

Organizational Behaviour in Healthcare

Series Editors

Jean-Louis Denis
School of Public Health
University of Montreal
Montréal, QC, Canada

Justin Waring
Nottingham University Business School
University of Nottingham
Nottingham, UK

Paula Hyde
Birmingham Business School
University of Birmingham
Birmingham, UK

Published in co-operation with the Society for Studies in Organizing Healthcare (SHOC), this series has two strands, the first of which consists of specially selected papers taken from the biennial conferences held by SHOC that present a cohesive and focused insight into issues within the field of organizational behavior in healthcare.

The series also encourages proposals for monographs and edited collections to address the additional and emergent topics in the field of health policy, organization and management. Books within the series aim to advance scholarship on the application of social science theories, methods and concepts to the study of organizing and managing healthcare services and systems.

Providing a new platform for advanced and engaged scholarship, books in the series will advance the academic community by fostering a deep analysis on the challenges for healthcare organizations and management with an explicitly international and comparative focus.

More information about this series at
<http://www.palgrave.com/gp/series/14724>

Marie-Pascale Pomey
Jean-Louis Denis • Vincent Dumez
Editors

Patient Engagement

How Patient-provider Partnerships
Transform Healthcare Organizations

palgrave
macmillan

Editors

Marie-Pascale Pomey
School of Public Health
University of Montreal
Montreal, QC, Canada

Jean-Louis Denis
School of Public Health
University of Montreal
Montreal, QC, Canada

Vincent Dumez
Faculty of Medicine
University of Montreal
Montreal, QC, Canada

ISSN 2662-1045

ISSN 2662-1053 (electronic)

Organizational Behaviour in Healthcare

ISBN 978-3-030-14100-4

ISBN 978-3-030-14101-1 (eBook)

<https://doi.org/10.1007/978-3-030-14101-1>

© The Editor(s) (if applicable) and The Author(s), under exclusive licence to Springer Nature Switzerland AG 2019

This work is subject to copyright. All rights are solely and exclusively licensed by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The publisher, the authors and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, express or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

This Palgrave Macmillan imprint is published by the registered company Springer Nature Switzerland AG. The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Foreword

Our grandchildren will be astonished to learn that there was a time not so long ago when it was widely assumed that patients had no knowledge of anything of relevance to their healthcare. All medical knowledge rested with doctors, it was believed, and patients were expected to listen politely and follow the doctor's instructions unquestioningly. Those assumptions of medical superiority and passive obedience are largely behind us now, thank goodness, though pockets of resistance remain.

Meanwhile those of us who care about these things have set our sights higher, aiming for a world in which the knowledge and capabilities of patients, their families and communities are recognized as essential underpinnings of a high-quality health service. We start from the firm belief that patients are uniquely knowledgeable about their values and preferences, their social circumstances and milieu, and their own experiences of health and illness. This tacit knowledge is hugely valuable. It is, or should be, the basis for selecting appropriate treatments, for effective management of long-term conditions, for preventing ill-health and avoiding recurrence, for designing and redeveloping health services, and for shaping health policy. Those with ambitions to improve population health should value and build on these assets, not ignore them.

Self-care is the most prevalent form of healthcare. As children we learn from our parents how to monitor our health and cope with minor illnesses and we often manage to do this without recourse to professional

help. Indeed, we spend far more time looking after ourselves and our families than in direct contact with health professionals. With no formal training or preparation for this role, we may need to seek advice and support, but the popularity of media reports on diseases and treatments is evidence of how keen we are to learn more. Nowadays patients expect to be told about their treatment options and be involved in decisions about their care. They hope clinicians will recognize their strengths and capabilities, not just their vulnerabilities. Treat us like intelligent individuals, not just collections of body parts, is a common refrain. The chapters in this book underscore the importance of this—evidence is mounting that personalizing care and giving patients greater control leads to more effective self-care, improved professional practice and better health outcomes.

While patients' knowledge and activation can make a real difference to health experiences and outcomes at the individual level, it is just as powerful when mobilized collectively. We are fortunate that large numbers of people are motivated to share their healthcare experiences and use this knowledge to press for changes that will benefit all. Many examples of collective action are described in this book, some of which were generated and led by health professionals, while others emerged from patient-led organizations. These groups have played a major role in changing attitudes and behaviour both at the point of care and at more strategic levels. They have campaigned for better, safer, more humane healthcare and for improvements in the quality of care delivery. They are motivated by a conviction that we have a better chance of transforming health systems if we work together, combining all our assets to ensure they are responsive and sustainable into the future.

This ambition unites the authors of this book. Here you will find examples of patient involvement at all levels of healthcare and health policy—in individual care, in healthcare facilities, in regulatory processes, in education and research, and in policy developments. The chapters describe innovative approaches to building and strengthening collaborative partnerships between patients and professionals, showing how these are helping to transform healthcare. Inspiring case studies provide practical illustrations of what it means to work in a different way and the benefits that can ensue. And the editors have ensured that the professional

and academic authors practise what they preach, encouraging them to work with patient representatives to craft their chapters.

Each of the accounts reminds us how far we have come in the last 20 years or so. Patient and public involvement is now well embedded in the health policies of leading countries, while others are at an earlier stage but moving in the same direction. Progress is still patchy and fragile in places, but there is clear evidence of cross-fertilization that is helping these ideas to spread. Concepts such as shared decision making, personalized care planning, experts-by-experience, co-production, patient leaders, experience-based co-design and asset-based community development are becoming more widely understood. Anyone still flummoxed by these terms will find clear descriptions here, together with practical examples showing why they are relevant and important.

Yet this is no Panglossian account. The authors are realistic in their assessments of the many challenges still to be faced. How to build health literacy is one such challenge. While starting from the premise that everyone can make an important contribution to their health and that of their families and communities, it is nevertheless obvious that some people need more help than others to play an active role. Lack of basic literacy, numeracy and health knowledge skills has a detrimental effect, so development of these skills is key to building a healthier society. Even people with good basic literacy and numeracy skills may struggle to understand and interpret health information in a way that prompts them to act appropriately to protect and enhance their health. Tackling low levels of health literacy requires well-designed, carefully targeted approaches, but it is also important to address the health information needs of the whole population. Health literacy ought to be accorded higher priority than is the case.

