

Data Access & Discovery

11:00 - 12:00

Thursday, 13 October 2022

HDRUK
Health Data Research UK

Health Data Research
Innovation Gateway



#HealthDataGateway

Agenda

- 11:00-11:15 Welcome and Introduction, Ruth Milne, HDR UK
- 11:15-11:35 John Nolan, Senior Health Data Scientist, BHF Data Science Centre
- 11:35-11:55 Fiachra Woodman, Chief Technology Officer, the Brain Tumour Charity
- 11:55-12:15 Questions to our panel:
 - John Nolan, Senior Health Data Scientist, BHF Data Science Centre
 - Fiachra Woodman, Chief Technology Officer, the Brain Tumour Charity
 - Reecha Sofat, Associate Director and Enhancing Cohorts Theme Lead, BHF Data Science Centre
 - Andrew Short, Managing Director, Medli
- 12:15 Close

House Rules

Welcome!

- **Transparency:** Anyone is free to use information from our discussion, particular comments will not be attributed to individuals
- **Optimism:** Providing contributions that are positive and solutions-focused
- **Respect:** Promoting a culture of tolerance and inclusivity
- **Courage:** Be prepared to try new things and challenge
- **Humility:** Learning and respecting others and their diverse views

To read our meeting guidelines and etiquette in full visit our website:

www.hdruc.ac.uk/news-opinion-events/events/

Working across sectors to make research happen in the UK



www.amrc.org.uk/news/new-animation-explains-how-the-charity-public-and-industry-sectors-help-make-research-happen

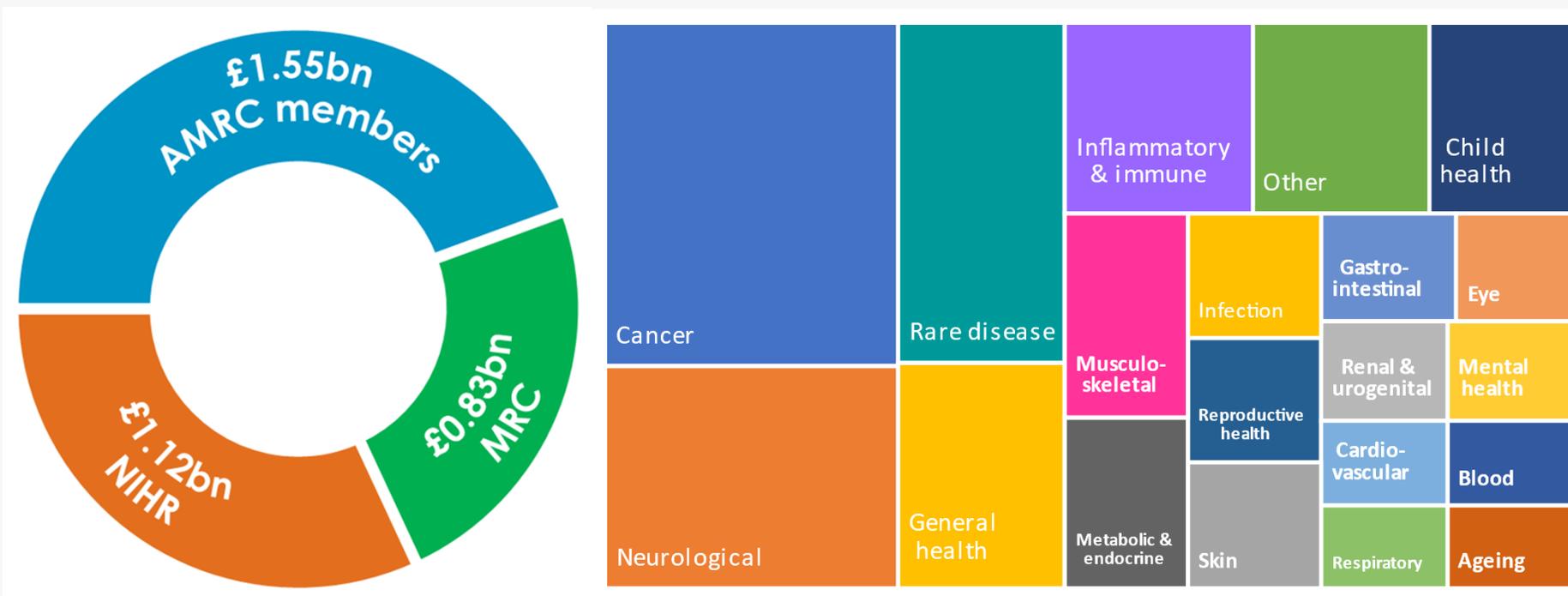
Medical Research Charities: 2021 Research Expenditure

