10 YEARS OF BREAKTHROUGHS
A HEALTHIER FUTURE

ROADMAP
Real world Outcomes across the AD spectrum for better care

THE UNIVERSITY OF EDINBURGH

Roche

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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).

Priority outcomes

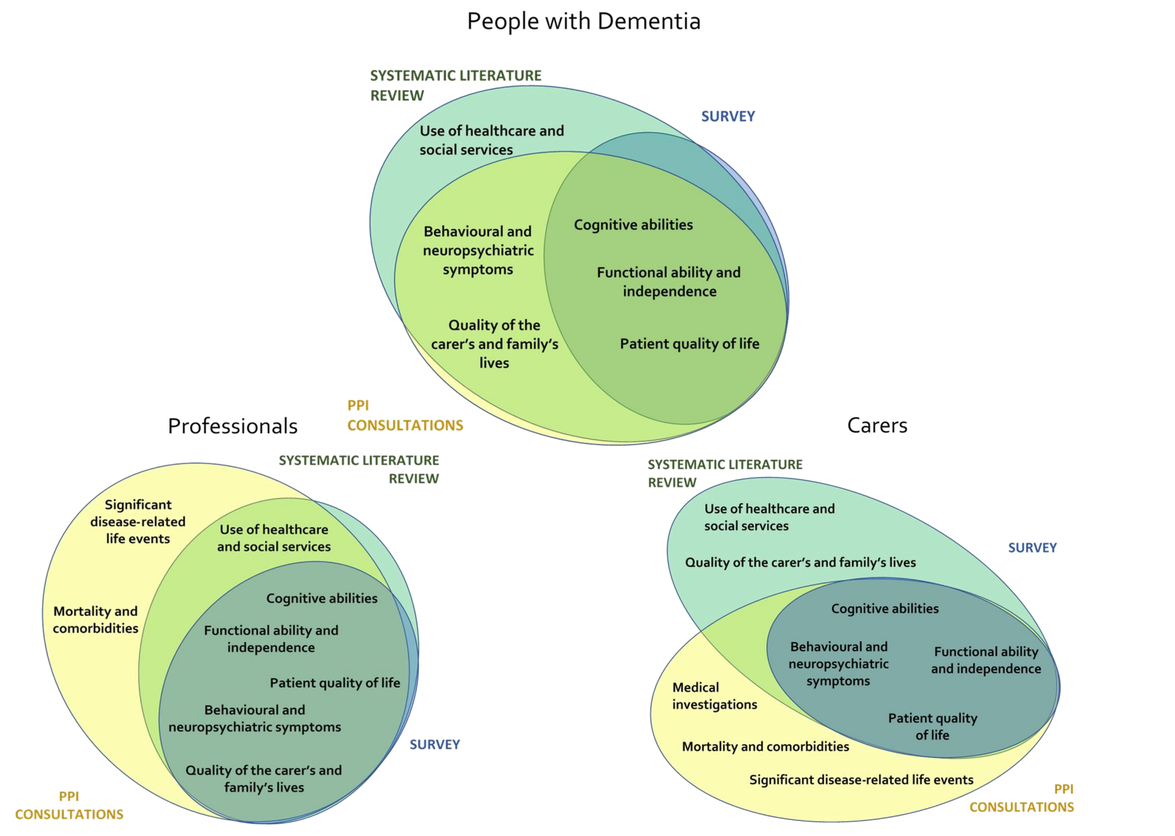
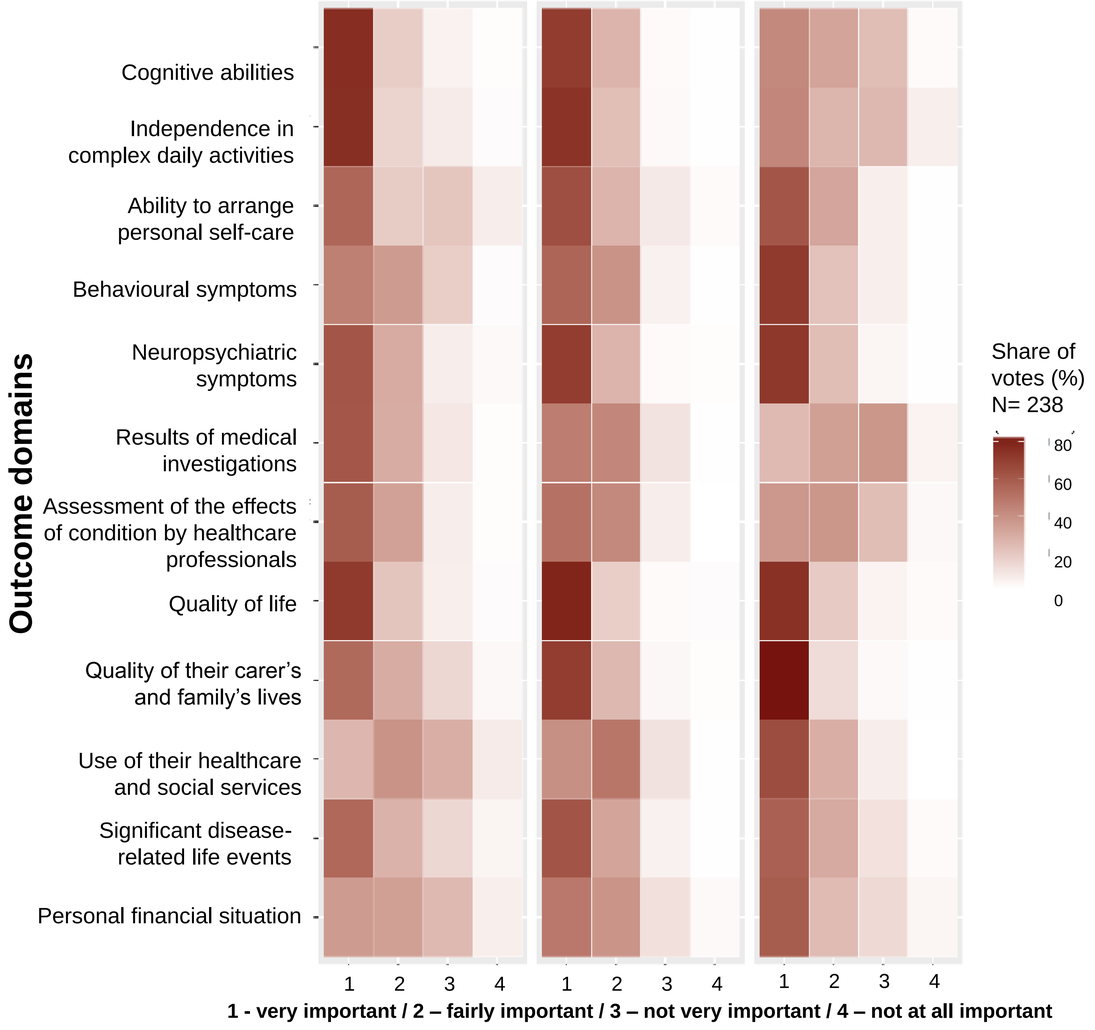


Figure 1: Overlapping priority outcomes for people with dementia, carers and professionals, and the work streams in which the outcomes emerged

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).



1 - very important / 2 – fairly important / 3 – not very important / 4 – not at all important

MCI – Mild Cognitive Impairment / MD - Mild dementia / Moderate to severe dementia

Figure 2: Importance of each outcome domain at different disease severity stages, from the perspective of professionals

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.

imi innovative medicines initiative
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