



# ROADMAP

## Real world Outcomes across the AD spectrum for better care: Multimodal data Access Platform

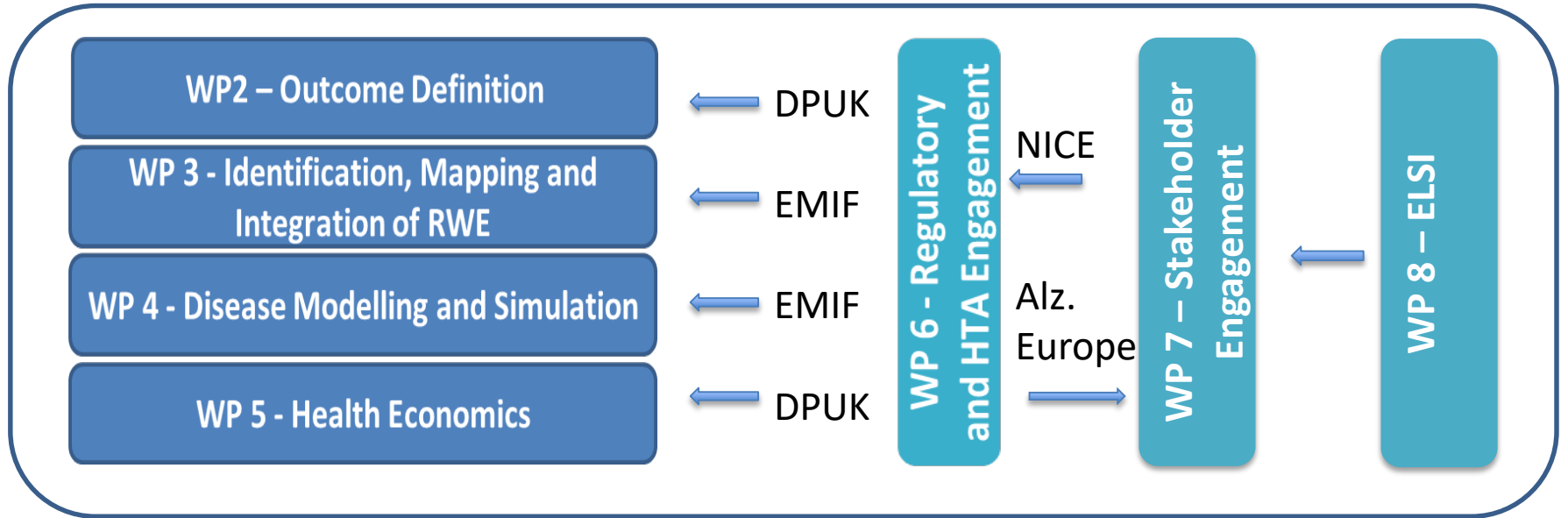
*EMIF-AD/DPUK General Assembly, Manchester, Feb 24, 2017*

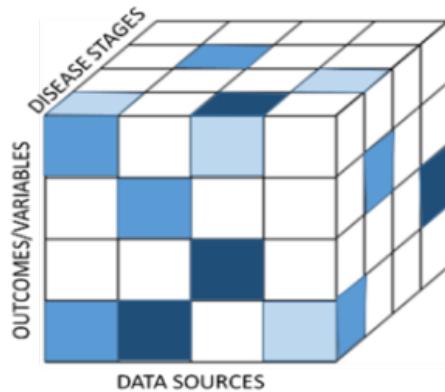
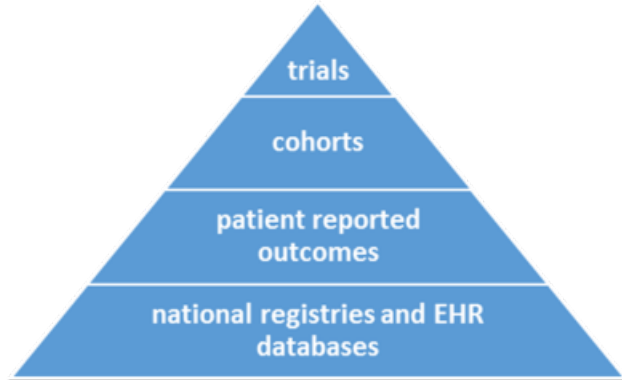
*Catherine Reed, Lilly*

