EMIF - European Medical Information Framework

WW-ADNI

alzheimer's association

Worldwide-ADNI Update Meeting
Friday, July 11, 2014 Copenhagen

EMIF Vision

To be the trusted European hub for health care data intelligence enabling new insights into diseases and treatments

EMIF consortium

- 56 partners
- 14 European countries represented
- 56 MM € worth of resources (in-kind / in-cash)
- “3 projects in one”
- 5 year project (2013 – 2017)

To be the trusted European hub for health care data intelligence enabling new insights into diseases and treatments

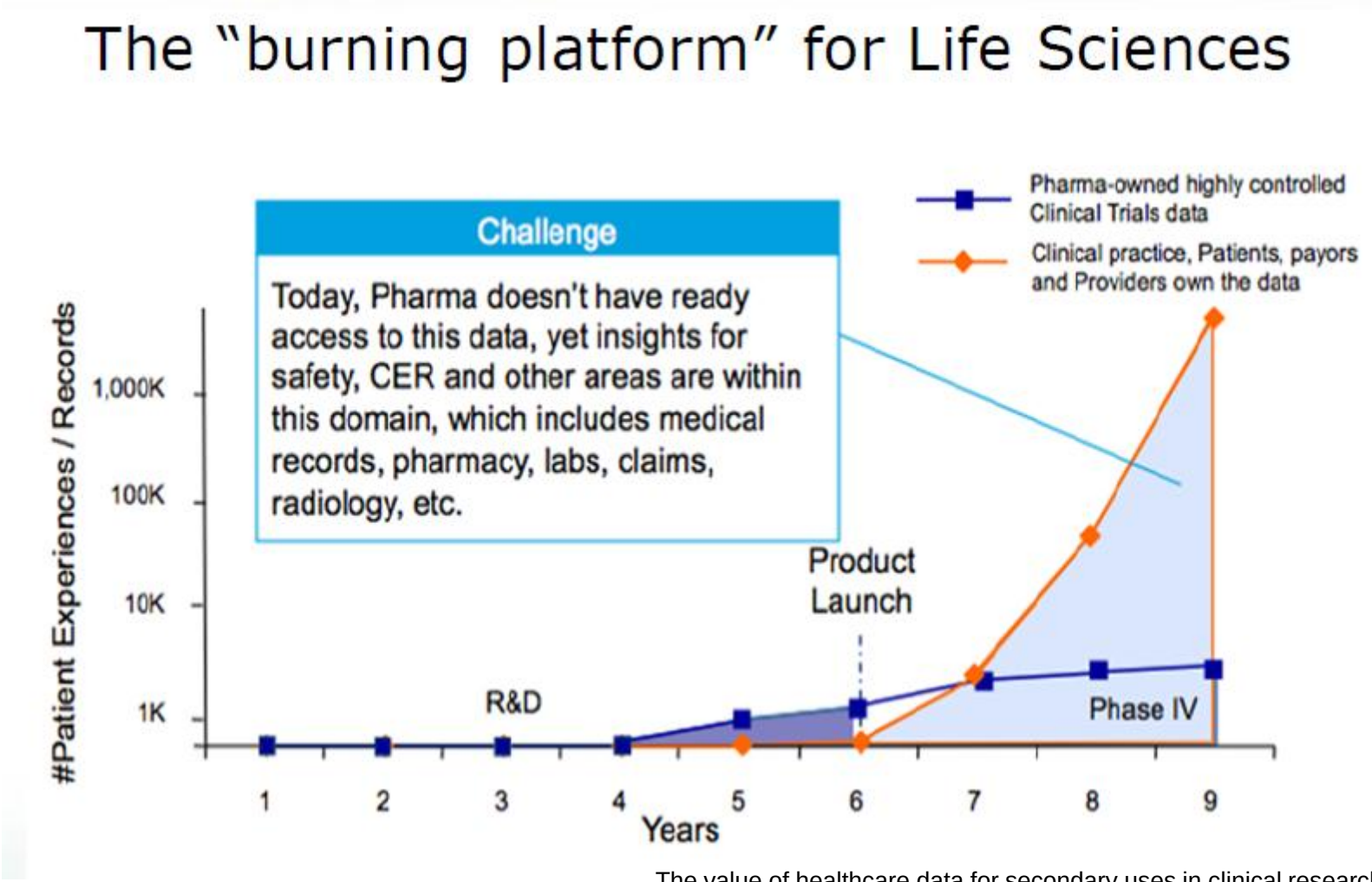
efpia imi

The EMIF project

European Medical Information Framework

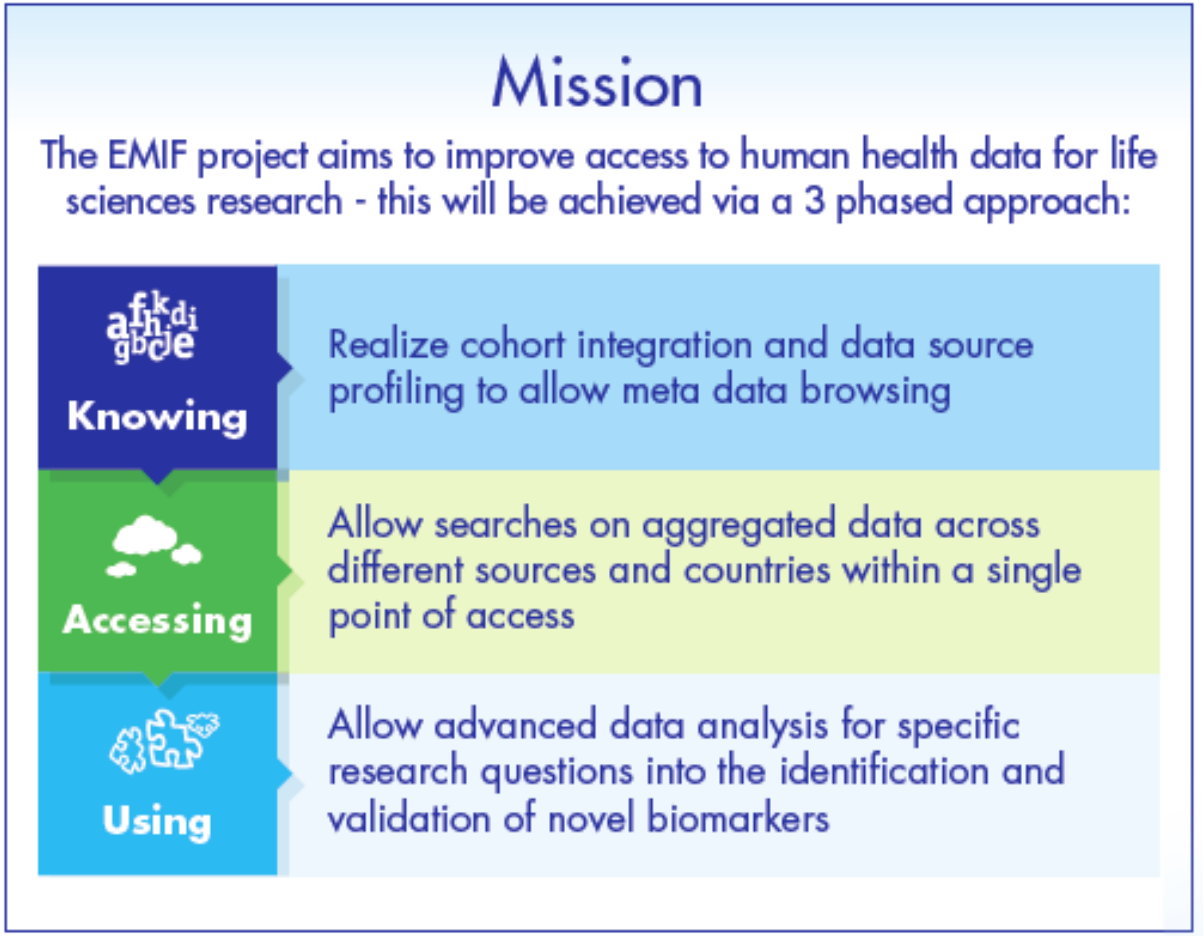
- Leadership team
  - Bart Vannieuwenhuyse (Janssen R&D, Beerse, Belgium)
  - Simon Lovestone (King's College, London, United Kingdom)
  - Johan van der Lei (Erasmus Universitair Medisch Centrum Rotterdam, Rotterdam, The Netherlands)
- AD topic leads
  - Pieter-Jelle Visser (VU Medical Center Amsterdam)
  - Johannes Streffer (Janssen R&D, Beerse, Belgium)

