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University of Cambridge study of public opinion on sharing data from UK health services for clinical and research purposes

Submission date	Recruitment status	[X] Prospectively registered
13/01/2020	No longer recruiting	[X] Protocol
Registration date	**Overall study status**	[X] Statistical analysis plan
17/01/2020	Completed	[X] Results
Last Edited	**Condition category**	[X] Individual participant data
20/03/2023	Other	

Plain English summary of protocol

Background and study aims.
This study is an anonymous online survey to establish patient and public views on the sharing of identifiable health data for clinical purposes, and de-identified health data for research within the UK. By health data we mean any information collected about a person's health, including things like medical notes, blood test results, etc. This may have personal information such as names and addresses attached (identifiable), or personal information removed (de-identified). Currently there is only limited sharing of health data for clinical purposes via implicit consent across the NHS. Recent reviews of public attitudes to using patient health data for research found little research about how acceptable it is to share patient health data for groups with specific health conditions, and that sharing some types of sensitive data (on mental health, sexual health, sexuality, religion, etc.) held greater concern than for other types of data. This study seeks opinions on whether the public holds different views about the sharing of mental versus physical health data, and, in the context of research, about structured versus "free text" de-identified data. It will also seek views about a national consent form, about data linkage for research, and about a national web portal to sign up to be contacted about health research. The study aims to recruit >1000 people over 6 months.

Who can participate?
The survey is open to anyone residing in the UK over the age of 16 (or under 16 with parental permission) who can access the online survey.

What does the study involve?
Completing an online survey. The survey takes about 18-25 minutes to complete but does not have to be completed in one sitting. It does ask questions about the respondent's own physical and mental health, and some personal demographics, but all questions have a "prefer not to answer" choice.

What are the possible benefits and risks of participating?
There are potential future benefits to others via the research, but no direct benefits to participants. No risks to participants are anticipated.

Where is the study run from?
University of Cambridge (UK)

When is the study starting and how long is it expected to run for?
March 2019 to December 2020

Who is funding the study?
Medical Research Council (MRC) (UK)

Who is the main contact?
Mrs Linda Jones
laj28@cam.ac.uk

Contact information

Type(s)
Scientific

Contact name
Dr Rudolf Cardinal

ORCID ID
https://orcid.org/0000-0002-8751-5167

Contact details
Chief Investigator
Department of Psychiatry
University of Cambridge
Behavioural and Clinical Neuroscience Institute
Sir William Hardy Building
Downing Site
Cambridge
United Kingdom
CB2 3EB
+44 (0)1223 768501
rnc1001@cam.ac.uk

Type(s)
Public

Contact name
Mrs Linda Jones

Contact details
Study Co-ordinator
University of Cambridge
Department of Psychiatry
Behavioural and Clinical Neuroscience Institute
Sir William Hardy Building
Downing Site

Cambridge
United Kingdom
CB2 3EB
+44 (0)1223 764670
laj28@cam.ac.uk

Additional identifiers

Integrated Research Application System (IRAS)
268811

Central Portfolio Management System (CPMS)
44205

Study information

Scientific Title
University of Cambridge NHS health data consent survey

Study objectives
Null hypotheses include:
1. The public's views on sharing mental health data will not differ from their views regarding physical health data
2. Their views on sharing will be uninfluenced by recipient type (e.g. NHS, academia, commercial researchers), or their own situation (demographics, experience of mental/physical health services)
3. Their views on sharing structured (coded) data for research will not differ from those on sharing de-identified free-text (narrative) data

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 20/12/2019, East of Scotland Research Ethics Service (Tayside Medical Science Centre, Residency Block Level 3, George Pirie Way, Ninewells Hospital and Medical School, Dundee, DD1 9S, UK; Tel: +44 (0)1382 383878; Email: eosres.tayside@nhs.net), REC ref: 19/ES/0144

Primary study design
Observational

Study design
Observational; Design type: Cross-sectional

Study type(s)
Other

Health condition(s) or problem(s) studied
Health data sharing

Interventions

This study is an anonymous online survey to establish patient and public views on the sharing of identifiable health data for clinical purposes, and de-identified health data for research within the UK. Currently, there is limited sharing of health data for clinical purposes via implicit consent across the National Health Service (NHS; HSC in Northern Ireland). Recent literature reviews of public attitudes to using patient health data for research noted there were few studies relating to the acceptability of sharing patient health data for groups with specific health conditions, and that sharing some types of sensitive data (on mental health, sexual health, sexuality, religion, etc.) held greater concern than for other types of data.

