

INPLASY PROTOCOL

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**Review Stage at time of this
submission:** Data analysis.

Assessing people's functioning through rehabilitation registries systems. A rapid scoping review protocol

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Review question / Objective: 1.- To systematize the available scientific evidence on rehabilitation models and rehabilitation registries systems, which allow for the assessment of people's functioning; 2.- To describe rehabilitation data registries systems used internationally and the "minimum data set" that relate to the functioning of persons.

Eligibility criteria: - Population: Studies that have enrolled adult or paediatric patients, with any condition or pathology that could potentially result in low functioning or disability, related to impairments, activity limitation or restriction in participation, according to the International Classification of Functioning, Disability and Health (ICF) framework will be included. - Concept: Studies that submitted data from a rehabilitation registry, bank, or database containing a minimum data set will be included. These registries may include clinical and administrative information that can be used to improve the quality of care, monitor or answer research questions. - Context: Studies that have been conducted in a context of rehabilitation programs and assessment of function or disability, at any level of care, and that have directly or indirectly addressed aspects or variables that can account for functioning, capacity, or participation according to the ICF framework will be included. The inclusion of studies will not be limited by their methodological design, since they will be used to identify rehabilitation registries or databases, so primary studies (cohort studies, case-control studies, among others) and secondary studies (systematic reviews, exploratory reviews, among others) will be considered.

INPLASY registration number: This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 05 February 2022 and was last updated on 05 February 2022 (registration number INPLASY202220006).

INTRODUCTION

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evidence on rehabilitation models and rehabilitation registries systems, which allow for the assessment of people's

functioning; 2.- To describe rehabilitation data registries systems used internationally and the "minimum data set" that relate to the functioning of persons.

Background: Global trends in health and ageing indicate the need for a major expansion of rehabilitation services in countries around the world, especially in low- and middle-income countries. Increased access to rehabilitation services is required to ensure healthy lives and promote well-being for all at all ages. In this context the World Health Organization (WHO) issues a Call to Action: Rehabilitation 2030, which declares rehabilitation as the key health strategy for the 21st century, needed for the entire population and urges countries to strengthen rehabilitation services, calling on States to "ensure all actions to improve access to rehabilitation services, incorporating them into universal health coverage, and urging countries to develop comprehensive service delivery models, build multidisciplinary workforces, expand financing mechanisms and improve health information systems". Given the nature and aim of rehabilitation to optimise functioning and reduce disability, it should be available to all who require it. Rehabilitation is considered a fundamental intervention in health care, alongside prevention, promotion, treatment, and palliative care, and should therefore be considered an essential component of integrated health services, whose actions should be monitored and evaluated. Rehabilitation thus becomes an investment in human capital that contributes to the economic and social development of States. Although several countries have had different levels of achievements in coverage and quality of care in rehabilitation, they recognise that there are still gaps to be filled, giving rise to new and challenging tasks, among them the optimisation of information and registration systems that allow for the initial evaluation of the different health models and the different strategies or interventions aimed at solving the problems identified. In addition, this will subsequently enable research and the generation of evidence, give a strong

impetus to the training of human resources specialised in rehabilitation.

Rationale: There are clinical registries and databases at local and global levels that focus on collecting information prospectively on general rehabilitation processes or related to specific health conditions. These registries, their characteristics and the results derived from their analyses are available in a dispersed manner in the literature, repositories and on governmental or scientific society sites. Depending on the objectives of these registers, the developer, resources, and health system in which they are embedded, they are likely to include different critical variables and data that directly or indirectly assess people's functioning and capacity. Therefore, collecting, evaluating, and obtaining input from them could contribute to generate a relevant basis for the development of clinical registers in countries lacking such instruments, tools that could allow the evaluation of specific strategies for improvements in rehabilitation processes and broader health care policies.

