Understanding the Use and data needs of Alzheimer's Society

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HOST ORGANISATION
Alzheimer's Society

BACKGROUND

- Dementia affects over 55 million people globally, with this number expected to rise [1]. Leveraging robust data is crucial for driving research, shaping policy, and improving care for those living with dementia.
- Detailed data is vital for ensuring equitable resource distribution and advocating for continued support, especially for vulnerable groups relying on government and donor funding [2].
- Alzheimer's Society aims to use data in enhancing its Evidence efforts, inform Policy, and Influencing system change.

AIM

To evaluate and enhance the processes and use of dementia data within Alzheimer's Society, identifying gaps and opportunities for improvement, and informing evidence-based advocacy, policy, and driving system change to enhance the data strategy.

METHODS

- **Stakeholder Interviews:** Collected insights from key stakeholders on data use.
- **Surveys:** Gathered quantitative data on current data practices across teams.
- **Analysis:** Thematic and SWOT to identify patterns and SWOT in data management.

RESULTS/FINDINGS

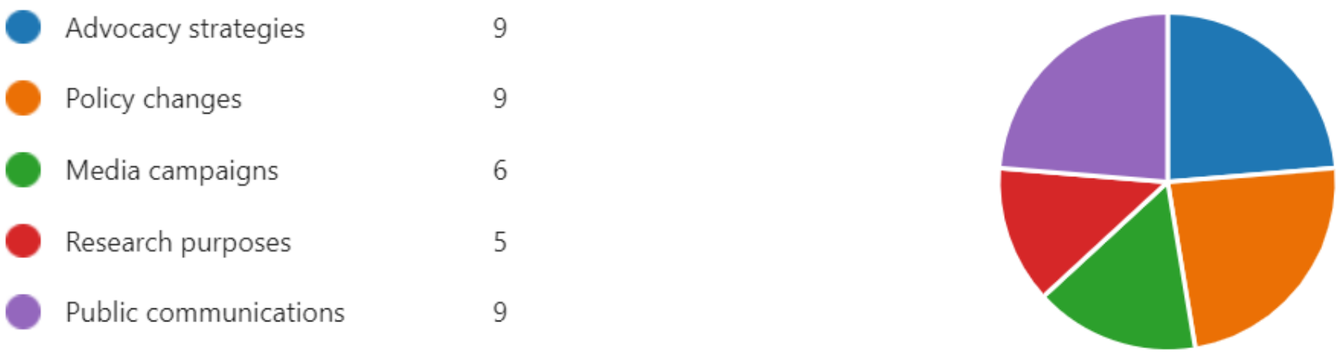

Figure 1: Visual representation of team use of dementia data

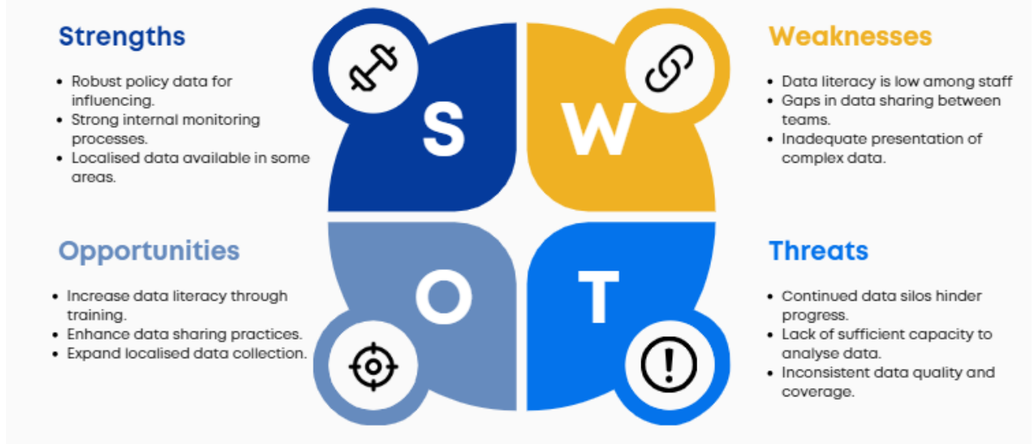

Figure 2: SWOT analysis of our current data practices

- **Data Assets:** Identified both internal (e.g., Fundraising database) and external (e.g., ONS dataset) dementia-related data assets.
- **Gaps in Data Use:** Challenges include data fragmentation, lack of training, and inconsistent data governance.
- **Opportunities:** Enhanced data visualisation and integration across teams can significantly improve decision-making.

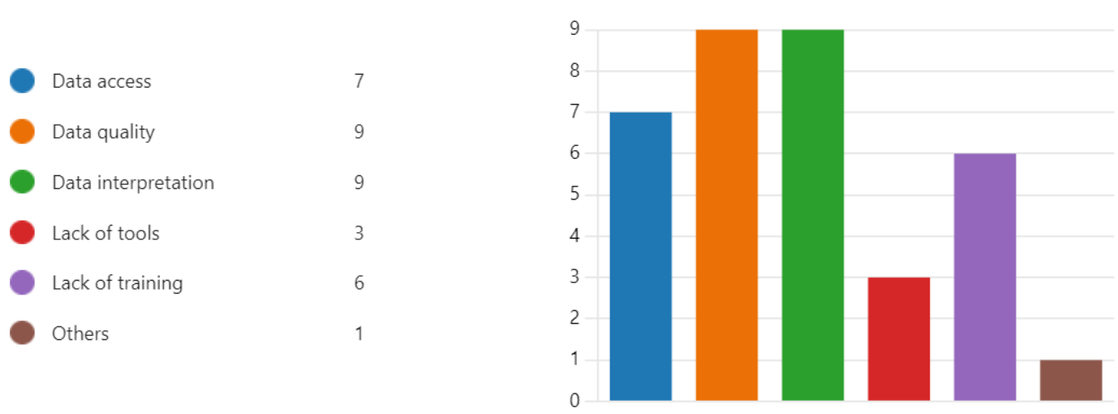

Figure 3: Challenges faced when working with dementia data

IMPLICATIONS

- Improve data practices to develop more precise, localised health interventions and better advocate for policies that directly benefit patients.
- Unify data management to enhance Alzheimer's Society's ability to influence policy effectively, ultimately improving patient outcomes.

CONCLUSION & RECOMMENDATIONS

- **Invest in Data Visualisation:** Tools like PowerBI can make data more accessible and useful across the organisation.
- **Centralise Data Access:** Develop a 'single point of truth' for dementia data to streamline processes.
- **Training & Capacity Building:** Equip staff with the necessary skills to interpret and use data effectively.

1. GBD 2019 Dementia Forecasting Collaborators, "Estimation of the Global Prevalence of Dementia in 2019 and Forecasted Prevalence in 2050: an Analysis for the Global Burden of Disease Study 2019," The Lancet Public Health, vol. 7, no. 2, Jan. 2022, doi: https://doi.org/10.1016/s2468-2667(21)00249-8.
2. A. McDonough and D. C. Rodríguez, "How Donors Support Civil Society as Government Accountability Advocates: A Review of Strategies and Implications for Transition of Donor Funding in Global Health," Globalization and Health, vol. 16, no. 1, Nov. 2020.
3. M. Storm and H. Borgman, "Understanding Challenges and Success Factors in Creating a Data-Driven Culture," scholarspace.manoa.hawaii.edu, Jan. 07, 2020. https://hdl.handle.net/10125/64405.