



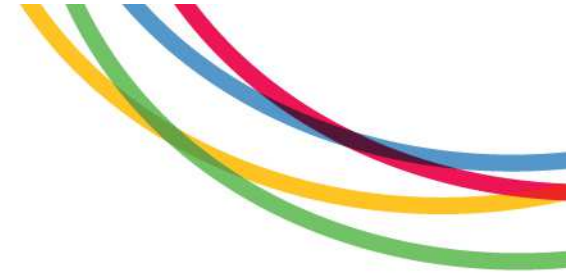
Understanding Society
THE UK HOUSEHOLD LONGITUDINAL STUDY

Getting informed consent to data linkage: The experience of the UK Household Longitudinal Study

An initiative by the Economic and Social Research Council, with scientific leadership by the Institute for Social and Economic Research, University of Essex, and survey delivery by the National Centre for Social Research.

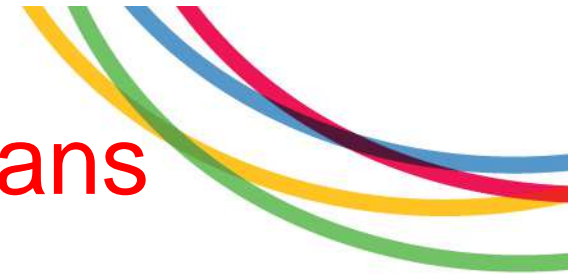


Understanding Society



- *Understanding Society*: The UK Household Longitudinal Study
 - UK – covers all of the UK
 - Household – interviews with all adults and children aged 10-15 in the household
 - Longitudinal – returns each year to contact, follow and re-interview
 - Sample
 - New representative sample of 26,000 households
 - Additional 4,080 ethnic minority boost households
 - Additional 8,100 households from the BHPS
 - Also around 1,500 households in the Innovation Panel
-

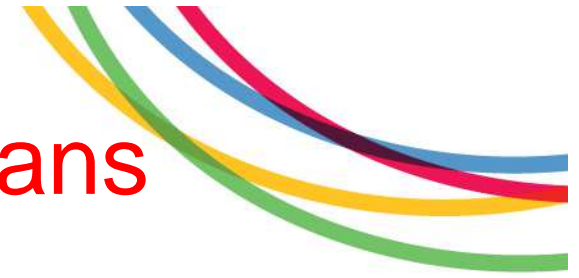
Administrative data linkage plans on Understanding Society (1)



Linking administrative data to survey data has always been the intention

- Wave 1 collection of consents to link to:
 - Health records
 - NHS Central Register
 - School education records
 - Wave 4
 - Benefit records
 - Health/Education (remind and re-ask)
 - Wave 5
 - Information about vehicles (DVLA)
 - Higher education
 - Income and taxes, employment histories (HMRC)
-

Administrative data linkage plans on Understanding Society (2)



Social Security data

- Department for Work and Pensions (DWP)
 - Benefit payments (such as disability-related benefits, Jobseeker's Allowance, housing benefit, winter fuel allowance)
 - Participation in employment programs (such as Welfare to Work programmes – New Deal, Pathfinder), participation spells, services used.
 - HM Revenue and Customs (HMRC)
 - Employment/self-employment history
 - National Insurance contributions (can be used to work out total state pension entitlements)
 - Income / profits
 - Tax credits (including Child Tax Credit, Working Families Tax Credit)
-

Administrative data linkage plans on Understanding Society (3)



Other data sources

- Education
 - Individual education records: information on attainment, demographic characteristics, special education needs, courses taken, attendance, exclusions, eligibility for free school meals
 - School-level information such as school-level test results, pupil characteristics (% ethnicity groups, eligible for free school meals), financial data (e.g., expenditure per pupil), some teacher-level information
 - Health
 - Admissions/attendance at hospital, diagnoses received, treatments given, surgical procedures, waiting times, records of specific conditions (e.g., cancer, diabetes)
 - Health registration information – health authority registered with, NHS numbers, date/cause of death
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Administrative data linkage plans on Understanding Society (4)



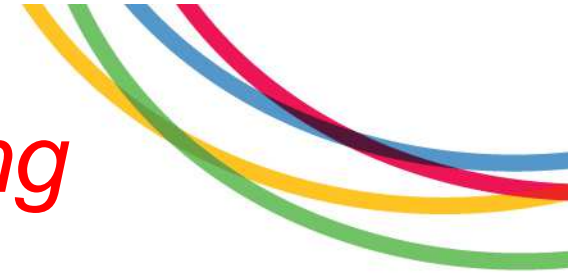
Also planned for Wave 5

- Department of the Vehicle Licensing Authority (DVLA)
 - Information about vehicles (age, engine size, fuel type CO² emissions)
- Higher education
 - Subjects studied, qualifications obtained at higher education

Wave 6?

