constructing longitudinal
7 trajectories from various time-stamped healthcare utilization events and related medical data⁸⁻¹³.
8 However, generating informative trajectories from disparate and often incompatible data sources
9 proves challenging¹⁴. As various initiatives have been developed independently, with distinct
10 methodologies and objectives, it is essential to examine systematically the proposed solutions in
11 order to derive principles of action to stimulate convergence of methods.
12
13

14
15 In the context of chronic conditions, the way patient trajectories are established may be subject to
16 multiple influences and analyzing routine care data can provide insights on how they have been
17 drawn over time and their potential sources of variation^{15,16}. In the literature, trajectories within
18 healthcare systems have been described using many terms, which makes it challenging to build
19 consensus on terminology and practical meaning^{17,18}. We will use the term data-driven 'care delivery
20 pathway' (CDP) to group several terms we will find in the selected studies to designate retrospective
21 trajectories obtained from EHD. To describe the methods proposed for quantifying and visualizing
22 chronic CDP, we will assess how they addressed three domains:
23
24

25 1) The selection of relevant clinical and health-related events.

26
27 This domain will examine how the methods define health status and evaluate disease progression or
28 stabilization, and how they show transitions between health status and acute manifestations¹³.
29 Usually, the trajectory timeline begins at diagnosis and involves more than one provider^{13,16,19}.
30 Treatment decisions are generally based on health status (indicated by biomarkers, clinical
31 examination, self-declared levels of quality of life, etc.), care units and settings, treatment availability
32 (medication, procedures, etc.), and patient-provider preferences¹⁵.
33
34

35 2) The technological development itself and considering issues related to data quality and
36 exchange.

37
38 This domain aims to describe how the method is built, which data sources and analyses are used, and
39 the necessary infrastructure surrounding its implementation. Digitalization of health-related data is a
40 global trend^{20,21} and highly detailed data are being collected daily in diverse settings and healthcare
41 services. Such methods may apply a range of techniques from basic algorithms to advanced statistical
42 and machine learning models²², which can provide useful insights into care delivery processes.
43 Technological developments in this field also need to meet strict criteria of data security, accuracy of
44 models and predictions, openness of development and validation processes, among others^{19,23}.
45
46

47 3) Considering behaviours of actors and interactions between them with the aim of effectively
48 improving care delivery.

49
50 Integrated care depends on multiple actions and decisions made collaboratively by patients,
51 healthcare providers, administrative staff and other actors concerning patients' course of
52 treatment²⁴. To inform these decisions, technological solutions must have access to clinical exams
53 and provide key actors with relevant information, such as the patients' past interactions with other
54 providers, the medical procedures performed, the medications prescribed²⁵. To have a positive
55 impact on improving care delivery, visualizations and quantitative indicators of the patient's prior
56 care need to be adapted to the user's needs at specific points in the trajectory, like after acute events
57 or hospitalizations. This domain will examine what behaviors and interactions the tools promote
58
59
60

(who are its target individuals, what actions need to be performed, in what context, when, and by whom)²⁶, and what strategies are proposed to encourage this performance.

Aims and objectives

We propose a systematic review of the methods to quantify and visualize data-driven chronic CDP. Given the complexity of their context of use, more than only reviewing technical methods, we aim to investigate how these tools have considered the three domains described above: how they have considered relevant clinical aspects, how they have addressed key technical challenges, and what behaviours and interactions they promote or facilitate between different providers in the context of chronic conditions and how. We will mix deductive and inductive content analysis²⁷ to appraise the selected studies: deductive when relying on pre-defined frameworks such as the categories previously described by Moreno-Conde et al. (2015)²⁸ (to describe the technical characteristics of the proposed solutions) and on the TACTA²⁶ (Target, Action, Context, Time, Actor, to describe the behavioural domain) and inductive when additional relevant characteristics need to be described.

For this end, we propose the following research questions:

Primary research question

1. What methods have been proposed to quantify and/or visualize data-driven CPDs of people living with chronic conditions?

Secondary research questions

2. What are the clinical aims of the method and what type of clinical information does it use?
3. How was the method developed and what data infrastructure does it relies on?
4. Which behaviours and interactions do they aim to promote among users and how?

Methods

The Cochrane Handbook²⁹ and the Preferred Reporting Items for Systematic review and Meta-Analysis Protocols (PRISMA-P)³⁰ were used to write this protocol and the systematic review will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)³¹. The review will be performed by one primary reviewer (LSP) and three secondary reviewers (AD, MV and SA) and will follow 6 steps: literature search, records screening and pre-selection (title and abstract), full-text screening and final selection, extraction of data, quality assessment, analysis and synthesis of data.

The studies expected to be analyzed in this work will likely be descriptive and not follow standard methodology (i.e., experimental or observational, method validation), yet considering the manuscripts as a qualitative corpus allows for coding the narratives according to the conceptual structure we propose^{7,28}. Content analysis has been used in many studies in health sciences²⁷ and an inductive content analysis applied in a systematic review of clinical information modeling processes²⁸ has developed descriptive categories in a context similar to the one we propose here. As we consider them relevant to the studies we will review, they will be included in our coding framework, as detailed below.

We will consider CDPs to be a series of time-stamped events describing the sequence of care of users with a diagnosed chronic condition (conditions requiring medical attention for a period longer than 12 months). These events can be the diagnosis itself, routine, non-scheduled or emergency consultations with a general practitioner and/or specialist, therapeutic education sessions and other

1
2
3 health-related interventions. These can result in prescriptions of medications, medical procedures
4 and tests, which may also appear in the trajectory.
5

6 Searches

7
8 A literature search will be performed in the following electronic databases: PubMed (MEDLINE),
9 Scopus, IEEE, CINAHL and EMBASE. The search will be adapted to each database, and the resulting
10 search strategies are provided as supplementary material. The terms searched will be related to
11 three main categories, connected by the AND operator: “data-driven” (MeSH terms like “Electronic
12 health record”, “data mining”, etc.), “clinical pathways” (MeSH terms like “clinical pathway”, “disease
13 management”, etc.), and “chronic conditions” (MeSH term “chronic diseases”). Searches will be
14 performed with MeSH terms or with keywords in Title/Abstract in PubMed; MeSH terms will be
15 adapted for the databases that do not permit their usage or use different indexed terms.
16 Bibliographies and citation tracking of relevant literature will be hand searched to identify additional
17 relevant studies. A first selection will be performed using abstracts and titles, followed by full-text
18 examination of entries selected.
19
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21

22 Types of publications/studies and eligibility criteria

23
24 We will consider peer-reviewed publications (1) reporting methods for visualization or quantification
25 of data-driven chronic CDP (including protocols and reports of study results), (2) using data from
26 people living with chronic conditions retrieved from EHD and (3) published in English. No restrictions
27 on publication date, study design, population characteristics, type of healthcare facility and level of
28 care will be applied.
29

30
31 Data-driven CDP analyzed here will need to be composed of at least two time-stamped events
32 recorded in EHD from people with the diagnosis of a chronic condition, with no duration restrictions
33 (e.g., CDP may cover periods from days or few months to several years).
34

35
36 We will exclude studies that do not mention population or data characteristics or do not state they
37 analyze data from people living with chronic conditions, papers with full-text not written in English,
38 conference abstracts, systematic or narrative reviews, meta-analyses and grey literature.
39

40 Screening

41
42 We will use Covidence, an online systematic review management software, for records screening.
43 After duplicates removal, titles and abstracts in the remaining records will be screened
44 independently by two reviewers for full text appraisal. If reviewer discordance arises, consensus will
45 be reached through discussion and arbitration with one of the secondary reviewers not involved in
46 the selection of the record. Studies selected in the first step will go through full text screening using
47 the same process to establish eligibility. Inter-rater reliability (Cohen’s Kappa) between primary and
48 secondary reviewers will be computed after title and abstract and full text screening and reported.
49

50 Data management

51
52 We will report the number of included and excluded articles as well as the number of full-text papers
53 obtained and assessed. Reasons for exclusion of screened full-text studies will also be stated in the
54 final review. The data will be managed using Covidence and Microsoft Excel spreadsheets.
55

56 Data extraction

57
58 Data from included studies will be extracted using a customized electronic data extraction form.
59 Information on study characteristics (authors, title, type of study, year and country of study,
60

1
2
3 objective and research questions); population characteristics (number of patients, age, gender,
4 condition) will be extracted directly from the included studies.
5

6 *Deductive-Inductive content analysis*

7
8 We will perform a deductive content analysis following existing theories, as described below, and
9 inductive analysis for observed relevant characteristics not yet covered by existing literature. If more
10 than one selected record describe development, validation and/or implementation of the same
11 method, we will extract basic paper characteristics, as described above, but the content analysis will
12 be performed per method.
13

14 1) For the clinical domain, we will extract information on clinical or cost outcomes the studies might
15 target (if reported and which ones) and on how the outcomes were considered relevant (e.g.,
16 involving experts, final users or other stakeholders).
17

18 2) For method development and data processing, we will analyze and compare to what has been
19 proposed by Moreno-Conde et al. (2015)²⁸. The categories detailed in the study are described below.
20

- 21 • Scope definition leading to selection of the domain and selecting relevant experts
- 22 • Analysis of the information covered in the specific domain
- 23 • Design of the tool
- 24 • Definition of implementable tool specifications
- 25 • Validation
- 26 • Publishing and maintenance
- 27 • Governance

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30
31 Other information extracted from studies regarding this domain will be healthcare utilization
32 characteristics (type of event, e.g., consultation, test, procedure) and data characteristics (sources of
33 data, data preparation, data analysis).
34

35 3) To describe behaviour and interactions the method might promote or facilitate, we will apply the
36 TACTA²⁶ (Target, Action, Context, Time, Actor) framework. Other information extracted from studies
37 will be output characteristics like intended final users, purpose and use scenarios. We will also code
38 the presence of strategies planned or performed to achieve these behavioural change objectives,
39 such as training, organizational changes, evaluation of the performance of the method in routine
40 care, if implemented, and other initiatives studies might present.
41

42
43 The primary reviewer and one secondary reviewer will pilot data extraction independently for a
44 subset of 10% of selected records to compare and discuss data extraction process. If necessary, we
45 will repeat the pilot extraction process (outlined above) until agreement is reached. Disagreements
46 will be solved with the help of a third reviewer and piloting may consist of several interactions
47 between reviewers to compare and reach consensus regarding relevant information to be extracted
48 from full-text analysis. After this first step, a codebook will be developed, and data extraction of the
49 remaining records will be performed by the primary reviewer.
50
51

52 **Quality and bias assessment**

53
54 As most quality assessment tools are developed for commonly-used study designs and there is no
55 consensus regarding tools for generic use, we propose to evaluate quality from a different
56 perspective. We will evaluate if main stakeholders (patients and/or family, healthcare professionals,
57 administrative personnel) were involved at any stage of the development of the method. Research
58 shows the importance of involving patients, the public and other stakeholders in health-related
59 research to obtain experiential knowledge, setting research priorities and focus on practical
60