*John Gallagher, UOXF*

[www.roadmap-alzheimer.org](http://www.roadmap-alzheimer.org)

- Develop a natural history model across disease stages
- Develop appropriate health economic and budget impact models
- Set new standards for the collation and evaluation of RWE to inform decisions





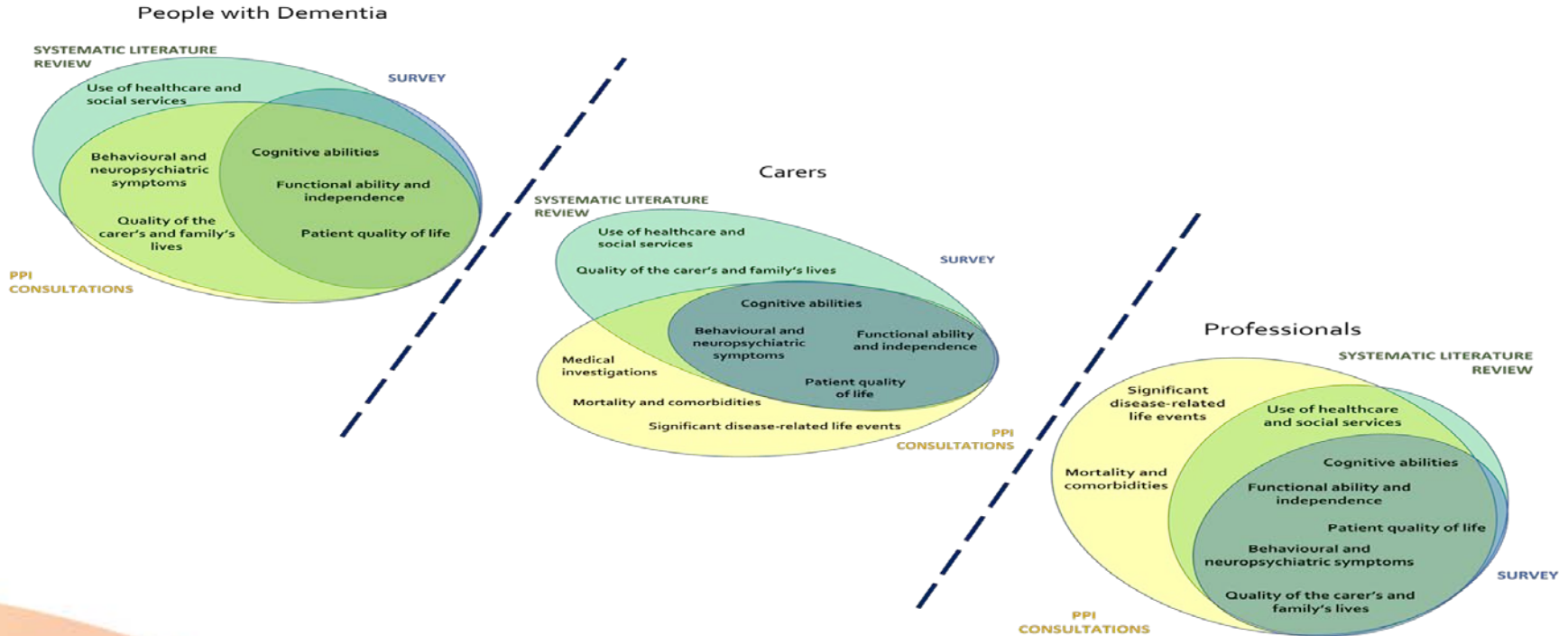
Leverage existing large data set to perform pilots

