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Titolo	Challenging Assumptions Around Dementia : User-led Research and Untold Stories // by Rosalie Ashworth, Sue Fyvel, Alyson Hill, Chris Maddocks, Masood Qureshi, David Ross, Stuart Hay, Martin Robertson, Willy Gilder, Winnie Henry, Myra Lamont, Agnes Houston, Fred S. Wilson
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Altri autori (Persone)	FyvelSue HillAlyson MaddocksChris QureshiMasood RossDavid HayStuart RobertsonMartin GilderWilly HenryWinnie
Disciplina	616.83
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Monografia

Nota di contenuto

1. Coproducing a book on dementia research -- 2. Taking part in Alzheimer's disease research -- 3. Taking part in Vascular dementia research -- 4. Taking part in Fronto-Temporal dementia research -- 5. Taking part in Parkinson's dementia research -- 6. Taking part in dementia with lewy bodies research -- 7. Taking part in PCA dementia research -- 8. Lessons for future research in dementia.

Sommario/riassunto

This open access book explores the expectations surrounding dementia, what it 'looks like' and how people have been treated by others. It aims to raise awareness of the different types of dementia, and how they impact the brain, body, and lived experience, including experience of Alzheimer's disease, Vascular Dementia, Posterior Cortical Atrophy, Frontotemporal Dementia, Semantic Dementia, and Lewy Body Dementia. The co-authors reflect on their experience with informal and formal care, before finishing with a focus on the spectrum of dementia research from clinical trials to user-led research. Throughout the book, co-authors have shared personal stories of how dementia has affected them and people with lived experience of dementia share what they wish people knew about living with the disease. Co-produced by people with lived experience of dementia, academics and health care professionals, this book is an accessible resource about dementia from the perspective of people actively involved in the field and essential reading for healthcare professionals wishing to learn more about the experience of this neuroprogressive condition, as well as policymakers, and members of the public. Dr Rosie Ashworth leads Partners in Research for NRS Neuroprogressive and Dementia Network, UK. As a research psychologist, Rosie is passionate about co-production, ethics, and actively involving people with lived experience in research. She is also the co-lead for ENRICH Scotlands 'Patient and Public Involvement' group RICH (Research in Care Homes) Voices, a Fellow with Advanced Higher Education, an advisor to the Dementia Enquirers, and a volunteer for About Dementia. Partners in Research co-authors including Agnes Houston, Chris Maddocks, David Ross, Fred S. Wilson, Masood Qureshi, Martin Robertson, Myra Lamont, Stuart Hay, Sue Fyvel, Willy Gilder, Winnie Henry, and Alyson Hill.