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3 questions^{32–35}. Also, it has been shown that trials funded by for-profit organizations can positively
4 bias interpretation of trial results³⁶, and research in data usage can be funded by companies
5 interested in selling their own methods. To assess potential bias, we will evaluate declared conflicts
6 of interest and sources of funding. Quality assessment will be discussed in the review, but no study
7 will be excluded from the analysis based on quality criteria.
8

9 10 Data analysis and synthesis

11 The technical methods will be synthesized using the content analysis described above and the studies
12 will be categorized and described using the 3 domains, depending on study type and reporting. We
13 will present it in tables along with study identification. We will compare the different characteristics
14 within the 3 domains to identify common, infrequent, or missing features of these tools, and extract
15 recommendations for future initiatives.
16

17 18 Patient and public involvement

19 A representative of a patients' association was involved in reading and approving of this protocol.
20 This protocol of a systematic review is part of a larger project that will be developed closely with
21 patients and healthcare providers.
22

23 24 Ethics and dissemination

25 Ethical approval is not required. Results will be disseminated in peer-reviewed journals and/or
26 conference presentations. Data used in this review will be made available through supplementary
27 materials and open trusted repositories.
28

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34 the Swiss Science Foundation (P2BSP3_ 178648).
35

36 37 Conflicts of interest

38 None declared.
39

40 41 Author statement

42 LSP, AD and SA designed the protocol and planned data extraction and quality assessment. LSP put
43 together the search strategy and SA helped adapt it to the different databases. LSP and AD conceived
44 the content analysis stages and conceptual framework. LSP wrote the first version of the manuscript,
45 AD extensively reviewed it, SA, DD, AMS and MV revised it critically for important intellectual
46 content. All authors have approved the publication of this protocol and contributed to the final
47 manuscript.
48

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53

54 55 References

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COMPLETE SEARCH STRATEGY

Category	Medical Subject headings (MeSH)	CINAHL Search	EMBASE	Keywords
Data-driven	Electronic health record; data mining; machine learning; clinical decision support systems; analysis, cluster; medical informatics application	MH Electronic Health Records OR MH Data Mining OR MH Nursing Informatics OR MH Machine Learning OR MH Decision Support Systems, Clinical OR MH Cluster Analysis OR MH Medical Informatics OR MH Computer Graphics OR MH Algorithms OR TI Data-driven OR TI visualisation OR TI computer graphics OR TI process mining OR TI data mining OR TI visualization OR TI supervised learning OR TI unsupervised learning OR TI practice based OR TI modelling OR TI mapping OR TI cluster* OR TI data analys* OR AB Data-driven OR AB visualisation OR AB computer graphics OR AB process mining OR AB data mining OR AB visualization OR AB supervised learning	(Electronic health record or data mining or machine learning or clinical decision support systems or analysis, cluster or medical informatics application).sh. or (Data-driven or visualisation or computer graphics or process mining or data mining or visualization or supervised learning or unsupervised learning or practice based or modelling or mapping or cluster* or data analys*).ti. or (Data-driven or visualisation or computer graphics or process mining or data mining or visualization or supervised learning or unsupervised learning or practice based or modelling or mapping or cluster* or data analys*).ab.	Data-driven OR visualisation OR computer graphics OR process mining OR data mining OR visualization OR supervised learning OR unsupervised learning OR practice based OR modelling OR mapping OR cluster* OR data analys*

		<p>OR AB unsupervised learning OR AB practice based OR AB modelling OR AB mapping OR AB cluster* OR AB data analys*</p>		
<p>Clinical pathways</p>	<p>Clinical pathways; delivery of health care, integrated; clinical practice pattern; disease management; care management, patient</p>	<p>MH Critical Path OR MH Health Care Delivery, Integrated OR MH Practice Patterns OR MH Disease Management OR MH Patient Care Plans OR TI Clinical course OR TI integrated care OR TI care map OR TI care pathway OR TI care plan OR TI treatment plan OR TI patient journey OR TI patient flow OR TI clinical redesign OR TI integrated care OR AB Clinical course OR AB integrated care OR AB care map OR AB care pathway OR AB care plan OR AB treatment plan OR AB patient journey OR AB patient flow OR AB clinical redesign OR AB integrated care</p>	<p>(Clinical pathways or delivery of health care, integrated or clinical practice pattern or disease management or care management, patient).sh. or (Clinical course or integrated care or care map or care pathway or care plan or treatment plan or patient journey or patient flow or clinical redesign or integrated care).ti. or (Clinical course or integrated care or care map or care pathway or care plan or treatment plan or patient journey or patient flow or clinical redesign or integrated care).ab.</p>	<p>Clinical course OR integrated care OR care map OR care pathway OR care plan OR treatment plan OR patient journey OR patient flow OR clinical redesign OR integrated care</p>

Chronic conditions	Chronic diseases; chronic illness	MH Chronic Disease OR TI Integrated chronic care OR AB Integrated chronic care		Integrated chronic care
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EQUATIONS

MEDLINE

((data-driven[Title/Abstract] OR health information[Title/Abstract] OR data analys*[Title/Abstract] OR computer graphics[MeSH Terms] OR visualization[Title/Abstract] OR machine learning[MeSH Terms] OR data mining[MeSH Terms] OR clinical decision support systems[MeSH Terms] OR medical informatics application[MeSH Terms] OR algorithm[MeSH Terms] OR supervised learning[Title/Abstract] OR unsupervised learning[Title/Abstract] OR analysis, cluster[MeSH Terms] OR practice-based[Title/Abstract] OR electronic health record[MeSH Terms] OR clinical decision support systems[Title/Abstract] OR process mining[Title/Abstract] OR data mining [Title/Abstract] OR machine learning [Title/Abstract] OR medical informatics application[Title/Abstract] OR cluster*[Title/Abstract] OR modeling[Title/Abstract] OR mapping[Title/Abstract]))

AND

(chronic diseases[MeSH Terms] OR chronic illness[MeSH Terms] OR integrated chronic care[Title/Abstract])

AND

(delivery of health care, integrated[MeSH Terms] OR clinical practice pattern[MeSH Terms] OR clinical pathway[MeSH Terms] OR critical pathway[MeSH Terms] OR clinical course[Title/Abstract] OR integrated care[Title/Abstract] OR care map[Title/Abstract] OR care pathway[Title/Abstract] OR care plan[Title/Abstract] OR treatment plan[Title/Abstract] OR disease management[MeSH Terms] OR disease management[Title/Abstract] OR care management, patient[MeSH Terms] OR patient journey[Title/Abstract] OR patient flow[Title/Abstract] OR clinical redesign[Title/Abstract] OR integrated care[Title/Abstract]))

SCOPUS

(TITLE-ABS-KEY("data-driven") OR TITLE-ABS-KEY("health information") OR TITLE-ABS-KEY("data analys*") OR INDEXTERMS("computer graphics") OR TITLE-ABS-KEY("visuali*ation") OR INDEXTERMS("machine learning") OR INDEXTERMS("data mining") OR INDEXTERMS("clinical decision support systems") OR INDEXTERMS("medical informatics application") OR INDEXTERMS("algorithm") OR TITLE-ABS-KEY("supervised learning") OR TITLE-ABS-KEY("unsupervised learning") OR INDEXTERMS("cluster analysis") OR INDEXTERMS("practice-based") OR INDEXTERMS("electronic health record") OR TITLE-ABS-KEY("clinical decision support systems") OR TITLE-ABS-KEY("process mining") OR TITLE-ABS-KEY("data mining") OR TITLE-ABS-KEY("machine learning") OR TITLE-ABS-KEY("medical informatics application") OR TITLE-ABS-KEY(cluster*) OR TITLE-ABS-KEY("modelling") OR TITLE-ABS-KEY("mapping"))

AND (INDEXTERMS("chronic diseases") OR INDEXTERMS("chronic illness") OR TITLE-ABS-KEY("integrated chronic care"))

AND (INDEXTERMS("integrated delivery of health care") OR TITLE-ABS-KEY("clinical practice pattern") OR INDEXTERMS("clinical pathway") OR INDEXTERMS("critical pathway") OR TITLE-ABS-KEY("clinical course") OR TITLE-ABS-KEY("integrated care") OR TITLE-ABS-KEY("care map") OR TITLE-ABS-KEY("care pathway") OR TITLE-ABS-KEY("care plan") OR TITLE-ABS-KEY("treatment plan") OR INDEXTERMS("disease management") OR TITLE-ABS-KEY("disease management") OR INDEXTERMS("patient care management") OR TITLE-ABS-KEY("patient journey") OR TITLE-ABS-KEY("patient flow") OR TITLE-ABS-KEY("clinical redesign") OR TITLE-ABS-KEY("integrated care"))

IEEE

((((((((((((((((((((((((((("Index Terms":electronic health records) OR "Index Terms":data mining) OR "Index Terms":machine learning) OR "Index Terms":clinical decision support systems) OR "Index Terms":cluster analysis) OR "Index Terms":medical informatics) OR "Index Terms":computer graphics) OR "Index Terms":algorithm) OR "IEEE Terms":medical information systems) OR "IEEE Terms":electronic medical records) OR "Author Keywords":healthcare practices) OR "Publication Title":data-driven) OR "Abstract":data-driven) OR "Publication Title":machine learning) OR "Abstract":machine learning) OR "Publication Title":cluster analys*) OR "Abstract":cluster analys*) OR "Publication Title":data mining) OR "Abstract":data mining) OR "Author Keywords":electronic health record) OR "IEEE Terms":Guidelines) OR "IEEE Terms":Data mining) OR "IEEE Terms":Algorithm design and analysis) OR data mining) OR data-driven) OR electronic health record) OR algorithm) OR visualization) OR clustering) OR algorithm)

AND (((((((((((("Index Terms":clinical pathway) OR "Publication Title":clinical pathway) OR "Abstract":clinical pathway) OR "Author Keywords ":clinical pathway) OR "Author Keywords":healthcare practices) OR "Author Keywords ":Pathway) OR clinical path*) OR care pattern) OR care plan) OR care map) OR critical path*)

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AND (((("Index Terms":chronic disease) OR "Publication Title":chronic disease) OR "Abstract":chronic disease) OR "IEEE Terms":Diseases)
OR chronic*)

For peer review only

Reporting checklist for protocol of a systematic review.

Based on the PRISMA-P guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the PRISMA-P reporting guidelines, and cite them as:

Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart LA. Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement. Syst Rev. 2015;4(1):1.

