

Strengthening health information systems for disability-related rehabilitation in LMICs

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Abstract

The purpose of this study was to describe the state of rehabilitation health information systems (HIS) in different settings, and identify key processes and actions which contribute to the development of HIS which can effectively support low- and middle-income countries (LMICs) allocate resources to health-related rehabilitation to people with disabilities. Nine case studies were conducted across different disability and developmental settings using documentary review and semi-structured key informant interviews ($N = 41$). Results were analysed against the six building blocks of a HIS, based on the Health Metrics Network Framework and Standards for Country Health Information Systems and existing HIS capacity. Key barriers or enablers to good disability data collection and use, were documented for each HIS component. Research results suggest there is no gold standard HIS for rehabilitation. There was broad consensus however, that effective health related disability planning requires reliable data on disability prevalence, functional status, access to rehabilitation services and functional outcomes of rehabilitation. For low-resource settings, and where routine HIS are already challenged, planning to include disability and rehabilitation foci starting with a minimum dataset on functioning, and progressively improving the system for increased utility and harmonization, is likely to be most effective and minimize the potential for overburdening fragile systems. The recommendations from this study are based on the successes and challenges of countries with established information systems, and will assist LMICs to prioritize strategic measures to strengthen the collection and use of data for rehabilitation, and progressively realize the rights of people with disabilities.

Key words: Disability, health information systems, LMICs, rehabilitation

Key Messages

- Health information systems (HIS) for disability and rehabilitation are typically weak and fragmented, and there is no gold standard for HIS for rehabilitation.
- Case studies in a range of disability, income and geographic settings identified several key steps and processes which facilitate the effective collection and use of data for rehabilitation.
- Recommendations for strengthening rehabilitation-HIS through a three-phased approach will assist LMICs to better use evidence to improve the planning and provision of rehabilitation to people with disabilities.

Introduction

Disability and rehabilitation data is often lacking from routine health information systems (HIS), or is incomplete, fragmented and unable to be compared or effectively shared. This is particularly the case in low- and middle-income countries (LMICs), where routine HIS tend to be weak (Mannava *et al.* 2005), and there remains a focus on infectious disease and maternal and child health priorities (Richards *et al.* 2016). Disability is a subjective term because it depends on people's expectations, context and the extent to which they are able to manage their condition. Consequently, disability measurement lacks standardization resulting in wide variations in estimates of prevalence (World Health Organization; World Bank 2011). The International Classification of Functioning, Disability and Health (ICF), however, provides a recognized framework for establishing shared terminology, and is used here-within as an umbrella term encompassing bodily impairments, activity limitations, participation restrictions and the impact of an individual's environment (World Health Organization 2001). Health-related rehabilitation is defined as measures to assist people with disabilities (or those likely to experience disability) to achieve and maintain optimal functioning in interaction with their environment (World Health Organization; World Bank 2011). This is also recognized in the World Health Organization's (WHO) recently released Priority Assistive Products List (APL), which includes 50 priority assistive products, and aims to play a similar role as the WHO Model List of Essential Medicines (World Health Organization 2016).

Globally, there is an acknowledged necessity to improve the collection and analysis of disability data (World Health Organization; World Bank 2011). Articles 25 and 26 of the Convention on the Rights of Persons with Disabilities (CRPD), obligate State Parties to help people with disabilities attain the highest possible standard of health through the provision of health-related rehabilitation (United Nations 2008). Article 31 also commits signatories to collect data to enable them to formulate and implement the Convention. Developing HIS that can adequately estimate disability prevalence and the need for assistive products for rehabilitation is therefore, a priority for realising the CRPD, supporting the effective implementation of the APL and ensuring that countries use their limited rehabilitation resources effectively and equitably.

This study arose from a gap identified in a literature review around the processes involved in developing, implementing and evaluating disability-related HIS. The specific aims of the study were: (i) to assess the state of rehabilitation-HIS in countries at different levels of income, disability/rehabilitation contexts, and levels of HIS development (see Table 1) and, (ii) to learn from these case studies and document key processes and actions which contribute to the development of effective HIS for rehabilitation. The overall intent is to provide guidance to donors, policy-makers and program managers seeking to integrate health information on people with disabilities into existing HIS in order to allocate and monitor equitable resource allocation, and progressively realize the CRPD. This is done by providing recommendations for strategic and incremental actions to strengthen each component of a rehabilitation-HIS. This article is of key importance as it provides lessons learned from a range of countries on how to strengthen HIS to support the planning and provision of rehabilitation for disability, an area which has been previously neglected.

Methods

The research program consisted of an extensive literature review and nine country case studies, developed to address the lack of

evidence available in the literature. The literature review searched the PubMed, ProQuest and Scopus databases using the terms: rehabilitation, disability, information systems, HIS and evidence-based policy. Grey literature was retrieved from Google and the websites of disability related organizations. Most of the retrieved literature was descriptive and originated from high-income countries. Several articles described the creation of information systems for specific disabling conditions, or to enhance management functions, but, overall, there was a lack of focus on integration into the broader HIS or on using information to assess or improve the quality of disability/rehabilitation-related HIS. The results of this review, along with the Health Metrics Network's (HMN) Framework for evaluating country HIS (Health Metrics Network 2008), were used to develop the key informant interview guide and as a framework for analysing the results.

