Defeating dementia: progress and challenges on the road to 2025

Data sharing panel

Moderator: Dr Steven Hyman
Harvard University Distinguished Professor and Director, Stanley Center at the Broad Institute of Harvard and MIT

#DefeatingDementia
Defeating dementia: progress and challenges on the road to 2025

Dr Maria Carrillo
Chief Science Officer, Alzheimer’s Association

#DefeatingDementia
Perspectives on Data Sharing

• Over 50 million people worldwide are living with dementia; Alzheimer’s up to 80%

• 2013 Dementia Summit emphasized DATA SHARING with goal to effectively treat and prevent Alzheimer’s by 2025
  – 2006 launch Alzheimer’s Disease Neuroimaging Initiative
  – World Wide ADNI & WW FINGERS

• Recommendation: Work together globally to accelerate research progress, maximize investments & lead to new discoveries
Since 2013 Dementia Summit

- 2012: Alzheimer’s Association funds GAAIN
- 2015: GAAIN and DPUK launch data portals, connecting research studies and researchers around the world
- 2015: Dementia Discovery Fund launched
- 2016: CAP publishes principles for data, sample sharing*
- Since 2013, international growth of AAIC and AAIC Satellite Symposia (GBHI/DIAN)
- Since 2013, Alzheimer’s & Dementia launches open access journals, DADM and TRCI
- 4X increase in U.S. federal funding for Alzheimer’s research
The AD Data Initiative – Gates Ventures
Aims to bring together international data and to augment existing efforts by creating a common platform to access the data

Opportunities:

- **Accelerate Progress**
- **Maximize Investment**
- **Lead to New Discoveries**

- Intellectual property and competitive forces
- **Resources to Support Data Sharing**
  - Historical lack of funding and support mechanisms (NIA, BAND, GEENA)

Adapted from Dr. Stacie Weninger
Defeating dementia: progress and challenges on the road to 2025

Professor Takeshi Iwatsubo
Department of Neuropathology, University of Tokyo

#DefeatingDementia
Opportunities for collaboration and data sharing in Alzheimer’s therapeutic research worldwide

Data sharing through Public Private Partnership

Current ADNI 2 PPSB Partners

NA-ADNI

E-ADNI

K-ADNI

C-ADNI

T-ADNI

I-ADNI

AIBL

Colin Masters

Michael Weiner

Ronald Petersen

Giovanni Frisoni

Simon Lovestone

Ricardo Allegri

Arg-ADNI

Takeshi Iwatsubo

WW-ADNI

AIBL

Colin Masters

Michael Weiner

Ronald Petersen

Giovanni Frisoni

Simon Lovestone

Ricardo Allegri

Arg-ADNI

Takeshi Iwatsubo
J-ADNI

a longitudinal observational study for biomarkers that predict clinical progression of MCI and other early stage AD

Using an identical protocol to North American ADNI

Data sharing revealed highly comparable progression profiles in MCI between J-ADNI and NA-ADNI
Next step and further plans for data sharing:

1. PPP in a competitive (exclusive) style facilitates data sharing in clinical trials

   • Anti-Amyloid treatment for Asymptomatic AD (A4) study
   • Secondary prevention trial in Aβ PET-positive elderly
   • Baseline data (N=1169, North America, Australia, Japan) being openly shared based on the public-private partnership setting!

2. From data sharing in observational studies to the establishment of Trial Ready Cohorts (sharing study participants and data)
Defeating dementia: progress and challenges on the road to 2025

Sir Simon Lovestone
Vice-President, Janssen

#DefeatingDementia
Data sharing platforms – research cohorts

European Medical Information Framework

Catalogue Patient Data Summary - dementia research cohorts

- AD dementia, 9949
- Mild cognitive impairment, 10843
- Subjective cognitive complaints, 4622

Total size: 85,016 patients [48 cohorts]

Catalogue Data Usage

- Catalogue homepage visits: 19,975
- AD database consults: 5,277

Dementias Platform UK

<table>
<thead>
<tr>
<th>Epidemiological cohort datasets</th>
<th>Number of subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Million Women</td>
<td>1.0 M</td>
</tr>
<tr>
<td>EPIC Norfolk</td>
<td>25K</td>
</tr>
<tr>
<td>CFAS</td>
<td>30.5K</td>
</tr>
<tr>
<td>Aberdeen BC</td>
<td>12K</td>
</tr>
<tr>
<td>ELSA</td>
<td>12K</td>
</tr>
<tr>
<td>Whitehall 2</td>
<td>10K</td>
</tr>
<tr>
<td>Caerphilly</td>
<td>2.5K</td>
</tr>
<tr>
<td>UK Biobank cohort</td>
<td>500K</td>
</tr>
<tr>
<td>Generation Scotland</td>
<td>24K</td>
</tr>
<tr>
<td>NSHD (1946 BC)</td>
<td>5K</td>
</tr>
<tr>
<td>Chariot</td>
<td>9K</td>
</tr>
<tr>
<td>SABRE</td>
<td>5K</td>
</tr>
<tr>
<td>CamCan</td>
<td>3K</td>
</tr>
</tbody>
</table>

Total: 1.6 m
Data sharing - real world data

14
NHS Mental Health Trusts across the UK

2.5m+
De-identified electronic patient records

UK-CRIS datacentre and secure network

Output files sent via secure FTP to UK-CRIS. Data is encrypted.

NHS Trust Controlled Environment

Trust network

Input files

Output files

Output files sent via secure FTP to UK-CRIS. Data is encrypted.

UK-CRIS receives encrypted files. Data de-identified and uploaded.

Elastic index (local)
Elastic index (OMOP)
PostgreSQL (local)
PostgreSQL (OMOP)

Data Dictionary

EHR
Backup and Data Dictionary

Extracted NHS Trust database

sFTP client

Secure tunnel

N3

NHS computer access

Private network

Access outside Trust (Authorised staff)

Web
SQL

Web
SQL

NHS Trust secure VPN tunnel

NHS Trust secure
VPN tunnel

Data Dictionary

EHR
Backup and Data Dictionary

Extracted NHS Trust database

sFTP client

Secure tunnel

N3
Data sharing – opportunities and challenges

- South London & Maudsley NHS CRIS data
  - n=2460 people with dementia
  - response to dementia treatment derived from **coded and uncoded** data
- 6.5 m UK Primary care patients
  - n=5814 people with Rheumatoid Arthritis
  - Treatment with Methotrexate reduces dementia incidence
- 500k UK Biobank volunteers
  - Effects of all drugs on cognition
  - Treatment with anti-inflammatories associated with better cognition

Can the data be Found, Accesssed, made Interoperable and Re-used?

Defeating dementia: progress and challenges on the road to 2025

Questions?

#DefeatingDementia