- Further education
 - Individualised Learner Records – courses taken, grades achieved, funding source
-

Data linkage on *Understanding Society*: Geo-coded data

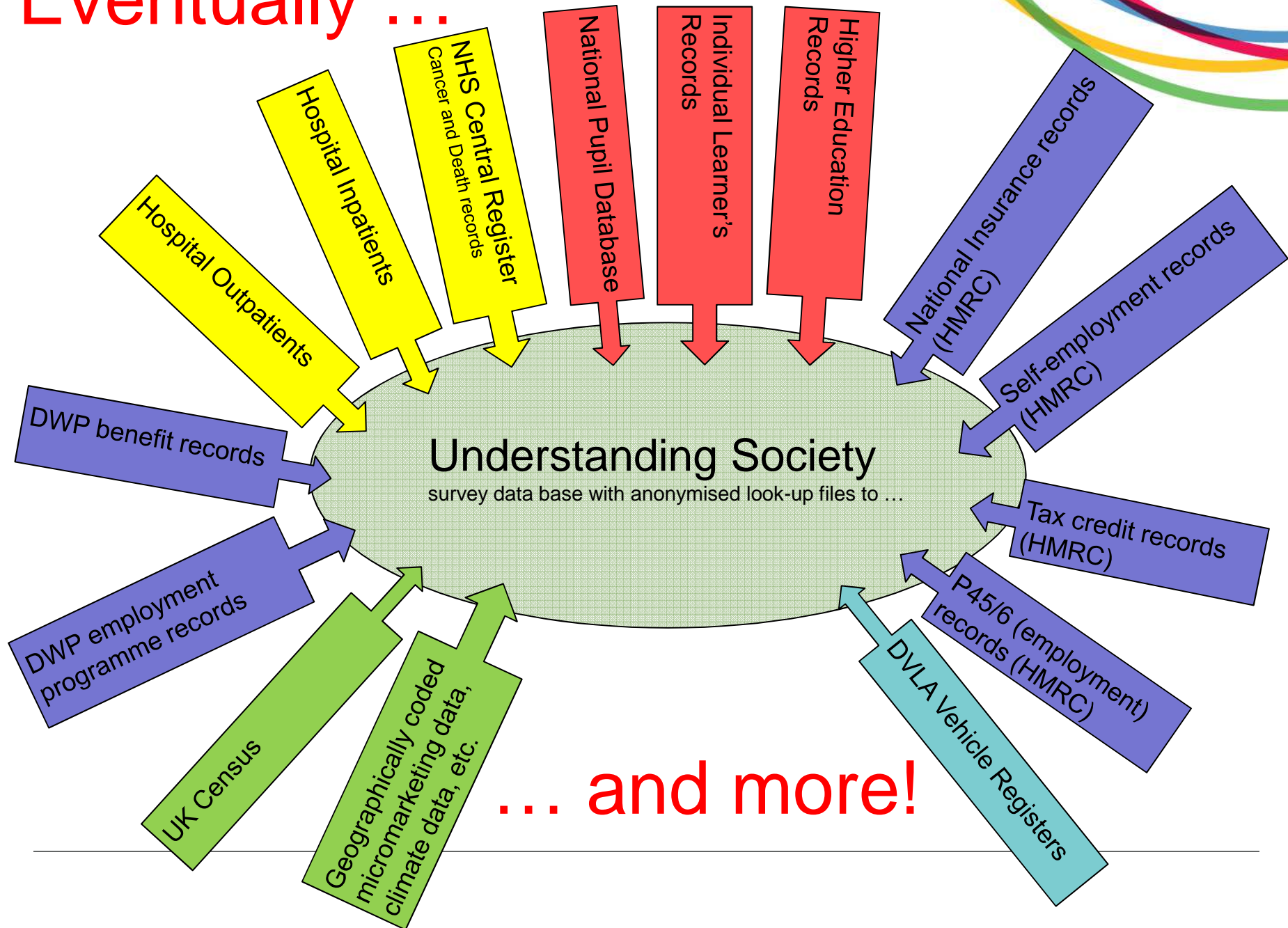


We have information on where the sample are living, so can add geographically coded information without requiring consent

- Local Authority District information
- Westminster parliamentary constituencies
- Census area statistics wards
- Lower Layer Super Output Areas (small geographic areas)
- Local Education Authorities
- Strategic Health Authorities
- Primary Care Trusts
- Travel to Work areas
- Grid reference

http://www.esds.ac.uk/doc/6910/mrdoc/pdf/us_geographical_identifiers_nov11.pdf

Eventually ...