This article focuses on the case study component of the research. The case studies were chosen through purposive sampling, an accepted qualitative research technique for identification and selection of information-rich cases (Patton 2002). We wanted to identify different approaches to HIS development and provide broad guidelines on the type of interventions that were likely to be needed depending on HIS capacity. For this reason, the case studies were selected to reflect a diversity of economic development, epidemiological profiles, health systems and existing HIS capacity. The nine case studies (Table 1) were: Australia; the Australian mental health HIS; Thailand; the Lao People's Democratic Republic (PDR); Sri Lanka; Ghana; Mozambique; Uganda; and a combined study for Pacific Island Countries and Territories (PICTs), incorporating the Solomon Islands, the Cook Islands, Fiji and Tonga. Australia was the only country where we chose to examine a mental health specific information system. This was in order to capture potential lessons from a relatively newly developed system located in a high-income country. In Ghana, Mozambique and Uganda, rather than conducting key informant interviews, a local researcher with knowledge of the system was employed to conduct a literature review only.

In 2013, primary data was collected through key informant interviews ($N=41$), conducted in person or via phone, following a semi-structured interview guide developed by the research team. Approval for the research was obtained from The University of Queensland's Ethical Review Committee, and all interviewees gave prior informed consent. Key informants included people with disabilities, representatives of government and non-government organizations (NGOs), health professionals, policy-makers and planners. Informants were identified purposively for their involvement in, or knowledge of, HIS and/or disability and rehabilitation, as well as by recommendation from other key informants. Building upon the aforementioned systematic review, a secondary document review was also undertaken, and included published and grey literature, i.e. policy documents, organizational reports and plans and peer-reviewed articles focused on disability and/or rehabilitation information systems. Textual analysis of the interview transcripts and results of the literature reviews was performed, and the findings were manually coded into themes based on the six HMN components of a HIS (resources; indicators; data sources; data management; information products and dissemination and use). Two team members performed coding, and a third team member cross-checked the results for consistency. Based on the themes of the HMN framework, the qualitative data from the country case studies, and secondary data from grey literature, content analyses were aggregated to identify findings and propose a three-phased incremental approach to strengthening of rehabilitation-HIS.

Table 1. Overview of case studies (in order of HIS capacity)

Country	Income level*	HIS capacity**	Disability/rehabilitation setting	Organizational affiliation of key informants
Australia	High	Strong	General	<ol style="list-style-type: none"> 1. National Disability Services 2. Policy and Planning Division, State Health Department 3. Department of Physiotherapy, Public Hospital 4. Evidence Reporting and Performance Unit, State Disability Services Department 5. Functioning and Disability Unit, Australian Institute of Health and Welfare
Australia	High	Strong	Mental health	<ol style="list-style-type: none"> 1. Mental Health Branch, State Health Department 2. Information and Communications, Mental Health Branch, State Health Department 3. Metropolitan Mental Health Services, State Health Department 4. Professor of Mental Health, Public University 5. Queensland Alliance for Mental Health 6. Clinician, Mental Health Services, State Health Department 7. Mental Health Nurse, Private Hospital
Thailand	Upper-middle	Adequate	General	<ol style="list-style-type: none"> 1. Disabled Persons Organization 2. Division of Social Welfare, Department of Local Administration, Ministry of Interior 3. Public Health Officer, National Medical Rehabilitation Center, Ministry of Public Health 4. Health professional, National Rehabilitation Center, Ministry of Public Health 5. National Office of Empowerment of Persons with Disabilities (NEP) 6. Executive, Medical Rehabilitation, National Health Security Office 7. Thai Disability Foundation 8. Council of Disabled People of Thailand
Sri Lanka	Lower-middle	Adequate	General	<ol style="list-style-type: none"> 1. Executive, Rheumatology and Rehabilitation hospital
Ghana	Lower-middle	Adequate	General	No interviews performed
Uganda	Low	Adequate	General	No interviews performed
Pacific Island Countries and Territories (Solomon Islands, The Cook Islands, Fiji, Tonga)	Lower-middle to upper-middle	Weak	General	<ol style="list-style-type: none"> 1. Solomon Islands Disabled Persons Organization 2. Ministry of Health, Cook Islands 3. Disabled Person's representative, Fiji
Lao PDR	Lower-middle	Weak	General as well as disability from unexploded ordnance	<ol style="list-style-type: none"> 1. Centre for Medical Research (N =2) 2. COPE (NGO) (N =2) 3. Save the Children 4. National Regulatory Authority for UXO Lao sector (N =2) 5. Lao People's Disability Organization 6. Disability/UXO injury advisors (N =2) 7. National Committee for Disabled Persons 8. Health systems international advisor 9. World Education (N =2) 10. Handicap International (N =2) 11. World Health Organization
Mozambique	Low	Weak	General	No interviews performed
Total				41

Sources: *Income level (World Bank 2014), **HIS assessment (WHO 2008; HMN and WHO 2012).

Results

This section presents the findings across the themes of the HMN framework, as summarized in Table 2.