METHODS

Strategy of data synthesis: A systematic search will be carried out in the following major electronic databases: Medline/Pubmed, EMBASE, Cochrane Library, and Epistemonikos. The strategy will consider a sensitive approach and the use of controlled (MeSH, Emtree) and natural language. In addition, a manual search will also be carried out in repositories of rehabilitation records such as: Center for Large Data Research and Data Sharing in Rehabilitation (<https://www.utmb.edu/cldr/about-us/about-cldr>) and Archive of Data on Disability to Enable Policy and research (<https://www.icpsr.umich.edu/web/pages/ADDEP/about.html>), and in the database of International Network of Health Technology Assessment Agencies (INAHTA). The search strategy used in Medline/Pubmed, which will be adapted to the other databases, will be as follows: (((((((((((((((((((((((((((((((("Rehabilitation"[Mesh]) OR ("Rehabilitation Centers"[Mesh])) OR

("Physical and Rehabilitation Medicine"[Mesh]) OR ("Hospitals, Rehabilitation"[Mesh]) OR ("Rehabilitation Research"[Mesh]) OR ("Telerehabilitation"[Mesh]) OR ("Exercise Therapy"[Mesh]) OR ("Physical Therapy Modalities"[Mesh]) OR ("Physical Therapy Specialty"[Mesh]) OR ("Physical Therapy Department, Hospital"[Mesh]) OR ("Occupational Medicine"[Mesh]) OR ("Occupational Therapy"[Mesh]) OR ("Occupational Therapy Department, Hospital"[Mesh]) OR ("Speech Therapy"[Mesh]) OR ("rehabilitation" [Subheading]) OR ("Disabled Persons"[Mesh]) OR ("Persons With Hearing Impairments"[Mesh]) OR ("Health Services for Persons with Disabilities"[Mesh]) OR ("International Classification of Functioning, Disability and Health"[Mesh]) OR ("Recovery of Function"[Mesh]) OR (rehabilita*[Title/Abstract]) OR (occupational therap*[Title/Abstract]) OR (physical medicin*[Title/Abstract]) OR (physical therap*[Title/Abstract]) OR (speech therap*[Title/Abstract]) OR (physiotherap*[Title/Abstract]) OR (physiat*[Title/Abstract]) OR (ICF) AND (((((((((((((((((((("Health Information Systems"[Mesh]) OR ("Common Data Elements"[Mesh]) OR ("Data Curation"[Mesh]) OR ("Health Information Exchange"[Mesh]) OR ("Registries"[Mesh]) OR ("Datasets as Topic"[Mesh]) OR ("Databases as Topic"[Mesh]) OR ("Data Warehousing"[Mesh]) OR (registr*[Title]) OR (dataset*[Title]) OR (databas*[Title]) OR ("health information system*[Title]) OR (repositor*[Title]) OR ("data warehous*[Title]) OR ("research network*[Title]) OR ("data shar*[Title]) OR ("core outcome*[Title]) OR ("model system*[Title])).

Eligibility criteria: - Population: Studies that have enrolled adult or paediatric patients, with any condition or pathology that could potentially result in low functioning or disability, related to impairments, activity limitation or restriction in participation, according to the International Classification of Functioning, Disability and

Health (ICF) framework will be included. - Concept: Studies that submitted data from a rehabilitation registry, bank, or database containing a minimum data set will be included. These registries may include clinical and administrative information that can be used to improve the quality of care, monitor or answer research questions. - Context: Studies that have been conducted in a context of rehabilitation programs and assessment of function or disability, at any level of care, and that have directly or indirectly addressed aspects or variables that can account for functioning, capacity, or participation according to the ICF framework will be included. The inclusion of studies will not be limited by their methodological design, since they will be used to identify rehabilitation registries or databases, so primary studies (cohort studies, case-control studies, among others) and secondary studies (systematic reviews, exploratory reviews, among others) will be considered.

Source of evidence screening and selection: Once the search for scientific evidence has been conducted, in a first stage, the titles and abstracts of the studies will be independently screened by two reviewers, who will determine compliance with the eligibility criteria, rating the studies as "included", "excluded" or "maybe" using the Rayyan application. Where disagreements exist at this stage, consensus will be considered in the first instance, and if this persists, a third reviewer will be included. Studies that are rated as "included" or "maybe" will proceed to the next stage, where the names of the registries or databases of all studies will be extracted. Subsequently, all clinical or administrative registries or databases will be subject to a final selection, and finally only registries focused to rehabilitation programmes will be included in this rapid scoping review. In the case of registries identified in other sources (not scientific journals), the same process will be followed, applying the eligibility criteria to information related to the objectives and components of the registries. Compliance with the eligibility criteria by clinical registries or databases

will be checked by one reviewer and validated in a non-blinded way by a second reviewer.