Gaining informed consent



Conditions of informed consent (1)



- The study has to be approved by the university ethics committee
 - Also includes reviewing consent materials
 - Any linkage to information held by the National Health Service also requires approval from the NHS National Research Ethics Service (NRES)
 - Much more detailed information about the whole study
 - Reviews the procedures of the whole study – not just the data linkage
 - More thorough process
 - Lengthy form
 - Additional paperwork
 - Attendance at a meeting to answer questions
-

Conditions of informed consent (2)



- *individual's consent should be absolutely clear and has to be "explicit". It should cover:*
 - *the specific processing details;*
 - *the type of information (or even the specific information);*
 - *the purposes of the processing;*
 - *and any special aspects that may affect the individual, such as any disclosures that may be made.*
 - *information on how to withdraw*

Data Protection Act 1998 and the European Data Protection Directive to which the Act gives effect

Conditions of informed consent (3)



- Information
 - Sent in advance?
 - At point-of-request?
 - Verbal or written consent?
 - Consent forms
 - Signed/counter-signed
 - Additional information required?
 - Privacy notice
 - FAQs
-



Information on adding education records



Introduction

Government departments and agencies collect a range of information about all of us for administrative purposes. This is so they can provide education and other services to us when we need them. While we can learn about people's lives, economic circumstances, experiences, behaviour and beliefs by asking direct questions, it can sometimes be easier to obtain some of this information from government departments. During the interview this year, we would like to ask for your permission to link administrative information held about your education to your survey responses. The interviewer will be able to explain more about this when they visit. You do not have to give your consent and if you do, you are free to withdraw it at any time. This leaflet gives you more information about what information would be linked and how this is done.

What information would be added?

Education Records including:	From:
<ul style="list-style-type: none"> National tests and formal assessments, for example SATS and GCSEs in England, Wales and Northern Ireland and Standard Grades and Highers in Scotland Basic information on pupils like demographic characteristics or special educational needs Courses taken 	<ul style="list-style-type: none"> In England, the Department for Education. In Wales, the Welsh Department for Children, Education, Lifelong Learning and Skills. In Scotland, local education authorities as well as the Scottish Government Education Directorate In Northern Ireland, the Department of Education and the Education and Skills Authority.

Who will use it?

Like your survey responses, the additional information would be used by academic and social policy researchers for non-commercial statistical analysis. Any sensitive information would only be made available to them under restricted access arrangements which make sure that the information is used responsibly and safely. Names and addresses are never included in the results and no individual can be identified from the research.

Your permission – what does it cover?

Any information can only be released with your permission. In order to access the information, we will provide some necessary personal details including your full name, full address, gender and date of birth to the government departments and agencies holding the information. We will only pass your details to the government department or agency that holds your records. For example, if you were only ever educated in England, we will only pass your details to the English Department for Education. Your details would not be passed on to departments or agencies in Scotland, Wales or Northern Ireland.

These details will only be used to identify your information. Before the departments and agencies send any information you have authorised back to us, your name and other details will be removed.

Like the answers you have given us in the survey, the information from other sources will be completely confidential and treated in accordance with the Data Protection Act. Your current or future dealings with any of the departments or agencies will not be affected.

How long does your consent last?

We would like to add information relating to your present, past and future circumstances. We would like to continue to link in your data for as long as the study lasts. However, we will ask you for your permission in future interviews (every three years) to ensure you are still happy for us to do so. If, for any reason you are unable to take part in the study and are therefore unable to renew your consent, future data linking would stop. No new data would be added to your survey responses. However, all data which had been linked up to that point would be kept and used for research and statistical purposes. You are free to withdraw your consent at any time.

What about your children's information?

We would like to add information on your child(ren) from age 4 up to age 16. We need to seek parental consent to add information on your children aged under 16. We understand that some children would be able to make this decision on their own behalf. You should make the decision that represents your child's wishes and best interests. You could discuss this with your child, and you can withdraw your consent at any time. Once your child reaches the age of 16 we will ask your child directly.





Information on adding administrative health records

Introduction

The National Health Service (NHS) maintains routine medical and other health-related records on all patients accessing the health services so they can provide health services to us when we need them. While we can learn about people's lives, well-being, experiences, and behaviour by asking direct questions, it can sometimes be easier to obtain some of this information from administrative records. Administrative health records may also help us to keep in touch with you and keep our records up to date.

We would like to ask for your permission to add information from administrative health records to the answers you have provided in the interview. This leaflet explains more about this.

Please take a moment to read it.

What information would be added?

The information to be added is collected for administrative purposes by the NHS and held within statistical health databases by the NHS Information Centre, the Departments of Health, the General Register Offices and the Office for National Statistics. Some of this information is linked across central UK NHS and registration bodies.

The information may include, for instance:

- Admissions or attendances at hospital (including dates of admission, discharge or attendance, diagnoses received, treatments and surgical procedures, waiting times).
- Records of specific conditions such as cancer or diabetes (including type of condition)
- Health registration details (including name of the Health Authority registered with, NHS numbers, and if a person who took part in the study were to have passed away, the date and cause of death).

Who will use it?

Like your survey responses, the additional information may be used by academic and social policy researchers for non-commercial statistical analysis. Any sensitive information about specific health conditions or treatments would only be made available to them under restricted access arrangements such as legally binding licences, which make sure that the information is used responsibly and safely. Names, addresses and NHS numbers are strictly confidential and are not available to those using the data for statistical analysis. No individual can be identified from research findings.

Your permission – what does it cover?

Any information can only be released with your permission. In order to access the information, we will provide some necessary personal details such as your name, date of birth and address to the NHS and government departments holding the information. These personal details will only be used to identify your information. Before any information you have authorised is sent back to us, your name and other details will be deleted by the NHS. None of your survey responses will be disclosed to the NHS or government departments for any other purpose.

Like the answers you have given us in the survey, the additional health information will be completely confidential in accordance with the Data Protection Act. Your current or future dealings with the NHS or any government department or agency will not be affected.

How long does your consent last?

We would like to add information relating to your present, past and future circumstances. We are not putting an expiry date to this consent as we do not know exactly when we will obtain and add the information. We will remind you every three years of the permissions you have given, and you are free to withdraw your consent at any time.

What about your children's information?

We would like to add information on your child(ren) from birth up to age 16. We need to seek parental consent to add information on your children aged under 16. We understand that some children would be able to make this decision on their own behalf. You should make the decision that represents your child's wishes and best interests. Please discuss this with your child as appropriate. You can withdraw your consent at any time. Once your child reaches the age of 16 we will ask your child directly for their permission.



Information on adding economic records



Understanding Society

Data linking

Government departments and agencies collect a range of information about all of us for administrative purposes, so they can plan and provide services. Added to the responses you have provided in this study the information can inform further analyses and help us get a better picture of those who are using services provided by the government.

What am I being asked to give permission for?

The Department for Work and Pensions (DWP) keeps records of everybody's benefit claims and any periods people spend on employment programmes.

The *Understanding Society* study at the University of Essex would like to add these records to the responses you have given to this study.

If you give your permission, it will inform further analysis to help us get a better picture of those who are claiming benefits and how they can best be helped.

What will happen if I give permission?

- 1) The *Understanding Society* study will give the DWP your name, address, sex and date of birth.
- 2) The DWP will use these details to identify the correct records it holds about you.
- 3) The DWP will send your DWP records to the *Understanding Society* study.
- 4) The DWP will not keep any of the personal information passed on to them.
- 5) The *Understanding Society* study will add the DWP records to your study responses.
- 6) Your personal information (name and address) will be removed before any research is done.

What will the research be used for and who will use it?

Like your study responses, the additional information would be used by professional academic and social policy researchers for non-commercial research and statistics. Any sensitive information would only be made available to them under restricted access arrangements which make sure that the information is used responsibly and safely. Names and addresses are never included in the results and no individual can be identified from the research.

The data will not be used to work out whether any individual is claiming benefits they should not be and will not affect any current or future claims for benefits

What if I change my mind?

You can withdraw permission at any time for your DWP records to be added to your study answers.

Who do I contact?

If you would like any further information or want to withdraw your permission, please contact us at:

FREEPOST RRRX-KEKJ-JGKS,
Understanding Society,
University of Essex,
Wivenhoe Park,
Colchester,
CO4 3SQ.