Secondary use of health data to improve clinical research
- Opportunities

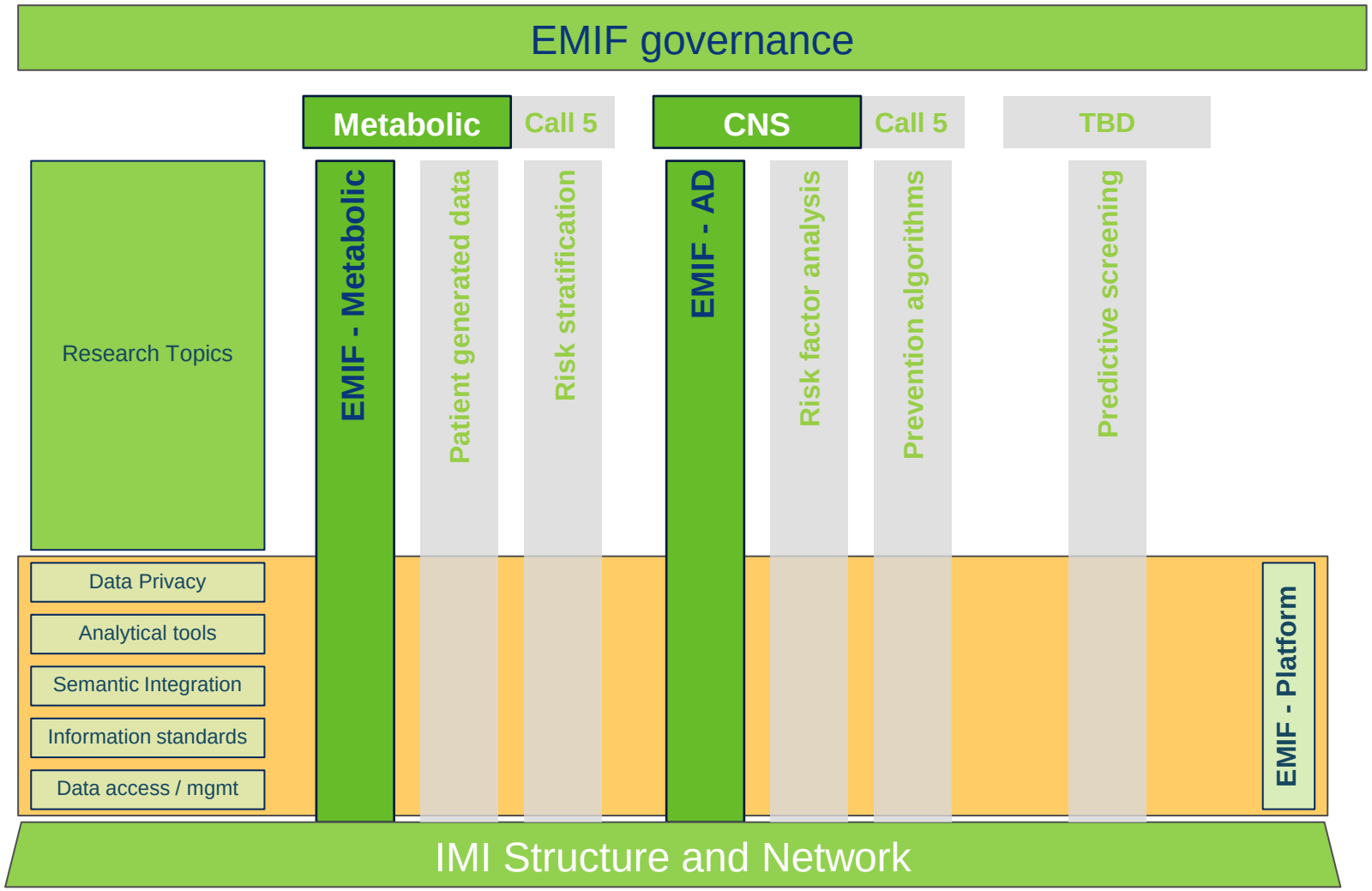


The value of healthcare data for secondary uses in clinical research and development - Gary K. Mallow, Merck, HIMSS 2012

EMIF roadmap



EMIF – platform for modular extension



EMIF-AD – Overall aproach

- Use existing datasets through data platform
- Use extreme phenotypes as an outcome
  - Amyloid pathology
  - APOE4 negative/positive
  - Hippocampal atrophy
  - Cognitive decline

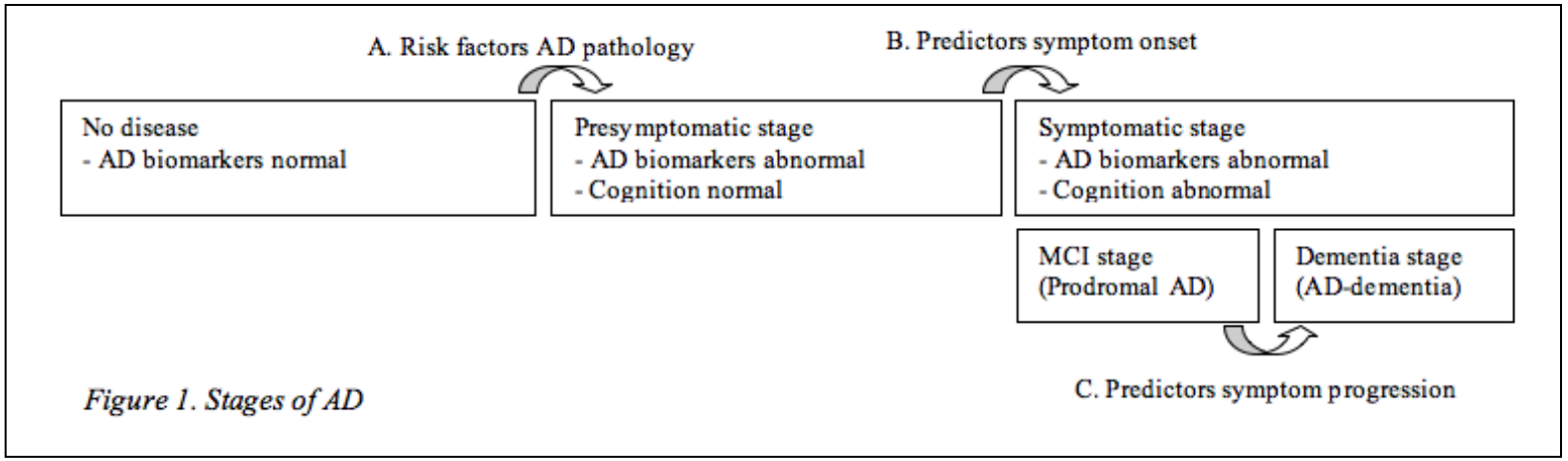


Figure 1. Stages of AD

Cohorts linked

- Preclinical AD studies
  - Barcelona study (Spain)
  - SIGNAL study (Spain)
  - GAP study (Spain)
  - Leuven study (Belgium)
  - Geneva study (Switzerland)
  - EMIF-AD 60-80 cohort (Netherlands/UK)
  - EMIF-AD 90+ cohort (Netherlands/UK)
- Population studies
  - Heinz-Nixdorf recall study (Germany)
  - LOLIPOP (UK)
  - CFAS-1 (UK)
  - Manchester and Newcastle longitudinal study of cognitive aging (UK)
  - Rotterdam study (Netherlands)
  - Maastricht Aging study (Netherlands)
  - SNAC-K (Sweden)
  - CAIDE study (Finland)
  - Finger study (Finland)
  - Athens study (Greece)
- Single centre memory-clinic based studies
  - VUmc (Netherlands)
  - Milan (Italy)
  - Perugia (Italy)
  - Brescia (Italy)
  - London-SlaM (UK)
  - Antwerp (Belgium)
  - Erlangen (Germany)
  - Kassel (Germany)
  - Barcelona (Spain)
  - Vaudois (Switzerland)
  - Aveiro (Portugal)
  - Oslo (Norway)
- National memory-clinic based multi-centre studies
  - Brainpower (Sweden)
  - String of Pearls (Netherlands)
  - PreAL (France)
  - Memento (France)
- European memory-clinic based multi-centre studies
  - Pharma-Cog
  - Addneuromed
  - DESCRIPA
  - EDAR
  - DiMi
  - NEST-DD
  - PredictAD
  - EADC FDG PET study
  - EADC prodromal AD study
- International multi-centre studies
  - ADNI
- Prodromal AD trials
  - Lipididiet
  - MCI Donepezil study
- EHR

Diverse data ownership and availability

One Example AddNeuroMed

	Subjects recruited	Subjects scanned
Alzheimer's Disease	**247**	**136**
Mild Cognitive Impairment	**242**	**129**
Normal controls	**208**	**119**
Total	**697**	**384**

Clinical assessments, MRI and blood based biomarkers

Baseline plus three assessments year 1 ; follow up for three – eight years

