



Aging, Functioning, and Rehabilitation: A Workshop

16-17 February 2024
University of Lucerne
Lucerne, Switzerland

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16 February 2024

Dear Colleagues,

Welcome to the National Academies of Sciences, Engineering, and Medicine workshop, *Aging, Functioning, and Rehabilitation*. This workshop is hosted at the University of Lucerne, with generous support from The NOMIS Foundation and THE VELUX FOUNDATIONS.

Functioning, as a concept, constitutes a rethinking of health that goes beyond the medical model, which is focused almost exclusively on disease and disability. Rehabilitation professionals are key in this transformative approach. A recent World Health Organization (WHO) [statement](#) has noted the need for rehabilitation is increasing due to the epidemiological shift from communicable to noncommunicable diseases, while taking account of the fact that there are also new rehabilitation needs emerging from infectious diseases, such as COVID-19. Further, the need for rehabilitation is increasing due to the global demographic shift towards rapid population aging accompanied by a rise in physical and mental health challenges, and injuries. The WHO statement emphasized that rehabilitation needs are largely unmet globally and that rehabilitation services are key to the achievement of Sustainable Development Goal 3 (to ensure healthy lives and promote well-being for all at all ages). Efforts are needed in identifying the economic challenges in operationalizing the concept of function as a measure for health policy, rethinking disability as a universal human experience, and formulating a feasible public health agenda that addresses the increasing relevance of rehabilitation for the 21st century. Shaping health systems, education, research, and policy in ways that promote functioning can help people live their best lives.

This workshop will facilitate a discussion focused on the WHO's concept of functioning and its role in rethinking the concept of health, with a focus on healthy aging and the future of rehabilitation as a health strategy. We encourage workshop participants to explore the opportunities and challenges in improving human functioning across the life-course.

The proceedings of the workshop will be published by the National Academies Press and may incorporate your comments and ideas. Archived presentations and videos from the workshop will be available at <https://www.nationalacademies.org/our-work/aging-functioning-and-rehabilitation-a-workshop>.

Sincerely,

Walter Frontera, MD, PhD, FRCP
Planning Committee Chair
Professor
University of Puerto Rico School of Medicine

AGING, FUNCTIONING, AND REHABILITATION

Hybrid Workshop
16-17 February 2024
University of Lucerne
Lucerne, Switzerland

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- Bickenbach, J., S. Rubinelli, C. Baffone, and G. Stucki. 2023. [The human functioning revolution: Implications for health systems and sciences. *Frontiers in Science* 1.](#)
- Chatterji, S., J. Byles, D. Cutler, T. Seeman, and E. Verdes. 2015. [Health, functioning, and disability in older adults--present status and future implications. *Lancet* 385\(9967\):563-575.](#)
- Meyer, T., C. Gutenbrunner, C. Kiekens, D. Skempes, J. L. Melvin, K. Schedler, M. Imamura, and G. Stucki. 2014. [Isprpm discussion paper: Proposing a conceptual description of health-related rehabilitation services. *Journal of Rehabilitation Medicine* 46\(1\):1-6.](#)
- Stucki, G., and J. Bickenbach. 2017. [Functioning: The third health indicator in the health system and the key indicator for rehabilitation. *European Journal of Physical and Rehabilitation Medicine* 53\(1\):134-138.](#)
- Stucki, G., and J. Bickenbach. 2019. [Health, functioning, and well-being: Individual and societal. *Archives of Physical Medicine & Rehabilitation* 100\(9\):1788-1792.](#)
- Stucki, G., J. Bickenbach, and W. Frontera. 2019. [Why rehabilitation should be included in international healthy ageing agendas. *American Journal of Physical Medicine & Rehabilitation* 98\(4\):251-252.](#)
- World Health Organization. 2023. [Strengthening rehabilitation in health systems. Seventy-Sixth World Health Assembly, Agenda Item 13.4.](#)
- See also: USAID. 2024. [Using the World Health Assembly Resolution as a tool to strengthen local and national advocacy for rehabilitation.](#)

Aging, Functioning, and Rehabilitation

Workshop Agenda

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16-17 FEBRUARY 2024

LECTURE HALL 1

UNIVERSITY OF LUCERNE

LUCERNE, SWITZERLAND

ACCESS WEBCAST [HERE](#)

FRIDAY, 16 FEBRUARY 2024 – DAY 1

8:30

Welcome and Workshop Overview

Walter Frontera, *Chair, Planning Committee*

University of Puerto Rico School of Medicine

Welcome by the U.S. National Academies of Sciences, Engineering, And Medicine

Victor Dzau

U.S. National Academy of Medicine

Welcome by the University of Lucerne & the Swiss Academy of Medical Sciences

Gerold Stucki

University of Lucerne

Bruno Staffelbach

University of Lucerne

Henri Bounameaux

Swiss Academy of Medical Sciences

9:00

Keynote: The Functioning Revolution

Jerome Bickenbach

University of Lucerne

9:30

Keynote: Healthy Longevity

John Beard

Columbia University

10:00 [Keynote: World Health Organization's Perspective on Rehabilitation](#)

Alarcos Cieza

World Health Organization

10:30 [BREAK](#)

10:45 [Panel 1: Functioning and the Realization of Healthy Longevity Through Rehabilitation](#)

Moderator: Somnath Chatterji, World Health Organization, Emeritus, *Planning Committee Member*

Operationalization of Functioning for Population Health

Francesca Gimigliano

University of Campania "Luigi Vanvitelli"

The Role of Functioning in Healthy Longevity Research

Eleanor Simonsick

National Institute on Aging

Implications of Tracking Functioning for Health Systems and Health Care

Alan Jette

Boston University

11:45 [LUNCH](#)

12:45 [Panel 2: Functioning and the Investment Case for the Role Of Rehabilitation in Healthy Longevity](#)

Moderator: Gerold Stucki, University of Lucerne, *Planning Committee Member*

Measuring and Enhancing Functioning in Health Systems

Paola Sillitti

Organisation for Economic Co-operation and Development

Making a Compelling Investment Case for Optimizing Functioning for Healthy Longevity

Carl Willers

Karolinska Institutet

13:45

Panel 3: The Foundation for Improving Rehabilitation Service Delivery and Care Across the Life Course: Continuity and Person-Centered Care and the Lived Experience of Health

Moderator: NiCole R. Keith, Indiana University, *Planning Committee Member*

Rehabilitation as an Interprofessional and Transdisciplinary Health Strategy for Healthy Aging

Patricia Morsch

Pan American Health Organization

Integrating Pre-habilitation, Prevention, and Maintenance to Maximize Functioning

Fary Khan

University of Melbourne

Reorienting Rehabilitation as a Health Strategy for All Populations in the Community

Elias Mpofu

University of North Texas; University of Sydney

14:45

BREAK

15:00

Panel 4: Functioning as the Key to a Comprehensive 360-Degree Life-Course Foundation for Healthy Longevity Research

Moderator: Julia Patrick Engkasan, Universiti Malaya, *Planning Committee Member*

Harmonizing Research Addressing Functioning within Aging and Rehabilitation Ecosystems

Jonathan Bean

Harvard Medical School; VA Boston Healthcare System; Spaulding Rehabilitation Hospital; Massachusetts General Hospital

Challenges and Opportunities in the Standardized Collection of Functioning Information for Research in Rehabilitation and Healthy Longevity

Birgit Prodingier

University of Augsburg

Utilizing Functioning Data for 360 Degree Research: Using the Example of Prospective Budgeting and Performance-oriented Incentive Mechanism for Insurance Payment for Rehabilitation Episodes based on WHO's International Classification of Functioning, Disability and Health

Jan Reinhardt

Sichuan University; Jiangsu Province Hospital; University of Lucerne

February 2024 | 3

16:00

Panel 5: Advocating for Health and Social Policy in Support of Healthy Longevity: Functioning as the Third Indicator Of Health

Moderator: Matilde Leonardi, IRCCS Foundation “Carlo Besta” Neurological Institute, *Planning Committee Member*

The Challenges and Opportunities of Advocating for Functioning as the Third Indicator of Health

Dorothy Boggs

London School of Hygiene and Tropical Medicine

The Policy Advocate Perspective: Raising Policy Awareness and Championing Communications Related to Functioning

Ruth Katz

Association of Jewish Aging Services

New Directions on Health and Disability

Abderrazak Hajjioui

Sidi Mohamed Ben Abdellah University

17:00

ADJOURN DAY 1

19:00

WORKSHOP DINNER FOR INVITED PANELISTS

SATURDAY, 17 FEBRUARY 2024 – DAY 2

8:30

Welcome to Day 2 of the Workshop

Walter Frontera, *Chair, Planning Committee*

8:35

Facilitated Breakout Sessions

Access virtual breakout link: [HERE](#)

FUNCTIONING [Room 4.B47]

- Facilitator: Somnath Chatterji, World Health Organization, Emeritus, *Planning Committee Member*
- Supporting Scientist: Nicola Diviani, Swiss Paraplegic Research

ECONOMICS [Room 4.B51]

- Facilitator: Gerold Stucki, University of Lucerne, *Planning Committee Member*

- Supporting Scientist: Diana Pacheco, University of Lucerne

HEALTH SERVICES [Room 4.B54]

- Facilitator: NiCole R. Keith, Indiana University, *Planning Committee Member*
- Supporting Scientist: Carla Sabariego, University of Lucerne

RESEARCH [Room 4.B55]

- Facilitator: Julia Patrick Engkasan, Universiti Malaya, *Planning Committee Member*
- Supporting Scientist: Marija Glisic, Swiss Paraplegic Research

ADVOCACY [Room 4.A05]

- Facilitator: Matilde Leonardi, IRCCS Foundation “Carlo Besta” Neurological Institute, *Planning Committee Member*
- Supporting Scientist: Sara Rubinelli, University of Lucerne

9:30 BREAK

9:45 Report Backs from Facilitated Discussions and Workshop Reflections

Moderator: Walter Frontera, *Planning Committee Chair*

Somnath Chatterji
World Health Organization, Emeritus

Gerold Stucki
University of Lucerne

NiCole R. Keith
Indiana University

Julia Patrick Engkasan
Universiti Malaya

Matilde Leonardi
IRCCS Foundation “Carlo Besta” Neurological Institute

11:00 BREAK

11:30 **Next Steps for the Way Forward: Fireside Conversation with Discussants**

Co-moderators: Walter Frontera, *Planning Committee Chair*, and Gerold Stucki, *Planning Committee Member*

John Beard
Columbia University

Jerome Bickenbach
University of Lucerne

Alarcos Cieza
World Health Organization

12:50 **Closing Remarks**

Walter Frontera
Chair, Planning Committee

13:00 **MEETING ADJOURNS**

The National Academies of
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Aging, Functioning, and Rehabilitation

Planning Committee Roster

Walter Frontera, MD, PhD, FRCP (*Chair*)

Professor

University of Puerto Rico School of
Medicine

Somnath Chatterji, MD

Emeritus Director, Department of Data and
Analytics

World Health Organization

Julia Patrick Engkasan, PhD, MBBS

Associate Professor

University of Malaysia

NiCole R. Keith, PhD, MS

Executive Associate Dean

Indiana University Bloomington

Matilde Leonardi, MD

Director

Fondazione IRCCS Istituto Neurologico Carlo
Besta

Gerold Stucki, MD, MS

Professor of Health Sciences and Health
Policy

University of Lucerne

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Aging, Functioning, and Rehabilitation

Workshop Participant Roster

Jonathan F. Bean, MD, MS, MPH

Professor, Department of PM&R,
Harvard Medical School
Director, New England Geriatric Research,
Education and Clinical Center
VA Boston Healthcare System

John Beard, PhD, MBBS

Irene Diamond Professor of Epidemiology and
Health Policy and Management
Mailman School of Public Health
Director of the International Longevity Center
Columbia University

Jerome Bickenbach, PhD, LLB

Permanent Visiting Professor
Faculty of Health Sciences and Medicine
University of Lucerne
Professor Emeritus
Department of Philosophy and Faculties of Law
and Medicine
Queen's University

Dorothy Boggs, PhD, OTR/L, MScPH, FHEA

Assistant Professor
International Centre for Evidence in Disability
Department of Population Health
London School of Hygiene and Tropical
Medicine

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President
Swiss Academy of Medical Sciences
Professor (hon)
Faculty of Medicine
University of Geneva

Alarcos Cieza, PhD, MPH, MSc

Head
Integrated Service Delivery Unit
Sensory Functions, Disability, and
Rehabilitation Unit
Department of Noncommunicable Diseases
World Health Organization

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Senior Research Associate
Swiss Paraplegic Research
Lecturer
Faculty of Health Sciences and Medicine
University of Lucerne

Victor Dzau, MD

President
U.S. National Academy of Medicine

Marija Glisic, MD, PhD, PD

Co-lead
Cardiometabolic and Respiratory Research
Swiss Paraplegic Research

Francesca Gimigliano, MD, PhD

Professor of Physical and Rehabilitation
Medicine
Chair of the Clinical Unit of General and
Specialist Rehabilitation Medicine
Coordinator of the PhD National Program in
Public Administration and Innovation for
Disability and Social Inclusion
President
Bachelor Program of Speech and Language
Therapy
Department of Mental and Physical Health and
Preventive Medicine, University of Campania
"Luigi Vanvitelli"
President
International Society of Physical and
Rehabilitation Medicine

Abderrazak Hajjioui, MD, MPM, PhD

Physical and Rehabilitation Medicine
Department, University Hospital Mohamed VI,
Tangier, Morocco
Full Professor
Faculty of Medicine and Pharmacy, Abdelmalek
Essaâdi University, Tetouan, Morocco
President
Moroccan Association for the Promotion of
Rehabilitation Sciences and Prevention of
Disability
Vice-President of the Middle Eastern and North
African Network

Alan M. Jette, PhD

Emeritus Professor and Dean
Sargent College of Health and Rehabilitation
Services
Boston University

Ruth Katz, MEd

President and CEO
Association of Jewish Aging Services

Fary Khan, MD, AM, MBBS, FAFRM

Director of Rehabilitation Services
Royal Melbourne Hospital
Clinical Director
Australian Rehabilitation Research Centre
Clinical Professor
Department of Medicine at University of
Melbourne and the Nossal Institute of
Global Health, and the PeterMac.

Patricia Morsch, PhD, MA, PT

Advisor, Healthy Aging
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Pan American Health Organization
Regional WHO Office for the Americas

Elias Mpofu, PhD, DEd

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University of Lucerne
Group Leader
Health Economics Group
Swiss Paraplegic Research

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Chair and Professor of Inclusive Health Care
Faculty of Medicine
University of Augsburg

Jan D. Reinhardt, PhD

Professor and Director of Health Services
Institute for Disaster Management and
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Department of Rehabilitation and Functioning
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Organisation for Economic Cooperation and
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Epidemiologist
Intramural Research Program
National Institute of Aging
U.S. National Institutes of Health
Co-Director
Baltimore Longitudinal Study of Aging
Federal Project Officer
Health, Aging and Body Composition Study

Bruno Staffelbach, PhD

Professor
Business Administration
Director
Center for Human Resource Management
President
University of Lucerne

Carl Willers, MD, PhD

Postdoctoral researcher
Department of Neurobiology, Care Sciences and
Society,
Karolinska Institute
Intern physician
Karolinska University Hospital
Stockholm Region Council,
Affiliated researcher
Research and Development Center for the
Elderly

Workshop on Aging, Functioning, and Rehabilitation

Participant Biosketches



Jonathan F. Bean, M.D., M.S., M.P.H., is a Professor in the Department of Physical Medicine and Rehabilitation at Harvard Medical School. Dr. Bean is an internationally recognized expert in geriatric rehabilitation. The goal of his work is to foster the development of new models of care that optimize the functioning of older adults. This includes an emphasis on principles that are prioritized within Age-Friendly healthcare systems. These overarching goals are addressed through his leadership of the based New England Geriatric Research, Education and Clinical Center (GRECC). This one of the 20 congressionally mandated VA GRECCS. Dr. Bean is the first Psychiatrist to

ever lead a VA GRECC. Specifically, his own research program focuses on developing new models of care that position rehabilitation as the center piece of secondary prevention of functional decline and adverse health outcomes among older adults. He leads a strong federally funded (NIH and VA) research training program for trainees of all levels desiring to pursue a career in patient-oriented research.



John Beard, Ph.D., M.B.B.S., is Irene Diamond Professor and Director of the International Longevity Center-USA at Columbia University, New York. He was previously Director of Ageing and Life Course with WHO in Geneva. While at WHO he led multiple large international initiatives including the 2015 *World report on ageing and health*, the Integrated Care for Older People (ICOPE) programme, and the *Global Network of Age-friendly Cities and Communities* which now spans over 300 million people. He has worked extensively with the World Economic Forum and was a commissioner with the recent US National Academy of Medicine Commission on Healthy Longevity.



Jerome Bickenbach, Ph.D., LL.B., is a permanent visiting professor at the Faculty of Health Sciences and Medicine at the University of Lucerne and professor emeritus in the Department of Philosophy and Faculties of Law and Medicine at Queen's University. Since 1995, he has been a consultant with the World Health Organization (WHO) working on the revision of the ICIDH to the final draft leading to the ICF. Prof. Bickenbach has participated in nearly all revision activities, and continues to consult with WHO on ICF dissemination and international disability social policy. His research is in disability studies, using qualitative and

quantitative research techniques within the paradigm of participatory action research. Most recently his research includes disability quality of life and the disability critique, disability epidemiology, universal design and inclusion, modelling disability statistics for population health surveys, the relationship between disability and wellbeing, disability and ageing issues and the application of ICF to monitoring the implementation of the UN Convention on the Rights of Persons with Disabilities. As a lawyer, Prof. Bickenbach was a human rights litigator, specializing in anti-discrimination for persons with intellectual impairments and mental illness. Since 2007, he has led the Disability Policy Unit at Swiss Paraplegic Research in Nottwil. He is the author of *Physical Disability and Social Policy* (1993) and the co-editor of *Introduction to Disability* (1998), *Disability and Culture: Universalism and Diversity* (2000), *A Seat at the Table: Persons with Disabilities and Policy Making* (2001), *Quality of Life and Human Difference* (2003) and numerous articles and chapters in disability studies, focusing on the nature of disability and disability law and policy.



Dorothy Boggs, Ph.D. O.T.R./L., M.Sc.P.H., F.H.E.A., is a mixed methods researcher at the London School of Hygiene & Tropical Medicine who works with the International Centre for Evidence on Disability. For her background, she is a US Occupational Therapist who received her Bachelors in Occupational Therapy at Boston University and both her Masters in Public Health and her PhD in Clinical Research at LSHTM. She worked for Disability INGO HI for almost 7 years before joining LSHTM as a researcher in 2016. Dorothy's work focuses primarily on health, functioning and disability metrics and measurement approaches, and access to

rehabilitation and assistive technology globally. She has published over 25 peer-reviewed publications, in addition to a variety of grey literature publications and international conference presentations. She has over 15 years' experience in rehabilitation, disability, inclusion and maternal, newborn & child health in low and middle-income countries.



Henri Bounameaux, M.D., is an honorary professor and emeritus Dean of the Faculty of medicine of the University of Geneva. He was active during 40 years at the University Hospitals of Geneva, as Chief of the Division of angiology and hemostasis, Chairman of the Department of Internal medicine and lastly Director of Education and Research. His research topics dealt with all aspects of venous thromboembolic disease, mainly pulmonary embolism. Since 2020, he is the President of the Swiss Academy of Medical Sciences.



Somnath Chatterji, M.D., worked with WHO for over 20 years, most recently as the outgoing director of the department of Data and Analytics. He trained as a medical doctor and specialized in Psychiatry. He has coordinated several large international projects, including the development of the International Classification of Functioning, Disability and Health, the revision of the International Classification of Diseases and related Health Problems, the World Health Surveys, WHO's Study on Global Ageing and Adult Health, the World Mental Health surveys and several other large international projects funded by the National Institute on Aging, the National

Institute of Mental Health, National Institute of Alcohol and Alcoholism, National Institute of Drug Abuse, the European Commission and other funding agencies. He has participated as a speaker at several National Academies of Sciences meetings on Subjective Wellbeing, Ageing and Healthy Longevity. He has a published track record of estimating the impact of health conditions and their burden globally including books on the burden of mental disorders and on the cross-cultural study of disability. He has been listed by the Web of Science as being among the world's most cited researchers (h-index 102) and has over 200 publications in prestigious peer reviewed journals.



Alarcos Cieza, Ph.D., M.P.H., M.Sc., is Head of the Integrated Service Delivery Unit and the Sensory Functions, Disability and Rehabilitation Unit at the WHO Department of Noncommunicable Diseases. In this role, she provides strategic leadership, management support and overall direction to WHO's work on integrated service delivery with a focus on Noncommunicable Diseases, eye and hearing care, rehabilitation, and Disability. Prior to joining WHO in September 2014, she served as Chair and Professor of Medical Psychology at the Faculty of Social and Human Sciences at the University of Southampton in the United Kingdom and led a research unit for over ten years at the Department of Physical Medicine and Rehabilitation and then at

the Pettenkofer School of Public Health at the Ludwig-Maximilians-University, Munich, Germany.



Nicola Diviani, Ph.D., serves as a Senior Research Associate at Swiss Paraplegic Research (SPF), within the Person-Centered Health Care & Health Communication Group. He is also a lecturer at the University of Lucerne's Faculty of Health Sciences and Medicine. At present, he leads a pivotal four-year project focusing on the existential aspects of self-management for individuals recently diagnosed with spinal cord injuries, generously supported by the Swiss National Science Foundation. His involvement extends to numerous projects exploring health behavior and related factors. Diviani is an active member of the University of Lucerne's Center for Rehabilitation in Global Health Systems and has offered

his expertise as a consultant to the World Health Organization's "Make Listening Safe" program and the World Rehabilitation Alliance (WRA). Furthermore, from 2016 to 2022, he represented Switzerland on the Advisory Committee of the International Association for Communication in Healthcare (EACH). Holding a PhD in Communication Sciences from the University of Lugano, Diviani's research primarily explores health behavior, literacy, self-management, health information seeking (both online and offline), health empowerment, eHealth, and mHealth. His work critically examines the challenges individuals face in leveraging (new) communication technologies for health-related purposes, such as cancer prevention, vaccination, or self-management, aiming to identify effective solutions to these issues. Over the years, Diviani has conducted extensive research at the Institute of Communication and Health at the University of Lugano, as well as at the Harvard School of Public Health and the Amsterdam School of Communication Research, contributing significantly to the field.



Victor Dzau, M.D., is the President of the U.S. National Academy of Medicine (NAM), formerly the Institute of Medicine in the United States. In addition, he serves as Vice Chair of the National Research Council. Dr. Dzau is also James B. Duke Professor of Medicine and Chancellor Emeritus at Duke University and the past President and CEO of the Duke University Health System. Dr. Dzau is recognized globally for a long and highly decorated career as a scientist, administrator and leader. His important work on the renin angiotensin system (RAS) paved the way for the contemporary understanding of RAS in cardiovascular disease and the

development of widely used, lifesaving drugs. Dr. Dzau also pioneered gene therapy for vascular disease, and his recent work on stem cell paracrine mechanisms and the use of microRNA in direct reprogramming provides novel insight into stem cell biology and regenerative medicine.



Julia Patrick Engkasan, Ph.D., M.B.B.S., is an Associate Professor at the Department of Rehabilitation Medicine, Universiti Malaya (UM). Her primary research area is in spinal cord injury rehabilitation but she is also leading research in pulmonary and geriatric rehabilitation. She has research collaborative work within different disciplines within Universiti Malaya, Malaysia and internationally. She is the chair of International Society of Physical and Rehabilitation Medicine (ISPRM)-WHO Subcommittee as well as committee member of the International Classification of Functioning, Disability and Health (ICF) Taskforce. She sits in the editorial board of Spinal Cord journal, Journal of Rehabilitation Medicine, and ASEAN Journal of

Rehabilitation Medicine. She graduated with Masters of Rehabilitation Medicine degree from Universiti Malaya in 2006. She subsequently pursued PhD in Shared Decision Making, also in the Universiti Malaya and graduated in 2017.



Walter R. Frontera, M.D., Ph.D., F.R.C.P., is a professor of physical medicine and rehabilitation at the University of Puerto Rico School of Medicine. He formerly served as the inaugural chair and professor of physical medicine and rehabilitation at Harvard Medical School and Vanderbilt University School of Medicine. Dr. Frontera's main research interest is study of the mechanisms underlying muscle atrophy and weakness in the elderly and the development of rehabilitative interventions for sarcopenia. He is editor-in-chief of the American Journal of Physical Medicine and Rehabilitation and the immediate past president of the International Society of Physical and Rehabilitation Medicine. He received his medical degree from the University of Puerto Rico School of Medicine and a Ph.D. in applied anatomy and physiology from Boston University. Dr. Frontera is a member of the National

Academy of Medicine and has served on numerous National Academies' committees, including the Standing Committee of Medical and Vocational Experts for the Social Security Administration's Disability Programs and the Committee on the Use of Selected Assistive Products and Technologies in Eliminating or Reducing the Effects of Impairments. He is also a Fellow of the Royal College of Physicians (London).



Marija Glisic, M.D., Ph.D., P.D., is a medical doctor with a Master's degree in Health Sciences and a PhD in Clinical Epidemiology from Erasmus University Rotterdam Medical Center (Rotterdam, the Netherlands). She has also completed a post-doctoral qualification (Habilitation) in Clinical Epidemiology at the University of Bern, Switzerland. Marija is leading a research group at the Institute for Social and Preventative Medicine, University of Bern that focuses on cardiometabolic disease and spinal cord injury. She also works at the Swiss Paraplegic Research (SPF) in Campus Nottwil, Switzerland, where she co-leads Cardiometabolic and

Respiratory Research group. Marija's research aims to understand the determinants of cardiometabolic disease risk in individuals with neurotrauma. Additionally, she seeks to support the development and implementation of cost-effective personalized interventions to reduce disease burden and improve the lived experience of people with injuries. Her research has a special focus on sex/gender differences, women's health, and lifestyle.



Francesca Gimigliano, M.D., Ph.D., is a Professor of Physical and Rehabilitation Medicine, Chair of the Clinical Unit of General and Specialist Rehabilitation Medicine, Coordinator of the PhD National Program in Public Administration and Innovation for Disability and Social Inclusion, and President of the Bachelor Program of Speech and Language Therapy, in the Department of Mental and Physical Health and Preventive Medicine at the University of Campania "Luigi Vanvitelli". Gimigliano is also the President for the International Society of Physical and Rehabilitation Medicine



Abderrazak Hajjioui, M.D., M.P.M., Ph.D., has specialized in physical and rehabilitation medicine since 2009 and in pain medicine since 2011. Currently serving as a full Professor at the Faculty of Medicine and Pharmacy, University Abdelmalek Essaâdi of Tangier, Morocco, he holds a European Master's degree in PRM and earned a master's degree in public management in 2014. In 2017, he was awarded the national prize for research and innovation in disability. His extensive contributions include the publication of numerous articles and books. As an international expert in Rehabilitation and Health System, he serves as the co-chair of the workforce workstream of the World Rehabilitation Alliance, a member of the ISPRM ClinFIT Committee, the ISPRM Task Force on Physical Activity for PwD, and the International Society of Physical and Rehabilitation Medicine (ISPRM)-World Health Organization (WHO) Liaison Committee. Additionally, he holds the

positions of president of the Moroccan Association for the Promotion of Rehabilitation Sciences and Prevention of Disability, vice-president of the Middle Eastern and North African (MENA) network, and is a member of the African SCI Network.



Alan M. Jette, Ph.D., is Emeritus Professor and Dean at Boston University's Sargent College of Health & Rehabilitation Sciences and served as Professor of Health Policy & Management at the Boston University School of Public Health from 2005-2017. He also served as Professor of Rehabilitation Sciences at the Massachusetts General Hospital Institute of Health Professions from 2012-2021. He is an international expert on rehabilitation and a leader in developing patient-centered rehabilitation outcome measures in a range of challenging clinical areas such as work disability, post-acute care, spinal cord injury, and neurological, orthopedic, and geriatric conditions. He has authored more than 250 publications in the rehabilitation sciences field and served as a principal investigator for numerous studies funded by the National

Institutes for Health, the National Institute on Disability, Independent Living, and Rehabilitation Research, the Agency for Healthcare Quality and Research, and several foundations. He has served as a member of more than a dozen NASEM boards and committees. He chaired the Institute of Medicine (IOM) committee that authored the 2007 report, "The Future of Disability in America." In addition to co-chairing the IOM Forum on Aging, Disability, and Independence he was chair of the IOM Committee on the Use of Selected Assistive Products and Technologies in Eliminating or Reducing the Effects of Impairments. He was elected to the National Academy of Medicine in 2013. He earned a bachelor's degree in physical therapy from the State University of New York at Buffalo and a master's degree and Ph.D. in public health from the University of Michigan.



Ruth Katz, M.Ed., is the incoming President and CEO of Association of Jewish Aging Services (AJAS) in late February 2024. From 2018 to 2024 she served as Senior Vice President for Policy and Advocacy at LeadingAge. Both AJAS and LeadingAge are membership organizations of nonprofit providers of aging services across the continuum of care, including nursing homes, assisted living, home care, hospice, low-income senior housing, and independent living services. At LeadingAge she led the Public Policy and Advocacy team - developing, leading and overseeing the successful execution of LeadingAge's public policy agenda, including legislation and regulation. Based on the Board approved public policy agenda, and in collaboration with state partners, Ruth oversaw the development of LeadingAge's public policy positions and employed strategies to advance

LeadingAge's policy agenda through Congress and the Executive Branch. She ensured thoughtful analysis of policy options and direction and activated the membership to achieve the LeadingAge agenda through engagement and grassroots efforts. Ruth was is a principal spokesperson for the Association's public policy positions and the primary representative of the policy agenda to other organizations and coalitions concerned with policy issues affecting LeadingAge membership. Prior to joining LeadingAge, Ruth was a longtime executive at the U.S. Department of Health and Human Services (HHS) with a

focus on development and execution of policy research and analysis for programs in aging, long-term care and disability. Ruth built her career at HHS' office of the assistant secretary for planning and evaluation (OASPE) and the office of disability, aging and long-term care policy (ODALTCP). In her dual roles as the associate deputy assistant secretary and the director, division of aging and disability, she led, directed, and coordinated policy regarding OASPE/ODALTCP's disability, aging, Medicare, and long-term care policy agenda; managed staff; and oversaw policy research.



NiCole R. Keith, Ph.D., M.S., is dedicated to research and programming that increases physical activity participation, improves fitness, and positively influences health outcomes while addressing health equity. She has served on the IU Bloomington faculty since 2023. She also is a research scientist at the IU Center for Aging Research in the IU School of Medicine and a Regenstrief Institute investigator. Keith was the 2020–2021 American College of Sports Medicine (ACSM) vice president of membership, communication, education, and policy, the 2020–21 ACSM president, and serves on several other ACSM national committees.

A Fellow of the National Academy of Kinesiology (NAK), Keith serves on the NAK Justice, Equity, Diversity, and Inclusion Presidential Committee, the Membership Committee, and the Editorial Board. She is currently the Chair of the National Physical Activity Plan and serves on the Physical Activity Alliance Advisory Committee. Keith earned a B.S. degree in physical education from Howard University in 1992, an M.S. degree in exercise science from the University of Rhode Island in 1994, a Ph.D. degree in exercise physiology from the University of Connecticut in 1999, and an M.S. degree in clinical research from Indiana University in 2011. She is trained in physical activity, community, and clinical research.



Fary Khan, M.D., A.M., M.B.B.S., F.A.F.R.M., is a Specialist in Rehabilitation and Physical Medicine, and a Fellow of the Royal Australasian College of Physicians (RACP). Currently, she is the Director of Rehabilitation Services, Royal Melbourne Hospital and Clinical Director, Australian Rehabilitation Research Centre; Clinical Professor, Department of Medicine at University of Melbourne and the Nossal Institute of Global Health, and the PeterMac. She is an elected international member for the U.S. National Academy of Medicine for her contribution to Rehabilitation Medicine and Research. She was awarded the Member for the Order of Australia (2022) for significant contribution to Rehabilitation Medicine and Research. She is the Inaugural Academic Fellow to the Board of the Australasian Faculty of Rehabilitation Medicine (AFRM)-RACP and elected Board Member of the Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ). She has 20 years

of experience in neurological, cancer and trauma rehabilitation. She set up evidence-based specialized rehabilitation programs for specific conditions such as Multiple sclerosis, Guillain-Barre Syndrome, stroke, oncology, musculoskeletal injuries, and disaster

management. She is the current Chair of the Disaster Rehabilitation Committee, International Society of Physical and Rehabilitation Medicine (ISPRM) and Disaster Rehabilitation Special Interest Group, RMSANZ. She holds over 20 National/International Executive positions and over 15 international academic appointments at various Universities. She is an Executive member of ISPRM Women's Taskforce and Cancer Rehabilitation Working Group. She has an interest in Refugee Health and Disability. She works with the Executive for the UN-International Council for Caring Communities and WHO-ISPRM Liaison Committee representing medical disability. She leads the Global Rehabilitation 'Flying Faculty' (endorsed by the Australasian Faculty of Rehabilitation Medicine, RACP, ISPRM), established to support capacity-building activities in Rehabilitation Medicine, with educational training programs in over 15 countries. Prof Khan has a leadership role in Rehabilitative care in Australia with over 20 years of experience in health outcomes and health services research. She has published over 500 scientific papers in peer-reviewed academic journals (including 14 Cochrane reviews, 20 book chapters).



Matilde Leonardi, M.D., is the Director of Neurology, Public Health, and Disability Unit and Coma Research Centre, and is Director Italian of the WHO Collaborating Centre-Research Branch- Fondazione IRCCS Istituto Neurologico Carlo Besta, Milan, Italy. Leonardi is a Neurologist, Pediatrician, Neonatologist, and Child neurologist, and specializes in Bioethics. Leonardi is also a WFNR Presidium member, WFNR Flying Faculty, One Neurology Ambassador, EAN Chair Communication Committee and Board member, FEAN Fellow of the European Academy of Neurology. WFN Board member of Advocacy, EFRR board member, WHO expert on disability and neurology. Co-chair WHO NeuroCovid Forum—essential neurological services Group and member of

Neuro Covid Global Research Coalition. Leonardi is a Corresponding member of the Pontificia Academia Pro Vita and sits on the Board of Directors of the Bioethics Centre at the Catholic University of Milan. Leonardi was nominated by Italian Government as Member of National Bioethics Committee in 2022, was an elected Board Member of the National Neurology Society in October 2023, and was elected by EFRR (European Federation Research in Rehabilitation) in November 2023.



Patricia Morsch, Ph.D., M.A., P.T., is a physical therapist and has over 18 years of combined experience in clinical physical therapy and research on aging, older adults' health and public health. She holds a graduate certificate in Public Health, a Master of Arts in Gerontology from the University of North Carolina at Charlotte (USA) and a PhD in Biomedical Gerontology from the Pontifical Catholic University of de Rio Grande do Sul (Brazil). Currently work as the Healthy Aging Advisor in the Department of Health Systems and Services at the Pan American Health Organization (PAHO) headquarters in Washington D.C., Regional WHO office for the Americas.



Elias Mpofu, Ph.D., D.Ed., is a Professor of Aging and Rehabilitation Sciences at the University of North Texas, and honorary professor of health sciences at the University of Sydney. His aging and rehabilitation sciences research focuses on the development, implementation, and evaluation of resilience, social supports, and other health promotive relationships of older adults aging with or into disability. It frames aging and disability questions on the World Health Organization's International Classification of Disability, Health, and Functioning, an integrative approach for biological, psychological, and behavioural data. This provides for a holistic person x environment interaction perspective in which contextual factors are moderators between health and

wellbeing components (body function and structure, activity limitations and participation restrictions) and with feedback pathways among the components. His research advances the design of person-centric approaches for the successful community living and participation of older adults, supporting their empowered aging.



Diana Pacheco, Ph.D., is currently Professor at the Faculty of Health Sciences and Medicine, and Group Leader of the Health Economics Group at Swiss Paraplegic Research. She has a Ph.D in Economics (2013) from the University of Neuchatel, Switzerland, and a MSc. in Economics from the University of Lausanne (2008), Switzerland. Between 2015 and 2020, she was a Postdoctoral Fellow at Swiss Paraplegic Research in the Rehabilitation Services, Economics & Statistics Group. Since her PhD, Prof. Pacheco has taught several courses, including Social Policy, Health Systems and Services, Applied Economics, and Social Impact of Health. Her research interests include health economics, applied economics, and social policy.



Birgit Prodinger, Ph.D., is a health and rehabilitation scientist with extensive experience in studying and teaching functioning, was recently appointed as Chair and Professor of Inclusive Health Care at the Faculty of Medicine at the University of Augsburg. Birgit's research focuses on describing and understanding the lived experience of people with disability and how in particular health systems respond to their needs. She has contributed considerably to establish methods for the standardized reporting of routinely collected functioning data in clinical practice by using the International Classification of Functioning, Disability and Health (ICF) as a reference.



Jan D. Reinhardt, Ph.D., is an epidemiologist and rehabilitation researcher. He is currently employed as Full Professor and Director of Health Sciences at the Institute for Disaster Management and Reconstruction (IDMR) of Sichuan University and Hong Kong Polytechnic University, China. In addition, Dr. Reinhardt holds the following positions: Visiting Professor at Jiangsu Province Hospital/Nanjing Medical University First Affiliated Hospital, China; Lecturing Professor at the Department of Health Sciences and Medicine of the University of Lucerne, Switzerland. He is a PhD Supervisor at the West China School of Public Health and School of Nursing, Sichuan University, China as well as at the Department of Health Sciences and Medicine, University of Lucerne, Switzerland. He is a former Chairman of the Disaster

Rehabilitation Committee (DRC) of the International Society of Physical and Rehabilitation Medicine (ISPRM) and current chairman of the Disaster Special Interest Group of the Asia-Oceania Society of Physical and Rehabilitation Medicine (AOSPRM). Prof. Reinhardt is furthermore Associate Editor of the International Journal of Public Health. He has authored over 150 original articles in international journals listed in science citation index with over 3,700 citations and an h-index of 37. His research interests comprise among others: Rehabilitation research, International Classification of Functioning, Disability, and Health, epidemiology of functioning and disability; theory, measurement and models of environmental factors and their relation to human health; labor market participation of persons with health conditions; effectiveness of clinical and health services interventions; international NGOs in disability and rehabilitation; health and rehabilitation after natural disaster; clinical trial design and research methodology; prediction models for health care demand and payment.



Sara Rubinelli, Ph.D., holds a degree in Classics and Philosophy from the Catholic University of Milan (I) and a PhD from the University of Leeds (UK) in the areas of argumentation theory, persuasion and rhetoric. She is Professor in Health Communication at the Faculty of Health Sciences and Medicine of the University of Lucerne (CH), and vice-Dean Health Sciences. Since September 2009 she leads the Person-Centered Healthcare/Health Communication Group at Swiss Paraplegic Research (CH). Since 2017 she is scientific advisor for the World Health Organization.



Carla Sabariego, Ph.D., M.P.H., is a clinical psychologist and holds a Master's degree in Public Health and Epidemiology from the Ludwig-Maximilians-Universität (LMU) in Munich, Germany. She completed her PhD in 2011 with a focus on cost-effectiveness evaluations of rehabilitation programs. Her habilitation, finished in 2016, focused on the implementation of the WHO ICF as a conceptual framework in clinical rehabilitation and public health. She pursued both her PhD and habilitation at the Medical Faculty of LMU Munich, where she worked for 15 years as a senior researcher and lecturer at the Institute of Public Health and Health Services Research. From 2011 to 2018, she was a consultant to the WHO in the area of functioning and disability measurement: she mainly contributed to the development, pilot testing and implementation of the

WHO Model Disability Survey - a dedicated functioning and disability survey - in several countries worldwide. From May 2017 to July 2018, she worked in the WHO's Disability and Rehabilitation Programme in the Department of Noncommunicable Diseases, Disability, Violence and Injury Prevention in Geneva. In January 2021, she was appointed Assistant Professor (tenure track) for Rehabilitation and Healthy Ageing at the Faculty of Health Sciences and Medicine, University of Lucerne, and is currently Vice Dean of the Department of Rehabilitation and Functioning Sciences. Together with Prof. Gerold Stucki, she also heads the Faculty's Centre for Rehabilitation in Global Health Systems, which has been a WHO Collaborating Centre since 2018. Through her bridge professorship, she also leads the Ageing, Functioning Epidemiology and Implementation working group, together with Professor Jerome Bickenbach, at the Swiss Paraplegic Research in Nottwil.



Paola Sillitti, M.Sc., is a Research Officer at the Organization for Economic Cooperation and Development (OECD), within the Health Division. Her work covers mainly the topics of end-of-life care, long-term care, and integrated care. She holds a Master of Science in Economics and Management and a Bachelor of Science in Economics from Bocconi University (Milan, Italy). She has also studied Economics at HEC Lausanne (Lausanne, Switzerland) and International Affairs at Sciences Po Paris (Paris, France).



Eleanor Simonsick, Ph.D., is an epidemiologist in the Longitudinal Studies Section of the Translational Gerontology Branch within the Intramural Research Program (IRP) of the National Institute on Aging (NIA) where she serves as Co-Director of the Baltimore Longitudinal Study of Aging and Federal Project Officer of the Health, Aging and Body Composition study. For over 35 years she has conducted aging-related research within the context of longitudinal observational studies focused on assessment of higher-order physical function and evaluating the behavioral, psychological, biomechanical and physiologic factors and conditions that impact maintenance and decline in function and the overall aging process.



Bruno Staffelbach, Ph.D., is a Professor for Business Administration, Director of the Center for Human Resource Management (CEHRM) and President of the University of Lucerne. Dr. Staffelbach is an Honorary Member of the International Committee of the Red Cross, and is a former Brigadier General and Commander of an Infantry Brigade of the Swiss Armed Forces.



Gerold Stucki, M.D., M.S., is a Professor in the Faculty of Health Sciences and Medicine and Director of the Center for Rehabilitation in Global Health Systems, a WHO Collaborating Center, at the University of Lucerne. He is also Director of Swiss Paraplegic Research and the ICF Research Branch (Switzerland). A physician with clinical training in Physical and Rehabilitation Medicine and Rheumatology, Prof. Stucki holds a Master of Science in Health Policy and Management from the Harvard School of Public Health (U.S.A.) and a diploma in Biostatistics and Epidemiology from the University of McGill (Canada). He has been a member of the

National Academy of Medicine (U.S.A.) since 2012.



Carl Willers, M.D., Ph.D., holds a PhD in public health and epidemiology from Karolinska Institutet where he is a postdoctoral researcher at the department of Neurobiology, Care Sciences and Society. He is a member of a multidisciplinary research group focusing on rehabilitation, collaboration and aging, and has taught at various courses on the subjects of health equity and registry data studies. Ongoing research projects include health economic analysis of healthcare and social care for the Swedish geriatric population, evaluation of existing models for discharge from geriatric inpatient care, and development of new ways of working to optimize care transitions. He is employed as an intern physician at the Karolinska University hospital and is an affiliated researcher at the Research and Development Center for Elderly, an initiative for enhancing operationalization of research for older adults, run by the Stockholm Region

Council and its municipalities. He also holds a degree in economics from the Stockholm School of Economics and has been working within management consultancy (McKinsey & Company) and health economics (i3, United Health Group) before entering academia.

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Functioning and the realization of healthy longevity through rehabilitation

Concept Note, Panel 1

Context

The aim of this Workshop is to facilitate a discussion of the World Health Organization's concept of functioning as introduced in its *International Classification of Functioning, Disability and Health (ICF)*, and to explore its role in rethinking the operationalization of health and its application to healthy longevity and the increasing relevance of rehabilitation as a key health strategy for the 21st Century.

In the ICF, functioning includes the functions and structures of the body that constitute the intrinsic health capacity of a person as well as the actual performance of simple and complex activities in interaction with the person's physical and social environment. Conceptually, functioning comprises the domains of both biological health and lived health, where lived health is fully contextualized as an outcome of interactions between a person's intrinsic health capacity and features of their environment.

Across the lifespan, all of us may experience pain, anxiety, fatigue and weakness, tight joints, skin sores, and other sensory, mobility, and cognitive impairments. When these impairments impact on our lives – when we cannot climb stairs painlessly, walk as far as we used to, clean or dress ourselves, read a book, make and keep friends, do all the homework we need to do, or perform our jobs – these concrete, real-life difficulties affect and shape our lived experience of health. And this lived experience is what matters to us about our health and why we seek out healthcare in the first place. When we do not experience these difficulties, we are well advised to invest in health promotion activities to make us more resilient in functioning. In short, the notion of functioning creates a more meaningful operationalization of what health means to us.

WHO's concept of human functioning constitutes a new understanding and conceptualization of health with wide-ranging consequences, for ageing and rehabilitation research, practice and policy.

Functioning constitutes a third health indicator of health, augmenting the traditional indicators of mortality and morbidity. As the third indicator, functioning completes our intuitive sense of why health matters: Avoiding premature mortality and controlling morbidity are clearly important to us, both individually and as members of society at large. But there is a third dimension that is missing to this picture: our everyday functioning and lived experience of our state of health. This is most clear in the case of population aging: as improved healthcare and other social improvements continues

to add more years to our lives, it becomes equally important to add more life to our years.

As well as population ageing, the increased prevalence of non-communicable diseases – whose impact is primarily assessed in terms of changes in functioning – is a substantial public health concern, warranting increased investment in rehabilitation which aims to optimize functioning. These trends point to the need to prepare our healthcare systems by reorienting their focus to optimizing functioning through strengthening rehabilitation.

The operationalization of health as functioning helps to explain the contribution the healthcare system can make to individual well-being and societal welfare, providing as well a more robust foundation for our understanding of disability, as a decrement of functioning, and how we for health and social purposes assess disability.

Objective of the Panel

The objective of this panel is to prepare the ground for the Workshop by scrutinizing WHO's notion of functioning. The focus is conceptual and focuses on

- A. The role of functioning as the third indicator of health in the operationalization of health for ageing and rehabilitation research, practice and policy.
- B. Functioning as a robust and sound basis for the healthy longevity agenda, specially in ensuring that rehabilitation – the health strategy whose primary aim is to optimize functioning – can contribute to these goals.
- C. The potential of functioning to capture what the health care system can contribute to individual well-being and societal welfare, in light of population ageing.
- D. The role of functioning for reorienting the notion of disability, especially for standardized, transparent and fair assessment for health and social benefits.

Questions for Discussion

- 1) What is the role of functioning in operationalizing health for measurement, the health sciences, practice and policy – how can functioning as the third indicator of health being concretely implemented?
- 2) How can functioning in practice provide a robust and sound basis for the healthy longevity agenda, specially in ensuring that rehabilitation – the health strategy whose primary aim is to optimize functioning – can contribute to those goals?
- 3) How can functioning directly contribute to the explanation of what the health care system can contribute to individual well-being and societal welfare?

- 4) How can functioning reorient our understanding of disability, especially for to achieve standardized, transparent and fair assessment of disability for health and social benefits?

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Drafted by Jerome Bickenbach

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Functioning and the investment case for the role of rehabilitation in healthy longevity

Concept Note, Panel 2

Context

This panel will show how expanding the focus on human functioning can bring enormous economic gains, both to individuals and society at large. The focus on functioning emphasizes that people care about their health not just because of the stock of health they can accumulate but because of what they can do when healthy, i.e., their functioning. In general, people with a wider range and more robust functioning are more independent and actively participate in society, which has important implications for the financial stability of families, the economy, and health and social systems.

People are living longer – the product of the great success of medicine and technology – but they are also more likely to face chronic health conditions that limit their everyday lives. Increasing prevalence of chronic health conditions means more disability, which in turn creates economic challenges both for the individual and the rest of society. People facing disability not only require more care, support and accommodation, but also many people with disabilities have to limit their labor market participation. As these epidemiological and social trends continue, the increasing dependency and accommodation levels will bring significant financial constraints for individuals, their families, and the economy in general, with important impacts on how our health and social systems are organized.

While expanding services and insurance coverage may be the first solution to cope with the increasing needs of the population, the increasing health and social care costs will constrain the growth possibilities of societies. Therefore, a more proactive solution will be to fundamentally shift the policy focus from a limited one of treating health conditions, to a more comprehensive measure of functioning. If successful, we will get a more productive and effect societal structure, more financially stable individuals and families, more dynamic economies, and sustainable health and social systems.

Objective of the Panel

This panel discusses how re-centering the focus of health and social systems to people's functioning can bring significant economic gains to society. This panel will take a societal perspective and will consider whether:

- A. Targeting functioning translates into more active and participating citizens in the labor market, and the potential economic gains: this shift directly impacts the labor supply currently limited in industrialized economies.
- B. Targeting functioning translates into a more independent population that relies less on the support, care and accommodation from others: this shift will have important implications for the financial situation of individuals and their families.
- C. Targeting functioning will result in healthier and more active people and contain the increasing health and social care expenditure: this shift will impact health and social cost, and the sustainability of health and social systems, in the long term.

Questions for Discussion

- 1) Demographic dynamics put disability at the center of public health. Therefore, how can we show health and social systems that what matters for society is functioning and not only health?
- 2) One of the main challenges for health and social systems is coping with the increasing needs of care in the population. Currently, long-term care is extremely expensive and covers a small part of the population. How can we shift the focus of health and social systems towards functioning and not only expanding care services?
- 3) While health is important, what matters at the social level is that people be independent. Therefore, how can we incentivize the active measurement of other relevant outcomes, such as working status, in the health and social care systems?
- 4) How can we expand the focus toward a more comprehensive understanding of human health in terms of functioning within the existing structure of health and social systems? Do health and social services need to adapt their information systems and their reimbursement and other financial arrangements in order to include indicators that allow us to measure functioning?

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Drafted by Diana Pacheco

The foundation for improving rehabilitation service delivery and care across the life course: person-centered care, integrated care principles and the lived experience of health

Concept Note, Panel 3

Context

The overall aim of this workshop is to facilitate a discussion on how rehabilitation services, focusing on effective, accessible, integrated and person-centered care, can contribute to achieving the goals of the UN Decade of Healthy Ageing. As the main goal of rehabilitation is to optimize functioning, the concept of functioning provides the basis for achieving this goal and fully realizing the healthy longevity agenda.

Rehabilitation is recognized by WHO as one of its five health strategies in the Astana Declaration, in which Member States committed to "*...meet the health needs of all people across the life course through comprehensive preventive, promotive, curative, rehabilitative and palliative care*". Due to its importance in a world increasingly characterized by ageing societies and "epidemic" non-communicable diseases, in 2017 WHO launched a specific agenda - WHO Rehabilitation 2030 - calling on member states to strengthen health systems to provide rehabilitation to all people in need, including people with health conditions, the ageing population and people with disabilities. Finally, access to rehabilitation is a human rights issue. The Convention on the Rights of Persons with Disabilities (CRPD) devotes Article 26 to rehabilitation, stressing the need to strengthen services and programs and access to assistive technology.

The global need for rehabilitation is profound. In 2019, a landmark article in The Lancet using data from the Global Burden of Disease showed that 2.41 billion people have health conditions that would benefit from rehabilitation. This represents one in three people worldwide, many of whom are older adults. The main health conditions associated with the needs of people over 65 are musculoskeletal disorders, neurological disorders, sensory disorders (hearing, vision) and chronic respiratory diseases. A Resolution on Rehabilitation was adopted by the World Health Assembly in 2023, emphasizing the need to strengthen rehabilitation into health systems worldwide.

The importance of giving rehabilitation a more prominent role in healthy longevity agenda has been well justified, especially to improve health and social support services and assistive technologies for the ageing population. At the European level, scoping

reviews and online consultations currently being performed under the auspices of WHO EURO will lead to an expert consultation on priority setting for strengthening rehabilitation services for healthy ageing in Europe and a WHO EURO Regional Summit for National Policy Experts on Healthy Ageing in Lisbon in October 2023 focused on the United Nations goals as part of the Decade on Healthy Ageing. All these initiatives to strengthen rehabilitation, however, depend on concerted efforts to ensure changes and reforms to health systems to support rehabilitation and international ageing agendas.

Objective of the Panel

The objective of this panel is to interrogate health systems in light of international healthy ageing agendas and in particular the essential role that rehabilitation, as the health strategy whose aim is to optimize functioning, in healthy longevity and ageing. The panel focuses on

- A. the role of rehabilitation service delivery and care across the life course;
- B. rehabilitation as a key WHO health strategy to achieve healthy ageing;
- C. the potential of health systems reforms to ensure that rehabilitation contributes to individual well-being and societal welfare, in light of population ageing;
- D. rehabilitation as a health strategy to all people in need, including people with health conditions, the ageing population and people with disabilities.

Questions for Discussion

- 1) What is the role of rehabilitation service delivery and care across the life course for the health sciences, practice and policy – how can rehabilitation as a health strategy be concretely strengthened in health systems?
- 2) How can rehabilitation as a key health strategy contribute to achieve a healthy longevity of populations worldwide?
- 3) What is the potential of rehabilitation to contribute to individual well-being and societal welfare, in light of population ageing, and how this should be communicated to policy makers?
- 4) How can we reorient our understanding of rehabilitation, from a service exclusive to specific groups to a health strategy relevant to all people in need, including people with health conditions, the ageing population and people with disabilities?

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Drafted by Carla Sabariego

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Functioning as the key to a comprehensive 360-degree life-course foundation for healthy longevity research

Concept Note, Panel 4

Context

As functioning is a multifaceted concept, when used as the foundation for research into the lived experience of health, it is a challenge to capture in study design its complexity integrating different methodologies, measures and perspectives that represent the biomedical, psychological and social dimensions of functioning. This is not merely a matter of collaboration across disciplines, but also collecting comparable functioning information. While the *International Classification of Functioning, Disability and Health* (ICF) provides the framework for describing and organizing comparable functioning information, there remains considerable work to be done to develop standardized assessment and statistical analysis of functioning information, including harmonization across different data sources, clinical, cohort and population studies, and administrative data. Particularly challenging, given that functioning changes over time, and across different environmental contexts, is assessing change longitudinally. This is especially important for ageing studies when life events and the ageing process itself influence trajectories of functioning.

Rehabilitation involves diverse populations with different health conditions, impairments, and health and health-related needs. This heterogeneity can make it difficult to generalize findings and develop universally applicable interventions. Because functioning is influenced by diverse contextual factors – from the climate, to interpersonal relations and attitudes, to social and economic structures – researchers are challenged to ensure that findings are applicable across diverse populations and settings. Statistical analysis of heterogeneous samples requires large sample sizes, which are often difficult to achieve in rehabilitation settings.

Finally, as with all health research that aims to capture the full experience of health, functioning research that a 360 degree perspective faces considerable practical challenges. Investigating rehabilitation interventions can be resource-intensive and economic constraints may limit the scope and scale of these studies, which in turn affect the researchers' ability to address all aspects of functioning. It is also challenging to ensure that functioning research addresses issues that are aligned with individuals' priorities and values, as well as achieving meaningful patient participation in the research process. Disparities in access to rehabilitation services, particularly in underserved communities or low-income populations, pose challenges for study recruitment, may introduce selection bias, and compromise the external validity of studies. More generally, rehabilitation and healthy longevity research is underfunded, making it difficult to conduct high-quality research and to recruit and retain talented

researchers. There is, as well, a need to train health scientists in functioning and to build academic capacity for a new generation of health researchers. Finally, functioning research results must be translated into practice and inform policy, which will require new strategies of implementation.

Objective of the Panel

The notion of functioning opens up the possibility for innovative research in health sciences, and rehabilitation and health longevity specifically, but capturing the full 360-degree of the lived experience of health comprising a range of scientific perspective, from the biomedical, the clinical, epidemiological, psychosocial and socio-humanistic. The goals of this workshop is to explore this potential and opportunities of functioning-based health research and to identify key challenges in research on functioning for rehabilitation and healthy longevity.

Questions for Discussion

- 1) Does reorienting health sciences around the concept of functioning augment our understanding of the lived experience of health, and if so in which ways?
- 2) How can the use of functioning as a framework for 360 degree research on the lived experience of health conditions be fully utilized in service of the scientific advancement of rehabilitation and the healthy longevity agenda?
- 3) How can functioning within rehabilitation and healthy longevity research have maximum impact and recognition, given the need to emphasis multidisciplinary collaboration rather than prioritizing specific scientific disciplines or methodological approaches?
- 4) Do we need tailored scientific research careers in rehabilitation and healthy longevity to address its challenges and enhance efforts to study functioning, and what would ideal research curriculum look like in detail?
- 5) Are their unique, and uniquely challenging issues in bridging the gap between functioning-based rehabilitation and healthy longevity research findings and practice and policy; is new and novel translational research required to ensure that evidence-based interventions and policies are effectively implemented.

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Drafted by Armin Gemperli

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Advocacy for health and social policy in support of healthy longevity: Functioning as the third indicator of health

Concept Note, Panel 5

Context

This panel will highlight the crucial role of advocacy in bringing awareness of the importance of the World Health Organization's concept of functioning from the *International Classification of Functioning, Disability, and Health* (ICF) as a fundamental pillar in reimagining health operationalization, and specifically the potential for rehabilitation being the health strategy of the 21st Century.

Advocacy, at its heart, is the act of promoting and championing a particular cause or policy. In the realm of health and healthcare, advocacy takes on a pivotal role, serving as the bridge between innovative concepts and their acceptance in the broader society. The revolutionary concept of functioning in particular, while groundbreaking, is not immediately grasped or universally understood. The depth of its meaning, interlinking biological health factors with lived experiences, often clashes with prevalent, more monolithic interpretations of health. Addressing these misconceptions and the variety of interpretations requires targeted, informed advocacy.

Functioning melds the biological dimension of health with real-world, lived experiences. These experiences, reflecting the dynamic between individual health states and their environment, shape our perceptions and understanding of health and what it means for us in our daily lives. Yet, this very depth and intricacy make it susceptible to misinterpretation or oversimplification. For functioning to truly reshape how we perceive health and rehabilitation, especially in the context of healthy longevity, strong advocacy initiatives are required to elucidate its nuances and significance.

Introducing functioning as the third health indicator, augmenting traditional indicators of mortality and morbidity, demands a shift in societal perspective. Especially as the world contends with challenges like an ageing population and the rise of non-communicable diseases. These challenges underscore the need not just for quantitative longevity but also ensuring quality and purpose in those added years. Advocacy, then, becomes the key to stressing this nuance and urging the healthcare system to reorient its priorities towards optimizing functioning and recognizing the central role of rehabilitation.

In this light, the concept of functioning not only transforms our understanding of health but also refines our perspective on disability, framing it as a decrement in functioning.

However, for this concept to take root, and to influence policies and public opinion, focused advocacy efforts are essential.

This panel seeks to emphasize the paramount importance of advocacy in solidifying the place of functioning within our healthcare discourse. It will explore the challenges and strategies in promoting this nuanced concept, and how, through informed and evidence-based advocacy, we can pave the way for a more comprehensive and effective approach to rehabilitation.

Objective of the Panel

The objective of this panel is to highlight the vital role of advocacy in advancing the understanding and integration of the World Health Organization's functioning concept within the broader healthcare and societal discourse, thereby paving the way for a central role of rehabilitation in health systems. Specifically:

1. **Awareness & Clarification:** To illuminate the depth and intricacies of the functioning concept, identifying what it difficult to communicate about it.
2. **Strategizing advocacy:** To discuss effective advocacy strategies that can resonate with diverse stakeholders — from healthcare professionals and policymakers to the general public.
3. **Case studies & Challenges:** To share instances where advocacy for functioning faced hurdles, providing insights on overcoming these barriers and the lessons learned from these experiences.
4. **Interdisciplinary collaboration:** To underscore the importance of multi-disciplinary collaboration in advocacy, bringing together voices from healthcare, policy, academia, and patient advocacy to create a unified and compelling narrative.
5. **Futurescape:** To envision the potential impact on healthcare and society should the advocacy for functioning succeed, emphasizing the transformations in policy, practice, and public perception.

Questions for Discussion

1. What are the most common misconceptions and challenges in communicating and speaking about functioning, and how can we more effectively explain its depth and nuances to varied audiences?
2. What best practices or innovative approaches can be adopted to ensure that advocacy strategies for the concept of functioning to resonate not only with medical professionals but also with policymakers and the general public?
3. How can we foster a more collaborative advocacy approach that integrates perspectives from healthcare, policy, academia, and patient advocacy to present a cohesive and impactful message about the concept of functioning"?

4. Looking ahead, if our advocacy efforts concerning the concept of functioning are successful, what transformative changes can we anticipate in healthcare policies, practices, and public perceptions in the coming years?

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The human functioning revolution: implications for health systems and sciences

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Abstract

The World Health Organization (WHO) concept of human functioning represents a new way of thinking about health that has wide-ranging consequences. This article explicates this paradigm shift, illustrates its potential impact, and argues that societies can profit by implementing functioning as the third indicator of health, complementing morbidity and mortality. Human functioning integrates biological health (the bodily functions and structures that constitute a person's intrinsic health capacity) and lived health (a person's actual performance of activities in interaction with their environment). It is key to valuing health both in relation to individual well-being and societal welfare—operationalizing the United Nations Sustainable Development Goal (SDG) 3 principle that health is a public good. Implementing functioning as defined and conceptualized in the International Classification of Functioning, Disability and Health (ICF) could profoundly benefit practices, research, education, and policy across health systems and health strategies and help integrate health and social systems. It also offers a foundation for reconceptualizing multidisciplinary health sciences and for augmenting epidemiology with information derived from peoples' lived experiences of health. A new interdisciplinary science field—human functioning sciences—itself holds the promise to integrate research inputs and methods from diverse biomedical and social disciplines to provide a more comprehensive understanding of human health. To realize these opportunities, we must address formidable methodological, implementation, and communication challenges throughout health systems and broader society. This endeavor is vital to orientate health systems toward what matters most to people about health, to unlock the societal economic investment in health that is essential for individual and population-level well-being, and to drive progress toward achieving the SDGs.

KEYWORDS

functioning, health, well-being, health system, sustainable development goals

Key points

- The concept of human functioning integrates biological health (the bodily functions and structures that constitute a person's intrinsic health capacity) with lived health (a person's actual performance of activities in interaction with their environment).
- Functioning is the bridge that links health to individual well-being and societal welfare—thereby accounting for the value of health and potentially unlocking investment and progress toward achieving United Nations Sustainable Development Goal (SDG) 3.
- A paradigm shift implementing human functioning as the third indicator of health (complementing mortality and morbidity) could profoundly benefit practices, research, and policy across health systems and health strategies.
- Functioning also provides a basis for reconceptualizing multidisciplinary health sciences; a new interdisciplinary science field—human functioning sciences—itself holds promise to integrate diverse research inputs and methods to provide a fuller understanding of human health.
- To realize the opportunities offered by this rethinking of health we must address formidable methodological, implementation, and communication challenges within health systems and society.

Introduction

At the core of the United Nations' 2030 Agenda for Sustainable Development adopted in 2015 are the 17 Sustainable Development Goals (SDGs) that provide a “blueprint for peace and prosperity for people and the planet, now and into the future”. Among these goals is SDG3 Good Health and Well-being: “To ensure healthy lives and promote well-being for all at all ages” (1). Progress in the implementation of SDG3 is measured in terms of targets to reduce mortality and morbidity through public health measures and health system strengthening. These targets are interdependent and consistent with the other Goals that seek global agreement and concerted action on fundamental 21st-century development concerns, such as global poverty, hunger and inequality, environmental degradation, and weakening institutions. In recent years, the global situation has been made more dire by the COVID-19 pandemic, growing pressure on health services, and increased disparities in health outcomes between and within countries (2).

Academic discussions regarding SDG3 have criticized the adequacy of the indicators of mortality and morbidity (3–5), but little has been said about the purported link between health and well-being. Scholars standardly distinguish subjective from objective well-being: the former is analyzed into a composite of positive affect and cognitive evaluation or life satisfaction (6) and the latter either as a capability, the material conditions to achieve an individual life goal (7), or more generally as an opportunity to flourish (8). Yet there is general agreement that health is either a component or a determinant of individual well-being. There is also

agreement that the provision of healthcare and public health are public goods that contribute to overall societal welfare. By contributing to individual well-being in the aggregate they enable everyone to realize their potential, thereby enhancing productivity, increasing social opportunity, and reducing inequalities, thus improving societal welfare (9, 10).

The wording of SDG3 nonetheless poses a challenge: why should we think that a robust public health and healthcare system that extends life and decreases the incidence of diseases, injuries, and other health conditions will alone significantly improve individual well-being and societal welfare? After all, living a long time is not necessarily living well: data suggest that living longer can mean living in worse health (11), and while the absence of disease and injury may be necessary, it is not sufficient for human flourishing or societal welfare. There is something else that health contributes. Intuitively, while living longer without diseases and injuries is obviously relevant to well-being, a key driver of both individual well-being and societal welfare is being able to do and become what we wish—achieving our aspirations, goals, and values and in general acting in ways that make our lives worth living. If we are to take seriously the claim that there is a bridge between health and individual well-being and societal being, we need to fundamentally rethink why health is important to us or, more precisely, what actually matters to us about our health.

The World Health Organization (WHO) has initiated just such a rethinking. WHO collects international comparable health information, understood biomedically and standardized in terms of the International Statistical Classification of Diseases and Related Health Problems (ICD) (12). This information is used to monitor the health indicators of mortality and morbidity. In recent decades, WHO has argued that another body of health information that is equally important both for clinical and public health must be systematically collected and used across all components of the health system. Conceptually, this is information about how a person's health state affects their daily life, i.e., information that describes the actual lived experience of health. In 2001, WHO released its International Classification of Functioning, Disability and Health (ICF) to operationalize this concept by capturing these essential data in an internationally comparable way (13).

The concept of human functioning—WHO's technical term—is at the core of the ICF. Functioning includes the functions and structures of the body that constitute the intrinsic health capacity of a person as well as the actual performance of simple and complex activities in interaction with the person's physical, human-built environment and social environment. In other words, functioning comprises the domains of both biological health and lived health, where lived health is fully contextualized as an outcome of interactions between a person's intrinsic health capacity and features of their environment (Figure 1). Across the lifespan, all of us experience pain, anxiety, fatigue and weakness, tight joints, skin sores, and other sensory, mobility, and cognitive impairments. These experiences are what matters to us and why we seek out healthcare in the first place. When we find that we cannot climb stairs painlessly, walk as far as we used to, clean or dress ourselves, read a book, make and keep friends, do all the homework we need to do, or perform our jobs, these concrete, real-life difficulties are the

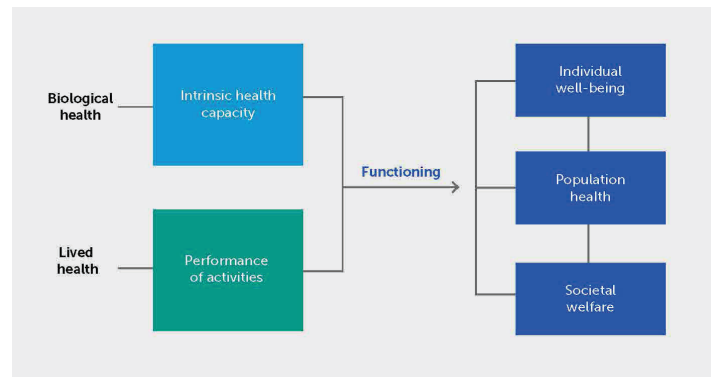


FIGURE 1

Human functioning is the bridge that links health to individual well-being and societal welfare. Functioning incorporates biological health (the physiological and psychological functions and anatomical structures of the body that constitute the intrinsic health capacity of a person to perform human activities) and lived health (the individual's actual performance of activities in interaction with their actual physical, built, and social environments). Functioning—both capacity and performance—is the bridge between health and individual well-being: objective human flourishing or subjective happiness and cognitive satisfaction. Functioning also drives overall population health and societal welfare. This link to individual well-being and societal welfare constitutes the value of health for individuals and society at large, operationalizing the underlying principle of SDG3 that health is a fundamental public good.

lived experience of health. Complementing the traditional biomedical understanding of health, this essential component of lived health creates a more meaningful operationalization of what health means to us.

WHO's concept of human functioning, we argue, constitutes a rethinking of health: a new understanding and conceptualization of health with wide-ranging consequences. Although domains of functioning have been used in health outcome measures for decades, this application does not fully capture the power of the concept of functioning. Functioning is not simply an outcome of health; by capturing the lived experience of health it is conceptually intrinsic to health and accounts for the value of health both for individuals and society at large.

From a public health perspective, functioning augments the biomedical view of health measured in terms of the indicators of mortality and morbidity. Functioning constitutes WHO's third health indicator of health (14). Avoiding premature mortality and controlling morbidity are obviously important to us, as individuals and as society at large, but only to the extent to which they are conducive to enhanced functioning and so better health. Population aging (15), adding more years to our lives, underscores the equal importance of adding more life to our years (16). The increased prevalence of non-communicable diseases and chronic health conditions—which lead to a decline in functioning—is concerning, and from the perspective of society they warrant increased investment in prevention and cure. But the impact of these trends also points to the need to prepare our healthcare systems to focus on optimizing functioning (17). Moreover, operationalizing health as human functioning completes the picture of health envisaged by SDG3 by explaining why health is a driver of individual well-being and, in turn, why population health contributes to societal welfare.

This article explicates more fully WHO's notion of human functioning, illustrates its potential impact on health and society at

large, and argues that societies can profit by implementing functioning systematically as the third indicator of health. Specifically, we first explain functioning as a rethinking of health, one that more clearly exposes the conceptual and empirical link between health and both individual well-being and societal welfare. Secondly, we illustrate the implications of this paradigm shift across all components of health systems and other social systems. Finally, we outline the broader scientific and social opportunities as well as the formidable methodological, implementation, and communication challenges that this new thinking about health entails.

Human functioning as the new thinking about health

James Fries' seminal 1980 article highlighting “compression of morbidity” might in retrospect be seen as an important starting point for raising awareness of the need to assess the successes of preventive, promotive, and curative health interventions in terms of people's actual lived experience of health (18). Fries was in effect pointing to the need for a new outcome measure that captures what people actually care about when it comes to their health. Fries was one of the first to signal the importance of assessing health interventions and health states in terms of people's daily lived experiences. Since then, outcomes research has flourished, relying on a myriad of measures, from the Health Assessment Questionnaire (HAQ) that Fries himself was involved in to a variety of “functional status” measures: the Sickness Impact Profile (SIP), Nottingham Health Profile (NHP), Medical Outcomes Study Questionnaire Short Form 36 (SF-36), WHO's own Disability Assessment Schedule (WHODAS 2.0), and many others. The application of the functioning perspective has also informed health and social policy, most significantly in the development of econometric tools such as the Global Burden of Disease (19).

Recognizing the salience of the lived experience of health in people's lives was the starting point of a rethinking of health incorporated into WHO's development of the ICF. The foundational premise was that human functioning was not simply a consequence of health conditions such as diseases and injuries, but was actually *constitutive* of the lived experience of health states. More significantly, it was recognized that, as experienced, functioning is the result of complex interactions between intrinsic bodily states and the external world—the environment in all its dimensions. More recent work has emphasized that functioning incorporates two fundamental health phenomena, which can be called biological health and lived health (20). Biological health comprises all physiological and psychological functions, anatomical structures, and, by virtue of these functions in various combinations, the resulting “capacity” of the person to perform all human activities, from the very simple to the very complex. Lived health, while grounded in biological health, goes beyond it to include the actual performance of activities in the physical, human-built, attitudinal, and social environments that constitute the person's complete lived context. These environmental factors may make it harder to perform activities (e.g., poor air quality, inaccessible physical environments, or stigma and social exclusion) or easier (e.g., assistive technology, accessible buildings, supportive attitudes, and social arrangements) (21). The notion of functioning in effect brings health down to earth to the practical, everyday experience in which all of us live with health-related reductions in our capacity to carry out activities and, given the demands and assistance provided by environments in which we live, how we actually perform these activities.

This, then, is the revolution in our understanding of health represented by the notion of human functioning: from the perspective of lived health, the actual performance of activities in one's actual environment, functioning constitutes the bridge between biological health and our well-being, understood either as an objective good—human flourishing—or subjectively as happiness, both affective and cognitive. There is qualitative evidence in support of this proposition (22), but it is also highly intuitive: people care about their health when it impacts their lives, their ambitions, their plans, and their happiness. Well-being is achieved through functioning, and so health is a driver of well-being. In short, the ICF notion of functioning is the key to understanding the value of health in terms of individual well-being and societal welfare (21), operationalizing the underlying message of SDG3 that health is a fundamental public good.

Implications for health systems and society at large

The novel conceptualization of health in terms of human functioning, operationalized by the ICF classifications, could profoundly change practice, education, research, and policy across health systems and wider social systems. It is difficult to precisely map all these implications since health systems are

complex adaptive systems (23). And each of these areas face implementation challenges that are unique to them, and often formidable: there is not enough research, the science is simply not there, relevant technologies are unavailable, and there can be economic and political obstacles that get in the way. That said, ongoing work provides insight into what we can expect.

Integrating human functioning across health system building blocks

The implications of functioning across WHO's six building blocks of health systems are shown in Figure 2 (24), and an overview of use cases of functioning information across these six functions of the health system is displayed in Table 1. Rather than discuss the role of functioning in each function, we take a step back and focus on WHO's own interest in formalizing the classification of functioning.

From WHO's perspective, ICF is most relevant to the health information component of health systems, complementing its two other data classifications, ICD and the International Classification of Health Interventions (ICHI) (37), which together allow for the routine collection of data concerning all three indicators of health status—mortality, morbidity, and functioning. To be useful at all levels of the health system—i.e., to health professionals, managers, policymakers, and global health agencies—health information must not only be reliable but comparable and thus standardized and interoperable.

Considerable advances have already been made to standardize human functioning data for optimal use across the health system, using ICF as a reference system for routine reporting of functioning information for clinical, research, management, and policy purposes. Considerable effort has gone into developing and validating ICF-derived ICF Core Sets for perspicuous reporting of functioning for many health conditions and application areas (38) as well as minimal generic sets for basic health data reporting requirements (39–41). The ICF is widely used in the development and validation of both specific and general measurement instruments that can be tailored for clinical use (42, 43), as well as population-level data collection questionnaires and clinical intervention monitoring and quality management. Linking rules have been developed that map data on functioning collected with any standard patient data collection tool—HAQ, SF-36, and Functional Independence Measure (FIM)—onto ICF categories (44–46). These and other developments give us confidence that applications of functioning information in the context of health will not be confronted with unsurmountable methodological obstacles in the future (30, 47).

But the recognition of the importance of the concept of human functioning has implications beyond health information encompassing every other component of the health system (Figure 2). Leadership and governance provide oversight, regulation, and design of health systems, including setting priorities, scaling up interventions, and implementing sustainable and accountable policies. For example, WHO has argued, health systems governance has the responsibility to create the

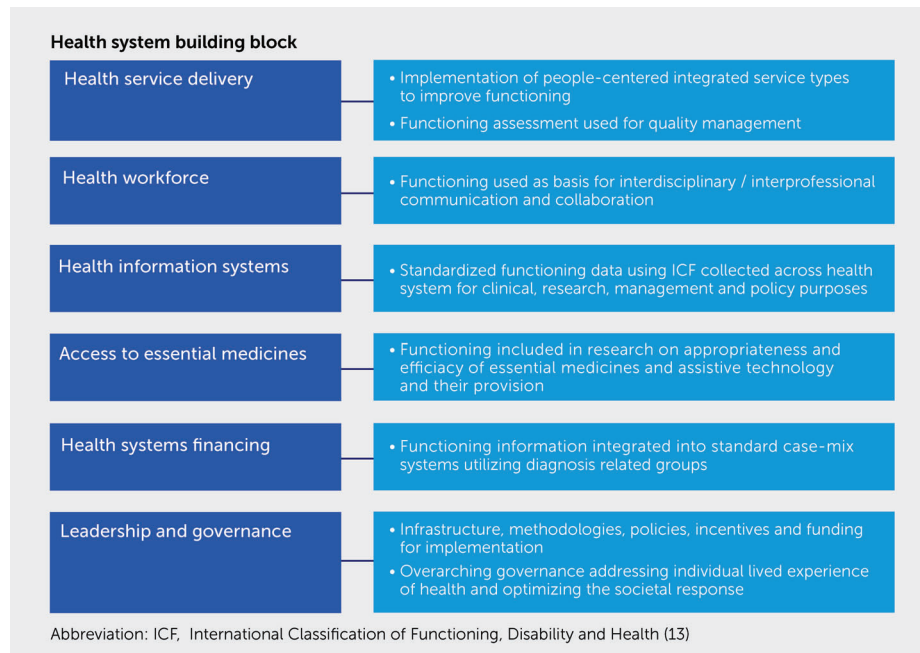


FIGURE 2

Highlights for implementing human functioning within health systems. The implementation of functioning has implications across all six of the World Health Organization building blocks of health systems.

infrastructure, methodologies, and financial support to ensure the systematic collection and use of functioning information in order to move beyond a purely biomedical understanding of health to one that more fully reflects societal requirements (33, 48). Among other things, the COVID-19 pandemic showed the importance of governance to fully address the individual lived experience of this pandemic (35). Functioning also directly impacts service delivery, both in terms of analysis of service types (25, 49, 50) and as a basis for quality management (26, 51, 52). In the case of the health workforce, one of the first applications of the ICF was to provide a “language” in which interdisciplinary teams of health professionals could communicate (28, 53). It is a common theme that interprofessional collaboration, demanded by increasingly complex treatment plans that cross health disciplines, is often stymied by communication obstacles that a functioning-based common language can remove (54). This is particularly relevant to WHO’s consistent call for “people-centered healthcare” (55), which encourages health professionals and healthcare systems to ensure that services are designed and delivered in ways that are directly relevant to people’s lived experiences. The appropriateness and efficacy of many essential medical products and certainly all assistive technologies depends on the degree to which they contribute not merely to survival or patient satisfaction, but also to improvement in functioning, as is increasingly being recognized (56). Finally, for health financing, adding functioning information into standard case-mix systems utilizing diagnosis-related groups improves the capacity of these financing structures to capture the differences in patient needs for services in the acute care setting and influence financial priorities (34).

Human functioning and the health strategy of rehabilitation

Functioning is relevant across all five of the health strategies (14). Health promotion and disease prevention need information on biological health to create and provide public health interventions. The curative strategy depends on information about biological health for treatment planning and information about lived health for outcomes to assess treatment efficacy. Palliation relies on appraisals of levels of functioning to make sense of quality of life near and at the end of life. But it is the health strategy of rehabilitation that depends most strongly on functioning information; indeed, functioning is at the core of the *raison d’être* of rehabilitation.

The ICF has fundamentally transformed our understanding of the aim and rationale of rehabilitation. The ICF insight that at the core of health is an experience shaped both by states of the body and mind and by features of the person’s environment and personal attributes is directly aligned with the core aim of rehabilitation. Accordingly, rehabilitation professionals were quick to recognize the significance of the notion of functioning as a core element of rehabilitation science and practice. Although rehabilitation traditionally relied on cognate terms such as “functional loss,” “functional limitation,” and “functional incapacity,” it was only after ICF was introduced that it was possible to succinctly define rehabilitation as the health strategy that aims to optimize patients’ functioning in the context of their personal capabilities and in interaction with the physical, human-built, attitudinal, and social environment (17, 20, 50, 57–61).

TABLE 1 Human functioning information in the World Health Organization's six building blocks of the health system.

Building block	Use case	Context	Description	Key reference
Health service delivery	ICF implementation in clinical quality management for rehabilitation	Malaysia and Europe	Europe: the ICF has been used to categorize rehabilitation service types and clinical assessment schedules to identify patient groups for quality management since 2015, under leadership of the Physical and Rehabilitation Medicine Section (PRM) and Board of the UEMS Malaysia: the Department of Rehabilitation Medicine at the University of Malaya Medical Centre, Cheras Rehabilitation Hospital of the Ministry of Health, and the Social Security Organisation Rehabilitation Centre together initiated a similar project in 2017	(25–27)
Health workforce	ICF implementation by multiprofessional rehabilitation teams	Switzerland and Europe	Switzerland: an ICF-based framework was proposed in Switzerland to guide the rehabilitation process by facilitating interaction between health professionals and the patient Europe: UEMS-PRM developed the Individual Rehabilitation Project for Europe (EUR-IRP), a multi-element, person-centered rehabilitation management scheme in which rehabilitation is provided by a multiprofessional team	(28, 29)
Health information systems	ICF-based and interval-scaled standardized reporting system (StARS) for functioning information to optimize current national practice for quality improvement in rehabilitation clinics	Switzerland	StARS has been used for national quality reports for neurological and musculoskeletal rehabilitation in Swiss rehabilitation clinics; the common metric made it possible to compare data between clinics that use different assessment tools and to calculate the valid change scores for patients between hospital admission and discharge	(30)
Access to essential medicines	ICF-based model applied to assistive technologies and as outcome measure in rheumatology	International	Essential medicines include assistive technologies (AT), which are environmental factors in the ICF and the goal of the “biopsychosocialtech” approach was to achieve an individualized and customized solution to people's AT needs In the context of rheumatology, the ICF was introduced as an outcome measure reference system in the 8th meeting of OMERACT in Malta	(31, 32)
Financing	Value of integrating functioning information in reimbursement systems and stakeholder perspectives	Germany	To investigate the value of integrating functioning information into case-mix reimbursements systems in Germany, a study collected data from experts on the DRG systems to identifying potential benefits and costs Literature suggests that integrating functioning information into case-mix reimbursement systems improves predictive ability and fosters homogeneity in case-mix groups with respect to costs and length of stay	(33, 34)
Leadership and governance	Functioning information and the case of missing COVID-19 data	International	As the COVID-19 pandemic shows, data on mortality and morbidity must be complemented by data on functioning to inform evidence-based public health delivery and planning; the Clinical Functioning Information Tool (ClinFIT) for COVID-19 is an ICF tool for collecting data on the pandemic As a syndemic, the COVID-19 pandemic involves a complex interaction of health and social forces; the ICF is optimal for capturing these impacts	(35, 36)

ICF, International Classification of Functioning, Disability and Health; OMERACT, Outcome Measures in Rheumatology; UEMS-PRM, Physical and Rehabilitation Medicine Section and Board of the European Union of Medical Specialists.

For rehabilitation practice and science, the concrete implementation of the ICF has primarily meant integrating functioning information into existing health information systems as an important way to advance WHO's Rehabilitation 2030 Initiative aimed at strengthening rehabilitation in national health systems (62). Technical developments and guidelines (20, 63) help to identify, for particular rehabilitation interventions or services, what ICF domains to use, how to link existing data collected from standard questionnaires, measures, and instruments to ICF domains, and how to quantitatively align scoring systems from different instruments into a single common metric (30, 47) to provide standardized and internationally comparable functioning information. Although much additional technical and implementation research is required, and many practical challenges have yet to be overcome, or even identified, enough has been accomplished in the last decade to begin the development of guidelines for applying the ICF as a standard reference language

for reporting rehabilitation interventions in the clinic and in research studies.

Societal gains from human functioning

Rethinking health in terms of human functioning can underpin economic arguments supporting and defining adequate levels of social investment in health and healthcare. All countries are concerned about health systems performance and the economic efficiency of healthcare service delivery, and WHO's flagship initiative of Universal Health Coverage (64) addresses the necessity for equitable distribution and availability of healthcare resources. It is well recognized that there are indirect socioeconomic benefits of healthcare, such as avoiding productivity losses associated with ill health and the associated loss of functioning. These benefits, the added societal value of healthcare, have been

argued to be a component of well-being that can lead to higher gross domestic product (GDP) per capita in the long run as a result of increased labor force participation and productivity (65). Measuring the contribution of health to well-being has been challenging since the relationship between the two has been under-conceptualized (66). Yet the notion of human functioning can support the economic case for the social investment in health because it bridges health and well-being and accounts for the intrinsic and instrumental value of healthcare (8). Recently, functioning has provided the value-base for economic investment in specific service areas, such as rehabilitation (67).

The repeated calls for “value-based” healthcare, championed by Harvard Business School professor Michael Porter, urge a transformation of the healthcare system away from competition over ways to shift or limit costs and restrict services to maximize profit to a competition of increasing value for patients (68). The goal of healthcare, Porter argues, is what matters for patients and what should unite the interests of all actors in the system, namely good health outcomes (69, 70). A strategy of healthcare reform, in short, needs to identify and rigorously measure not only survival and recovery but sustainability and optimization of functioning.

The notion of functioning may also help to bridge another gap in our understanding of the impact of health on societal welfare overall. We have known for decades that individual and population health outcomes are shaped by a complex interaction between our genes, age and sex, features of our physical, social, and economic environment, and our own behaviors. Healthcare itself accounts for only 10–20% of the modifiable (i.e., non-genetic) contribution to positive health outcomes (71), while the remaining 80–90% consists of health behaviors, socio-economic conditions, and physical environmental factors (72). This suggests that while health system improvements will undoubtedly improve population health, a far greater benefit might be achieved by systematic societal actions in other areas of social policy (education, employment, transportation, social welfare, and the environment).

The political, administrative, and policy bifurcation between “health” and “social” hampers policy action to improve population health. Recently, the United Kingdom’s Health Foundation has suggested that local National Health Services (NHS) should be empowered as “anchor institutions” to broker non-healthcare inputs into local communities from social sectors—transportation, environment, and social services (73). Nevertheless, this approach does not dismantle the entrenched health vs social structural dichotomy; rather, it trades on the fact that the NHS can oversee employment-related health determinants as an employer, as a source of procurement strategies, and as a land and capital asset holder and environmental advocate. A true resolution would find a path to integrate health and health-related social sectors so that the collaboration between them is fluid and facilitates policy reforms that can only be achieved by means of cross-sectorial cooperation. Rethinking health in terms of human functioning has the potential to, finally, bridge the traditionally separate “health” and “social” cultures in order to improve our understanding of the determinants of health to society’s considerable benefit.

Opportunities for health sciences, education and training

We can envisage many opportunities from rethinking health in terms of human functioning and focus here on two broad areas: health sciences and education and training.

Health sciences

Fundamentally, the concept of human functioning could be the basis to reconceptualize multidisciplinary health sciences as an integrated and coherent scientific field of study. This reconceptualization opens the door to a broader understanding of epidemiology by moving beyond its traditional focus on mortality and morbidity and incorporating functioning. An emerging “functioning epidemiology” could pave the way towards the recognition of the need for human functioning sciences as a distinct component of health sciences. At this point, although we can only glimpse these potential developments, they clearly signal both the opportunity and the need to expand academic capacity accordingly.

It is not an understatement to say that health research has expanded astoundingly over the last century, thanks to the contributions of numerous scientific disciplines, from the biological and natural sciences to social sciences, humanities, and engineering (74). The field of health sciences faces a challenge in encompassing and integrating diverse scientific disciplines to comprehensively understand and respond to individual and population-level health needs within a single field of study. The concept of human functioning—particularly the distinction between biological and lived health—can help here by identifying the relevant sciences that comprise health research and how they contribute to the societal response to health needs. A scientific description of biological health depends on biological and other natural science tools to account for a person’s intrinsic ability to perform activities. The description of lived health, on the other hand, involves sciences that explain the interaction between the biological and the environmental. Finally, explaining society’s response to the individual’s health needs depends on scientific understanding of institutions and social processes involved in society’s health and health-related systems that respond both to underlying biological needs and environmental determinants of health and lived health.

The comprehensive, multi-dimensional model of human functioning therefore offers a foundational understanding of health sciences that takes account of biological, social, and other environmental determinants of health and the societal response to health needs.

Integrating lived experience into epidemiology

Currently, the scope of epidemiology mirrors the conventional understanding of health as primarily explicable in terms of normal biological processes disrupted by disease, injury, and other sources of

impairment or infirmity, manifested at the individual and population levels. As such, it is the study and analysis of distributional patterns, causes, and effects of disruptive health conditions on clinical or general populations. Mortality and morbidity are the conventional health indicators capturing (albeit to a limited degree) the effects of health conditions through premature death and impairments or morbidities. Even the relatively new sub-disciplines of social epidemiology and life-course epidemiology, which more fully appreciate the significance of the wider social context and human health trajectories, restrict their investigations to the impact of context and time on health conditions as primary outcomes. This traditional epidemiology is a robust science grounded in powerful statistical and other highly credible methodologies. However, it is of limited value in comprehending people's lived experience of health, which demands consideration of health states in light of personal resources and in interaction with a contextual environment, broadly construed. There is, therefore, an opportunity to augment traditional epidemiology with a "functioning epidemiology" to fully account for the lived experience of health (75). The first step to doing this is the recognition that functioning is the third health indicator after mortality and morbidity (14, 36).

Functioning also paves the way for a new interdisciplinary science field, human functioning sciences, that holds the promise of integrating research inputs and methods from diverse biomedical and social disciplines to provide a fuller understanding of human health (Figure 3). Although there are undoubtedly challenges to address, the aim of the human functioning sciences is clear: to understand the lived experience of health at the personal level. It would explore the links between health and individual well-being, identifying and implementing the societal response to functioning needs so as to secure the bridge between healthcare and public health and societal welfare. It is not inconceivable that human functioning sciences might emerge in much the same way that neuroscience did in the 1950s and 1960s (76) with the recognition of an integrative conception of brain and behavior that relied on the results of anatomy, biochemistry, neurology, physiology, and pharmacology but which went beyond this and was more than the sum of those sciences. Human functioning sciences, in short, not only respond to the call to reject reductionism in health research (and "putting the patient back together" (77)) but also to use functioning as the integrative conception of health as the basis for a truly interdisciplinary health science.

Human functioning sciences: an emerging distinct scientific field

Human functioning, as we have argued, can provide a multidimensional foundation for the field of health sciences.

Teaching and training capacity

Concomitant with the emergence of human functioning sciences is the need to develop a new generation of researchers and policy entrepreneurs who will constitute the research and

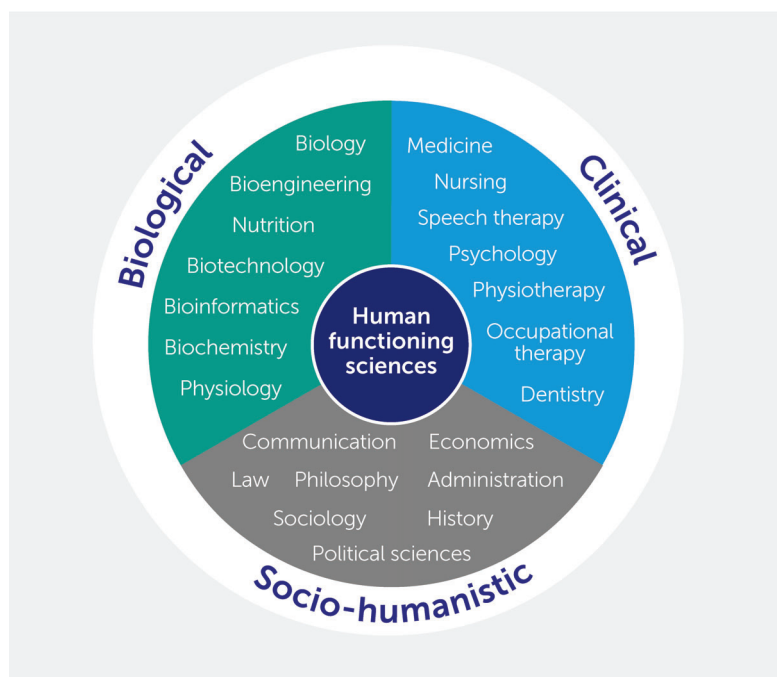


FIGURE 3
Examples of scientific disciplines rooted in the biological, clinical, and socio-humanistic traditions engaging in the new field of study termed human functioning sciences.

academic workforce for the implementation of the new thinking in healthcare, health science and society at large. This opportunity entails potential transformative academic changes requiring innovative curriculum and program development as well as institutional and organizational changes to degree programs that include collaborative or cross-faculty arrangements (78). Training in human functioning sciences, from bachelor's degrees through to doctoral degree programs and beyond, should emphasize interdisciplinary research with an implementation orientation. The conceptual model of functioning can clarify how we describe the adaptive processes constitutive of changes—not only changes in individual health capacity but also changes in performance arising from alterations to the person's environment to better accommodate individual needs. Realistically, these academic arrangements would likely be structured around focal applications of particular societal interaction, such as rehabilitation (79) and healthy aging (80).

Communication challenges in rethinking health

The recognition and implementation of human functioning as a new way of thinking about health entail communication challenges that need to be addressed. This challenge is at the heart of moving from theory to practice, from a shift in conception to new institutions, new actions, and a new cultural understanding of health.

First, for a new paradigm to become effective practice, it is fundamental to agree on the appropriateness, value, and benefits of the terms, concepts, and operational guidance that it proposes. Knowledge translation from evidence to practice must spread at the macro-, meso-, and micro-levels of health systems and along the continuum of care. This requires an awareness of the role of functioning from truly interdisciplinary work and, at the same time, a focus on functioning as a promising language to enhance interdisciplinarity in healthcare, in light of what really matters to patients. All this can be achieved by promoting communication around the notion of functioning and increasing awareness among health professionals using successful implementation cases and scientific evidence gathered during the last two decades. System communication has the important but difficult task of preparing for the global implementation of functioning as a bridge between health and well-being, which is an essential conceptual issue with practical implications.

Second, the question of how to inform the public about human functioning (public dissemination) is another challenge. There are benefits to achieving public understanding: knowledge about functioning, health, and well-being can help the public better understand and accept health investments and resource allocation, especially when other social goods are in competition for limited resources. Participatory democracies flourish when, putting the important distinction between “lay” people and “experts” aside, people understand what can influence optimal

health policies. Targeting the public is a task embedded in institutional communication and requires strategies for public campaigns centered on functioning.

Third, at the level of healthcare provider-patient interaction, there is strong evidence that the use of the functioning framework and the ICF during the interaction facilitates goal-setting and intervention management (81, 82). ICF provides a common language between health professionals and patients for shared decision-making. In light of this, knowledge of functioning constitutes an important topic to enrich patients' health literacy. Patient education on functioning holds the promise of a “language” to bridge the gap between the point of view of the health professionals and the lived experience of the patients.

Conclusion

The conceptual and evidence base exists to support the implementation of human functioning as the third indicator of health, complementing morbidity and mortality. This requires coordinated action across health systems, including the scaling and extension of use cases. Significant challenges in implementing this new paradigm exist: while the methodological challenges are well on the way to being resolved, true implementation is in its infancy and the communication challenge has yet to be fully comprehended. Addressing these challenges and associated inertia is vital to orientate health systems toward what matters most to people about health based on their lived experience of health. Moreover, by bridging health and well-being, human functioning offers a basis for the societal economic investment in health that is essential both for individual and population-level well-being and for progress toward achieving all of the SDGs to which all countries are committed.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material. Further inquiries can be directed to the corresponding author.

Author contributions

JB and GS conceived the underlying concept and designed the manuscript together with SR and CB. JB, with assistance from CB, wrote the section on the application of functioning information in the six building blocks of WHO's health system. SR wrote the section on communication. JB wrote the overall manuscript with support from CB, GS, and SR. All authors provided critical feedback. CB coordinated the project. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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The reviewer WF declared a past collaboration with the authors JB, GS to the handling editor.

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Health, functioning and disability in older adults – current status and future implications

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Summary

Aging is a dynamic process with trends in health status of older adults varying over time due to a range of factors. We examined reported trends in morbidity and mortality among older adults over the past two decades in order to determine patterns of ageing across the world. We found some evidence for compression of morbidity, i.e., less amount of time spent in worse health, when: a) studies were of a good quality based on evaluation criteria scores; b) a disability- or impairment-related measure of morbidity was used; c) studies were longitudinal or; d) studies were conducted in the United States and some other high income countries. Many studies reported evidence to the contrary, i.e., for an expansion of morbidity but with different methods these are not directly comparable. Expansion of morbidity was more common when trends in chronic disease prevalence were studied. Our secondary analysis of data from longitudinal ageing surveys present a similar picture. However, there are considerable variations across countries in patterns of limitations in functioning and within countries over time with no discernible explanations. Data from low income countries is very sparse and efforts to collect information on the health of older adults in less-developed regions of the world is urgently required. Studies focussing on refining measurement with a core set of domains of functioning and studying the impacts of these evolving patterns on the health care system and their economic implications are needed.

Introduction

Demographic projections indicate that the populations of all countries are ageing, which will have wide-ranging impacts on social, economic and health systems. The world's population aged 60 years and over is set to increase from 841 million in 2013 to more than 2 billion by 2050 and, indeed, exceed the number of children by the year 2047. By 2050, 21.1% of the world population will be aged 60 years or older, and 80% of this demographic will live in low and middle income countries as compared to about two thirds at present. Over the same period, global life expectancies are predicted to rise, reaching 83 years in more developed

regions and 75 years in less-developed regions by 2045–2050; when compared to life expectancy figures for 2010–2015, the gap between life expectancies in more- and less-developed world regions is expected to narrow as less-developed regions achieve accelerated gains(1). The population aged 60 years and older in less developed regions is projected to increase from 554 million in 2013 to nearly 1.6 billion by 2050 given that the annual growth rate of the population of persons 60 years or over in these regions is almost three times that of the more developed regions of the world. This growth in the older population is occurring in parallel with increasing income inequality, disparities in access to health care and social support systems, and widening health gaps as a result of complex disease burden patterns and globalization of health risks. In most developing countries, these issues are compounded by a lifetime of accumulated health risks associated with poverty and inadequate access to health care. The changing epidemiological profiles in low and middle income countries are largely driven by a set of conditions, such as rapid urbanization, changing dietary habits and levels of physical activity, that are different from those that were prevailing when these shifts in profiles occurred in the high income countries. These populations seem to be experiencing an increase in the incidence and prevalence of chronic non-communicable diseases that appear before the onset of old age with a natural history that takes place in conditions of poverty – what has been referred to as ‘post-transitional illnesses in pre-transitional circumstances’.

In light of these trends, there has been much speculation about the health experiences that will accompany this aging cohort: will the years gained be productive and healthy, or will the elderly live longer lives in conditions of ill-health?

Three main hypotheses have been proposed to address this question (2). The *compression of morbidity* hypothesis posits a situation where the age of onset of morbidity is delayed to a greater extent than life expectancy increases, thereby compressing morbidity into a shorter period at a later age (3). The *expansion of morbidity* hypothesis maintains the opposite, that increases in life expectancy are matched or exceeded by added periods of morbidity (4). Both compression and the expansion of morbidity could happen in absolute or relative terms: changes in the absolute number of years lived with disability or in terms of healthy life expectancy as a proportion of total life expectancy.

Healthy life expectancy is a measure that combines mortality and morbidity information in a single index, expressing the number of healthy years of life lost due to poor health with a range of severities being incorporated into quantifying poor health based on different weights being assigned to different severity levels of disability resulting from different health conditions. Data from the Global Burden of Disease 2010 show that from 1990 to 2010 as life expectancy increased, healthy life expectancy increased more slowly; relatively little progress was made in reducing the non-fatal health impacts of diseases. For example, over this period, males aged 50 years had a healthy life expectancy increase of 0.75 years for each year of increase in life expectancy. The corresponding increase in healthy life expectancy for women at age 50 was 0.77 years. While life expectancy among Japanese women— currently the highest in the world with also some of the lowest disability levels in the world—increased by 3.9 years, healthy life expectancy increased only by 3.2 years over the same period (5).

Evidence for the *equilibrium of morbidity* theory supports a more multidimensional perspective, whereby lessened progression and severity of morbidity are accompanied by increases in moderate or mild morbidity (6).

Data suggest that though severe disability free life expectancies may have declined in some high income countries over the last four decades, there has been stagnation in disability free life expectancy (7). In fact, among older adults there may have been a relative expansion of morbidity (8). Health interventions that are targeted at lethal diseases may lead to an increase in years spent with disability suggesting that it is critical to improve the dissemination and uptake of lifestyle change interventions that reduce risk across a range of chronic conditions. The co-existence of many diseases in an individual may mean that when mortality due to one disorder is prevented, disability due to another may become increasingly important.

While it is clear that life expectancy is on the rise, the patterns of increase have not been consistent, with variable surges and periods of stagnation (9). There is debate about whether gains in life expectancy will occur at a diminishing rate, or continue indefinitely (6).

Studies of morbidity trends have drawn conflicting conclusions, and are highly subject to a number of study-design and contextual factors, including the definition of morbidity, time period and study population (9;10). A number of review studies from high income country settings have reported declining disability over the past few decades (3;11;12), with concurrent increases in chronic disease prevalence (13–16), noting a lack of evidence from those aged 85 and older (9). This, however, is not uniformly true. In 2007, a review by the OECD, that used disparate data reported by countries, revealed that though there is clear evidence of a decline in disability among elderly people in five of the twelve countries studied, in other countries rates are increasing or stable. Although prevalence in most of these conditions and risk factors has increased, no clear judgment could be made about the linkages between chronic conditions and severe disabilities. The OECD study relied on a proxy operationalisation of ‘severe disability’, namely one that a) was most clearly consistent with the available national, self-report, survey data, and b) was intuitively linked to long-term care needs. The paper concludes that ‘it would not seem prudent for policy-makers to count on future reductions in the prevalence of severe disability among the elderly, but rather to expand national capacity in long-term care and programs to prevent or postpone chronic conditions.’ The situation in low and middle income countries has much less extensively studied with very limited data available.

Delineating the path of health and morbidity in old age has important public health and economic consequences for aspects of medical spending (17), social program planning (18), predicting trends in the workforce (18) and the social patterning of poverty (19).

In this paper we have first performed a systematic literature search to explore trends in morbidity among older adults and life expectancy, and weighed the evidence to determine whether trends presented a pattern of compression, expansion or equilibrium. Specifically, we aimed to answer the questions: Have there been changes in the age of onset and/or

severity of late-life morbidity, in relation to life expectancy? Which hypotheses of health and aging trends have been supported by recent literature?

Second, we have also undertaken new analyses of publicly available cross-national data sets that contain harmonised items related to the health status of older adults over multiple periods in time. In these analyses we address the related questions: has the proportion of older adults with disability remained stable, increased or decreased over time? Is this change due to age or cohort effects? What are the factors that influence these longitudinal trends? And, how do these patterns compare across countries? We use data from all years that are currently available for public use. We describe below the approaches undertaken and the resulting findings.

We have focussed our analysis on trends in functioning in older adults as the review by Prince et al in this series address the issue of trends in chronic diseases in far greater detail with an analysis of the Global Burden of Disease data that shows that nearly a quarter of all disease burden globally is being experienced by those 60 years and older with the per capita burden being higher in developing countries driven mainly by cardiovascular diseases, sensory impairments and respiratory diseases.

Trends in morbidity

Conceptualising health for purposes of measurement

The major issues while trying to understand levels and trends in the health of older adults is the lack of a common definition of health, an understanding of its constructs, and the subsequent measurement of health in a way that is comparable over time and across populations. We address these aspects, essential for addressing our questions, below.

Health and social surveys rely heavily on self-reported measures. Self-reported health state has been traditionally measured in the older population using three main strategies. The first approach is to ask respondents a global question on overall health that rates their overall health using a 5-point rating scale that ranges from very good to very bad (or from excellent to poor). Though this overall rating of health has been shown to be correlated with future mortality in cohort studies, it is not clear what dimensions of health this question captures and whether it produces inconsistent patterns in population level studies across all ages. This has led to the second strategy of asking multiple questions across a parsimonious set of multiple domains that is believed to capture most of the variance in health states across population groups as elaborated later. The third strategy, frequently employed in aging studies, is a set of questions that measure functional independence by asking about activities of daily living (ADLs), such as bathing and dressing, and instrumental activities of daily living (IADLs), such as shopping or managing one's finances. Counts of ADLs and IADLs are then used to quantify health states and measure changes over time.

Comparable measurement of health states is essential in order to examine relationships between current levels of health to other aspects such as future non-fatal health outcomes, risk factor profiles, and causes of death. In order to address this issue, the World Health Organization (WHO) has conceptualised a health state as a multi-dimensional attribute of an

individual that reflects his or her levels of the various components or domains of health at a given point in time and differs from pathology, risk factors or etiology, and from health service encounters or interventions. All societies have an intuitive notion of being ‘in a good state of health’ that allows us to make statements such as an individual ‘A’ is in a better state of health than another individual ‘B’. These non-fatal aspects of an individual’s health state have been the focus of an extensive body of literature that has grown steadily in the last three decades, and have been incorporated into national and international health statistics such as the regular reporting by the WHO of Disability-Adjusted Life Years (DALYs) and healthy life expectancy (HALE) which are essentially individual health states aggregated to population levels.

Within the framework of WHO’s International Classification of Functioning, Disability and Health (ICF) (20) an individual’s health state is understood as a vector of capacities to function in a set of domains that range from hearing and seeing to moving around to cognition and affect. An individual’s capacity to function in a domain of health is, thus, an individual’s intrinsic ability irrespective of the environmental barriers or facilitators that may be in place in the person’s real-life situation. This notion of capacity corresponds with the common-sense interpretation of health for health— an attribute of the person and not their environments. The latter will admittedly have a substantial effect on the way the health state plays out in the individual’s actual environment but that is not the individual’s health per se. For the purposes of measurement, these domains of health need to be reduced to a parsimonious set that captures most of the variation and approximates the respondents’ intuitive notion of health. The measurement across these different domains must be combined into a single metric of functioning that ranges from good functioning (health) to difficulties in functioning (disability or poor health) that can then be compared across populations and over time. . This then allows the direct comparison of health states across single and multiple diseases as well (21).

This conceptualisation preserves the spirit of the WHO Constitution definition of health. It does not equate health with diseases or diagnostic categories, it recognizes a causal chain through which risk factors and environmental factors are determinants of diseases, and diseases and environmental factors in turn are determinants of health states. Using a parsimonious but comprehensive set of domains as the basis for descriptions of health states allows detailed data collection on key components of individual health and provides a basis for describing and measuring health states, and for carrying out causal analysis of determinants of those states, including risk factors and environmental factors. The differing choice of domains in studies means that comparisons are often possible across studies only for specific areas of functioning such as cognition or mobility or for a small subset of items such as activities of daily living (ADLs) or instrumental activities of daily living (IADLs). A set of domains that spans physical, cognitive and affective aspects of functioning has been used by the WHO for its population surveys over the past decade (22;23). A similar set has been developed for use in health interview surveys by the Budapest Initiative of the United Nations Economic Commission for Europe and used in European and American surveys (24). While a common set of domains for use across international studies is helpful for comparisons, long running national longitudinal studies also have a need for comparisons of trends over time within their respective survey and therefore maintain existing questions.

Hence, adding a subset of common domains to these studies would allow comparability with international efforts by developing a robust domain-based summary measure without losing the important ability to examine changes over time within a given survey.

To date, however, the field continues to suffer from the lack of a single, “gold standard” approach to creating a single metric of health. Different strategies have been used to create a single metric of health combining the capacities in the different domain. These strategies have either used the valuation of different health states by individuals and used this valuation function to create a cardinal scale of health or, alternatively, used different psychometric approaches to combine the information from the different domains using either classical test approaches such as factor analysis or modern psychometric techniques based on Item Response Theory (IRT) (22;25). Attempts have also been made to address problems of comparability surrounding self-reported health in surveys by using anchoring vignettes to detect and correct for systematic biases in reporting (26). Among other issues, this use of different statistical approaches to create a single composite measure of health makes comparison across studies problematic.

Patterns and trends in the health of older adults and their determinants

Currently studies across the world do not offer consistent support for any one of the three hypothesized theories (compression, expansion, or equilibrium of morbidity). Many studies have reported some evidence for compression of morbidity (8;27–32) and several others reported some evidence for expansion of morbidity (27;33–38). Of the studies that have addressed more than one level of severity in decrements in health, five had support for equilibrium of morbidity theory (7;39–42). Several studies reported inconclusive or variable results (27;43–45).

A recent review concluded that the answer to the question of whether increases in life expectancies across the world, and especially among the oldest old, have been accompanied by a postponement of disability is still open (9). While studies in most high income countries have generally tended to conclude that most indices of ADL are improving, there has been some conflicting evidence. A study from Spain reported consistent worsening in an index of ADLs over time, more so for women than for men (31). A study in Sweden has reported increases in ADLs over the last 2 decades (46).

Morbidity Measures

Patterns of morbidity-free life expectancies have varied according to the definition of morbidity used in the different studies. Disability- or impairment-related measures of morbidity, including functional limitation, discomfort and/or activity restriction, have been the most commonly studied. As noted earlier, most often morbidity is self-reported, though increasingly studies on ageing have begun to incorporate performance-based measures as well (42) and have at times reported severe disability determined by a medical expert (30). Of the studies that defined morbidity as a form of disability or impairment, twice as many studies contain evidence to support compression of morbidity (8;27–32;39;41;47) than expansion (27;33;34;48;49). Four of the studies reviewed offered support for equilibrium of

morbidity, and five had inconclusive results. Three studies have reported data that span a long time over 20 years (27–29).

Many studies have quantified morbidity-free life expectancy by the absence of major chronic disease(s), with seven of the studies reviewed considering multiple diseases or disease clusters (32;36;41;43–45;47), and two looking at a single major chronic disease (38;48). Three of the seven studies examining multiple diseases reported evidence for expansion of morbidity, and none supported a compression of morbidity depending on how this was defined. Most notably, in the Netherlands (36) between 1989 and 2000 life expectancy without chronic diseases decreased significantly, and this was more so for women with the gap in 1989 being 0.6 years, with women having longer disease free lives, while in 2000 the gap was 2.9 years with males now having longer lives free from chronic diseases. In Denmark (47) an increase in total life expectancy between 1987 and 2000 was accompanied by an absolute decrease in disability-free life expectancy among those 65 years of age and older suggesting improving health status of older adults. However, the life expectancy with chronic illnesses showed little change for older adults with some increase in cardiovascular diseases among men. Two studies looking at a single disease reported patterns of expansion of morbidity for cancer (38), and an increase in stroke prevalence(48), but also noted improvements in stroke recovery and cancer cure rates. Only one study investigated disease severity (limiting vs. non-limiting illness), and reported equilibrium of morbidity (41). Five studies had inconclusive/variable results, including sex-specific (32;43;44) or disease-specific (45) variance.

Studies adopting indirect indicators of morbidity such as age at first hospitalization (35) and patterns in the need for long term care (30), reported a pattern of expansion and compression, respectively.

Geographically, studies of populations within European countries provide conflicting evidence as noted earlier with studies offering support for compression of morbidity and expansion of morbidity being almost equally divided. Studies from Asian countries have failed to report evidence for compression of morbidity (50;51). Two studies have shown some evidence for expansion but most studies from the region show variable results. Evidence for compression of morbidity (as disability) has been reported by many studies from the United States.

A longitudinal study, which explored stroke prevalence in China, suggested expansion of morbidity with regard to disability-free life expectancy (48).

Severity

Twelve studies reviewed included two or more categories of morbidity severity, and could thus test the equilibrium of morbidity hypothesis. All studies reported trends of increasing total life expectancy. Five studies found evidence to support equilibrium of morbidity, defining morbidity according to disability (7;39;42), functional limitation (40) and illness/limiting-illness (41).

Specific domains of functioning

Recent data from the United States and Europe provide further evidence with regard to the questions raised and have addressed specific questions about declines in specific domains of functioning. A recent analysis of data from the United States suggested that risks associated with diseases of older adults such as obesity and inflammation are increasing (52). While survival with cardiovascular disease and cancers may have improved there is no evidence that their incidence is actually on the decline. Musculoskeletal conditions and arthritis have been increasing. Furthermore, this study showed that there has been an expansion of life with disease and with limitations in mobility functioning. Several other recent studies have also suggested that disabilities may be increasing in newer cohorts of older adults. Using newer forecasting methods, a recent study has concluded that the increasing trends in obesity prevalence in the United States are likely to not only threaten life expectancy gains but also considerably increase morbidity and worsen health outcomes in future cohorts due to related complication such as diabetes and cardiovascular disease (52).

A recent study examining cognitive impairment in two cohorts of older adults 70 years and older in 1993 and 2002 respectively showed that the latter cohort had fewer IADLs limitations but higher rates of hypertension, obesity, diabetes and heart disease. The proportion of people with cognitive impairment was lower (8.7%) in the latter cohort as compared to the former cohort (12.2%). Multivariable analyses concluded that increasing levels of education and net worth among the older population explained a large part of this difference lending support to the cognitive reserve hypothesis. This led the authors to conclude that, while the risks had increased over time, early identification and more-effective treatment had perhaps led to a lack of decline in cognitive function. However, assessing trends in cognition using longitudinal data poses a challenge since respondents may learn how to do the tests and the practice effect may compensate for declines in cognitive performance (53). Additionally, missing data on respondents who become severely cognitively impaired (such as due to stroke or dementia), or those lost to follow up due to death or other reasons, poses a challenge.

Analyses of longitudinal studies of ageing

We have undertaken an analysis of multiple longitudinal studies of ageing and of cross sectional analysis of a large dataset from the World Health Surveys as described in the supplementary material. Box 2 describes the basic characteristics of these data sets. We present the results of these analyses below.

Levels of disability by age over time

ADLs: Across all countries in the surveys the proportion of respondents with ADL limitations shows a steady increase with age. However, this increase is significant between the ages of 50–70 years in countries like Greece, Spain, and Italy compared to countries such as the Netherlands, Sweden and Switzerland where these increases seem to happen predominantly among those over 70 years of age. The steady gradient is also observed in the United States and England.

Over the two waves of SHARE (54), in the majority of countries, the proportion of respondents with ADL limitations across age groups seems to have stayed fairly constant. In the United States these proportions seem to have increased since 1995 steadily across all age groups. In England, this seems, in contrast, to be declining over the period of the survey across all respondents except the oldest old (see Figure 1).

IADLS: The proportion of respondents with IADL limitations is consistently lower than those with ADL limitations across all the countries. This was not surprising, given the typical hierarchy of ADLs as the most-severe and least-common form of disability, when compared with IADL disabilities, and to a greater extent, physical functional limitations (which are the least severe and most common). The age patterns of IADLs across age groups and across countries are very similar to that of ADL limitations: a steady increase in the proportion with IADL limitations with age in most countries except Netherlands, Sweden and Switzerland with increases predominantly among those over 70 years of age.

As with ADL limitations, a larger proportion of respondents in Italy report limitations in IADLs across all ages in the second wave while this proportion seems to be declining in Spain over the two waves of the study, with all other countries showing little change across the two waves. In the United States the proportion of this population seems to be declining over time especially in the older age groups (75 years and older) while in England the pattern seems to be the reverse with increases in these proportions over time, more so in the oldest age groups (see Figure 2).

Longitudinal analysis

Age-Period-Cohort analysis—ADLs: Analysis of the age, period and cohort effects across the different studies shows a very clear linear effect with a clear trend of increasing levels of disability with age. However, though this trend is consistently seen throughout the age span over the age of 50 in the SHARE countries and in England, this becomes apparent only in the older age groups, after age 70, in the United States. The cohort effects show that in the SHARE countries levels of ADL limitations have been declining steadily across consecutive cohorts and have continued to do so right up to the most recent cohorts included in the study. In the United States ADL limitations steadily rose up until those born in 1935 and began declining thereafter with a suggestion of a rise again in the cohort born between 1952–1954, though not to the levels comparable to those that were born around 1935. In England, in contrast, the levels of ADL disability seem to have remained more or less constant among cohorts born since the 1920s, with some suggestion of a cohort effect in 1942 and 1946 with increases in ADL limitations in those cohorts.

IADLs: With regard to IADLs, the results are more consistent across studies with an age effect being evident across all countries only in those over the age of 70, with steady increases in IADL limitations thereafter. There are no evident cohort effects in any of the studies.

Generalised estimating equations analysis—We also carried out longitudinal analyses of these data sets using a generalised estimating equation model. In the HRS, ELSA and SHARE studies (54–56) across all age groups, the likelihood of developing

disabilities, as measured by ADL and IADL limitations, increased with every wave. Women were also more likely to develop disabilities as compared to men (see supplementary online material).

In order to compare these results with those from low and middle income countries, we analysed data from the 10/66 group of studies (57). The study sample consisted of community residing individuals aged 65+ in Cuba, Dominican Republic, Peru, Mexico, Venezuela, Puerto Rico, China, and India. Two waves of data from 2003 and 2007 are available. We used a score derived from the measure of disability, the WHO Disability Assessment Schedule, version 2.0, used in this study to compare changes in disability over time. Our analysis shows that in these countries, consistent with our analysis of other surveys, the health of women declined more significantly than men, as did the health of those with poorer education and increasing age. This was consistent across all the sites.

Finally, our cross-sectional analysis using the data from the World Health Surveys shows that health status declines as the population grows older with a marked decline in the oldest old. This decline in health is greater in lower-income than higher-income countries. Further examination of declines in health by socioeconomic status reveals that the magnitude of age-related decline is the same across wealth quintiles in lower-income countries while in high-income countries health declined far more rapidly in the poorest quintiles as compared to the richest section of the population. The health status of older adults in the poorest quintiles was at least decade behind that of those in the richest quintile. Of interest is our finding that the health of the poorest quintile of the population in higher-income countries was comparable to the health of the upper income population from lower-income countries.

Analysis of this data set also showed that those with the least education or wealth had the worst health. Further examination showed that this difference in health was significant in the domains of mobility, self-care, pain, cognition, interpersonal activity and vision. Relative inequalities in the different domains in health were higher in the higher-income countries than the lower-income countries.

Implications for the future and possible interventions

Our systematic examination of the literature revealed that support for morbidity pattern hypotheses varied primarily according to the type of health indicator. Disability- or impairment-related measures of morbidity tended to support compression of morbidity, whereas chronic disease morbidity tended to support expansion of morbidity hypothesis. Similar patterns were previously reported in a review by Parker & Thorslund (58).

A simplified view of population health change progresses through the following stages: risk factors → diseases/conditions → loss of function → disability → death (10). Our findings suggest that loss of functioning and disability over the life course may be improving. This might be attributed to advances in the field of rehabilitative medicine, modifications to physical living environments, or education and early-life experiences (59). Contrarily, morbidity as chronic disease, at the other end of the spectrum, could be worsening (although fewer studies reported data on this dimension of morbidity). The extent to which this

phenomenon is a product of heightened awareness of diseases versus actual disease increase is likely disease- and setting-dependent. Our study did not encompass trends in risk factors, which may be worsening (in the case of obesity and sedentary lifestyles) or improving (in the case of tobacco use) (3). Equilibrium of morbidity may also be roughly placed within this spectrum, with more-severe disability positioned to the right, and less-severe disability, leftward. Among studies that assessed morbidity severity, we did not find predominating evidence for any one health and aging hypothesis.

Possible trends according to geography and study design were detected, although these may be somewhat attributed to differing morbidity definitions. Cambois et al., for example, aptly demonstrated the importance of consistently defining the morbidity constructs, as four different health surveys in France had comparable findings for a range of morbidity indicators as long as consistent definitions were used across the different data sources (27). Geographically, studies from the United States indicated compression of morbidity, but all studies reported morbidity as disability and thus it is unclear whether the United States experienced similar patterns for other measures of morbidity. Data from Asian countries, on the other hand, demonstrated expansion of morbidity more often than compression (using disability measures), but results were largely inconclusive or variable. Regrettably, the studies included in our review did not adequately represent developing countries. The strengthening of data collection and epidemiological research capacity within these settings is fundamental to better understanding health and aging trends, as data from more developed countries may not be relevant. A shifting disease burden from infectious to chronic diseases, for example, implies changing patterns of illness and disability within populations (60).

The use of prevalence-based life tables (primarily by cross-sectional studies) enabled the detection of shifting health patterns over the long term. Prevalence-based life tables are less sensitive to dynamic health states with multiple morbidity-related transitions (61;62). Nearly 70% of the reviewed studies were cross-sectional, reporting mixed support for the three hypotheses according to various health indicators. This was not surprising, as specific diseases or conditions may demonstrate characteristic progression patterns (60). Multistate life tables, which can be employed with longitudinal data, have the advantage of detecting transitions between stages of morbidity (61). Longitudinal study designs tended to report compression of morbidity as disability, although there was limited longitudinal data on other dimensions of morbidity. As more longitudinal data becomes available, the development of advanced methods of analysis, such as multivariate stochastic process models, will help to more accurately delineate trends in dimensions of morbidity and mortality (63). Studies that analyzed administrative data aligned closely with the trends reported by morbidity definition, finding compression of disability, and expansion of chronic disease.

Preventative measures initiated early in life may be fundamental to negating expansion of morbidity later in life, or sustaining situations of morbidity compression. Reviewed studies suggested a possible expansion of chronic disease, with some support for expansion of disability- or impairment-related morbidity. Previously, health problems later in life have been linked to earlier life experiences, such as possession of risk factors (64;65). Because the direction of health and aging trends in future years may be different from the current

situation, ongoing research through population surveys is justified to anticipate and meet changing needs.

The paucity of studies from less-developed countries highlights the need for population research in such regions. Less-developed countries are predicted to experience the greatest gains in life expectancy over the coming years (1); epidemiological patterning of health trends will enable the ability to foresee and plan for changes in population health. In addition, research that explores relationships between various dimensions of morbidity is also warranted. As longitudinal data becomes more available, sophisticated methods of multivariate analysis can help to delineate disease- and population-specific health trajectories. Furthermore, detailed analyses of data that includes life histories (including reproductive histories) will also be required to understand the reasons why gender differences exist in these health trajectories. A recent decomposition analysis that addressed differences in disability between older men and women revealed that a large part of these differences arise from the social determinants such as education, employment, economic and marital status (66).

Our search strategy included two major databases and was limited to English language results, thus relevant studies may have been missed. Decreasing the sensitivity of the search keywords would have expanded the pool of results, but we found that key articles were retrieved by the employed strategy, and generalizing search terms did not appear to be advantageous over hand searching of relevant publications and reviews. We adopted a broad definition of morbidity to include studies with multiple dimensions of morbidity and assess their relationship with mortality. Diversifying the morbidity construct allowed us to assess broader patterns, although varying outcome measurements and study designs decreased the degree of comparability between reviewed studies (67). Because we aimed to review studies from diverse geographical regions, we did not include studies that assessed trends in general, self-rated health. General self-rated health is a useful indicator of overall physical health, but has limited comparability across cultures and gender (68). Lastly, certain morbidity measures, geographical regions and study designs were more heavily represented than others within the 25 datasets that we reviewed, and not all studies reported morbidity by severity level. Thus, we cannot conclude with certainty about the trends of various dimensions of morbidity.

Secondary analysis of data

Our analysis of three large longitudinal surveys of older adults with a harmonized assessment of disability with regard to ADL and IADL limitations, shows varying patterns. All countries do not seem to provide consistent evidence for a compression of morbidity. Countries like Italy, Spain and Greece seem to have much larger proportions of persons who are disabled across all ages irrespective of the measure used. However, problems with IADLs seem to become more apparent among the older of the respondents across all these countries. While consecutive cohorts seem to be steadily in better health with regard to declines in ADL limitations, this is not true for limitations in IADLs. Also, in the United States and England, the apparent increase in ADL disability in more recent cohorts (1955 and 1944 respectively) needs to be watched over time.

We have chosen not to undertake a meta-analysis given the very disparate outcomes used in the studies in the literature as well as the different approaches to conceptualise and construct a single measure of health status.

Issues of conceptualisation and measurement

In order to track the health of older adults over time and across populations it is imperative to have a common conceptual framework and approach to measurement. Current longitudinal studies of ageing are increasingly working towards an effort at harmonisation of these studies such that a common set of measures are used in these disparate studies. A minimum sub-set of measures with standardised approaches to implementation will go a long way in increasing the robustness of these comparisons. Continuous measures of functioning capacity coupled with measures of more severe levels of disability such as ADLs will perhaps be complementary in this regard. In addition, incorporating performance measures of functioning such as tests of cognition, gait speed and grip strength, along with measures of physiological risk such as raised body-mass index, increased waist hip ratios, hypertension, hyperglycemia, hyperlipidemia and increased inflammatory markers such as C reactive protein will further the efforts at comparing health outcomes in these populations. Thus, rather than focussing on trends in the prevalence of chronic diseases alone, functioning based assessments of health status (comprised of a core set of domains) need to become an integral part of national data collection efforts to monitor trends in healthy life expectancies especially for older adults.

Implications for the future

The expectations are that with early detection and intervention for a range of risk factors and chronic health conditions, an increasing number of individuals globally will live into older ages. Recent studies from the United States and Denmark suggest that about 30–40% of the oldest old may live independently without marked disability. This levelling off of disability in the very old suggests that interventions aimed at promoting health in older adults are likely to pay dividends.

However, many of the causes of disability in later life are the result of accumulated lifestyle and other risks much earlier in life, interventions must be directed at reversing trends in smoking and obesity at younger ages for payoffs in the future as also suggested by the review by Prince et al in this series. Increased physical activity, greater mental stimulation, participation in leisure activities, coupled with early detection may help preserve cognitive function into older ages. Additionally though, as noted by Beard and Bloom in their Viewpoint in this series, these risks continue into older ages warranting ongoing surveillance and interventions in older adults as well.

Training strategies that may alter cognitive-behavioural styles of older adults to adapt to changing life circumstances may also help in keeping older adults in better health in later life by preserving cognitive function in later ages.

The key question remains that as populations worldwide continue to live longer will they remain in good health for those added years. As we have pointed out, an individual's health, irrespective of having a chronic illness, is defined by being able to execute series of

day to day actions and tasks. The capacity to do this with as little difficulty as possible defines good health. As noted by Beard and Bloom, comprehensive assessments of functioning are needed since this conceptualisation of an individual's health is not only particularly relevant for older adults who may have multiple chronic illnesses, they are also far better predictors of survival than merely the presence of single or multiple diseases. Health interventions can then focus on improving the functioning of older adults within an integrated people centred care strategy across the entire continuum of care (69). As noted in the comments by Fried and Rodriguez-Manas and Banerjee in this series, drawing attention to the identification and management of the health of older adults as they grow frail with multiple chronic conditions is particularly urgent.

Moreover, as Steptoe et al point out in their review, the relationship between health and subjective well-being (SWB) is bidirectional. Older adults with chronic illnesses are likely to have decreased well-being. SWB is predictive of longer survival. As Bloom et al point out in their review in this series the right economic, social and health system policies coupled with individual behaviour changes can ensure the future health and well-being of older adults. While we keep adding increasing years to life we must ensure that these years are spent in good health as far as possible, thereby keeping this burgeoning section of the population healthier and with preserved well-being.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key Messages

- Populations are rapidly ageing worldwide with major implications for health systems. This is more so in low and middle countries
- A key question, is will older generations be healthier than those that have preceded them. In other words will we be adding life to years as populations age by ensuring maintained functioning and well-being.
- In high income countries there is some evidence that a compression of morbidity is taking place as seen from trends of functioning and disability status. However, uncertainty remains about the health of future older generations given different risk factor exposures in different cohorts and trends in increases in the prevalence of chronic diseases.
- In low and middle countries there is currently no reliable evidence of compression and there may even be an expansion of morbidity happening driven by lifestyle risk factors and increasing chronic diseases.
- Given the paucity of data, robust evidence needs to be generated on these trends to ensure an appropriate response from health and social systems.

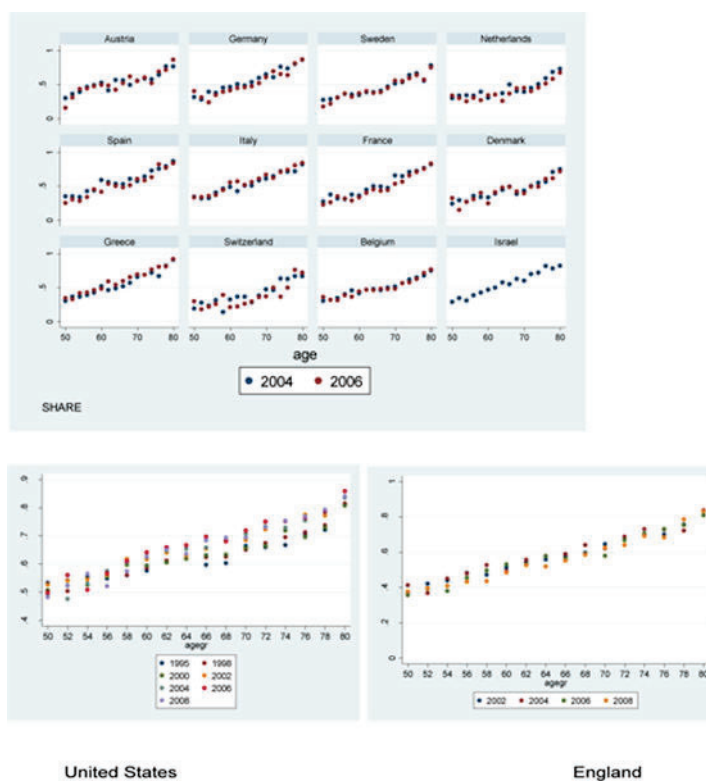


Figure 1. Levels of ADL limitations by country, age and time
Data taken from SHARE (54).

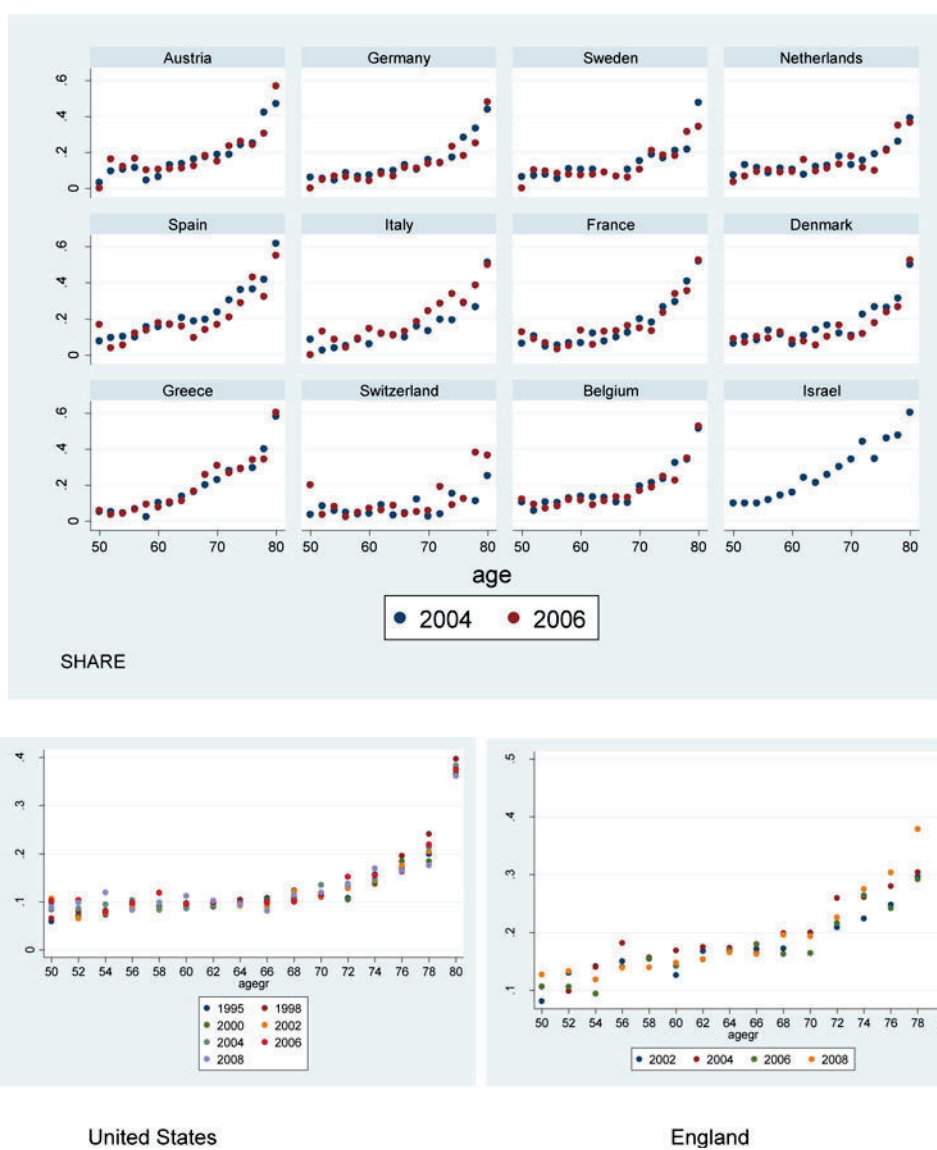
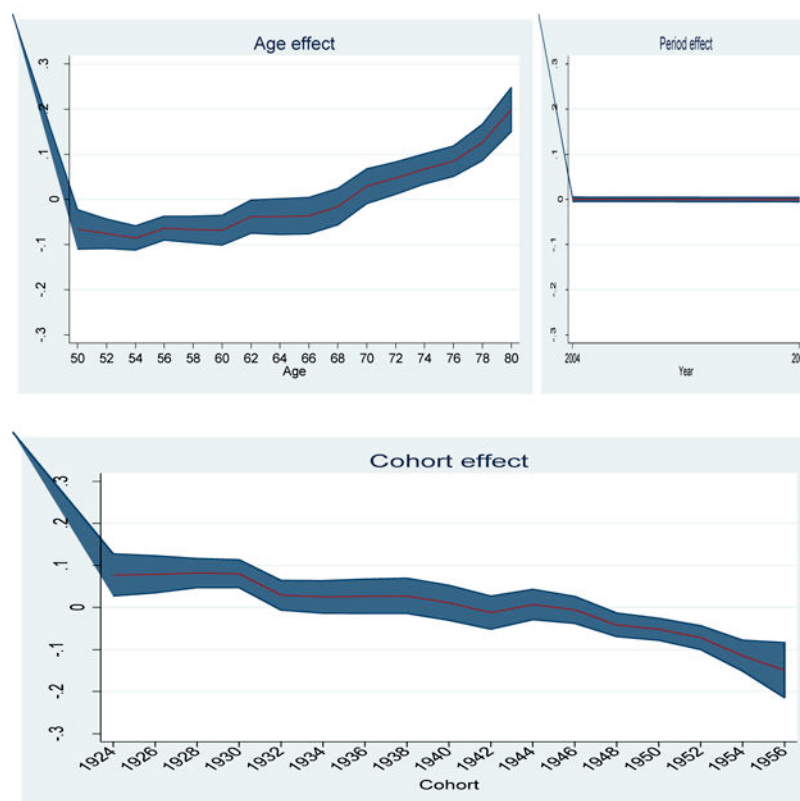
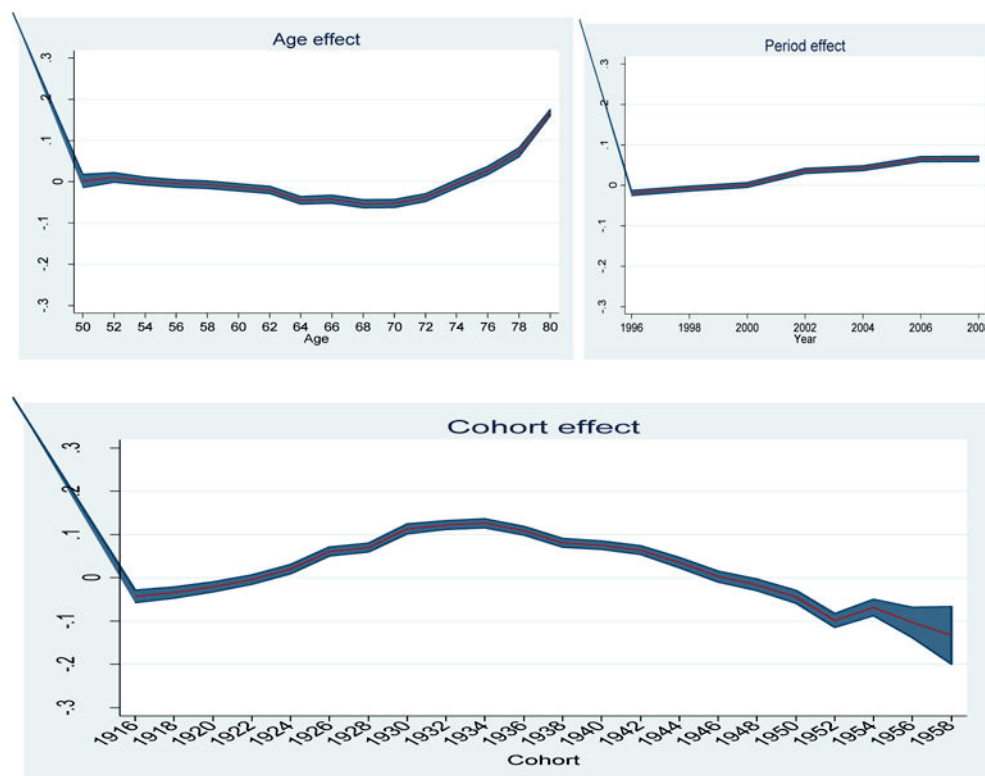


Figure 2. Levels of IADL limitations by country, age and time
Data taken from SHARE (54).

SHARE – pooled across countries



HRS – United States



ELSA - England

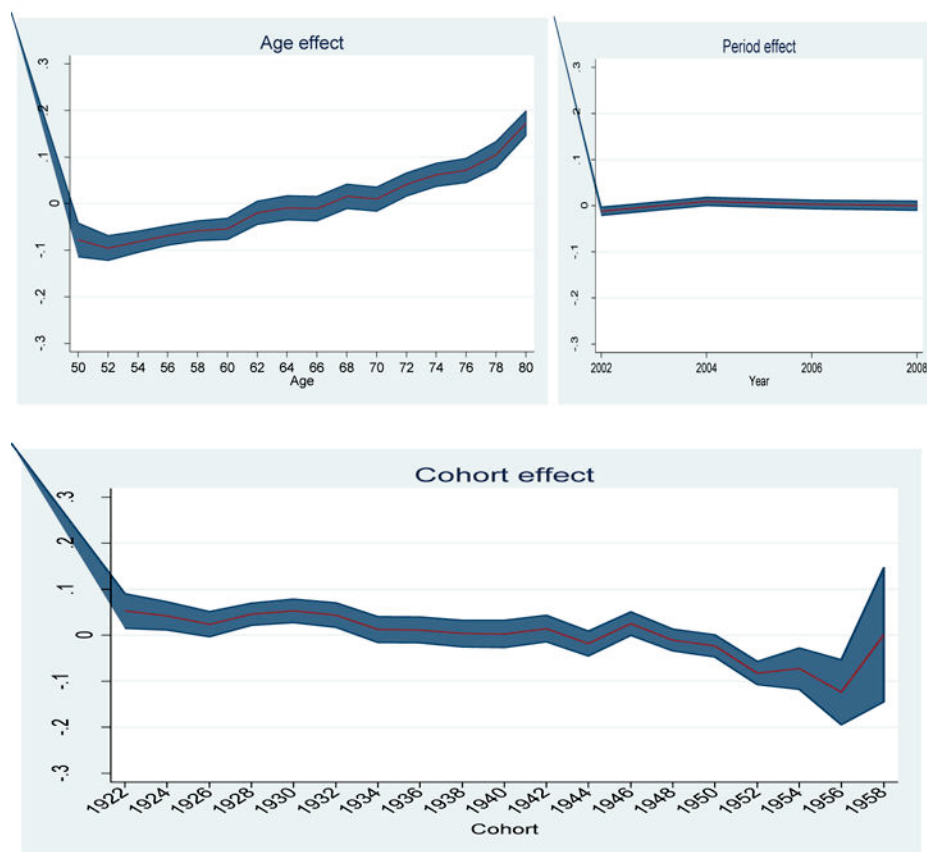
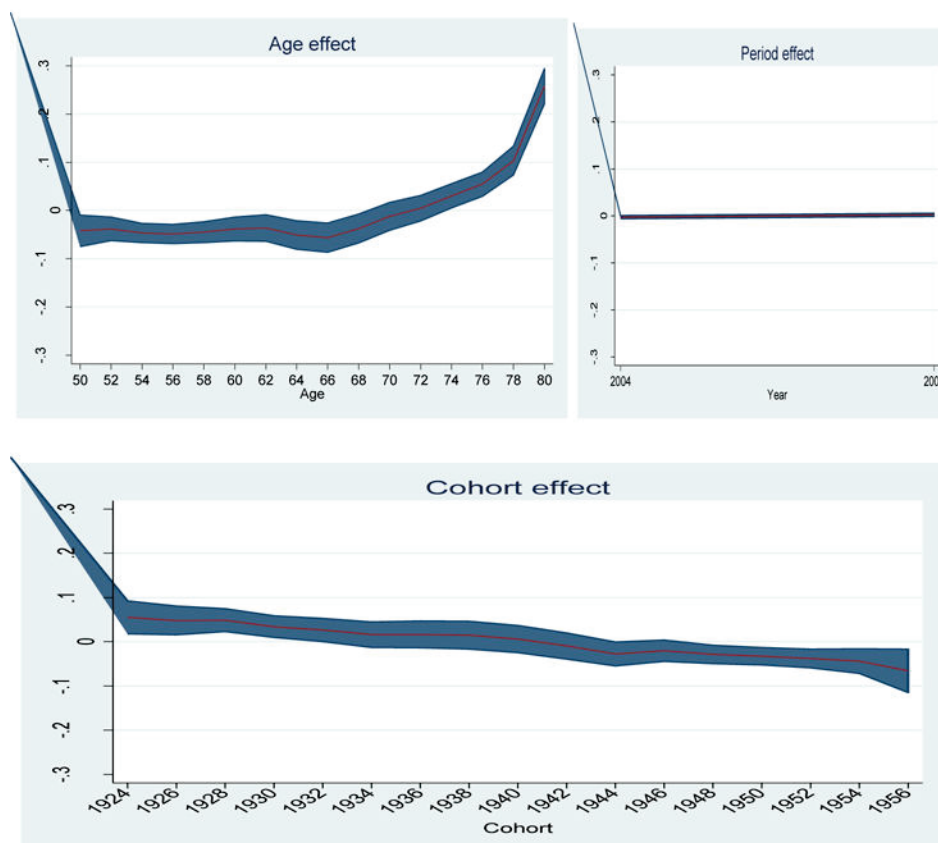
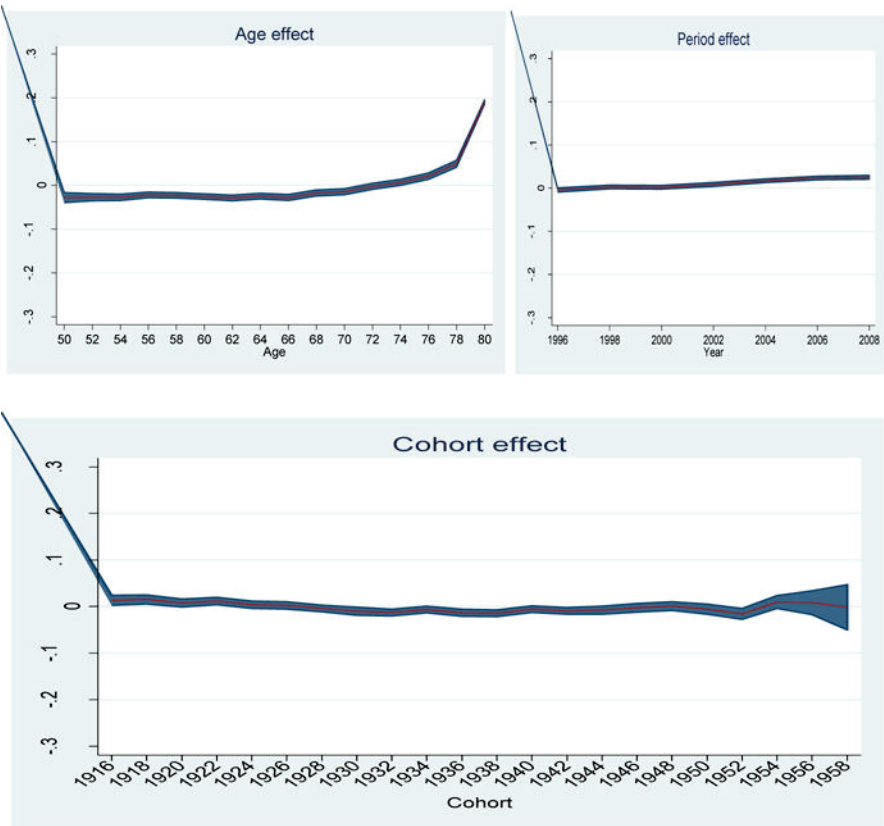


Figure 3.
Age-period-cohort effects for ADL limitations by survey (54–56)

SHARE – pooled across countries



HRS – United States



ELSA - England

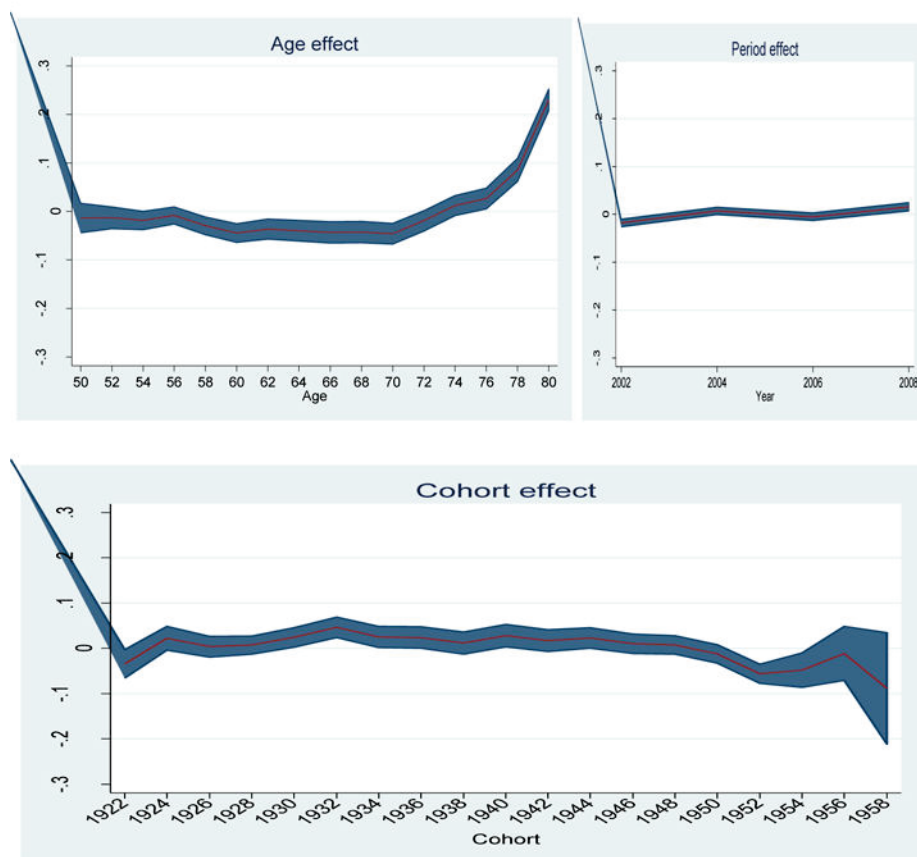


Figure 4.
Age-period-cohort effects for IADL limitations by survey (54–56)

SPECIAL REPORT

ISPRM DISCUSSION PAPER: PROPOSING A CONCEPTUAL DESCRIPTION OF HEALTH-RELATED REHABILITATION SERVICES

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There is a need for a comprehensive classification system of health-related rehabilitation services. For conceptual clarity our aim is to provide a health-related conceptual description of the term “rehabilitation service”. First, we introduce a common understanding of the term “rehabilitation”, based on the current definition in the World Health Organization’s *World Report on Disability*, and a conceptual description of rehabilitation agreed upon by international Physical and Rehabilitation Medicine organizations. From a health perspective, rehabilitation can be regarded as a general health strategy with the aim of enabling persons with health conditions experiencing or likely to experience disability to achieve and maintain optimal functioning. Secondly, we distinguish different meanings of the term “service”, that have originated in management literature. It is important to distinguish between micro, meso and macro level uses of the term “service”. On a meso level, which is central for the classification of rehabilitation services, 2 aspects of a service, i.e. an offer of an intangible product and an organizational setting in which the offer is upheld, are both essential. The results of this conceptual analysis are used to develop a conceptual description of health-related rehabilitation, which is set out at the end of this paper. This conceptual description may provide the basis of a classification of health-related rehabilitation services, and is open for comments and discussion.

Key words: rehabilitation; health services; organization; classification; conceptual analysis.

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INTRODUCTION

Health systems development became a major focus of the work of the World Health Organization (WHO) under the aegis of its

director general Dr Gro Harlem Brundtland, with the publication of the *World Health Report* in 2000 (1). This development was later taken up by other major political players for global health, such as the World Health Assembly and the World Bank, giving the issue of “strengthening health systems” a high political priority (2, 3). A health systems framework, consisting of 6 building blocks, including leadership and governance, service delivery, human resources, essential medical products and technologies, health information systems and health financing, was developed by the WHO in order to understand health systems, target development gaps and monitor change (2, 4). A strong commitment to the importance of good health system data, which should guide health policy decisions, is at the heart of this development.

Rehabilitation, as a key health strategy to address disability (5, 6), is essential to a health system addressing the needs of its population. The seminal publication of the *World Report on Disability* by the WHO and the World Bank (7) emphasized the potential rehabilitation has to tackle disability-related health issues. However, a lack of data on disability became apparent, including data on rehabilitation services and their role within the health system. Lack of (access to) available rehabilitation services has been pinpointed as a major barrier to rehabilitation, especially in low-income countries or rural areas. Data on rehabilitation are often not disaggregated from data on other healthcare services, and administrative data on the provision of services is often fragmented due to the fact that rehabilitation may take place in a variety of settings and be performed by different professions. There is no common framework for the evaluation of these rehabilitation services.

There are international classification systems that provide a common language to describe aspects of health and healthcare. They enable the comparison of health-related data within populations over time and between populations at the same point in time, as well as the compilation of internationally consistent data (8). However, the reference classifications of the WHO, the International Classification Diseases (ICD), the International Classification of Functioning, Disability and Health (ICF), as

well as the upcoming International Classification of Health Interventions (ICHI), all relate to the personal level, i.e. to the micro level of patient care. A comprehensive description of healthcare for persons with disabilities should also include the context, i.e. setting, in which an intervention takes place. We refer to this as the meso level of healthcare. To date, we are missing this important piece of meso level information: what types of services are offered in relation to which patients' needs? A sound comparative description of service provision and analysis of service gaps is hampered without sound information on rehabilitation services. A classification system for rehabilitation services could be used as a common framework to describe rehabilitation services within a defined region or country. It would offer the opportunity for inter-regional or international comparisons, and should provide the information needed for better planning, organization and monitoring of rehabilitation care as well as prioritizing rehabilitation services in national and global health policy agendas. Therefore, there is a need to develop a respective classification system.

The International Society for Physical and Rehabilitation Medicine (ISPRM), as the international umbrella organization of physical and rehabilitation medicine, has identified the development of a rehabilitation service classification system as one of its policy agenda items (9). Following the procedures of ISPRM, ISPRM leadership had mandated the WHO/ISPRM-Liaison-Committee, and specifically its Medical Rehabilitation Sub-Committee to develop a series of discussion papers, of which the present paper is the first.

The starting point of such a classification should be a clear understanding of the basic underlying concepts. Therefore, we aim to provide a conceptual description of the term "rehabilitation service". First, we will discuss our understanding of the terms "rehabilitation" and "service". Then we will bring both lines of thought together, and propose a conceptual description of health-related¹ rehabilitation services.

WHAT IS REHABILITATION?

Rehabilitation *in the area of health* is a complex concept. It has no single or common location, such as a hospital, for secondary or tertiary curative care, nor is it performed by a circumscribed profession defined by an organ system, such as ophthalmology or cardiology. Therefore, a definition of rehabilitation requires other starting points. Rehabilitation is best described by its aim, to *re-habilitate*, i.e. to restore or return a person to a state of optimal functioning in interaction with his or her environment. Hence, rehabilitation relates to the individual level. Interventions on the societal level, e.g. barrier removal initiatives, are not considered rehabilitation (7, p. 96).

¹The *UN Convention on the Rights of Persons with Disabilities* (United Nations General Assembly, 2006) distinguishes health-related rehabilitation (§25) and rehabilitation as a general term (§26) that can be related besides health to areas of employment, education and social services. While, in practice, it is not easy to draw a clear-cut line between these areas, in the present paper we apply a health-related rehabilitation perspective.

Rehabilitation has been defined as an idea, or "concept" (10, p. 3). It has been conceptually specified as 1 of 4 health strategies (11).² Essentially, rehabilitation might be best characterized as a general health strategy that is specific in its aim of optimizing human functioning. For example, the *World Report on Disability* defines rehabilitation as "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments" (7, p. 96). Accordingly, a recently developed conceptual description of rehabilitation based on the model of the ICF (12) is constituted by the goal "to enable persons with health conditions experiencing or likely to experience disability to achieve and maintain optimal functioning" (6, p. 282). This conceptual description of rehabilitation has been endorsed by various international professional societies in the field of physical and rehabilitation medicine³.

It is worth considering whether we could define rehabilitation services by viewing rehabilitation first and foremost as a health strategy characterized by a specific aim. It could be argued that almost everything we do in healthcare is, to some degree, related to improvement of functioning. For example, an operation on the cardiac valve is not made just because of an organ defect, but to restore adequate levels of functioning in a person, e.g. the ability to do a physical job. In many cases, problems with functioning might be the initial reason for patients to contact healthcare (primary or community care), or resolving these may be regarded as the ultimate goal of medical care.

There is no specific location or single profession related to rehabilitation in these definitions (7).⁴ Rehabilitation needs may be present along the continuum of care, from the acute or initial phase immediately following recognition of a health condition, through to post-acute and maintenance phases, and involves hospitals, rehabilitation facilities and community institutions (6, 7, 13).

While, in 1981, WHO described the target group of rehabilitation as "the disabled and handicapped" (15, p. 9), the current approaches converge to target individuals who experience, or who are likely to experience, disability in interaction with their environments (7). Differences arise as to whether the presence of a health condition should be a specifying characteristic (6). All descriptions convey the notion of optimizing functioning as the ultimate aim of rehabilitation. An explicit reference to health-related aspects of rehabilitation is in line with the understanding of rehabilitation as 1 of 4 health strategies (5).

²These 4 health or healthcare strategies include prevention, curation, rehabilitation and support.

³Section of Physical and Rehabilitation Medicine of the Union Européenne des Médecins Spécialistes (UEMS-PRM section), European Society of Physical and Rehabilitation Medicine (ESPRM), European Academy of Rehabilitation Medicine (EARM), ISPRM.

⁴It should be noted that specialties of various professions have evolved that are specific to the field of rehabilitation (6), e.g. physicians specializing in physical and rehabilitation medicine (14) or rehabilitation psychologists, in the USA and Germany.

According to the ICF a *health condition* is not related only to acute or chronic diseases, but is an umbrella term also encompassing disorders, injuries or trauma (12).

In the *United Nations Convention on the Rights of Persons with Disabilities* (16), the most rapidly negotiated human rights treaty of the 21st century, rehabilitation is again understood and characterized by its aim, i.e. “to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life” (article 26, § 1). It should start as early as possible, be multidisciplinary and based on individual needs and strengths, be voluntary, and access to services should be in close proximity to a person’s place of residence in the community.

To sum up, from a health perspective, rehabilitation can be thought of as a general health strategy with the aim of enabling persons with health conditions experiencing, or likely to experience, disability to achieve and maintain optimal functioning. This definition allows the inclusion of consideration of very different settings or professions who deal with rehabilitation issues, such as geriatrics, social psychiatry, or a physical therapy office.

WHAT IS A SERVICE?

All healthcare systems provide health services. However, within the health sector there is a lack of conceptual clarity on the meaning of the term “service”, despite its widespread use.

From an etymological perspective the term “service” comes from the act of serving, as has been attested from the early 13th century. From the 16th century onwards the term related to the “duty of a military man”. This use of the term has carried into the present. The use of the term in relation to the service industry (as distinct from production) is attested from 1941.⁵ The term “service” has been widely used in management theory, specifically in the sub-discipline of marketing and production (17). Contrary to tangible products, i.e. goods, services are intangible products, e.g. accounting, consultancy, education, transportation. No transfer of possession or ownership takes place when services are sold. They cannot be stored or transported, are instantly perishable, and come into existence at the time they are bought and consumed. Services are supplied in themselves (“service industry”), but they might also be closely associated with goods. For example, when buying a car, a customer may rely on a wide set of additional services that are linked to this car and which increase the overall customer value of this transaction (18). In a medical context, establishing a diagnosis is a service that might go along with the delivery of a good, e.g. a medication, or the delivery of a further service, e.g. a therapy or any type of intervention.

While this definition implies that all medical services are in direct contact with a person in need or in demand of a service, there are also *non-personal services* important for the health

sector, e.g. so-called ancillary services (19), such as laboratory services.

In the context of governmental services it has been highlighted that public services often do not address a conventional customer who buys a readymade product. Rather, public services are often co-produced by so-called *pro-sumers* (a combination of a producer and a consumer of the service) (20). The peculiar situation of a service provider in this case is that the success of his efforts depends on the cooperation of the client. This is true for the teacher–student relationship, for the relationship between social worker and client, but also for the relationship between therapist and patient in rehabilitation.

From a general healthcare perspective, it should be noted that the term “service” has wide uses and may refer to very different levels of care. It relates to the micro level of care where the delivery of interventions is focused. It relates to a meso level of healthcare in 2 ways. Services characterize what a health institution *offers* in principle in terms of intangible products to patients with certain health-related characteristics. Also, the organizational units of healthcare, i.e. facilities or delivery points of services, are sometimes called services⁶ (21). While, in principle, the first meso level description of a service can be thought of without the second, e.g. telephone counselling, the second meso level description of a service only makes sense in combination with the first meso level description of a service. It might be thought of as the setting necessary to provide services. Lastly, it has also been used on a macro or policy level, exemplified in the term “military services” or even “health services”, as in health services research (Fig. 1). Therefore, it is necessary to specify our use of the term, accordingly.

Health service provision takes place in a particular organizational setting and leads to the delivery of (a series of) health interventions. It appears that health services, due to their prominent role in healthcare, are the main product, while goods, if present at all, are part of a service or intervention. Healthcare interventions are part of a service⁷. Interventions relate to personal services, not to non-personal services.

For the sake of a classification of rehabilitation service, it should be stated that we are not interested on the micro level perspective on services, i.e. the actual provision of services on an individual level. Here, a classification system (ICHI) is already under development (8). We are also not interested in the macro level distinguishing different policy domains. A classification of rehabilitation services should relate to the meso level of healthcare, i.e. a description of offers of personal

⁵Definition from online etymology dictionary, www.etymonline.com.

⁶In both German and Dutch we distinguish between a “Dienstleistung” (German) or “dienstverlening” (Dutch) and a “Dienst”, which can also refer to the setting in which a service is provided.

⁷In fact, the definition of a health intervention within the development of the ICHI uses the term “service” in this restricted sense: [A health intervention is a] “service performed for or on behalf of a client(s) whose purpose is to improve health, to alter or diagnose the course of a health condition or functioning, or to promote wellness”. (Unpublished paper, ICHI development project plan, version 2.1, July 2010, p. 8).

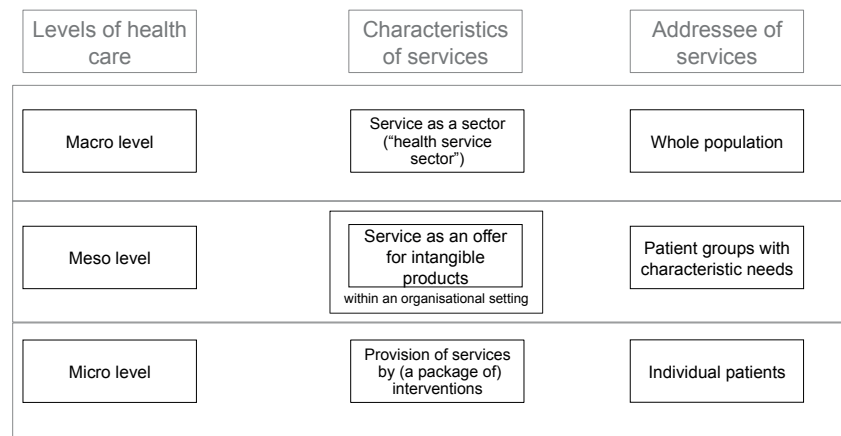


Fig. 1. Different levels of services in health care.

or non-personal intangible products for persons with specified health-related needs. These products are inherently related to the setting in which they are offered and delivered. In addition, it might be useful to identify rehabilitation services by identifying the setting in which rehabilitation is offered and delivered (e.g. clinics, hospital units, rehabilitation facilities, organizations).

For example, a rehabilitation clinic can represent a rehabilitation service on an organizational level, i.e. a rehabilitation facility. It may offer and deliver different rehabilitation services, e.g. for persons with chronic back pain and amputees, providing both rehabilitation interventions and non-personal products, including goods such as prosthetics.

Health services, as defined on this meso level, can be further characterized by their degree of professionalism. People offering a service should have a minimum degree of special education in health issues, i.e. professionalism might be thought of as a prerequisite for a health service.

To sum up, services within the healthcare field are personal and non-personal intangible products offered to improve health, to alter or diagnose the course of a health condition or functioning, or to promote wellness, by delivering interventions within an organizational setting by health professionals and, under certain conditions, appropriately trained community-based workers.

WHAT IS A REHABILITATION SERVICE?

Table I depicts our proposal for a conceptual description of rehabilitation services. It is fair to assume that, in healthcare, most products delivered are intangible (i.e. they are services), and that the delivery of tangible products (i.e. goods) is usually integrated into a service (line 2 of Table I).

Services might be thought of as a potential or an offer that is held available for provision, as indicated in line 3 of Table I. Here, as in line 5, we prefer to use the term "person", rather than "patient", to describe the addressee of the service. This is in line with the *UN Convention on the Rights of Persons with Disabilities*. This person is characterized in line 3, referring both to the broad ICF term "health condition" as introduced above,

to relate this conceptual description to the area of health, and to the disabling experience of the person, as in the definition of the *World Report on Disability* or by the conceptual description of rehabilitation provided by Meyer et al. (6). Also, we have included family or informal care-givers of a person with a health condition as possible addressees of a rehabilitation service.

A service is always offered within a special organizational setting (line 4), that is inherently related to the service itself. These characteristics should be strongly related the quality of the service. Therefore, in practice, services can hardly be viewed independently of their respective organizational setting. These settings could be part of a rehabilitation classification system themselves, or serve as the point of departure to identify rehabilitation services.

Line 5 illustrates the *pro-sumer* role of the person that characterizes an interaction between partners, i.e. professional and person.

Line 6 points to the fact that any health service should address individuals' needs, and rehabilitation services should react to functioning needs in terms of the ICF. These services related to functioning needs could comprise the performance, application or integration of biomedical and technological interventions, psychological and behavioural, educational and counselling,

Table I. A conceptual description of health-related rehabilitation services

Line	
1	Rehabilitation services,
2	are personal and non-personal intangible products
3	offered to persons with a health condition experiencing or likely to experience disability or to their informal care-givers within an organisational setting
4	in interaction between provider and person
5	addressing individual functioning needs
6	that aim at enabling persons to achieve and maintain optimal functioning
7	considering the integration of other services addressing the individual's needs
8	including health, social, labour and educational services
9	and delivered by rehabilitation professionals, other health professionals, or appropriately trained community-based workers.
10	

occupational and vocational, social and supportive, and physical environmental interventions, as has been exemplified in a conceptual description of physical and rehabilitation medicine (22).

Line 7 is taken from the conceptual description of rehabilitation (6) and pinpoints the central aim of rehabilitation as its defining core element. Services should be identified as *rehabilitation* services if their primary goal is related to enabling persons to achieve and maintain optimal functioning (line 7). For example, a classification of rehabilitation services in terms of *rehabilitation settings* would need to specify the organizational units providing the services. It can be a community rehabilitation centre, a department of a community centre, a rehabilitation clinic, or a department within a hospital. As can be seen, the size and scope of the different organizational settings can vary to a large extent. Also, the primary goal of the respective organizational setting has to be determined. If the *core interest* and the competencies of the professionals of the organizational setting are to enable persons experiencing or likely to experience disability to achieve and maintain optimal functioning, the service provided by the organizational setting should be called a rehabilitation service. For example, this could be an early rehabilitation unit in a hospital. If the organizational unit is a surgical unit that performs interventions aiming at the enhancement or prevention of deterioration of body structures or function, this should not be called a rehabilitation setting.

It is interesting to note that the System of Health Accounts (SHA) of the Organisation of Economic Cooperation and Development (OECD), in trying to identify rehabilitation care, came to a comparable solution (19). Here the term “focus” is used, comparable to what we have called “core interest”. The SHA document states that “Whereas curative services focus primarily on the health condition, rehabilitation services focus on the functioning associated with the health condition.” (p. 87). In distinguishing rehabilitation from other health functions, the SHA claims that “only rehabilitative components with a primary purpose related to health functioning” should count within the category of rehabilitation. In the SHA, too, rehabilitation is thought to take place over the course of the health condition, along a continuum of care and across sectors from health, education and labour to social affairs (19).

There is a special characteristic of rehabilitation services that should be kept in mind. In rehabilitation, individuals with chronic care conditions are often characterized by multiple and/or complex needs. Therefore, rehabilitation service provision has to face the complexity of these needs, which require the integration and management efforts between service providers for integrated medical and social support service (line 8). Individuals with chronic needs must access a number of diverse systems of care and services, including the areas of health, education, labour, and social affairs (line 9). These diverse systems of care and services need to be integrated in order to meet the needs of the person (23, 24). Individuals with chronic care conditions are often unable to navigate a non-integrated service system on their own. Therefore, organizations need to form inter-organizational ties with one another within integrated systems (25, 26), often arranged through interme-

diaries which have in-depth knowledge of a system of health services in a specific field or region (27). The *World Report on Disability* points out that, to ensure the continuity of care, coordination should be present when more than 1 service provider is involved in rehabilitation, (7).

In providing specific rehabilitation services, it is essential that the professionals involved possess appropriate qualifications (7) (line 10). These professionals can be rehabilitation personnel, health personnel, or community-based workers, who usually address a wide range of individual problems.⁸ It should be noted that professional expertise specific to rehabilitation is a prerequisite for a professional rehabilitation service. This does not preclude that individuals with disabilities (peer counsellors) or family members can be taught to provide functioning interventions themselves. The availability of the different needed professions is often an issue in low-income countries (7).

DISCUSSION

The *UN Convention on the Rights of Persons with Disabilities* calls on state parties to organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services (Art. 26). The *World Report on Disability* pinpointed the need for appropriate data and more accurate statistics, which is also the prerequisite of the health systems strengthening initiatives initiated by WHO. Service delivery is 1 of the 6 building blocks of health systems that need to be strengthened, particularly in developing countries. However, there is a lack of consensus on what constitutes a health service. For the area of health-related rehabilitation, we have presented and argued for a proposal of a conceptual description of rehabilitation services. This is based on a thorough discussion of the ideas of rehabilitation and services. It might be possible and useful to extend our approach to other areas of health, or to other areas of rehabilitation, such as labour, education or social affairs. However, this discussion is beyond the scope of the present paper. This conceptual description aims to be comprehensive and descriptive, without making statements about what should be regarded as a good or bad service. Other approaches are needed to follow that thread; for example, related to the health systems building blocks approach, which has included some quality indicators for monitoring health systems.

We have tried to emphasize that a rehabilitation services classification system should not be about classifying rehabilitation interventions. Health interventions are currently in the process of being classified in the ICHI of the WHO. Rather, we are aiming at distinguishing different rehabilitation “packages” of interventions and further non-personal products, addressing functioning needs, and offered within *different types of organizational settings* that are related by a *common goal*, to

⁸The issues of different fields of expertise in different rehabilitation professions, and of training of rehabilitation professionals are closely related to national laws and local customs, and are beyond the scope of this paper.

enhance functioning in persons with a health condition experiencing, or likely to experience, disability.

Rehabilitation services are special services within the realm of healthcare. They are intangible; however, the provision of goods can be part of a service. They can be very complex, e.g. part of the care for a person with a spinal cord injury in a specialized spinal cord injury centre. Or they can be quite simple, e.g. exercise training for cardiovascular patients in a sports club supervised by a physical therapist as part of a rehabilitation plan.

One challenge of the results of this paper lies in the fact that we cannot just classify services that call themselves rehabilitation services, as that could be too restrictive.⁹ We might miss services that, to all intents and purposes, are rehabilitative. And we might include services that might call themselves rehabilitative, but should be run under a different label. Therefore, the challenge is to identify and characterize appropriate organizational settings and to pinpoint the main goals of their services. In doing so, we might cope with the problem that rehabilitation services are inherently dependent on the health system they are part of. An approach that is able to integrate the peculiarities of the individual health systems is a prerequisite for the development of a common classification of rehabilitation services.

However, classifying rehabilitation services involves more than just classifying rehabilitation institutions. An institution can offer different rehabilitation services, e.g. an early rehabilitation unit might offer services for stroke patients, for patients before and after elective surgery, and for geriatric patients.

In order to open debate, the WHO/ISPRM-Liaison-Committee is publishing its work as discussion papers in the official journal of ISPRM. We are working towards the goal of developing a framework for a classification system of rehabilitation services. Obviously this process must be comprehensive with respect to the involvement of expertise from all world regions. It is also important to recognize that these discussion papers are seen as a starting point for a collaborative effort in partnership with other interested non-governmental organizations. Therefore, we strongly encourage readers to discuss our proposals and we invite comments.

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⁹The term “rehabilitation” can also refer to political issues, e.g. in Dutch and French, where this is the most common meaning; there, what we call rehabilitation in the meaning of the present paper, is called “revalidatie” (Netherlands) or “rééducation fonctionnelle” “réadaptation” (France).



METHODOLOGICAL NOTES ON APPLYING THE INTERNATIONAL
CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)
IN REHABILITATION
SPECIAL ARTICLE

Functioning: the third health indicator in the health system and the key indicator for rehabilitation

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ABSTRACT

In this methodological note on applying the ICF in rehabilitation, we introduce functioning as the third health indicator complementing the established indicators mortality and morbidity. Together, these three provide a complete set of indicators for monitoring the performance of health strategies in health systems. When applying functioning as the third health indicator across the five health strategies, it is fundamental to distinguish between biological health and lived health. For rehabilitation, functioning is the key indicator. Since we can now code mortality and morbidity data with the ICD, and functioning data with the ICF, and since given current plans to including functioning properties in the proposed ICD-11 revision, we should in the future be able to report on all three health indicators.

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Key words: Rehabilitation - Health systems plans - International Classification of Functioning, Disability and Health.

Population health is a key goal of modern society. As with systems of education and labor, health systems are now seen as societal investments rather than a cost.^{1, 2} The relevance of health for societal development has recently been reiterated in the Sustainable Development Goals (SDGs), which embody a “universal call to action to end poverty, protect the planet and ensure that all people enjoy peace and prosperity”.³ Goal 3 of the SDGs is to “Ensure healthy lives and promote well-being for all at all ages”. Health is also instrumental for the realization of the other 16 Goals. Recently, the World Health Organization (WHO) has supplemented this goal by underscoring the need to ensure that all people obtain the health services they need without suffering financial hardship when paying for them.⁴

To monitor the response of health systems to people's

health needs, three health indicators are relevant: mortality is the indicator for a population's length of life and the survival of individuals with health conditions. Morbidity is the indicator for the distribution of health conditions in the population and the use of health services. The data for these two indicators can be coded with the International Classification of Diseases (ICD),⁵ currently in its 11th revision. During this revision, in addition to a mortality and morbidity advisory topic group, a functioning advisory group was added, suggesting that WHO now recognizes a third indicator of health, operationalized as a combination of biological health and lived health and captured by the term “functioning”. Functioning can serve not only as an indicator for a population's health state and the outcome of clinical interventions and service delivery, but also as an in-

indicator for the impact on the population of the output of the health system on individual's lived experience of health. The data for this indicator can be coded with the WHO's International Classification of Functioning Disability and Health (ICF), endorsed in 2001.⁶

In this methodological note on applying the ICF in rehabilitation, we first introduce how these three health indicators can be used to monitor the performance of the five health strategies of the health system. We then explain the need to distinguish biological health from lived health when applying functioning as the third health indicator across health strategies, and next the application of this indicator. Finally, we briefly discuss the coding of functioning data with the ICF and the upcoming ICD-11.

Monitoring the performance of health strategies with health indicators

The primary objective of a health system is to achieve and maintain the highest attainable level of population health.⁷ This is achieved by means of health strategies, that is, plans designed to achieve particular health goals.⁸ Five health strategies are currently recognized. In 1978, the Declaration of Alma Ata⁹ recognized four of these strategies: promotive, preventive, curative and rehabilitative — more recently, in the context of the WHO initiative for universal health coverage: promotion, prevention, treatment, rehabilitation and palliative care have been identified as health strategies.¹⁰

It is important to recall that although health strategies provide an important foundation for health system design, in clinical practice these strategies are often combined when addressing the health needs of an individual patient. This is particularly relevant when collecting and interpreting data on health indicators at both the individual and population levels. There is vast experience with the collection of mortality and morbidity data including causes of death. With respect to the use of the ICF as an indicator for health, we are at the beginning. A first example of its application in a population is the Swiss Spinal Cord Injury (SwiSCI) Cohort Study.^{11, 12}

The successful implementation of health strategies requires the capacity and resources (input) within the health system that is sufficient to deliver services (output) that will successfully lead to outcomes such as equity, access, quality and efficiency, which in turn have

a desired impact on population health: the reduction of morbidity and mortality and optimal functioning.¹³ According to WHO's systems thinking, the capacity of a health system must be developed in terms of the six "building blocks" of a health system:¹⁴ health services delivery, health workforce, health information systems, essential medicines, health systems financing, and leadership and governance.

Health information is instrumental for the successful operation of all six building blocks. Most importantly, information on health indicators allows us to monitor the output of the main health strategies, making it possible for health systems to "learn".¹⁵ Because the indicators vary across health strategies and goals, health system monitoring requires the use of all indicators. Goals and indicators, as well as main use cases for the five health strategies are shown in Table I.^{16, 17}

Distinguishing biological health from lived health when using functioning as the third health indicator across health strategies

When applying functioning as the third health indicator across health strategies, it is fundamental to distinguish biological health from lived health. This distinction has been operationalized in the ICF by means of two qualifiers in the Activities and Participation component: capacity and performance.⁶

Biological health is a person's intrinsic health capacity. Its assessment includes the assessment of impairments in body functions and structure and capacity limitations across Activities and Participation. A person's biological health comprises what a person can do in light of his or her health condition and should not be confused with what a person actually does or is restricted in doing in her/his environment. This latter notion is captured by the concept of lived health. Its assessment consists of the assessment of levels of performance across Activities and Participation.

Applying functioning as an indicator across the five health strategies

Functioning as the third health indicator for prevention and health promotion

The primary goal of prevention is population health. Prevention targets risk factors characterized in the ICF

TABLE I.—*Health information for the monitoring and evaluation of the five health strategies.*

Strategy	Health goals	Health indicator	Data coding	Health information use cases
Preventive	Prevent the occurrence of health conditions	Morbidity	ICD – Health condition entities – Risk factors of health conditions	<i>Health statistics</i> Incidence of health conditions <i>Service delivery</i> Planning of public health programs
	Prevent mortality related to the occurrence of health conditions	Mortality	ICD – Health condition entities – Causes of death	<i>Health statistics</i> Years of life saved from the non-occurrence of health conditions <i>Service delivery</i> Evaluation of public health programs
	Prevent the loss of functioning related to the occurrence of health conditions	Biological Health (intrinsic health capacity)	ICF – Impairment qualifier – Capacity qualifier ICD 11 – Functioning properties ²⁰	<i>Health statistics</i> Biological health saved from the non-occurrence of a health condition <i>Service delivery</i> Evaluation of public health programs
Promotive	Optimal health	Biological Health (intrinsic health capacity)	ICF – Impairment qualifier – Capacity qualifier	<i>Health statistics</i> Incidence of impairments in body functions and structures; capacity limitations in activities and participation
Curative	Cure (full recovery) Remission Disease control	Mortality	ICD – Health condition entities – Causes of death	<i>Health statistics</i> Epidemiology of the causes of death
		Morbidity	ICD 11 – Health condition entities – Properties in development for the ICD 11	<i>Health services delivery</i> Reasons for encounters Quality and safety <i>Financing</i> Case-mix for reimbursement
		Functioning (intrinsic health capacity)	ICD 11 – Functioning properties ¹⁶	<i>Financing</i> Improved case-mix for reimbursement in the frail, disabled and co-morbid patient ¹⁷ <i>Service delivery</i> Functioning outcomes in health care performance assessment and quality and safety management
Rehabilitative	Optimal functioning	Functioning – Complete lived experience of health: biological and lived health in light of health conditions, under consideration of a person's resources, and in interaction with the environment	ICF – Impairment – Capacity qualifier – Performance qualifier	<i>Health statistics</i> Epidemiology of functioning and functioning needs <i>Governance and leadership</i> National rehabilitation policy and program planning <i>Service delivery</i> Rehabilitation quality management at the individual, service and national program level
Palliative	Optimize wellbeing	Appraised functioning (quality of life)	ICF – Appraisal of impairments and performance restrictions (qualifier not available in the ICF – one may use a satisfaction or preference qualifier)	<i>Health statistics</i> Epidemiology of appraised functioning in the end-of-life context <i>Governance and leadership</i> National palliation policy and program planning <i>Service delivery</i> Palliative care quality management at the individual, service and national program level

by means of personal and environmental factors. The goal of prevention is to prevent the occurrence of health conditions and premature mortality. This is typically reported as years of life saved from premature mortality from one or more health conditions. Functioning can serve as an additional indicator⁸ and may be reported as biological health — intrinsic health capacity — preserved thanks to the non-occurrence of health conditions.

Health promotion aims to improve people's intrinsic health capacity. It is not concerned with a particular health condition but rather targets the range of known risk factors including those of the most burdensome health conditions.¹⁸ Health promotion is not concerned with how intrinsic health capacity plays out in people's real life. The key indicator for health promotion is thus functioning, from the perspective of biological health.

Functioning, the key indicator for rehabilitation

Functioning is the key indicator for rehabilitation.^{8, 19} Both perspectives of biological and lived health are fundamental for the evaluation of rehabilitation interventions. This is because rehabilitation aims to optimize a person's functioning by improving both biological health and lived health in concert. This is achieved by providing the best treatment for health conditions — and so developing a person's intrinsic health capacity — by strengthening a person's psychological resources, by creating a facilitating physical and social environment, and finally and most importantly, by translating the potential from these improvements into better lived health.^{8, 20, 21}

Functioning, a health indicator for the curative strategy

The curative strategy aims at the restoration of full health, and if this is not possible, at remission or disease control. The first and foremost concern of the curative strategy is survival, both in the context of acute and chronic health conditions. The key indicator for cure is thus mortality.

Secondly, cure is concerned with the optimal management of a health condition including the minimization of complications (temporally closely related to the occurrence of an index health condition) and comorbidities (either unrelated to, or temporally more distant

consequences of an index health condition, perhaps mediated by environmental risk factors). The second indicator for the curative strategy is thus morbidity.

Finally, the curative strategy is concerned with optimal patient-centred outcomes, that is, people's health capacity to live a full life. People's actual living experience is obviously relevant for clinical decision making, at least insofar as the person's life is affected by their health state. But what people do or are restricted from doing in their actual environment cannot be the primary outcome of a curative intervention since performance is determined by many external factors that go far beyond what a health strategy could possibly affect (e.g. income levels, social position, climate). The third indicator of cure thus is functioning from the perspective of biological health.

In this context we may recall that the Food and Drug Agency (FDA) in the United States, and the European Medicine Agency (EMA), when approving drugs now require not only the demonstration of an improvement in biological parameters but also the benefit for person's functioning. To be able to statistically demonstrate a potential advantage of one drug over another in an ethically required sample that is as small as possible, it is thus paramount for clinical trials to reduce the influence of the environment as much as possible and to evaluate benefits in terms of biological health.

Functioning, a proxy indicator for palliation

The aim of the palliative strategy is to optimize well-being in the context of dying. Functioning undoubtedly contributes to this goal, and for this reason functioning may serve as proxy indicator. Beyond reporting a person's biological and, more importantly, lived health, one should also consider reporting a person's appraisal — a person's valuation or preference for a certain level of functioning.

Coding of the health indicator functioning with the ICF and the ICD

Functioning information is ideally coded with the ICF. It will also be possible to code functioning information as functioning properties in the upcoming ICD-11.¹⁶ It remains to be seen, however, how this coding will be implemented. It is already clear that the func-

tioning properties will only include domains of Activities and Participation. Also, there will be no distinction made between capacity and performance. (The practical aspects of coding functioning information for health statistics and reimbursement¹⁷ along the continuum of services dedicated to the different health strategies will be the subject of a future methodological note.)

Conclusions

With WHO's introduction of the notion of functioning we now can rely on a third health indicator that complements the established health indicators of mortality and morbidity. Together these provide a complete set of indicators for the monitoring of the performance of health strategies in the health system. When applying functioning as the third health indicator across the five health strategies it is fundamental to distinguish biological health from lived health. For rehabilitation, functioning is the key indicator. With the possibility of coding mortality and morbidity data with the ICD and functioning data either with the ICF and or in terms of functioning properties in the upcoming ICD-11, we can now rely on data for each of the three health indicators.

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SPECIAL COMMUNICATION

Health, Functioning, and Well-being: Individual and Societal



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Abstract

As a society we invest an enormous amount of resources in health because we are convinced that health is linked in some way to a person's well-being, and that population health is linked to overall societal welfare. But the nature of this link, and the evidence for it, are more controversial. After exploring current attempts to operationalize well-being in a manner amenable to measurement, in this article we offer a way for securing the link between the provision of health care and individual well-being, and societal welfare by highlighting what matters to people about their health. We argue that it is the lived experience of health and its effect on daily life that matters. This experience is captured by the notion of *functioning* in the World Health Organization's International Classification of Functioning, Disability and Health. Moreover, viewed as an indicator of health on par with mortality and morbidity, functioning provides the essential bridge that links the provision of health care both to individual well-being and, at the population level, societal welfare.

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Introduction: health and well-being

It is reasonable to believe that a person's state of health plays some role in his/her overall well-being. After all, we spend a huge amount of social resources on the health sector because we are convinced that health makes life and living better, for the individual and for the society at large. The World Health Organization's (WHO) famous 1948 definition of health went much further than this and insisted that health is both a necessary and sufficient condition for well-being.¹ Researchers since then have more cautiously suggested that there is a positive association between a person's state of health and his/her well-being, and that at the population level it is plausible to argue that societal welfare depends on the provision of health care and public health interventions. What is less clear is why this is so, and what evidence we have for it. Since the enormous institutional investment every society makes to provide health care to its population ultimately depends on the assumption that health contributes to individual well-being, not being able to secure this linkage, conceptually and quantitatively, is troubling. In this article we suggest that we have

the conceptual means for making this link and providing the information to quantitatively substantiate it. We argue in particular that information about the lived experience of health—or functioning—captures the link between health and well-being.

In what follows we make the case for the need of an indicator of health that can be used to measure what is important to us about our health, introduce the concept of functioning as that indicator, and, finally, show how functioning can clarify, conceptually and quantitatively, the link between health and well-being. But first, to avoid potential confusion, it is important to separate different uses of the term *well-being* and to distinguish well-being from *welfare* for the purposes of this article.

Well-being and welfare

International and national agencies agree that health is, or is at least, one of several determinants of well-being. The Organization for Economic Co-operation and Development's multiyear Better Life Initiative, for example, conceptualizes well-being in terms of material living conditions, the sustainability of socioeconomic and natural systems, and quality of life. Health shares this last category with 6 other determinants: (1) work and life balance; (2) education; (3) civil engagement; (4) social

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connection; (5) environmental quality; and (6) personal security and subjective well-being.^{2,3} The Human Development Index, often used as a proxy for aggregate population well-being, by contrast conceptualizes well-being as comprised of 3 dimensions: a long and healthy life, knowledge, and a decent standard of living.⁴ At the United Nations, both the Millennium Development Goals⁵ and their successor, the Sustainable Development Goals, identify health as essential for development and human well-being. The Sustainable Development Goals explicitly state this with goal 3: “Ensure healthy lives and promoting well-being for all at all ages.”^{6(para.2)}

Although these are, fundamentally, purely aspirational assertions, they do have a measure of academic and scientific support. Generally speaking, although there is little agreement about the precise composition of individual well-being (or what makes a life go well for an individual⁷) no proposed account fails to include health as a component or determinant. Following a tradition that goes back to Aristotle, academics divide well-being into 3 nonoverlapping dimensions including objective well-being and 2 forms of psychological well-being, namely, subjective well-being and eudemonic well-being (meaningfulness, human flourishing). The currently favored account of subjective well-being identifies 2 related subcomponents, positive affect and cognitive evaluation, or life satisfaction.⁸ Psychologist Carol Ryff has characterized eudemonic well-being in terms of the psychological factors of self-acceptance, personal growth, purpose in life, and autonomy.⁹

Turning to the literature on objective well-being, the most influential theoretical account is the capability theory of Amartya Sen and Martha Nussbaum.¹⁰⁻¹³ A capability, for Sen and Nussbaum, comprises the provision of all preconditional individual abilities and external resources required to provide an individual with a realistically realizable opportunity to achieve a life goal.¹⁰ A capability, in other words, is an objective opportunity that embodies all necessary preconditions for its achievement. For both Sen and Nussbaum, health (and health-related factors such as normal lifespan, good nourishment, emotional resilience, and cognitive abilities) is firmly part of the set of capabilities essential for an objectively good life. Conceptualized as a capability, moreover, health incorporates the societal resources required to optimize or preserve individual health. Other capability theorists go further and claim that health is a *master capability*, in the sense that health is not only itself a human good, but it instrumentally makes it more likely that the individual can achieve other valuable things in life, such as productivity, security, and supportive relationships.^{14,15} In a similar vein, philosopher Norman Daniels has argued that health is an essential component of individual well-being because it is instrumental for any goal or value the individual wishes to pursue in life.¹⁶

As with individual well-being, be it subjective or objective, there is rough agreement that population health is an essential component of the sphere of the public good, or what makes life in a society go well. Although there is no consistent vocabulary here, it is helpful to call this societal welfare to clearly distinguish it from individual well-being. The distinction is implicit in an account recently been enunciated by the Centers for Disease Control.¹⁷ The Centers for Disease Control first characterizes individual well-being in very

broad, subjective terms, “...types of positive experiences of people’s daily lives—the quality of their relationships, their positive emotions, resilience, and realization of their potential.”^{18(p.2)} They then argue that individual well-being in this sense is an appropriate public health outcome in the aggregate, because it contributes to the overall good of the society at large. In other words, the universal provision of health care and public health are a public good that contributes to health, which in turn has an effect on individual well-being across the population thereby enhancing overall societal welfare.

If this distinction between individual well-being—objective and subjective—and societal welfare can be sustained, the literature makes it clear that there is overwhelming agreement that health contributes to, or is a component of, both notions. For our purposes here this agreement is good enough as a place to start. We now turn to the health determinant of individual well-being and societal welfare in the key notion of *functioning*.

Operationalizing health

To explore and provide a sufficiently robust evidence base for whatever associations there may be between health and individual well-being and societal welfare, it is important to operationalize health for measurement purposes. Agreeing beforehand on a single, universal definition of health has proven to be difficult, and, given that the term has a wide variety of different but equally legitimate connotations, probably unnecessary as well.¹⁹ But making sense of associations between health and well-being and welfare require us to set the stage for measuring these associations, and that requires the initial step proposing a workable operationalization of health for measurement purposes.²⁰

To do this sensibly we need to start with biological functions and structures. Fortunately, there are a myriad of clinical tests and instruments for measuring these items. Yet for these functions and structures, health is understood as an intrinsic state of the person’s body and mind. Intuitively, health is also more than that. Our state of health matters to us because it affects our lives and our actions. When we experience pain, anxiety, weakness, tight joints, or skin sores it directly affects how we live our lives. We find it difficult to climb stairs, walk as far as we used to, clean or dress ourselves as quickly as we need to, read a book, make and keep friends, do all our housework or perform our job as expected. When these kinds of limitations are associated with how our bodies and minds function—our biological health, so to speak—health matters to us as a lived experience.