Freephone 0800 252853
Email: contact@understandingsociety.org.uk



Adding information from administrative health records - adults (16+)

Please read this form and sign below if you give your permission for us to add information from health records to your survey responses. It is completely up to you which permissions you choose to give. You can withdraw your permission at any time in the future.

I have received a leaflet explaining what information held by the National Health Service and related agencies may be added to the survey and how it would be used. I have had the opportunity to ask questions.

Please write your initials to indicate that you give permission

HEALTH DATA

I authorise the National Health Service, the Department of Health, the General Registration Office and the Office for National Statistics to disclose to the organisation responsible for this survey information about my health treatment and use of health services for future research studies of the frequency, causes, treatment or outcome of diseases and health conditions.

INITIALS

FOLLOW-UP ON HEALTH REGISTRATION

I authorise the organisation responsible for this survey to obtain information about my National Health Service registration from the National Health Service Central Register, and to follow my registration and health status.

INITIALS

If you give permission for us to collect any of this information please sign below. Your permission will stay in place unless you write to us to say you want it removed. This is detailed in the information leaflet. We will remind you of the permissions you have given periodically. You can contact the research team on, Freephone 0800 252 853 or by writing to Freepost RRXX-KEKJ-JGKS, Understanding Society, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ

Respondent

Sign Date Print name

Interviewer

Sign Date Print name

Thank-you!

Serial	Address	HH.No	P.No	ChkL
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>



Adding information from administrative health records - children (0-15 yrs)

Please read this form and sign below if you give your permission for us to add information from health records to your child(ren)'s survey responses. It is completely up to you which permissions you choose to give. You can withdraw your permission at any time in the future.

I have received a leaflet explaining what information held by the National Health Service and related agencies may be added to the survey and how it would be used. I have had the opportunity to ask questions.

HEALTH DATA

I authorise the National Health Service, the Departments of Health, the General Registration Office and the Office for National Statistics to disclose to the organisation responsible for this survey information about my child's health treatment and use of health services for future research studies of the frequency, causes, treatment or outcome of diseases and health conditions.

FOLLOW-UP ON HEALTH REGISTRATION

I authorise the organisation responsible for this survey to obtain information about my child's National Health Service registration from the National Health Service Central Registers, and to follow my child's registration and health status.

Please write your initials to indicate that you give permission

	First Name	Last Name	P.No	D.O.B dd / mm / yyyy	Health Data INITIALS	Follow-up on Health Registration INITIALS
Child 1				/ /		
Child 2				/ /		
Child 3				/ /		
Child 4				/ /		

If you give permission for us to collect any of this information please sign below. Your permission will stay in place unless you write to us to say you want it removed. This is detailed in the information leaflet. We will remind you of the permissions you have given periodically. You can contact the research team on, Freephone 0800 252 853 or by writing to Freepost RRXX-KEKJ-JGKS, Understanding Society, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ

Respondent

Sign Date Print name

Interviewer

Sign Date Print name

Serial	Address	MR.No	P.No	CHK
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

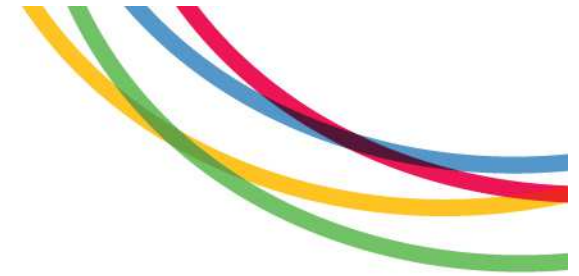
Thank-you!

Conditions of informed consent



	Consent type	Information leaflet	Additional information
DVLA (vehicles)	Verbal	None	None
DWP/HMRC	Verbal	Yes	None
Dept. Health	Written	Yes	None
Dept. Education	Written	Yes, in advance	Privacy Notice, website FAQs

Consent rates



These are the rates of adults giving consent to their own data being matched

Administrative records	Survey/Wave	Consent rate	Number
Health	BHPS W18	40%	5,341
Health	UKHLS W1	68%	32,436
NHS Register	BHPS W18	40%	5,309
NHS Register	UKHLS W1	67%	32,018
Benefits	BHPS W18	31%	4,038
Benefits	UKHLS W4*	63%	4,069
Education	BHPS W18	39%	759
Education	UKHLS W1	78%	4,734