Characterize the natural disease history and economic model

Harmonize collation methods and analytical tools

- EMIF Catalogue
- Jerboa, Octopus, OMOP, OHDSI
- UKSeRP, SAIL, SHIP, CRIS
- Utrecht, UKB, DPUK
- IXICO's 'mehealth one'

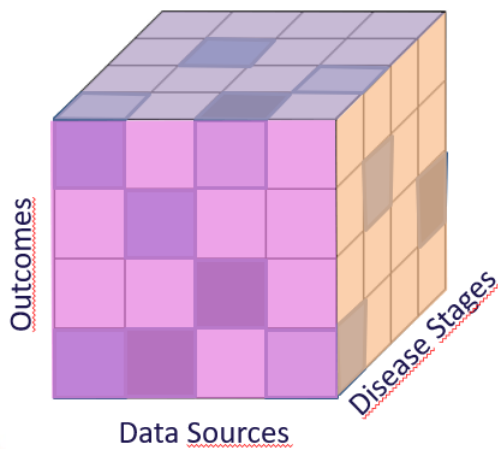
- Stakeholder generated lists of priority outcomes



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	✓	✓	✓	✓				✓	✓	✓	✓
				✓	✓	✓				✓	✓	✓	✓

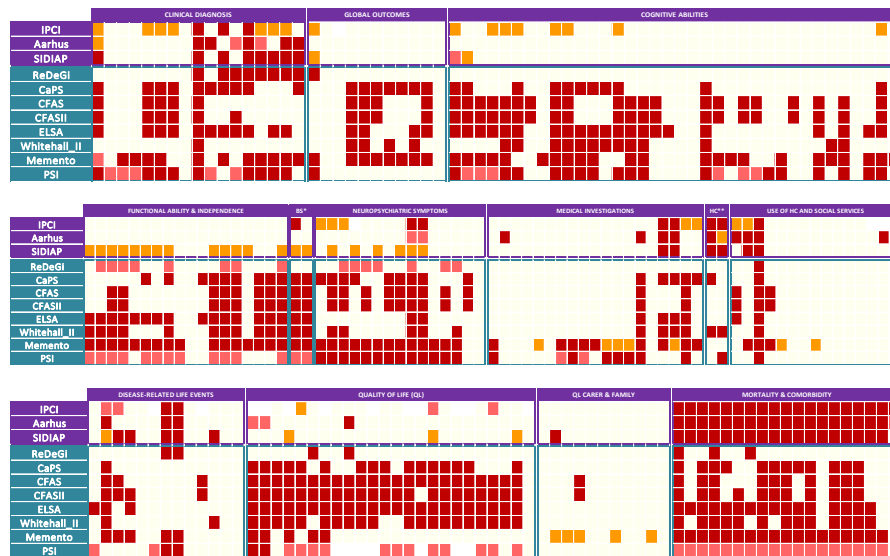
## Data Cube Workshop (Amsterdam, 07/03/2018)

- Concept behind the Cube, edges and facets
- WP2 to provide AD-outcomes
- WP3 to start populating the Cube



