

# Supplementary Material

## Dementia Research on Facebook and Twitter: Current Practice and Challenges

**Supplementary Table 1.** Search terms used to find Facebook groups and pages.

---

**Search terms**

---

Dementia, dementia research, Alzheimer's, Alzheimer's research, frontotemporal dementia, lewy body dementia, vascular dementia, dementia research participate OR participant OR recruit, EPAD dementia

---

**Supplementary Table 2.** Examples of major and minor themes under aspect of dementia.

| Theme                             | Sub-theme                 | Illustrative quote   |
|-----------------------------------|---------------------------|--|
| Prevention/risk                   |                           | “Looking for tips to reduce your risk of dementia this #AlzheimersAwarenessMonth? Join researchers from @ccna_ccnv to learn more about supporting a #healthybrain in a free webinar next Wednesday.”<br>-Twitter   |
|                                   |                           | “did you know poor sleep may raise levels of protein linked to alzheimer's? a lack of sleep in healthy young men increased the levels of tau protein in their blood compared to uninterrupted sleep, according to a new study.” -Facebook  |
| Treatment                         |                           | “FDA APPROVES ALZHEIMER'S DRUG: In a medical breakthrough, the FDA has approved the use of a new drug, Aduhelm, for treating early Alzheimer's disease, marking the first new treatment approved for the disease in nearly two decades.” -Twitter  |
|                                   |                           | “a drug with a 30-year track record as an effective tool for fighting cancer may significantly improve memory and thinking in patients with mild-to-moderate alzheimer's disease, new research suggests.”<br>-Facebook   |
| Ethical, legal, and social issues | Race, ethnicity, and CALD | “Overall, Black individuals account for less than 5% of participants in most clinical trials for new drugs...Participation of Black individuals in #Alzheimers-related trials is at similar rates. We must work on increasing diversity in clinical trials.” -Twitter  |
|                                   |                           | “with one in three older people being from a culturally and linguistically diverse (cald) background, australia is both an increasingly ageing and multicultural nation. however, there is an under-representation of cald communities in dementia research. this seminar will outline the current gaps in australian dementia research vis-a-vis the inclusion of cald communities; ways to ameliorate some of these gaps including addressing methodological difficulties around recruitment, accessing big data, and costs of such research; and the potential advances for individual researchers as well as australian-research and policy on a global stage.” - Facebook |

---

Sex and gender “Study says #stress can lead to a higher risk of #dementia in women” -Twitter

“600,000 women in the UK are living with dementia — two-thirds of the total. Despite the gender imbalance, researchers are only starting to investigate fully how the disease affects men and women in different ways.” -Facebook

---

Risk-benefit “Biogen's controversial Alzheimer’s drug brought in \$2 million in its first few weeks of availability. The approval of Aduhelm, which is priced at \$56,000, generated intense scrutiny, in large part because there is scant evidence that it can help patients.” -Twitter

“Being Patient spoke with [the director] of clinical operations at the Cleveland Clinic Lou Ruvo Center for Brain Health, about dementia’s neuropsychiatric symptoms and how clinicians weigh the risks and benefits of drug interventions.” -Facebook

---

Access “#COVID19 has increased existing inequalities in accessing #dementia care and highlighted the digital divide in older adults” -Twitter

“social determinants of health can significantly impact brain health disparities & the ability to access care.” -Facebook

---

**Supplementary Table 3.** Examples of major and minor themes under type of post.

| Theme                        | Sub-theme         | Illustrative quote  |
|------------------------------|-------------------|---|
| Sharing knowledge            | Research findings | <p>“Gourmaud &amp; Stewart et al. show that seizure-induced hyperexcitability accelerates Alzheimer’s disease pathology and cognitive deficits, and that activation of the mTORC1 pathway mediates the relationship between Alzheimer’s disease and hyperexcitability.” -Twitter</p> <p>‘A Norwegian study, in which 35 people with dementia were interviewed about their needs in order to facilitate their involvement in services, finds that their three greatest needs were to stay connected, be active and participate, and to live for the moment. The study, reported in BMJ Open, also identifies an overarching theme: “the need to be who I am”.’ -Facebook</p> |
|                              | General knowledge | <p>“Did you know stroke is the leading cause of vascular dementia? During #StrokeAwarenessMonth our Dementia Research Infoline team are on hand to answer any questions you may have about stroke &amp; dementia.” -Twitter</p> <p>“Did you know: The World Health Organization recommends that countries invest 1% of the societal cost of dementia in research. In Canada, that would translate to a research budget of about \$100 million—more than twice the current investment.” -Facebook</p>  |
| Sharing personal experiences |                   | <p>“[This Professor] describes her career in #dementia research as both challenging and extremely satisfying in our latest blog” -Twitter</p> <p>“Check out the truly remarkable interview from [this research participant] about his reasons for joining the study and what’s practically like to be a research participant. #WorldAlzMonth -Facebook</p>  |
| Sharing opportunities        | Recruitment       | <p>“A brain study pinpointing the early signs of Alzheimer's disease is seeking volunteers in the #Oxford area. Over 50? Your participation could help speed up clinical trials of new treatments for dementia.” -Twitter</p> <p>“Have you considered taking part in a dementia research study? Participating in dementia research can be a rewarding experience for families, carers and people living</p>   |

---

with dementia.” -Facebook

---

Events

“Join us tomorrow at 2 pm CET for a zoom meeting featuring the latest progress of Abeta and Tau in Alzheimer's disease.” -Twitter

“Are you aged 65 or over?  
Want to be more involved in our exciting research and feedback on new project ideas?  
Join us for our first ADRC virtual coffee morning on 6th January 2021 @ 10am” -Facebook

---