
Contents

Foreword by Vincent Dumez	xiii
Foreword by David Darmon	xv
Introduction	xvii
Luigi FLORA, Corinne GRENIER and Frédéric PONSIGNON	
Part 1. Crossed Perspectives on Experiential Knowledge	1
Introduction to Part 1	3
Corinne GRENIER, Luigi FLORA and Frédéric PONSIGNON	
Chapter 1. User Knowledge, a Key Ingredient for Health Innovation and the Sustainability of our Health Systems	11
Geneviève CYR and Marie-Pascale POMEY	
1.1. Introduction	11
1.2. Innovation	12
1.2.1. Linear innovation model	12
1.2.2. Contemporary vision	13
1.3. Towards open innovation	13
1.4. Health innovation	15
1.5. Responsible health innovation	15
1.6. Participation of patient-caregivers and citizens in innovation	18
1.6.1. Level of participation	19
1.7. Open innovation practices to bring patient-caregivers and citizens to contribute to innovations	20
1.7.1. Hackathon	20
1.7.2. Living Labs	21

1.8. Conclusion	23
1.9. References	23
Chapter 2. The Experience of Caregivers in Supporting People with Neurodegenerative Diseases	27
Anaïs CHENEAU and Valérie FARGEON	
2.1. Introduction	27
2.2. Theoretical framework	29
2.3. Data and method	32
2.4. Results	33
2.4.1. The components of care and the meaning of involvement	33
2.4.2. The dynamics of the involvement of informal caregivers and their challenges.	35
2.5. Conclusion	41
2.6. References	42
Chapter 3. The Experiential Approach and Alzheimer's Disease: Including the Spiritual Dimension for a More Global Approach	45
Ruth Laure ALAMARGUY and Pauline LENESLEY	
3.1. Introduction	45
3.2. Alzheimer's disease: loss or search for meaning?	46
3.2.1. At the macrosociological level: Alzheimer's disease, a predicted loss of meaning.	47
3.2.2. At the microsociological level: sick people in search of meaning	50
3.2.3. And the spiritual in all this?	52
3.3. Obstacles to taking the spiritual dimension into account in support.	54
3.3.1. Institutional side: the biomedical approach, a reductive filter.	55
3.3.2. The caring aspect: the relationship to spirituality guides the approach of the "patient"	56
3.4. Perspectives: ways to approach the overall lived experience	58
3.4.1. Raising awareness among professionals about their relationship to the spiritual and intimate	58
3.4.2. Initiating collective reflection	58
3.5. Conclusion	59
3.6. References	60
Chapter 4. Rethinking the Organization of SDCCs in Light of the Experience of Volunteers in a State of Great Social Precariousness	65
Corinne GRENIER	
4.1. Introduction	65
4.2. Theoretical framework: social regulation and experiential knowledge	68
4.2.1. Regulation work.	68

4.2.2. Experiential knowledge	69
4.3. A situation to transform: the Boutique Solidarité de Marseille (BSM) of the Abbé Pierre Foundation	71
4.3.1. Presentation of the BSM	71
4.3.2. 2017: a problematic situation calling for work on the organization of the BSM	73
4.4. The intervention-research (IR) approach	75
4.5. The transformation of the BSM: the establishment of the Mutual Agreement Contract (MAC) as a regulation tool	76
4.5.1. The MAC	77
4.5.2. The general operation of the Boutique	78
4.5.3. The experiential knowledge of volunteers	78
4.6. Analysis of the transformation: more balanced regulations	79
4.6.1. A weak but enriched control regulation	80
4.6.2. Autonomous regulation justified	81
4.6.3. A peaceful but “floating” joint regulation	82
4.7. Conclusion	83
4.8. Appendix	84
4.9. References	86
Chapter 5. Professional, Team and Digital Identity: The Impact on Patient Experience	89
Stephanie BEST, Ann DADICH and Sharon WILLIAMS	
5.1. Introduction	89
5.1.1. Why is identity relevant to health and social care practitioners?	89
5.1.2. How does identity relate to patient experience?	90
5.1.3. Why measure patient experience?	90
5.1.4. What is the aim of this chapter?	91
5.2. Conceptual background	91
5.2.1. Health and social care professionals’ identity	91
5.2.2. Patient experience.	92
5.3. Patient experience and health and social care professionals’ identity	93
5.3.1. Professional identity	95
5.3.2. Team identity	97
5.3.3. Digital identity	97
5.3.4. Lexical analysis	97
5.4. Implications	100
5.4.1. For researchers	100
5.4.2. For health and social care professionals and service managers	100
5.4.3. For patients and carers	101
5.5. Conclusions	101
5.6. References	102

Chapter 6. Mobilizing the Experience of People with Disabilities: A Necessity in the Transfer of Innovations	107
Éléonore SÉGARD and Philippe CHERVIN	
6.1. Introduction	107
6.2. The transfer of innovations to accelerate the transformation of services: a new approach.	109
6.3. People's experience at the heart of the development of ground innovations in the field of disability.	112
6.4. Taking into account the experience of people with disabilities in the transfer process	112
6.4.1. Evaluation	112
6.4.2. Capitalization	115
6.4.3. Transferability.	115
6.5. Implementation	116
6.6. Conclusion	117
6.7. References	118
Part 2. Crossed Perspectives on the Impacts on Organizations and Health Systems	121
Introduction to Part 2	123
Corinne GRENIER, Luigi FLORA and Frédéric PONSIGNON	
Chapter 7. Reorienting Our Health System towards its Users Thanks to Design Thinking: The Experience of Kaiser Permanente	131
Inès GRAVEY	
7.1. Introduction	131
7.2. A lever for rebalancing powers between users and traditional experts	136
7.2.1. The power of empathy: from traditional experts to users in order to identify needs	136
7.2.2. The power of ideation: from managers to users in order to imagine solutions	137
7.2.3. The power of prototyping and testing: from the theoretical to empirical in bringing solutions to life	139
7.3. A lever for cultural transformation in the dual bureaucratic and health context	140
7.4. Obstacles and facilitators to integration	142
7.5. Discussion	143
7.6. Appendix: methodology.	144
7.7. References	146