## 5<sup>th</sup> GAM (Barcelona, 25-26/04/2018)

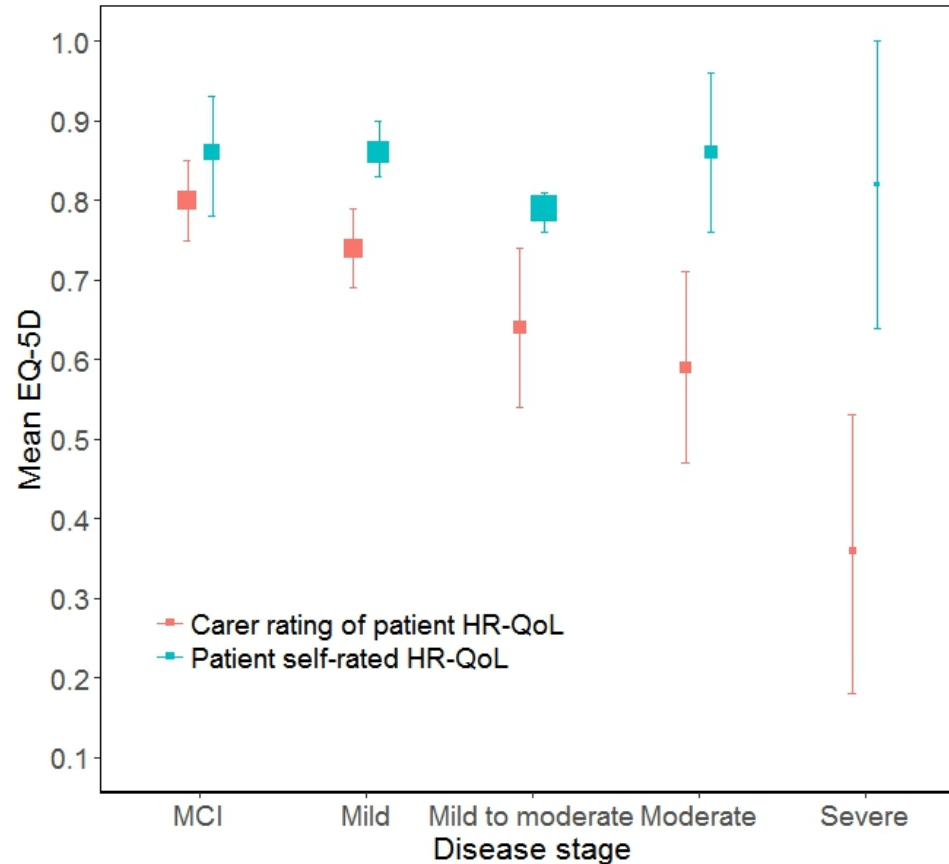
- Data availability Questionnaire
- First version of the AD-outcomes vs. Data sources facet





- Developed model validation pipeline
  - Fill in TRIPOD checklists → Specify SAP → Extract data locally (Jerboa) → Generate validation results (R script, Remote Research Environment)
- Applied pipeline to variety of data sources
  - EHRs (IPCI, SIDIAP), population cohort (Gothenburg), memory clinics (Girona, MEMENTO, ICTUS, EDAR)
  - Results indicate poor to moderate prediction for individual cases
- Also applied pipeline to development cohort (Kungsholmen)
  - Results show moderate prediction for individual cases

Meta-analysis of HRQoL measured using EQ-5D



- We know how to work together
  - demonstrated the ability of academic, industry, patients, and regulatory partners to work together on a highly complex, widely distributed, and tightly time constrained project
- We know where to go
  - established a broad-based and evidence based consensus on the priority outcomes for dementia treatment pathways
- We know what we know
  - Developed a comprehensive database of available European real world datasets (data cube)
- We know what we don't know
  - Demonstrated that the current evidence base is inadequate for disease progression modelling and detailed health economic evaluation.
- We know what to do
  - Made a strong case for the collection of new data that is designed for early detection and disease progression modelling

