Fiona Carragher – Chief Policy & Research Officer, Alzheimer’s Society

Dementia is not just a medical challenge; it is a societal issue that demands bold, united action and innovative solutions

07.01.2025

Tags: United Kingdom, Alzheimer's Society, Alzheimer's, Charity

Fiona Carragher, Chief Policy and Research Officer at Alzheimer’s Society, delves into the organization’s mission to transform dementia care through innovation, advocacy, and global collaboration. Carragher addresses critical challenges, including delayed diagnoses, gaps in social care, and the need for inclusivity in clinical trials, while emphasizing the role of technology and training in driving change.

What inspired your transition into Alzheimer’s research and your role at Alzheimer’s Society?

My journey in health and life sciences spans over three decades, with 25 years devoted to the National Health Service (NHS). Starting as a clinical biochemist, I progressed to senior leadership roles, ultimately serving as Deputy Chief Scientific Officer for NHS England. This position encompassed professional oversight of 50,000 scientists and engineers, many working in diagnostics—my area of expertise—and a strategic focus on advancing policy and innovation within health and life sciences.

Throughout my career, I have been privileged to witness transformative developments in medicine. As a Fellow of the Royal College of Pathologists and a visiting professor at Ulster University, my work has intersected with groundbreaking advancements in whole genome sequencing,

metabolomics, and early disease detection, including newborn screening. Yet, amid this wave of scientific progress across fields like cancer and antimicrobial resistance, I was struck by the stagnation in Alzheimer's and neurodegenerative research. Despite the potential for groundbreaking discoveries, tangible advancements in this area remained scarce.

On a personal note, Alzheimer's and dementia have significantly impacted my family, adding profound meaning to this work. When the opportunity arose in 2019 to join Alzheimer's Society as Chief Policy and Research Officer, it felt like the perfect convergence of my professional expertise and personal passion. This role allows me to harness the best of scientific innovation, shape impactful policies, and contribute to a field on the brink of transformative change. Over the past five years, I have been deeply committed to advancing research and driving meaningful outcomes, combining my background in diagnostics and policy with the Society's mission to improve lives and foster breakthroughs.

What is Alzheimer's Society, and how does it contribute to addressing dementia?

Alzheimer's Society is the UK's largest dementia charity, offering a comprehensive approach that combines support, advocacy, and research. With nearly 900 advisors embedded in communities, it provides tailored guidance to families, helping them navigate the complexities of dementia and avoid crises. This hands-on support is complemented by its role as a trusted advocate, shaping evidence-based policies and driving systemic change in collaboration with the government.

A cornerstone of its mission is funding research to advance understanding and treatment of dementia. Last year, the Society allocated nearly £24 million to research initiatives, often partnering with other organizations to enhance reach and impact. Its approach is grounded in the lived experiences of those it serves, ensuring its efforts align with real-world challenges and priorities.

The organization's influence extends through millions of interactions on its helpline and website, alongside direct assistance to hundreds of thousands of families. This deep engagement reinforces its authority as a trusted source of information and strengthens its advocacy at the national level. Dementia, as a complex group of diseases affecting the brain, poses significant challenges not only to individuals but also to systems and communities. Alzheimer's Society is uniquely positioned to bridge these challenges, integrating its expertise in support, policy, and research to deliver meaningful progress across all fronts.

What advancements in Alzheimer's research over the past five years bring hope, and how does the landscape in 2024 differ from 2019?

Over the past five years, Alzheimer's research has witnessed transformative progress, fostering a sense of genuine optimism. Three key developments stand out. Firstly, our understanding of the disease has significantly advanced, bolstered by substantial investments in discovery science. Alzheimer's Society played a foundational role in establishing the UK Dementia Research Institute (UK DRI), which has become a centrepiece for groundbreaking research. While there remains much to achieve, the growing commitment to this field is unmistakable.

Secondly, biomarkers—particularly blood-based —have emerged as a game changer. These tools now enable precise identification, stratification, and outcome measurement in clinical trials, paving the way for more targeted and effective treatments. Beyond trials, biomarkers hold the promise of revolutionizing clinical practice, though integrating them into healthcare systems presents its own complexities.

Thirdly, the approval of two drugs in the UK—lecanemab and donanemab—by the Medicines and Healthcare products Regulatory Agency (MHRA) represents a pivotal moment. These treatments signify a shift from theoretical possibilities to tangible solutions, offering the potential to slow disease progression. With over 120 drugs currently in clinical trials worldwide, the trajectory of Alzheimer's research is more promising than ever.

Together, these advancements signal a profound change in the Alzheimer's landscape. From foundational science to practical therapies, the progress achieved since 2019 underscores a future where meaningful improvements in diagnosis, treatment, and patient outcomes are becoming increasingly attainable.

What challenges surround the accessibility of new Alzheimer's drugs in the UK, and how must the healthcare system evolve to meet future needs?

The approval of lecanemab and donanemab marks a significant milestone in Alzheimer's treatment, signaling the arrival of therapies that can slow disease progression and remove amyloid. However, NICE (National Institute for Health and Care Excellence) has not yet endorsed these drugs for use on the NHS, citing concerns about cost-effectiveness. There remains, however, an urgent need for the healthcare system to prepare for the next wave of advancements.

A central challenge lies in the diagnostic pathway, which is critical for both current care and the adoption of new therapies. On average, people live with dementia for 3.5 years before getting a diagnosis. Even then, only about 65% of those affected are diagnosed, and many of these diagnoses are either late or inaccurate. This leaves a third of individuals undiagnosed and unable to access appropriate care or emerging treatments.

Compounding this issue is the limited implementation of advanced diagnostic tools, such as PET-CT scans and cerebrospinal fluid testing, for distinguishing between Alzheimer's and other forms of dementia. These tools are pivotal for identifying eligible patients and ensuring the effective use of new therapies. Addressing these gaps requires a systemic transformation to prioritize early and accurate diagnosis. Without this shift, the potential of new treatments will remain unrealized, and individuals living with dementia will continue to face barriers to receiving timely and effective care.

How could blood biomarkers revolutionize Alzheimer's diagnosis, and what considerations are critical for their implementation?

Blood biomarkers hold immense promise for transforming Alzheimer's diagnosis, providing a less invasive and more accessible alternative to traditional diagnostic methods such as cerebrospinal fluid testing. However, these biomarkers are not standalone solutions; their effectiveness depends on integration into a broader diagnostic framework that includes clinical evaluations, family history, and complementary tests. While they have demonstrated significant potential in clinical trials, their real-world application introduces complex challenges that must be addressed to ensure their successful implementation.

To accelerate this transition, Alzheimer's Society, together with Alzheimer's Research UK and NIHR, has launched the £9 million Blood Biomarker Challenge, raised by players of People's Postcode Lottery This initiative aims to move biomarkers from clinical trials to practical use within the NHS. Two major centres in Oxford and London, supported by UK-wide networks, are leading large-scale studies involving thousands of patients. These efforts focus on building robust evidence to demonstrate the biomarkers' clinical efficacy, safety, and economic viability, providing a foundation for decisions by the MHRA, NICE and other healthcare policymakers.

A key aspect of this program involves determining where these biomarkers fit best within the diagnostic pathway. One potential approach is their integration into primary care settings, where general practitioners could use them as part of routine assessments for patients with memory concerns. This could enable earlier referrals for advanced imaging, such as PET-CT scans, and

ensure timely access to specialist evaluations. Alternatively, these tests may prove more effective when used directly within specialist clinics. Ongoing evaluations are exploring these scenarios to identify the most effective and efficient use of biomarkers in clinical practice.

The progress made in blood biomarker research marks a pivotal shift from discovery to application, with tools that are well-tested in clinical trials now nearing readiness for broader use. While challenges remain in scaling and integrating these innovations into healthcare systems, the advancements over the past five years suggest that their widespread adoption is within reach, offering the potential to significantly improve early and accurate diagnosis for Alzheimer's patients.

What makes the UK a key player in Alzheimer's clinical trials, and how is it addressing challenges to ensure broader participation?

The UK has established itself as a significant global contributor to Alzheimer's clinical trials, supported by a uniquely integrated life sciences ecosystem. During the COVID-19 pandemic, the collaboration between world-leading universities, the NHS, and the life sciences industry demonstrated the country's ability to drive transformative advancements. The UK's single-payer healthcare system provides a cohesive framework for large-scale research, and ongoing governmental investments reinforce its role as a leader in pioneering clinical innovations.

Despite these strengths, challenges remain, particularly in achieving diverse participation in clinical trials. Historically, these studies have often included a narrower demographic—predominantly white, affluent, and male participants—not by deliberate exclusion, but due to systemic barriers. Limited diagnosis rates exacerbate the issue, with a third of people with Alzheimer's in the UK remaining undiagnosed and many receiving diagnoses too late. This lack of early identification reduces the pool of potential trial participants, particularly from underrepresented communities.

To tackle these challenges, Alzheimer's Society has introduced a groundbreaking program focused on dementia research nurses. This pilot initiative, the first of its kind in the UK, is dedicated to increasing trial accessibility and representation. These nurses work directly with patients to recruit participants from diverse backgrounds, improve their trial experience, and ensure equitable inclusion. By addressing these critical barriers, the program strengthens the UK's ability to deliver meaningful breakthroughs that benefit all communities. Combined with continued investment in the clinical trials infrastructure, these efforts underscore the UK's commitment to advancing Alzheimer's research. By fostering diversity and inclusivity, the UK is not only enhancing its leadership in global trials but also ensuring that the outcomes are relevant and impactful for a

broader spectrum of patients.

How does the UK’s position outside the European Union influence its approach to Alzheimer’s, and why is global collaboration essential in addressing this growing challenge?

Alzheimer’s and dementia are global health crises of unprecedented scale, often described as a slow tsunami due to their far-reaching societal and economic impact. In the UK alone, dementia costs society £42 billion annually—a figure expected to rise to £90 billion by 2040. This challenge cannot be addressed in isolation; it requires a globally coordinated effort to share knowledge, data, and solutions.

The UK remains an active and integral participant in international collaborations. Organizations like Alzheimer’s Disease International (ADI), and the World Dementia Council (WDC) exemplify the kind of partnerships that are vital to tackling this issue. These relationships allow for cross-border scientific advancements and the exchange of best practices, ensuring that progress is not confined to individual nations but benefits the global community. Science must transcend geographical boundaries to accelerate breakthroughs in diagnosis, treatment, and care.

Addressing Alzheimer’s effectively requires a comprehensive, three-pronged approach. The first priority is continued progress in diagnostics and treatments, ensuring earlier and more accurate detection while advancing therapeutic options. The second is prevention and risk reduction, which are critical to reducing the future burden of dementia. Finally, as Alzheimer’s increasingly becomes a chronic condition, the focus must shift toward providing high-quality, personalized care and support. Technology will play a pivotal role in enabling tailored solutions that improve patient outcomes and quality of life.

The UK has demonstrated its commitment to remaining an active global leader in Alzheimer’s research and care. The scale of this challenge necessitates unity, and the UK’s continued engagement in global partnerships underscores the importance of a collective, international response to this growing crisis.

What challenges does Alzheimer’s care in the UK face, and how can training, technology, and innovation improve outcomes for patients and caregivers?

The landscape of Alzheimer’s care in the UK presents considerable challenges, with many families struggling to access the resources necessary to provide individuals with a meaningful quality of life. Late diagnoses often result in advanced care needs that place a disproportionate burden on unpaid family caregivers, leading to burnout and crisis situations, such as hospital admissions caused by falls or dehydration. Currently, one in six hospital beds in the UK are occupied by someone with dementia, further straining an already stretched healthcare system. The social care sector, which bears much of the responsibility for dementia care, is similarly under strain. Chronic underfunding, high staff turnover, and a workforce that feels undervalued exacerbate these difficulties, leaving the system ill-prepared to meet the growing demand.

A key solution lies in comprehensive dementia-specific training for the social care workforce. This training equips caregivers with the skills to manage the progressive and fluctuating nature of dementia, enhancing both the quality of care provided and the morale and retention of staff. Alzheimer’s Society has championed such initiatives, demonstrating their potential to transform outcomes for patients and improve conditions for caregivers. By investing in training, the system can begin to create a care environment that allows individuals to live with dignity and independence in their own homes for as long as possible.

Technology also holds significant promise in augmenting dementia care. While it cannot replace the essential human connection that individuals with dementia require, assistive technologies and artificial intelligence (AI) can fill critical gaps, helping patients maintain independence and easing the burden on caregivers. However, many existing solutions are not designed with the specific needs of people with dementia in mind. Recognizing this, Alzheimer’s Society launched the £7.5 million Longitude Prize on Dementia, a global competition in collaboration with Innovate UK and international partners, to encourage the development of innovative, user-centred solutions.

The program, which began with 178 entries from 28 countries, has progressed to five finalists, including teams from the UK, Portugal, Australia, and the United States. These finalists have received funding to develop prototypes informed by the lived experiences of individuals with dementia. The competition emphasizes co-design and iterative feedback, ensuring that solutions address real-world challenges. A £1 million prize will be awarded to the winner in early 2025, with the goal of fostering scalable innovations that meaningfully improve care and support.

Addressing the challenges of Alzheimer’s care in the UK requires a multifaceted approach that prioritizes early diagnosis, workforce training, and human-centred technology. By tackling these issues cohesively, the system can evolve to provide individuals and their families with the dignity, support, and resilience they need to navigate life with dementia.

Looking ahead, what gives you the greatest cause for optimism in the Alzheimer's field, and what causes you the most concern?

The Alzheimer's field is entering a period of profound transformation, offering tangible reasons for optimism. Advances in blood biomarkers and the approval of the first drugs through regulatory processes mark significant milestones, signaling a shift toward earlier and more precise diagnosis and treatment. These breakthroughs represent the impactful progress that many have been working toward, providing hope for meaningful improvements in the lives of those affected by Alzheimer's.

At the same time, a critical challenge remains: ensuring that this progress is inclusive and equitable. The human experience must be at the forefront of all decision-making, from clinical trials to the development and rollout of new diagnostics and treatments. Achieving this requires addressing disparities in access, which are particularly evident in the UK, where significant regional variations highlight systemic inequalities. Without deliberate efforts to bring diverse communities into the fold, the potential impact of these advancements risks being unevenly distributed.

Looking ahead, the priority must be to balance scientific innovation with a commitment to inclusivity and equity. By ensuring that these breakthroughs reach all individuals, regardless of background or geography, the Alzheimer's field can fulfil its promise to transform the landscape of care and improve outcomes for everyone living with this condition.

See more interviews