A related problem is how to ensure that improvement efforts take account of the diversity of needs and views, especially those in less advantaged groups. Many patient activists come from relatively privileged sections of society. People from more vulnerable groups may not have the time or inclination to join committees engaged in what may seem like endless meetings to plan improvements. What can be done to ensure that the needs and preferences of these “seldom heard” groups are placed at

the forefront of improvement efforts? Several chapters touch on this—readers may find some useful ideas here on how to tackle this conundrum.

Another problem lies in the common tendency to overestimate the efficacy of medical care and underplay its limitations. If we are overly-dependent on technical solutions to health problems, it's largely because various vested interests—professional and commercial organizations, media, politicians and others—have encouraged an over-optimistic view of what can be achieved through medical intervention. The risk is that we waste time and resources searching for medical solutions to problems that are essentially socio-economic in nature. The demand for costly technical solutions masks the need for more humane care for those whose health problems cannot be fixed and distracts attention from tackling the wider determinants of health. Somehow we have to find a way to encourage a more sceptical and balanced approach without undermining trust in valued institutions.

Finally, what are the priority issues we'll be grappling with now and into the future? Digital technologies and genomics are already beginning to make a difference to the way we access medical advice and manage our care. Many of these technologies depend on accessing, linking and sharing personal data. Data-driven systems have the potential to improve individual care and build knowledge on better ways to prevent and treat illness, but there are legitimate concerns about privacy and how to safeguard personal information. How can we encourage innovation that benefits people's health while maintaining trustworthiness? I don't know what the right answer is, but I'm sure the best way to find out is to involve patients right from the outset of these developments.

Oxford, UK

Angela Coulter

Contents

- 1 Introduction** 1
Marie-Pascale Pomey, Nathalie Clavel, and Jean-Louis Denis
- 2 From Medical Paternalism to Care Partnerships: A Logical Evolution Over Several Decades** 9
Vincent Dumez and Marie-Pascale Pomey
- 3 The Participation of Patients and Relatives in Quebec's Health System: The Montréal Model** 17
Marie-Pascale Pomey, Vincent Dumez, Antoine Boivin, Ghislaine Rouly, Paule Lebel, Alexandre Berkesse, Annie Descoteaux, Mathieu Jackson, Philippe Karazivan, and Nathalie Clavel
- 4 Implementing Patient and Carer Participation in Self-Care and Co-Care in Sweden: Policy, Practice and the Future of Person-Centred Care** 63
John Øvretveit and Eskil Degsell

5	Patient and Family Engagement in the United States: A Social Movement from Patient to Advocate to Partner	91
	<i>Maureen Maurer, Pam Dardess, and Tara Bristol Rouse</i>	
6	Connections: The Power of Learning Together to Improve Healthcare in the United Kingdom	129
	<i>Rachel Matthews, Stuart Green, Rowan Myron, Catherine French, Susan Barber, Dionne Matthew, Sandra Jayacodi, Jenny Trite, Adrian Brown, Justin Baker, Howard Bluston, Ron Grant, Jean Straus, Richard M Ballerand, Maurice Hoffman, Fran Husson, Laura Fischer, and Cherelle Augustine</i>	
7	Partnering with Patients for Change and Improvement: An Australian Perspective	169
	<i>Jeffrey Braithwaite, Kate Churruca, Leanne Wells, Frances Rapport, Tony Lawson, Paula Arro, and Jo Watson</i>	
8	The Engagement Conundrum of French Users	199
	<i>Véronique Ghadi, Luigi Flora, Pascal Jarno, and Hélyette Lelievre</i>	
9	Expert by Experience: Valuing Patient Engagement in Healthcare	233
	<i>Yann Le Cam and Matthew Bolz-Johnson</i>	
10	Discussion and Conclusion	269
	<i>Marie-Pascale Pomey</i>	
11	Future Directions for Patient Knowledge: A Citizen-Patient Reflection	279
	<i>Carolyn Canfield</i>	
	Index	285

Notes on Contributors

Paula Arro is the consumer and carer participation coordinator—Mental Health, Suicide Prevention, Alcohol and other Drugs (MHAOD) Program at Brisbane North Primary Health Network (PHN). Paula has a lived experience with MHAOD both as a consumer and as a carer. She is employed by the PHN to develop the capacity and support opportunities for people with a lived experience to actively participate in MHAOD reforms. Her role was also established to build the capacity of the PHN to embed lived experience engagement in all aspects of the PHN’s commissioning process, including working with funded services to ensure this occurs. Along with establishing a regional framework for engagement with people with a lived experience and the Peer Participation in Mental Health Services (PPIMS) network, her role has also been expanded to Chair and provide secretariat support to the National PHN Mental Health Lived Experience Engagement Network (MHLEEN). Paula has been an active leader in the development of the Lived Experience Workforce, both in Queensland and Australia. She has been invited to present at a range of state, national and international conferences and forums in relation to strategies for ensuring authentic and “nothing about us without us” engagement. Paula has worked in the social and community services sector for over 30 years across a range of areas including child protection, disability, young people, volunteerism and community development, and has been an active advocate for ensuring social justice

principals are applied to all. She has a BA, a postgraduate diploma in Psychology and Training and Assessment qualifications. Her life and work goal is “to make it better than what it was before”.

Cherelle Augustine is the engagement co-ordinator at Collaboration for Leadership in Applied Health Research and Care, National Institute for Health Research, London, UK. She is a founding member of the Exchange Network and a CLAHRC NWL Improvement Leader Fellow. Diagnosed with sickle cell at six weeks old, Cherelle, at 19, co-founded the charitable organization Broken Silence, with the ambition to gain equality for those living with sickle cell. Broken Silence was founded by young people; it champions young people and targets awareness towards young people. After a decade of campaigning, she hopes to challenge health stereotypes and break the stigma associated with sickle cell disease.

Justin Baker is a volunteer at Central and North West London NHS Foundation Trust, London, UK. He experienced multiple hospital admissions related to alcohol misuse, leading to the removal of his spleen and part of his pancreas in April 2011. He was warned that if he carried on drinking, it would lead to early death. He stayed free from alcohol for just over a year, although he continued to use drugs, mainly cannabis and crack cocaine. He started drinking alcohol again in May 2012. At first, it was restricted to weekends, before, inevitably, it became every day. Justin stopped using crack but carried on using cannabis. In January 2014, Justin attended Addaction services. It was there that he met Sean Hendry. Sean proved a massive influence in supporting people on the road to recovery. Justin was “fast-tracked” to receive a three-month residential rehabilitation, but fell seriously ill and yet again ended up in hospital. His parents were both warned to prepare for the worst. He went straight from hospital to rehabilitation where he completed the full stay and left three months later in 2014. Justin has not touched alcohol since then and continues in recovery contributing his experience to improve care for others with addiction.