			Page
		Reporting Item	Number
Title			
Identification	#1a	Identify the report as a protocol of a systematic review	1
Update	#1b	If the protocol is for an update of a previous systematic review, identify as such	n/a

1 **Registration**

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4 [#2](#) If registered, provide the name of the registry (such as 1

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6 PROSPERO) and registration number

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10 **Authors**

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13 **Contact** [#3a](#) Provide name, institutional affiliation, e-mail address of all 1

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15 protocol authors; provide physical mailing address of

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17 corresponding author

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20 **Contribution** [#3b](#) Describe contributions of protocol authors and identify the 7

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22 guarantor of the review

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26 **Amendments**

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29 [#4](#) If the protocol represents an amendment of a previously n/a

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31 completed or published protocol, identify as such and list

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33 changes; otherwise, state plan for documenting important

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35 protocol amendments

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39 **Support**

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42 **Sources** [#5a](#) Indicate sources of financial or other support for the review 7

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45 **Sponsor** [#5b](#) Provide name for the review funder and / or sponsor 7

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48 **Role of sponsor or** [#5c](#) Describe roles of funder(s), sponsor(s), and / or institution(s), n/a

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50 funder

51 if any, in developing the protocol

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54 **Introduction**

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57 **Rationale** [#6](#) Describe the rationale for the review in the context of what is 2,3

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1		already known	
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4	Objectives	#7 Provide an explicit statement of the question(s) the review will	4
5		address with reference to participants, interventions,	
6		comparators, and outcomes (PICO)	
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11	Methods		
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14	Eligibility criteria	#8 Specify the study characteristics (such as PICO, study design,	4,5
15		setting, time frame) and report characteristics (such as years	
16		considered, language, publication status) to be used as	
17		criteria for eligibility for the review	
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24	Information	#9 Describe all intended information sources (such as electronic	4
25		databases, contact with study authors, trial registers or other	
26	sources	grey literature sources) with planned dates of coverage	
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32	Search strategy	#10 Present draft of search strategy to be used for at least one	4
33		electronic database, including planned limits, such that it	
34		could be repeated	
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39	Study records -	#11a Describe the mechanism(s) that will be used to manage	5
40		records and data throughout the review	
41	data management		
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45	Study records -	#11b State the process that will be used for selecting studies (such	5
46		as two independent reviewers) through each phase of the	
47	selection process	review (that is, screening, eligibility and inclusion in meta-	
48		analysis)	
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54	Study records -	#11c Describe planned method of extracting data from reports	5,6
55		(such as piloting forms, done independently, in duplicate), any	
56	data collection		
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1	process		processes for obtaining and confirming data from investigators	
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4	Data items	#12	List and define all variables for which data will be sought	5,6
5			(such as PICO items, funding sources), any pre-planned data	
6			assumptions and simplifications	
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11	Outcomes and	#13	List and define all outcomes for which data will be sought,	n/a
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13	prioritization		including prioritization of main and additional outcomes, with	
14			rationale	
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19	Risk of bias in	#14	Describe anticipated methods for assessing risk of bias of	6
20				
21	individual studies		individual studies, including whether this will be done at the	
22			outcome or study level, or both; state how this information will	
23			be used in data synthesis	
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29	Data synthesis	#15a	Describe criteria under which study data will be quantitatively	6
30			synthesised	
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34	Data synthesis	#15b	If data are appropriate for quantitative synthesis, describe	n/a
35			planned summary measures, methods of handling data and	
36			methods of combining data from studies, including any	
37			planned exploration of consistency (such as I ² , Kendall's τ)	
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44	Data synthesis	#15c	Describe any proposed additional analyses (such as	n/a
45			sensitivity or subgroup analyses, meta-regression)	
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49	Data synthesis	#15d	If quantitative synthesis is not appropriate, describe the type	n/a
50			of summary planned	
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54	Meta-bias(es)	#16	Specify any planned assessment of meta-bias(es) (such as	n/a
55			publication bias across studies, selective reporting within	
56				
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1 studies)

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4 Confidence in [#17](#) Describe how the strength of the body of evidence will be n/a
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6 cumulative assessed (such as GRADE)
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8 evidence
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15 tool made by the [EQUATOR Network](#) in collaboration with [Penelope.ai](#)
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BMJ Open

Quantification and visualization methods of data-driven chronic care delivery pathways: protocol for a systematic review

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Primary Subject Heading:	Health informatics
Secondary Subject Heading:	Health services research, Public health
Keywords:	clinical decision support systems, medical informatics application, data visualization, clinical pathway, delivery of health care, integrated, electronic healthcare databases

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Title

Quantification and visualization methods of data-driven chronic care delivery pathways: protocol for a systematic review

Corresponding author

Luiza Siqueira do Prado

luiza.siqueira-do-prado@univ-lyon1.fr

EA 7425 HESPER

Health Services and Performance Research

Université Claude Bernard Lyon 1

Domaine Rockefeller- 2eme étage (aile CD)

8 avenue Rockefeller

69373 Lyon 8

+33 (0) 7 83 45 23 66

Authors

Luiza Siqueira do Prado (luiza.siqueira-do-prado@univ-lyon1.fr)¹,

Samuel Allemann (s.allemann@unibas.ch)^{1,2},

Marie Viprey (marie.viprey@chu-lyon.fr)^{1,3},

Anne-Marie Schott (anne-marie.schott-pethelaz@chu-lyon.fr)^{1,3},

Dan Dediu (dan.dediu@univ-lyon2.fr)⁴,

Alexandra Dima (alexandra.dima@univ-lyon1.fr)¹

Affiliations

¹ EA 7425 Health Services and Performance Research HeSPeR – Université Claude Bernard Lyon 1, Lyon, France

² Pharmaceutical Care Research Group, Department of Pharmaceutical Sciences, University of Basel, Basel, Switzerland

³ Pôle de Santé Publique, Hospices Civils de Lyon, Lyon, France

⁴ Laboratoire Dynamique du Langage UMR 5596, Université Lumière Lyon 2, Lyon, France

Abstract

Introduction Chronic conditions require long periods of care and often involve repeated interactions with multiple healthcare providers. Faced with increasing illness burden and costs, healthcare systems are currently working towards integrated care to streamline these interactions and improve efficiency. To support this, one promising resource is the information on routine care delivery stored in various electronic healthcare databases (EHD). In chronic conditions, care delivery pathways (CDPs) can be constructed by linking multiple data sources and extracting time-stamped healthcare utilization events and other medical data related to individual or groups of patients over specific time periods; CDPs may provide insights into current practice and ways of improving it. Several methods

1
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3 have been proposed in recent years to quantify and visualize CDPs. We present the protocol for a
4 systematic review aiming to describe the content and development of CDP methods, to derive
5 common recommendations for CDP construction.
6

7 **Methods and analysis** This protocol followed the Preferred Reporting Items for Systematic review
8 and Meta-Analysis Protocols (PRISMA-P). A literature search will be performed in PubMed
9 (MEDLINE), Scopus, IEEE, CINAHL and EMBASE, without date restrictions, to review published papers
10 reporting data-driven chronic CDPs quantification and visualization methods. We will describe them
11 using several characteristics relevant for EHD use in long-term care, grouped into three domains: 1)
12 clinical (what health-related events it includes and for what clinical aims?), 2) data science (how is
13 the method developed and what data infrastructure it relies on?), and 3) behavioral (what behaviors
14 and interactions does it promote in users and through what methods?). Data extraction will be
15 performed via deductive content analysis using previously defined characteristics and accompanied
16 by an inductive analysis to identify and code additional relevant features. Results will be presented in
17 descriptive format and used to compare current CDPs and generate recommendations for future CDP
18 development initiatives.
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22 **Ethics and dissemination** Ethical approval is not required for this review. Results will be disseminated
23 in peer-reviewed journals and conference presentations.
24

25 **PROSPERO registration** CRD42019140494
26

27 **Keywords** clinical decision support systems; medical informatics application; data visualization;
28 clinical pathway; delivery of health care, integrated; electronic healthcare databases.
29

30 **Word count** 2612
31

32 **Strengths and Limitations**

- 33 • While most reviews of health technology tools focus on clinical objectives and technical
34 characteristics, we will also consider behaviours of and interactions between users to
35 describe the selected methods.
- 36 • We will perform both deductive and inductive content analysis to fully describe the methods.
- 37 • We will focus on methods described in peer-reviewed papers and exclude conference
38 proceedings and other types of reports, to obtain detailed validated descriptions; this may
39 limit our access to more recent studies due to the fast-paced development in the field.
- 40 • Lack of completeness in methods descriptions may limit our ability to assess all
41 characteristics, such as the stages of development, the involvement of stakeholders or
42 experts prior to data acquisition and analysis.
- 43 • As this is a relatively new field of health technology, there are no guidelines for reporting and
44 no consensus on quality criteria for the studies we will evaluate; our work will also contribute
45 to the development of such recommendations.
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51 **Introduction**

52 Effective delivery of integrated care is a priority for healthcare systems worldwide and has been the
53 focus of considerable efforts in recent years, particularly in response to the increasing demands of
54 chronic care^{1,2}. Long-term conditions may require lifetime care, which may consist of multiple
55 interactions with a variety of healthcare providers at variable time intervals^{3,4}. When service delivery
56 is fragmented, the overall effectiveness of these interactions in terms of long-term quality of life and
57 health-related outcomes is reduced, and risk of harm is increased^{5,6}. Centralizing patient information
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3 produced by different providers in electronic healthcare databases (EHD) has the potential to help
4 implementing new ways of service delivery to improve outcomes⁷. Several attempts have been made
5 to link multiple data sources to generate comprehensive descriptions of patients' healthcare
6 journeys in long-term conditions. These descriptions are produced by constructing longitudinal
7 trajectories from various time-stamped healthcare utilization events and related medical data⁸⁻¹⁷. For
8 example, Zhang et al. have produced longitudinal trajectories using electronic health records (EHR)
9 and cost pathways^{14,16,17} of people living with chronic kidney disease to inform patient engagement
10 and to detect common pathways. Bettencourt-Silva et al. (2015) have reported on the development
11 of a patient-centric database from multiple Hospital Information Systems (HIS)¹⁸ and on building
12 data-driven pathways from routine hospital data on people living with prostate cancer to explore
13 their potential use in biomedical research¹⁵. However, generating these informative trajectories from
14 disparate and often incompatible data sources proves challenging^{18,19}. As various initiatives have
15 been developed independently, with distinct methodologies and objectives, it is essential to examine
16 systematically the proposed solutions in order to derive principles of action to stimulate convergence
17 of methods.
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22 In the context of chronic conditions, the way patient trajectories are established may be subject to
23 multiple influences and analyzing routine care data can provide insights on how they have been
24 drawn over time and their potential sources of variation^{14,20}. In the literature, trajectories within
25 healthcare systems have been described using many terms, which makes it challenging to build
26 consensus on terminology and practical meaning^{21,22}. We will use the term data-driven 'care delivery
27 pathway' (CDP) to group several terms we will find in the selected studies to designate retrospective
28 trajectories obtained from EHD. To describe the methods proposed for synthetically displaying
29 objective measures or assessments of health status or healthcare utilization (e.g., quantifying) and
30 graphically showing the temporal elements of chronic CDP (e.g., visualizing), we will assess how they
31 addressed three domains:
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34

35 1) The selection of relevant clinical and health-related events.

