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

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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

alzheimer's association®
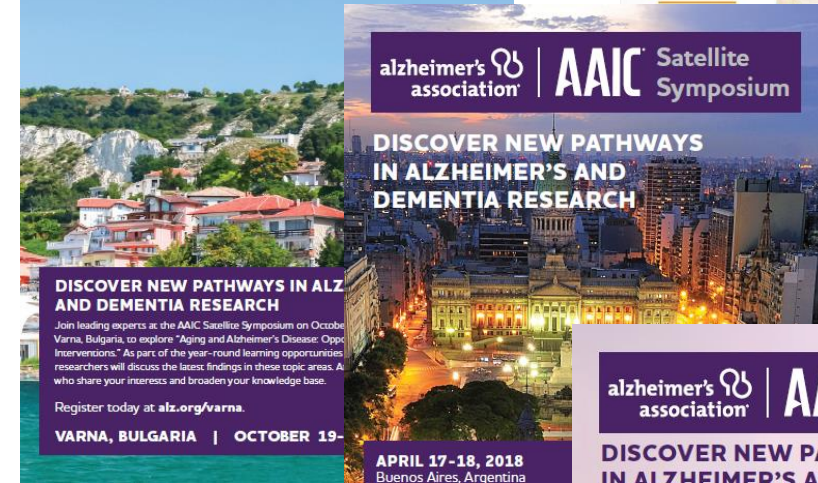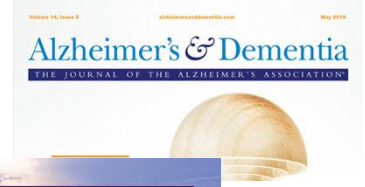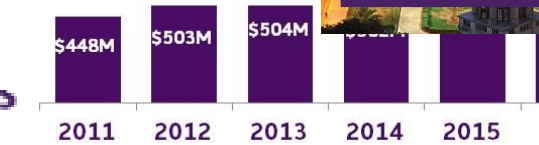
The AD Data Initiative – Gates Ventures

Aims to bring together international data and to augment existing efforts by creating a common platform to access the data

Op

- ▪ 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)

CRITICAL PATH FOR ALZHEIMER'S DISEASE

Dementias Platform UK
Medical Research Council

alzheimer's association®

Defeating dementia: progress and challenges on the road to 2025

Professor Takeshi Iwatsubo

Department of Neuropathology, University of Tokyo

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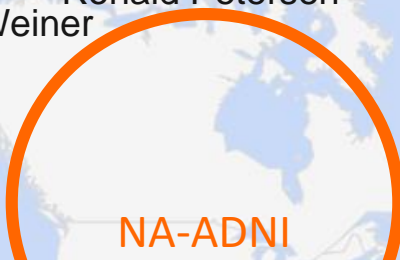Opportunities for collaboration and data sharing in Alzheimer's therapeutic research worldwide
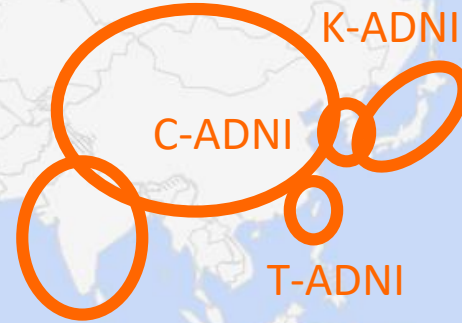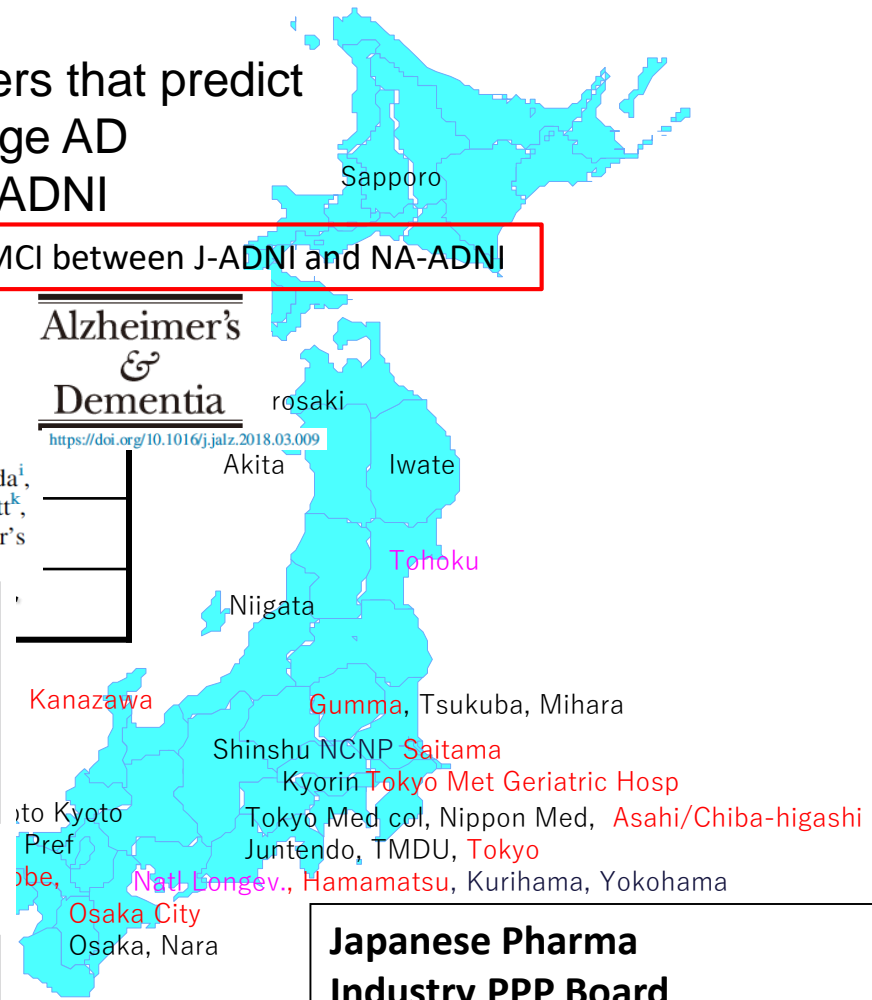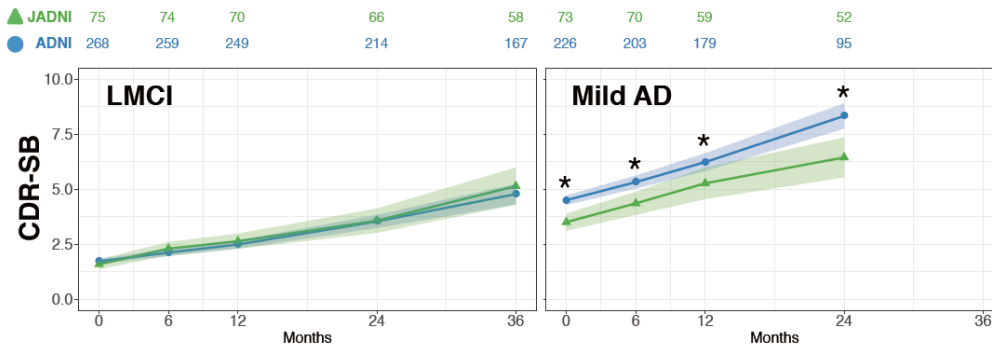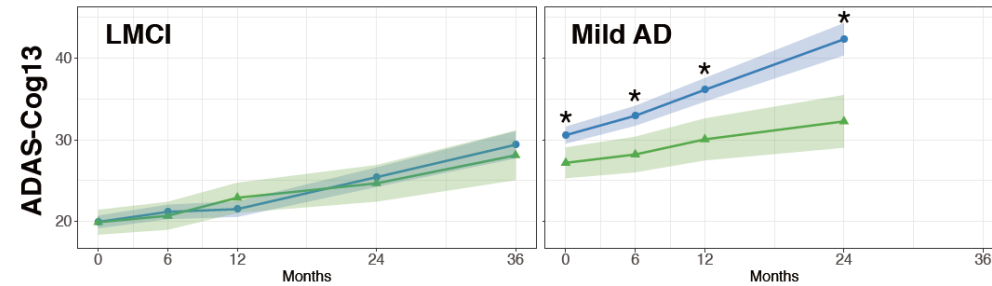
J-ADNI

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

Featured Article

Japanese and North American Alzheimer's Disease Neuroimaging Initiative studies: Harmonization for international trials

Alzheimer's & Dementia

https://doi.org/10.1016/j.jalz.2018.03.009

Takeshi Iwatsubo[a,b,*], Atsushi Iwata[c], Kazushi Suzuki[a], Ryoko Ihara[a], Hiroyuki Arai[d], Kenji Ishii[e], Michio Senda[f], Kengo Ito[g], Takeshi Ikeuchi[h], Ryozo Kuwano[h], Hiroshi Matsuda[i], Japanese Alzheimer's Disease Neuroimaging Initiative[1], Chung-Kai Sun[j], Laurel A. Beckett[k], Ronald C. Petersen[l], Michael W. Weiner[m], Paul S. Aisen[j], Michael C. Donohue[j], Alzheimer's Disease Neuroimaging Initiative

Sapporo

rosaki

Akita   Iwate

Tohoku

Niigata

Kanazawa   Gumma, Tsukuba, Mihara

Shinshu NCNP Saitama

Kyorin Tokyo Met Geriatric Hosp

oto Kyoto   Tokyo Med col, Nippon Med,   Asahi/Chiba-higashi

Pref   Juntendo, TMDU, Tokyo

be,   Natl Longev., Hamamatsu, Kurihama, Yokohama

Osaka City

Osaka, Nara

Japanese Pharma Industry PPP Board
Astellas, Eisai, Daiichi Sankyo
Dainippon-Sumitomo, Shionogi
Takeda, Tanabe-Mitsubishi
Eli-Lilly, Merck-Banyu, BMS, Pfizer
Chugai, Novartis

▲ JADNI	75	74	70	66	58	73	70	59	52
● ADNI	268	259	249	214	167	226	203	179	95

▲ JADNI	75	74	70	66	57	73	70	60	55
● ADNI	269	260	248	221	173	230	210	185	101

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tive setting
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J-ADNI database made available from the National Bioscience Database Center to academic and industry researchers worldwide; also through GAAIN!

Next step and further plans for data sharing

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

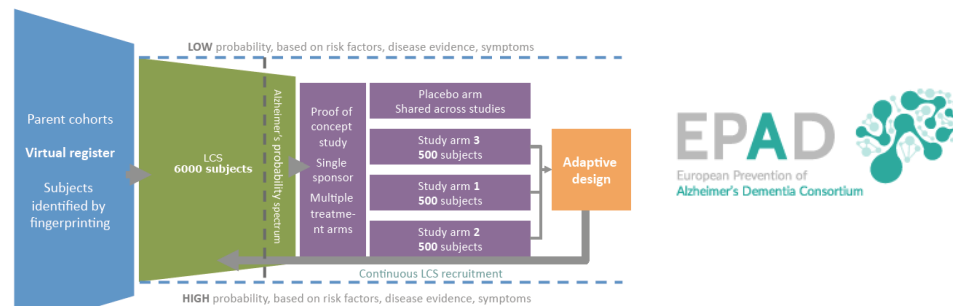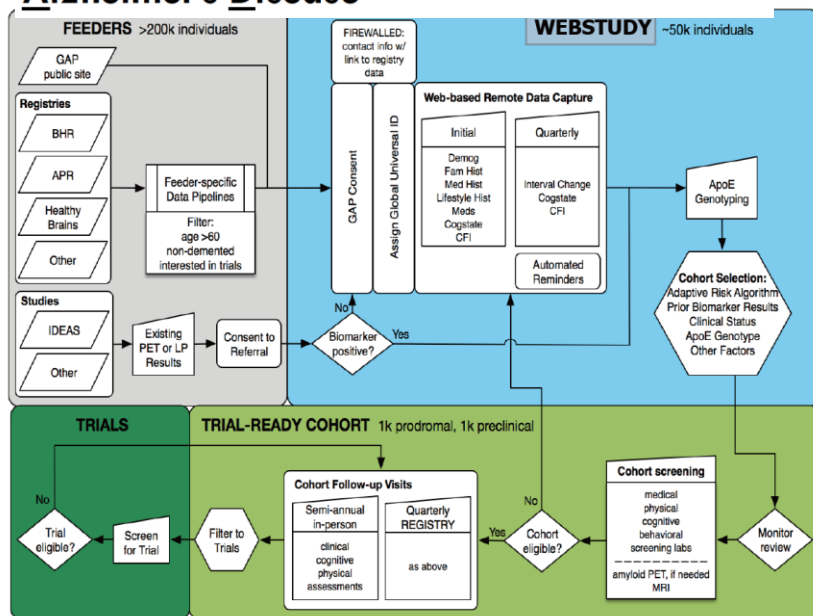- **Anti-Amyloid treatment for Asymptomatic AD (A4) study**
- Secondary prevention trial in Aβ PET-positive elderly
- Baseline data (N=1169, North America, Australia, Japan) being openly shared based on the public-private partnership setting!
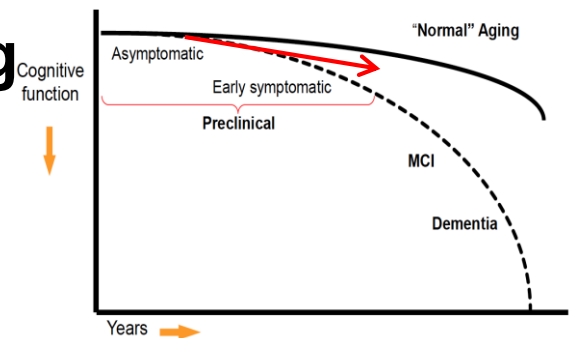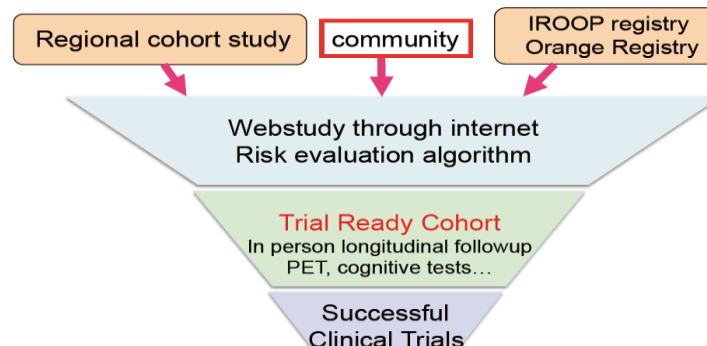
PI Reisa Sperling

2. From data sharing in observational studies to the establishment of Trial Ready Cohorts (sharing study participants and data)

Japanese Trial Ready Cohort for Prevention of AD

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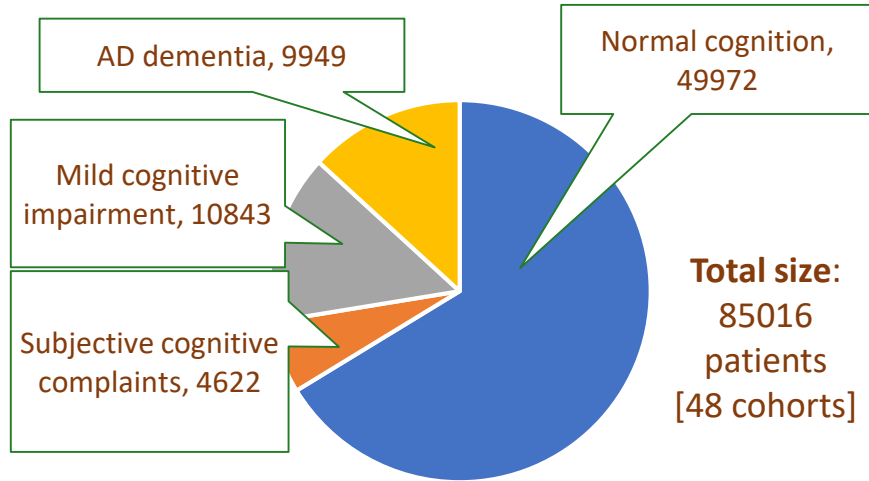
Sir Simon Lovestone

Vice-President, Janssen

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Data sharing platforms – research cohorts

European Medical Information Framework

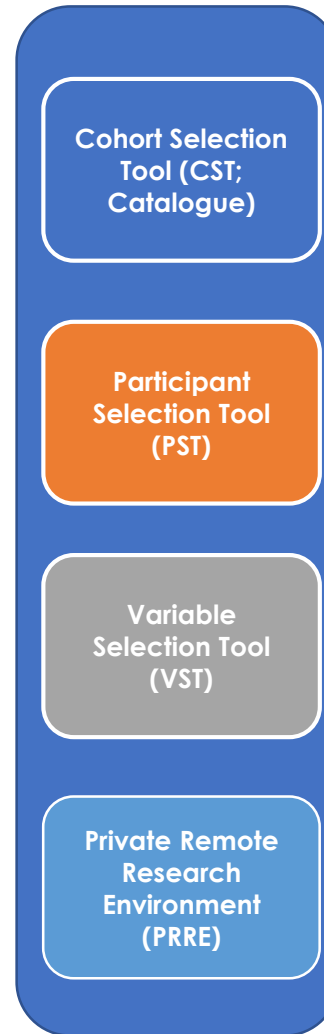**Catalogue Patient Data Summary - dementia research cohorts**

AD dementia, 9949

Normal cognition, 49972

Mild cognitive impairment, 10843

Subjective cognitive complaints, 4622

Total size: 85016 patients [48 cohorts]

Catalogue Data Usage	
Catalogue homepage visits	**19975**
AD database consults	**5277**

Dementias Platform UK

Cohort Selection Tool (CST; Catalogue)

Participant Selection Tool (PST)

Variable Selection Tool (VST)

Private Remote Research Environment (PRRE)

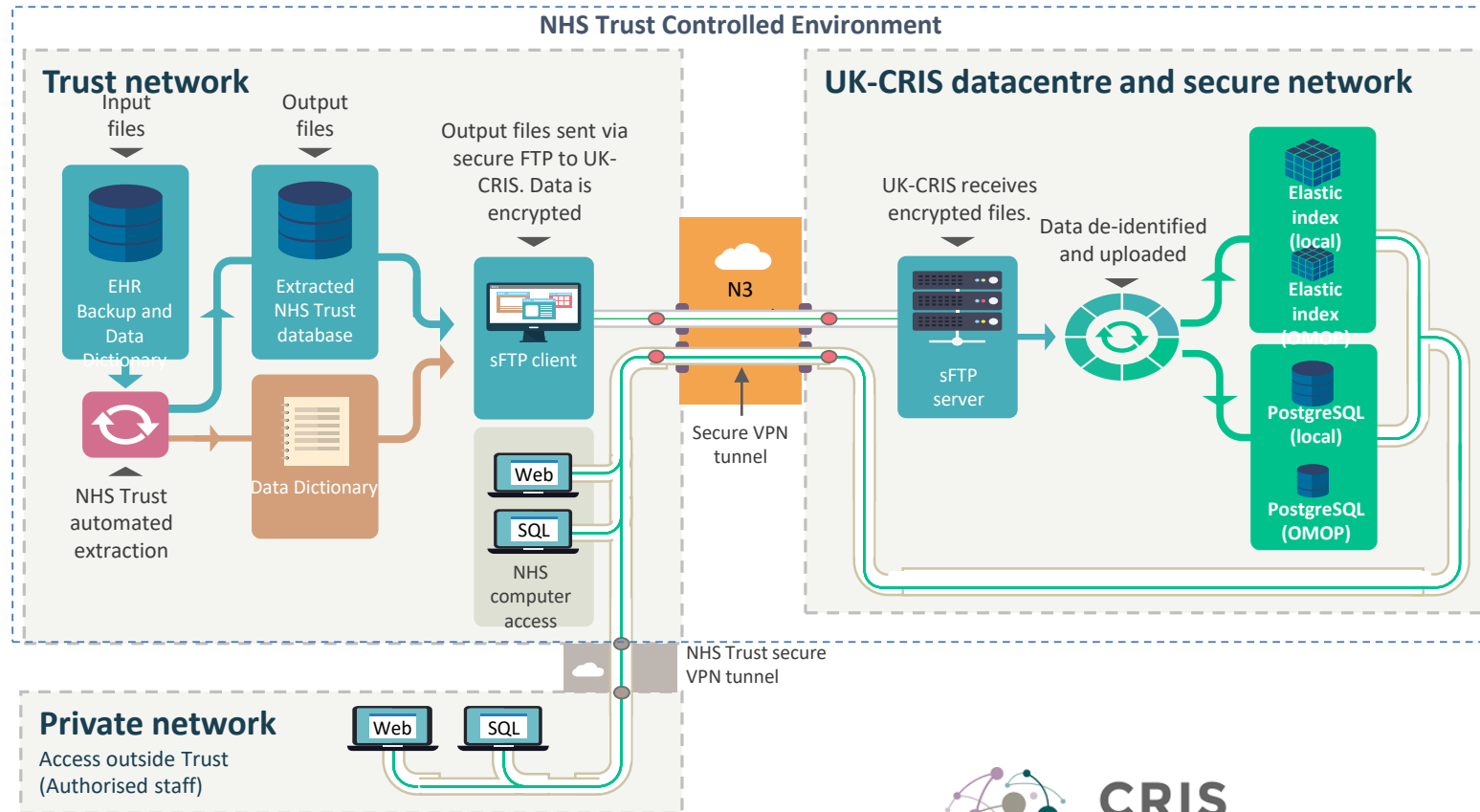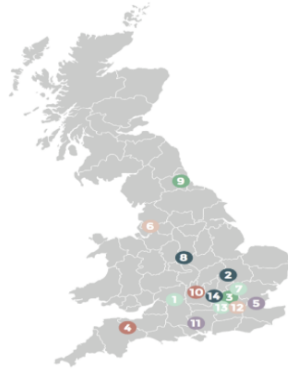| Epidemiological cohort datasets	Number of subjects
Million Women	1.0 M
EPIC Norfolk	25K
CFAS	30.5K
Aberdeen BC	12K
ELSA	12K
Whitehall 2	10K
Caerphilly	2.5K
UK Biobank cohort	500K
Generation Scotland	24K
NSHD (1946 BC)	5K
Chariot	9K
SABRE	5K
CamCa	3K
	1.6 m

Data sharing - real world data

14

NHS Mental Health Trusts across the UK

2.5m+

De-identified electronic patient records

NHS Trust Controlled Environment

Trust network

Input files

Output files

EHR Backup and Data Dictionary

Extracted NHS Trust database

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

sFTP client

NHS Trust automated extraction

Data Dictionary

Web

SQL

NHS computer access

N3

Secure VPN tunnel

NHS Trust secure VPN tunnel

UK-CRIS datacentre and secure network

UK-CRIS receives encrypted files.

Data de-identified and uploaded

sFTP server

Elastic index (local)

Elastic index

PostgreSQL (local)

PostgreSQL (OMOP)

Private network

Access outside Trust (Authorised staff)

Web

SQL

CRIS NETWORK

Data sharing – opportunities and challenges
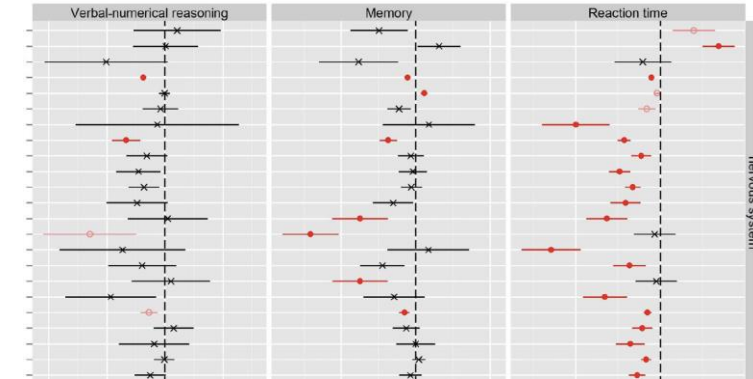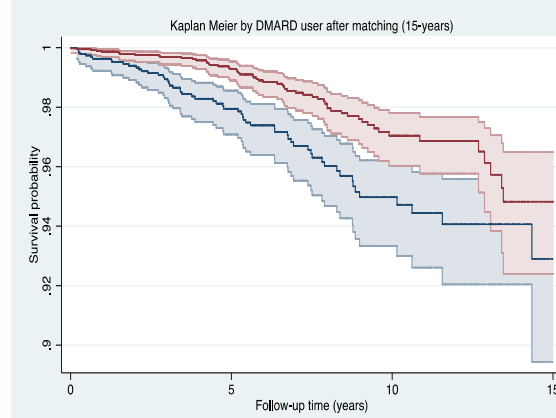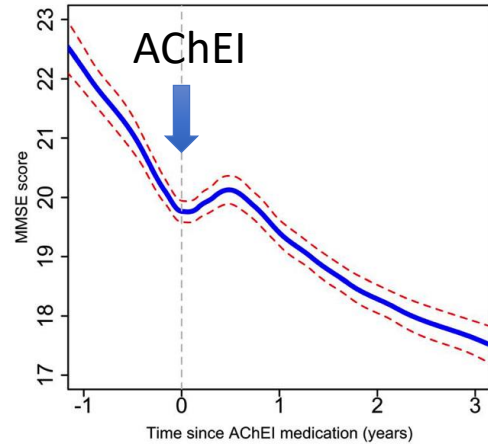
- South London & Maudsley NHS CRIS data
- n=2460 people with dementia
- response to dementia treatment derived from **coded and uncoded** data

- 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, Accessed, made Interoperable and Re-used ?

gister in london. *PLoS One* 2014, **9**(11):e109484.

7.

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Questions?

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