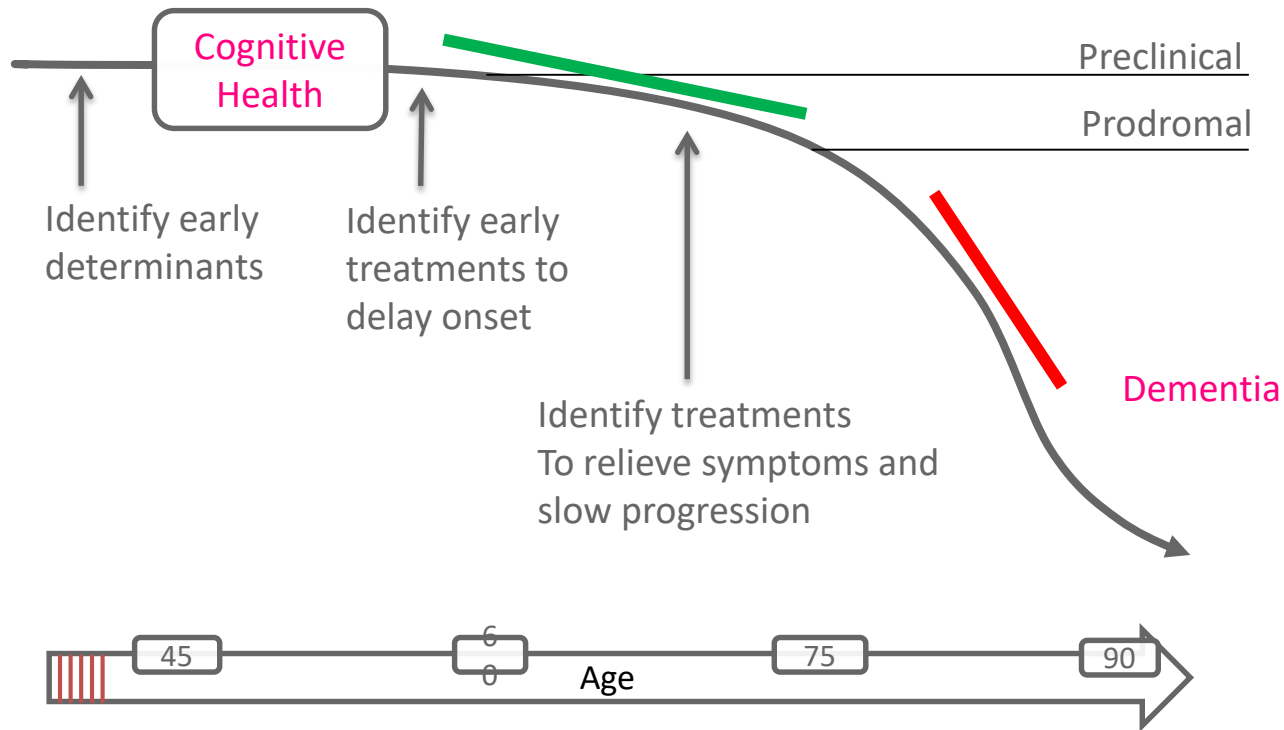
Available data sources to inform the real world trajectory and impact of AD are limited

- Lack of consensus on study design and endpoints in real world data sources
- Lack of AD-related outcomes in medical records relevant across the spectrum of disease
- Lack of clarity on how best to model of natural history of the disease using real world data sources