Data management: The unit of analysis will be the identified registers or databases, whose data will be extracted from each register's own web pages, repositories of rehabilitation or disability registers, or from reports of published studies that have used these registers as a source of information. A reviewer will extract the data from the records directly using a standard form available on the REDCap platform, which will be validated non-blindly by a second reviewer. Disagreements will be resolved by consensus, or ultimately by a third reviewer.

Reporting results / Analysis of the evidence: The information to be extracted will consider: 1) General characteristics of the registries, such as name, country, target health condition or pathology, methods of data collection in the different registries, responsible for data collection, sources of funding, barriers and facilitators of registry implementation; 2) Variables and data collected at the user or patient level; 3) Variables and data on the characteristics of the provider, health centre or service; 4) Exposure variables and data included, such as interventions received, characteristics and timing of the intervention, specific rehabilitation program, professionals involved, equipment; 5) Variables related to resource utilization; 6) Outcome variables of clinical interest included, which may be questionnaires, scales, instruments, or specific evaluation tests. Outcome variables will be classified according to the life areas (actions or tasks) described by the ICF to assess people's functioning and capacity. In addition, the type of activities of daily living (ADLs) assessed by the different registries will be classified, considering the following rule: A) Basic ADLs: (1) Mobility, (2) Self-care. B) Instrumental ADLs: (1) General tasks and demands, (2) Communication, (3) Domestic life. C) Advanced ADLs: (1) Learning and applying knowledge, (2) Interpersonal interactions and relationships, (3) Major life areas, (4) Community, social and civic life.

Presentation of the results: The process of study and registry selection will be presented in a modified PRISMA flowchart, as primary (e.g., observational studies) and secondary (e.g., systematic reviews) study reports will be checked for compliance with eligibility criteria in the first instance, and ultimately these criteria will be checked in the identified registries or databases. The information extracted from the rehabilitation records identified will be synthesized qualitatively, using tables for presentation, and quantitatively using descriptive statistics according to the type of variable. In addition, a matrix will be created to cross-reference the records and the outcome variables identified, and figures to show the vital areas of the ICF and the type of ADLs assessed by the different records.

Language: The search and inclusion of studies and registers will not be limited by language.

Country(ies) involved: Chile.

Other relevant information: This rapid scoping review is part of a project of the Department of Rehabilitation and Disability of the Ministry of Health of Chile (Tender n° 757-25-L121), and conducted by Universidad de la Frontera, aimed the creation of a national registry to assess the functioning and capacity of people under the ICF proposed by the WHO. In addition to this literature review, the project contemplates the characterisation of the functioning or capacity of people through the analysis of the National Health Survey 2016-17 carried out in Chile, and finally, the generation of a proposal for minimum data set on rehabilitation, according to level of care, to assess the functioning or capacity of people, compatible with the national rehabilitation model.

Keywords: Rehabilitation; International Classification of Functioning, Disability and Health; Registries; Health Information Systems.

Dissemination plans: The results will be made available to those in charge of the

Department of Rehabilitation and Disability of the Chilean Ministry of Health, to be an input for the generation of a proposal of minimum data set in rehabilitation to assess the person's functioning. In addition, the results of this rapid scoping review will be published in a scientific journal related to rehabilitation or with health information management.

Contributions of each author:

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Conflicts of interest: The authors Neculhueque-Zapata and Valenzuela-Suazo are employees of the Department of Rehabilitation and Disability of the Chilean Ministry of Health, who will be part of the conceptualisation of the idea, interpretation of results and review of the final manuscript, and will not participate in the collection and analysis of the results, so that belonging to the Ministry of Health will not influence a possible selective reporting of results. The other authors have no conflicts of interest.