

Dementia Prevention: Data Challenges and Opportunities

Graciela Muniz-Terrera, PhD

Senior Lecturer in Biostatistics and Epidemiology

University of Edinburgh

Background

- Worldwide, around 50 million people have dementia, and there are nearly 10 million new cases every year (WHO, Sept 2019)
- There is no cure yet. Hence dementia *prevention* is essential
- However, to fully understand it and develop interventions to delay onset of dementia or prevent it, large amounts of good quality data are needed

Science is a collaborative activity and is common practice for scientists to join efforts and work together

Large good - quality data sets

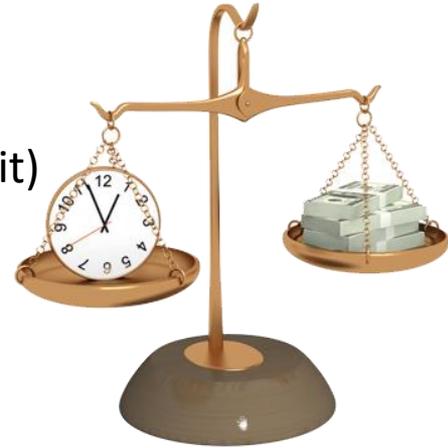
Multiple factors impact dementia research. One highly important factor is *data availability* to allow us to fully understand it.

- Large good quality datasets are needed to answer key questions of interest (for ex: who has higher risk of developing dementia?). Need of large datasets is often cited as a challenge in genetic studies
- However, it is also a challenge in several other areas of dementia research, from disease modelling to epidemiology
- Collecting new data is not a quick, easy nor cheap task

Large good quality datasets

From **researchers'** perspective:

- Cost is very important factor (ex. approx. £3500 per person per visit)
- Often key questions are about understanding change in biomarkers, behaviours, cognitive and physical function.



But the study of these questions requires the follow up of participants over time, usually a number of years

- Time is a critical factor and studies need to mature

Large good quality datasets

From ***participants'*** perspective:

- Some individuals see participation in research as burdensome. Huge efforts are devoted to engage participants in studies & important progress in research involvement has been made. *European Prevention of Alzheimer's Dementia* study (EPAD, IMI funded) an outstanding example
- Yet, some individuals still have concerns & are still be reluctant to get involved in research

Large good - quality data sets

In some contexts, there are additional challenges

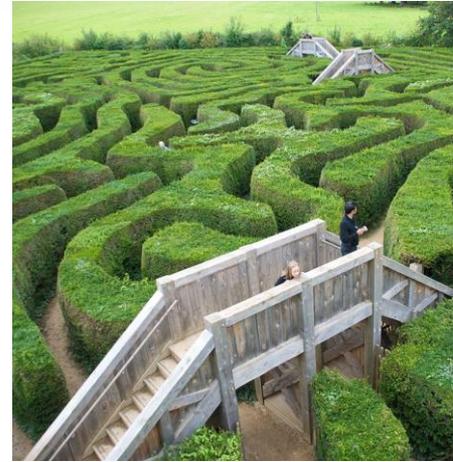
- Most research in dementia has been conducted in western wealthy societies where some groups are under-represented (ex. ethnic minorities)
- Despite large increases in dementia cases in low and middle income countries, data collection in these countries may be hampered due to lack of resources and sometimes, because of cultural factors

Data sharing challenges

Faced with challenges of new data collections, scientists often work jointly and consider using existing data

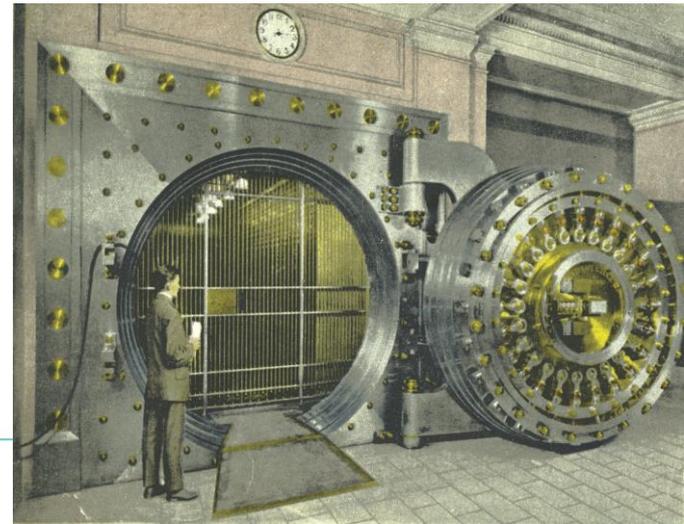
But then, other challenges emerge:

- Identification of adequate datasets can be difficult
- Sometimes research studies are easier to find than studies done by industry
- Once studies are identified, an in-depth understanding of actual data available is extremely time consuming as data documentation practices vary & also depend on setting (research / industry)



Data sharing challenges

- Sometimes datasets become dated due to advances in knowledge & technologies
- Data requests procedures can be slow (personal experience: up to 1.5 years to get data request approved) or not clear
- Confidentiality and non identifiability of study participants are essential to be preserved, institutions have own processes in place to guarantee them. But these can be painfully slow
- Institutions/researchers can also be reluctant to share data or transfer data (requiring physical presence of analyst in the building hosting data)



Future

Therefore, despite enormous and very positive advances in open data initiatives, data catalogues and standardisation of data documentation practices, there are still huge hurdles that slow down or hamper scientific developments in dementia prevention research

Future

- *Advances in data science are offering a way forward to overcome these challenges and disrupt obsolete practices*
- *As scientists, we have (an obligation) to adopt new practices to advance research*

We are living in exciting times.

So let's be open minded, work together in a trusting collaborative environment to embrace new opportunities!

Thanks...

ESOF2020
EUROSCIENCE OPEN FORUM
TRIESTE

Euro
Science 

 Fondazione
Internazionale
Trieste