REHABILITATION
2030
a call for action

# Health information systems and rehabilitation

## Key messages

- Health information systems (HIS) underpin decision-making in health policy, management and clinical care through the collection, standardization, coding and management of information relevant to indicators of health status, determinants of health, and health systems.
- Improving the capacity of national HIS to collect reliable and comprehensive information is crucial for health systems strengthening, both nationally and internationally.
- WHO has developed a framework and standards for national HIS and a global reference list of 100 core health indicators to support countries to strengthen their HIS. There are opportunities to further expand this framework to capture the information needs of rehabilitation.
- Including information on functioning in HIS is essential for strengthening rehabilitation in the health system. "Functioning", as introduced in WHO's *International classification of functioning, disability and health* (ICF), refers to the impact of health conditions (injuries, diseases, ageing) on a person's experience in every aspect of his/her life.
- As well as information on functioning, systems level information about all aspects of the delivery and financing of rehabilitation services is necessary. This includes inputs (e.g. policy, financing, human resources and infrastructure) to, and outputs (e.g. service availability and quality) and outcomes (e.g. service coverage and utilization) of, rehabilitation.
- The WHO meeting on Rehabilitation 2030: A call for action calls for stakeholders to enhance HIS by including system level rehabilitation data and information on functioning, utilizing the ICF.

## Health information systems (HIS)

HIS are used to collect, standardize, code and manage information relevant to indicators of health status, determinants of health, and health systems. This sort of information is needed by: policy-makers to identify and respond to problems with evidence-based solutions, and to allocate resources effectively; planners to design more effective services, and managers to monitor and evaluate these services; and clinicians to provide high quality and evidence-based care.*(1)* Thus HIS underpin health and health-related decision-making in health policy, management and clinical care.

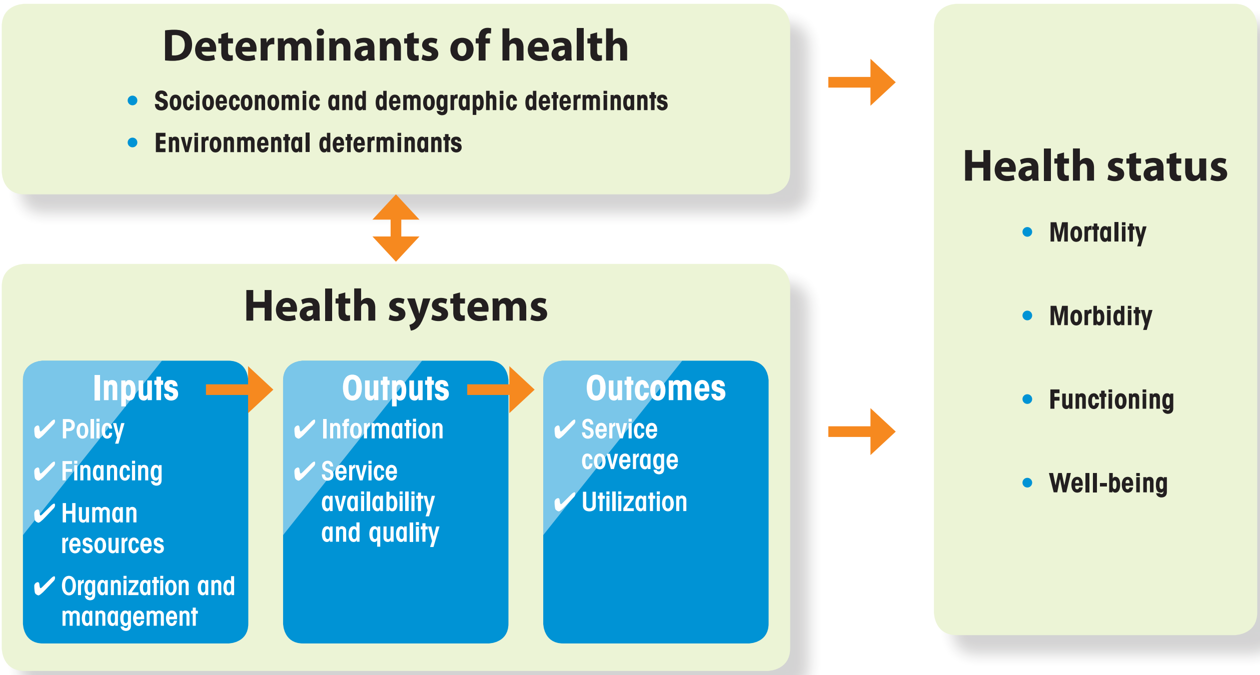
World Health Organization
WHO/NMH/NVI/17.2

Many low- and middle-income countries lack robust and effective HIS and often cannot afford to invest in data collection and analysis.*(2)* Even in developed HIS, data that are out of date or incomplete may be used. As a consequence, decision-makers at all levels of the health system may lack the information they need to identify problems and needs, to allocate resources optimally or to provide evidence-based services. This can result in a significant gap between what policy-makers, health professionals and researchers know and what they need to know to improve the health of the population.*(3)* Furthermore, weak national HIS and associated paucity of relevant data are major challenges for monitoring progress in achieving Sustainable Development Goal 3 (SDG3): ensure healthy lives and promote well-being for all at all ages.*(4)*

## Health information and data sources

To support countries in strengthening their HIS, WHO has developed a framework and standards for national health information systems,*(1)* and a global reference list of 100 core health indicators in line with this framework.*(5)* In the framework, three domains of measurement for HIS are recognized: health status, health system and determinants of health (Figure 1).

**Figure 1: Domains of measurement of health information systems based on Figure 3 presented in *Framework and standards for country health information systems*, second edition. Geneva: World Health Organization, 2012**



Relevant data to cover these domains are generated from **population sources** (censuses, civil registries, household and other population surveys) and from health or other institutional sources (individual clinical records, service records, resource records). Health research is also an essential source of information for decision-making.

Not all of this information is collected within the health system however, and it is important that a national HIS is able to link with, and collect comparable data from, other governmental agency statistical offices (e.g. for vital statistics), and from ministries of social affairs, labour and education (for socioeconomic information).

## Rehabilitation-relevant information

Health status information in national HIS is typically focused on three indicators: mortality, the indicator of a population's length of life and the survival of individuals with health conditions; morbidity, the indicator of the distribution of health conditions in the population, and the use of health services. Recently, because of demographic shifts such as population ageing and the epidemiological trend towards increased prevalence of noncommunicable diseases, there have been calls to expand the range of health status indicators to include those related to functioning.*(6,7,8)* "Functioning" is the term introduced in WHO's *International classification of functioning, disability and health* (ICF) *(9)* to identify all dimensions of the impact of health conditions (injuries, diseases, and ageing) on an individual's experience in the context of his/her life. The ICF provides a complete internationally standardized language and coding system for data comparability. Information on functioning according to the ICF includes information about body functions and structures, as well as information on activities and participation. The ICF also includes the environmental factors that may have an impact on functioning.

Information on functioning is essential to decision-making in rehabilitation at all levels of the health system since the goal of rehabilitation is to optimize functioning in light of impairments, injuries, and acute or chronic diseases:

- **At user level**, information on functioning guides goal setting and outcome evaluation across the continuum of rehabilitation care (at service provision level (primary, secondary and tertiary) and in the treatment phases (acute care, post-acute care and long-term care)).
- **At facility or programme level**, information on functioning from users can be aggregated to help monitor clinical outcomes and improve service planning and quality assurance.
- **At policy level**, aggregated clinical information on functioning gives policy-makers a source of evidence for planning health and rehabilitation services and monitoring their impact.

Although functioning is of vital importance as an impact indicator to the success of rehabilitation within the health system, it is not the only information that needs to be collected by national HIS for rehabilitation decision-making. Information about service delivery and financing is needed for clinical, managerial and policy decisions concerning rehabilitation; this information can be classified as:

- inputs (e.g. total current expenditure on rehabilitation, out-of-pocket payment, density and distribution of rehabilitation professionals);
- outputs (e.g. utilization of rehabilitation services, availability of essential assistive products);
- outcomes (e.g. coverage of rehabilitation services for persons with specific health conditions such as spinal cord or traumatic brain injury, coverage of essential assistive products).

In addition, to fully capture the rehabilitation needs at population level and the range of relevant rehabilitation interventions required, with details on their efficacy, information about the socioeconomic, demographic, genetic, and behavioural determinants of declines in functioning must also be systematically collected.

## Looking forward

Too often, national HIS do not adequately integrate rehabilitation-related information. This hampers decision-making at all levels and is one of the obstacles to strengthening rehabilitation services around the world. A key action to strengthen rehabilitation, called for during the WHO Rehabilitation 2030: A call for action meeting, is to collect information relevant to rehabilitation to enhance health information systems, including system level rehabilitation data and information on functioning, utilizing the ICF. Although there is much work to be done to address this call for action, we can look to the future with optimism as many of the existing data sources that national HIS traditionally draw upon can easily be modified or expanded to meet the informational needs of rehabilitation.

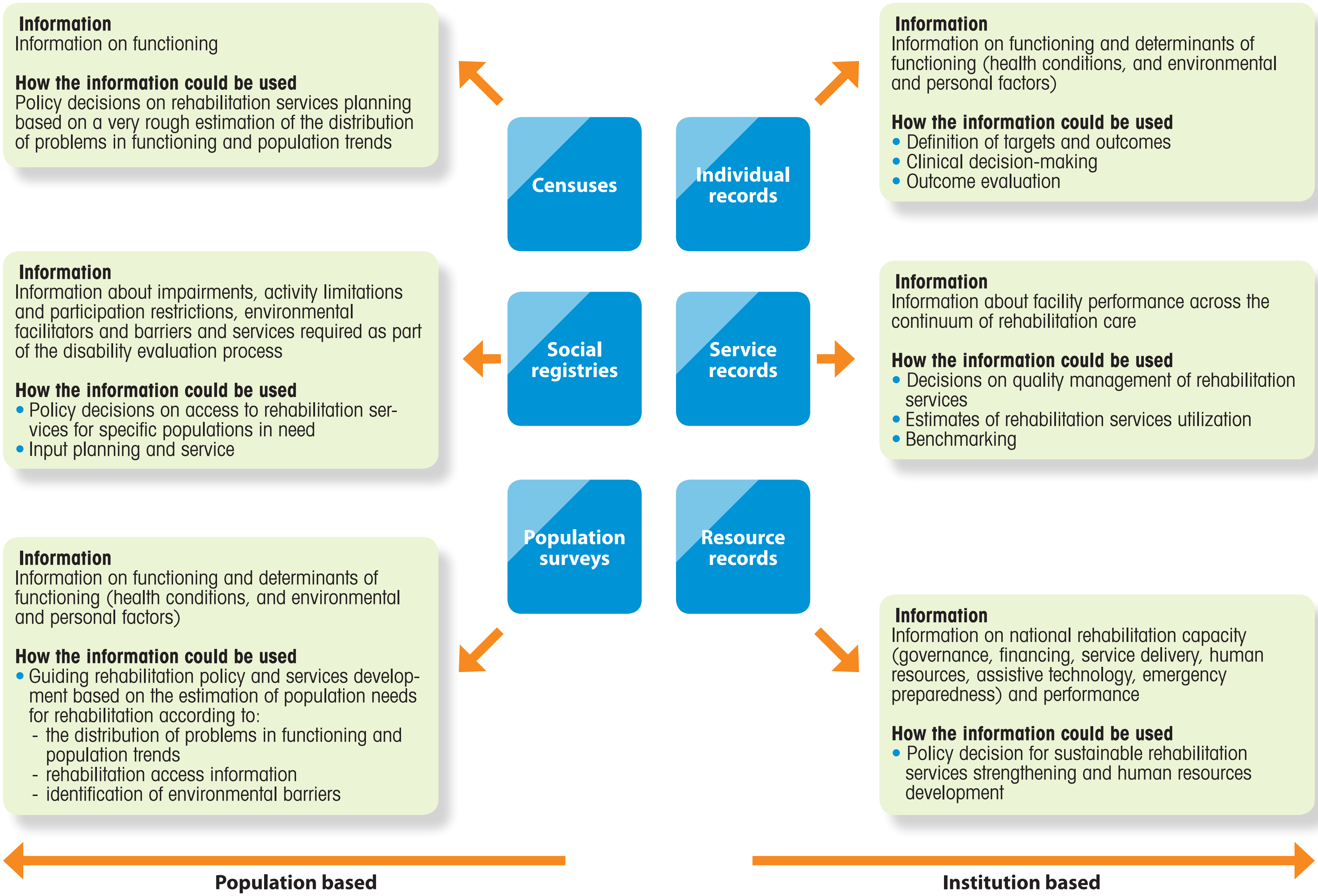
Figure 2 suggests the kinds of information relevant to rehabilitation that could plausibly be collected by the six traditional HIS data sources, as well as how this information might be used to strengthen rehabilitation and improve decision-making at all levels. In some instances, the described modifications or enhancements have already been implemented, although often these data are not fully utilized. Other ways to modify or enhance existing data collection sources are certainly possible and need to be explored and tested. The ultimate goal is to create concrete guidance for countries on how to enrich their HIS with rehabilitation-related information, to strengthen the health system in general and rehabilitation services in particular.

## References

1. Framework and standards for country health information systems. Second edition. Geneva: World Health Organization, 2012.
2. Upadhaya N, Jordans MJ, Abdulmalik J, Ahuja S, Alem A, Hanlon C et al. Information systems for mental health in six low and middle income countries: cross country situation analysis. Intern J Mental Health Sys. 2016;10:60.
3. Heeks R. Health information systems: Failure, success and improvisation. Intern J Med Informatics. 2006;75(2):125–37.
4. World Health Statistics 2016. Monitoring health for the SDGs. Geneva: World Health Organization, 2016.
5. 2015 Global reference list of 100 core health indicators. Geneva: World Health Organization, 2015.
6. Bradley SM, Rumsfeld JS, Ho PM. Incorporating health status in routine care to improve health care value: the VA patient reported health status assessment (PROST) system. JAMA. 2016;316(5):487–8.
7. World Health Organization. The global strategy and action plan on ageing and health 2016–2020 (http://who.int/ageing/GSAP-Summary-EN.pdf?ua=1, accessed 15 January 2017).
8. Stucki G, Bickenbach J, Melvin J. Strengthening rehabilitation in health systems worldwide by integrating information on functioning in national health information systems. Am J Phy Med & Rehabil. 2016,Dec 15.

**This background paper was prepared by WHO for the meeting on Rehabilitation 2030: A Call for Action.**

**Figure 2. Data sources and information for decision-making and strengthening rehabilitation**



**Information**
Information on functioning

**How the information could be used**
Policy decisions on rehabilitation services planning based on a very rough estimation of the distribution of problems in functioning and population trends

**Information**
Information about impairments, activity limitations and participation restrictions, environmental facilitators and barriers and services required as part of the disability evaluation process

**How the information could be used**
- Policy decisions on access to rehabilitation services for specific populations in need
- Input planning and service

**Information**
Information on functioning and determinants of functioning (health conditions, and environmental and personal factors)

**How the information could be used**
- Guiding rehabilitation policy and services development based on the estimation of population needs for rehabilitation according to:
  - the distribution of problems in functioning and population trends
  - rehabilitation access information
  - identification of environmental barriers

**Information**
Information on functioning and determinants of functioning (health conditions, and environmental and personal factors)

**How the information could be used**
- Definition of targets and outcomes
- Clinical decision-making
- Outcome evaluation

**Information**
Information about facility performance across the continuum of rehabilitation care

**How the information could be used**
- Decisions on quality management of rehabilitation services
- Estimates of rehabilitation services utilization
- Benchmarking

**Information**
Information on national rehabilitation capacity (governance, financing, service delivery, human resources, assistive technology, emergency preparedness) and performance

**How the information could be used**
- Policy decision for sustainable rehabilitation services strengthening and human resources development