



# Health Studies User Conference

30 June 2020

[#UKDSHealth20](https://twitter.com/UKDSHealth20)

## Breakout sessions

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# Breakout session 1: COVID-19 - opportunities and challenges for the health surveys

Deb Wiltshire, UK Data Service  
30 June 2020

## Discussion points: COVID-19 - opportunities and challenges for the health surveys

- Will the new data collections be useful to you as researchers? How will they be useful? Any data missing?
- Ideas for how data from non Covid-19 surveys can help inform studies that ask about Covid-19 directly?
- Are there concerns from researchers re: data collection as a result of lockdown – such as gaps in data collection or move to telephone/online data collection?
- The future of face-to-face data collection – how do we re-engage and reassure participants once restrictions are lifted? What measures should we put in place to restart data collection research?
- What are the opportunities and challenges over data access during lockdown or in general for the COVID-19 data?
- Is there any training that you need from UKDS in order to use the health surveys for COVID-19 research?

# Key points from discussion

- **Missing groups:**

- Children are excluded – children have been very impacted by lockdown, separation from friends & home schooling, etc. but are not included in the COVID data collections. We don't have any young national birth cohorts, missing opportunity to follow children to see long term impact of COVID
- Are shielders fully represented in the surveys/questions? These groups have had a very different experience of lockdown & will have different concerns/challenges.
- Domestic violence – are we able to accurately capture this or will this group be missing from the data? What will the impact be on those in lockdown with perpetrators?

- **Mode of data collection –**

- No F2F data collection, key groups might be underrepresented –including elderly, shielders, those who don't use/have internet, low income households who might not have internet or have previously accessed internet through local library. These are the groups who are likely to be more at risk of COVID/experiencing health inequalities/economically disadvantaged through job loss/recession
- are the data comparable if we switch from F2F to CAWI/CATI back to F2F? What impact will this have on people's responses?
- language barriers, how will translation of questionnaires differ between modes & who might be excluded as a result?

# Key points from discussion

- **Opportunities:**

- CSEW is going to use previous respondents for this years survey, so briefly will be 'longitudinal', no information about whether it will be possible to use it in this way (i.e. whether will keep the same Id), but there is an opportunity to use existing cross-sectional samples to create a new cohort study going forward.
- UK forms 'natural experiment', can look at any potential differences in outcomes between 4 countries who have operated different lockdown rules & timing.
- longstanding standard questions such as GHQ questions, especially in longitudinal studies, will have been asked pre, during & post COVID. Great tool for examining impact of COVID.
- working remotely/virtually has made cross-institution collaborations much easier, stimulated greater interdisciplinary cooperation.

- **Challenges –**

- Secure data access – created barriers to access where institutions cannot meet the additional conditions
- Knowing where to find data sources & previous studies, health data can be accessed through many organisations, signposting not always clear, a central 'library' would be useful, role of Open Science Framework.

# Breakout session 2: COVID-19 - opportunities and challenges for the health surveys

30 June 2020

Vanessa Higgins, UK Data Service

## Discussion points:

### COVID-19 - opportunities and challenges for the health surveys

1. Will the new data collections be useful to you as researchers? How will they be useful? Any data missing?
2. Ideas for how data from non Covid-19 surveys can help inform studies that ask about Covid-19 directly?
3. Are there concerns from researchers re: data collection as a result of lockdown – such as gaps in data collection or move to telephone/online data collection?
4. The future of face-to-face data collection – how do we re-engage and reassure participants once restrictions are lifted? What measures should we put in place to restart data collection research?
5. What are the opportunities and challenges over data access during lockdown or in general for the COVID-19 data?
6. Is there any training that you need from UKDS in order to use the health surveys for COVID-19 research?

