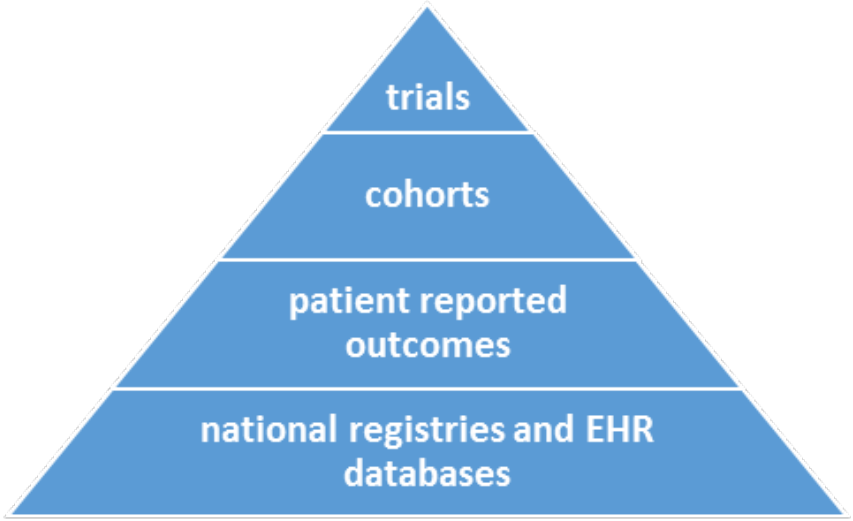
ROADMAP

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:

Data Pyramid



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.

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Data Sources accessible by ROADMAP

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

National registers
Databases, Cohorts

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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 infrastrctures:
  - Utrecht, DPUK, IXICO's 'mehealth one'

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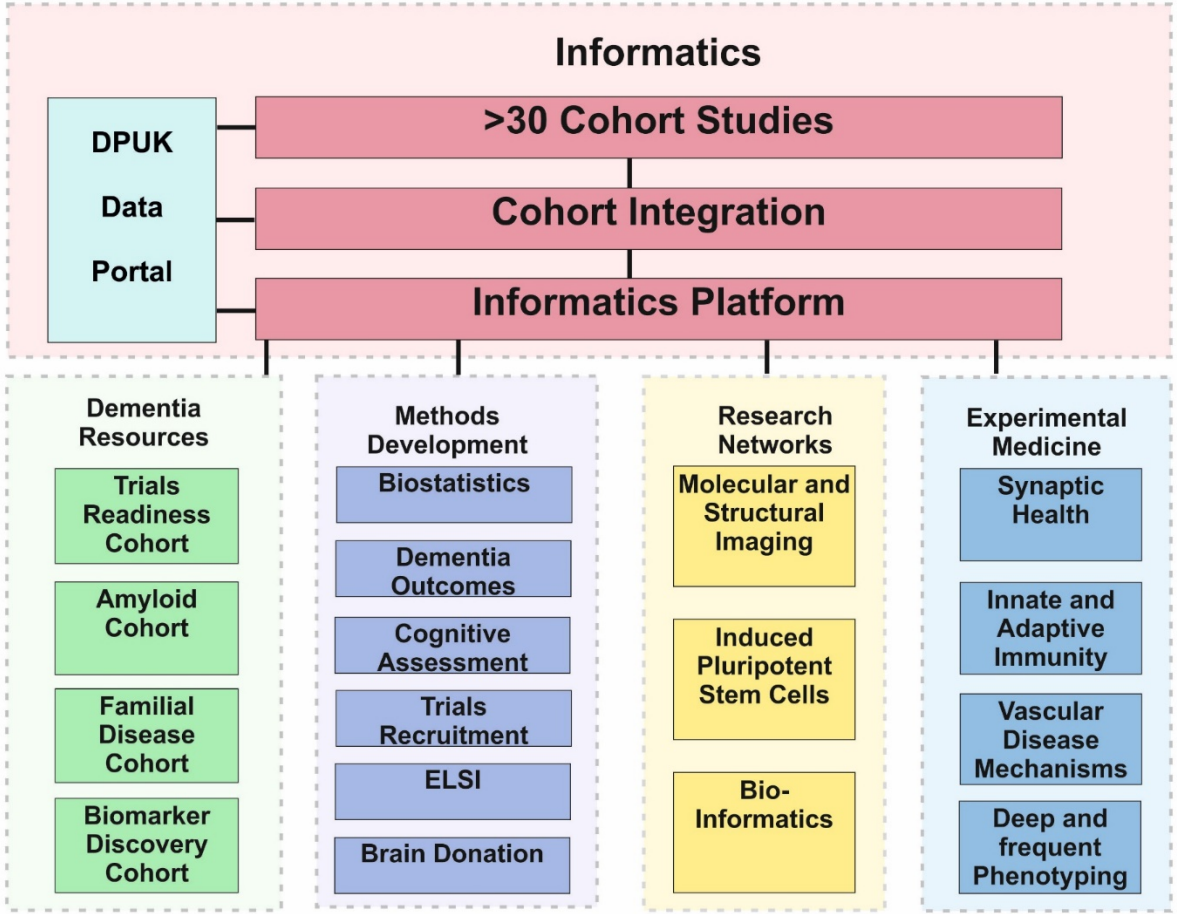
Creating the context for a new generation of highly targeted, highly informative clinical trials

INTEGRATED INFRASTRUCTURE



DPUK NETWORKS:

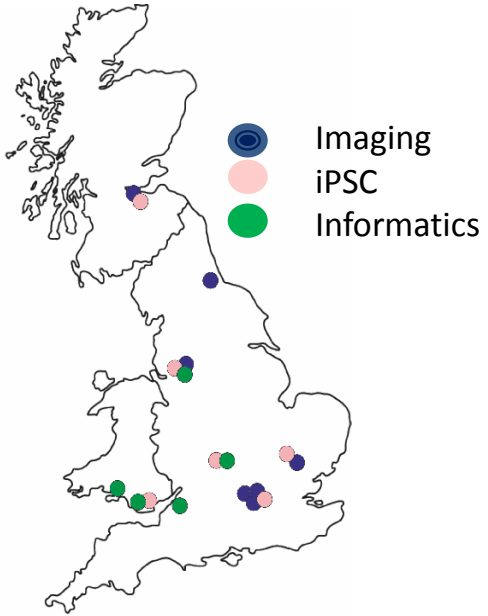
LINKING CELLULAR AND MOLECULAR CHANGES TO PATIENT SELECTION AND RESPONSE

Imaging: PET/MR
Stem cell:
Informatics:

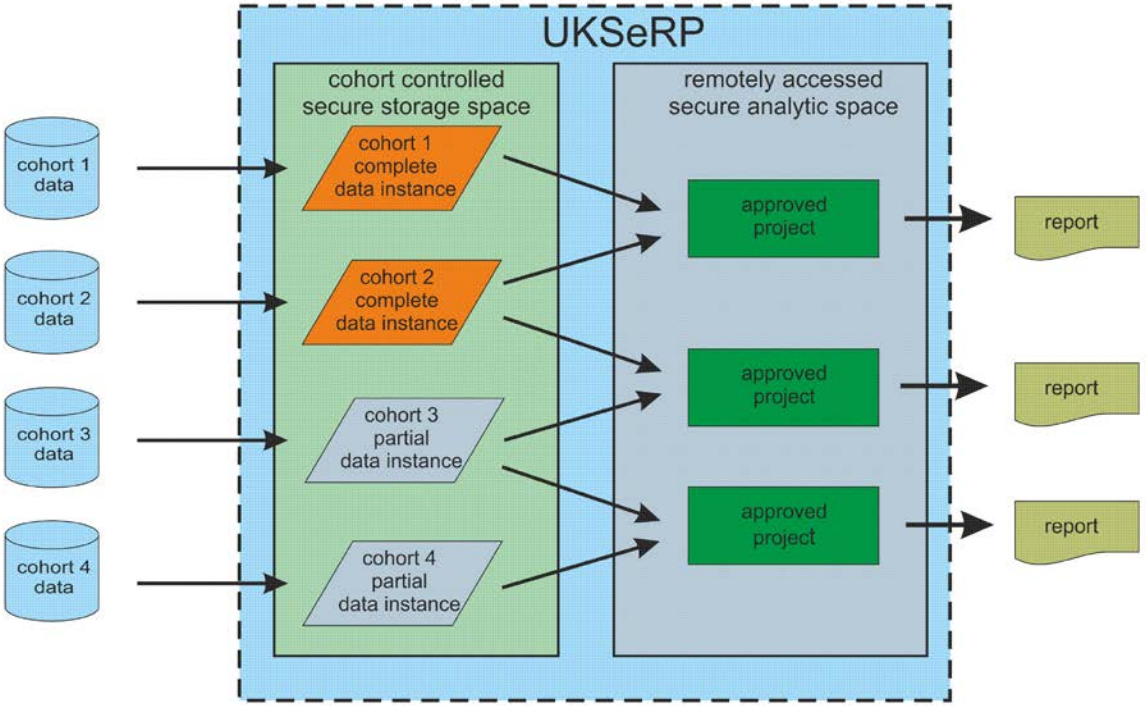
- **Cohorts**
- **EHRs**
- **Imaging**
- **Wearables**
- **Genomics**
- **Brain banking**