Richard M Ballerand is a tri-national policy advisor and managing partner of Axolotl Associates. He is a Public Governor at the Chelsea and Westminster Hospital NHS Foundation Trust, London, UK. With a back-

ground in the financial and defence sectors, Richard has degrees in economics, strategy and psychology. In earlier years, he served as charity trustee (Royal Institution, Royal United Services Institute, Chelsea Society), London University senator and Zoological Society London vice president. He is a lay member of NHS England's London Clinical Senate, National Institute of Health Research (NIHR's) Health Technology Assessment (HTA) prioritization committee and the National Institute for Health and Care Excellence (NICE) Technology Appraisal Committee. A Central Commissioning Facility (CCF) public reviewer and *British Medical Journal* patient reviewer, he also serves on several NHS trust advisory bodies.

Susan Barber is a social scientist with research interests relating to patient and carer engagement and involvement in and co-production of health service improvement, evaluation and the changing roles of services and infrastructure to support patient self-management. She has extensive experience of working for the NHS and in Third Sector organizations on health-related initiatives including policy development, policy analysis, applied research and piloting of innovations, including how to spread good practice and the application of it in new and often complex settings.

Alexandre Berkesse is a management consultant, social responsibility researcher and PhD candidate in philosophy. He has been contributing to the patient partnership cultural and organizational transformation since 2010 through medical education, as project manager of the reform of the MD programme at the Université de Montréal and now as scientific advisor at the Collaboration and Patient Partnership Unit of the Faculty of Medicine. He led the integration of patient partnerships within major healthcare continuous improvement projects in 19 health institutions across Quebec and he has accompanied five Canadian research networks in the elaboration and the implementation of their patient partnership strategies. He also co-teaches with a patient the first masters degree seminar on patient partnership at the University of Montreal, Canada.

Howard Bluston is an independent investment adviser with expertise in Local Authority Pension Funds. He was a city investment manager for nearly forty years and a local councillor for eight years and still chairs and

is a trustee of various charities. Howard is a service user with many interests in improving care and advocating for people with inflammatory bowel disease (IBD). He was integral to a quality improvement project at St Mark's Hospital in London to improve the experience of people using hospital and community services, for example introducing telephone consultation instead of hospital appointments for people in remission with IBD. He is a founder member and Acting Chair of the St Mark's Hospital Patient Panel.

Antoine Boivin, MD, PhD, is a practising family physician and holds the Canada Research Chair on Patient and Public Partnership at CHUM Research Centre, University of Montreal, Montreal, QC, Canada. His research programme focuses on patient and citizen engagement in community health, end-of-life and research. He is the co-director of the Centre of Excellence for Partnership with Patients and the Public and the Strategy for research in partnership with patients and the public for the Quebec SPOR-SUPPORT Unit.

Matthew Bolz-Johnson has worked for EURORDIS since 2014 and has led on advocating for the rare disease community by shaping the development and delivery of European Reference Networks (ERNs). Matt has worked under two Joint Action for Rare Diseases to structure patient involvement in the ERNs and the PACE-ERN consortium that develops technical proposals for the ERN accreditation framework. Prior to joining EURORDIS, Matt worked for 14 years in the National Health Service in England in hospitals and commissioning organizations, specializing in highly specialized healthcare services.

Jeffrey Braithwaite is founding director, Australian Institute of Health Innovation; director, Centre for Healthcare Resilience and Implementation Science; and Professor of Health Systems Research, Faculty of Medicine and Health Sciences, Macquarie University, Australia. His research examines the changing nature of complex health systems, having attracted funding of more than AUD\$111 million. These projects have a strong patient focus, with Jeffrey leading multiple research teams that are reconceptualizing how we engage with consumers and communities in healthcare. He has contributed over 450 peer-reviewed publications including 12 edited books and 69

book chapters, and presented at international and national conferences on more than 930 occasions, including over 90 keynote addresses. His research appears in journals such as *JAMA*, *BMC Medicine*, *The BMJ*, *The Lancet*, *Social Science & Medicine*, *BMJ Quality & Safety*, *Cancer Medicine* and *International Journal for Quality in Health Care*. He has received 45 different national and international awards for his teaching and research, including the prestigious Health Services Research Award by Research Australia (2015).

Adrian Brown is the Alcohol Nurse Specialist, Addiction Services, Central and North West London NHS Foundation Trust, London, UK. He has worked in acute hospital trusts as an alcohol nurse specialist since 1994. At St Mary's Paddington, he was part of the clinical research team which developed the Paddington Alcohol Test. This work fed into national studies on alcohol brief interventions. Since 2014, Adrian has worked with the liaison psychiatry teams at Northwick Park and Central Middlesex, in Harrow and Brent. He provides training for medical and nursing staff, and support for managing complex cases—such as substance use and mental health—and he has begun work with head and neck cancer nurses, to help pre-surgery screening. He has been project lead for the alcohol care bundle supported by NIHR CLAHRC NWL and is now back in the deep end of daily alcohol withdrawal management.

Yann Le Cam was one of the founders of EURORDIS-Rare Diseases Europe in 1997. He has been the organization's Chief Executive Officer since 2001. Yann initiated Rare Diseases International (RDI) in 2009. He is an elected member of the RDI Council and Chair of the RDI Advocacy Committee. He is a founding member of the NGO Committee for Rare Diseases (United Nations, New York), in 2014, and a member of its Executive Committee. Since 2016, Yann Le Cam is a member of the Management Board of the European Medicines Agency (EMA). Recent past positions include: Chair of the Therapies Scientific Committee of the International Rare Diseases Research Consortium (IRDiRC), 2013–2017; Vice Chairman of the EU Committee of Experts on Rare Diseases (EUCERD), 2011–2013; and a member of the Commission Expert Group on Rare Diseases, 2014–2017. He was also one of the first patient representatives appointed to the Committee for Orphan

Medicinal Products (COMP) at the EMA, where he served for nine years and was its elected vice chair for six years. Yann holds an MBA from HEC Paris. He has three daughters, the eldest of whom is living with cystic fibrosis.

Carolyn Canfield works as a citizen-patient across Canada and internationally to expand opportunities for patients, carers and communities to partner with healthcare professionals. Arising from personal tragedy in 2008, Carolyn's full-time volunteering has earned her recognition as Canada's first Patient Safety Champion in 2014, appointment at the University of British Columbia as Adjunct Professor in the Department of Family Practice, and Admissions Subcommittee member with the Faculty of Medicine. She co-founded "Patients In Education" in British Columbia and the Patient Advisors Network to develop capacity and leadership in citizen-patients across Canada.