Clinical and imaging Work package: Simon Lovestone (London), Hilkka Soininen (Kuopio), Patrizia Mecocci (Perugia), Bruno Vellas (Toulouse), Magda Tsolaki (Thessaloniki), Iwona Kłoszewska (Lodz), Christian Spenger (Karolinska)

45 publications to 2006-2014

Fingerprinting

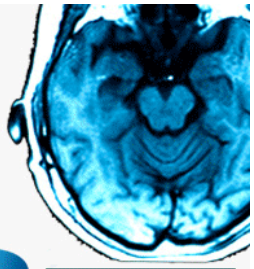
- A detailed questionnaire to characterize AD cohorts was sent to cohort owners of 52 European AD cohorts
- Information on 27 AD cohorts made available in the EMIF browser

	Control	SCI	MCI	AD
All	**4147**	**1469**	**5245**	**2725**
Cognitive data	3261	1394	4969	1940
Plasma	1402	511	1504	962
Serum	3704	227	766	1272
DNA	1853	511	1607	1594
RNA (blood)	963	341	1077	185
CSF	195	342	1513	1048
Urine	306	0	85	0
MRI	1872	950	3643	1345
PET-FDG	45	103	801	71
PET-amyloid	115	0	72	0
SPECT	0	24	143	21
EEG	61	757	648	1015
MEG	0	100	100	100

Selection of data based on Research questions

- Combination of EHR and Cohort studies from the same region
- Collection of samples for biomarker discovery/ confirmation
- Pooling of epidemiologic cohorts and/or EHR for risk factors

Alzheimer's Disease Big Data DREAM Challenge



Scientific Advisory Board

Name	Institution	Role
Peter St. George Hyslop	University of Cambridge/University of Toronto	Co-Chair
Robert Green	Harvard	Co-Chair
David Bennett	Rush, ROS/MAP PI	Member, Data Contributor
Michael Weiner	UCSF, ADNI PI	Ex Officio, Data Contributor
Simon Lovestone	University of Oxford, AddNeuroMed PI	Member, Data Contributor
John Kauwe	Brigham Young University	Member
Alan Evans	McGill University	Member
George Vradenburg	USAgainstAlzheimer's	Member
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Kaj Blennow	Göteborg University	Member
Kristine Yaffe	UCSF	Member
Maria Isaac	EMA	Member
Nolan Nichols	University of Washington	Member
Paul Thompson	UCLA	Member
Reisa Sperling	Harvard	Member
Scott Small	Columbia	Member
Maria Carillo	Alzheimer's Foundation	Ex Officio
Neil Buckholz	NIA	Ex Officio

Challenge Organizers

Name	Institution	Role
Andy Simmons	King's College London	Data Scientist
Arno Klein	Sage Bionetworks	Neuroimaging Lead
Benjamin Logsdon	Sage Bionetworks	Data Scientist
David Fardo	University of Kentucky	Data Scientist
Christine Suver	Sage Bionetworks	Data Governance
Christopher Bare	Sage bionetworks	Synapse Software Engineer
Gustavo Stolovitzky	IBM	Sage/DREAM Executive Committee
John "Keoni" Kauwe	BYU	Scientific Lead
Mette Peters	Sage Bionetworks	Challenge Co-Lead
Nicholas Tustison	UVA	Data Scientist
Richard Dobson	King's College London	Data Scientist
Satrajit Ghosh	MIT	Data Scientist
Stephen Friend	Sage Bionetworks	Sage/DREAM Executive Committee
Stephen Newhouse	King's College London	Data Scientist
Taylor Maxwell	GWU	Data Scientist
Thea Norman	Sage Bionetworks	Challenge Strategy and Logistics

Subchallenge 1:
Predict the change in cognitive scores 24 months after initial assessment.

Scientific Rationale: Answers to this question will help predict cognitive trajectory and potentially provide new approaches for early diagnosis of AD. This earlier identification would allow for more efficient selection of samples for clinical trials and possibilities for earlier disease treatment.

Training Set

ADNI
Alzheimer's Disease Neuroimaging Initiative

Ancillary Data

The AddNeuroMed Study

Test Set

RUSH UNIVERSITY MEDICAL CENTER

ROS/MAP

Subchallenge 3:
Classify individuals into diagnostic groups using MR Imaging.

Scientific Rationale: If a single MR image could be used to differentiate AD patients from people with mild cognitive impairment or from healthy individuals, research can focus on the specific anatomical structures that are different between the groups. Currently, MRI data are acquired routinely in hospitals: thus a winning algorithm could potentially be retrospectively applied to existing archives of clinical data as well as to future scans without requiring additional resources or expertise.

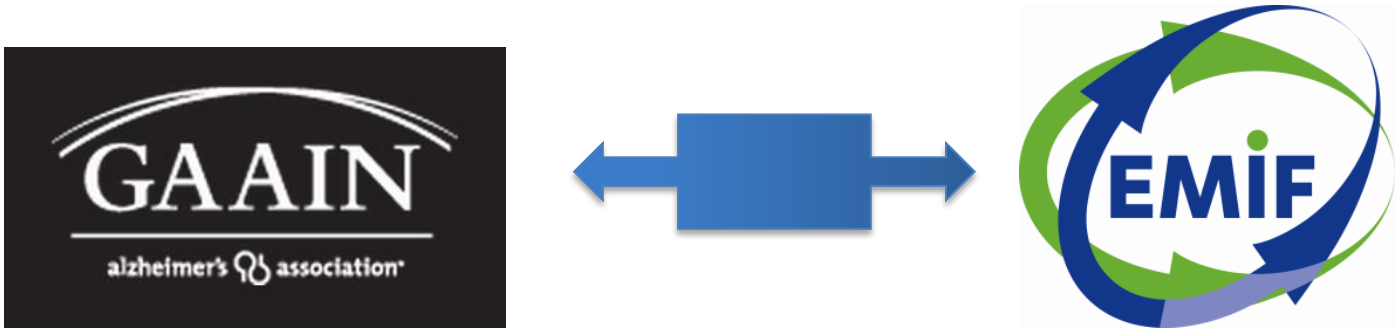
Training Set

ADNI
ALZHEIMER'S DISEASE NEUROIMAGING INITIATIVE

Test Set

The AddNeuroMed Study

Data aggregation and access – US and Europe



- Phase 1
  - Exchange and mapping of meta-data (‘fingerprints’)
  - 24 attributes in GAAIN; >200 in EMIF
  - Cross programme mapping underway
- Phase 2
  - “search on GAAIN = search on EMIF” and vice versa
  - Access to cohorts across Europe and USA
- Phase 3
  - Joint analysis
  - Data-standardisation