In conjunction with the study team's research advisory group, made up of mental health service users and carers, an online survey has been designed to seek public views on data sharing across the UK and the design of a unified consent form. The survey has been thoroughly tested by members of the public, both with and without mental health conditions.

Participants living in the UK will be invited to take part in the survey through advertising leaflets, posters and postcards as well as messages for social media. The study team also hope to use the NHS National Institute for Health Research (NIHR) Clinical Research Network (CRN) to reach out across the UK. The team will engage with other MRC MHDP-funded university sites and UK charities to promote the survey. Local media (radio, TV, and written) will be approached with the hope that it may gain some national coverage. The study team also have contacts in other hospitals and universities across the UK. ‘Pop-ups’ in towns and cities may be used, as well as stands at local and national events.

Participants will enter, consent, and complete the survey online (pilot work indicates that this takes 18-25 minutes). There is no contact from the University of Cambridge study team to the participants, unless they wish to receive the results of the survey or contact the study team directly themselves. Once the survey has been completed by the participant, their involvement in the study ends.

For one question in the survey, the team have superimposed a randomised intervention, namely a framing statement, prior to seeking views relating to the sharing of mental versus physical health data. The framing statement will be one of three: a "security" framing emphasising previous work reporting others' greater concerns about sharing mental health data versus other kinds of health data; a "neutral" statement; and a "holistic" framing emphasising the interrelationship between mental and physical illness. Randomisation to the three framing statements will be in a 1:1:1 ratio, without stratification.

The study team hope to complete the survey over 6 months with an aim to produce the final report within 3 months of the study closing.

Intervention Type
Other

Primary outcome(s)
Views on how health data may be shared across the UK, how these are related to demographic variables, and how opinions on sharing mental versus physical health data are affected by the framing of risk versus benefit. All preferences in relation to data sharing will be measured using Likert-style scales, yielding interval/ordinal data on preferences (e.g. "very unlikely to share"/" strongly disagree" through to "very likely to share"). Self-reported overall degree of support for:
1. Sharing physical health data for NHS clinical care without explicit consent each time, and how far such sharing should extend
2. Likewise for mental health data

3. Sharing de-identified structured physical health data for research without explicit consent, and how far such sharing should extend (e.g. NHS, academic, charities, industry, publicly)
4. Likewise for mental health data
5. As for 3 but with de-identified free text data
6. As for 4 but with de-identified free text data
Measured using an online survey at a single timepoint

Key secondary outcome(s)
Views on the design of a national consent form and on whether there should be a separate national web portal for mental health research as well as views on data linkage. Secondary measures will include:
1. The effect of the framing interventions
2. The degree of support for a single national sign-up mechanism for sharing one's health data for clinical care and/or research
3. Views on a prototype national NHS data sharing consent form
4. Views on trusted-third-party linkages between health data and a range of other UK state-held data sources (e.g. education, criminal justice)
Measured using an online survey at a single timepoint

Completion date
31/12/2020

Eligibility

Key inclusion criteria
1. Participant is willing and able to give informed consent for participation in the study
2. Participant currently resides in the UK
3. Participant is able to access the online survey

Participant type(s)
All

Healthy volunteers allowed
No

Age group
Adult

Sex
All

Total final enrolment
29275

Key exclusion criteria
Under 16 years of age without parent or guardian permission (the researchers have put 8 as a lower age limit as one is required; they would not wish to exclude anyone with parental permission on the basis of age but the numbers of participants < 16 is likely to be very low)