Kate Churruca is a health services researcher with a PhD in psychology. Her research focuses on the application of complexity science to healthcare and using social-psychological theories to understand organizational culture. She has been involved in projects understanding how mental health professionals collaborate during uncertainty, and men's perceptions of risk in prostate cancer and its impact on their treatment decisions. As part of her doctoral thesis, she previously conducted research with women about their experiences of eating disorders, including their interactions with the healthcare system and the potential benefits of taking a recovery-oriented approach. She uses both quantitative and qualitative research methods, including surveys, social network analysis, observations and interview. Kate is involved in the supervision of multiple Master of Research and PhD students, and is a postdoctoral research fellow at the Centre for Healthcare Resilience and Implementation Science, Australian Institute of Health Innovation at Macquarie University, Australia.

Nathalie Clavel is a PhD candidate in public health, University of Montreal, School of Public Health and Research Centre of the University of Montreal Health Centre (CHUM). She is also a member of the

research chair in Technology Assessment, and Advanced Practices at the CHUM, which centres on Citizen and Patient Engagement in Organizational and Health System Transformation. Since 2013, she has been working on several research projects on patient and family partnership in direct care, continuous quality improvement and patient safety. Her thesis focuses on the practices of healthcare organizations' managers in the implementation of patient and family engagement in quality improvement and direct care.

Angela Coulter is a UK-based health policy analyst and researcher, with special interests in patient and public involvement. A social scientist by training, she has higher degrees in health services research from the University of London and the University of Oxford. Now freelance and still involved in research, her previous roles include Chief Executive of Picker Institute Europe, Director of Policy and Development at the King's Fund, Director of the Health Services Research Unit at the University of Oxford and Director of Global Initiatives at the Informed Medical Decisions Foundation. She is an associate member of the Health Services Research Unit at the University of Oxford, honorary professor at the University of Southern Denmark, an honorary fellow of the Royal College of General Practitioners and a non-executive director of the National Institute for Health and Care Excellence (NICE). Angela has published more than 350 research papers, articles and reports and several books including *The Autonomous Patient*, *The European Patient of the Future* (winner of the 2004 Baxter Award), *The Global Challenge of Healthcare Rationing*, *Hospital Referrals*, *Engaging Patients in Healthcare* and *Understanding and Using Health Experiences*. She was the founding editor of *Health Expectations*, an international peer-reviewed journal on patient and public involvement in healthcare and health policy. She has won awards for her work from the Donabedian Foundation of Barcelona in 2012 and the International Shared Decision Making Conference in 2013.

Pam Dardess is Vice President of Strategic Initiatives and Operations at the Institute for Patient- and Family-Centered Care (IPFCC), where her work focuses on providing training and technical assistance to healthcare

organizations, helping them improve quality, safety and experiences of care through the development of meaningful partnerships with patients and families. Pam is also responsible for strategic planning to develop evidence for and scale up the practice of patient- and family-centred care nationally and internationally. Prior to joining IPFCC, Pam was a principal researcher at the American Institutes for Research (AIR), where her work concentrated on stakeholder engagement; patient-centred measurement; and the development, evaluation, and dissemination of strategies and interventions to promote patient and family engagement (PFE). While at AIR, Pam served as Director for the virtual Center for Patient and Consumer Engagement (AIR CPCE). Pam's contributions to the field include the development of resources to guide the conceptualization and implementation of PFE across multiple settings and stakeholders, including an influential framework for patient and family engagement that has been cited in over 600 articles since its 2013 publication. Pam has also led work to develop and evaluate practical training and educational resources to promote PFE, including the Agency for Healthcare Research and Quality-funded Guide to Patient and Family Engagement in Hospital Quality and Safety—strategies from which have been implemented in hospitals across the United States and internationally. Pam holds an MPH in Maternal and Child Health from the University of North Carolina—Chapel Hill, Gillings School of Global Public Health.

Eskil Degsell is a Patient or Informal caregiver Representative at Malignant Brain Tumour Pathway at Karolinska University Hospital, Department of Quality and Safety at Karolinska University Hospital. He is associated with Regional Cancer Centre Stockholm-Gotland and co-investigator at Co-care research programme at LIME, MMC, AIM at Karolinska Institute.

Jean-Louis Denis is Full Professor of Health Policy and Management at the School of Public Health, Université de Montréal, researcher at the CHUM Research Center (CRCHUM) and holds the Canada research chair (tier I) on health system design and adaptation. He is a visiting professor at the Department of Management, King's College London. His research looks at healthcare reforms and health system transforma-

tion, roles of the medical profession in health systems, professional leadership and clinical governance. In recognition of his academic contribution to the field of health policy and management, he was nominated member of the Academy of Social Sciences of the Royal Society of Canada in 2002 and fellow of the Canadian Academy of Health Sciences in 2009. Recent papers have been published in *Journal of Health Politics, Policy and Law*, *Organization Science*, *Academy of Management Annals*, *Milbank Quarterly*, *Administration and Society*, *Implementation Science* and *Journal of Public Administration Research and Theory*. Since 2016, he has been co-editor of the new Palgrave series of research monographs on healthcare organizing.

Annie Descoteaux learned self-management and the importance of taking part in medical decisions after kidney disease severely hit her newborn daughter. She has developed a specific interest in the skills and expertise that patients develop in living with chronic disease on a daily basis. Annie has a background in Economics and holds a masters degree in Education. She has been a project manager at the Collaborative Partnership and Patient Partnership (DCPP) at the Faculty of Medicine of the University of Montréal since 2014 and a strategic advisor at the Center of Excellence on Patient and Public Partnership. Among other things, she is responsible for managing the expertise of the patient partners who collaborate with the DCPP and the CEPPP.

Vincent Dumez holds a finance degree and a master in science of management from Montreal's international business school, Hautes Études Commerciales (HEC). Up until 2010, Vincent was an associate in one of Montreal's most influential consulting firms, where he acted as a senior strategic consultant. Suffering from severe chronic diseases for more than three decades, Vincent has been actively involved in the development of the "patient partner" concept at Montreal University. This involvement has come forward through the completion of his masters dissertation on the patient—doctor relationship, his contribution to the training of patients, his work on boards of healthcare organizations and his involvement as a speaker at international healthcare conferences. Since 2010, Vincent has founded and developed the patient partnership programme

at the Faculty of Medicine. He now co-leads the Centre of Excellence on Partnership with Patients and the Public with Philippe Karazivan, Antoine Boivin and Marie-Pascale Pomey.