How much did medical research charities spend on research in 2021?

- £750m
- £1.1bn
- £1.5bn
- £1.7bn



Charity funding is an essential component of UK medical research



Together, AMRC members are the top public funder of medical research in the UK

AMRC members fund essential research into a wide range of health conditions

20,000



researchers' salaries were funded by AMRC members in 2021, including 2,800 PhD students

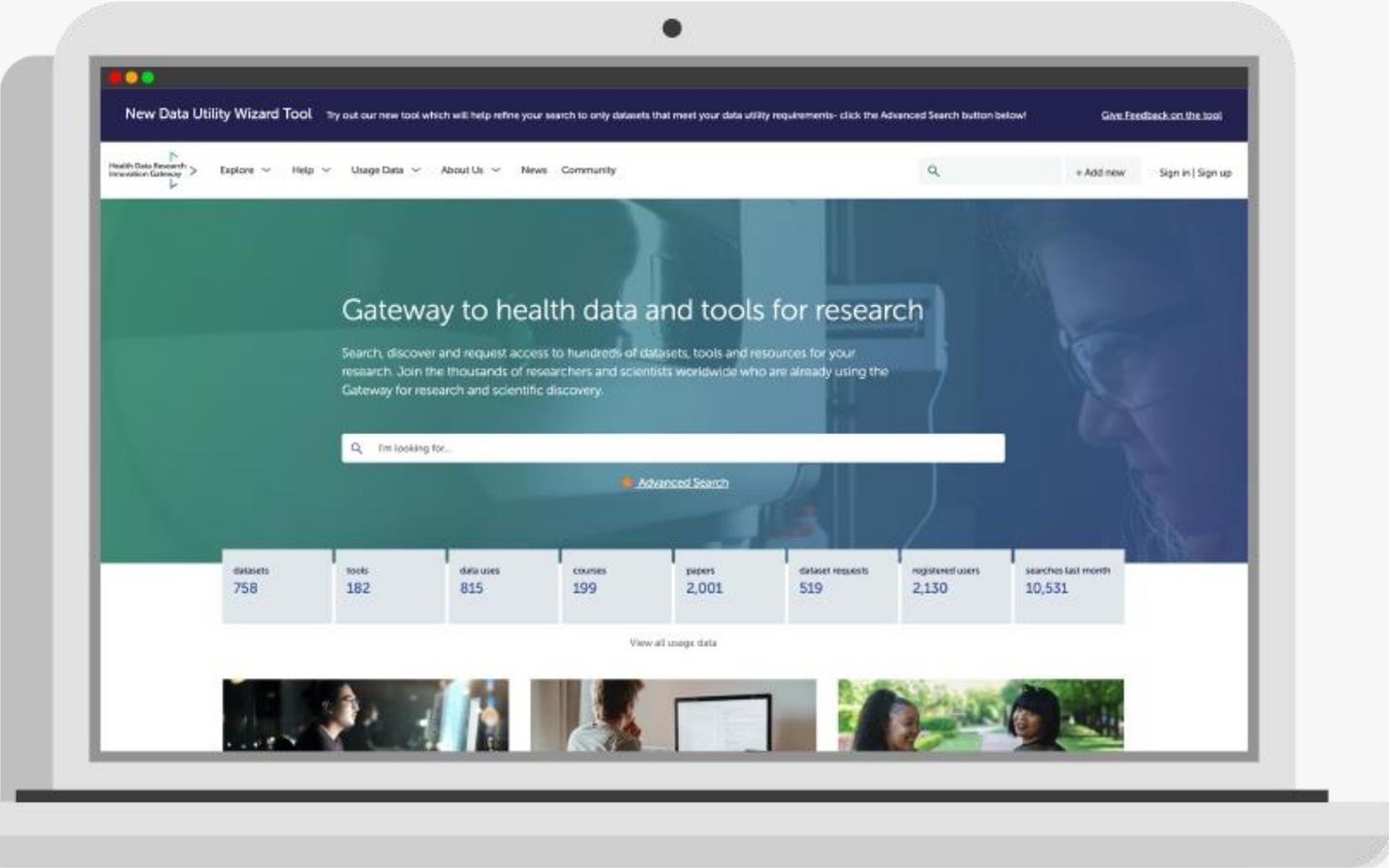
63%



of AMRC members co-funded research with other organisations in 2021

We are the national institute in the UK for health data science

Our mission is to unite the UK's health data to enable discoveries that improve people's lives.



DISCOVERY



ACCESS



TRANSPARENCY



PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

icnarc | intensive care
national audit &
research centre **25**
years and counting...

+
Our
Future
Health

HDRUK
Health Data Research UK

biobank^{uk}
Improving the health of future generations

 **British Heart Foundation
Data Science Centre**
Led by Health Data Research UK

**Cystic
Fibrosis Trust**

RCGP Royal College of
General Practitioners
Research & Surveillance Centre

 **NCIMI**
National Consortium of
Intelligent Medical Imaging

 **UK
Brain
Banks
Network**
Leading Translational
Neuroscience Research

THE RENAL
ASSOCIATION
founded 1950 

**THE
BRAIN
TUMOUR
CHARITY**

 **Research
Data
Scotland**

 **HQIP**
Healthcare Quality
Improvement Partnership

 **CANCER
RESEARCH
UK**

ukhealthdata.org/members/

 **UK Health Data
Research Alliance**  **Health Data Research
Innovation Gateway**

Charity datasets on the Gateway

2019 UK Parkinson's Audit - Elderly care and neurology

✓ PARKINSONS UK

Metadata last updated: 27/09/2021 ?



Platinum metadata

Publishing frequency: OTHER ?

Dataset Secondary care geriatrician neurologist Parkinson's specialist nurse

Show ▾

