

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

<b>Submission date</b> 13/01/2020	<b>Recruitment status</b> No longer recruiting	<input checked="" type="checkbox"/> Prospectively registered <input checked="" type="checkbox"/> Protocol
<b>Registration date</b> 17/01/2020	<b>Overall study status</b> Completed	<input checked="" type="checkbox"/> Statistical analysis plan <input checked="" type="checkbox"/> Results
<b>Last Edited</b> 20/03/2023	<b>Condition category</b> Other	<input checked="" type="checkbox"/> Individual participant data

## 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

**Study website**  
<https://www.climbproject.org.uk/>

## Contact information

**Type(s)**  
Scientific

**Contact name**  
Dr Rudolf Cardinal

**ORCID ID**  
<http://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**

### **EudraCT/CTIS number**

Nil known

### **IRAS number**

268811

### **ClinicalTrials.gov number**

Nil known

### **Secondary identifying numbers**

CPMS 44205, IRAS 268811

## **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

### **Study design**

Observational; Design type: Cross-sectional

### **Primary study design**

Observational

## **Secondary study design**

Cross sectional study

## **Study setting(s)**

Internet/virtual

## **Study type(s)**

Other

## **Participant information sheet**

No participant information sheet available

## **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 measure**

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

## **Secondary outcome measures**

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

## **Overall study start date**

01/03/2019

## **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

**Age group**

Adult

**Sex**

Both

**Target number of participants**

Planned Sample Size: 1266; UK Sample Size: 1266

**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**

England

Scotland

United Kingdom

**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  
Greet's 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

### **Sponsor details**

Elizabeth House  
Fulbourn Hospital  
Cambridge Road  
Fulbourn  
Cambridge  
England  
United Kingdom  
CB21 5EF  
+44 (0)1223217418  
R&D@cpft.nhs.uk

### **Sponsor type**

Hospital/treatment centre

## **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, 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

**Publication and dissemination plan**

1. Peer-reviewed scientific journals
2. Internal report
3. Conference presentation
4. Publication on website
5. Other publication
6. Submission to regulatory authorities
7. Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

**Intention to publish date**

31/12/2021

**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?
<a href="#">Protocol file</a>	version v4	19/12/2019	17/01/2020	No	No
<a href="#">Plain English results</a>		18/10/2021	18/10/2021	No	Yes
<a href="#">Preprint results</a>		19/07/2021	18/10/2021	No	No
<a href="#">Results article</a>		27/04/2022	11/05/2022	Yes	No
<a href="#">Dataset</a>	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
<a href="#">Statistical Analysis Plan</a>	statistical analysis plan is in the protocol version 4	19/12/2019	20/03/2023	No	No
<a href="#">HRA research summary</a>			26/07/2023	No	No