Date of first enrolment

21/01/2020

Date of final enrolment
30/09/2020

Locations

Countries of recruitment
United Kingdom

England

Scotland

Study participating centre
Cambridgeshire and Peterborough NHS Foundation Trust
Elizabeth House
Fulbourn Hospital
Cambridge Road
Fulbourn
Cambridge
United Kingdom
CB21 5EF

Study participating centre
The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
Royal Bournemouth General Hospital
Castle Lane East
Bournemouth
United Kingdom
BH7 7DW

Study participating centre
North Staffordshire Combined Healthcare NHS Trust
Bellringer Road
Trentham
Stoke-On-Trent
United Kingdom
ST4 8HH

Study participating centre
North Staffordshire Combined Healthcare NHS Trust
Bellringer Road

Trentham
Stoke-On-Trent
United Kingdom
ST4 8HH

Study participating centre
Norfolk and Suffolk NHS Foundation Trust
Hellesdon Hospital
Drayton High Road
Norwich
United Kingdom
NR6 5BE

Study participating centre
Salisbury NHS Foundation Trust
Salisbury District Hospital
Odstock Road
Salisbury
United Kingdom
SP2 8BJ

Study participating centre
Kent and Medway NHS and Social Care Partnership Trust
Farm Villa
Hermitage Lane
Maidstone
United Kingdom
ME16 9PH

Study participating centre
Sherwood Forest Hospitals NHS Foundation Trust
Mansfield Road
Sutton-In-Ashfield
United Kingdom
NG17 4JL

Study participating centre
Royal Cornwall Hospitals NHS Trust
Royal Cornwall Hospital
Treliske
Truro

United Kingdom
TR1 3LJ

Study participating centre
East Lancashire Hospitals NHS Trust
Royal Blackburn Hospital
Haslingden Road
Blackburn
United Kingdom
BB2 3HH

Study participating centre
Worcestershire Acute Hospitals NHS Trust
Worcestershire Royal Hospital
Charles Hastings Way
Worcester
United Kingdom
WR5 1DD

Study participating centre
Worcestershire Health and Care NHS Trust
Isaac Maddox House
Shrub Hill
Industrial Estate
Worcester
United Kingdom
WR4 9RW

Study participating centre
Airedale NHS Foundation Trust
Airedale General Hospital
Skipton Road
Steeton
Keighley
United Kingdom
BD20 6TD

Study participating centre
Taunton and Somerset NHS Foundation Trust
Musgrove Park Hospital
Taunton

United Kingdom
TA1 5DA

Study participating centre
University Hospital Southampton NHS Foundation Trust
Mailpoint 18
Southampton General Hospital
Tremona Road
Southampton
United Kingdom
SO16 6YD

Study participating centre
Somerset Partnership NHS Foundation Trust
2nd Floor
Mallard Court
Express Park
Bristol Road
Bridgwater
United Kingdom
TA6 4RN

Study participating centre
Dorset Healthcare University NHS Foundation Trust
Sentinel House
4-6 Nuffield Road
Nuffield Industrial Estate
Poole
United Kingdom
BH17 0RB

Study participating centre
University Hospitals Plymouth NHS Trust
Derriford Hospital
Derriford Road
Plymouth
United Kingdom
PL6 8DH

Study participating centre

University Hospitals Birmingham NHS Foundation Trust
Trust HQ, PO Box 9551
Queen Elizabeth Medical Centre
Edgbaston
Birmingham
United Kingdom
B15 2TH

Study participating centre
Dudley and Walsall Mental Health Partnership NHS Trust
Trafalgar House
47-49 King Street
Dudley
United Kingdom
DY2 8PS

Study participating centre
East Suffolk and North Essex NHS Foundation Trust
Colchester District General Ho
Turner Road
Colchester
United Kingdom
CO4 5JL

Study participating centre
Tameside and Glossop Integrated Care NHS Foundation Trust
Tameside General Hospital
Fountain Street
Ashton-Under-Lyne
United Kingdom
OL6 9RW

Study participating centre
Nottinghamshire Healthcare NHS Foundation Trust
The Resource
Trust HQ
Duncan Macmillan House
Porchester Road
Nottingham
United Kingdom
NG3 6AA

Study participating centre
Avon and Wiltshire Mental Health Partnership NHS Trust
Jenner House
Avon Way
Langley Park
Chippenham
United Kingdom
SN15 1GG

Study participating centre
Nottingham University Hospitals NHS Trust
Trust Headquarters
Queens Medical Centre
Derby Road
Nottingham
United Kingdom
NG7 2UH

Study participating centre
Surrey and Borders Partnership NHS Foundation Trust
18 Mole Business Park
Randalls Road
Leatherhead
United Kingdom
KT22 7AD

Study participating centre
Birmingham and Solihull Mental Health NHS Foundation Trust
Unit 1
50 Summer Hill Road
Birmingham
United Kingdom
B1 3RB

Study participating centre
James Paget University Hospitals NHS Foundation Trust
Lowestoft Road
Gorleston
Great Yarmouth
Norfolk
United Kingdom
NR31 6LA

Study participating centre
The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust
Queen Elizabeth Hospital
Gayton Road
Kings Lynn
United Kingdom
PE30 4ET

Study participating centre
Norfolk and Norwich University Hospitals NHS Foundation Trust
Colney Lane
Colney
Norwich
United Kingdom
NR4 7UY

Study participating centre
Derbyshire Healthcare NHS Foundation Trust
Trust Headquarters
Kingsway Hospital
Kingsway
Derby
United Kingdom
DE22 3LZ

Study participating centre
The Royal Orthopaedic Hospital NHS Foundation Trust
The Woodlands
Bristol Road South
Northfield
Birmingham
United Kingdom
B31 2AP

Study participating centre
Hertfordshire Partnership University NHS Foundation Trust
99 Waverley Road
St. Albans
United Kingdom
AL3 5TL

Study participating centre
Bedford Hospital NHS Trust
South Wing
Kempston Road
Bedford
United Kingdom
MK42 9DJ

Study participating centre
Royal Papworth Hospital NHS Foundation Trust
Papworth Everard
Cambridge
United Kingdom
CB23 3RE

Study participating centre
Lincolnshire Partnership NHS Foundation Trust
Units 8 & 9
The Point
Lions Way
Sleaford
United Kingdom
NG34 8GG

Study participating centre
Leicestershire Partnership NHS Trust
Riverside House
Bridge Park Plaza
Bridge Park Road
Thurmaston
Leicester
United Kingdom
LE4 8PQ

Study participating centre
Cambridgeshire Community Services NHS Trust
Unit 3
Meadow Lane
St. Ives
United Kingdom
PE27 4LG

Study participating centre
East of England Ambulance Service NHS Trust
Ambulance Station
Hospital Lane
Hellesdon
Norwich
United Kingdom
NR6 5NA

Study participating centre
Bridgewater Community Healthcare NHS Foundation Trust
Bevan House
17 Beecham Court
Wigan
United Kingdom
WN3 6PR

Study participating centre
Torbay and South Devon NHS Foundation Trust
Hengrave House
Torbay Hospital
Newton Road
Torquay
United Kingdom
TQ2 7AA

Study participating centre
Cornwall Partnership NHS Foundation Trust
Porthpean Road
St Austell
United Kingdom
PL26 6AD

Study participating centre
Pennine Acute Hospitals NHS Trust
Trust Headquarters
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester

United Kingdom
M8 5RB

Study participating centre
North East London NHS Foundation Trust
West Wing
C E M E Centre
Marsh Way
Rainham
United Kingdom
RM13 8GQ

Study participating centre
Southern Health NHS Foundation Trust
Maples Buildings
Tatchbury Mount Hospital
Calmore
Southampton
United Kingdom
SO40 2RZ

Study participating centre
Essex Partnership University NHS Foundation Trust
The Lodge
Runwell Chase
Runwell
Wickford
United Kingdom
SS11 7XX

Study participating centre
Salford Royal NHS Foundation Trust
Salford Royal
Stott Lane
Salford
United Kingdom
M6 8HD

Study participating centre
Midlands Partnership NHS Foundation Trust
Trust Headquarters