The dataset contains data provided by specialist elderly care and neurology services on the configuration of their service (service audit) and on the care provided to individual patients in connection with their Parkinson's (patient audit)

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

2019 UK Parkinson's Audit - Occupational therapy

✓ PARKINSONS UK

Metadata last updated: 15/10/2021 ?



Platinum metadata

Publishing frequency: STATIC ?

Dataset occupational therapist rehabilitation reablement

The dataset contains data provided by occupational therapy services on the configuration of their service (service audit) and the care provided to individual patients in connection with their Parkinson's (patient audit).

web.www.healthdatagateway.org/search?search=&datasetpublisher=PARKINSONS%20UK&tab=Datasets

2019 UK Parkinson's Audit - Patient Reported Experience Measure (PREM)

✓ PARKINSONS UK

Metadata last updated: 22/10/2021 ?



Platinum metadata

Publishing frequency: STATIC ?

Dataset Access Information Provision Inpatient Medication Carers

The dataset contains data provided by 8247 people affected by Parkinson's (or by their carer on their behalf) attending 451 services participating in the audit on their experiences of the whole of their Parkinson's service.



Charity datasets on the Gateway

UK Renal Registry - Kidney PREM dataset

✓ RENAL ASSOCIATION

Metadata last updated: 26/05/2021 ?



Platinum metadata

Publishing frequency: ANNUAL ?

Dataset UK Renal Registry kidney failure CKD Chronic kidney disease (disorder) Show ▼

Anonymous patient-level data for adults with CKD or an AKI on dialysis who are under the care of NHS hospital renal centres in England, Northern Ireland, Scotland and Wales. The data are collected annually via a national survey.



UK Renal Registry - CKD and AKI on Dialysis Dataset

✓ RENAL ASSOCIATION

Metadata last updated: 26/05/2021 ?



Platinum metadata

Publishing frequency: ANNUAL ?

