




THE ROLE OF INFORMATION AND COMMUNICATION TECHNOLOGIES AND BIG DATA IN ACCELERATING INNOVATION FOR ALZHEIMER'S DISEASE

Take-Home Messages and Key Points

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 Key Points

- What is already happening
 - What needs to be done: key action points from discussions
 - How can the OECD take recommendations forward?
 - Where Next?
- 



What is already happening: Big Data

- The multi-factorial, complex nature of AD disease requires large streams of multidimensional data and observation points – integrated multidisciplinary programs and new sophisticated computational capabilities
- Rapid growth of the range of data collected (behavioural, genetic, environmental, epigenetic, clinical data, etc.) , development of databases and networks
- The bottleneck in AD research has moved downstream from generating data (e.g. sequence data, measuring markers, MRI images) to accessing this data, interpretative capacity and creating knowledge.



What is already happening: International Data Sharing Networks

- A proliferation of initiatives and models on how to promote data sharing and accelerate innovation internationally and move forward quickly
- *Knowledge about these networks and about what data is available and how useful these data might be should be part of an international research agenda*



What needs to be done: Address the Key Barriers

- Robust privacy and enforceable norms to secure data that could reveal identities (Big Data-Big Privacy)
- Ownership and control of data in an integrated data ecosystem
- Problems of meta-data heterogeneity and need for standards , quality assurance , availability and quality of metadata
- Misalignment of incentives for research institutions and companies/business models
- Create the conditions for integrated “Better Care + Better Research” models



What actions could the OECD take forward in 2013-2014 ?

- Work could be taken forward under three main areas of the current OECD programme of work :
 - Big Data and Open Science
 - ICTs for Smarter Health, Wellness and Ageing
 - Smart Technologies, Applications and Open Networks



Key goals and objectives of OECD international action:

Assist countries :

- Increase the efficiency of current data sharing practices
- Make better use of scarce resources and avoid duplication through international cooperation
- Take full advantage of the Internet and today's computational power (to model disease-to put patients/individuals at the center of the care and research enterprise)



Possible focus of OECD work in 2013-2014:

- Data sharing and open access models used across OECD countries
- Incentive programmes developed and designed to promote data sharing, open access and open science initiatives.
- Emerging smart participatory/integrated care and research models



What Next ?

- Report Back
- Establish a Multidisciplinary Task Force
- A range of workshops on the horizon
- Survey and Case Study Work
- UK-led G8 Summit