Research on consents

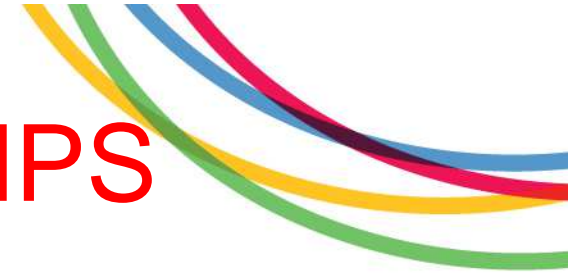


Research on consents: BHPS



- Consenting to health record linkage: evidence from a multi-purpose longitudinal survey of a general population
 - Uses BHPS Wave 18 (40% consent rate)
 - Examining whether the need for informed consent creates a potential for bias when using linked data
 - Multivariate logistic regression to model consent
 - Standard demographic information, common to health registration data
 - Broader set of socio-demographic characteristics
 - Indicators of health conditions
 - Information on the use of health services
 - Consent is not biased with respect to socio-economic characteristics or health
 - Recent users of GP services under-represented

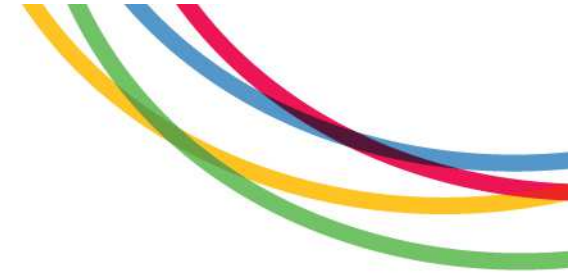
Research on consents: BHPS



- Correlates of Obtaining Informed Consent to Data Linkage: Respondent, Interview, and Interviewer Characteristics
 - BHPS Wave 18 plus survey of BHPS interviewers
 - Health and social security consents
 - Consider respondent socio-economic characteristics, information about the interview and data on the characteristics and attitudes of the interviewers
 - Consent related to respondents' attitudes to privacy, community-mindedness and salience of data linkage domain
 - Consent related to 'household contagion' – whether previous household members have given or withheld consent
 - Consent not related to interviewer personality, attitudes towards persuading respondents or job experience
 - But consent is related to the number of interviews conducted by the interviewer in the present wave and their track record of eliciting consent

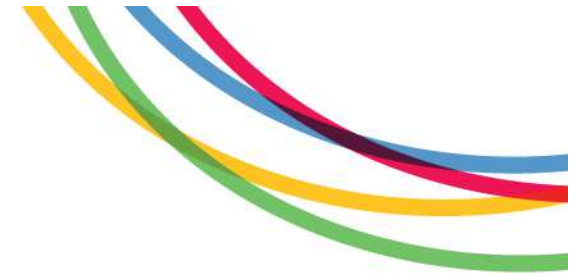
Sociological Methods & Research, Vol. 41(3), August 2012
<http://smr.sagepub.com/content/41/3/414>

Experimentation on Understanding Society (1)



- Innovation Panel – Wave 4 (IP4)
 - Original households, plus 500 refreshment households
 - Two experiments
 - Dependent interviewing
 - Placement of question
 - Follow-up question on why give/not give consent
 - Ask for consent to link to social security data (DWP)
 - DWP linkage also asked of 80% of sample at IP1
-

Experimentation on Understanding Society (2)



- Dependent interviewing
 - Half original sample asked for consent to DWP independently
 - Other half asked for consent, after reminding of their IP1 response

IP4 type of question	IP1 consenters		IP1 non-consenters	
	YES	NO	YES	NO
Independent	70	30	44	56
Dependent	89	11	22	78
n	534	133	133	275

Chi square test: 38.611, p. 0.000

Chi square test: 22.056, p. 0.000

Experimentation on Understanding Society (3)

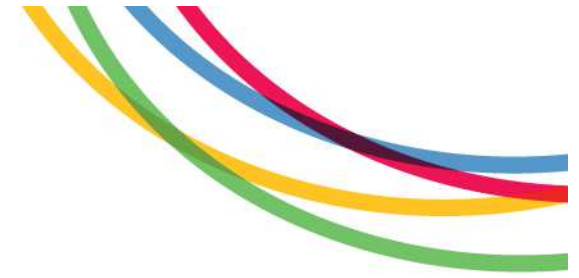


- Question placement
 - Half of sample asked after the benefits section (in context)
 - Other half asked at the end of the interview

