Changing perceptions, policy and practice
to improve the lives of people affected by dementia

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Understanding European perspectives on data sharing

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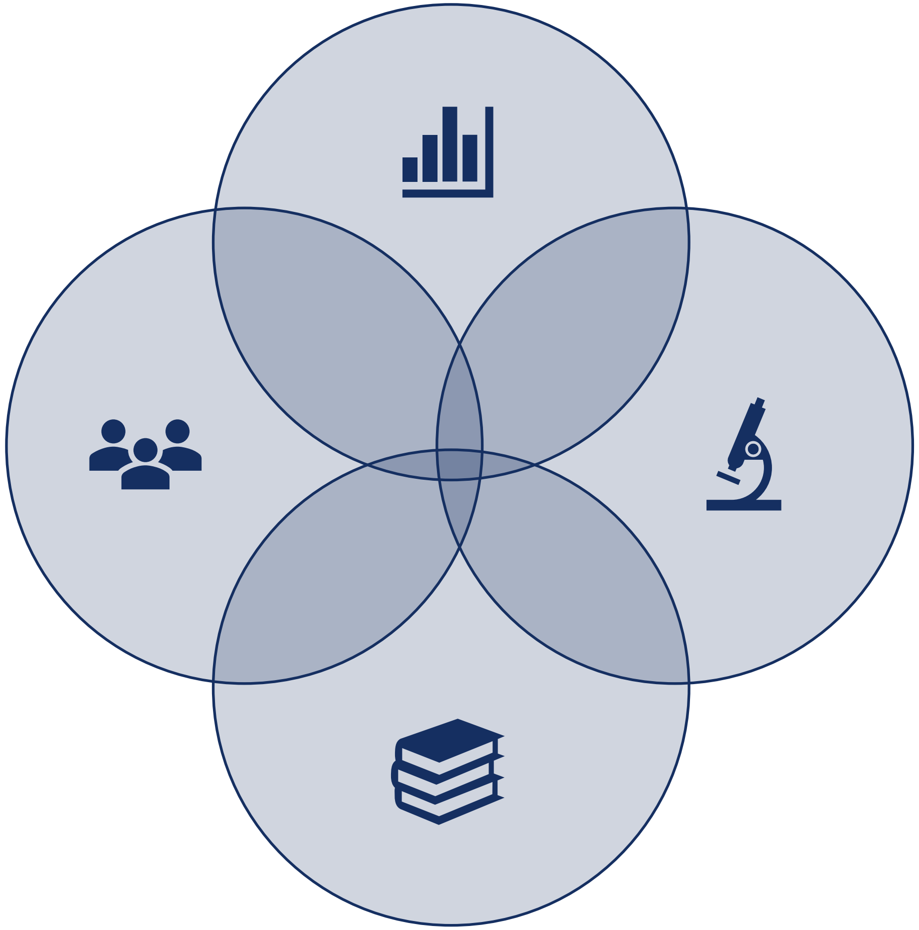
Methods



Public opinion poll
Assessing attitudes towards data sharing and research participation in the general public

Focus groups
With people with dementia and carers

Interviews
With dementia researchers across research domains

Scoping review
Of the scientific literature

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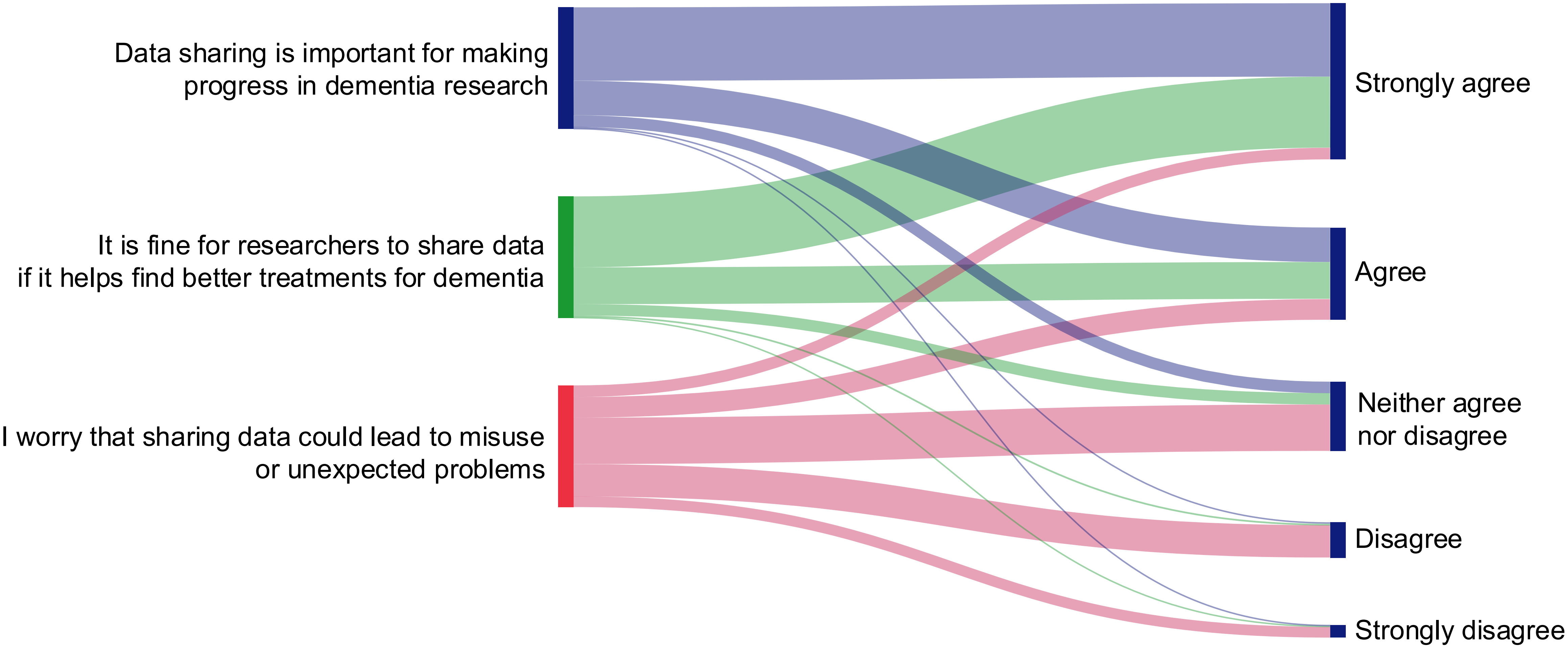

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Alzheimer Europe

Trust

- Protection of privacy when sensitive genetic data is being shared
- Informed consent procedures supporting the building of trust

Communication

- Explanation of procedures and how data will be used
- Feedback and data access
- Representation of carer’s perspective

Fragmentation

- Additional burden for patients and carers due to fragmented registry landscape
- Fragmented informed consent procedures

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“There needs to be much more of a unified group of researchers working on a global basis, not in a fragmented view, which is what's happening at the moment. Different pieces here and here. It's not unified, it's duplicated”.

“The benefits outweigh the risks, but people should have the right to know who’s using their data and why.”