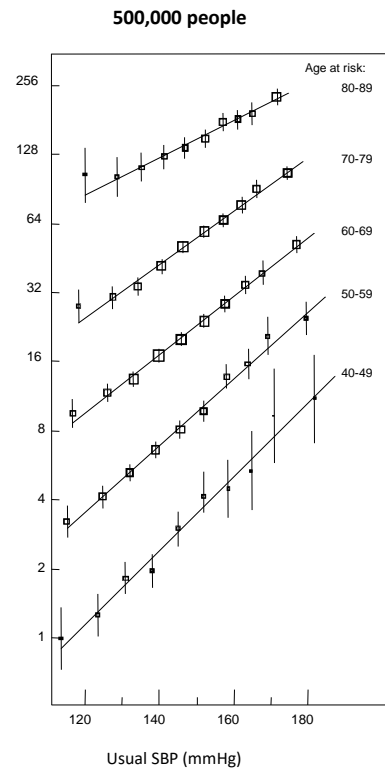
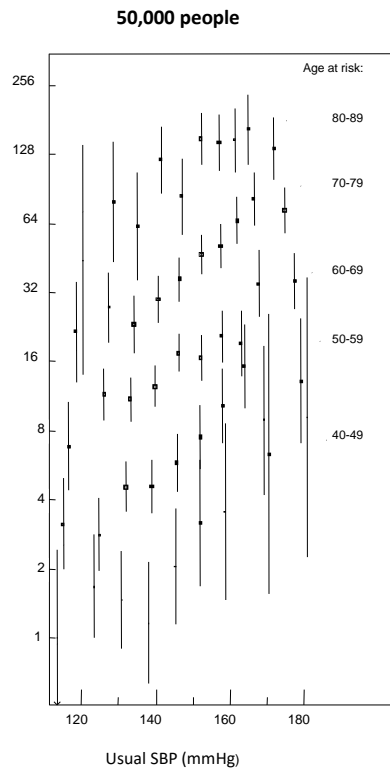
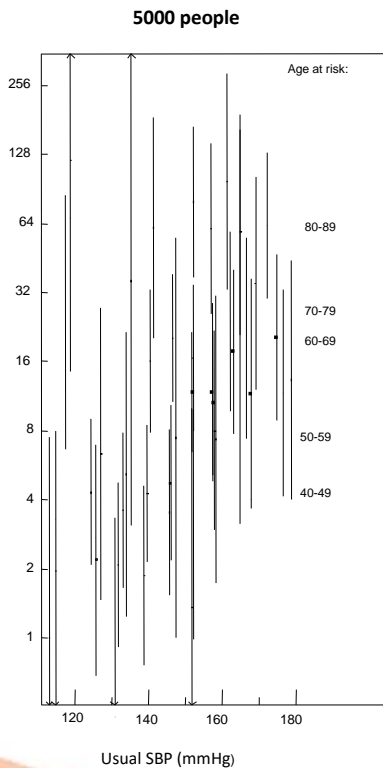
Diagnosis

- What is the question?
  - Generic (disease agnostic) datasets inadequate
- What are the (standard) measures?
  - Diverse measures perform poorly and are poorly understood
- How can we do this quickly?
  - Standardised cognitive assessment in cohorts
  - Standardised clinical assessments
  - Consent for recontact

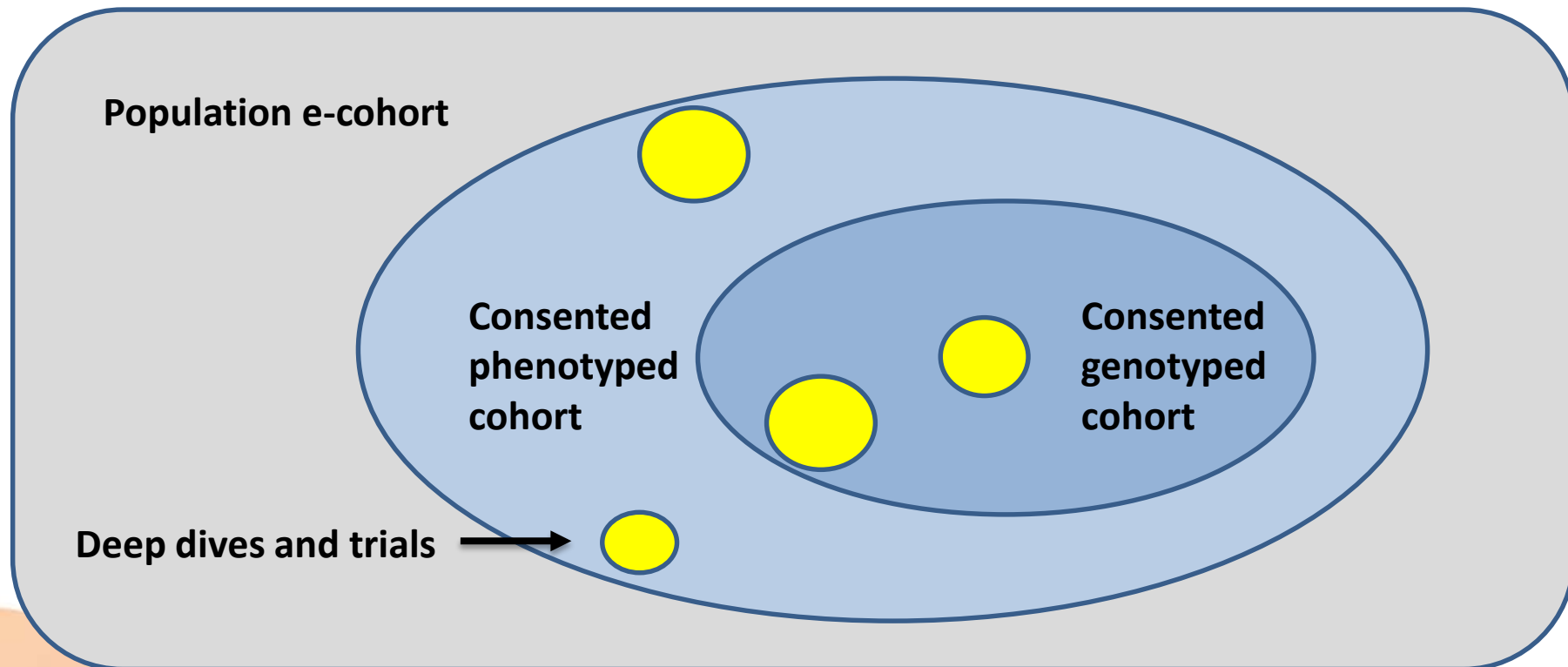
# ROADMAP The experimental medicine challenge