36 This domain will examine how the methods define health status and evaluate disease progression or
37 stabilization, and how they show transitions between health status and acute manifestations¹³.
38 Usually, the trajectory timeline begins at diagnosis and involves more than one provider¹³⁻¹⁵.
39 Treatment decisions are generally based on health status (indicated by biomarkers, clinical
40 examination, self-declared levels of quality of life, etc.), care units and settings, treatment availability
41 (medication, procedures, etc.), and patient-provider preferences²⁰.
42
43

44 2) The technological development itself and considering issues related to data quality and
45 exchange.

46 This domain aims to describe how the method is built, which data sources and analyses are used, and
47 the necessary infrastructure surrounding its implementation. Digitalization of health-related data is a
48 global trend^{23,24} and highly detailed data are being collected daily in diverse settings and healthcare
49 services. Such methods may apply a range of techniques from basic algorithms to advanced statistical
50 and machine learning models²⁵, which can provide useful insights into care delivery processes.
51 Technological developments in this field also need to meet strict criteria of data security, accuracy of
52 models and predictions, openness of development and validation processes, among others^{15,26}.
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56 3) Considering behaviours of actors and interactions between them with the aim of effectively
57 improving care delivery.
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3 Integrated care depends on multiple actions and decisions made collaboratively by patients,
4 healthcare providers, administrative staff and other actors concerning patients' course of
5 treatment²⁷. To inform these decisions, technological solutions must have access to clinical exams
6 and provide key actors with relevant information, such as the patients' past interactions with other
7 providers, the medical procedures performed, the medications prescribed²⁸. To have a positive
8 impact on improving care delivery, visualizations and quantitative indicators of the patient's prior
9 care need to be adapted to the user's needs at specific points in the trajectory, like after acute events
10 or hospitalizations. This domain will examine what behaviors and interactions the methods promote
11 (who are its target individuals, what actions need to be performed, in what context, when, and by
12 whom)^{29,30}, and what strategies are proposed to encourage this performance.
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16 Aims and objectives

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18 We aim to identify and describe the methods that have been proposed to quantify and/or visualize
19 data-driven CPDs of people living with chronic conditions. Given the complexity of their context of
20 use, more than only reviewing technical methods, we aim to investigate how these tools have
21 considered the three domains described above.
22

23 For this end, we propose the following research questions:

- 24 1. What clinical information does the method use and how was it considered relevant?
 - 25 2. What are the method's development and implementation characteristics?
 - 26 3. Which behaviours and interactions does the method aim to promote among users and how?
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31 Methods

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33 The Cochrane Handbook³¹ and the Preferred Reporting Items for Systematic review and Meta-
34 Analysis Protocols (PRISMA-P)³² were used to write this protocol and the systematic review will
35 follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)³³. PRISMA-
36 P checklist is in Supplementary File 1. The review will be performed by one primary reviewer (LSP)
37 and three secondary reviewers (AD, MV and SA) and will follow 6 steps: literature search, records
38 screening and pre-selection (title and abstract), full-text screening and final selection, extraction of
39 data, quality assessment, analysis and synthesis of data.
40
41

42 The studies expected to be analyzed in this work will likely be descriptive and not follow standard
43 methodology (i.e., experimental or observational, method validation), yet considering the
44 manuscripts as a qualitative corpus allows for coding the narratives according to the conceptual
45 structure we propose^{7,34}. Content analysis has been used in many studies in health sciences³⁵ and an
46 inductive content analysis applied in a systematic review of clinical information modeling processes³⁴
47 has developed descriptive categories in a context similar to the one we propose here. As we consider
48 them relevant to the studies we will review, they will be included in our coding framework, as
49 detailed below.
50
51

52 Searches

53
54 A literature search will be performed in the following electronic databases: PubMed (MEDLINE),
55 Scopus, IEEE, CINAHL and EMBASE. The search will be adapted to each database, and the resulting
56 search strategies are provided as Supplementary File 2. The terms searched will be related to three
57 main categories, connected by the AND operator: "data-driven" (MeSH terms like "Electronic health
58 record", "data mining", etc.), "clinical pathways" (MeSH terms like "clinical pathway", "disease
59 management", etc.), and "chronic conditions" (MeSH term "chronic diseases"). Searches will be
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2
3 performed with MeSH terms or with keywords in Title/Abstract in PubMed; MeSH terms will be
4 adapted for the databases that do not permit their usage or use different indexed terms.
5 Bibliographies and citation tracking of relevant literature will be hand searched to identify additional
6 relevant studies. A first selection will be performed using abstracts and titles, followed by full-text
7 examination of entries selected.
8
9

10 Types of publications/studies and eligibility criteria

11 We will consider CDPs to be a series of time-stamped events describing the sequence of care of users
12 with a diagnosed chronic condition (conditions requiring medical attention for a period longer than
13 12 months)³⁶. These events can be the diagnosis itself, routine, non-scheduled or emergency
14 consultations with a general practitioner and/or specialist, therapeutic education sessions and other
15 health-related interventions. These can result in prescriptions of medications, medical procedures
16 and tests, which may also appear in the trajectory. Data-driven CDP analyzed here will need to be
17 composed of at least two time-stamped events recorded in EHD from people with the diagnosis of a
18 chronic condition, with no duration restrictions (e.g., CDP may cover periods from days or few
19 months to several years).
20
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22

23 We will consider peer-reviewed publications (1) reporting methods for visualization or quantification
24 of data-driven chronic CDP (including protocols and reports of study results), (2) using data from
25 people living with chronic conditions retrieved from EHD and (3) published in English. No restrictions
26 on publication date, study design, population characteristics, type of healthcare facility and level of
27 care will be applied.
28
29

30 We will exclude studies that aim only to assess healthcare utilization over a specific period as part of
31 a single research study, for example as an outcome to evaluate health-related interventions, to
32 describe populations or disease prevalence, or as a proxy measure of disease aggravation risk. We
33 will also exclude studies that do not mention population or data characteristics or do not state they
34 analyze data from people living with chronic conditions, papers with full-text not written in English,
35 conference abstracts, systematic or narrative reviews, meta-analyses and grey literature.
36
37

38 Screening

39 We will use Covidence, an online systematic review management software, for records screening.
40 After duplicates removal, titles and abstracts in the remaining records will be screened
41 independently by two reviewers for full text appraisal. If reviewer discordance arises, consensus will
42 be reached through discussion and arbitration with one of the secondary reviewers not involved in
43 the selection of the record. Studies selected in the first step will go through full text screening using
44 the same process to establish eligibility. Inter-rater reliability (Cohen's Kappa) between primary and
45 secondary reviewers will be computed and reported.
46
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49 Data management

50 We will report the number of included and excluded articles as well as the number of full-text papers
51 obtained and assessed. Reasons for exclusion of screened full-text studies will also be stated in the
52 final review. The data will be managed using Covidence and Microsoft Excel spreadsheets.
53
54

55 Data extraction and analysis

56 We will use both deductive and inductive content analysis³⁵ to appraise the selected studies:
57 deductive when relying on pre-defined frameworks such as the categories previously described by
58 Moreno-Conde et al. (2015)³⁴ to describe the technical characteristics of the proposed solutions and
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3 on the AACTT framework^{29,30} (action, actor, context, target, time), to describe the behavioural
4 domain, and inductive when additional relevant characteristics need to be described.
5

6 Data from included studies will be extracted using a customized electronic data extraction form.
7 Information on study characteristics (authors, title, type of study, year and country of study,
8 objective and research questions); population characteristics (number of patients, age, gender,
9 condition) will be extracted directly from the included studies.
10

11 *Deductive-Inductive content analysis*

12 We will perform a deductive content analysis following existing theories, as described below, and
13 inductive analysis for observed relevant characteristics not yet covered by existing literature. If more
14 than one selected record describe development, validation and/or implementation of the same
15 method, we will extract basic paper characteristics, as described above, but the content analysis will
16 be performed per method.
17
18

19
20 1) For the clinical domain, we will extract information on clinical or cost outcomes the method might
21 target (if reported and which ones) and on how the outcomes were considered relevant (e.g.,
22 involving experts, final users or other stakeholders).
23

24 2) For method development and data processing, we will analyze and compare to what has been
25 proposed by Moreno-Conde et al. (2015)³⁴. The categories detailed in the study are briefly described
26 below.
27

- 28 • Scope definition leading to selection of the domain and selecting relevant experts:
29 identifying the domain and expected uses of the method through the creation of a group
30 of experts.
- 31 • Analysis of the information covered in the specific domain: creation of definitions,
32 identification of clinical scenarios, workflows, users, guidelines, literature, etc., so the
33 method meet the requirements of clinical practice or other intended usages.
- 34 • Design of the tool: detailing the set of attributes associated with the method, domain
35 terminologies, ensuring compatibility across domains.
- 36 • Definition of implementable tool specifications: description of implementable technical
37 specification.
- 38 • Validation: use of techniques to validate the method, such as peer-review validation or
39 creation of prototype screens.
- 40 • Publishing and maintenance: availability in public repositories.
- 41 • Governance: description of the organization responsible for developing and maintaining
42 the tool.