Dataset Chronic kidney disease (disorder) Acute kidney injury Transplant Show ▼

Patient-level data for adults and children with chronic kidney disease (CKD) or adults with an acute kidney injury (AKI) on dialysis who are under the care of NHS hospital renal centres in England, Northern Ireland, Scotland and Wales.

web.www.healthdatagateway.org/search?search=&datasetpublisher=RENAL%20ASSOCIATION&tab=Datasets

UK Renal Registry - COVID-19 dataset

✓ RENAL ASSOCIATION

Metadata last updated: 25/05/2021 ?



Platinum metadata

Publishing frequency: MONTHLY ?

Dataset UK Renal Registry Chronic kidney disease (disorder) Acute kidney injury CKD AKI Show ▼

Patient-level data for adults and children with CKD or adults with an AKI on dialysis who are under the care of NHS hospital renal centres in England, Northern Ireland and Wales and who have a positive laboratory test for SARS-CoV-2.



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Data Access and Discovery: BHF Data Science Centre

John Nolan
Senior Health Data Scientist, BHF Data Science Centre

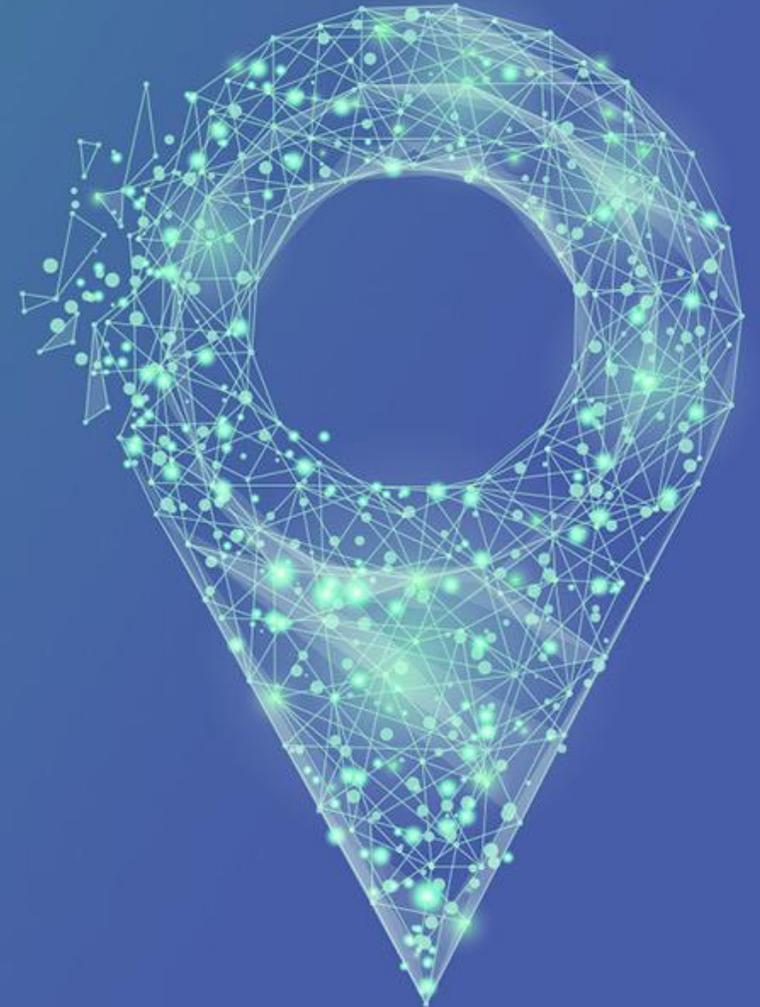
18/10/2022



The Medli Platform

Fiachra Woodman
Chief Technology Officer, the Brain Tumour Charity

18/10/2022



A Q&A with...

John Nolan

Senior Health Data Scientist, BHF Data Science Centre

Fiachra Woodman,

Chief Technology Officer, the Brain Tumour Charity

Reecha Sofat

Enhancing Cohorts Theme Lead, BHF Data Science Centre

Andrew Short

Managing Director, Medli



**Thanks for attending.
We hope to see you again soon!**