Laura Fischer is an interdisciplinary practitioner who blends scientific methods with creative approaches, and vice versa. She is an artist, activist, researcher, speaker, and author. Her work is woven around mental health, with a particular focus on trauma and the socio-cultural context of violence and abuse. She aims to challenge societal constructs, raise awareness, create space for the voices of trauma survivors and others with lived experience of mental health issues, reframe survivors or ‘patients’ as active leaders of change, and improve our approach to treatment. Her main projects seeks to understand the neuropsychological and neurophysiological underpinnings of trauma and develop a creative body-based practice for the expression and processing of traumatic memories. As a CLAHRC Improvement Leader Fellow (National Institute for Health Research, London, UK), she draws from this work to improve current trauma treatments. Laura is also a consultant on several other projects in healthcare and in research, and she has spoken, exhibited and published internationally.

Luigi Flora is a patient researcher with a PhD in education sciences. A specialist in experiential knowledge resulting from living with disease and the interactions disease generates with health systems and their actors, he is co-author of a summary note published on the subject in 2010 as part of a book coordinated with Emmanuelle Jouet on how the patients’ share of knowledge in the health system. In 2012, as part of his doctoral thesis, he identified the “patient” competency framework that has since been developed with the Patient Partnership Collaboration Department to stabilize the concepts and methodologies of the Montreal model. Collaborating since 2011 with Vincent Dumez, he is the main pedagogical advisor in Quebec to organizations proving the Montreal model, co-initiator of the first university of patients in a medical school in France from 2009 and co-designer of the UniverCité du Soins in Nice, a module of which was awarded by the French Ministry of Higher Education and Research as a pedagogical innovation for lifelong learning in 2018. Luigi is also an associate researcher at the EXPERICE laboratory of the

University of Paris 8/Paris Lumière in the area of lifelong learning and in the RETINES interdisciplinary team at the University of Côte d'Azur, Nice, France.

Catherine French is a health service manager and researcher specializing in developing organizational approaches and capacity building to translate research into practice. Catherine's research background is in social science and her interests include knowledge mobilization, academic healthcare organizations, and qualitative methodology. Catherine was awarded an NIHR Doctoral Research Fellowship to undertake her PhD at UCL (researching boundary spanning processes in Academic Health Science Centres) which she completed in November 2016. Catherine has over 15 years' experience in operational management, programme management, capacity building, and service improvement roles in the NHS across acute care, commissioning, and mental health, including from 2104 to 2018 as Collaborative Learning and Partnerships lead at CLAHRC North West London where she was responsible for developing a quality-improvement, capacity-building programme informed by an action research approach. Since 2018 Catherine has been leading a programme of transformation to integrate clinical care and research across a large university and NHS partnership.

Véronique Ghadi is a sociologist and conducted many research projects on patient engagement and user representation for ten years before joining the Haute Autorité de Santé (HAS) to develop the issue of well-treatment, patient rights and the participation of representatives of users in the certification of health facilities. She is director of the social and medico-social sector of the HAS, aiming to produce recommendations for social and medico-social structures and build the evaluation system of these same structures. Today, Véronique participates in the work of the network "combine our knowledge" to promote the commitment of care-receivers and to accompany the training of professionals.

Ron Grant became passionate about prevention following a massive heart attack and triple bypass and was inspired to give something back. In 2003, he pioneered Lifestyle road shows going into the community to

do blood pressure, BMI and blood cholesterol testing. He is an accredited tutor on the LDX cholesterol testing machine. He became an active member of the Upbeat Heart Prevention & Patient Support Group and is now the CEO, a role for which he was awarded the British Heart Foundation's "Heart Hero" award in 2013. In 2012, he was awarded the West Middlesex University Hospital "Inspirational Volunteers" award as well as Barclay's "Let's Do It" award for community spirit. Ron is a Royal Institute of Public Health-accredited health trainer and regularly holds screening events for cardiovascular diseases and diabetes in the community. Ron has contributed to a number of NIHR CLAHRC NWL projects including the Hounslow Community Atrial Fibrillation Screening project, and is an NIHR CLAHRC NWL Improvement Leader Fellow.

Stuart Green is a public health research fellow at Imperial College London within the NIHR CLAHRC, London, UK. Over the last ten years he has been involved in a range of quality improvement projects in Northwest London, working in a range of specialities from acute medicine, to primary care and mental health. Since 2013, he has been undertaking a part-time Doctor of Public Health course at the London School of Hygiene and Tropical Medicine (LSHTM), which explores the implementation of evidence-based guidelines in clinical services. His research particularly focuses on participatory approaches to engaging clinicians and patients in improving "knowledge to practice". Stuart has published over 25 peer-reviewed papers and contributes to teaching and supervision on the Masters of Public Health at Imperial College London, University of Liverpool and LSHTM.

Maurice Hoffman is a member of the NIHR CLAHRC Northwest London Early Years steering group. Maurice joined the NIHR Imperial Biomedical Research Centre because he believes that through his knowledge of the research process, together with an understanding of service improvement, he can provide valuable input into patient safety research projects. He is a lay member of National Research Ethics Service (NRES) Brent Research Ethics Committee, reviews grant applications for the NIHR and provides input as a patient member of the Imperial Biomedical Research Centre. He is also an independent member of the Statinwise Trial Steering Committee. Within the NHS, he is a lay member of the

Advisory Committee for Clinical Excellence Awards, London North West, patient representative on the NHS Digital E-Referrals Advisory Board and lay partner of Imperial College Healthcare NHS Trust.

Fran Husson is a Patient Adviser at Collaboration for Leadership in Applied Health Research and Care, National Institute for Health Research, London, UK. She has extensive experience in championing the views of patients with a background in journalism. She was instrumental in the development of “My Medication Passport” and has contributed to many initiatives across Imperial College, Imperial College NHS Trust and in the UK. Fran is particularly interested in the ownership, accuracy and access to electronic patient records, digital innovations, health literacy and antimicrobial resistance.

Mathieu Jackson has Haemophilia B moderate. He is vice president of the Canadian Hemophilia Society (CHS). He is also Patient Coordinator of the School of Partnership at the Centre of Excellence on Partnership with Patients and the Public (CEPPP) at the University of Montreal Health Centre (CR-CHUM), where he participates in training patients, caregivers, health professionals and researchers to work together in a partnership healthcare model. Mathieu completed the 2017–2018 International AFFIRM fellowship.