## Key points from discussion

- **Importance of non-COVID-19 surveys** to assess the wider impact of the pandemic and unexpected impact.. UKDS has role in identifying non Covid-19 surveys (theme pages, blogs/news). Noted that HSE may be exploring the impacts of COVID-19 e.g. trends in obesity.
- **There is very little data available around diagnosis.**
- **Issue of fragmented survey datasets on different topics.** Routine surveys should be asking questions about COVID-19 in future, even if they don't contain questions currently, so that we can explore impacts (e.g. Labour Force Survey). For those surveys with blood collection this would be good to analyse longitudinally e.g. longitudinal follow up for the Health Survey for England
- **Data linkage** is important for cause and effect. ONS (SRS) linkage 2011 Census and mortality data. Would be good to be linked with ONS Longitudinal study.
- **Children:** need to look at the effect of living conditions/physical environment on social activities. Need linkage at small geographical areas (IMD, aggregate /geocoded Census data)
- **Future of data collection** (children and elderly)– would be useful to collect experiences of surveys of children during lockdown via online/telephone collection. How are children without ICT included? Elderly access to online surveys?
- **Capturing people in care homes?** Can that data be separated out? Most surveys don't cover care homes (ELSA). Data collection in care homes needed. ONS survey in institutions (5 years ago)?. Health Stats User Group to feedback this point to ONS re: adult social care and care homes (
- **Voluntary organisations/NGOs** – would be useful to have voluntary organisations and NGOs collaborating with survey organisations on research as they have practical insight. UKDS could act as a broker to put people in touch. Strengthening NGO relationship with survey producers. Make it more welcoming culture.



# Breakout session 3: Data Linkage

30 June 2020

Nicola Shelton, UCL



## Discussion points:

### Data linkage

- What are your experiences of accessing and using the linked data sets that are available from UKDS?
- How can researchers and data depositors work together to ensure the needs of researchers are met?
- Are the current linked data sets available covering your needs as researchers?
  - Are there any other data sets you would like to see linkage to?
- Is there any training you would like in order to use linked data?
- What haven't we covered?

# Key points from discussion

## Patient experience surveys

- Linking CQC data to HES to be considered
- PROMS data linkage to HES is possible

## Discussion about funding

- Possible to quote at outset
- Building in to grant proposal
- UKRI ADR-UK has funding for data linkage that has wider use e.g. NPD – linked to HES deposited in Secure Research Service
- Only funding things can be deposited

## Training

- Approved researcher status and approved projects

## IQVIA

- Is it possible to get data direct from NHS digital?

## Local authority access

- Separate access to HES data sent via local support units
- Researchers could work with them – in their interest

## Problems with linkage

- Consents vary
- Timeline for decision is long and sometimes ends in a NO
- Unclear how linked to other (non NHS Digital) data sets



# Breakout session 4: Longitudinal studies

30 June 2020

Beate Lichtwardt, UK Data Service

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## Discussion points: Longitudinal Studies

- What are your experiences of accessing and using the longitudinal surveys that are available from the UK Data Service?
- Is there any training you would like in order to use these surveys?
- How can researchers and data depositors work together to ensure the needs of researchers are met?
- Experiences of teaching with the longitudinal surveys – is there anything you need?
- Do you carry out cross-study research with longitudinal surveys? Are there any needs for harmonisation of data?
- Are the current longitudinal studies covering your needs as researchers? (Birth Cohorts, ELSA, Understanding Society).
  - Are there any other topics you would like to see within these surveys?
  - Are there any sample boosts you'd like within these surveys?

## Key points from discussion - 1

- Longitudinal datasets provide fantastic opportunities regarding research on how the Pandemic (COVID-19) impacts on various aspects of life.
- Swift response to COVID-19, immediate additional data collections on the issue, e.g. USoc (ISER), CLS birth cohorts (UCL), ELSA (NatCen) etc.. UK Data Service has been brilliant to make these data available quickly.
- User Foren considered by more data owners and providers, pros and cons discussed, first experiences rather positive. Alternative: github.
- Sharing code/syntax rather important; would form an important (training) resource.
- More information on domestic violence (during COVID-19 Pandemic) wanted; however, duty of care for respondents issues have to be considered (limited resources to do so responsibly hindered domestic violence data collection on many occasions). There is a need for adequate resourcing to enable capture of that information in an ethical manner.
- Webinars have proven to be fantastic training resources for many.

## Key points from discussion - 2

- Longitudinal data and subsequent research on digital inequality is needed, especially in the light of COVID-19, as interaction with and availability of technology re-shapes lives in that it decides whether one can sustain access to basic services and meet basic needs in terms of work, education, health care, community services, communication/ social interaction, shopping, banking, etc. etc.. (Oxford Internet Surveys were mentioned as well as Ofcom's annual Internet Use and Attitudes reports (media literacy), however, these are not considered sufficient for what is needed in the current, unprecedented situation); (Regarding older age and digital access to hospital, primary care and medication it was mentioned that ELSA has been awarded a COVID grant which includes looking at these aspects (<https://www.elsa-project.ac.uk/covid-19>))
- Importance of good variable documentation was stressed and USoc praised for their efforts on this.
- Data management issues discussed when handling multifaceted longitudinal data and various training sources available highlighted.