HIS resources/governance

Commitment, policy and planning

In terms of high-level commitment to the rights of people with disabilities, all of the case study countries had signed the CRPD, and

were thus obligated to collect health-related information on people with disabilities (United Nations 2008). Australia, the African countries, Lao PDR and Thailand had also ratified the Convention. A key difference between the case studies, was that countries with more developed HIS had also developed and implemented legislation, policy and plans to enact this commitment. For example, Thailand has established a strategic plan for disability statistics which aims to: improve the revision of acts; improve the quality and efficiency of disability statistics; introduce disability modules into

Table 2. Key findings by level of HIS capacity

Component	Details	Level of HIS capacity		
		Weak	Adequate	Strong
Resources	HIS architecture	<ul style="list-style-type: none"> – Reliance on paper-based and localized systems 	<ul style="list-style-type: none"> – Integration of paper and computer-based systems which operate across regions/nationally 	<ul style="list-style-type: none"> – Predominately computer-based national/global systems which can integrate with international datasets (i.e. use ICD coding) – Integration of rehabilitation data into the existing HIS infrastructure
	Governance: high level commitment, policy and planning	<ul style="list-style-type: none"> – Signatory to CRPD but limited legislative framework for implementation and poor enabling factors (i.e. no local translations and poor awareness/understanding of the CRPD and disability laws) – Limited/no plans or policies for the collection and use of disability statistics 	<ul style="list-style-type: none"> – Signed and ratified the CRPD – Creation of strategic plans for disability statistics 	<ul style="list-style-type: none"> – Signed and ratified the CRPD – Implementation, monitoring and evaluation of funded strategic and operational plans for disability statistics and the management of disability/rehabilitation information management systems
	Governance: establishment of mechanisms for data integration and sharing	<ul style="list-style-type: none"> – Established government-led CRPD coordination mechanisms but inadequate focus on the provision of health-related rehabilitation – No structures for sharing and integration of data across sectors/systems resulting in data siloes 	<ul style="list-style-type: none"> – Limited or ad-hoc sharing of data through informal mechanisms – Substantial duplication of data – A lack of integration of data into the HIS from community based and/or private providers of rehabilitation and healthcare 	<ul style="list-style-type: none"> – Established MoUs between organizations, in particular between government ministries and disability support organizations to facilitate routine data sharing and use – Integration of data on need for rehabilitation from non-health actors
Indicators, data sources and data management	Standardization of terms of measurement	<ul style="list-style-type: none"> – Differences in terms of reference, classification and data collection methods resulting in wide variations in estimates of disability prevalence and supply and demand of rehabilitation services 	<ul style="list-style-type: none"> – Ad-hoc adoption of the ICF to describe functionality within the health sector only 	<ul style="list-style-type: none"> – Adoption of ICF, translation into local language and establishment of committees to monitor and evaluate its use – Using the ICF in its entirety (i.e. for functionality and interaction with the environment) to establish standardized terms and facilitate data sharing, research and planning between government ministries – Production of national data dictionaries which describe metadata in accordance with ICF – Coding of health data according to ICD – Use of standardized, locally validated assessment tools by appropriately trained staff
	Measuring type and severity of disability	<ul style="list-style-type: none"> – Use of one basic question on disability, or proxy indicators in population surveys/census to determine disability prevalence – No collection of information on severity and functionality 	<ul style="list-style-type: none"> – Inclusion of the WG SS into census or other population surveys 	<ul style="list-style-type: none"> – Inclusion of questions related to functioning, restrictions to participation and use of assistive devices/measure into population surveys – Additional data collection through regular thematic/dedicated disability surveys and the integration of CRVS data using multiple cause of death reporting
	Measuring supply and demand for rehabilitation, the administrative	<ul style="list-style-type: none"> – No/limited evaluation and monitoring of rehabilitation services 	<ul style="list-style-type: none"> – Infrequent monitoring or reporting of health system performance (i.e. through donor projects/funding) 	<ul style="list-style-type: none"> – Inclusion of patient/consumer-centred outcomes including subjective quality of life measures

(continued)

Table 2. Continued

Component	Details	Level of HIS capacity		
		Weak	Adequate	Strong
	functions and performance of the health system	<ul style="list-style-type: none"> – Inability to calculate supply and demand for rehabilitation 	<ul style="list-style-type: none"> – Use of functional assessment in place of formal diagnosis to assess need for rehabilitation in low-resource settings 	<ul style="list-style-type: none"> – Development of indicators which adequately capture the multiple aims of rehabilitation including, limiting physical deterioration in conditions that are unlikely to improve, particularly in CBR settings – Ongoing monitoring and evaluation of unmet need for rehabilitation – Establishment of a national clinical registry of rehabilitation outcomes which facilitates benchmarked calculations of service performance and research
	Creation of a national minimum dataset	<ul style="list-style-type: none"> – Ad-hoc collection of mainly demographic indicators as well as diagnosis with often incomplete records 	<ul style="list-style-type: none"> – Indicators which are locally relevant depending on nature and cause of disability 	<ul style="list-style-type: none"> – Creation of a national disability minimum dataset which is consistent with the ICF – Involvement of people with disabilities and end users in planning of included indicators
Information products, dissemination and use	Collation of data into information products which are accessible and useful	<ul style="list-style-type: none"> – Failure to aggregate data and produce reports 	<ul style="list-style-type: none"> – Some level of data aggregation but unfit for the data needs and not in a timely fashion to adequately inform planning 	<ul style="list-style-type: none"> – Production and dissemination of a range of information products in formats accessible to people with disabilities (i.e. online, in Braille), vulnerable and minority groups (i.e. non-English speaking background, illiterate) – Considering data end-users (including people with disabilities) and purposes when planning data collection – Regular reporting and assessment of utility of information products
	Creating data feedback cycles and incentivising data collection	<ul style="list-style-type: none"> – No feedback on data collection and a failure to understand why it is done, or why it is important 	<ul style="list-style-type: none"> – Minimal feedback on data collection processes and quality but insufficient staff training and resourcing 	<ul style="list-style-type: none"> – Creation of a culture of information – Ensuring that people who are required to collect data understand reasons why data is collected and receive feedback on their practice – Making data collection a formal job requirement and enforcing collection through incentives or disincentives (i.e. withholding pay)