Pascal Jarno is a medical doctor. On the one hand, he coordinates the evaluation unit in the public health department of CHU de Rennes, Rennes, France, and on the other hand, the regional structure supporting quality of care and patient safety in Brittany (CAPPS Bretagne). In this context, since the beginning of the 2000s, he has been developing activities to promote the involvement of patients in the health system at the local, regional and national levels, whether in the field of care, evaluation of practices or organizations, teaching or research.

Sandra Jayacodi is a qualified solicitor, with a law degree from the University of Westminster and a postgraduate diploma from Bournemouth University. Since 2014 Sandra has been involved in the SHINE project at Central and North West London NHS Foundation Trust, which aims to

improve the physical health of people with severe mental illness. Sandra has been involved in the co-design of a patient-held physical healthcare record, with healthcare professionals. She has also contributed to developing the project aims and deliverables, process mapping and designing health education materials. She was awarded a CLAHRC Improvement Leader Fellowship (National Institute for Health Research, London, UK) in 2016. Throughout the project Sandra has demonstrated growing confidence as a presenter and speaker, and has presented amongst others, at the Trust board, to senior members of the NIHR, and taught on the Masters in Public Health at Imperial College London.

Philippe Karazivan is a family physician, a teacher and a researcher at Université de Montréal. He is the co-director of the Office of Collaboration and Patient Partnership (DCPP) within the Faculty of Medicine and co-director of the Center of Excellence on Partnership with Patients and the Public (CEPPP). The DCPP is co-directed by a patient (Vincent Dumez) and a physician (Philippe Karazivan), and it brings patients and their specific expertise into the medical school where they can mobilize their competencies to help students develop theirs. They coordinate over 250 patients who are not only active members of their own healthcare team but are also involved in research and provide valuable training to health science students. Philippe is also the lead author of the first academic paper on the Patient as Partner approach in 2015.

Tony Lawson is Chair of the Consumers Health Forum (CHF) of Australia, elected to this role in 2015 and recently re-elected for a further three years. In total, Tony has been a board director of Consumers Health Forum for 12 years. He is a member of the Minister of Health Advisory Committee on Private Health Insurance and a former member of the Australian Commission on Safety and Quality in Health Care's Australian Atlas of Healthcare Variation Advisory Group. Tony is also a board director of the Australian Council on HealthCare Standards. He has over 30 years' expertise in public policy-making, including the introduction of mutual recognition and the establishment of national health and social programmes (e.g. Home and Community Care Program (HACC)). As a CEO, he has been responsible for multi-million dollar budgets

and significant employees and undertaken large-scale organizational change programmes. As Director of Tony Lawson Consulting, he has undertaken many health policy projects in conjunction with the University of South Australia, Baker IDI Heart and Diabetes Research Institute and SA Medical and Health Research Institute, particularly in Aboriginal and Torres Strait Islander health. Through this work Tony is the co-author of a number of published articles, including “Essential service standards for equitable national cardiovascular care for Aboriginal and Torres Strait Islander people” (Brown et al., 2015) and “A strategy for translating evidence into policy and practice to close the gap - developing essential service standards for Aboriginal and Torres Strait Islander cardiovascular care” (Brown et al., 2015).

Paule Lebel is a specialist in public health and preventive medicine and medical advisor at the Regional Director of Public Health in Montreal (CIUSSS du Centre-Sud-de-l’Île-de-Montréal). She is a Clinical Associate Professor in the Department of Family Medicine and Emergency Medicine (DMFMU) at the Université de Montréal. Since 2018, she has been working to develop and evaluate collaborative practices in partnership with patients, families and communities in the clinical aspects, continuous quality improvement and management of care and services, and partnerships with the public health population.

Hélyette Lelievre is a representative of users at the CHU de Rennes, Rennes, France, and the Beaulieu Centre of medicine and pedagogy in RENNES, administrator of the Maison Associative de la Santé, and member of the “users-professionals” group of the Coordination Group for Improving Practices of Health Professionals in Brittany (CAPPS Bretagne).

Dionne Matthew is the Improvement Science Manager for CLAHRC (National Institute for Health Research, London, UK) NWL’s Breathlessness Theme and currently supports improvements in heart failure and community atrial fibrillation screening services across Northwest London. Her research interests include improvement science, exercise and health promotion, and the use of technology to enhance patient care. Dionne obtained her PhD in cardiovascular health in

November 2013. Her PhD research assessed the benefits of using a mobile application for heart rate variability in patients with heart failure. She holds an MSc in sport and exercise science, along with a Bachelor of Arts in psychology and kinesiology.

Rachel Matthews supports research improvement teams to involve patients and carers across a range of clinical and community settings. She is a registered nurse with clinical experience in cardiorespiratory care. She completed postgraduate studies in Health Education and Health Promotion at King's College London and completed the King's Fund Top Manager Programme in 2014 and NIHR Leaders Programme in 2018. Rachel is a member of the Health Foundation Q Community.

Maureen Maurer is a principal researcher at the American Institutes for Research, where she directs health services research projects focused on patient and family engagement and communicating about medical evidence. In her work to conceptualize and implement patient and family engagement practices, Maureen was a co-author on a framework and roadmap for patient and family engagement, led an environmental scan that catalogued engagement interventions, and has developed strategies and materials to engage patient and families in hospital quality and safety. She is the project director for the Patient-Centred Outcomes Research Translation Center that creates plain language summaries of research findings for the public within a legislatively mandated 90-day time frame. Recently, she led the development and evaluation of an intervention that helped pregnant women more effectively use maternity care quality information. As an experienced qualitative researcher, Maureen designed large-scale qualitative research studies exploring the influence of patient and other stakeholder engagement in research and getting public input into policy decisions about the use of medical evidence in healthcare. Maureen is passionate about working to achieve health equity. She is a founding member of a non-profit, community-based organization that hosts racial equity workshops, trains community organizers and works to confront overt and subtle forms of racism. Previously, Maureen was a Peace Corp volunteer in Mali, West Africa. She holds an MPH in health behaviour and health education from the University of North Carolina at Chapel Hill.

