ROADMAP

REAL WORLD OUTCOMES ACROSS THE AD SPECTRUM FOR BETTER CARE: MULTI-MODAL DATA ACCESS PLATFORM

Scalable and transferable tools for consensual and efficient uses of RWE for the benefit of AD patients and their caregivers.
Integrating data differing in modality and provenance, **conceptualising trials and cohorts as structured studies nested** within a less well defined but wider population-based data-space.
### Data Sources accessible by ROADMAP

**National registers**
Databases, Cohorts

<table>
<thead>
<tr>
<th>Country</th>
<th>Source (n)</th>
<th>Setting</th>
<th>Diagnosis</th>
<th>Cognition</th>
<th>Comorbidities</th>
<th>Medication</th>
<th>Care Quality</th>
<th>Imaging</th>
<th>Genetics</th>
<th>Health status</th>
<th>Lifestyle</th>
<th>Socio-econ</th>
<th>Devices/PRO</th>
</tr>
</thead>
</table>
| Denmark | Nat. patient registers (5.6M)  
50 linked clinical databases (5.6M) | Hospital | ✓ | ✓ | ✓ | | | | | | | | | |
| France  | Memento | Memory clinic | ✓ | ✓ | ✓ | | | | | | | | | |
| Netherlands | IPCI (2M)  
Amsterdam Dementia cohort (4K)  
Parelsnoer clinical cohort (1K)  
ACTIFCare cohort (400)  
Learn cohort (300) | Primary care  
Memory clinic  
N. memory clinic  
Home living  
Memory clinic | ✓ | ✓ | ✓ | ✓ | ✓ | | | | | | | | | |
| Spain   | SIDIAP (5.8M)  
ReDeGi register (6K) | Primary care  
Hospital | ✓ | ✓ | ✓ | ✓ | ✓ | | | | | | | | |
| Sweden  | LISA register (10M)  
Nat. Patient registers (10M)  
Social services register (10M)  
Tax Agency’s register (10M)  
VEGA health care reg. (1.6M)  
QRegPV (10M)  
National health care regs. (10M)  
Military service register (7M)  
Gothenburg pop. studies (10K)  
Women’s cohort (400) | Insurance data  
Hospital  
Administrative  
Administrative  
Regional reg.  
Primary care  
Administrative  
Administrative  
Population cohorts  
Population cohort | ✓ | ✓ | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | |
| UK      | CPRD (5M)  
SAIL (3M)  
UK CRIS (3M)  
HSCIC (56M)  
SHIP (5.7M)  
Dementias Platform UK (2M)  
Cygnus care cohort (500) | Primary care  
National linkage  
Mental health  
Hospital  
National linkage  
Population cohorts  
Memory Clinic | ✓ | ✓ | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
Core Technologies and Infrastructures

• Cohort metadata:
  • EMIF Catalogue, Participant finder, Variable finder

• EHR integration, harmonisation and analysis:
  • Jerboa, Octopus, OMOP, OHDSI

• Secure data analysis:
  • UKSeRP, SAIL, SHIP, CRIS

• Data infrastructures:
  • Utrecht, DPUK, IXICO’s ‘mehealth one’
Creating the context for a new generation of highly targeted, highly informative clinical trials
DPUK NETWORKS: LINKING CELLULAR AND MOLECULAR CHANGES TO PATIENT SELECTION AND RESPONSE

Imaging: PET/MR
Stem cell:
Informatics:
  • Cohorts
  • EHRs
  • Imaging
  • Wearables
  • Genomics
  • Brain banking

• Sharing best practice
• Standardising protocols
• Niching expertise

National coverage

Imaging
iPSC
Informatics
RAPID DATA ACCESS
Highly characterised trials recruitment

Informatics Platform (>30 cohorts n=2M)

UKB baseline (inc. genetics n=500K)

3T brain and body imaging (n=100K)

2 yr repeat imaging (n=10K)
Industrial Consortium

Modelling for:
(1) natural history of disease
(2) health economics

Project Management
Observational/cohorts
Study execution
Outcomes research

Data management
Data integration
Informatics, statistics

Expert Advisory Boards (led by NICE):
(1) HTA bodies/payers from different archetypes
(2) Regulators
(3) Patient Associations

National/Regional Health Authorities

Public Consortium

Jun-2016

Associated Data Providers

IMI Related Projects

Public stakeholders