St. Georges Hospital
Corporation Street
Stafford
United Kingdom
ST16 3SR

Study participating centre
Pennine Care NHS Foundation Trust
225 Old Street
Ashton-Under-Lyne
Lancashire
United Kingdom
OL6 7SR

Study participating centre
Norfolk Community Health and Care NHS Trust
Norwich Community Hospital
Bowthorpe Road
Norwich
United Kingdom
NR2 3TU

Study participating centre
Coventry and Warwickshire Partnership NHS Trust
Wayside House
Wilsons Lane
Coventry
United Kingdom
CV6 6NY

Study participating centre
Calderdale and Huddersfield NHS Foundation Trust
Royal Infirmary
Acre Street
Huddersfield
United Kingdom
HD3 3EA

Study participating centre
Wye Valley NHS Trust
County Hospital

Union Walk
Hereford
United Kingdom
HR1 2ER

Study participating centre
Greater Manchester Mental Health NHS Foundation Trust
Prestwich Hospital
Bury New Road
Prestwich
Manchester
United Kingdom
M25 3BL

Study participating centre
Devon Partnership NHS Trust
Wonford House Hospital
Dryden Road
Exeter
United Kingdom
EX2 5AF

Study participating centre
North West Ambulance Service NHS Trust
Ladybridge Hall
399 Chorley New Road
Bolton
United Kingdom
BL1 5DD

Study participating centre
Solent NHS Trust
Solent NHS Trust Headquarters
Highpoint Venue
Bursledon Road
Southampton
United Kingdom
SO19 8BR

Study participating centre

Isle of Wight NHS Trust
St Mary's Hospital
Parkhurst Road
Newport
United Kingdom
PO30 5TG

Study participating centre
Central London Community Healthcare NHS Trust
Ground Floor
15 Marylebone Road
London
United Kingdom
NW1 5JD

Study participating centre
Oxford University Hospitals NHS Foundation Trust
John Radcliffe Hospital
Headley Way
Headington
Oxford
United Kingdom
OX3 9DU

Study participating centre
Shrewsbury and Telford Hospital NHS Trust
Mytton Oak Road
Shrewsbury
United Kingdom
SY3 8XQ

Study participating centre
Walsall Healthcare NHS Trust
Manor Hospital
Moat Road
Walsall
United Kingdom
WS2 9PS

Study participating centre

Berkshire Healthcare NHS Foundation Trust
Fitzwilliam House
Skimped Hill Lane
Bracknell
United Kingdom
RG12 1BQ

Study participating centre
University Hospitals Coventry and Warwickshire NHS Trust
Walsgrave General Hospital
Clifford Bridge Road
Coventry
United Kingdom
CV2 2DX

Study participating centre
Black Country Partnership NHS Foundation Trust
Delta Point
Greets Green Road
West Bromwich
United Kingdom
B70 9PL

Study participating centre
The Royal Wolverhampton NHS Trust
New Cross Hospital
Wolverhampton Road
Heath Town
Wolverhampton
United Kingdom
WV10 0QP

Study participating centre
Portsmouth Hospitals NHS Trust
De La Court House
Queen Alexandra Hospital
Southwick Hill Road
Portsmouth
United Kingdom
PO6 3LY

Study participating centre
Sussex Partnership NHS Foundation Trust
Assessment and Treatment Centre
Chapel Street
Chichester
United Kingdom
PO19 1BX

Study participating centre
Hampshire Hospitals NHS Foundation Trust
Aldermaston Road
Basingstoke
United Kingdom
RG24 9NA

Study participating centre
The Christie NHS Foundation Trust
550 Wilmslow Road
Withington
Manchester
United Kingdom
M20 4BX

Study participating centre
University Hospitals of North Midlands NHS Trust
Newcastle Road
Stoke-On-Trent
United Kingdom
ST4 6QG

Study participating centre
North West Anglia NHS Foundation Trust
Edith Cavell Hospital
Bretton Gate
Bretton
Peterborough
United Kingdom
PE3 9GZ

Study participating centre

Oxford Health NHS Foundation Trust
Warneford Hospital
Warneford Lane
Headington
Oxford
United Kingdom
OX3 7JX