Rowan Myron is a healthcare researcher with expertise in psychology and improvement science. Rowan graduated from Dundee University in 1995 with an MA (Hons) first class in Psychology. She then studied for her PhD at Goldsmiths. Rowan first lectured on Psychology at the University of Hull, and then Rowan moved out of academia to the Mental Health Foundation where she became Associate Head of Research and began working with service user researchers on a range of projects. In 2009, Rowan joined the NIHR CLAHRC NWL programme. Rowan holds a joint role between the University of West London, as Associate Professor for Healthcare Management, and the role of Education Lead at CLAHRC NWL. Rowan leads doctoral, masters and fellowship programmes which aim to build capacity in improvement methodologies. She works with multi-disciplinary front-line clinical staff and patients to improve services and implement evidence-based change.

John Øvretveit is Director of Research and Professor of Health Care Improvement Implementation and Evaluation at the Medical Management Centre, The Karolinska Institute, Stockholm, Sweden. His research examines implementation of management and organization improvements, and clinical care coordination for safety and lower costs. His recent work concerns adaptive implementation and evaluation and combining quality improvement and implementation science. Projects include co-care, integration and coordination of services. His work is based on the belief that organization and management can bring out the best and worst in people, and that the right organization design is critical for effective healthcare. A theme underlying his work is how practical research can contribute both to better care for patients and to “healthy work organization”. John has pioneered action evaluation methods for giving rapid feedback for service providers and policy-makers to improve their services, and for assessing the role of context on implementation. He was awarded the 2014 Avedis Donabedian international quality award for his work on quality economics and has served for 12 years as a board member of the USA joint commission international, and is chair of their healthcare quality and safety standards committee. He is founder and chair of the Quality Improvement Research Network; a board member of the Global Implementation Initiative and chair of the Global Implementation Society. He chairs the

UK selection panel for the future programme of applied collaborative research University—NHS partnerships.

Marie-Pascale Pomey is a public health doctor with a doctorate in public health from the University of Montreal and the University of Paris 7. She is a professor in the Department of Health Management, Evaluation and Policy at the University of Montreal's School of Public Health, and a researcher at the Research Center of the University of Montreal Health Centre (CR-CHUM) in the Crossroads of Innovation and Health Assessment. She is also a medical advisor to the National Institute of Excellence in Health and Social Services (INESSS) where she is responsible for the CoMPAS programme to improve front-line services and integrate patients and families in all the work of INESSS. She has led the International Masters Degree, the DESS diploma and the Quality Management and Care Security programme, QUÉOPS-I, from 2005 to date. Since March 2017, she has led a research chair in Technology Assessment and Advanced Practices at the CHUM. Her research programme, which centres on Citizen and Patient Engagement in Organisational and Health System Transformation, focuses on three areas: (1) the contribution of new e- and m-health technologies that change the relationship between health professionals and patients and the organization of care; (2) assessing the contribution of patient and relative involvement at all levels of the health system (policy, organizational and care); and (3) the development of tools to measure the commitment of patients and their families at all levels of the health system. She is also co-director of the Centre of Excellence on Partnership with Patients and the Public.

Frances Rapport is Professor of Health Implementation Science and Academic Lead MD Research at the Australian Institute of Health Innovation (AIHI), Macquarie University, Australia. She retains an Honorary Professorship in Qualitative Health Research at Swansea University, UK and has visiting professorships in Norway, Bournemouth and Riyadh (previously Harvard and Texas). Before moving to Australia (2015), Frances was Professor of Qualitative Health Research and Founding Director of both the Qualitative Research Unit (QUARU) and

the Qualitative Enquiry Supporting Trials (QUEST) Unit at Swansea University's Medical School. Her research examines the use of Implementation Science in patient-reported determinants of health and wellbeing, hearing loss and listening effort, cancer genomics and melanoma. She has contributed over 340 publications and refereed outputs in journals such as *The Lancet GH*, *The BMJ*, *Clinical Epidemiology*, and *Epilepsy and Behaviour* and is the top-cited Qualitative Health Researcher worldwide. She has won prizes for publication excellence, a Julian Tudor Hart Senior Research Fellowship (2003–2006) and an award from the American Anthropology Association for use of poetic ethnographic methods with survivor testimonials.

Ghislaine Rouly was born with two rare genetic diseases and has been a patient partner for most of her life. She has been accompanying patients in their end of life care for the last 45 years and she is on two committees on Aid in Dying. She is also the primary patient in two research studies at CHUM Research Centre, University of Montreal, Montreal, QC, Canada: “Caregiving Community” and “Compassionate Community”. For the last six years she has taught along with clinicians and medical students, especially on the topic of clinical ethics.

Tara Bristol Rouse is a Patient and Family Engagement (PFE) Project Consultant for the American Hospital Association (AHA), where she supports PFE strategy and provides technical assistance and subject matter expertise to the Health Research & Educational Trust (HRET) Hospital Improvement Innovation Network (HIIN). Inspired by her experience as a patient and caregiver, Tara's work focuses on building partnerships among healthcare professionals, patients and families. In 2006, she became a founding member of the Newborn Critical Care Center Family Advisory Board at NC Children's Hospital, developing Family Faculty and Family Support Programs and integrating family partners into localized quality improvement efforts. Tara is the former director of Patient and Family Partnerships for the Perinatal Quality Collaborative of North Carolina (PQCNC) and has served as a patient family partner on numerous hospital, state and national committees over the past 13 years, including faculty appointments with the Institute for

Healthcare Improvement (IHI), the National Institute for Children's Healthcare Quality (NICHQ) and Patient and Family Centered Care Partners (PFCCpartners). In 2014, Tara's work was recognized by the Caregiver Action Network (CAN) as one of the Nation's top 25 for Best Practices in Patient and Family Engagement. Tara holds an MA in Psychology from Wake Forest University.

Jean Straus is an Improvement Leader Fellow at Collaboration for Leadership in Applied Health Research and Care, National Institute for Health Research, London, UK, who draws on her professional background in education and her experience of sudden hearing loss to raise awareness of this condition in the healthcare system. She promotes the use of visual formats and innovative participatory approaches, for example hackathons, to generate better insight and empathy between people and to foster improvement.

Jenny Tritte is a service improvement project assistant at Central and North West London NHS Foundation Trust. Through this role she has been involved with the SHINE project since 2014, which aims to improve the physical health of people with serious mental illness. She has contributed to the co-design of an innovative patient-held physical health record that supports people with mental illness to take control of their physical health and supported ward nurses to use Plan-Do-Study-Act cycles to share learning. She has presented at national conferences and co-authored a number of reports and academic papers. Prior to this, Jenny worked with the NIHR Mental Health Research Network North London Hub.