Chapter 8. Patient-Centered Care at Public Hospitals: A War of the Worlds?	149
Marie-Eve LAPORTE, Patrick GILBERT and Karim ZINAI	
8.1. Introduction	149
8.2. Patient-centered care	150
8.2.1. Definition of patient-centered care	150
8.2.2. An international enthusiasm for patient-centered care.	150
8.2.3. A counter-nature approach for the French public hospital.	151
8.3. The theory of economies of worth – a key for understanding tensions	152
8.4. Study of the orthopedics department of a Parisian hospital	153
8.4.1. War of the worlds.	154
8.4.2. Responses segmented by patient profile	155
8.4.3. The debrief room, a place for conciliation and the establishment of arrangements	158
8.5. Conclusion	159
8.6. References	159
 Chapter 9. A Brief History of Changes in the Medico-Social Sector over Recent Decades. Interview with Marielle Ravot.	163
Luigi FLORA and Marielle RAVOT	
9.1. Introduction	163
9.2. Interview	164
9.3. The experience.	165
9.3.1. In terms of human resources	168
9.3.2. Concerning the reform of EHPAD pricing	169
9.3.3. About the implementation of a quality approach within EHPAD.	169
9.4. Appendix: list of acronyms	180
9.5. References	182
 Chapter 10. EPoP: An Approach to Developing Peer Intervention.	183
Sabrina SINIGAGLIA	
10.1. Introduction.	183
10.2. The EPoP approach: a necessary framework for action.	189
10.3. The choice of a territorial approach.	192
10.4. The stabilization of a new function, peer-intervener and of a new mission, peer intervention representatives	199
10.5. Presentation of a panel of peer-intervener projects supported by EPoP	201
10.5.1. Presentation of Mr. B's project.	201
10.5.2. Presentation of Mr. A's project.	202
10.5.3. Presentation of Mrs. S's project	203
10.5.4. Presentation of Mr. J's project	204

10.5.5. Presentation of Mr. JB's project	205
10.5.6. Presentation of Mrs. D's project	206
10.6. Conclusion	207
10.7. References	208
Chapter 11. The Potential for Digital Health to Reframe the Role of Compassion in Patient Experience Innovation	211
Lester LEVY, Ann DADICH and Kevin LOWE	
11.1. Introduction	211
11.2. Definitions	213
11.2.1. Compassion	213
11.2.2. Digital health.	214
11.3. Compassion in digital health	214
11.4. Deconstructing patient experience	216
11.4.1. Patient one	216
11.4.2. Patient two	217
11.4.3. Patient three	218
11.5. Blending digital health with the human touch for positive patient experiences	219
11.6. Conclusion	220
11.7. References	221
Chapter 12. Help with Prescribing Mobile Health Applications: A Partnership Design	227
Luigi FLORA, David DARMON, Stephen DARMONI, Julien GROSJEAN, Christian SIMON, Parina HASSANALY and Jean-Charles DUFOUR	
12.1. Introduction	227
12.2. ApiAppS research, a response adapted to the times?	230
12.3. Design carried out with the participation of citizens	231
12.4. Categorization choices and their development during this research	232
12.5. A dynamic mobilizing cross-perspectives between patients and doctors	233
12.6. Conclusion	235
12.7. References	236
Chapter 13. Beyond the Testimony: Patient Partners and Ongoing Education Program	239
Yves COUTURIER, Marie-Eve POITRAS, Marie-Dominique POIRIER and Anaëlle MORIN	
13.1. Introduction	239
13.2. Train-the-trainer program an effective strategy for professional development in primary care.	239

13.3. Innovation in the train-the-trainer approach through increased patient participation.	241
13.4. Study context	242
13.5. Theoretical framework.	243
13.6. Intervention	245
13.7. Methodology	246
13.8. Results.	246
13.9. Favorable conditions for full recognition of trainer status for patients in the context of ongoing training	247
13.10. An enrichment proposal for the Montreal model.	248
13.11. Conclusion.	250
13.12. References.	250
Chapter 14. The Care Partnership: Challenges and Perspectives for Healthcare Systems	253
Philippe ANHORN	
14.1. Introduction.	253
14.2. Context and definitions	254
14.2.1. The Réseau Santé Région Lausanne (RSRL)	254
14.2.2. The care partnership.	255
14.2.3. The anticipated care plan (ProSA)	257
14.3. Theoretical foundations of the research	259
14.4. Methodology	260
14.5. Main research results.	260
14.5.1. The importance of the care partnership	260
14.5.2. The need for an action plan.	261
14.5.3. On the need to remove or alleviate structural obstacles	262
14.5.4. The opportunity to act in a favorable temporal context	263
14.6. Conclusion	264
14.6.1. Conclusion and managerial recommendations	265
14.7. References	268
List of Authors	271
Index.	275