# The precision medicine challenge







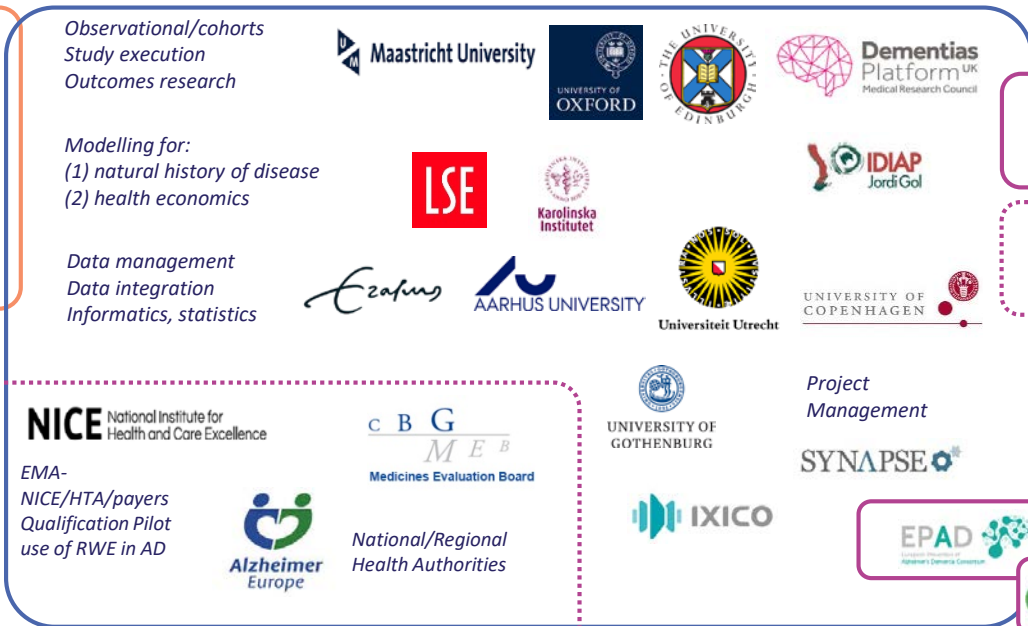
## Industrial consortium



## Public stakeholders



## Public consortium



## Associated Data Providers



## IMI-related projects

