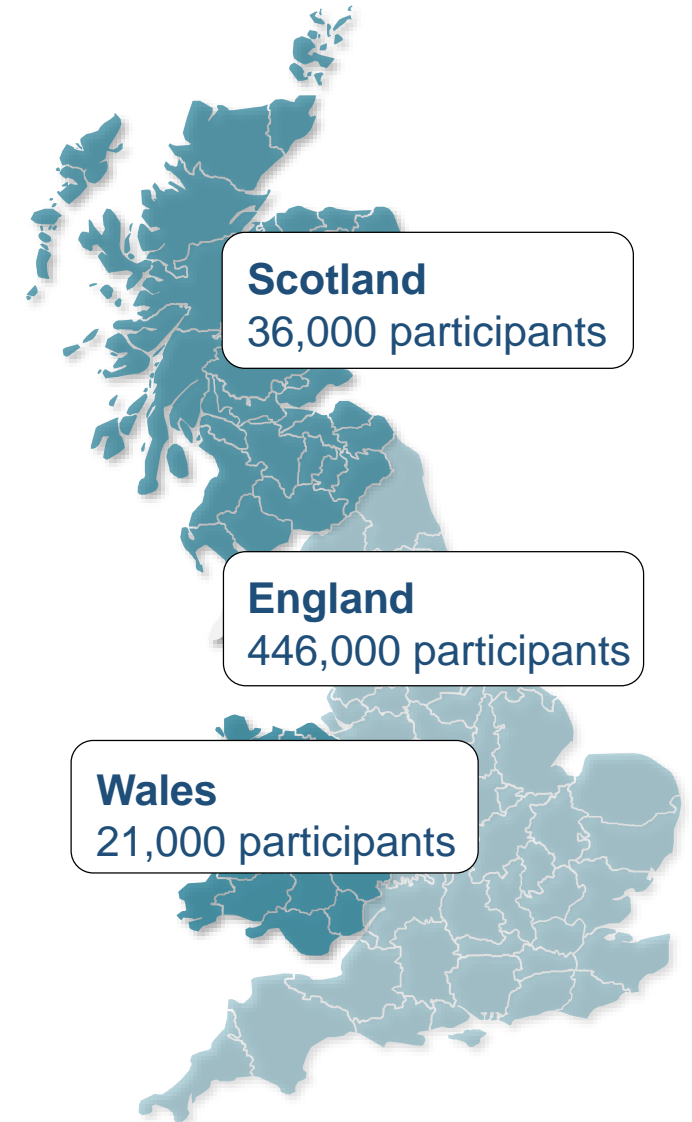


# Following the health of 0.5 million UK Biobank participants



## Follow-up of participants in very large prospective cohorts

**Aim:** identify a wide range of incident diseases and other health related outcomes

**Active methods** requiring participant re-engagement

- face to face reassessment
- postal or web-based surveys
- with electronic capture can acquire data very rapidly
- prone to incomplete coverage & selective loss to follow-up
- miss cases emerging between assessments

**Passive methods** via linkages to national health records

- can follow all participants without need for re-engagement
- should be efficient and cost effective
- broad consent at recruitment important
- rely on universal healthcare system & availability of relevant datasets
- can only detect cases of disease diagnosed in a healthcare setting
- data need to be accurate and sufficiently detailed for research studies

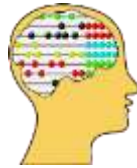
## Web Questionnaires



- Email for 350,000
- Every 6-12 months
- 30-50 % response



2011/12 - 24hr diet recall x4



2014/15 - Cognitive function



2015 - Occupational history



2016 - Mental health



2017 - Digestive health



2019 – Pain



2019 – Dietary preferences

**Next few years**

Cognitive function repeat

Sleep

Autistic traits

Mental health repeat

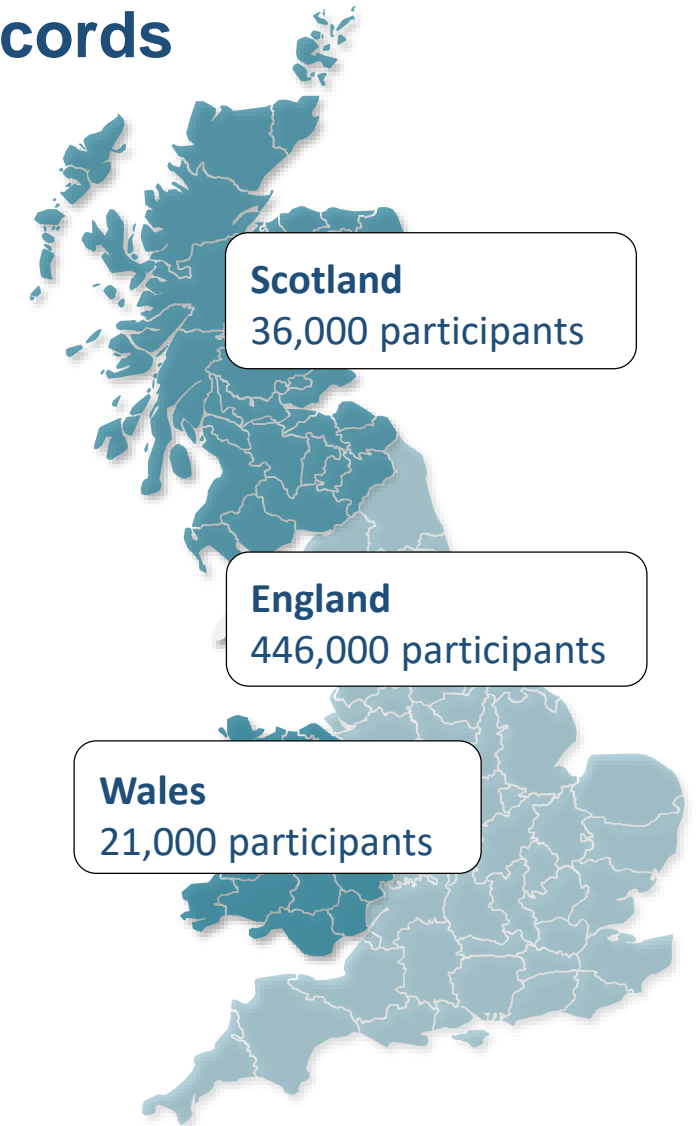
Moles

Healthy Aging

## Following the health of 0.5 million UK Biobank participants through linking to National Health Service (NHS) records

Regularly updated information on a wide range of diseases from NHS datasets in England, Scotland and Wales:

- Deaths - date and cause of death  
for all participants  
>20,000 by early 2018
- Cancers – date, stage and grade of cancer  
for all participants  
90,000 cancer cases by late 2017
- Admissions to hospital – dates, diagnoses, procedures  
for all participants  
1000's of cases of many incident diseases
- Primary care data – dates, diagnoses, symptoms, signs, referrals, prescriptions, labs etc  
currently about HALF of the participants  
1000's more cases of many incident diseases



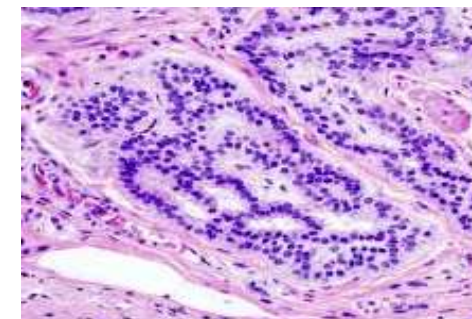
## A resource to study the causes of cancer: cancer cases ascertained from the national cancer registries

	Observed		Predicted
	By recruitment	Incident by 2015	Incident by 2022
Breast cancer	9,000	4,200	10,000
Colorectal cancer	2,300	2,500	7,000
Prostate cancer	3,000	4,300	9,000

→ Date, stage and grade of cancer

Piloting feasibility of additional regional linkages to:

- histopathology reports
- digitised histopathology slides
- tumour specimens



## Cohort-wide linked data: received & available for research

Data type	Diagnostic coding systems	Country	Data providers	Complete follow-up data received	Data available for research
Certified deaths by cause	ICD-10	England Wales	NHS Digital & ONS	2006-2018	-2017
		Scotland	Central Register & ISD	2006-2018	-2016
		England Wales	NHS Digital & Public Health England	1971-2018	-2017
Cancer registry and enhanced cancer data	ICD-9 & 10	Scotland	Central Register & ISD	1957-2018	-2016
		England	NHS Digital (HES)	1996-2018	-2017
		Wales	SAIL (PEDW)	1998-2018	-2016
Hospital admissions	ICD-9 & 10 OPCS3 & 4	Scotland	eDRIS, NSS (SMR)	1981-2018	-2016

## Additional datasets obtained / being explored / sought

Data Set	Current status
Outpatient	Received
Accident and Emergency	Received England & Scotland, in progress Wales
Diabetes Audit/Registry	Access agreed Scotland, in progress England & Wales
Infectious disease (microbiology data)	Access agreed Scotland, in progress England & Wales
Enhanced Critical Care	Agreement in progress
Renal Registry	Access agreed Scotland, in progress England & Wales
Stroke national audit	Access agreed Scotland, in progress England & Wales
National Joint Register	Being explored England
Cancer Screening	Being explored England, Scotland & Wales
MI national audit	Being explored England & Wales
Prescribing/dispensing data	Received Scotland
NHS radiology images	Being explored Scotland
NHS laboratory data	Watching brief

# If you would like to help or make suggestions

Data linkages: [Robin.Flaig@ed.ac.uk](mailto:Robin.Flaig@ed.ac.uk)

Web questionnaires: [jo.holliday@ndph.ox.ac.uk](mailto:jo.holliday@ndph.ox.ac.uk)



Funding bodies:

