Identifying priority outcomes and understanding meaningful delay in disease progression for Alzheimer’s disease across the spectrum

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Facts & Figures

Start date 01/11/2016
End date 31/10/2018
Contributions
IMI funding 3,998,250 €
EFPIA in kind 4,210,843 €
Other 1,288 €
Total Cost 8,210,381 €

Project website roadmap-alzheimer.org
Social media @IMI2_ROADMAP

Challenge

With an ageing population and rising costs, effective treatment for dementia, with Alzheimer’s disease (AD) as its leading cause, is urgently required. Intervention trials may not be using the most stakeholder-relevant endpoints to improve outcomes. Eliciting multiple stakeholder perspectives on outcomes that matter the most and use of relevant outcomes derived from real-world data could change this.

Approach & Methodology

ROADMAP Work Package 2’s aims:

• to obtain a consensus on real-world priority outcomes relevant to people with dementia (PWD), carers, and professionals
• to establish understanding of meaningful delay in disease progression

Activities conducted to fulfil these aims included:

Value of IMI collaboration

Unified by a common goal, this public-private partnership enabled us to streamline efforts through increasing consensus and synergistic collaboration.

Results

Thirty four articles were synthesised in the SLR. The European Working Group of People With Dementia, their carers and 13 professionals engaged in PPI consultations. A total of 390 survey responses were analysed. Nine outcome domains emerged, reflecting clinical, social and practical aspects of dementia (Figure 1).

Differences across the disease spectrum

Surveyed professionals were also asked to highlight the importance of a series of outcome domains for mild cognitive impairment, mild dementia and moderate-severe dementia (Figure 2).

Meaningful delay in disease progression

Rationales for outcomes prioritisation should be understood. Although experiences may be broadly similar, each patient journey is different; delay in particular symptoms or experiences and retention of particular abilities are meaningful to individuals.

Impact & take home message

Outcomes we have identified as priority (cognition, functional ability and independence, PWD and carer quality of life, neuropsychiatric symptoms) should be further investigated in RWD sources to better understand their value for incorporation into intervention trials and cohort studies.