existing surveys/censuses; ensure data are relevant to users' needs and improve integration of data collection and information sharing by promoting the use of the ICF (NEP 2012). Uganda also has a national policy on disability, which affirms government commitment to develop disability management information systems and generate disaggregated disability data (Ministry of Gender, Labour and Social Development 2006). In contrast, in Lao PDR, while a legislative framework exists and there is a cross-ministerial body to

implement the legislation (the National Committee for Disabled Persons: NCDP), the funding and resources to do so remain inadequate.

Establishment of bodies to coordinate data collection, integration and sharing

Article 33 of the CRPD calls for the establishment of government coordination mechanisms to implement, monitor and promote the

Convention (United Nations 2008). Most of the case study countries had such a body; however, respondents agreed that further work was needed to improve the facilitation of data sharing and integration between multi-sectoral partners. In countries with weak HIS, a lack of data sharing was reported to hinder the provision of clinical care for people with disabilities. For example, in the Pacific, there were limited or non-existent mechanisms for coordination between government ministries and disability support organizations which reportedly led to a lack of data integration from community-based rehabilitation (CBR) providers, and made it difficult for hospitals and health clinics to provide continuity of care for people with disabilities. In countries with weak HIS, data that are pertinent to the provision of rehabilitation, but which are collected by non-health actors, were not commonly integrated into the HIS. For example, in Lao PDR, the National Regulatory Authority for the unexploded ordnance (UXO) sector collects information on UXO-related injuries and disabilities, but this information is not linked to the HIS and, thus, cannot be used for rehabilitation planning (Durham *et al.* 2013). Furthermore, while the Medical Rehabilitation Centre maintains an excel database of clients, data is incomplete, not standardized and not linked to the broader HIS. Similarly, in Uganda, the inability to share data between ministries and NGOs involved in rehabilitation was reported to be a major weakness.

A lack of integration of data within and across sectors was also a challenge in countries with more advanced HIS (i.e. Ghana, Sri Lanka, Thailand and Australia). Despite the fact that Thailand collects a large amount of disability data, they could only provide less than half of the disability indicators surveyed by the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) due, in part, to a lack of coordination for data collection and validation between ministries (Mbat and Amorntum 2013). For example, the Thai National Office for Empowerment of Persons with Disabilities (NEP) is responsible for coordinating disability policy and planning, but the Ministry of Interior processes disability payments and maintains a Disability Premium Database. At present, the two ministries share data only once a year however a memorandum of understanding (MoU) is apparently being created to facilitate data sharing and reduce the large amounts of reported duplication. In Australia, stakeholders said that a major failure of the system was the fact that private and public mental health data cannot be shared and data-sharing mechanisms were reported to be crucial for the development of a national mental health HIS. Stakeholders in Australia also reported a need for a national rehabilitation strategy which designates one body with the responsibility for rehabilitation policy, planning, service provision and workforce development (Australasian Faculty of Rehabilitation Medicine, n.d.).

Indicators and data management

Standardization of terms and measurement

A lack of standard definitions and measurement methods is a barrier to data validation and sharing; however, this was only raised as a dominant concern in the Australian and Thai case studies. Thailand reported that ‘variations in definition of “disability type” and “people with disabilities” had resulted in differences in terms of reference, classification, data collection method and numbers of people with disabilities’ (Mbat and Amorntum 2013). Thailand has, however, made efforts to standardize disability measurement, particularly through adoption of the ICF for measuring both functioning and interaction with environment. To support this they have translated the ICF into Thai, produced an ICF user guide, and established local committees to monitor and evaluate its use. They have also

undertaken pilot studies using ICF codes and qualifiers to describe functionality and environmental barriers, which has enabled health personnel to work with the local administrative organizations to modify housing environments and physical barriers and to objectively measure change (Tongsiri 2013; Tongsiri and Riewpaiboon 2013).

In Australia, the Australian Institute of Health and Welfare (AIHW) produces an Australian ICF User Guide to provide advice on its potential applications and routine use (AIHW 2003a). They also produce two data dictionaries, which describe the metadata relevant to health-related rehabilitation services based on ICF descriptions of functioning and disability (AIHW 2010a,b). In spite of this, at a national level, the definition of ‘disability services’ excludes clinical care and rehabilitation of people with disabilities. More specifically, the term ‘mental health rehabilitation’ was said to be poorly defined within the sector, with reported differing views as to whether CBR ‘should be considered within a recovery paradigm rather than as rehabilitation’.

