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Perspective

Taking stock: A multistakeholder perspective on improving the delivery of care and the development of treatments for Alzheimer's disease

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Abstract Health-care stakeholders increasingly recognize that the scientific and economic challenges associated with Alzheimer's disease (AD) are simply too great for individual stakeholder groups to address solely from within their own silos. In the necessary spirit of collaboration, we present in this perspective a set of multicountry multistakeholder recommendations to improve the organization of existing AD and dementia care and the development of new treatments. In brief, the five recommendations are (1) health-care systems must make choices regarding the patient populations to be diagnosed and treated, (2) health-care systems should use an evidence-based standard of care, (3) increased collaboration between public and private institutions is needed to enhance research, (4)

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reimbursement end points need to be agreed on and validated, and (5) innovative business models should be used to spur the introduction of new medicines.

Keywords: Multistakeholder; Alzheimer's disease; Collaboration; Biomarker; Diagnosis; Care standard; Reimbursement; Innovation; Clinical development; Payer

1. Introduction

Alzheimer's disease (AD), the most common form of dementia, creates a vast social and economic burden on society and takes a heavy emotional toll on patients, caregivers, and families [1]. With the prevalence of dementia expected to exceed 115 million worldwide by 2050, it is noteworthy that relatively little progress has been made in developing and introducing medicines that may slow or halt the progression of AD or in establishing integrated systems to manage patient care [2]. Additionally, before 2007, the diagnostic guidelines for AD dementia had remained unchanged for 23 years [3]. Recent scientific advances have driven the advancement of new clinical diagnostic criteria for AD dementia and mild cognitive impairment (MCI) due to AD, together with a research agenda for preclinical AD [4–8]. These diagnostic criteria should yield a more accurate assessment of AD prevalence and increase our understanding of its etiology, pathophysiology, and progression.

In 2012, the Alzheimer's Disease Working Group (ADWG) was assembled as a multicountry multistakeholder forum for public- and private-sector stakeholders to address the challenges of AD and identify potential solutions that could benefit European health systems [9]. Over the course of three in-person meetings and numerous group teleconferences, the ADWG integrated international perspectives across the varied elements of health and social care that touch AD patients and their carers. ADWG participants and guests included general practitioners, clinical specialists, patient/policy advocates, medicine and diagnostic developers, health economists, social care representatives, regulators, health technology assessors (HTAs), and payers. All participants acknowledged that the scientific and economic challenges associated with AD are simply too great for stakeholders to address solely from within their own silos.

The ADWG was assembled and independently led by Tapestry Networks and was financially underwritten by Bristol-Myers Squibb, GE Healthcare, and Johnson & Johnson. Tapestry Networks endeavored to include as many competing stakeholder viewpoints as possible in the ADWG while maintaining an intimate size (∼20–25 participants) to foster engaged discussion and active development of new approaches. The ADWG had continuous engagement from the same participants throughout the yearlong multimeeting process. Stakeholder representation was balanced to ensure strong public-sector presence and cross-sector expertise including: 6 to 8 regulators, HTAs, and payers; 6 to 8 subject matter experts; 2 to 3 patient and policy advocates; and 5 to 6 industry representatives. Nonindustry participants or their institutions received an honorarium and/or were reimbursed by Tapestry Networks for travel expenses to the extent it was in accordance with the mandates of the participant's institution and not incompatible with national laws or professional bodies of which the participant was a member.

All ADWG participants co-shaped the agenda and had an equal voice in the discussion. The focus was generally on European countries' health-care challenges in AD with the acknowledgment that the science and challenges in AD were global. Given the size parameters, the ADWG did have limitations. For example, the ADWG did not have direct patient participation. Instead, to integrate the broad consortia of advocacy across AD and ensure strong technical knowledge, the ADWG had representation from Alzheimer's Disease International and the Alzheimer's Society in the United Kingdom. Guest speakers were brought in to challenge viewpoints or balance overrepresented viewpoints. ADWG meeting summaries with full lists of participants and guests are freely available via Tapestry Networks' Web site.

In this perspective, we present a set of recommendations that highlight key consensus areas and gaps that need to be bridged across stakeholder groups to make progress in the fight against AD. The recommendations are an attempt to faithfully capture and summarize the ADWG's discussions, and the vast majority of ADWG participants have contributed to the authorship of this article. All participants, regardless of authorship, had an opportunity to comment, and all views were integrated. However, because a small number of participants chose not to author or were precluded by their organizational mandates, we note that the recommendations are those of the individual coauthors and not the entire ADWG. Most importantly, the authorship group accurately reflects the broad range of stakeholder views expressed within the ADWG meetings.

The following recommendations together encompass the view that stakeholders must work together to improve the organization and delivery of existing treatments and simultaneously create a more receptive environment for the development and use of future medicines Table 1.