Cohort Profiling
Work Package 1

Objective(s):

To provide the background information to develop a comprehensive epidemiologic platform for the dementias
1) Produce a summary of available background information on cohorts
2) To collect cohort meta data
3) To create cohort directory and matrix
4) Conduct a survey of DPUK cohorts

Overview Summary:

This work package consisted of foundational activities which led to the successful delivery of the Data Portal (see work package 2). Scoping exercises were performed to identify cohorts that could potentially form part of DPUK, together with relevant information on their participants and modes of operation. These details formed the basis for the successful set up of the Data Portal.

Executive Summary:

This work provided the foundation for much of the activity leading to the successful delivery of the Data Portal. After scoping the UK for suitable cohorts, the PIs and study teams were interviewed to gather critical information such as protocols, lab procedures, data structures and key outputs. This work formed the basis of an online brochure or fingerprint of each cohort, initially leveraging the EMIF cataloguing system. Once in place this was used to delve deeper into the cohort data structures to form the portal. This was a short lived work package build on by other parts of DPUK, particularly work package 2 (Data Portal).

Summary of Outputs: (as per Researchfish categories)

Publications: none

Collaborations & Partnerships

The cohorts originally joining DPUK at initial set-up are provided in a table at the end of this document.

Further Funding

None

Next Destinations

None

Engagement Activities

Multiple engagements with cohort PIs and Study Teams

Influence of policy, practice, patients & the public

None

Research Tools & Methods

The scoping methodology has been shared with similar initiatives including the Gates Ventures Alzheimer's Disease Data Interoperability (ADDI) Programme and cFOS consortium.

Research Databases & Models

Foundation for work package 2 (Data Portal).

Intellectual property & licencing
None
Medical products, interventions & clinical trials
None
Artistic & creative products
None
Software & technical products
None
Spin outs
None
Awards & recognition
None
Other outputs & knowledge/future steps
As above re influence on work package 2 activities.
Use of facilities & resources
None
Most successful outcome and what it means for future dementia research:
The successful launch and operation of the Data Portal, and its subsequent utility for dementia research, would not have been possible without the scoping exercises performed by this work package.
Lessons learned:
The main lesson learned was that there are substantial technical challenges in creating data portals but these are downstream of the quite marked human challenges of engaging with PIs and outlining the values of collaboration on a platform like DPUK i.e. addressing 'what is in it for me?' Conversations to engage cohorts and reiterate the value of entities such DPUK remain a key priority. Moreover, it is clear that the standards for cohort design and delivery have evolved and improved over time and data quality and governance from historic cohorts are obviously not the same as contemporary standards.
Other:
This was a critical work package that laid a solid foundation for the establishment of the data portal and a methodology that is once more being replicated by other groups currently.

	UKDP Cohorts	Primary Outcome	Size	Age at Recruitment	Follow-up	Genotyping	Cognitive tests	Biosamples	Imag-ing
Case-rich population cohorts	Million Women	Cancer	1.3M	50-64	10	x	-	x	-
	EPIC Norfolk	General	25K	40+	17	x	x	x	-
	CFAS I	Dementia	18K	65+	10	x	x	x	-
	CFASII	Dementia	12.5K	65+	2	x	x	x	-
	Aberdeen BC	General	12K	0	50	x	x	x	-
	ELSA	Ageing	12K	65+	10	x	x	x	-
	Whitehall 2	CHD	10K	35-55	30	x	x	x	x
	Caerphilly	CHD	2.5K	45-59	30	x	x	x	-
Prodromal population cohorts	UK Biobank cohort	General	500K	40-69	5	x	x	x	-
	UK Biobank imaging cohort	Dementia	100K	45-74	0	x	x	x	x
	Generation Scotland	General	24K	35-55	5	x	x	x	-
	NSHD (1946 BC)	General	5K	0	60	x	x	x	x
	Chariot	Dementia	9K	60-85	0	-	-	-	-
	SABRE	Dementia	5K	40-69	0	-	x	x	x
	CamCan	Dementia	3K	18-88	0	x	x	x	x
	Prevent	Dementia	750	40-59	0	x	x	x	x
Genetic at-risk cohorts	FAD	FAD	40	-	-	x	x	x	-
	Track-HD	HD	366	20-60	4	x	x	x	x
	MRC_ FTLD	FTD	117	-	-	x	x	x	x
	CamPaIGN	PD	142	40-85	10	x	x	-	-
	PICNIC	PD	274	40-85	4	x	x	x	x
	NIMROD	MCI	300	50+	3	-	-	-	-