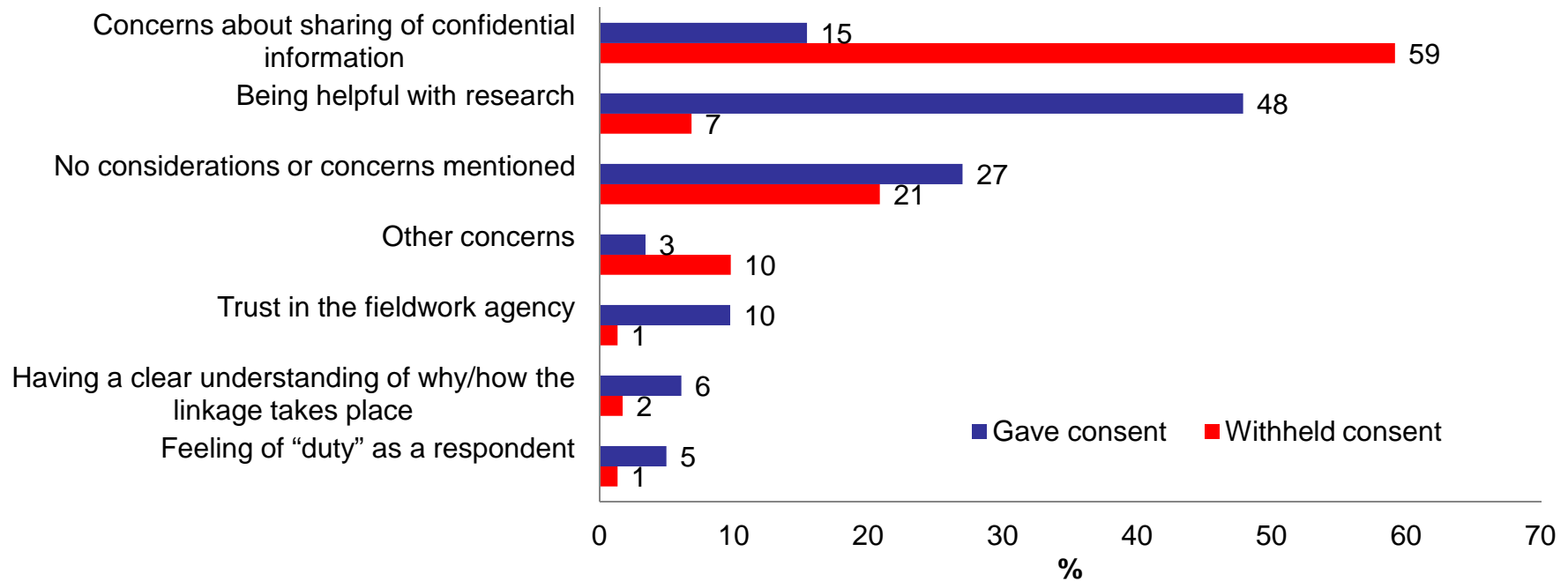
Consent given at IP4?	Question in context %	Question at end %
Yes	65	60
No	35	40
n	1,006	1,039

Chi square test: 4.5142, p. 0.034

Experimentation on Understanding Society (4)



- Reasons for consenting/not consenting
 - All respondents asked “Different things can be important when deciding to give consent to add information from DWP administrative records to survey data. What were you considering when answering?”





Linking to administrative data

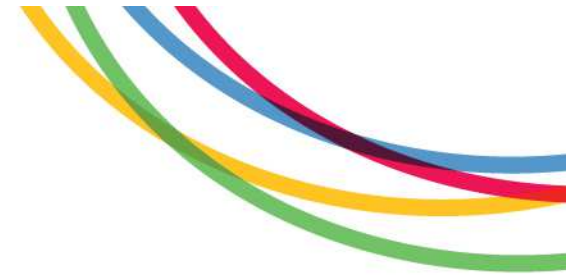


ISMIE project: Improving Survey Measurement of Income and Employment



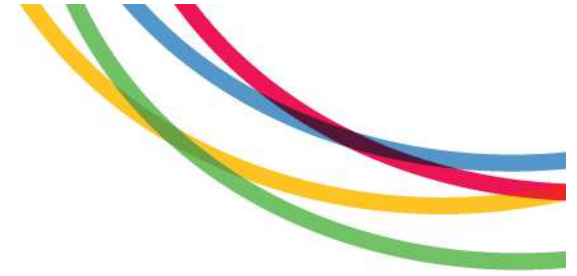
- Validation study
 - Fieldwork – spring 2003
 - “Low income” subsample of the UK part of the ECHP
 - 89% survey response
 - Includes two data linkage exercises
 - employer records (for those in employment)
 - records held by the Department of Work and Pension (DWP)
 - social benefits, tax credit data
 - Focus on the DWP data linkage
 - During the interview, respondents were asked for
 - (i) their National Insurance Number (NINO)
 - (ii) signed consent to data linkage (at the end of the interview)
 - Matching performed by DWP
-