Study participating centre
Tees, Esk and Wear Valleys NHS Foundation Trust
Trust Headquarters
West Park Hospital
Edward Pease Way
Darlington
United Kingdom
DL2 2TS

Study participating centre
South Central Ambulance Service NHS Foundation Trust
7-8 Talisman Road
Bicester
United Kingdom
OX26 6HR

Study participating centre
East and North Hertfordshire NHS Trust
Lister Hospital
Coreys Mill Lane
Stevenage
United Kingdom
SG1 4AB

Study participating centre
South West London and St George's Mental Health NHS Trust
Springfield Hospital
61 Glenburnie Road
London
United Kingdom
SW17 7DJ

Study participating centre

Yeovil District Hospital NHS Foundation Trust
Yeovil District Hospital
Higher Kingston
Yeovil
United Kingdom
BA21 4AT

Study participating centre
NHS Greater Glasgow and Clyde
J B Russell House
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
United Kingdom
G12 0XH

Study participating centre
The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust
Gobowen
Oswestry
United Kingdom
SY10 7AG

Study participating centre
South Warwickshire NHS Foundation Trust
Warwick Hospital
Lakin Road
Warwick
United Kingdom
CV34 5BW

Study participating centre
The Hillingdon Hospitals NHS Foundation Trust
Pield Heath Road
Uxbridge
United Kingdom
UB8 3NN

Study participating centre
Southern Health NHS Foundation Trust
Maples Buildings

Tatchbury Mount Hospital
Calmore
Southampton
United Kingdom
SO40 2RZ

Study participating centre
The Rotherham NHS Foundation Trust
Moorgate Road
Rotherham
United Kingdom
S60 2UD

Study participating centre
York Teaching Hospital NHS Foundation Trust
York Hospital
Wigginton Road
York
United Kingdom
YO31 8HE

Study participating centre
West Suffolk NHS Foundation Trust
Hardwick Lane
Bury St Edmunds
United Kingdom
IP33 2QZ

Study participating centre
The Dudley Group NHS Foundation Trust
C Block
Russells Hall
Hospital
Pensnett Road
Dudley
United Kingdom
DY1 2HQ

Study participating centre
Gloucestershire Care Services NHS Trust
Edward Jenner Court

1010 Pioneer Avenue
Gloucester Business Pk
Brockworth
Gloucester
United Kingdom
GL3 4AW

Study participating centre
East Cheshire NHS Trust
Macclesfield District Gen Hospital
Victoria Road
Macclesfield
United Kingdom
SK10 3BL

Study participating centre
North Cumbria University Hospitals NHS Trust
West Cumberland Hospital
Hensingham
Whitehaven
United Kingdom
CA28 8JG

Study participating centre
Northern Devon Healthcare NHS Trust
North Devon District Hospital
Raleigh Park
Barnstaple
United Kingdom
EX31 4JB

Study participating centre
Lincolnshire Community Health Services NHS Trust
Beech House
Witham Park
Waterside South
Lincoln
United Kingdom
LN5 7JH

Study participating centre

Barnsley Hospital NHS Foundation Trust
Gawber Road
Barnsley
United Kingdom
S75 2EP

Study participating centre
Whittington Health NHS Trust
The Whittington Hospital
Magdala Avenue
London
United Kingdom
N19 5NF

Study participating centre
Cambridge University Hospitals NHS Foundation Trust
Addenbrookes Hospital
Hills Road
Cambridge
United Kingdom
CB2 0QQ

Study participating centre
East London NHS Foundation Trust
9 Alie Street
Aldgate
London
United Kingdom
E1 8DE

Study participating centre
Birmingham Community Healthcare NHS Foundation Trust
3, Priestley Wharf
Holt Street
Birmingham Science Park
Aston
Birmingham
United Kingdom
B7 4BN

Study participating centre

South Western Ambulance Service NHS Foundation Trust
Westcountry House
Abbey Court, Eagle Way
Sowton Industrial Estate
Exeter
United Kingdom
EX2 7HY

Study participating centre
Royal Brompton & Harefield NHS Foundation Trust
Royal Brompton Hospital
Sydney Street
London
United Kingdom
SW3 6NP

