

EDITED BY  
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



Escuela Andaluza de Salud Pública  
CONSEJERÍA DE SALUD







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# 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

### **María Carmen Griñán Martínez**

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

**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. Lyons**

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

**M<sup>a</sup> 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

---

\*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 Higuera 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

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## Dealing with the challenges of polypathology, together: What's next?

This chapter is continuously evolving at [www.opimec.org](http://www.opimec.org)

In March of 2009, we wondered if it would be possible to co-create a book on polypathology, within a year, from scratch, with volunteer contributors from all over the world, using online social media and with no financial incentives.

Well, we did it!

Once the lead contributors produced the first version of each of the chapters, and they were reviewed by an editor-guarantor (ARJ), we embarked on a massive e-mail campaign to reach potential contributors (1). The outgoing messages, which were sent in 17 waves, were adapted to the language, area of interest and contents of each of the message recipients.

Between December of 2009 and March of 2010, 550 people were targeted. They included not only experts suggested by lead contributors, but also the corresponding authors of articles that had been selected as references in the initial versions of the chapters.

In addition to the e-mail outreach efforts, we included banners on key websites of the Andalusian School of Public Health (2) and the Andalusian Ministry of Health (3), and in the blogs of two of the lead contributors (4, 5). We also optimized the contents of the OPIMEC platform for top search engines and created a space on Facebook describing the project and inviting participation.

During the four months in which the chapters were available for contributions, the OPIMEC site received more than 13,000 visits from people in 80 different countries. Of these visitors, 55 people from 18 countries made 235 contributions to the chapters. The

theme that received most comments was health promotion and prevention (Chapter 3), with over 40% of the contributions, followed by patient education and self-management with 10% (Chapter 5).

By the end of March of 2010, all of the draft chapters had been reviewed at least twice by one or more of the editors. By the time of the launch, in early June of 2010, the entire edited version was available as a free hard copy or in portable document format (PDF), for free download (6). Each of the chapters will also continue to be available through [www.opimec.org](http://www.opimec.org), as a «live» version, enabling continuous updates and improvements.

## What did we learn during the process?

We gained valuable insights during the co-creation of the book, particularly in relation to the use of online collaborative tools and the engagement of experts in the process.

The following lessons are worth highlighting, as they may be useful to those interested in embarking in similar exercises:

- Technological glitches are unavoidable: At times, we faced technological problems with the tools that we used to facilitate content co-creation, which made the process frustrating to the editorial group, to the support team and to the volunteers who were willing to contribute to the book. Along the way, some contributors found such glitches unacceptable and decided to give up, despite having a help line available as well as the option to make contributions through e-mail at any time. We hope that these colleagues will be keener to join the project in the future, and that they understand that, as they continue to evolve, information and communication technologies will continue to present challenges to early adopters.
- It is difficult to match versions of the same document as they evolve in multiple languages at a different pace: To make facilitate this process, we produced the initial version of the book in English, translating and incorporating contributions in Spanish as they emerged. Throughout the process, however, all comments were visible in both languages in the corresponding section of the chapter.
- Firm deadlines for contributions must be set and enforced: This was perhaps the greatest challenge, as prominent colleagues pleaded to have additional time to provide their input. Instead of jeopardizing the overall project by extending the timelines, we thanked those interested and reiterated that their contributions would

be welcome, at any time, as the book would continue to evolve on the OPIMEC platform, as a living entity.

- It is essential to have a clear common goal, a diverse editorial group, and institutional support: By starting with 10 clearly defined topics, we could enlist leading contributors quickly. Having a strong and diverse editorial group enabled us to distribute functions in a way that made the workload manageable throughout the process, while building on individual areas of strength. Thanks to the strong backing from the Andalusian Ministry of Health, we could set the date for the book launch during Spain's presidency of the European Union. This acted as a strong incentive and justification for the contributions to be made within the established deadlines.
- Copyleft and contributorship are viable options: This book is a living proof that it is possible to motivate a large group of experts to embrace «copyleft» (7) and «contributorship» (8), as viable alternatives to their more restrictive siblings, «copyright» and «authorship».

## Now, what? Are we ready to meet common challenges, together?

The use of a standardized structured format, with key questions as the main drivers for content development in all chapters, also paid off. The book not only provides easy access to the best available knowledge on 10 major aspects of polypathology but also a long list of unaddressed questions and issues that require urgent attention.

We feel that the collaborative work that resulted in this book could easily become the foundation for joint projects that could fill many of the identified gaps, in record time.

The following are some examples of questions that could drive the design, execution and dissemination of large-scale collaborative projects through which we could attempt to meet the challenges created by polypathology, at all levels:

- Is it possible to promote an ongoing global survey to monitor polypathologies in different regions of the world simultaneously?
- Is it possible to create a taxonomy that could facilitate the exchange of knowledge and the evaluation of innovations for the management of polypathology worldwide?

- What strategies or interventions are needed to facilitate the development of the knowledge base, attitudes, skills and behaviours required by professionals to bridge social and health services in a way that would contribute to meeting the unmet methodological, technological, management, social, political and economic needs associated with polypathology?
- Are polypills cost-effective interventions for polypathologies? If so, how can their widespread use be encouraged?
- Is it possible to design, implement and evaluate a flexible model of care that brings together the power of de-centralized innovation and leadership by front-line professionals and the public, with the efficiency of a centralized policy-making and management structure?
- Is it feasible to use online social media to create and sustain a global network of self-management and peer-to-peer resources for people living with multiple chronic diseases?
- What are the new functions or whole occupations or the new roles for existing occupations that are required to bridge or blend social and health services in a way to that would meet the needs of people living with multiple chronic diseases and their caregivers?
- To what extent could effective innovations for the management of polypathology be adopted and adapted across different regions of the world?
- How do different combinations of diseases or disease trajectories influence the supportive and palliative care needs of people with polypathologies and their caregivers?
- What is the impact of multiple chronic diseases on the lives of caregivers? What new roles, workflows and supportive services are needed to relieve their burden?
- Could Integrative Medicine promote the demedicalization of the management of polypathologies? Could it promote greater acceptance, among patients and caregivers, of the unavoidable suffering associated with multiple chronic diseases and the ageing process?
- What are the total costs associated with the management of polypathologies?
- Does the level of complexity associated with most polypathologies exceed the capacity of GRIN technologies to offer tangible solutions?

- Could key regions be transformed into living laboratories with the conditions necessary for the development, refinement, implementation and evaluation of innovative ways to optimize the management of polypathology?
- What strategies are needed to position the management of polypathology among the top priorities for leading political, academic, community and corporate organizations interested in the sustainability of the health system?

Answering these questions, and many others that remain unaddressed, will not be easy. It will require a very creative blend of public engagement; creative partnerships among the government, academic institutions, the public and industry; rigorous trans-disciplinary research and development; strong input from social and political scientists; visionary technological innovation; effective knowledge mobilization and management; and extraordinary political will.

Such effort will require unprecedented levels of generosity to overcome the powerful perverse incentives that have made us so vulnerable to polypathology.

We have already proven, by co-creating this book through OPIMEC, that we can work across traditional boundaries, contributing to a common ambitious agenda. We must now scale up the level of our commitment to create and implement the potent interventions that are required to overcome the apparently insurmountable challenges we face, together.

---

### *Contributors*

Andrés Cabrera wrote the initial draft of this chapter in Spanish. Alejandro Jadad wrote the last version and translated it into English. This chapter received contributions from Begoña Isac, Diana Gosálvez, Alejandro López and Antonio J. Contreras (in Spanish).

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

### *Acknowledgments*

Book editors and contributors.

### *How to reference*

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## 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

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

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