- **Sharing best practice**
- **Standardising protocols**
- **Niching expertise**

National coverage



RAPID DATA ACCESS



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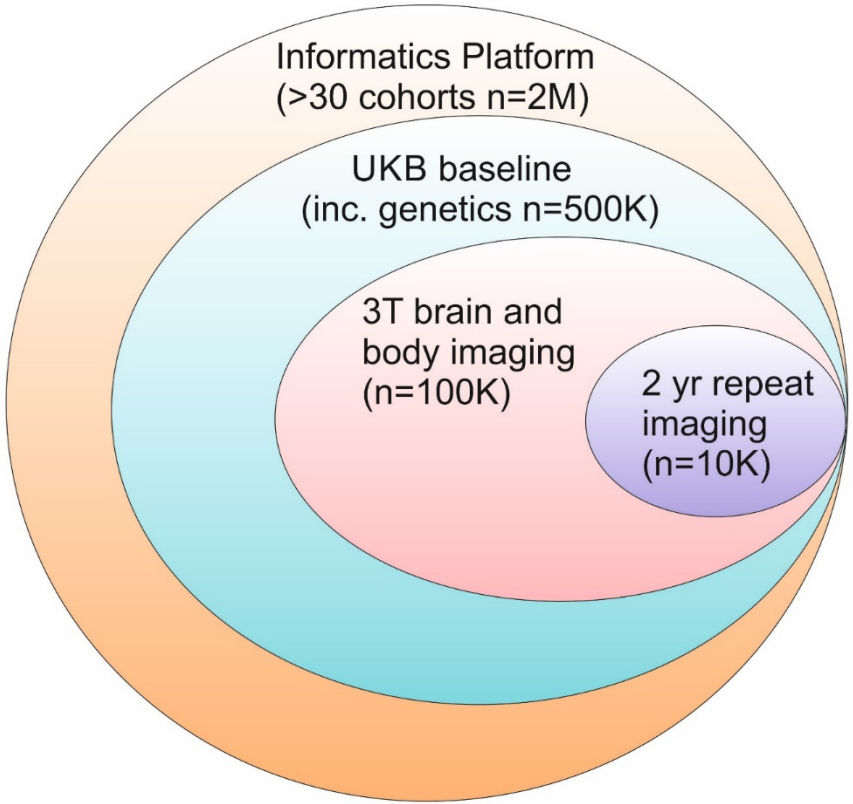
Highly characterised trials recruitment