To adequately measure a person’s health, therefore, we need to be able to measure not only our biological state of health, including pathologies and injuries, but also what matters to us about our health— aspects of the lived experience of our health.²¹ But this is no easy matter and indeed many researchers have seen this as the stumbling block to measuring the effects of health on well-being. This assumes that we can capture, with existing instruments, what the WHO helpfully calls the *intrinsic capacity* of the body.²² How can we capture the *lived experience* of health; what is our indicator? What exactly are we measuring here?

Measuring what matters to us about our health

Classical epidemiology tells us that mortality and morbidity are the indicators of health states. However, this is an unsatisfactory

List of abbreviations:

ICF International Classification of Functioning, Disability, and Health
WHO World Health Organization

solution. Although premature death matters to us, and specific disease symptoms affect our lives, in the end what matters to us about our state of health is how our lives are affected—that is, the lived experience of health. The lived experience is an experience of an objective phenomenon, and that is important. We may not care whether we can walk, it might not bother us at all, we might, in short, appraise that condition neutrally, or even positively. But to operationalize health we need an objective indicator, one that will allow us to disclose the relationship between our health and our well-being.

Traditionally, health practitioners and researchers have turned to the somewhat open-ended and vague notion of *quality of life* to capture the objective phenomenon of health not captured by mortality and morbidity. But, not only is there no consensus about the components or domains of quality of life (that is, what we are measuring), but more fundamentally, quality-of-life instruments invariably get bogged down in a confusion between the objective state of health of an individual and the individual's subjective appraisal of that state. It is time for a different approach. We require a new objective health indicator.

The need for a health indicator that moves beyond mortality and morbidity has become more urgent because of dramatic demographic and epidemiological trends that are changing, or soon will change, the face of health care. As a result of the groundbreaking 1978 Declaration of Alma-Ata, 4 health care strategies are now widely recognized. These include promotion, prevention, cure or treatment, and rehabilitation. The WHO has more recently added palliation to that list.^{23,24} Although each health strategy is essential for an effective working health system, arguably it is rehabilitation that is best suited to meet the challenges created by demographic and epidemiological trends.

Rehabilitation primarily seeks to restore a person's ability to function in day-to-day life. It does this by ameliorating the effect of the reduction in biological capacity, by minimizing further effects of diseases, injuries and aging, and by providing assistive devices and other supports that can replace lost function or enhance residual function in mobility, sensory, communication, and other domains of daily life. The focus of rehabilitation is on living with a health problem, especially one that is chronic, incurable, and progressively debilitating. Because of this, rehabilitation can be seen as the health strategy for the 21st century, one that can meet the societal challenge of population aging and increased prevalence of chronic health problems.²⁵

Coming fully circle, given its primary objective, rehabilitation outcomes are not fully captured by the standard health indicators of mortality and morbidity. To be sure, rehabilitative interventions may well extend a person's life, and reduce disease symptoms, but the primary objective is to improve the person's lived experience of health, not merely adding years to life but life to years. To capture this information, we require an additional health indicator, one that describes the phenomenon of interest both in terms of biological health and lived health. That indicator is functioning.

Functioning, the WHO's third indicator of health

Health information has traditionally been understood as primarily biomedical, since health is a matter of the human body and the biological sciences provide the essential theoretical basis, vocabulary, and evidence base for describing the human body. This is the sort of information that the WHO mandated to collect,

internationally comparable health information, collected in terms of the International Classification of Diseases.²⁶ This information was used to monitor mortality and morbidity internationally, and was the primary input into national reimbursement systems such as diagnostic related groups. In recent decades, the WHO has insisted that, however essential this kind of health information is, there is another body of health information that is equally important across all components of the health system, including public health, and it provides a more complete and realistic understanding of health. This is information about how the state of a person's health plays out in one's daily life—the lived experience of health.

This body of health information was formally acknowledged with the endorsement in 2001 of the WHO's International Classification of Functioning, Disability and Health (ICF) and the introduction of the technical term *functioning* (capturing a notion familiar in rehabilitation literature in phrases such as functional state, gain, loss, or limitation, functional (in)capacity, and functionality).²⁷ In the classification itself—primarily for ease of use and the need to maintain distinctions that are familiar to health practitioners—a *body-person-society* distinction is assumed and the major classification dimensions are labeled, *Body Functions and Structures*, *Activities*, and *Participation*. This terminology is primarily heuristic and not conceptually grounded. There is an underlying model of the ICF that is conceptually clearer in its distinctions and preferable for our task here as it provides a coherent understanding of this key term *functioning*.

In this underlying model of the ICF, functioning is understood both biomedically, in terms of the functions and structures of the body and the resulting intrinsic health capacity of a person to perform simple or complex activities, as well as the actual performance of those activities in interaction with features of the person's physical, human-built environment, and social environment. In other words, functioning comprises the domains of both biological health and lived health. Lived health is fully contextualized, in the sense that it is an outcome of interactions between a person's intrinsic capacity and features of the environment. Hence, in the ICF, the experience of lived health is determined both by the intrinsic biological health state and the overall physical and social environment in which that person lives. Information about the level of performance of activities, though more complex and socially constructed, is what needs to be collected to describe, measure, and ultimately explain the interaction between a person's biological health and the environment. Although the ICF is somewhat vague on this point, the notion of disability might best be thought of as some degree of problem or limitation in a person's actual performance of some daily activity, or in the nature or quality of participation in some social activity or role, that results from the person-environment interaction.

Functioning, in this ICF sense, is an indicator of health.²⁸ Although people are concerned about how long they will live and the diseases and other health conditions they have, what really matters to us about our health is what we can and cannot do in our real-life situation—our functioning. If functioning matters to all of us individually, then it stands to reason that epidemiology could profit from an indicator of what matters about the health of each member of a population, taken collectively. As an indicator, functioning summarizes information about biological and lived health in interaction with features of the person's environment. The classifications in the ICF—and the underlying conceptual model—therefore provide us with a complete operationalization of functioning.

The societal challenge of health and information about functioning

The societal challenge posed by the demographic and epidemiological trends described above can be reframed as an investment in health care services that not only reduce mortality and morbidity, but also optimize functioning across the population. The ICF provides us with a conceptually stable and fully operationalized indicator of functioning, in the first instance, this challenge requires the standardized reporting and routine collection of functioning information across the lifespan and at every stage in the continuum of care.²¹

This is a prerequisite for the successful application, not only of the health strategy of rehabilitation but for all the other health strategies. The primary goal of prevention at the population level is to prevent the occurrence of health conditions and premature mortality by targeting risk factors, both environmental and personal behaviors. Although often monitored in terms of years of life saved from premature mortality, when reported in terms of biological health, functioning is also a relevant indicator for prevention. Health promotion aims to improve people's intrinsic health, primarily by targeting risk factors, but its outcome can be best measured in terms of the effect on lived experience. The curative or treatment strategy is most clearly focused on survival, both in the context of acute and chronic health conditions and for this reason the key indicator for cure is mortality. At the same time, cure is also a matter of optimal management of a health condition and the minimization of complications and comorbidities, therefore, information about morbidity is also relevant. Finally, the aim of the palliative strategy is to optimize well-being in the context of dying and functioning contributes to this goal, if not directly, then as a proxy indicator.

The standardized and comparable reporting of data about biological and lived health will improve clinical decision making, clinical quality management toward continuous improvement of health outcomes of individual services, and benchmarking across services and programs. Comparable health data of this sort is basic for continuous improvement of national health systems at all 3 levels of the health system—policy and programming; service delivery and financing; and clinical practice.²⁹

When it comes to measurement of functioning, the issue becomes considerably more complex. The measurement of biological health is no easy task, but it theoretically can be more manageable using agreed-upon clinical and other measurement tools, with metrics that can be validated clinically. By contrast, the lived experience of health is dependent on context, which includes where the person lives and acts, the climate, the way the houses are built, people's values and attitudes, social customs and beliefs, and economic and political structure. Given this, how could there be a universal, context-free, measure of the lived experience, or in ICF terminology, the construct of performance?

Recent work has seen important advances in this area. With sufficient data, there are statistical techniques that can be used to construct metrics of functioning for specific domains or sets of domains (eg, concerning mobility) or specific health conditions, settings and populations. In practice, these metrics can be constructed and used for clinical practice and epidemiology, and, eventually, for policy purposes. There is no doubt that this is an emerging and extremely challenging area of health measurement, and there is a long way to go before we have any confidence in a constructed universal lived health metric that has suitably interval scale characteristics.

Functioning, the health indicator for individual well-being and societal welfare

If we are optimistic about the prospects for the science of measurement of functioning—as we believe we should be—the next step is to make the case for the association between health, conceptualized as functioning, and individual well-being and societal welfare.

As we noted, few of us would need to be convinced that the resources we spend on health care are well spent because health is a component of individual well-being; the challenge has always been to substantiate the association, if not a causal relationship, between health and well-being. Relying on data about mortality and morbidity is not enough since living longer does not mean living better. Indeed, the data suggests just the opposite, living longer means living in worse health. To make the link between health and individual well-being (and societal welfare), we have to turn to the indicator of functioning, and specifically our lived health, regarding how our intrinsic health capacity (operationalized by body functions and structures) plays out in what we do in the actual context in which we live, taking all environmental factors into account.

In the ICF model of functioning and disability, environmental factors either put limits on what we do in our ordinary life (barriers) or improve our performance beyond what would be expected from the level of health capacity we experience would predict (facilitators). Our overall lived experience of health is why we care about our health and it includes the direct effect of our health capacity, especially when that means pain, discomfort, or other direct assault on our well-being. Also, and in the long run, our overall lived experience of health is important as far as how we live our lives. The ICF approach explains why a person with severely limited body functions (eg, a person with lower body paralysis resulting from spinal cord injury) can nonetheless have a high level of work performance because of extensive environmental facilitators (wheelchair, modified work environment, personal supports); while an individual with relatively high levels of intrinsic capacity, facing environmental hurdles (unaccommodating work environment, stigmatizing attitudes of coworkers, unsympathetic employer) will experience just the opposite. When we consider what matters about people's health, including how they live their health in their actual environment, then we have a sense of the relationship between health and individual well-being.

The similar point can be made in the language of capability. Health is indeed a capability, or a realistic opportunity to achieve the good life, not merely because good health entails living longer, but because it means to be able to do and achieve the things one wants to in life. Living longer, but with low levels of functioning, does not enhance our well-being. As Amartya Sen has argued, at the end of the day, well-being is a matter of *doings and beings*. This means having real opportunities to perform all of the activities that one wishes and to sustainably thrive in the social roles one wishes to take on. In the domain of health, it is the ability to do and be what one wishes that contributes to well-being and this is what is captured by functioning.

In summary, the ICF notion of functioning captures conceptual linkage between health and individual well-being. As we advance and perfect our measurement science, functioning will provide the basis for measuring that association across health conditions, along the lifespan, and across societies. This conceptual linkage helps to explain why our health means so much to us and why we believe society's substantial investment in health care is fully

justified. Focusing on functioning shows us that society's commitment to provide the resources and opportunities needed for individual well-being is, in fact, a commitment to ensure both a long life and an active and full life. In the well-being literature, this is often termed *human flourishing* and that metaphor provides a good image for societal welfare. Society thrives when the population flourishes, when people have realistic opportunities to do and be what they choose. Health contributes directly to this by providing not just a long life, but an active and flourishing life, a life of optimal functioning.

Keywords

Health; Rehabilitation

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Why Rehabilitation Should be Included in International Healthy Ageing Agendas

Gerold Stucki, MD, MS, Jerome Bickenbach, PhD, LLB, and Walter Frontera, MD, PhD

Health systems worldwide are preparing for a dramatic demographic shift in population ageing with a related increase in the number of persons living with chronic health conditions and experiencing disability. At the national level, policy makers are addressing these challenges through national health strategies and action plans in ageing, noncommunicable diseases and disability. At the international level, two major efforts have been launched, one by the World Health Organization (WHO) and one by the National Academy of Medicine (NAM) of the United States. The WHO has summarized the best evidence in its 2015 *World Report on Ageing and Health*¹ and adopted a draft resolution entitled “The global strategy and action plan on ageing and health 2016–2020: towards a world in which everyone can live a long and healthy life.”² The NAM, the preeminent national health academy, has identified ageing and healthy longevity as global grand challenges that it proposes to address by means of a concerted effort including awards and prizes and a global roadmap.

We argue that both agendas must integrate rehabilitation as the fundamental health strategy that addresses the challenges of healthy ageing. Failure to do so is a true missed opportunity, for two important reasons.

First, rehabilitation is key to realizing the potential for improving healthy ageing resulting from advances in biology and technology, behavioral change, and social and environmental adaptations. This case for rehabilitation has been made by the WHO's recent call for action called “Rehabilitation 2030.” Recognizing the needs of an ageing population and the increases in noncommunicable diseases and disability, this call for action has identified rehabilitation as a key health strategy for the 21st century.^{3–5} Although healthy lifestyles and the modification of biological processes can prevent or delay the occurrence of chronic diseases, rehabilitation is of central importance to healthy ageing because it aims to optimize a person's functioning in light of existing and chronic health conditions.^{6,7} Specifically, rehabilitation can optimize both a person's intrinsic health capacity and his or her functional ability in interaction with the environment.

To achieve these goals, rehabilitation starts with an assessment of a person's functioning in light of his or her health conditions, life situation and material and psychological resources, as well as those facilitators and barriers in the social and environment that limit or enhance daily life.⁸ With this diagnosis in hand, effective interventions can be crafted. These will generally be multimodal and conducted by a multiprofessional team led by a rehabilitation physician. The team typically involves physiotherapy and occupational therapy and, depending on the health condition and setting along the continuum of care, psychology and neuropsychology, speech therapy, and social work, among others. The team will set rehabilitation goals together with patients, their families, and significant others. Interventions include education, exercise training and physical activity, physical modalities, medications, as well as the provision of assistive devices and environmental modifications. The team coordinates and integrates these approaches to support patients in the translation of optimized intrinsic health into the actual performance of daily activities in interaction with the environment.⁹

The evidence base that supports the effectiveness of rehabilitation interventions is increasing dramatically. This increase is the result of scientifically rigorous evaluations of rehabilitation interventions, including the use of technology, interventions based on an emerging understanding of mechanisms underlying biological treatments, and the increased application in rehabilitation of research methods developed in the field of health services research. There is also increasing evidence

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of the economic benefits of maintaining an autonomous life and delaying or reducing dependency. Rehabilitation is on a firm scientific basis.

Secondly and from a human rights perspective, rehabilitation is the essential social response to ageing healthy because it is instrumental in enhancing the social inclusion of ageing persons with chronic conditions who experience disability. We cannot prevent or indefinitely delay the occurrence of chronic health conditions with ageing. Although some health problems can be prevented with behavioral change, for example, lung cancer associated with tobacco use, this is not true for most age-related health conditions, such as musculoskeletal ageing that can only be minimized or delayed through healthy lifestyles. Care must be taken, therefore, to avoid the suggestion that individuals should bear the burden of responsibility for the occurrence of health conditions and a decline of health capacity inextricably entwined with ageing.

From a human rights perspective, it is society's obligation to achieve social inclusion for the ageing population. This is not a matter of prevention but rather of optimizing functioning and opportunities so that individuals can fully participate in all aspects of life. This is the central theme of the WHO's *World Report on Ageing and Health*.¹ Many, if not most, ageing persons with unavoidably decreasing intrinsic health capacity associated with chronic health conditions can live a fully meaningful and satisfying life and become major contributors to society. Living with any form of disability, whatever the cause, should not be seen as inferior nor tragic or for that matter all that dissimilar from living without disability. As a matter of human rights, for society, the central question must be how best to ensure that the ageing population experiencing disability has opportunities to live a full life. Indeed, this obligation is the central mandate of the United Nations' *Convention on the Rights of Persons with Disabilities*.¹⁰ However, this is precisely what rehabilitation can help achieve by enhancing functioning and the largely untapped potential of full participation by the ageing population experiencing disability.

In conclusion, as a health strategy, rehabilitation is fundamental to the societal challenge of bringing together advancements

in biological, technological, and behavioral interventions as well as advances in the built environment and the social design of society to meet the needs of the ageing population and to ensure social inclusion. Rehabilitation combines functioning interventions addressing targets at the level of a person's functioning and the environment and guides persons in the translation of intrinsic health capacity into real-life performance in their immediate environment.

It is therefore essential that rehabilitation be put at the forefront of all healthy ageing agendas and in particular the international efforts of the NAM and the WHO. Failure to do so is a missed opportunity, for purely economic reasons, to achieve social and political goals, and in terms of the basic human rights to full participation and social inclusion that the ageing population must enjoy.

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Strengthening rehabilitation in health systems

The Seventy-sixth World Health Assembly,

Having considered the consolidated report by the Director-General;¹

Considering that the need for rehabilitation is increasing due to the epidemiological shift from communicable to noncommunicable diseases, while taking note of the fact that there are also new rehabilitation needs emerging from infectious diseases like coronavirus disease (COVID-19);

Considering further that the need for rehabilitation is increasing due to the global demographic shift towards rapid population ageing accompanied by a rise in physical and mental health challenges, injuries, in particular road traffic accidents, and comorbidities;

Expressing deep concern that rehabilitation needs are largely unmet globally and that in many countries more than 50% of people do not receive the rehabilitation services they require;

Recognizing that rehabilitation requires more attention by policy-makers and domestic and international actors when setting health priorities and allocating resources, including with regard to research, cooperation and technology transfer on voluntary and mutually agreed terms and in line with their international obligations;

Deeply concerned that most countries, especially developing countries, are not sufficiently equipped to respond to the sudden increase in rehabilitation needs created by health emergencies;

Emphasizing that rehabilitation services are key to the achievement of Sustainable Development Goal 3 (ensure healthy lives and promote well-being for all at all ages), as well as an essential part of achieving target 3.8 (achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all);

Reaffirming that rehabilitation services contribute to the enjoyment of human rights, such as the right to the enjoyment of the highest attainable standard of physical and mental health, including sexual and reproductive health, the right to work and the right to education, among others, and that Member States' obligations and commitments in this regard are consistent with the United Nations Convention on the Rights of Persons with Disabilities;

Noting the Declaration of Astana, which emphasizes that rehabilitation is an essential element of universal health coverage and an essential health service for primary health care;

¹ Document A76/7 Rev.1

Recalling resolution WHA54.21 (2001) and the International Classification of Functioning, Disability and Health, which provides a standard language and a conceptual basis for the definition and measurement of health, functioning and disability;

Recalling also the role of rehabilitation for effective implementation of: resolution WHA66.10 (2013), in which the Health Assembly endorsed the global action plan for the prevention and control of noncommunicable disease 2013–2020; resolution WHA69.3 (2016) on the global strategy and action plan on ageing and health 2016–2020; resolution WHA71.8 (2018) on improving access to assistive technology; decision WHA73(33) (2020) on the road map for neglected tropical diseases 2021–2030; resolution WHA74.7 (2021) on strengthening WHO preparedness for and response to health emergencies; and resolution WHA74.8 (2021) on the highest attainable standard of health for persons with disabilities;

Recalling further the political declaration of the high-level meeting on universal health coverage (2019), including the commitment therein to increase access to health services for all persons with disabilities, remove physical, attitudinal, social, structural, and financial barriers, provide quality standard of care and scale up efforts for their empowerment and inclusion;

Noting that persons in marginalized or vulnerable situations often lack access to affordable, quality and appropriate rehabilitation services and to assistive technology, accessible products, services and environments, which impacts their health, well-being, educational achievement, economic independence and social participation;

Concerned about the affordability of accessing rehabilitation services, related health products and assistive technology, and inequitable access to such products within and among Member States, as well as the financial hardships associated with high prices, which impede progress towards achieving universal health coverage;

Reaffirming that universal health coverage implies that all people have access, without discrimination, to nationally determined sets of needed treatment, promotive, preventive, rehabilitative and palliative essential health services, while recognizing that, for most people, rehabilitation services and access to rehabilitation-related assistive technology are often an out-of-pocket expense, and ensuring that users' access to these services is not restricted by financial hardship or other barriers;

Noting with concern that, in most countries, the current rehabilitation-related workforce is insufficient in number and quality to serve the needs of the population, and that the shortage of rehabilitation professionals is higher in low- and middle-income countries and in rural, remote and hard-to-reach areas;

Stressing that disability-sensitive, quality, basic and continued education and training of health professionals, including effective communication skills, are crucial to ensure that they have the adequate professional skills and competencies in their respective roles and functions to provide safe, quality, accessible and inclusive health services;

Noting that rehabilitation is a set of interventions designed to optimize functioning in individuals with health conditions or impairments in interaction with their environment and, as such, is an essential health strategy for achieving universal health coverage, increasing health and well-being, improving quality of life, delaying the need for long-term care and empowering persons to achieve their full potential and participate in society;

Noting as well that the benefits of improving access to affordable assistive technology, accessible products, services and infrastructures and rehabilitation include improved health outcomes following a range of interventions, as well as facilitated participation in education, employment and other social activities, and significantly reduced health care costs and burden of care providers, and that telerehabilitation can contribute to the process of rehabilitation;

Further noting that rehabilitation requires a human-centred, goal-oriented and holistic approach, guiding coordinated cross-governmental mechanisms that integrate measures linked to public health, education, employment, social services and community development and to work in collaboration with civil society organizations, representative organizations and other relevant stakeholders;

Recognizing that the provision of timely care for the acutely ill and injured will prevent millions of deaths and long-term disabilities and contribute to universal health coverage;

Concerned that lack of access to rehabilitation may expose persons with rehabilitation needs to higher risks of marginalization in society, poverty, vulnerability, complications and comorbidities, and impact on function, participation and inclusion in society;

Noting with concern that the fragmentation of rehabilitation governance in many countries and the lack of integration of rehabilitation into health systems and services and along the continuum of care result in inefficiencies and failure to respond to individual and populations' needs;

Also noting with concern that the lack of awareness among health care providers of the relevance of rehabilitation across the life course and for a wide range of health conditions leads to preventable complications, comorbidities and long-term loss of functioning;

Appreciating the efforts made by Member States, the WHO Secretariat and international partners in recent years to strengthen rehabilitation in health systems, but mindful of the need for further action;

Deeply concerned that, without concerted action, including through international cooperation, for strengthening rehabilitation in health systems, rehabilitation needs will continue to go unmet with long-term consequences for persons and their families, societies and economies;

Noting the Rehabilitation 2030 Initiative, which acknowledges the profound unmet need of rehabilitation, emphasizes the need for equitable access to quality rehabilitation and identifies priority actions to strengthen rehabilitation in health systems,

1. URGES Member States:¹

- (1) to raise awareness of and build national commitment for rehabilitation, including for assistive technology, and strengthen planning for rehabilitation, including its integration into national health plans and policies, as appropriate, while promoting interministerial and intersectoral work and meaningful participation of rehabilitation users, particularly persons with disabilities, older persons, persons in need of long-term care, community members, and community-based and civil society organizations at all stages of planning and delivery;

¹ And, where applicable, regional economic integration organizations.

- (2) to incorporate appropriate ways to strengthen financing mechanisms for rehabilitation services and the provision of technical assistance, including by incorporating rehabilitation into packages of essential care where necessary;
- (3) to expand rehabilitation to all levels of health, from primary to tertiary, and to ensure the availability and affordability of quality and timely rehabilitation services, accessible and usable for persons with disabilities, and to develop community-based rehabilitation strategies, which will allow rehabilitation to reach underserved rural, remote and hard-to-reach areas, while implementing person centred strategies and participatory, specialized and differentiated intensive rehabilitation services to meet the requirements of persons with complex rehabilitation needs;
- (4) to ensure the integrated and coordinated provision of high-quality, affordable, accessible, gender-sensitive, appropriate and evidence-based interventions for rehabilitation along the continuum of care, including strengthening referral systems and the adaptation, provision and servicing of assistive technology related to rehabilitation, including after rehabilitation, and promoting inclusive, barrier-free environments;
- (5) to develop strong multidisciplinary rehabilitation skills suitable to the country context, including in all relevant health workers; to strengthen capacity for analysis and prognosis of workforce shortages as well as to promote the development of initial and continuous training for professionals and staff working in rehabilitation services; and to recognize and respond to different types of rehabilitation needs, such as needs related to physical, mental, social and vocational functioning, including the integration of rehabilitation in early training of health professionals, so that rehabilitation needs can be identified at all levels of care;
- (6) to enhance health information systems to collect information relevant to rehabilitation, including system-level rehabilitation data, and information on functioning, utilizing the International Classification of Functioning, Disability and Health, ensuring data disaggregation by sex, age, disability and any other context-relevant factor, and compliance with data protection legislation, for a robust monitoring of rehabilitation outcomes and coverage;
- (7) to promote high-quality rehabilitation research, including health policy and systems research;
- (8) to ensure timely integration of rehabilitation into emergency preparedness and response, including emergency medical teams;
- (9) to urge public and private stakeholders to stimulate investment in the development of available, affordable and usable assistive technology and support for implementation research and innovation for efficient delivery and equitable access with a view to maximizing impact and cost effectiveness;

2. INVITES international organizations and other relevant stakeholders, including intergovernmental and nongovernmental organizations and organizations of persons with disabilities, private sector companies and academia:

- (1) to support Member States,¹ as appropriate, in their national efforts to implement the actions in the Rehabilitation 2030 Initiative and to strengthen advocacy for rehabilitation, as well as

¹ And, where applicable, regional economic integration organizations.

support and contribute to the WHO-hosted World Rehabilitation Alliance, a multistakeholder initiative to advocate for health system strengthening for rehabilitation;

(2) to harness and invest in research and innovation in relation to rehabilitation, inclusive of available, affordable and usable assistive technology, including the development of new technologies, and support Member States, as appropriate, in collecting health policy and system research to ensure future evidence-based rehabilitation policies and practices;

3. REQUESTS the Director-General:

(1) to develop, with input from Member States and in collaboration with relevant international organizations and other stakeholders, and to publish, before the end of 2026, a WHO baseline report with information on the capacity of Member States to respond to existing and foreseeable rehabilitation needs;

(2) to develop feasible global health system rehabilitation targets and indicators for effective coverage of rehabilitation services for 2030, focusing on tracer health conditions, for consideration by the Seventy-ninth World Health Assembly, through the 158th session of the Executive Board;

(3) to develop and continuously support the implementation of technical guidance and resources to provide support to Member States in their national efforts to implement the actions of the Rehabilitation 2030 Initiative, building on their national situations in access to physical, mental, social and vocational rehabilitation;

(4) to ensure that there are appropriate resources as regards the institutional capacity of WHO, at headquarters and at regional and local levels, to support Member States in strengthening and increasing the variety of available rehabilitation services and access to available, affordable and usable assistive technology, and to facilitate international collaboration in this regard;

(5) to support Member States to systematically integrate rehabilitation and assistive technology into their emergency preparedness and response as part of their investment in strengthening their own emergency medical teams, including by addressing the long-term rehabilitation needs of those affected by health emergencies, including COVID-19;

(6) to report on progress in the implementation of this resolution to the Health Assembly in 2026, 2028 and 2030.

Ninth plenary meeting, 30 May 2023
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