ISMIE: linkage process



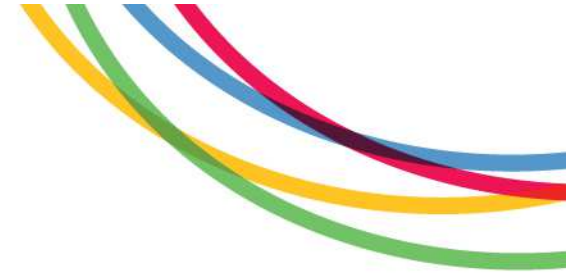
- Consent to data linkage: 77.4%
 - Of those, 88.6% willing/able to supply NINO
 - Some evidence for consent bias (Jenkins et al. 2006)
 - Suggests a latent individual consent propensity
 - Deterministic matching; non-hierarchical matching strategy
 - Variables used:
 - survey data and National Insurance number (NINO)
 - ISER sample info: sex, date of birth, surname, first name, postcode, and first line of address
 - Validation sample was matched 5 times with the DWP Primary data to obtain an accurate NINO
 - 1. NINO
 - 2. Sex, date of birth and postcode
 - 3. Surname, First name, sex and date of birth
 - 4. Surname, First name, sex and postcode,
 - 5. Surname, First name, sex and first line of address
 - Criterion 2: better performance overall (Jenkins et al. 2008)
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ISMIE: matching rates



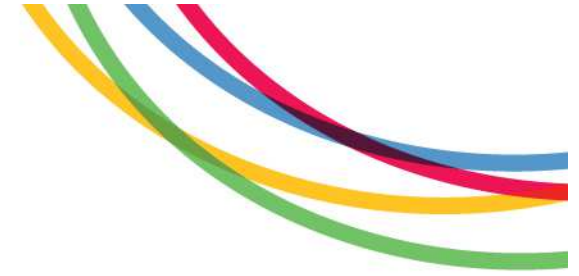
- Matching rate (for those who gave consent): 73.7% using the five criteria
 - 100% match not possible (only persons who had received some state benefits since 1999 were represented in the DWP data)
 - Non-matched cases: impossible to know whether they were:
 - ‘true non-matches’ (respondents who have never received a benefit) or
 - ‘false non-matches’ (respondents who should have been matched but could not be due to errors in the matching variables)
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Summary



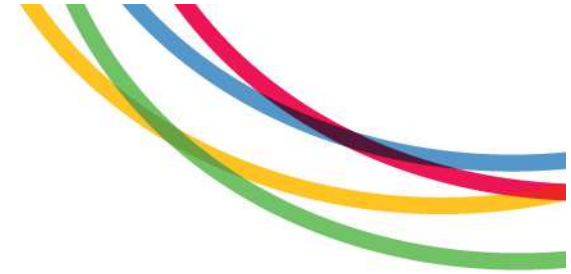
- Some departments getting more light touch (with an eye to mixed-mode surveys & poor consent rates)
 - Some departments requiring more documentation
 - Ethics approval harder for health records
 - Getting informed consent can be a long process and so planning needs to start early
 - Getting agreement with the data holders
 - Designing documents which gain approval of data holders
 - Ethics committees
 - However, still able to ask for consent and get a good rate
 - Scope for analysis to detect potential consent bias
 - Our analysis of the BHPS suggests no bias for health data, but under-represent recent users of GP service
 - Larger project underway for consent bias in *Understanding Society*, the 1946 and 1958 birth cohorts
 - Data linkage has the potential to be a rich data resource for researchers
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Outlook



- Some interesting partnerships are developing around data linkage issues in UK
 - New ESRC funded research centre to assist data linkage projects on British cohort studies and Understanding Society
 - Piloting linkage of cohort studies to hospital episodes
 - Sharing code to derive key indicators from a range of sources
 - Development of a one-stop information platform on consent and data linkage
 - Pooling £££ to do the linkage where costs do not depend on number of cases but number of variables
 - and a number of exciting new research studies!
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References



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