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47 Other information extracted from studies regarding this domain will be healthcare utilization
48 characteristics (type of event, e.g., consultation, test, procedure) and data characteristics (sources of
49 data, data preparation, data analysis).
50

51
52 3) To describe behaviour and interactions the method might promote or facilitate, we will apply the
53 AACTT^{29,30} framework. Other information extracted from studies will be output characteristics like
54 intended final users, purpose and use scenarios. We will also code the presence of strategies planned
55 or performed to achieve these behavioural change objectives, such as training, organizational
56 changes, evaluation of the performance of the method in routine care, if implemented, and other
57 initiatives studies might present.
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3 The primary reviewer and one secondary reviewer will pilot data extraction independently for a
4 subset of 10% of selected records to compare and discuss data extraction process. If necessary, we
5 will repeat the pilot extraction process (outlined above) until agreement is reached. Disagreements
6 will be solved with the help of a third reviewer and piloting may consist of several interactions
7 between reviewers to compare and reach consensus regarding relevant information to be extracted
8 from full-text analysis. After this first step, a codebook will be developed, and data extraction of the
9 remaining records will be performed by the primary reviewer.
10
11

12 Quality and bias assessment

13
14 As most quality assessment tools are developed for commonly-used study designs and there is no
15 consensus regarding tools for generic use, we propose to evaluate quality from a different
16 perspective. We will evaluate if main stakeholders (patients and/or family, healthcare professionals,
17 administrative personnel) were involved at any stage of the development of the method. Research
18 shows the importance of involving patients, the public and other stakeholders in health-related
19 research to obtain experiential knowledge, setting research priorities and focus on practical
20 questions³⁷⁻⁴⁰. Also, it has been shown that trials funded by for-profit organizations can positively
21 bias interpretation of trial results⁴¹, and research in data usage can be funded by companies
22 interested in selling their own methods. To assess potential bias, we will evaluate declared conflicts
23 of interest and sources of funding. Quality assessment will be discussed in the review, but no study
24 will be excluded from the analysis based on quality criteria.
25
26

27 Data synthesis

28
29 The technical methods will be synthesized using the content analysis described above and the studies
30 will be categorized and described using the 3 domains, depending on study type and reporting. We
31 will present the results in tables along with method and study identification and summarize via
32 descriptive statistics. We will compare the different characteristics within the 3 domains to identify
33 common, infrequent, or missing features of these tools, and extract recommendations for future
34 initiatives.
35
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37 Patient and public involvement

38
39 A representant of a patients' association was involved in reading and approving of this protocol. This
40 systematic review is part of a larger project that will be developed closely with patients and
41 healthcare providers.
42

43 Ethics and dissemination

44
45 Ethical approval is not required. Results will be disseminated in peer-reviewed journals and/or
46 conference presentations. Data used in this review will be made available through supplementary
47 materials and open trusted repositories.
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49 Funding

50
51 DD was supported by an IDEXLYON (16-IDEX-0005) Fellowship grant (2018-2021), LSP was supported
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53 European Commission (MCRA-IF n°706028) during the preparation of this review protocol, and SA by
54 the Swiss Science Foundation (P2BSP3_ 178648).
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57 Conflicts of interest

58 None declared.
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Author statement

LSP, AD and SA designed the protocol and planned data extraction and quality assessment. LSP put together the search strategy and SA helped adapt it to the different databases. LSP and AD conceived the content analysis stages and conceptual framework. LSP wrote the first version of the manuscript, AD extensively reviewed it, SA, DD, AMS and MV revised it critically for important intellectual content. All authors have approved the publication of this protocol and contributed to the final manuscript.

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Reporting checklist for protocol of a systematic review.

Based on the PRISMA-P guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the PRISMA-P reporting guidelines, and cite them as:

Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart LA. Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement. *Syst Rev.* 2015;4(1):1.

		Reporting Item	Page Number
Title			
Identification	#1a	Identify the report as a protocol of a systematic review	1
Update	#1b	If the protocol is for an update of a previous systematic review, identify as such	n/a
Registration			
	#2	If registered, provide the name of the registry (such as PROSPERO) and registration number	1
Authors			
Contact	#3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author	1
Contribution	#3b	Describe contributions of protocol authors and identify the	7

guarantor of the review

Amendments

#4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	n/a
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Support

Sources	#5a	Indicate sources of financial or other support for the review	7
Sponsor	#5b	Provide name for the review funder and / or sponsor	7
Role of sponsor or funder	#5c	Describe roles of funder(s), sponsor(s), and / or institution(s), if any, in developing the protocol	n/a

Introduction

Rationale	#6	Describe the rationale for the review in the context of what is already known	2,3
Objectives	#7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	4

Methods

Eligibility criteria	#8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	4,5
Information sources	#9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage	4
Search strategy	#10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	4
Study records - data management	#11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	5
Study records -	#11b	State the process that will be used for selecting studies (such	5

1 2 3 4	selection process		as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)	
5 6 7 8 9 10 11	Study records - data collection process	#11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	5,6
12 13 14 15 16	Data items	#12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications	5,6
17 18 19 20 21 22	Outcomes and prioritization	#13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	n/a
23 24 25 26 27 28 29	Risk of bias in individual studies	#14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	6
30 31 32	Data synthesis	#15a	Describe criteria under which study data will be quantitatively synthesised	6
33 34 35 36 37 38 39	Data synthesis	#15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I ² , Kendall's τ)	n/a
40 41 42 43	Data synthesis	#15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)	n/a
44 45 46 47	Data synthesis	#15d	If quantitative synthesis is not appropriate, describe the type of summary planned	n/a
48 49 50 51 52	Meta-bias(es)	#16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)	n/a
53 54 55 56 57 58 59 60	Confidence in cumulative evidence	#17	Describe how the strength of the body of evidence will be assessed (such as GRADE)	n/a

1 The PRISMA-P checklist is distributed under the terms of the Creative Commons Attribution License
2 CC-BY 4.0. This checklist was completed on 08. August 2019 using <https://www.goodreports.org/>, a
3 tool made by the [EQUATOR Network](#) in collaboration with [Penelope.ai](#)
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For peer review only

COMPLETE SEARCH STRATEGY

Category	Medical Subject headings (MeSH)	CINAHL Search	EMBASE	Keywords
Data-driven	Electronic health record; data mining; machine learning; clinical decision support systems; analysis, cluster; medical informatics application	MH Electronic Health Records OR MH Data Mining OR MH Nursing Informatics OR MH Machine Learning OR MH Decision Support Systems, Clinical OR MH Cluster Analysis OR MH Medical Informatics OR MH Computer Graphics OR MH Algorithms OR TI Data-driven OR TI visualisation OR TI computer graphics OR TI process mining OR TI data mining OR TI visualization OR TI supervised learning OR TI unsupervised learning OR TI practice based OR TI modelling OR TI mapping OR TI cluster* OR TI data analys* OR AB Data-driven OR AB visualisation OR AB computer graphics OR AB process mining OR AB data mining OR AB visualization OR AB supervised learning	(Electronic health record or data mining or machine learning or clinical decision support systems or analysis, cluster or medical informatics application).sh. or (Data-driven or visualisation or computer graphics or process mining or data mining or visualization or supervised learning or unsupervised learning or practice based or modelling or mapping or cluster* or data analys*).ti. or (Data-driven or visualisation or computer graphics or process mining or data mining or visualization or supervised learning or unsupervised learning or practice based or modelling or mapping or cluster* or data analys*).ab.	Data-driven OR visualisation OR computer graphics OR process mining OR data mining OR visualization OR supervised learning OR unsupervised learning OR practice based OR modelling OR mapping OR cluster* OR data analys*

		OR AB unsupervised learning OR AB practice based OR AB modelling OR AB mapping OR AB cluster* OR AB data analys*		
Clinical pathways	Clinical pathways; delivery of health care, integrated; clinical practice pattern; disease management; care management, patient	MH Critical Path OR MH Health Care Delivery, Integrated OR MH Practice Patterns OR MH Disease Management OR MH Patient Care Plans OR TI Clinical course OR TI integrated care OR TI care map OR TI care pathway OR TI care plan OR TI treatment plan OR TI patient journey OR TI patient flow OR TI clinical redesign OR TI integrated care OR AB Clinical course OR AB integrated care OR AB care map OR AB care pathway OR AB care plan OR AB treatment plan OR AB patient journey OR AB patient flow OR AB clinical redesign OR AB integrated care	(Clinical pathways or delivery of health care, integrated or clinical practice pattern or disease management or care management, patient).sh. or (Clinical course or integrated care or care map or care pathway or care plan or treatment plan or patient journey or patient flow or clinical redesign or integrated care).ti. or (Clinical course or integrated care or care map or care pathway or care plan or treatment plan or patient journey or patient flow or clinical redesign or integrated care).ab.	Clinical course OR integrated care OR care map OR care pathway OR care plan OR treatment plan OR patient journey OR patient flow OR clinical redesign OR integrated care

Chronic conditions	Chronic diseases; chronic illness	MH Chronic Disease OR TI Integrated chronic care OR AB Integrated chronic care		Integrated chronic care
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EQUATIONS

MEDLINE

((data-driven[Title/Abstract] OR health information[Title/Abstract] OR data analys*[Title/Abstract] OR computer graphics[MeSH Terms] OR visualization[Title/Abstract] OR machine learning[MeSH Terms] OR data mining[MeSH Terms] OR clinical decision support systems[MeSH Terms] OR medical informatics application[MeSH Terms] OR algorithm[MeSH Terms] OR supervised learning[Title/Abstract] OR unsupervised learning[Title/Abstract] OR analysis, cluster[MeSH Terms] OR practice-based[Title/Abstract] OR electronic health record[MeSH Terms] OR clinical decision support systems[Title/Abstract] OR process mining[Title/Abstract] OR data mining [Title/Abstract] OR machine learning [Title/Abstract] OR medical informatics application[Title/Abstract] OR cluster*[Title/Abstract] OR modeling[Title/Abstract] OR mapping[Title/Abstract]))

AND

(chronic diseases[MeSH Terms] OR chronic illness[MeSH Terms] OR integrated chronic care[Title/Abstract])

AND

(delivery of health care, integrated[MeSH Terms] OR clinical practice pattern[MeSH Terms] OR clinical pathway[MeSH Terms] OR critical pathway[MeSH Terms] OR clinical course[Title/Abstract] OR integrated care[Title/Abstract] OR care map[Title/Abstract] OR care pathway[Title/Abstract] OR care plan[Title/Abstract] OR treatment plan[Title/Abstract] OR disease management[MeSH Terms] OR disease management[Title/Abstract] OR care management, patient[MeSH Terms] OR patient journey[Title/Abstract] OR patient flow[Title/Abstract] OR clinical redesign[Title/Abstract] OR integrated care[Title/Abstract]))

SCOPUS

(TITLE-ABS-KEY("data-driven") OR TITLE-ABS-KEY("health information") OR TITLE-ABS-KEY("data analys*") OR INDEXTERMS("computer graphics") OR TITLE-ABS-KEY("visuali*ation") OR INDEXTERMS("machine learning") OR INDEXTERMS("data mining") OR INDEXTERMS("clinical decision support systems") OR INDEXTERMS("medical informatics application") OR INDEXTERMS("algorithm") OR TITLE-ABS-KEY("supervised learning") OR TITLE-ABS-KEY("unsupervised learning") OR INDEXTERMS("cluster analysis") OR INDEXTERMS("practice-based") OR INDEXTERMS("electronic health record") OR TITLE-ABS-KEY("clinical decision support systems") OR TITLE-ABS-KEY("process mining") OR TITLE-ABS-KEY("data mining") OR TITLE-ABS-KEY("machine learning") OR TITLE-ABS-KEY("medical informatics application") OR TITLE-ABS-KEY(cluster*) OR TITLE-ABS-KEY("modelling") OR TITLE-ABS-KEY("mapping"))

AND (INDEXTERMS("chronic diseases") OR INDEXTERMS("chronic illness") OR TITLE-ABS-KEY("integrated chronic care"))

AND (INDEXTERMS("integrated delivery of health care") OR TITLE-ABS-KEY("clinical practice pattern") OR INDEXTERMS("clinical pathway") OR INDEXTERMS("critical pathway") OR TITLE-ABS-KEY("clinical course") OR TITLE-ABS-KEY("integrated care") OR TITLE-ABS-KEY("care map") OR TITLE-ABS-KEY("care pathway") OR TITLE-ABS-KEY("care plan") OR TITLE-ABS-KEY("treatment plan") OR INDEXTERMS("disease management") OR TITLE-ABS-KEY("disease management") OR INDEXTERMS("patient care management") OR TITLE-ABS-KEY("patient journey") OR TITLE-ABS-KEY("patient flow") OR TITLE-ABS-KEY("clinical redesign") OR TITLE-ABS-KEY("integrated care"))

IEEE

((((((((((((((((((((((((((("Index Terms":electronic health records) OR "Index Terms":data mining) OR "Index Terms":machine learning) OR "Index Terms":clinical decision support systems) OR "Index Terms":cluster analysis) OR "Index Terms":medical informatics) OR "Index Terms":computer graphics) OR "Index Terms":algorithm) OR "IEEE Terms":medical information systems) OR "IEEE Terms":electronic medical records) OR "Author Keywords":healthcare practices) OR "Publication Title":data-driven) OR "Abstract":data-driven) OR "Publication Title":machine learning) OR "Abstract":machine learning) OR "Publication Title":cluster analys*) OR "Abstract":cluster analys*) OR "Publication Title":data mining) OR "Abstract":data mining) OR "Author Keywords":electronic health record) OR "IEEE Terms":Guidelines) OR "IEEE Terms":Data mining) OR "IEEE Terms":Algorithm design and analysis) OR data mining) OR data-driven) OR electronic health record) OR algorithm) OR visualization) OR clustering) OR algorithm)

AND (((((((((((("Index Terms":clinical pathway) OR "Publication Title":clinical pathway) OR "Abstract":clinical pathway) OR "Author Keywords ":clinical pathway) OR "Author Keywords":healthcare practices) OR "Author Keywords ":Pathway) OR clinical path*) OR care pattern) OR care plan) OR care map) OR critical path*)

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5 OR chronic*)
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Quantification and visualization methods of data-driven chronic care delivery pathways: protocol for a systematic review and content analysis

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Title

Quantification and visualization methods of data-driven chronic care delivery pathways: protocol for a systematic review and content analysis

Corresponding author

Luiza Siqueira do Prado

luiza.siqueira-do-prado@univ-lyon1.fr

EA 7425 HESPER

Health Services and Performance Research

Université Claude Bernard Lyon 1

Domaine Rockefeller- 2eme étage (aile CD)

8 avenue Rockefeller

69373 Lyon 8

+33 (0) 7 83 45 23 66

Authors

Luiza Siqueira do Prado (luiza.siqueira-do-prado@univ-lyon1.fr)¹,

Samuel Allemann (s.allemann@unibas.ch)^{1,2},

Marie Viprey (marie.viprey@chu-lyon.fr)^{1,3},

Anne-Marie Schott (anne-marie.schott-pethelaz@chu-lyon.fr)^{1,3},

Dan Dediu (dan.dediu@univ-lyon2.fr)⁴,

Alexandra Dima (alexandra.dima@univ-lyon1.fr)¹

Affiliations

¹ EA 7425 Health Services and Performance Research HeSPeR – Université Claude Bernard Lyon 1, Lyon, France

² Pharmaceutical Care Research Group, Department of Pharmaceutical Sciences, University of Basel, Basel, Switzerland

³ Pôle de Santé Publique, Hospices Civils de Lyon, Lyon, France

⁴ Laboratoire Dynamique du Langage UMR 5596, Université Lumière Lyon 2, Lyon, France

Abstract

Introduction Chronic conditions require long periods of care and often involve repeated interactions with multiple healthcare providers. Faced with increasing illness burden and costs, healthcare systems are currently working towards integrated care to streamline these interactions and improve efficiency. To support this, one promising resource is the information on routine care delivery stored in various electronic healthcare databases (EHD). In chronic conditions, care delivery pathways (CDPs) can be constructed by linking multiple data sources and extracting time-stamped healthcare utilization events and other medical data related to individual or groups of patients over specific time periods; CDPs may provide insights into current practice and ways of improving it. Several methods

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3 have been proposed in recent years to quantify and visualize CDPs. We present the protocol for a
4 systematic review aiming to describe the content and development of CDP methods, to derive
5 common recommendations for CDP construction.
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7 **Methods and analysis** This protocol followed the Preferred Reporting Items for Systematic review
8 and Meta-Analysis Protocols (PRISMA-P). A literature search will be performed in PubMed
9 (MEDLINE), Scopus, IEEE, CINAHL and EMBASE, without date restrictions, to review published papers
10 reporting data-driven chronic CDPs quantification and visualization methods. We will describe them
11 using several characteristics relevant for EHD use in long-term care, grouped into three domains: 1)
12 clinical (what health-related events it includes and for what clinical aims?), 2) data science (how is
13 the method developed and what data infrastructure it relies on?), and 3) behavioral (what behaviors
14 and interactions does it promote in users and through what methods?). Data extraction will be
15 performed via deductive content analysis using previously defined characteristics and accompanied
16 by an inductive analysis to identify and code additional relevant features. Results will be presented in
17 descriptive format and used to compare current CDPs and generate recommendations for future CDP
18 development initiatives.
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22 **Ethics and dissemination** Database searches will be initiated in May 2019. The review is expected to
23 be completed by February 2020. Ethical approval is not required for this review. Results will be
24 disseminated in peer-reviewed journals and conference presentations.
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27 **PROSPERO registration** CRD42019140494
28

29 **Keywords** clinical decision support systems; medical informatics application; data visualization;
30 clinical pathway; delivery of health care, integrated; electronic healthcare databases.
31

32 **Word count** 2612
33

34 Strengths and Limitations

- 35 • While most reviews of health technology tools focus on clinical objectives and technical
36 characteristics, we will also consider behaviours of and interactions between users to
37 describe the selected methods.
- 38 • We will perform both deductive and inductive content analysis to fully describe the methods.
- 39 • We will focus on methods described in peer-reviewed papers and exclude conference
40 proceedings and other types of reports, to obtain detailed validated descriptions; this may
41 limit our access to more recent studies due to the fast-paced development in the field.
- 42 • Lack of completeness in methods descriptions may limit our ability to assess all
43 characteristics, such as the stages of development, the involvement of stakeholders or
44 experts prior to data acquisition and analysis.
- 45 • As this is a relatively new field of health technology, there are no guidelines for reporting and
46 no consensus on quality criteria for the studies we will evaluate; our work will also contribute
47 to the development of such recommendations.
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52 Introduction

53 Effective delivery of integrated care is a priority for healthcare systems worldwide and has been the
54 focus of considerable efforts in recent years, particularly in response to the increasing demands of
55 chronic care^{1,2}. Long-term conditions may require lifetime care, which may consist of multiple
56 interactions with a variety of healthcare providers at variable time intervals^{3,4}. When service delivery
57 is fragmented, the overall effectiveness of these interactions in terms of long-term quality of life and
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3 health-related outcomes is reduced, and risk of harm is increased^{5,6}. Centralizing patient information
4 produced by different providers in electronic healthcare databases (EHD) has the potential to help
5 implementing new ways of service delivery to improve outcomes⁷. Several attempts have been made
6 to link multiple data sources to generate comprehensive descriptions of patients' healthcare
7 journeys in long-term conditions. These descriptions are produced by constructing longitudinal
8 trajectories from various time-stamped healthcare utilization events and related medical data⁸⁻¹⁷. For
9 example, Zhang et al. have produced longitudinal trajectories using electronic health records (EHR)
10 and cost pathways^{14,16,17} of people living with chronic kidney disease to inform patient engagement
11 and to detect common pathways. Bettencourt-Silva et al. (2015) have reported on the development
12 of a patient-centric database from multiple Hospital Information Systems (HIS)¹⁸ and on building
13 data-driven pathways from routine hospital data on people living with prostate cancer to explore
14 their potential use in biomedical research¹⁵. However, generating these informative trajectories from
15 disparate and often incompatible data sources proves challenging^{18,19}. As various initiatives have
16 been developed independently, with distinct methodologies and objectives, it is essential to examine
17 systematically the proposed solutions in order to derive principles of action to stimulate convergence
18 of methods.
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23 In the context of chronic conditions, the way patient trajectories are established may be subject to
24 multiple influences and analyzing routine care data can provide insights on how they have been
25 drawn over time and their potential sources of variation^{14,20}. In the literature, trajectories within
26 healthcare systems have been described using many terms, which makes it challenging to build
27 consensus on terminology and practical meaning^{21,22}. We will use the term data-driven 'care delivery
28 pathway' (CDP) to group several terms we will find in the selected studies to designate retrospective
29 trajectories obtained from EHD. To describe the methods proposed for synthetically displaying
30 objective measures or assessments of health status or healthcare utilization (e.g., quantifying) and
31 graphically showing the temporal elements of chronic CDP (e.g., visualizing), we will assess how they
32 addressed three domains:
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36 1) The selection of relevant clinical and health-related events.

37 This domain will examine how the methods define health status and evaluate disease progression or
38 stabilization, and how they show transitions between health status and acute manifestations¹³.
39 Usually, the trajectory timeline begins at diagnosis and involves more than one provider¹³⁻¹⁵.
40 Treatment decisions are generally based on health status (indicated by biomarkers, clinical
41 examination, self-declared levels of quality of life, etc.), care units and settings, treatment availability
42 (medication, procedures, etc.), and patient-provider preferences²⁰.
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46 2) The technological development itself and considering issues related to data quality and
47 exchange.

48 This domain aims to describe how the method is built, which data sources and analyses are used, and
49 the necessary infrastructure surrounding its implementation. Digitalization of health-related data is a
50 global trend^{23,24} and highly detailed data are being collected daily in diverse settings and healthcare
51 services. Such methods may apply a range of techniques from basic algorithms to advanced statistical
52 and machine learning models²⁵, which can provide useful insights into care delivery processes.
53 Technological developments in this field also need to meet strict criteria of data security, accuracy of
54 models and predictions, openness of development and validation processes, among others^{15,26}.
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58 3) Considering behaviours of actors and interactions between them with the aim of effectively
59 improving care delivery.
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3 Integrated care depends on multiple actions and decisions made collaboratively by patients,
4 healthcare providers, administrative staff and other actors concerning patients' course of
5 treatment²⁷. To inform these decisions, technological solutions must have access to clinical exams
6 and provide key actors with relevant information, such as the patients' past interactions with other
7 providers, the medical procedures performed, the medications prescribed²⁸. To have a positive
8 impact on improving care delivery, visualizations and quantitative indicators of the patient's prior
9 care need to be adapted to the user's needs at specific points in the trajectory, like after acute events
10 or hospitalizations. This domain will examine what behaviors and interactions the methods promote
11 (who are its target individuals, what actions need to be performed, in what context, when, and by
12 whom)^{29,30}, and what strategies are proposed to encourage this performance.
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16 Aims and objectives

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18 We aim to identify and describe the methods that have been proposed to quantify and/or visualize
19 data-driven CPDs of people living with chronic conditions. Given the complexity of their context of
20 use, more than only reviewing technical methods, we aim to investigate how these tools have
21 considered the three domains described above.
22

23 For this end, we propose the following research questions:

- 24 1. What clinical information does the method use and how was it considered relevant?
 - 25 2. What are the method's development and implementation characteristics?
 - 26 3. Which behaviours and interactions does the method aim to promote among users and how?
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31 Methods

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33 The Cochrane Handbook³¹ and the Preferred Reporting Items for Systematic review and Meta-
34 Analysis Protocols (PRISMA-P)³² were used to write this protocol and the systematic review will
35 follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)³³. PRISMA-
36 P checklist is presented in Supplementary File 1. The review will be performed by one primary
37 reviewer (LSP) and three secondary reviewers (AD, MV and SA) and will follow 6 steps: literature
38 search, records screening and pre-selection (title and abstract), full-text screening and final selection,
39 extraction of data, quality assessment, analysis and synthesis of data.
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42 The studies expected to be analyzed in this work will likely be descriptive and not follow standard
43 methodology (i.e., experimental or observational, method validation), yet considering the
44 manuscripts as a qualitative corpus allows for coding the narratives according to the conceptual
45 structure we propose^{7,34}. Content analysis has been used in many studies in health sciences³⁵ and an
46 inductive content analysis applied in a systematic review of clinical information modeling processes³⁴
47 has developed descriptive categories in a context similar to the one we propose here. As we consider
48 them relevant to the studies we will review, they will be included in our coding framework, as
49 detailed below.
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52 Searches

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54 A literature search will be performed in the following electronic databases: PubMed (MEDLINE),
55 Scopus, IEEE, CINAHL and EMBASE. The search will be adapted to each database, and the resulting
56 search strategies are provided as Supplementary File 2. The terms searched will be related to three
57 main categories, connected by the AND operator: "data-driven" (MeSH terms like "Electronic health
58 record", "data mining", etc.), "clinical pathways" (MeSH terms like "clinical pathway", "disease
59 management", etc.), and "chronic conditions" (MeSH term "chronic diseases"). Searches will be
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3 performed with MeSH terms or with keywords in Title/Abstract in PubMed; MeSH terms will be
4 adapted for the databases that do not permit their usage or use different indexed terms.
5 Bibliographies and citation tracking of relevant literature will be hand searched to identify additional
6 relevant studies. A first selection will be performed using abstracts and titles, followed by full-text
7 examination of entries selected.
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10 Types of publications/studies and eligibility criteria

11 We will consider CDPs to be a series of time-stamped events describing the sequence of care of users
12 with a diagnosed chronic condition (conditions requiring medical attention for a period longer than
13 12 months)³⁶. These events can be the diagnosis itself, routine, non-scheduled or emergency
14 consultations with a general practitioner and/or specialist, therapeutic education sessions and other
15 health-related interventions. These can result in prescriptions of medications, medical procedures
16 and tests, which may also appear in the trajectory. Data-driven CDP analyzed here will need to be
17 composed of at least two time-stamped events recorded in EHD from people with the diagnosis of a
18 chronic condition, with no duration restrictions (e.g., CDP may cover periods from days or few
19 months to several years).
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23 We will consider peer-reviewed publications (1) reporting methods for visualization or quantification
24 of data-driven chronic CDP (including protocols and reports of study results), (2) using data from
25 people living with chronic conditions retrieved from EHD and (3) published in English. No restrictions
26 on publication date, study design, population characteristics, type of healthcare facility and level of
27 care will be applied.
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30 We will exclude studies that aim only to assess healthcare utilization over a specific period as part of
31 a single research study, for example as an outcome to evaluate health-related interventions, to
32 describe populations or disease prevalence, or as a proxy measure of disease aggravation risk. We
33 will also exclude studies that do not mention population or data characteristics or do not state they
34 analyze data from people living with chronic conditions, unavailable full texts, papers not written in
35 English, conference abstracts or abstract-only papers, systematic or narrative reviews, meta-analyses
36 and grey literature.
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39 Screening

40 We will use Covidence, an online systematic review management software, for records screening.
41 After duplicates removal, titles and abstracts in the remaining records will be screened
42 independently by two reviewers for full text appraisal. If reviewer discordance arises, consensus will
43 be reached through discussion and arbitration with one of the secondary reviewers not involved in
44 the selection of the record. Studies selected in the first step will go through full text screening using
45 the same process to establish eligibility. Inter-rater reliability (Cohen's Kappa) between primary and
46 secondary reviewers will be computed and reported, values greater than 0.80 will be considered
47 adequate.
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51 Data management

52 We will report the number of included and excluded articles as well as the number of full-text papers
53 obtained and assessed. Reasons for exclusion of screened full-text studies will also be stated in the
54 final review. The data will be managed using Covidence and Microsoft Excel spreadsheets.
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Data extraction and analysis

We will use both deductive and inductive content analysis³⁵ to appraise the selected studies: deductive when relying on pre-defined frameworks such as the categories previously described by Moreno-Conde et al. (2015)³⁴ to describe the technical characteristics of the proposed solutions and on the AACTT framework^{29,30} (action, actor, context, target, time), to describe the behavioural domain, and inductive when additional relevant characteristics need to be described.

Data from included studies will be extracted using a customized electronic data extraction form. Information on study characteristics (authors, title, type of study, year and country of study, objective and research questions); population characteristics (number of patients, age, gender, condition) will be extracted directly from the included studies.

Deductive-Inductive content analysis

We will perform a deductive content analysis following existing theories, as described below, and inductive analysis for observed relevant characteristics not yet covered by existing literature. If more than one selected record describe development, validation and/or implementation of the same method, we will extract basic paper characteristics, as described above, but the content analysis will be performed per method.

1) For the clinical domain, we will extract information on clinical or cost outcomes the method might target (if reported and which ones) and on how the outcomes were considered relevant (e.g., involving experts, final users or other stakeholders).

2) For method development and data processing, we will analyze and compare to what has been proposed by Moreno-Conde et al. (2015)³⁴. The categories detailed in the study are briefly described below.

- Scope definition leading to selection of the domain and selecting relevant experts: identifying the domain and expected uses of the method through the creation of a group of experts.
- Analysis of the information covered in the specific domain: creation of definitions, identification of clinical scenarios, workflows, users, guidelines, literature, etc., so the method meet the requirements of clinical practice or other intended usages.
- Design of the tool: detailing the set of attributes associated with the method, domain terminologies, ensuring compatibility across domains.
- Definition of implementable tool specifications: description of implementable technical specification.
- Validation: use of techniques to validate the method, such as peer-review validation or creation of prototype screens.
- Publishing and maintenance: availability in public repositories.
- Governance: description of the organization responsible for developing and maintaining the tool.

Other information extracted from studies regarding this domain will be healthcare utilization characteristics (type of event, e.g., consultation, test, procedure) and data characteristics (sources of data, data preparation, data analysis).

3) To describe behaviour and interactions the method might promote or facilitate, we will apply the AACTT^{29,30} framework. Other information extracted from studies will be output characteristics like intended final users, purpose and use scenarios. We will also code the presence of strategies planned

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3 or performed to achieve these behavioural change objectives, such as training, organizational
4 changes, evaluation of the performance of the method in routine care, if implemented, and other
5 initiatives studies might present.
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7 The primary reviewer and one secondary reviewer will pilot data extraction independently for a
8 subset of 10% of selected records to compare and discuss data extraction process. If necessary, we
9 will repeat the pilot extraction process (outlined above) until agreement is reached. Inter-rater
10 reliability (Cohen's Kappa) will be computed, and values greater than 0.80 will be considered
11 adequate. Disagreements will be solved with the help of a third reviewer and piloting may consist of
12 several interactions between reviewers to compare and reach consensus regarding relevant
13 information to be extracted from full-text analysis. After this first step, a codebook will be developed,
14 and data extraction of the remaining records will be performed by the primary reviewer.
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17 18 **Quality and bias assessment**

19 As most quality assessment tools are developed for commonly-used study designs and there is no
20 consensus regarding tools for generic use, we propose to evaluate quality from a different
21 perspective. We will evaluate if main stakeholders (patients and/or family, healthcare professionals,
22 administrative personnel) were involved at any stage of the development of the method. Research
23 shows the importance of involving patients, the public and other stakeholders in health-related
24 research to obtain experiential knowledge, setting research priorities and focus on practical
25 questions³⁷⁻⁴⁰. Also, it has been shown that trials funded by for-profit organizations can positively
26 bias interpretation of trial results⁴¹, and research in data usage can be funded by companies
27 interested in selling their own methods. To assess potential bias, we will evaluate declared conflicts
28 of interest and sources of funding. Quality assessment will be discussed in the review, but no study
29 will be excluded from the analysis based on quality criteria.
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32 33 **Data synthesis**

34 The technical methods will be synthesized using the content analysis described above and the studies
35 will be categorized and described using the 3 domains, depending on study type and reporting. We
36 will present the results in tables along with method and study identification and summarize via
37 descriptive statistics. We will compare the different characteristics within the 3 domains to identify
38 common, infrequent, or missing features of these tools, and extract recommendations for future
39 initiatives.
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42 43 **Patient and public involvement**

44 A representant of a patients' association was involved in reading and approving of this protocol. This
45 systematic review is part of a larger project that will be developed closely with patients and
46 healthcare providers.
47
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49 50 **Ethics and dissemination**

51 The search strategy was developed in collaboration with health sciences librarian services in early
52 2019. Database searches will be initiated in May 2019. The review is expected to be completed by
53 February 2020. Ethical approval is not required. Results will be disseminated in peer-reviewed
54 journals and/or conference presentations. Data used in this review will be made available through
55 supplementary materials and open trusted repositories.
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Conflicts of interest

None declared.

Author statement

LSP, AD and SA designed the protocol and planned data extraction and quality assessment. LSP put together the search strategy and SA helped adapt it to the different databases. LSP and AD conceived the content analysis stages and conceptual framework. LSP wrote the first version of the manuscript, AD extensively reviewed it, SA, DD, AMS and MV revised it critically for important intellectual content. All authors have approved the publication of this protocol and contributed to the final manuscript.

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Reporting checklist for protocol of a systematic review.

Based on the PRISMA-P guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the PRISMA-P reporting guidelines, and cite them as:

Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart LA. Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement. *Syst Rev.* 2015;4(1):1.

		Reporting Item	Page Number
Title			
Identification	#1a	Identify the report as a protocol of a systematic review	1
Update	#1b	If the protocol is for an update of a previous systematic review, identify as such	n/a
Registration			
	#2	If registered, provide the name of the registry (such as PROSPERO) and registration number	1
Authors			
Contact	#3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author	1
Contribution	#3b	Describe contributions of protocol authors and identify the	7

guarantor of the review

Amendments

#4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	n/a
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Support

Sources	#5a	Indicate sources of financial or other support for the review	7
Sponsor	#5b	Provide name for the review funder and / or sponsor	7
Role of sponsor or funder	#5c	Describe roles of funder(s), sponsor(s), and / or institution(s), if any, in developing the protocol	n/a

Introduction

Rationale	#6	Describe the rationale for the review in the context of what is already known	2,3
Objectives	#7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	4

Methods

Eligibility criteria	#8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	4,5
Information sources	#9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage	4
Search strategy	#10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	4
Study records - data management	#11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	5
Study records -	#11b	State the process that will be used for selecting studies (such	5

1	selection process		as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)	
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5	Study records -	#11c	Describe planned method of extracting data from reports	5,6
6	data collection		(such as piloting forms, done independently, in duplicate),	
7	process		any processes for obtaining and confirming data from	
8			investigators	
9				
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11				
12	Data items	#12	List and define all variables for which data will be sought	5,6
13			(such as PICO items, funding sources), any pre-planned data	
14			assumptions and simplifications	
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16				
17	Outcomes and	#13	List and define all outcomes for which data will be sought,	n/a
18	prioritization		including prioritization of main and additional outcomes, with	
19			rationale	
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23	Risk of bias in	#14	Describe anticipated methods for assessing risk of bias of	6
24	individual studies		individual studies, including whether this will be done at the	
25			outcome or study level, or both; state how this information will	
26			be used in data synthesis	
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30	Data synthesis	#15a	Describe criteria under which study data will be quantitatively	6
31			synthesised	
32				
33	Data synthesis	#15b	If data are appropriate for quantitative synthesis, describe	n/a
34			planned summary measures, methods of handling data and	
35			methods of combining data from studies, including any	
36			planned exploration of consistency (such as I ² , Kendall's τ)	
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40	Data synthesis	#15c	Describe any proposed additional analyses (such as	n/a
41			sensitivity or subgroup analyses, meta-regression)	
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44	Data synthesis	#15d	If quantitative synthesis is not appropriate, describe the type	n/a
45			of summary planned	
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48	Meta-bias(es)	#16	Specify any planned assessment of meta-bias(es) (such as	n/a
49			publication bias across studies, selective reporting within	
50			studies)	
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53	Confidence in	#17	Describe how the strength of the body of evidence will be	n/a
54	cumulative		assessed (such as GRADE)	
55	evidence			
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2 CC-BY 4.0. This checklist was completed on 08. August 2019 using <https://www.goodreports.org/>, a
3 tool made by the [EQUATOR Network](#) in collaboration with [Penelope.ai](#)
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COMPLETE SEARCH STRATEGY

Category	Medical Subject headings (MeSH)	CINAHL Search	EMBASE	Keywords
Data-driven	Electronic health record; data mining; machine learning; clinical decision support systems; analysis, cluster; medical informatics application	MH Electronic Health Records OR MH Data Mining OR MH Nursing Informatics OR MH Machine Learning OR MH Decision Support Systems, Clinical OR MH Cluster Analysis OR MH Medical Informatics OR MH Computer Graphics OR MH Algorithms OR TI Data-driven OR TI visualisation OR TI computer graphics OR TI process mining OR TI data mining OR TI visualization OR TI supervised learning OR TI unsupervised learning OR TI practice based OR TI modelling OR TI mapping OR TI cluster* OR TI data analys* OR AB Data-driven OR AB visualisation OR AB computer graphics OR AB process mining OR AB data mining OR AB visualization OR AB supervised learning	(Electronic health record or data mining or machine learning or clinical decision support systems or analysis, cluster or medical informatics application).sh. or (Data-driven or visualisation or computer graphics or process mining or data mining or visualization or supervised learning or unsupervised learning or practice based or modelling or mapping or cluster* or data analys*).ti. or (Data-driven or visualisation or computer graphics or process mining or data mining or visualization or supervised learning or unsupervised learning or practice based or modelling or mapping or cluster* or data analys*).ab.	Data-driven OR visualisation OR computer graphics OR process mining OR data mining OR visualization OR supervised learning OR unsupervised learning OR practice based OR modelling OR mapping OR cluster* OR data analys*

		<p>OR AB unsupervised learning OR AB practice based OR AB modelling OR AB mapping OR AB cluster* OR AB data analys*</p>		
<p>Clinical pathways</p>	<p>Clinical pathways; delivery of health care, integrated; clinical practice pattern; disease management; care management, patient</p>	<p>MH Critical Path OR MH Health Care Delivery, Integrated OR MH Practice Patterns OR MH Disease Management OR MH Patient Care Plans OR TI Clinical course OR TI integrated care OR TI care map OR TI care pathway OR TI care plan OR TI treatment plan OR TI patient journey OR TI patient flow OR TI clinical redesign OR TI integrated care OR AB Clinical course OR AB integrated care OR AB care map OR AB care pathway OR AB care plan OR AB treatment plan OR AB patient journey OR AB patient flow OR AB clinical redesign OR AB integrated care</p>	<p>(Clinical pathways or delivery of health care, integrated or clinical practice pattern or disease management or care management, patient).sh. or (Clinical course or integrated care or care map or care pathway or care plan or treatment plan or patient journey or patient flow or clinical redesign or integrated care).ti. or (Clinical course or integrated care or care map or care pathway or care plan or treatment plan or patient journey or patient flow or clinical redesign or integrated care).ab.</p>	<p>Clinical course OR integrated care OR care map OR care pathway OR care plan OR treatment plan OR patient journey OR patient flow OR clinical redesign OR integrated care</p>

Chronic conditions	Chronic diseases; chronic illness	MH Chronic Disease OR TI Integrated chronic care OR AB Integrated chronic care		Integrated chronic care
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EQUATIONS

MEDLINE

((data-driven[Title/Abstract] OR health information[Title/Abstract] OR data analys*[Title/Abstract] OR computer graphics[MeSH Terms] OR visualization[Title/Abstract] OR machine learning[MeSH Terms] OR data mining[MeSH Terms] OR clinical decision support systems[MeSH Terms] OR medical informatics application[MeSH Terms] OR algorithm[MeSH Terms] OR supervised learning[Title/Abstract] OR unsupervised learning[Title/Abstract] OR analysis, cluster[MeSH Terms] OR practice-based[Title/Abstract] OR electronic health record[MeSH Terms] OR clinical decision support systems[Title/Abstract] OR process mining[Title/Abstract] OR data mining [Title/Abstract] OR machine learning [Title/Abstract] OR medical informatics application[Title/Abstract] OR cluster*[Title/Abstract] OR modeling[Title/Abstract] OR mapping[Title/Abstract]))

AND

(chronic diseases[MeSH Terms] OR chronic illness[MeSH Terms] OR integrated chronic care[Title/Abstract])

AND

(delivery of health care, integrated[MeSH Terms] OR clinical practice pattern[MeSH Terms] OR clinical pathway[MeSH Terms] OR critical pathway[MeSH Terms] OR clinical course[Title/Abstract] OR integrated care[Title/Abstract] OR care map[Title/Abstract] OR care pathway[Title/Abstract] OR care plan[Title/Abstract] OR treatment plan[Title/Abstract] OR disease management[MeSH Terms] OR disease management[Title/Abstract] OR care management, patient[MeSH Terms] OR patient journey[Title/Abstract] OR patient flow[Title/Abstract] OR clinical redesign[Title/Abstract] OR integrated care[Title/Abstract]))

SCOPUS

(TITLE-ABS-KEY("data-driven") OR TITLE-ABS-KEY("health information") OR TITLE-ABS-KEY("data analys*") OR INDEXTERMS("computer graphics") OR TITLE-ABS-KEY("visuali*ation") OR INDEXTERMS("machine learning") OR INDEXTERMS("data mining") OR INDEXTERMS("clinical decision support systems") OR INDEXTERMS("medical informatics application") OR INDEXTERMS("algorithm") OR TITLE-ABS-KEY("supervised learning") OR TITLE-ABS-KEY("unsupervised learning") OR INDEXTERMS("cluster analysis") OR INDEXTERMS("practice-based") OR INDEXTERMS("electronic health record") OR TITLE-ABS-KEY("clinical decision support systems") OR TITLE-ABS-KEY("process mining") OR TITLE-ABS-KEY("data mining") OR TITLE-ABS-KEY("machine learning") OR TITLE-ABS-KEY("medical informatics application") OR TITLE-ABS-KEY(cluster*) OR TITLE-ABS-KEY("modelling") OR TITLE-ABS-KEY("mapping"))

AND (INDEXTERMS("chronic diseases") OR INDEXTERMS("chronic illness") OR TITLE-ABS-KEY("integrated chronic care"))

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IEEE

((((((((((((((((((((((((((("Index Terms":electronic health records) OR "Index Terms":data mining) OR "Index Terms":machine learning) OR "Index Terms":clinical decision support systems) OR "Index Terms":cluster analysis) OR "Index Terms":medical informatics) OR "Index Terms":computer graphics) OR "Index Terms":algorithm) OR "IEEE Terms":medical information systems) OR "IEEE Terms":electronic medical records) OR "Author Keywords":healthcare practices) OR "Publication Title":data-driven) OR "Abstract":data-driven) OR "Publication Title":machine learning) OR "Abstract":machine learning) OR "Publication Title":cluster analys*) OR "Abstract":cluster analys*) OR "Publication Title":data mining) OR "Abstract":data mining) OR "Author Keywords":electronic health record) OR "IEEE Terms":Guidelines) OR "IEEE Terms":Data mining) OR "IEEE Terms":Algorithm design and analysis) OR data mining) OR data-driven) OR electronic health record) OR algorithm) OR visualization) OR clustering) OR algorithm)

AND (((((((((((("Index Terms":clinical pathway) OR "Publication Title":clinical pathway) OR "Abstract":clinical pathway) OR "Author Keywords ":clinical pathway) OR "Author Keywords":healthcare practices) OR "Author Keywords ":Pathway) OR clinical path*) OR care pattern) OR care plan) OR care map) OR critical path*)

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AND (((("Index Terms":chronic disease) OR "Publication Title":chronic disease) OR "Abstract":chronic disease) OR "IEEE Terms":Diseases)
OR chronic*)

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