Datasets and what to measure

Respondents described the need for HIS to incorporate indicators which measured three key domains for rehabilitation: (1) type and severity of disability and level of functioning; (2) supply and demand for rehabilitation and (3) the administrative functions/performance of the health system, including patient-level outcomes. While global targets and goals were seen as useful for advocacy, informants said it was important for countries to also select locally appropriate, meaningful indicators. For example, respondents from the Solomon Islands said that estimates of disability due to non-communicable disease and violence against women were required, whereas in Lao PDR information on disability from UXO remains a relevant indicator. All countries reported constraints around data collection, and agreed that a minimum dataset would help to ensure that indicators are parsimonious and useful. As an informant from the Ministry of Health (MoH) in the Cook Islands said, ‘*We are facing challenges in collecting data and interpreting the data that have already been collected. Our aim now is to set up a template where we can easily document and measure relevant or important data*’. Australia was the only country that had evidence of such a dataset, having created the Disability Services National Minimum Data Set (DS NMDS) in 1994, with the aim of obtaining reliable, consistent and comparable data, with minimal load on disability services. It uses an agreed method of collection and transmission consistent with the ICF (AIHW 2003b). It is comprised of 47 indicators including: 27 on ‘service users’ (i.e. people with disabilities and their carers); 14 on ‘service type’, capturing administrative information and 6 on the type of services received. Most LMICs were, however, only using a small number of indicators related to disability/rehabilitation, and a disability dataset like that of Australia was seen by informants as unrealistic for their settings.

Indicators measuring disability prevalence

All countries surveyed used some form of indicator/s to measure disability prevalence, commonly in their national census or population surveys. The indicators varied across settings to meet a range of purposes and end-users, and depending on a country’s capacity to collect and use more detailed information. For example, several countries, including American Samoa, Fiji, Samoa and the Solomon Islands, reported asking one basic yes/no question, e.g. ‘Do you have a disability?’ (UNESCAP 2013). The 2010 Thai census also used this basic question, but added ‘If yes, specify’ (Thai National

Statistics Office 2010). Other PICTs reported using proxy indicators to establish disability prevalence: the Cook Islands, Fiji, Papua New Guinea, Tonga and Vanuatu use an activity status question (i.e. Are you employed? if no, why not? Option: because of a disability), and the Federated States of Micronesia and Palau use data on the receipt of disability payments (UNESCAP 2013). The information resulting from such basic questions and/or the use of proxy indicators is limited, and provides no information related to functioning and needs. Furthermore, real or perceived disability-related stigma was in some instances reported to result in under-reporting. Several countries used additional questions to establish functioning and the need for, and the type of, assistance required. For example, the 2011 Australian census included four questions related to disability, covering self-efficacy or assistance needed for the activities of communication, body movement and self-care, as well as the reason for requiring assistance. For the purposes of international comparison and informing policy on the full inclusion of people with disabilities, it has been recommended that the Washington Group on Disability Statistics short set of six questions (WG SS) is used as to obtain population-based data on disability and functioning (UNSC Statistical Commission 1994). Several countries had used this set of questions in one or more censuses, national surveys, disability modules or pre-tests (UNESCO 2014; United Nations 2014). Uganda used the WG SS (plus two additional questions covering: restrictions to participation at home/work/school; and the use of measures to reduce the impairment) in the National Panel Survey held in 2010/11. In Mozambique, the questions were used in national surveys on living conditions among people with disabilities (UNESCO 2014). In Lao PDR, it is proposed that the WG SS should be included in the next census and incorporated into the Lao PDR Social Indicator Survey (LSIS) for easy and cost-effective use of its existing infrastructure, reporting processes and channels for data dissemination (Durham *et al.* 2015).

Indicators measuring functioning

In terms of patient/episode-level indicators, a plethora of instruments were described for assessing disability, however, they do not always have sufficient focus on functioning to adequately inform rehabilitation planning. As a Laotian disability advisor stated, ‘*The key question is not how many people with disability are there and what are their types of disability but what are their needs to make them functional*’. A MoH informant from the Cook Islands said, ‘*We need to capture the difference between physical disability and the functional quality of life*’. In this respect, the use of indicators which measure functional assessment was highly supported by respondents, even in settings where the capacity of the HIS was limited. For example, a respondent from Lao PDR said that often in rural or remote settings, people with disabilities may not have a formal diagnosis due to shortages of trained health professionals. They can, however, be offered rehabilitation following a functional assessment, which is relatively simple to perform and can be undertaken by a range of health-workers and auxiliary staff (Durham *et al.* 2015). In Thailand, indicators of functioning based on the ICF have been used in a pilot project to create functional profiles of people with disabilities (Tongsiri and Hawsutisima 2013). These profiles were then used to inform and evaluate the effectiveness of home modifications in increasing functionality and independence. In Australia, a push towards patient-centred treatment goals, such as improvement in function rather than by diagnosis and procedure, led to the design of the Australian National Subacute and Non-Acute Patient (ANSNAP) case mix classification (Green and Gordon

2007; University of Wollongong 2012). ANSNAP allows case episode data to be subdivided on diagnosis and functional level (using the Functional Independence Measure [FIM]—a tool which measures the severity of a patient’s disability by assessing their functionality in 18 items covering six domains) (UDSMR 2009).

Outcome indicators

The need for further development of patient-centred and patient-reported outcome indicators was reported across the case study settings. The two Australian groups of respondents provided the most detail on these indicators. For example, a respondent in the Australian case study said that outcome measures which better reflect subjective improvements in the lives of people with disabilities were important, especially when considering the number of broader determinants of health that lie in the social, not biomedical domain. The need to develop indicators which can capture the prevention of deterioration in conditions which are unlikely to improve, as is often the case in CBR settings, was also highlighted. The Australian Department of Health and Ageing reports that the introduction of consumer outcome measures to monitor the impact of mental health services is a national priority (2005). An informant in the Australian mental health case study said there was also a need for better articulation between existing patient-reported measurement scales, such as the Kessler-10 (Kessler and Mroczek 1994), and clinician-reported scales, most commonly the Health of the Nation Outcome Scales; HoNOS (Royal College of Psychiatrists 1996).

As the Australian health system is predicated on extensive planning and monitoring and evaluation of performance, there was also a reported need for more outcome indicators for measuring change and the attainment of program goals and objectives. To this end, a clinical registry, the *Australasian Rehabilitation Outcomes Centre* (AROC), has been established to evaluate the efficiency of services and facilitate improvements in patient outcomes. It currently analyses data for around 180 rehabilitation facilities, and benchmarks the performance of each service based on changes in scores on the Functional Independence Measure. This enables services to track a patient’s functional ability over an episode of care and the resources utilized, and thus calculate a measure of cost efficiency and progress in achieving impairment-specific outcome targets (Simmonds 2011). AROC data has also been used for research into the outcomes of rehabilitation for specific conditions, including multiple sclerosis (Khan *et al.* 2009) and Parkinson’s disease (Khan and Amatya 2010).

In contrast, the majority of LMIC countries reported that a lack of evaluation of rehabilitation outcomes was common, and required additional targeted funding. An example was provided in the Ugandan case study in which a donor-funded CBR management information system was piloted in one district. There was, however, criticism that the program staff did not receive adequate training and, when external funding was withdrawn, the information system was not able to be sustained (Claussen *et al.* 2005; Uganda Bureau of Statistics 2005b; Kandyomunda *et al.* 2012). Whilst the CBR program continues in 16 districts, monitoring and evaluation are not done routinely (Kandyomunda *et al.* 2012).

Data sources

Population-based data sources

As discussed, all of the case study countries relied on their census as a key data source for disability prevalence. Notably, however, countries with stronger HIS also captured more detailed information from other sources including thematic or dedicated surveys and

death registries. For example, the Thai National Statistics Office undertakes five-yearly disability surveys, which provide in-depth information on disability, functional status, and use of health services and assistive devices. They are also able to link this information to other variables (i.e. education, income and place of residence) through the national citizen registration database (Thai National Statistics Office 2007). Australia also conducts a three-yearly Survey of Disability, Ageing and Carers (SDAC) which measures the percentage of people with disabilities experiencing limitations/restrictions, as well as information on long-term health conditions coded in accordance with the International Classification of Diseases Version 10 (ICD-10). Australia's strong HIS also enables them to collect information on death due to disability, through the practice of multiple cause-of-death coding, which they have done since 1997 within their civil registration and vital statistics (CRVS) system. This practice is reported to be valuable in recognising the impact of conditions which may result in disability, but are less likely to be the underlying cause of death (AIHW 2012), such as diabetes, asthma, dementia and Alzheimer's disease (AIHW 2014), as well as injuries which occur due to specific external events (AIHW 2007).

Administrative data and institution-based data sources

All countries had some form of health management information system (HMIS) or routine health information system (RHIS), which collates information from population and facility-based registers. In countries with weaker HIS, the HMIS/RHIS tended, however, to focus on routine collection of institutional sources of paper-based administrative data (i.e. discharge summaries, log-books and registers) and to rely on manual data entry. A common complaint was that there were few indicators on rehabilitation and disability within the RHIS/HMIS. For example, in Lao PDR, public rehabilitation centres collect data on the numbers of in- and out-patients, expenditure and income, but the HMIS does not include any specific indicators on the type of disability, functioning or access to services. A lack of integration of data collected in the community was also a common issue. For example, although CBR programs in Lao PDR routinely collect pertinent indicators, they did not report this data to the HMIS. There was also feedback from LMICs that health records may not provide complete data, e.g. the Ugandan HMIS only collects information about whether rehabilitation services are available and offered to children with poliomyelitis due to donor funding priorities (Ministry of Health 2012). Integration of data collected by other sectors into the RHIS was in most LMIC settings, not feasible despite acknowledgement that it could provide valuable information about the social determinants of health, risk factors for disability, as well as information about participation and limitations in other areas of life.

In Australia and Thailand, data was often collected and stored in sophisticated electronic databases featuring trans-institutional HIS architectures. In Australia, the use of standardized tools (i.e. the WHODAS2.0 [World Health Organization Disability Assessment Schedule 2.0], FIM and HoNOS) was also common-place in rehabilitation settings for capturing specific information on disability and rehabilitation needs. A respondent in the Australian mental health case study, however felt that such tools should first be validated in the local socio-cultural context and noted concern about the HoNOS tool, which was largely developed in a western setting and not validated in other cultures. The same respondent also noted that, when certain tools are completed by clinical staff from different backgrounds, they can yield different results, which leads to a lack of trust in the instrument. Appropriate training of

multidisciplinary staff was, thus, recommended. For example, the FIM (the most widely used instrument for outcome measurement and reimbursement in the Australian healthcare system), must be administered by a trained and certified evaluator, a process that is managed by AROC.

Information products, dissemination and use

A key outcome of any HIS should be the translation of data into information which meets the needs of end-users however in many of the case studies, especially those with weak HIS, this process was reported to be lacking. For example, a Cook Islands MoH informant said '*Some stakeholders are documenting their services but the data lie dormant somewhere*'. In Lao PDR, the health centres and district office do not produce yearly summaries of their data and, as a result, lack a coherent annual report to inform future planning. Furthermore, despite there being a comprehensive database on disability due to UXO injuries, this is only reported as an aggregation of the number of fatal and non-fatal injuries. Further analysis of the needs of UXO survivors is acknowledged to be of use for planning of rehabilitation therapy and assistive devices, but is beyond the present capacity of the system (Durham *et al.* 2013).

In Australia, there was an acknowledged need to provide information on disabilities in a range of accessible formats so that, in accordance with global recommendations, the information is available to a range of stakeholders and end-users, including people with disabilities. This group must be seen as priority data-users, alongside the more traditional audiences of clinicians, health workers and health policy/decision-makers (World Health Organization; World Bank 2011). Although the Australian government produces and disseminates several disability reports on their website, including, 'A Snapshot of People with a Need for Assistance' and 'Aspects of Disability and Health in Australia', they are not available in Braille or Auslan formats or in languages other than English. Disability advocate groups report concern over Australia's commitment to Article 31(3) of the CRPD, which obligates State Parties to ensure that people with disabilities have equal and adequate access to information (The Australian Civil Society Parallel Report Group 2012). It was reported in the case studies that, in most LMICs, disabled people's organizations, such as the National Union of Disabled Persons of Uganda and the Lao People's Disability Association, are considered to be important advocates, and are consulted in the planning of surveys to ensure that the needs and rights of people with disabilities are adequately represented.

The purpose of data collection should be clear to those who collect it. As a health systems advisor in Lao PDR said, '*If data on disability is going to be collected it is important to know 'why do we need it?' and, 'How will we use it?'*'. Different levels of the health system require data of differing detail and, as respondents in the mental health case study described, '*an essential step in deciding what information is useful depends largely on who is considered to be the steward of the system*'. Data was reported to be collected for a multitude of reasons: to inform patient care and clinical decision-making; to facilitate referrals; and to inform assessments of the availability, efficiency and effectiveness of rehabilitation services. In high-income countries, data was also collected for payment through third party payers, such as insurance companies or workers' compensation schemes. Motivating health personnel to collect complete and accurate data was reported as a challenge for all countries, and is also recognized as a key issue for strengthening routine HIS (Aqil *et al.* 2009). In Lao PDR, despite agreement that more data on people with disabilities was needed, there was concern about the

capacity of the system to handle and use this data. It was noted as crucial by many respondents that health workers understand why the data was being collected and how it would be used to improve patient outcomes. Australian mental health practitioners said that it is unfeasible to perform the HoNOS for each patient, noting that clinical staff are over-burdened. It was also reported that staff often question the utility of completing paperwork/data collection when they rarely receive feedback on it. In Queensland, a health department executive said that withholding payment until clinicians have adequately completed paperwork was a successful incentive for data collection, although this required updating job descriptions to include data collection. The introduction of performance indicators for benchmarking individuals and services was also reported to be an effective incentive for data collection. For example, the Consumer Integrated Mental Health Application Information System was developed to help clinicians improve their practice by receiving feedback comparing their performance with their peers. This approach emphasizes the importance of changing workplace culture so that data collection is seen as 'a means of driving quality improvement and benefits for consumers' (Department of Health and Ageing 2005) rather than as an administrative burden.

Discussion

State Parties to the CRPD have a legal obligation to collect health-related information on people with disabilities and progressively realising their rights to health. This study demonstrates however that in many LMICs, information systems for disability and rehabilitation are unable to support this commitment. Even where institutional, legal and organizational structures for the collection of disability-related health information exist, the functional capability of these structures was reported to be weak by the majority of countries, and there were few examples of standardized measurements of disability or functioning. Understanding functioning is crucial in terms of planning the support needed to enable people with disabilities to participate in daily activities. Indeed, functioning is one of the main indicators of need for health and rehabilitation services and functioning outcomes are a key means of evaluating rehabilitation service provision (Madden *et al.* 2012). Yet, in this study, data on impairments/health conditions was commonly used as a proxy

for disability. Such measures, however, are merely components of, not measures of disability and are likely to under-estimate disability and rehabilitation needs. While it is unrealistic to expect countries with weak HIS to integrate all the levels of functioning such as those captured in the ICF into their HIS, incorporation of the WG SS questions related to ICF-based functioning would capture multiple levels of severity across the main impairment types (Loeba *et al.* 2008; Madans *et al.* 2011). Additionally, as functional assessment does not require medical diagnosis and can be undertaken with the person, it is suitable for low-resource contexts and can provide a tool for strategic rehabilitation planning (Sinclair *et al.* 2013).

To accelerate HIS strengthening, the HMN Framework promotes a three-phased implementation process (Health Metrics Network 2008), which we have adapted for the rehabilitation context (Table 3). A key step in the first phase is the formalization of partnerships between the MoH (as the lead agency) and the body responsible for CRPD implementation and other key stakeholders. Most of the LMICs in the case studies agreed that they lacked HIS architectures and standardization of terminology and measurement to enable adequate data sharing and integration. A key action within phase one is thus establishing a common understanding of disability and rehabilitation concepts, their measurement, and processes for sharing data. Countries also identified the need for better definition of the end-users and data needs and it is thus recommended that the partnership should complete an assessment of the current capacity of the HIS in relation to stakeholders' data needs and uses. Key gaps should then inform the second stage of strategic HIS-strengthening with a focus on joint planning and prioritization to meet these needs through the creation of a minimum dataset and a strategic plan for progressive strengthening of the national disability and rehabilitation HIS. In the short term, in countries with weak HIS and limited disability and rehabilitation data, a 'good enough' approach to HIS strengthening should be supported (Durham *et al.* 2015). This approach focuses on the collection of a minimal amount of indicators which explicitly meet a purpose for specified end-users, aiming in the first instance to meet local data needs. At a minimum, disability related HIS should have the capacity to produce information on: (i) the number of people supported by a rehabilitation service, their characteristics and support needs; (ii) the type and quantity of support provided and received and (iii) service agency information, such as cost of services and outcomes for clients (WHO and

Table 3. An incremental approach to strengthening rehabilitation-HIS

Phase 1: Coordination, leadership and assessment	Phase 2: Prioritization and planning	Phase 3: Implementation of HIS strengthening activities
<ul style="list-style-type: none"> – MoH to conduct stakeholder analysis of those who provide health-related rehabilitation services and/or collect data which is pertinent to rehabilitation planning – Work with CRPD Implementing body and other parties to stimulate interest in strengthening rehabilitation-HIS capacity and garner the support of key stakeholders – Establish processes for sharing of data – Describe end users and their information needs and engage partners to conduct an assessment of current data collection strengths, weaknesses and gaps with the aim of establishing a common understanding of the concepts, benefits and capacities of the current system 	<ul style="list-style-type: none"> – Convene national workshop to discuss results of assessment, identify a vision for rehabilitation-HIS and agree on priorities for action – Define a core national indicator dataset and key data definitions based on the ICF – Draw up action plan and national strategy which delineates key roles and responsibilities and describes concrete and measurable steps to achieve the national vision over time 	<ul style="list-style-type: none"> – Design or adapt data collection tools and processes – Produce and disseminate regular reports to key stakeholders – In conjunction with key stakeholders, conduct comprehensive analysis of core indicators to inform planning cycles and evaluate dataset, processes and information products – Actively engage donors and global partners in aligning and harmonizing data collection and reporting with the least amount of duplication – Using data to influence policies, processes and for evidence-based planning

UNESCAP 2008). This should be supported where possible by data collection that informs on impairments, activity limitation and participation restrictions and in systems with greater sophistication should be cross-tabulated with other socio-economic variables.

The third stage of rehabilitation-HIS strengthening is an ongoing cycle of implementation, monitoring and evaluation. Few respondents from LMICs could provide examples of how disability/rehabilitation data was used for planning or program evaluation however and limitations around the use of evidence-based planning for rehabilitation were also given in the Australian case studies. It is thus clear that countries at all levels of HIS development need to ensure that this phase is given adequate focus and that data collection meets an explicit purpose. LMICs should plan to routinely evaluate the minimum dataset to assess whether it meets end-users data needs by providing reliable and timely data and all countries should evaluate how they could better use data to inform planning and policy to ensure that they meet their national and international commitments to provide health-related rehabilitation to people with disabilities.

This study has a number of limitations. While elements of the study have validity across settings, the findings and recommendations may not, as a whole, be generalizable to all LMICs/rehabilitation contexts. The purposive selection of cases meant that diverse countries with well-documented differences in their health system architecture were included; in particular, the inclusion of Australia as a high-income, highly developed nation may be questioned. The authors decided, however, to include Australia as there was a paucity of data and examples from LMICs and the study needed to document effective and proven strategies to develop and strengthen rehabilitation-HIS. The finding that the Australian rehabilitation-HIS also warranted improvement does however demonstrate that HIS strengthening is an ongoing and iterative process. The study is also limited in its ability to draw conclusions from the scarce literature and the opinions of key informants, which may not represent all opinions within each setting. Despite the limitations of the current study, it may serve to stimulate further focus on the under-served, but important, area of HIS for health-related rehabilitation.

Conclusion

With many countries undergoing an epidemiological transition, the prevalence of disability and the need for rehabilitation are also projected to increase, with the rise of chronic diseases such as diabetes, stroke and other neurological conditions (Richards *et al.* 2016). Better enumeration of disability prevalence and correlation with other factors, such as poverty, education and employment, will assist countries and global partners to understand the social determinants and consequences of disability, and to plan rehabilitation services which fulfil the health and human rights of people with disabilities, as stipulated in the CRPD. To this end, countries must assess the capacity of their broader HIS to provide the information they require to fulfil their national and global data needs and their CRPD obligations. They can then utilize the recommendations described here to undertake a phased approach to strengthening rehabilitation-HIS regardless of the stage of maturity and capacity of their HIS.

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Ethical Approval

Ethical approval was received from the University of Queensland's Ethical Review Committee.

Conflict of interest statement. None declared.

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