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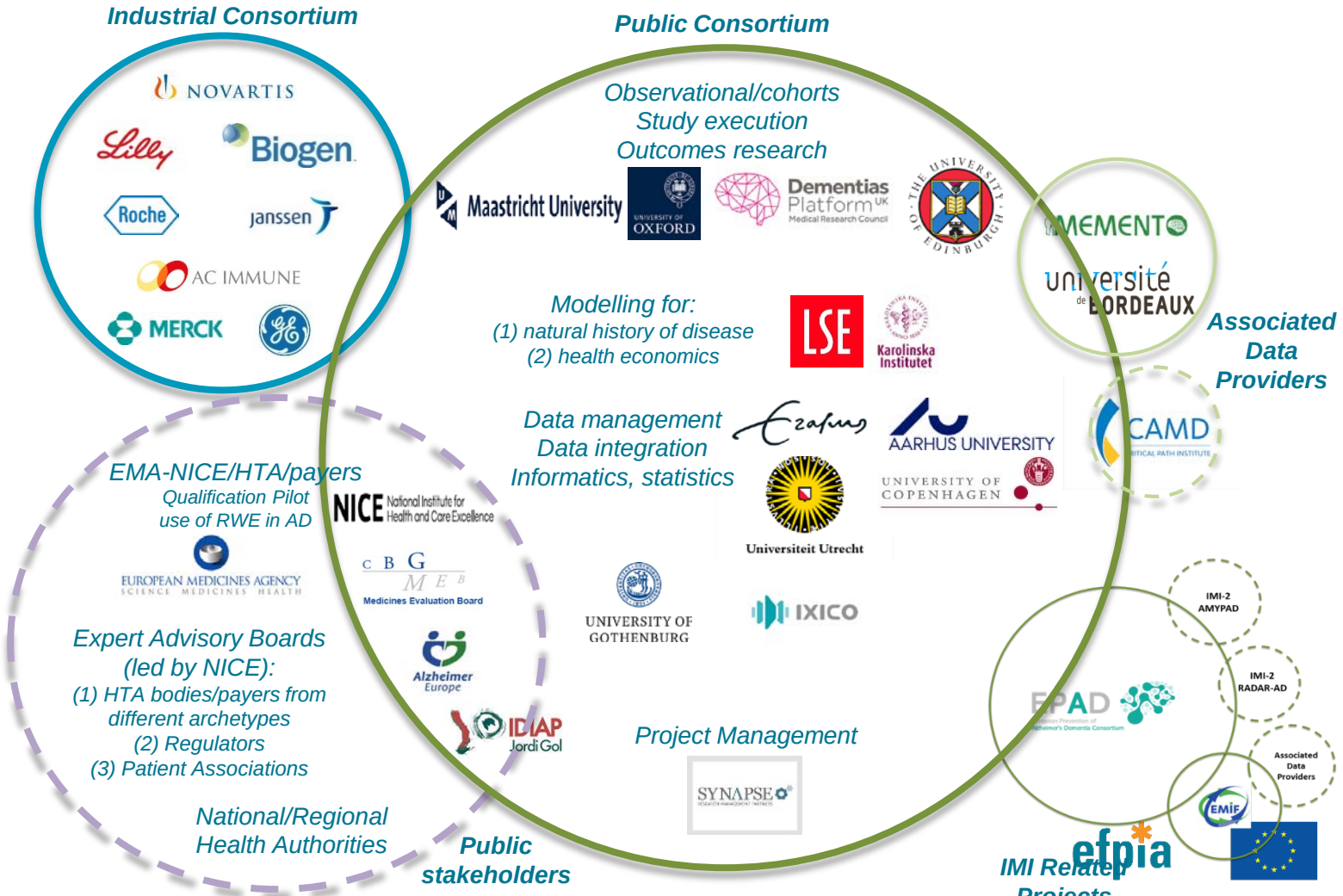
Industrial Consortium
NOVARTIS
Lilly
Biogen
Roche
janssen
AC IMMUNE
MERCK
Public Consortium
Observational/cohorts
Study execution
Outcomes research
Maastricht University
UNIVERSITY OF OXFORD
Dementias Platform UK
Medical Research Council
THE UNIVERSITY OF EDINBURGH
Modelling for:
(1) natural history of disease
(2) health economics
LSE
Karolinska Institutet
Data management
Data integration
Informatics, statistics
Erasmus
AARHUS UNIVERSITY
UNIVERSITY OF COPENHAGEN
Universiteit Utrecht
UNIVERSITY OF GOTHENBURG
IXICO
Project Management
SYNAPSE
MEMENTO
université de BORDEAUX
Associated Data Providers
CAMD
EMA-NICE/HTA/payers
Qualification Pilot
use of RWE in AD
EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH
NICE National Institute for Health and Care Excellence
CBG MEB
Medicines Evaluation Board
Alzheimer Europe
IDIAP Jordi Gol
Expert Advisory Boards
(led by NICE):
(1) HTA bodies/payers from different archetypes
(2) Regulators
(3) Patient Associations
National/Regional Health Authorities
Public stakeholders
IMI-2 AMYPAD
IMI-2 RADAR-AD
EPAD
Associated Data Providers
EMIF
efpia
IMI Related Projects
imi