Jo Watson is the inaugural deputy chair of the Pharmaceutical Benefits Advisory Committee (PBAC), and has been a consumer nominee on the Committee since 2013. She is the deputy chair of the Consumers Health Forum, the peak national health consumer organization in Australia, and the chair of the Consumer Consultative Committee within the Office of Health Technology Assessment in the Department of Health. Jo has been a community representative and patient advocate for the Australian HIV response since the early 1990s, including as the executive director of the

National Association of People living with HIV Australia (NAPWHA) from 1998 to 2014. She was also the consumer nominee on the Pharmaceutical Benefits Pricing Authority (PBPA) from 2002 to 2012. Her areas of interest include developing model pathways for patient engagement in health technology assessment, public health issues in population health, and capacity building for patient representatives at the national level. She has contributed to health policy reform and analysis in the areas of communicable diseases, the National Medicines Policy and Pharmaceutical Benefits Scheme (PBS) programmes over the past two decades, including contributions to peer-reviewed publications and both national and international research projects.

Leanne Wells is the chief executive officer of the Consumers Health Forum of Australia. She is a health advocate and service executive with over 30 years' experience in health and social policy, programme and service development. Leanne has held executive positions within federal government and in national and state non-government organizations. Leanne is Board Director of Coordinare South East New South Wales' Primary Health Network, the Ozhelp Foundation, PainAustralia and the Australian Pharmacy Council. She is the independent chair of Coordinare's Community Advisory Committee. She has several advisory appointments including the Commonwealth's Primary Health Care Advisory Group, NSW Agency for Clinical Innovation's International Expert Advisory Committee and the Primary Care Committee of the Australian Commission on Safety and Quality in Health Care's Board. Leanne has tertiary qualifications in communications and business. She is a member of both the Australian Institute of Company Directors and the Australian Institute of Management.

Abbreviations

AFD	Association Française des diabétiques (French Association of Diabetics)
AFDET	Association Française de développement et d'éducation thérapeutique (French Association for Therapeutic Education and Development)
AFM	Association française de Myopathie (French Association of Myopathy)
AIDES	Association française de lutte contre le VIH et les hépatites virales
APF	Association Française des Familles (French Association for Families)
ARS	Agence Régionale de Santé (Regional Health Agency)
CAB	Community advisory board
CAPPS	Coordination pour l'Amélioration des Pratiques des Professionnels de Santé en Bretagne (Coordination for Improving Practices of Health Professionals in Brittany)
CISS	Collectif Inter-associatif Sur la Santé (Inter-Associative Health Collective)
CDU	Commission des usagers (Users Commission)
CEG RD	Commission Expert Group on Rare Diseases
CHF	Consumers Health Forum
CLIAS	Comité de Lutte contre les Infections Associées aux Soins (Committee Against Healthcare-Associated Infections)

CLAHRC	Collaborations for Leadership in Applied Health Research and Care
CLAN	Comité de Liaison Alimentation Nutrition (Food-Nutrition Liaison Committee)
CLUD	Comité de Lutte contre la Douleur (Pain Control Committee)
CHMP	Committee for Human Medicinal Products
CRO	Contract research organizations
UD	University Diploma
TEP	Therapeutic Education for Patients
EATG	European Aids Treatment Group
EC	European Commission
EU	European Union
EUCERD	European Union Committee of Experts on Rare Diseases
EURORDIS	European Organisation for Rare Diseases
EMA	European Medicines Agency
ePAGS	European Patient Advisory Groups
ERN	European Reference Networks
ESMO	European Society for Medical Oncology
FDA	Food and Drug Administration
FAS	France Asso Santé
FORAP	Fédération des Organismes Régionaux et territoriaux pour l'Amélioration des Pratiques et organisations en santé (Federation of Regional and Territorial Bodies for the Improvement of Health Practices and Organisations)
GEM	Groupes d'entraide mutuelle (Mutual Help Groups)
GRAM	Groupe de Réflexion Avec les Associations de Malades (Patient Group Think Tank)
HAS	Haute Autorité de Santé (French National Authority for Health)
HTA	Health Technology Assessment
HPHT	Hôpital, Patients, Santé, Territoire (Hospital, Patients, Health, Territory)
INSERM	Institut National de la Santé et de la Recherche Médicale (National Institute of Health and Medical Research)
IPDS	Institut Pour la Démocratie en Santé (Institute for Health Democracy)
JARC	Joint Action Rare Cancers
JARD	Joint Action on Rare Diseases

MDT	Multidisciplinary team
NIH	National Institutes of Health
NIHR	National Institute of Health Research
NGO	Non-Governmental Organizations
OMP	Orphan Medicinal Products
PACE	The Parliamentary Assembly of the Council of Europe
PACE-ERN	Partnership for the Assessment of Clinical Excellence in European Reference Networks
PACTEM	Patients ACTeurs de l'Enseignement en Médecine (Patient ACTors in Medicine Education)
PNSP	Programme National Sécurité Patient - National Programme for Patient Safety
PREPS	Programme de Recherche en Evaluation et Performance en Santé (Research Program on Health Evaluation and Performance)
RD	Research and Development
TRT-5	Traitement Recherche Thérapeutique 5 (Therapeutic Research and Treatment 5)
UNAPEI	Union Nationale des Associations de parents et amis de personnes déficientes intellectuelles (National Association of Groups representing Parents and Friends of People with Intellectual Disabilities Groups)
UN	United Nations
WHO	World Health Organization

List of Figures

Fig. 3.1	Different expert patient types. (Source: Adapted from Flora et al. 2016a)	25
Fig. 3.2	Assessment of DCPD Activities between 2011 and 2017. (Source: Adapted from Dumez and Karazivan, 2018 and DCPD)	44
Fig. 3.3	Patients as trainers in education. (Source: DCPD)	45
Fig. 4.1	The model for co-care and the learning health system	70
Fig. 7.1	Australia's 31 Primary Health Networks. (Source: Adapted from Department of Health (2015a), map taken from https://d-maps.com/carte.php?num_car=25129&lang=en)	179
Fig. 7.2	An eight-stage model of implementing patient and consumer involvement. (Source: Adapted from Sarrami-Foroushani et al. 2014a)	189
Fig. 9.1	EURORDIS' strategy	238

List of Tables

Table 3.1	Patient Selection Criteria	32
Table 4.1	Definitions used in this chapter	83
Table 6.1	4 Pi framework	146