Study participating centre
George Eliot Hospital NHS Trust
Lewes House
College Street
Nuneaton
United Kingdom
CV10 7DJ

Study participating centre
Epsom and St Helier University Hospitals NHS Trust
St Helier Hospital
Wrythe Lane
Carshalton
United Kingdom
SM5 1AA

Study participating centre
Dorset County Hospital NHS Foundation Trust
Dorset County Hospital
Williams Avenue
Dorchester
United Kingdom
DT1 2JY

Study participating centre

St George's University Hospitals NHS Foundation Trust
St George's Hospital
Blackshaw Road
Tooting
London
United Kingdom
SW17 0QT

Study participating centre
Guy's and St Thomas' NHS Foundation Trust
Trust Offices
Guy's Hospital
Great Maze Pond
London
United Kingdom
SE1 9RT

Study participating centre
Croydon Health Services NHS Trust
Croydon University Hospital
London Road
Thornton Heath
United Kingdom
CR7 7YE

Study participating centre
NIHR CRN: North East and North Cumbria
United Kingdom
NE3 3HD

Study participating centre
NIHR CRN: North West Coast
United Kingdom
L7 8XP

Study participating centre
NIHR CRN: Yorkshire and Humber
United Kingdom
S10 2SB

Study participating centre
NIHR CRN: Greater Manchester
United Kingdom
M13 9WL

Study participating centre
NIHR CRN: East Midlands
United Kingdom
LE1 5WW

Study participating centre
NIHR CRN: West Midlands
United Kingdom
CV3 2TX

Study participating centre
NIHR CRN: West of England
United Kingdom
BS1 2NT

Study participating centre
NIHR CRN: Thames Valley and South Midlands
United Kingdom
OX3 9DU

Study participating centre
NIHR CRN: Eastern
United Kingdom
NR1 1QQ

Study participating centre
NIHR CRN: Kent, Surrey and Sussex
United Kingdom
ME8 0NZ

Study participating centre

NIHR CRN: Wessex
United Kingdom
SO30 2UN

Study participating centre
NIHR CRN: South West Peninsula
United Kingdom
PL6 8BX

Study participating centre
NIHR CRN: North Thames
United Kingdom
W1T 7HA

Study participating centre
NIHR CRN: South London
United Kingdom
SE1 9RT

Study participating centre
NIHR CRN: North West London
United Kingdom
W12 0HT

Sponsor information

Organisation
Cambridgeshire and Peterborough NHS Foundation Trust

Funder(s)

Funder type
Government

Funder Name
Medical Research Council; Grant Codes: MC_PC_17213

Alternative Name(s)
Medical Research Council (United Kingdom), UK Medical Research Council, Medical Research Committee and Advisory Council, MRC

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Funder Name
National Institute for Health Research (NIHR) (UK)

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study will be stored in a publicly available repository:
1. University of Cambridge Research Data Repository, https://www.data.cam.ac.uk/repository
2. Available from publication
3. Indefinitely
4. Public, unrestricted
5. Consent obtained from all participants for publication of anonymised data
6. Re anonymisation:
6.1. All e-mail addresses (given optionally for receipt of results) removed prior to final data set creation and analysis
6.2. All free-text data removed from raw data
6.3. Ages pre-blurred to ranges
6.4. All geographic indicators blurred to UK Lower Layer Super Output Area (LSOA) codes (England and Wales), Data Zones (Scotland), and Super Output Areas (Northern Ireland)

IPD sharing plan summary

Stored in repository

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		27/04/2022	11/05/2022	Yes	No
Dataset	Anonymised data from a 2020 UK survey of public opinion about sharing NHS health data for clinical and research purposes	16/07/2021	20/03/2023	No	No
HRA research summary			26/07/2023	No	No
Plain English results		18/10/2021	18/10/2021	No	Yes
Preprint results		19/07/2021	18/10/2021	No	No
Protocol file	version v4	19/12/2019	17/01/2020	No	No
Statistical Analysis Plan	statistical analysis plan is in the protocol version 4	19/12/2019	20/03/2023	No	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes