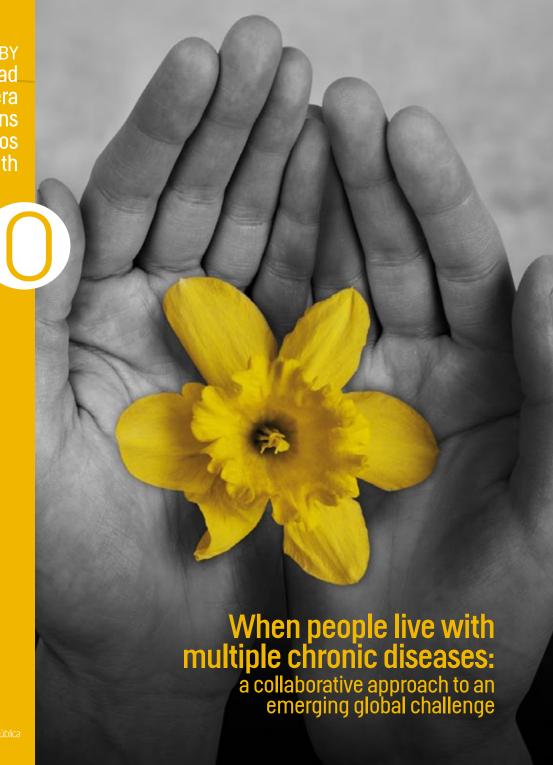
EDITED BY Alejandro R. Jadad Andrés Cabrera Renée F. Lyons Francisco Martos Richard Smith





Escuela Andaluza de Salud Pública CONSEJERÍA DE SALUD



# When people live with multiple chronic diseases:

a collaborative approach to an emerging global challenge

Alejandro R. Jadad Andrés Cabrera Renée F. Lyons Francisco Martos Richard Smith



# When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge

### Editors

### Alejandro R. Jadad

Chief Innovator and Founder, Centre for Global eHealth Innovation
Canada Research Chair in eHealth Innovation
Rose Family Chair in Supportive Care
Professor, Departments of Anesthesia; and Health
Policy, Management and Evaluation; and Dalla Lana
School of Public Health
University Health Network and University of Toronto
Canada

### Andrés Cabrera León

Professor, Statistics and Epidemiology Andalusian School of Public Health Spain

### Renée F. Lyons

Bridgepoint Chair in Complex Chronic Disease Research TD Financial Group Scientific Director, Bridgepoint Collaboratory for Research and Innovation Professor (status), Dalla Lana School of Public Health University of Toronto and Bridgepoint Health Canada

### Francisco Martos Pérez

Medical Processes Director Benalmádena High Resolution Hospital, Public Enterprise Costa del Sol Hospital Spain

### Richard Smith

Director, Ovations Chronic Disease Initiative United Kingdom

### Technical support team

### Juan Antonio Castillo Guijarro

Administrative assistant
Andalusian School of Public Health, Spain

### Antonio Contreras Sánchez

Computing manager Andalusian School of Public Health, Spain

### Diana Gosálvez Prados

Knowledge manager Andalusian School of Public Health, Spain

### Begoña Isac Martínez

Community manager Andalusian School of Public Health, Spain

### Alejandro López Ruiz

Professor, Information and Technology Andalusian School of Public Health, Spain

### Contributors

Christina Almonte

American Society of Complex Therapeutics

United States of America

Manuel Armayones

Open University of Catalonia, Spain

Alirio Arreaza\*

American Society of Complex Therapeutics

United States of America

Peter Bailey\*

Cambridgeshire Primary Care Trust

United Kingdom

Mario Barbagallo

University of Palermo, Italy

Jackie Bender

University of Toronto, Canada

Rafael Bengoa\*

Consumers and Health Department of the Basque

Government, Spain

Máximo Bernabeu Wittel\*

University Hospital Virgen del Rocío, Spain

Bob Bernstein

Bridgepoint Health, Canada

Andrés Cabrera León\*

Andalusian School of Public Health, Spain

Antonio Contreras Sánchez

Andalusian School of Public Health, Spain

Alejandro Cravioto\*

International Centre for Diarrhoeal Disease

Research, Bangladesh

Simon Chapman

University of Sydney, Australia

José María de la Higuera González\*

University Hospital Virgen del Rocío, Spain

Katia De Pinho Campos

University of Toronto, Canada

Ligia Dominguez

University of Palermo, Italy

Murray Enkin

McMaster University and University of Toronto

Canada

Jaime Espín Balbino

Andalusian School of Public Health, Spain

Josephine Fagan

Rowlands Gill Medical Centre. United Kingdom

John Gillies

Institute of Rural Health, United Kingdom

Esther Gil-Zorzo

Ministry of Health and Social Policy, Spain

Diana Gosálvez Prados

Andalusian School of Public Health, Spain

Maria Carmen Griñán Martinez

Open University of Catalonia, Spain

Juan Antonio Guerra de Hoyos

Andalusian Health Service, Andalusian

Government, Spain

Rajeev Gupta

Fortis Escorts Hospital, India

Narcis Gusi Fuertes

University of Extremadura, Spain

Antonia Herráiz Mallebrera

Blog «Salud@Información», Spain

### Emilio Herrera Molina\*

ES-Health & Wellness Telecom, Spain

### Begoña Isac Martínez

Andalusian School of Public Health, Spain

# Alejandro R. Jadad\*

University Health Network and University of Toronto, Canada

Carraua

### Jennifer Jones

University Health Network and University of Toronto, Canada

### Sara Kreindler

University of Manitoba, Canada

### Kerry Kuluski

Canadian Research Network for Care in the Community. Canada

### Angel Lee Onn Kei\*

Tan Tock Seng Hospital, Singapore

### Yan Lijing

Norhtwestern University
United States of America

### Alejandro López Ruiz

Andalusian School of Public Health, Spain

### Julio Lorca Gómez\*

Institute of Innovation for Human Wellbeing, Spain

### Kate R Lorig\*

Stanford University School of Medicine

United States of America

### Renée F. Lvons

University of Toronto and Bridgepoint Health, Canada Beatriz Marcet Champaigne InterAmerican Heart Foundation

United States of America

Francisco Martos Pérez\*

Costa del Sol Hospital, Spain

Patrick McGowan\*

University of Victoria, Canada

J. Jaime Miranda

Cayetano Heredia Peruvian University, Peru

Scott A. Murray

University of Edinburgh, United Kingdom

Maria Nabal

University Hospital Arnau de Vilanova, Spain

Tracy Novak

Johns Hopkins Bloomberg School of Public Health United States of America

Roberto Nuño Solinis\*

Basque Institute for Health Innovation (O+Berri)

Spain

Manuel Ollero Baturone\*

University Hospital Virgen del Rocío, Spain

Ma Ángeles Ortiz\*

Clinical Management Unit in primary care of

Camas, Spain

Rafael Pinilla Palleja

Best Quality of Life, Spain

Cristina Rabadán-Diehl\*

National Heart, Lung, and Blood Institute

United States of America

Manuel Rincón Gómez\*

University Hospital Virgen del Rocío, Spain

### Contributors (continued)

### Adolfo Rubinstein

Institute of Clinical Effectiveness, Argentina

### Manuel Serrano

Global Alliance for Self Management Support, Spain

### Mary Ann Sevick

University of Pittsburgh United States of America

### Richard Smith\*

Ovations Chronic Disease Initiative, United Kingdom

### Carmen Tamayo\*

American Society of Complex Therapeutics United States of America

### **Pritpal Tamber**

Map of Medicine, United Kingdom

### Ross Upshur

University of Toronto and Sunnybrook Health Sciences Centre, Canada

### Abraham Wall-Medrano\*

Autonomous University of Ciudad Juárez, Mexico

### Ong Yew Jin

National Health Group, Singapore

### Acknowledgements

### Isabel Alamar Torró

Casa Escritura, Spain

### Carlos Álvarez-Dardet

University of Alicante, Spain

### Joseph Ana

Health Science, Nigeria

### Robert Anderson

Global Alliance for Self Management Support United States of America

### Juan Carlos Arbonies Ortiz

Basque Health Service, Spain

### Neil Arnott

National Health Service, United Kingdom

### Julie Barlow

Global Alliance for Self Management Support United Kingdom

### Gerald Bloomfield

Duke University School of Medicine United States of America

### Ángela Cejudo

Bellavista-Los Bermejales Primary Care Center Spain

### Ana Clavería

Galician Health Service, Spain

### Jane Cooper

Global Alliance for Self Management Support United Kingdom

### Francisca Domínguez Guerrero

Hospital of Jerez, Spain

<sup>\*</sup>Main contributor

### Giulia Fernández Avagliano

Andalusian School of Public Health, Spain

### Isabel Fernández Ruiz

Andalusian School of Public Health, Spain

### Hermes Florez

Global Alliance for Self Management Support United States of America

### Martha Lucia Garcia Garcia

Human resources manager, Canada

# Marina Gómez- Arcas

Hospital of La Línea, Spain

### Rodrigo Gutiérrez

Health Service of Castilla-La Mancha Spain

### Camila Higueras Callejón

Andalusian School of Public Health Spain

# Anne Kennedy

Global Alliance for Self Management Support United Kingdom

### Svjetlana Kovacevic

Administrative Coordinator, Canada

### Doriane Miller

Global Alliance for Self Management Support United States of America

# José Miguel Morales Asencio

Universidad de Málaga, Spain

### José Murcia Zaragoza

Global Alliance for Self Management Support, Spain

### Jacqueline Ponzo

Center of Excellence for Cardiovascular Health in South America, Uruguay

### Barbara Paterson

University of New Brunswick, Canada

### Encarnación Peinado Álvarez

Health Ministry. Andalusian Government, Spain

### Juan José Pérez Lázaro

Andalusian School of Public Health, Spain

### Jim Philips

Global Alliance for Self Management Support United Kingdom

### José Luis Rocha

Health Ministry. Andalusian Government, Spain

### Anne Rogers

Global Alliance for Self Management Support United Kingdom

# Judith Schaeffer

Global Alliance for Self Management Support United States of America

Carmen F. Sigler
Transversal Arte y Estrategia, Spain

### Warren Todd

Global Alliance for Self Management Support United States of America

### Andy Turner

Global Alliance for Self Management Support United Kingdom

### Sheila Wylie

English language consultant

Spain

Published by ESCUELA ANDALUZA DE SALUD PÚBLICA

ISBN: 978-84-693-2470-7

DL: Gr-2653/2010

Printed in Granada: Alsur, S.C.A.

Layout and graphic design: Carmen F. Sigler. www.transversal.tv

### How to reference

Jadad AR, Cabrera A, Martos F, Smith R, Lyons RF. When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge. Granada: Andalusian School of Public Health; 2010. Available at: http://www.opimec.org/equipos/when-people-live-with-multiple-chronic-diseases/

### All rights reserved

The responsibility for the content rests with the contributors and does not necessarily represent the views of Junta de Andalucía or any other organization participating in this effort



# Contents

Foreword			15
Chapter	1	Why Multiple Chronic Diseases? Why now? What is going on around the world?	19
Chapter	2	The language of polypathology	39
Chapter	3	Prevention and health promotion	59
Chapter	4	Management models	89
Chapter	5	Patient education and self-management support	117
Chapter	6	Primary care, institutional services and integrated management processes	143
Chapter	7	Supportive and palliative care	163
Chapter	8	Integrative medicine	191
Chapter	9	Socioeconomic implications	213
Chapter	10	The promise of genomics, robotics, informatics and nanotechnologies	229
Chapter	11	Dealing with the challenges of polypathology, together: What's next?	243
Abbreviatio	ns		250
Figures and Tables		251	
Index			252



Chapter 1

# Why Multiple Chronic Diseases? Why now? What is going on around the world?

This chapter is continuously evolving at www.opimec.org

# The price of success

«In this fallen world everything good has unintended evil consequences, every Yang has a Yin» .(1)

In 2004, two scholars announced that they had discovered the earliest known version of a poem by Sappho, the Greek poetess known as the Tenth Muse (2). It was written on a fragment of a papyrus used to cover an Egyptian mummy kept at the University of Cologne, in Germany. The poem, which had been transcribed at least 300 years after the death of Sappho, became one of the most complete examples of her work available to date.

The poem is a compact masterpiece. In just 12 lines, it captures the poetess's insights into her own ageing process and the plight of humans as we grow old. Her words, which resonate more than ever 2700 years later, read as follows (those in brackets were missing from the fragment, and were filled in by the translator (3):

«[You for] the fragrant-blossomed Muses' lovely gifts [be zealous,] girls, [and the] clear melodious lyre:

[but my once tender] body old age now [has seized;] my hairs turned [white] instead of dark;

my heart's grown heavy, my knees will not support me, that once on a time were fleet for the dance as fawns. This state I oft bemoan; but what's to do? Not to grow old, being human, there's no way.

Tithonus once, the tale was, rose-armed Dawn, love-smitten, carried off to the world's end,

handsome and young then, yet in time grey age o'ertook him, husband of immortal wife.»

In the last four lines, Sappho refers to a myth that was very popular in the 7<sup>th</sup> century BCE as a means to convey the suffering associated with the decay of human bodies, as they age.

According to this story, the Goddess of the Dawn, Eos, had fallen in love with Tithonus, a Trojan. As she could not conceive of a life without her mortal lover, Eos persuaded Zeus to grant Tithonus eternal life. Zeus, however, took Eos's request literally. He made Tithonous immortal, but did not give him eternal youth. As a result, Tithonus started to grow old, becoming progressively debilitated by multiple chronic conditions and demented. The myth ends with Eos trying to mitigate Tithonus's suffering by transforming him into a grasshopper.

At the dawn of the 21<sup>st</sup> century, millions of people around the world are facing the same challenges illustrated in the myth of Tithonus and in Sappho's poem. The extraordinary level of control of acute conditions and the lengthening of life expectancy achieved by humans in the 20<sup>th</sup> century is now ushering in a global epidemic of chronic diseases and infirmity.

The high prevalence of chronic conditions is already having a major effect on mortality data across the world. In a landmark report entitled Preventing Chronic Diseases: a landmark investment, the World Health Organization (WHO) estimated that 60% of deaths around the world in 2005 were already due to chronic diseases, with 80% of the total occurring in low- to middle-income countries (4). In fact, chronic diseases are the leading cause of death in every country in the world, except for those with the lowest levels of income. Even in the latter, however, the gap separating them from infectious diseases is narrowing (5). To compound this, depression and not physical injury, is now the leading cause of years lost to disability in the world (6).

Sadly this epidemic, which has been the subject of many recent reports (7), is being underestimated and neglected (8).

# The emergence of polypathology

The high prevalence of chronic diseases has created yet another new phenomenon: a growing number of people are living with multiple chronic diseases.

This phenomenon includes not only those individuals with an index disease that has triggered secondary conditions (e.g., a person with diabetes who is affected by associated retinopathy and neuropathy), but also those in whom two or more diseases co-exist (e.g., people with diabetes, cancer and Alzheimer's disease at the same time).

As will be discussed in more detail in the next chapter, there is no accepted terminology for this phenomenon. The labels that seem to be used most frequently seem to be «comorbidity», «polypathology», «poly-pathology», «pluri-pathology», «multi-morbidity», «multimorbidity», «multi-pathology» or «multipathology» or «complex chronic disease» (Chapter 2). Polypathology will be the term used most often throughout this chapter.

Just like the fragments of Sappho's poems, however, there appears to be a patchy picture of knowledge on the prevalence of polypathology and its associated societal burden. Most reports provide data on specific disease clusters, in high risk groups, or in specific regions or countries (9). Very few, if any, seem to contain original data on the prevalence of several diseases, detected and documented simultaneously, across all age groups, worldwide.

A refined search of MEDLINE conducted on April 14, 2009 (Figure 1), complemented by a search of Google and Google Scholar on August 22, 2009, revealed a few glimpses of what may be happening.

Figure 1

### Search strategy

ORGAN-SYSTEM
1 polypatholog:.tw,mp. (5)
2 polypatholog:.tw,mp. (50)
3 pluripatholog:.tw,mp. (16)
4 polypatholog:.tw,mp. (5)
5 polypatholog:.tw,mp. (50)
6 pluripatholog:.tw,mp. (16)
7 (multiple adj5 condition).mp. (754)
8 (multiple adj5 illness).mp. (536)
9 multidisease.mp. (13)
10 multimorbid.mp. (142)
11 (multiple adj3 morbid).mp. (42)
12 (complex adj5 condition).mp. (813)
13 (complex adj5 illness).mp. (393)
14 (complex: adj3 disease).ti. (1296)
15 (multiple adj3 disease).ti. (1026)
16 or/1-15 (5043)

Database: Ovid MEDLINE(R) <1950 to April Week 1 2009>.

Source: U.S. National Library of Medicine. Ovid Medline [Web site]. [access April 1st, 2009]. Available at:http://ovidsp.tx.ovid.com/

One of the main messages from the patchy literature is that the estimates of the prevalence of polypathology among adult members of the general public vary widely, with figures ranging from 17% to just over 50% (10-13).

A more consistent finding is that people with polypathology may represent 50% or more of the population living with chronic diseases, at least in high-income countries. For instance, a systematic review of 25 Australian studies conducted from 1996 to 2007 found that half of the included elderly patients with arthritis also had hypertension, 20% had cardiovascular disease (CVD), 14% diabetes and 12% a mental health condition. Similarly, over 60% of patients with asthma reported living with arthritis, 20% CVD and 16% diabetes; and of those with CVD, 60% also had arthritis, 20% diabetes and 10% had asthma or mental health problems (14). A study of a random sample of 1,217,103 patients from the United States who had been receiving Medicare services for over a year (and so were 65 or older) showed that two thirds (65%) had multiple chronic conditions (15). Studies of patients admitted to hospitals in Spain also show a prevalence of polypathology ranging from 42% to just over 57% (16, 17).

Data from other studies show even higher prevalence levels among people living with specific chronic diseases. An analysis of five randomly selected clinical trials that included patients with hypertension in Canada in 2003 revealed that 89% to 100% had multiple chronic conditions with a mean number of chronic conditions that ranged from 5.5 to 11.7 (18). A similar pattern was found among people living with chronic obstructive pulmonary disease as their index condition in Italy, where 98% of participants in a large cohort of patients had been prescribed at least one non-respiratory drug. The coexisting disease was cardiovascular in 64% of cases, diabetes in 12% and depression in 8% (19). A prevalence of polypathology of 91% was also found in a sample of indigent, predominantly African-American patients in the United States (20).

As expected, the prevalence of polypathology seems to progress with age. An assessment of two large Australian national surveys conducted in 2001 and 2003 showed that the proportion of people who live with three or more chronic conditions increased from 34% for those members of the general public with ages between 20 and 39 years, through 57% between 40 and 59 years, to 80% between 60 and 74 years, and 86% at 75 years or more (12).

It is difficult to determine the proportion of people living with different numbers of coexisting diseases not only because of the scarcity of studies, but because of the use of different metrics across those available. A Danish analysis of data gathered over two decades suggested that four or more diseases were present in 7% of people with ages between 45 and 64 years, increasing to 30% between 65 and 74 years and to 55% among those 75 years and older (21). Analyses of Medicare beneficiaries have shown that 23% live with five or more diseases (22). In Spain, it was estimated that people with ages between 65 and 74 years had a mean of 2.8 chronic conditions, while those over the age of 75 had 3.2 diseases on average (23). A French study of 100 patients aged 80 and over who were hospitalized in a geriatric unit showed that the mean number of recognized diseases per patient was 4.1 (range 1-10) (24).

In addition to older age, multivariate analyses have found that obesity, being female with low socioeconomic status, and living alone are associated with a significantly greater probability of having three or more chronic illnesses (12). In addition to the association with gender and older age, another study showed an increased risk of polypathology among people with low levels of education, with health insurance and those living in a home for the elderly (10).

Data on the mortality rates by number of chronic diseases in people with polypathology are also limited. A study of individuals aged between 55 and 64 years that used Veterans Health Administration health care services between October 1999 and September 2000 showed a 5-year mortality rate that increased from 8% among people with two conditions, through 11% for those with three, to 17% for those with four or more (25).

Data on polypathology from low- and middle-income countries are sparse also. In a study of 844 patients with heart failure who attended a hospital in Soweto, South Africa, 172 (24%) also had renal dysfunction, 83 (10%) coronary artery disease, 18 (2%) a history of acute myocardial infarction, 86 (10%) diabetes, 72 (10%) anemia, 58 (7%) stroke, and 53 (6%) atrial fibrillation (26). A survey of households substantially affected by serious illness in two counties in China identified 2,259 people with chronic disease, of whom 2,140 (95%) had one condition, 110 (5%) two, and 9 (0.4%) three (personal communication) (27).

Only one of the identified studies provided data on the prevalence among children or adolescents. This effort, which used data from the Registration Network Family Practices in The Netherlands, showed that 10% of people from birth to 19 years of age are likely to have multiple chronic diseases (10).

# Why this book now?

Our limited knowledge about polypathology is not only restricted to an understanding of its prevalence. In 2006, the Veterans Health Administration (VHA) in the United States organized a conference entitled Managing Complexity in Chronic Care, motivated by the risk of having insufficient funds to meet the health service needs of its target population (e.g., war veterans, active service members in time of war and people affected by national emergencies). This concern was fueled by the realization that 96% of Medicare expenditure at that time was already being directed to people living with multiple chronic diseases (28)

The insights generated before, during and after this event were published as nine short articles in a special supplement of the Journal of General Internal Medicine in December of 2007 (29). An accompanying overview listed nine key research topics that had been identified as a result of the deliberations of the participants about unmet care needs for people living with multiple chronic diseases (Figure 2).

### Figure 2

Research topics in the management of patients with complex chronic care needs identified at the SOTA conference sponsored by the VHA in 2006 (28)

- 1. Characterize high risk cohorts of patiens with Multiple Chronic Conditions (MCCs) and social complexity, including health services impact. From this work develop and priority list of MCCs and social complexity for targeted interventions
- 2. Synthesize/systematically review literature of interventions that relate to MCCs and complex care needs for patiens with social complexity
- 3. Advance work in outcomes assessment, including measures of comprehensive care needs and optimized for patiens with MCCs
- 4. Increase the evidence-base of efficacy and effectiveness studies to support guidelines that are adaptive to MCCs and social complexity for high priority complex patiens
- 5. Development of more optimal performance measures that reflect complex morbidity including focus on patients self-management and coordination of care
- 6. Evaluate systems changes that organize care around MCCs and social complexity of illness management susch us:

- New team-based strategies for care in complex chronic care management
- New non-MD team member roles increased role in care
- The role of and different designs of an «advance medical home» in managing patiens with complex care needs
- The role of care sharing between physician specialties and service lines in optimal management of care
- Self-management support, including group-based learning stuctures
- High performance systems of care for patiens with high priority MCCs
- Technology assistance for patiens with visual, hearing, and other physicial limitations in optimizing complex care management
- 7. Examine best practices in patien-physician communication strategies for care management decisions for patiens with MCCs or with social complexity:
  - What are best methods for eliciting patiens with preferences in light of care complexity, and engaging patient social support structures (e.g. family)?
- 8. Evaluate new Health Information Technology strategies to support complex care management to advance knowledge of:
  - What decisión support tools are needed for patiens with complex care needs?
  - How can patient registries best support care management for patiens with MCCs?
  - What type of Patient directed HIT tools can be developed for optimizing self-management for such patiens?
- 9. Identify best practices for integration of rehabilitation services into patient management strategies for patiens with complex chronic care needs

Completely unaware of the unfolding VHA efforts, leaders at the Andalusian Ministry of Health in Spain also identified the growing prevalence and burden of complex chronic diseases among its target population, making it a top priority for action. As they had supported a long collaborative effort to develop, implement and evaluate a care process to optimize the management of polypathology, at all levels of their regional health system, they were fully aware of the slowly growing interest in this topic in other parts of the world. They were also conscious of the almost complete absence of meaningful collaboration among leading groups. They recognized that most of the available work

had evolved in isolated pockets, missing important opportunities for effective collective learning and for the creation of the large-scale joint efforts required to meet the needs of those living with multiple chronic diseases.

Back in 2006, there was no single place, physical or digital, in which interested people could collaborate across traditional institutional, geographic, professional, linguistic, political, disciplinary and cultural boundaries, to face the challenges created by polypathology.

Against this background, and encouraged by the rapid development and penetration of powerful online resources for collaboration (e.g., wikis, social networking tools), the Andalusian Ministry of Health decided to promote the creation of a global observatory designed to promote the exchange of knowledge and joint efforts among individuals and organizations interested in the management of complex chronic diseases, anywhere in the world.

The Observatory, which is known as OPIMEC (the Spanish acronym for Observatory of Innovative Practices for Complex Chronic Disease Management), is available in English and Spanish at www.opimec.org. In essence, it is a collaborative virtual environment that uses state-of-the-art tools to allow health professionals, researchers, policy-makers and the general public to:

- Access and contribute to the development of a common language with which to improve communication about poly-pathologies across traditional boundaries (supported by wikis).
- Identify, classify, suggest and adopt innovative practices that could improve quality of care in their own settings (supported by Google Maps).
- Communicate and collaborate with individuals who share an interest in meeting the challenges associated with polypathology (supported by online social networking tools).

In mid-2008, the members of the International Advisory Committee of OPIMEC, a group of leading experts in chronic disease management from North America, Europe and Australasia, suggested that the Observatory focus specifically on polypathology, as this was regarded not only as neglected, but also as a source of important opportunities for «glocal» impact (global and local, at the same time).

In March 2009, the Andalusian Ministry of Health convened a meeting in Seville of its key regional leaders in the management of chronic diseases and their closest collaborators

from other regions of Spain and around the world. Together, the participants identified ten poorly-understood areas related to polypathology that they felt could benefit from international collaborative initiatives:

- Epidemiological issues.
- The language of polypathology and assessment of complexity.
- Prevention and health promotion.
- Disease management models.
- Patient education and self-management.
- Primary care and integrated management processes.
- Supportive and palliative care.
- Demedicalization of care (with emphasis on complementary and alternative interventions).
- Economic, social and political implications.
- The Promise of Genomics, Robotics, Informatics/eHealth and Nanotechnologies (GRIN).

Collectively, the event participants expressed strong interest in using OPIMEC to codevelop and share a body of constantly evolving knowledge that could be made available to anyone, anywhere in the world, at any time, in digital form and free of charge. As a catalyst for this ambitious global collaborative effort, the group decided to produce a book, in digital and paper form, in English and Spanish, which could be launched during Spain's presidency of the European Union in the first half of 2010, and made available to anyone interested, free of charge.

# The approach

During the March 2009 meeting, participants were invited to lead (main) or identify lead contributors for specific book chapters focused on each of the neglected areas that they had identified

By the end of the month, all chapters had been assigned to a lead contributor who had committed to having the first draft ready by the summer of 2009. At that point, the initial

senior editorial group had also been confirmed (Dr. Lyons joined the editorial group at the end of the year), and a technical support team and a roster of potential contributors had been established.

All of the lead contributors agreed to follow a series of principles to ensure maximum transparency to future audiences, and to prevent any unnecessary perception of conflicts of interest or bias. They:

- Used language that would be accessible to different potential audiences, including policy-makers, clinicians, managers and researchers. A lay summary would make the essence of each chapter easy to grasp for the general public.
- Disclosed their affiliation with organizations that may have an interest in the management of poly-pathologies in general, or with a specific topic in particular.
- Made explicit any personal or organizational biases that may influence the tone and emphasis given to the topic being addressed.
- Avoided over-emphasizing or focusing just on issues that related to their professional activities or organizational goals, be they political, financial or academic.
- Acknowledged, whenever possible, the work of individuals and organizations with opposing views or with competing interests.
- Made their contributions without financial or political incentives.

The contributors also agreed to follow a structured format for each of the chapters, with the following sections:

- A vignette outlining a vision of the future using a 20- to 30-year horizon.
- A brief summary highlighting the main points covered in the rest of the chapter, using language that could be understood by any interested reader.
- Why is the topic important? This section described the magnitude of the challenge associated with this specific topic, providing as much data as possible, including all regions in the world, while trying to address the perspectives of different groups of stakeholders (patients and their caregivers, policy-makers, managers, funders and academics).
- What do we know? Here, contributors summarized the research literature available on the topic, highlighting the implications for each of the above groups of stakeholders.

In each chapter, contributors ensured that they had drawn from the initial literature search, as well as from their own collections of resources.

- What do we need to know? This section emphasized the knowledge gaps that exist around this topic, and why it would be important to fill them.
- What innovative strategies could fill the gap? The contributors ended each chapter with proposed innovative efforts that could be pursued to fill the identified gaps, focusing on methodological issues, resource needs (technological, financial and human) and the role that OPIMEC could play in the process.

Six of the chapters were produced initially in Spanish and four in English (those that dealt with epidemiological issues, prevention and health promotion, supportive and palliative care, and demedicalization of care).

One of the senior editors (FM) supported contributors writing in Spanish and another (AJ) those working in English. The latter, fluent in both languages, was responsible for reviewing all of the initial drafts, for harmonizing their content, eliminating redundant content, and identifying areas for improvement.

The revised draft chapters, with suggested changes, were sent to each of the lead contributors, who in turn produced refined versions. In most cases, two iterations of revisions were completed before the initial drafts were considered to be ready for translation.

Once each of the drafts had been translated to the alternate language, the same bilingual senior editor (AJ) reviewed them for accuracy and, whenever appropriate, edited the content further, in both languages.

The translated files were then sent to the respective lead contributors for verification and approval. Once approved by them, the draft chapters were uploaded to the OPIMEC platform by the support team, in a format that included separate interactive sections designed to allow readers to make comments and suggestions for improvement (Figure 3).

Figure 3

### Interactive table of contents with a section sample



- 1. Why Multiple Chronic Diseases? Why now? What is going on around the world? (In development)
- 2. The language of poly-pathology (In development)
- 3. Prevention and health promotion (In development)
- 4. Disease management models (In development)
- 5 Patient education and self-management (In development)
- 6 Primary care institutional services and integrated management processes (In development)
- 7. Supportive care and palliative care (In development)
- 8. Integrative medicine (In development)
- 9. Socioeconomic implications (In development)
- 10. The promise of Genomics, Robotics, Informatics/eHealth and Nanotechnologies (GRIN) (In development)
- 11. Towards a global collaborative approach to complex chronic disease management (In development

### What do we know?

The terms that have traditionally been used in relation to patients with chronic disease usually reflect the silos of the health system, either emphasizing the needs of individual diseases or

The limited work that has been done in relation to multiple chronic diseases has focused mostly on comorbidity>, understood mostly in terms of a primary disease and its associated conditions (see below). Other terms, more related to health services or overall health status, such as frequent flyers, hyper-attenders, polymedicated, frailty and disability, are also frequently used. However, there is a lack of standardization in the terminology employed both by clinicians and investigators in this field. We lack a poly-pathologic disease thesaurus, an unambiguous taxonomy with widely accepted, easy-to-follow and valid definitions of terms, and a clear framework designed to promote the exploration of the relationship among them.

The US National Library of Medicine's Medical Subject Headings (MeSH) provides the broadest coverage of concepts for health, but it lacks many terms related to the issues confronted by patients living with multiple chronic diseases. The World Health Organization (WHO)'s International Classification of Diseases (known as ICD), is widely used within many health systems around the world, but it is little more than an unidimensional ordering of terms describing medical concepts with little relevance for chronic complex patients. Even SNOMED CT (Systematized Nomenclature of Medicine- Clinical Terms), the most comprehensive clinical vocabulary available in any language, lacks specific terms to enable a clear and reproducible description of the conditions, the interventions or the outcomes achieved in any case in which two or more chronic diseases co-exist (1). The only significant attempt to classify disease management interventions through

Source: OPIMEC. [Web site]. [access May 5<sup>th</sup>, 2010]. Available at: http://www.opimec.org

While the chapters were being uploaded, the editors and lead contributors produced a list of peers they felt could provide useful comments on each of the drafts, selecting them from among colleagues they knew or the authors of key articles they had used as references. The editors then sent an electronic message to the members of this list, inviting them to read the chapters and make comments, either anonymously or by registering as members of the OPIMEC community. In all cases, the support team was available to provide technical assistance under supervision by one of the editors (AC).

Throughout the process, the terms contributor and contributorship were considered to be more consistent with modern approaches to acknowledging the work of members of collaborative groups than the more traditional author or authorship (30).

A minimum of a month after the chapters were uploaded to the platform, the editors reviewed all of the comments received and produced lists of substantive changes that were sent to the lead contributors for incorporation into the drafts.

The revised versions were then reviewed thoroughly by the editors (RS, RL and AJ in English, and PM, AC and AJ in Spanish), who could make modifications to the main text online. Those individuals who made substantive comments, as judged by the editors by consensus, were recognized as book contributors.

# The output

By the end of February of 2010, less than a year after the original meeting in Seville, the chapters that we present in this book had been completed, revised in draft form at least twice, and approved by the editors. The eleventh chapter was added soon before the submission of the final version of the paper edition of the book in April 2010.

Contributions were received from individuals living in all of the inhabited continents. Most of them, however, were made by colleagues who were approached at the outset by the editors and by members of their immediate teams or circles of collaborators.

Despite their ease of use and the availability of technical support at all times, some contributors preferred to use traditional electronic mail to produce content over the online resources available on the OPIMEC platform. This made the editing process difficult at times, as contributors would send different versions of their work directly to individual editors, creating unnecessary confusion and duplication of effort.

The editors, on the other hand, communicated mostly by electronic mail, complementing their frequent (at least weekly) text-based interactions with online videoconferences and in-person meetings whenever possible.

The conversion of the contributions into homogeneous versions in English and Spanish was not a straightforward process. The translations, which were mostly precise reflections of the original text, required heavy editing to make them flow as comfortably as possible for readers in the alternate language. This led to inevitable mismatches between the versions, which bilingual readers will recognize easily in most cases.

Another interesting aspect of this effort was the process to decide when to consider the digital content that was emerging through such a diverse collective of contributors to be ready for publication in book form. In most cases, the threshold was determined by the absence of comments from existing or new contributors. In the remaining few, the editors had to decide, by consensus, that the chapter was good enough for release in static form. Continued revision of these few chapters was not possible because of the limitations imposed by the publishing timelines and the need to launch the content as a paper-based book in early June 2010. Nevertheless, having the entire contents available online, through the OPIMEC platform, should enable any interested reader to make suggestions as to how to improve on what has been produced so far.

In any case, the book achieved its original overarching objective: to act as a powerful stimulus for collective effort, across traditional boundaries, among people interested in improving the management of complex chronic diseases. Without the incentive associated with the creation of something so tangible, or the pressure generated by publication deadlines and launch dates, it would have been difficult to achieve so much. in so short a period of time, and with no financial incentives. Along the way, those who responded made a substantial and generous attempt to summarize the limited knowledge available around this important and seriously neglected area, while proposing innovative strategies to fill the gap between what is known and what should be done to meet the needs and expectations of a growing number of vulnerable people in every society in the world.



When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge

### Contributors

Alejandro Jadad wrote the first draft of this chapter in English and approved its Spanish translation. All of the other editors (Andrés Cabrera, Francisco Martos, Renée F. Lyons and Richard Smith) reviewed the chapter and approved it, with minor comments. These, together with valuable contributions from Kerry Kuluski, were incorporated by AJ into the final version that was included in the paper-based book.

Responsibility for the content rests with the contributors and does not necessarily represent the views of Junta de Andalucía or any other organization participating in this effort.

### **Acknowledgments**

Joseph Ana, José Miguel Morales Asencio, Bob Bernstein, Murray Enkin, John Gilles, Marina Gómez-Arcas, Rodrigo Gutiérrez, Jacqueline Ponzo and Ross Upshur made insightful comments on the chapter that did not lead to changes to its contents. Such comments, which were greatly appreciated, were considered for inclusion in other chapters of the book.

### How to reference

Jadad AR\*, Cabrera A, Martos F, Smith R, Lyons RF. [\*Main contributor] Why Multiple Chronic Diseases? Why now? What is going on around the world? In: Jadad AR, Cabrera A, Martos F, Smith R, Lyons RF. When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge. Granada: Andalusian School of Public Health; 2010. Available at: http://www.opimec.org/eguipos/when-people-live-with-multiple-chronic-diseases/

# References

- 1. Boyd JH. Are Americans Getting Sicker or Healthier?. Journal of Religion and Health. 2006; 45(1. Boyd JH. Are Americans Getting Sicker or Healthier?. Journal of Religion and Health. 2006; 45(4):559-585.
- 2. Freedman N. Sappho: The Tenth Muse. New York: St. Martin's Griffin, 2001.
- 3. West M. A new Sappho poem. Times Literary Supplement. June 21st, 2005. Available at:http://www1. union.edu/wareht/story.html
- 4. World Health Organization. Global Report. Preventing Chronic Disease: a vital investment. Geneva: WHO; 2005. Available at: http://www.who.int/chp/chronic\_disease\_report/en/
- 5. Fuster V, Voute J. MDGs: Chronic diseases are not on the agenda. Lancet. 2005; 366 (9496): 1512-4.
- 6. World Health Organization. Depression. Geneva: WHO. Available at: http://www.who.int/mental health/ management/depression/definition/en
- 7. World Health Organization. Chronic Diseases. Geneva: WHO. Available at: http://www.who.int/topics/ chronic\_diseases/en
- 8. Horton R. The neglected epidemic of chronic disease. Lancet. 2005; 366 (9496): 1514.
- 9. Vogeli C, Shields AE, Lee TA, Gibson TB, Marder WD, Weiss KB, Blumenthal D. Multiple chronic conditions: prevalence, health consequences, and implications for quality, care management, and costs." J Gen Intern Med. 2007; 22(Suppl 3):391-5.
- 10. Van Den Akker M, Buntinx F, Metsemakers JF, Roos S, Knottnerus JA. Multimorbidity in general practice: prevalence, incidence, and determinants of co-occurring chronic and recurrent diseases. J Clin Epidemiol. 1998; 51(5):367-37.
- 11. Wilper AP, Woolhandler S, Lasser KE, McCormick D, Bor DH, Himmelstein DU. A national study of chronic disease prevalence and access to care in uninsured U.S. adults. Annals of Internal Medicine. 2008; 149 (3):170-6.
- 12. Walker AE. Multiple chronic diseases and quality of life: patterns emerging from a large national sample, Australia. Chronic Illn. 2007; 3 (3): 202-218.
- 13. Anderson G, Horvath J, Knickman JR, Colby DC, Schear S, Jung M. Chronic Conditions: Making the Case for Ongoing Care. Princeton, NJ: Robert Wood Johnson Foundation; 2002.
- 14. Caughey GE, Vitry AI, Gilbert AL, Roughead EE. Prevalence of comorbidity of chronic diseases in Australia. BMC Public Health. 2008; 8:221.
- 15. Wolff JL, Starfield B, Anderson G. Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. Arch Intern Med. 2002; 162 (20):2269-76.
- 16. Medrano Gónzalez, F. Melero Bascones M. Barba MA, Gómez J. Llabrés J. Moreno J. [Comorbidity, pluripathology, resource use and prognosis of patients hospitalized in internal medicine areas]. An Med Interna; 2007:24 (11):525-30.

- 17. Zambrana García JL, Velasco Malagon MJ, et al. [Characteristics of patients with multiple disease hospitalized in Internal Medicine services].[see comment]. Rev Clin Esp; 2005 205 (9):413.
- 18. Fortin M. Dionne J, Pinho G, Gignac J, Almirall J, Lapointe L. Randomized controlled trials: do they have external validity for patients with multiple comorbidities? Ann Fam Med. 2006; 4 (2):104-8.
- 19. Anecchino C, Rossi E, Fanizza C, De Rosa M, Tognoni G, Romero M; working group ARNO project. Prevalence of chronic obstructive pulmonary disease and pattern of comorbidities in a general population. Int J Chron Obstruct Pulmon Dis. 2007; 2 (4):567-74.
- 20. Kahn LS, Fox CH, Olawaiye A, Servoss TJ, McLean-Plunkett E. Facilitating quality improvement in physician management of comorbid chronic disease in an urban minority practice. J Natl Med Assoc. 2007; 99 (4):377-83.
- 21. Uijen AA, Van de Lisdonk EH. Multimorbidity in primary care: prevalence and trend over the last 20 years. Eur J Gen Pract. 2008;14 (Suppl 1):28-32.
- 22. Committee on Quality of HealthCare in America, Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st century. Washington D.C.: National Academies Press; 2001.
- 23. Ministerio de Sanidad y Politica Social (Spanish Ministry of Health and Social Policies). Unidad de Pacientes Pluripatológicos. Estandares y Recomendaciones. Madrid: Ministerio de Sanidad y Politica Social; 2009.
- 24. Saint-Jean O, Berigaud S, Bouchon JP. Polypathology and co-morbidity: a dynamic way for describing morbidity in aged patients. Study of 100 patients, aged 80 and over, in a short-stay geriatric internal medicine unit. Ann Med Interne.1991; 142 [8]:563-9.
- 25. Lee TA, Shields AE, et al. Mortality rate in veterans with multiple chronic conditions. J Gen Intern Med. 2007: 22 (Suppl 3):403-7.
- 26. Stewart S, Wilkinson D, Hansen C, Vaghela V, Myungi R, McMurray J, Silwa K. Predominance of heart failure in the Heart of Soweto Study cohort: emerging challenges for urban African communities. Circulation. 2008;118:2360-7.
- 27. Lucas H, Shijun Ding, Bloom G. What do we mean by major illness? The need for new approaches to research on the impact of ill health on poverty. Studies in HSO&P.; 2008:23:29-53.
- 28. Weiss KB. Managing complexity in chronic care: an overview of the VA state-of-the-art (SOTA) conference. J Gen Intern Med. 2007;22 (Suppl 3):374-8.
- 29. Kupersmith J. Managing Patient and System Complexities to Improve the Quality and Outcomes of Chronic Care: Papers from VAs State-of-the-Art Conference: Managing Complexity in Chronic Care. J Gen Intern Med. 2007;22 [Suppl 3]:373.
- 30. Smith R. Authorship is dying: long live contributorship. BMJ. 1997; 315(7110): 696. Available at: http://www.bmj.com/cgi/content/full/315/7110/696



### **Abbreviations**

AAL: Ambient Assisted Living

BMJ: British Medical Journal

CAM: Complementary And Alternative Medicine

CCD: Complex Chronic Disease

CCM: Chronic Care Model

CIRS: Chronic Illness Resources Survey

CMPs: Case Management Programs

CVD: Cardiovascular Disease

DMPs: Disease Management Programs

EASP: Escuela Andaluza de Salud Pública

EPP CIC: Expert Patients Programme Community Interest

Company

GRIN: Genomics, Robotics, Informatics and Nanotechnologies

ICCC: Innovative Care for Chronic Conditions

ICD: International Classification of Diseases

ICED: Index of Coexisting Disease

IDS: Individual Disease Severity

MCCs: Multiple Chronic Conditions

MD team: Medical Doctor

MeSH: Medicines Medical Subject Headings

MI: Motivational interviewing

MPOWER: Monitor (tobacco use and prevention policies), Protect (people from tobacco smoke), Offer (help to quit tobacco use), Warn (about the dangers of tobacco), Enforce (bans on tobacco advertising, promotion and sponsorship), Raise (taxes on tobacco)

NHIS: National Health Interview Survey

NHS: National Health Service

OECD: Organization for Economic Co-operation and

Development

OPIMEC: Observatorio de Prácticas Innovadoras en el Manejo de

Enfermedades Crónicas Complejas

PACE: Program of All-inclusive Care

QALY: Quality-Adjusted Life Year

QRISK: Cardiovascular disease risk score

RE-AIM: Reach, Effectiveness, Adoption, Implementation and

Maintenance

SNOMED CT: Systematized Nomenclature of Medicine-Clinical

Terms

SSPA: Sistema Sanitario Público de Andalucía

TCAM: Traditional Complementary And Alternative Medicine

TPE: Therapeutic patient education

VHA: Veterans Health Administration

WHO: World Health Organization

# Figures and Tables

Chapter 1		Chapter 4			
Figure 1.	Search strategy	20	Figure 1.	The Chronic Care Model	91
with complex chron	Research topics in the management of patients		Figure 2.	The Expanded Chronic Care Model	91
	with complex chronic care needs identified at the SOTA conference sponsored by the VHA in 2006	23	Figure 3.	WHO, Innovative Care for Chronic Conditions Framework	93
9	Interactive table of contents with a section simple	29	Figure 4.	Kaiser Permanente risk stratification pyramid	97
Simple			Figure 5.	The linear process of planned change	103
Chapter 2			Table 1.	Key elements of the ICCC model	92
Figure 1.	Baseline Functional Impairment (measured on the Barthel scale) at Admission and Discharge of General and Pluripathological Patient Cohorts	44	Table 2.	Effective interventions in the management of chronic patients	101
Table 1.	Criteria which define the Pluripathological		Chapter 8		
Patient Patient Territorial Patient		41	Table 1. CAM Treatments Based on Sound Eviden		195
Table 2.	Modified Charlson Index	47	Table 1. OAM Treatments based on Sound Evidence		
Table 3.	Cumulative Illness Rating Store	48	Chapter 9		
Table 4.	Kaplan-Feinstein Comorbidity Index	50	Figure 1.	Percent of medicare spending per person by number of Chronic Conditions	214
Chapter 3			Figure 2. Unnecessary hospital admissions related		
Figure 1.	igure 1. Effectiveness of Various Forms of Nicotine Replacement Therapy in Helping People to Stop Smoking			to the number of conditions coexisting in a person	215
			Figure 3.	A small percentage of patients account for many hospital bed days	
Figure 2. Overlap among Women and Men who will Experience a Cardiovascular Event in the nex			Figure 4.		215
	Years and who are Predicted to Do so by the QRISK and Framingham Risk Assessments	70	rigare 4.	Expenditure in Different Sectors of the Population	216
Table 1.	A Systematic Review of Interventions Designed to Improve the Diet and Promote		Figure 5.	Estimated 2008 US Healthcare Cost per person by extent of risk factors	218
Phy	Physical Activity	66	Table 1.	Cost per Group of Countries per	
Table 2.	Requirements for an Effective Screening Programme	74		Quality-adjusted Life-year of Cholesterol and Hypertension Level Control Measures	219
Table 3.	UK Criteria for Appraising the Viability, Effectiveness and Appropriateness of a Screening Programme	75			
Table 4.	Systematic Population Screening Programmes which have not been Recommended in the UK	78			

### Index

ICED 48 Assessment tools 45 Death 166, 168, 169 Associated factors 22 Demedicalization199 Illness rating store 48 Bottom up 104 Dependence 217 Individuals 69 CAM Treatments 195 Developing countries 22 Informatics 227 Cardiovascular Event 70 Diet 65 Innovative strategies 51, 82,102, 129, 149, 175, 201, 220, 234 Disease burden 45 Case management 96 Institutional services 141 Disease risk factors 217 Category 41 Institutions 166 CCM 90, 95 Dying phase 168 Instruments 50 Challenges 241, 243 Economic implications 198, 211, 219 Integrated care processes 103 Charlson Index 98 End of life 164, 167 Integrated management processes 141 Children 22 Entrepreneurship 104 Integration 129 Chronic care management 100 Environment 67 Integrative medicine 189, 198, 200 Chronic Care Model 91 EPP CIC 130 Kaiser model 96 Chronic diseases 18, 19, 45, 90 Evercare model 99 Kaiser Permanente risk stratification Chronic patients 101 Expanded Chronic Care Model 90 pyramid 97 CIRS Scale 47 Flinders Program 124 Kaplan-Feinstein Comorbidity Index 50 Collaborative effort 24, 243 Functional deterioration 44 Kaplan-Feinstein Index 49 Community 68, 200 G factor 230 Leadership 104, 105 Community self-management 129 Genomics 227 Levels, prevention 60 Comorbidity 39 Guided Care Model 96 Lifestyles 217 Comorbidity 39 Guided Mastery 126 Managed care 145 Complex adaptive systems 102 Health care professionals 121, 125 Management models 87, 90 Complex chronic care needs 23 Health Promotion 57 Management of patients 23 Complex chronic cases 95 Healthcare costs 217, 218 Mass media 67 Complex chronic disease 45 Hospital 215 Medicare 214, 216 Confluent morbidity 45 I factor 232 Metrics 22

Mortality 18

Multiple 19

Motivational Interviewing 122

ICCC 92

ICD 98

ICCC model 92,93, 101

Cooperation 102

Customization 175

Contributor, contributorship 29

Multivariate 22 Proffesional roles 147 The Charlson Index 46

N factor 233 RE-AIM framework 126 Tithonus 18

Nanotechnologies 227Rfactor 231Tobacco 62, 63Nicotine Replacement Therapy 63Reimbursement model 174Toolkit 51

Nicotine Replacement Therapy 63 Reimbursement model 174 Toolkit 51

O+Berri 105 Religious settings 68 Tools 50

Older adults 68 Research topics 23 Unmet needs 164

OPIMEC 25, 51, 149, 245 Restorative care 172 Workplace 67

Organization men 104 Risks 96
Palliative care 161, 164, 171 Robotics 227
Patient empowerment 128 Role 105

Palliative treatment 172 School settings 67
Pathology 47 Screening 73

Patient education 115, 119 Screening Programme 74, 75

Patient empowerment 128 Search strategy 20

Physical Activity 65 Secondary Prevention 73, 81
Pluripathological Patient 41 Self-management 118

Pluripathology 40 Self-management education 119
Policy 67 Self-management evaluation 127

Political implications 220 Self-management support 115, 121, 125

Polypathology 17, 19, 21, 22, 23, 40, 241 Social Determinants 61

Polypill 71 Socioeconomic implications 198, 211, 220

Populations 69 Sound Evidence 195

Prevalence 21 Supportive care 161, 165, 171

Preventable causes 61 System of care 173
Prevention 57, 59, 60 Taxonomy 39, 51, 102
Primary care 68, 141, 148 TCAM interventions 195

Primary Prevention 61, 69, 80 Technology 178

Primordial Prevention 61, 80 Terminal trajectories 168

Process re-engineering 146 The 5As 121



# When people live with multiple chronic diseases: a collaborative approach to an emerging global challenge





