



*Making dementia a priority:  
changing perceptions, practice and policy.*

## Alzheimer Europe response – consultation on EU4Health 2022 Work Programme

27 August 2021

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## Introduction

From the perspective of Alzheimer Europe, its members and the estimated 9.78 million people living with dementia in Europe, the Work Programme 2021 of the EU4Health programme was disappointing, with no dedicated programmes of work for Alzheimer's disease or dementia, nor any inclusion of matters related to brain health or neurodegenerative conditions.

In this contribution to the consultation on the 2022 Work Programme, Alzheimer Europe will reiterate some key points to underscore the seriousness and scale of the challenge presented by Alzheimer's disease and dementia, to underline the need to prioritise these conditions in the EU4Health programme.

Alzheimer Europe has already, along with other health NGOs, expressed our disappointment at the lack of inclusion of Operating Grants in the Work Programme 2021 and the manner in which health NGOs have been involved in the development process thus far.

These concerns have been conveyed during meetings with officials from DG SANTE, as well as during a meeting with Health Commissioner, Stella Kyriakides. These constructive discussions are ongoing and we remain hopeful for a positive outcome. As such, we will not restate the arguments in this response, however, an outline of the relevant points can be found in the following accompanying paper: [https://www.eu-patient.eu/globalassets/eu4health-consultation-response---csos---accompanying-paper\\_final.pdf](https://www.eu-patient.eu/globalassets/eu4health-consultation-response---csos---accompanying-paper_final.pdf)

## Prevalence and mortality of dementia

In 2019, Alzheimer Europe published its *Dementia in Europe Yearbook<sup>1</sup>* (funded through the EU Health Programme 2014-2020), providing updated prevalence estimates for the number of people living with it in Europe. By analysing and applying prevalence estimates (calculated from studies gathered through a literature review) to the UN's 2018 population figures<sup>2</sup>, the number of people living with the condition in European countries represented by AE members was 9,780,678.

Despite a reduction in prevalence amongst the majority of age groups, the number of people living with dementia across Europe is projected to double by 2050, rising to 18,846,286 (assuming consistent rates of prevalence amongst age groups). This is due to the continued ageing population of Europe, which will see significant increases in the older age groups in the coming decades.

Furthermore, in December 2020, the World Health Organization (WHO) published updated mortality figures for 2019<sup>3</sup>, showing that for the first time, Alzheimer's disease and other dementias were the **seventh leading global cause of mortality. For the European region, they were the third most common cause of death<sup>4</sup>.**

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<sup>1</sup> <https://www.alzheimer-europe.org/content/download/195515/1457520/file/FINAL%2005707%20Alzheimer%20Europe%20yearbook%202019.pdf>

<sup>2</sup> <https://population.un.org/wpp/>

<sup>3</sup> <https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates>

<sup>4</sup> <https://www.who.int/news/item/09-12-2020-who-reveals-leading-causes-of-death-and-disability-worldwide-2000-2019>

These figures clearly demonstrate a clear and ongoing challenge to health and social care systems across the European Union, with an ever-increasing number of people living with the condition, particularly as the population of Europe continues to age. Member States must adapt their health and social care systems to meet the inevitable increase in demand for supports and services.

Despite this, neither the EU4Health programme nor the 2021 Work Programme, refer to dementia or Alzheimer's disease, with no acknowledgement of the significant challenges that the increased demand for services and supports presents, both now and in the future.

### **Care and treatment of people with dementia**

Alzheimer Europe recently published its Dementia Monitor 2020 report<sup>5</sup>, examining the status of policy and practice, both within and between countries across Europe.

Whilst there has been an increase in the number of countries reporting that services for people with dementia are sufficiently available, a majority continue to report that most services are insufficiently available or do not exist at all within their countries. Furthermore, the overall level of services and support for people with dementia remains highly variable across the EU and within countries themselves. In addition, we are aware from our engagement with members and with national governments that diagnosis rates still remain low, even in countries with well-developed policies and services.

As such, there is a demonstrable need for dementia to be prioritised both at a national and EU level, with a co-ordinated approach to support health systems improve how they diagnose, treat and support people with dementia throughout the course of the illness.

### **Policy**

Since December 2018, Alzheimer Europe has brought together dementia policy leads from the health ministries of 25 countries to discuss, share and exchange information and resources on the latest developments in dementia policy and practice. These meetings have also been attended by representatives of the European Commission, OECD and WHO. This has been an excellent platform to support cooperation and collaboration between countries and international organisations, and would not have been possible without support from the EU's Health Programme.

The WHO has a number of policy areas which are relevant for dementia and provide a strong foundation for where the EU4Health programme can strengthen the health systems of Member States. Of particular relevance, the WHO's Global action plan on the public health response to dementia 2017–2025<sup>6</sup>, sets out seven areas of action for countries to improve the lives of people with dementia.

### **Conclusion and calls for action**

The EU4Health programme represents an excellent opportunity to support Members States improve the capacity of their health care systems to meet these challenges we have outlined,

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<sup>5</sup> <http://www.bit.ly/DementiaMonitor2020>

<sup>6</sup> <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1>

as well as improving the quality of the care and support for people living with Alzheimer's disease and other dementias.

In 2020, Alzheimer Europe set out a report entitled 'Dementia as a European priority: a policy overview'<sup>7</sup>, which recalled how the EU has previously prioritised dementia as a policy matter in recent years, whilst detailing how this should be continued in the EU's future work.

Whilst the EU4Health programme is one of a number of political programmes which influence policies affecting people with dementia, their families and carers (alongside areas such as research, social affairs, equalities etc.), it is undoubtedly one of the most important. Alzheimer Europe has presented a number of compelling arguments as to why dementia must be prioritised to be prioritised within the Work Programme 2022.

Specifically, we call for the following:

- Restoration of Operating Grants for European health NGOs
- A dedicated programme for Alzheimer's disease, dementia, neurodegenerative conditions and/or brain health
- Dedicated workstreams which supports Member States in their work towards the implementation of the World Health Organization's Global Action Plan on Dementia 2017–2025<sup>8</sup> (as well as other relevant areas of work – e.g. WHO Europe's flagship programme on Mental Health<sup>9</sup>)
- Work programmes which align with other relevant areas of EU work, such as within the equality portfolio, the European Pillar of Social Rights and Horizon Europe etc.
- Support for platforms such as the European Group of Governmental Experts on Dementia, to allow for the exchange of good practices, policies and information, which benefit members in implementing evidence-informed policy and practice at a national level.

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<sup>7</sup> <https://www.alzheimer-europe.org/content/download/231512/1707786/file/Dementia%20as%20a%20European%20priority.pdf>

<sup>8</sup> <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1>

<sup>9</sup> <https://www.euro.who.int/en/health-topics/health-policy/european-programme-of-work/european-programme-of-work-20202025-united-action-for-better-health-in-europe>