



TwInduction

Baseline sample and data collection for newly registered twin research volunteers

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Summary

- The TwinsUK cohort is a major epidemiology resource with longitudinal data from over **14,500 adult twins** from the UK
- Comparing genetically identical twins with non-identical twins enables researchers to separate the effects of genes from environmental factors such as lifestyle, diet and microbiome.
- **200** new twins sign up to the registry per annum.
- Following the outbreak of COVID-19 and the media coverage of TwinsUK, spearheaded by the Zoe covid-19 app – a partnership with TwinsUK, around **800** twins registered their interest to sign up
- Twins are invited to clinical visits at St Thomas' Hospital
- However since covid restrictions, had to develop postal collection and data digitisation initiatives.

Impacts of Covid-19

The impact of COVID-19 on longitudinal population studies (TwinsUK)

- Clinical visits coming to a halt during the pandemic - relied on physical visit for biomarkers and data collection
- Redesign studies/Rethink participant engagement
- Substituting face-to-face visits with remote and digital methods

New forms of data collection

- Continual advances in technology for collection and analysis of biological samples and data
- Remote collection of biological samples
 - Based on a project I set up before the pandemic in 2018 – Keeping Together
 - First pilot run now repurposing and scaling up for new twins
 - Blueprint used for all remote collection
 - Previously presented at this same conference last year
- Shift to digital domains to generate data
 - Previous method of new twin registrations used to be clunky and outdated using email forms and paper consent.
 - New digitised method much more streamlined and part of the pandemic was to move everything online

TwInduction Study Design

- Online portal – digitised registration and consent
- Emailed copy of study information sheet and consent
- Sent welcome postal boxes
- Online link to carry out cognitive assessment and core questionnaires on web-based software, Qualtrics and RedCap
- Samples analysed and stored in TwinsUK Biobank.
- The data will then be used for further research and will be accessible to independent researchers and collaborators
- The structure and rationale for this study paves the way for clinical studies moving forward in this post-pandemic world.



Remote Sample & Data Collection

Summary

Impact of
Covid-19

Study
Design

Data
Collection

Benefits &
Limitations



Biological samples (Self-collection by participant)

- Faecal
 - Zymo will be used for microbial DNA extraction
 - Raw gives us the possibility to measure metabolites and short-chain fatty acids
- Saliva = metabolites and microbiome
- Urine = metabolites
- Blood = plasma and DNA
- Serology – antibody
- Leak-proof secure packaging
- All stable for 24 hours once chilled
- Special next day delivery via royal mail straight to lab



Online and digital data capture

- Baseline information and digital consent obtained through RedCap
- Lifestyle and health online questionnaires on Qualtrics
- Cognitive function tests via Cambridge cognition web-based software

Benefits and Limitations



- Participants may be drawn from a wider geographical and social field.
- Greater flexibility in when and where research takes place: multimodal software allows participants to provide data when it suits them
- Replicate baseline visit at a cost of £25 per twin for the postal kits and online process. Significantly cheaper than visit.
- This change was not a deviation from the TwinsUK BioBank collection methods, governance, policy, or its protocol so no amendments were needed to ethics.



- Maintaining engagement as not face to face
 - to aid compliance twins sent email and text reminders.
 - In other twin studies we incorporated virtual visits with Zoom
- Relies on access to digital technology therefore harder to access vulnerable and marginalised groups.
 - Keeping Together - recognised this info was important so had a strategy of phone calls to cover this group to address the elderly groups.
 - Part of our general drive to move everything online and because of the pandemic a lot of our twins have email addresses. Zoe app twins join and log symptoms. We've seen that in our own cohort so can only imagine population have had similar change.
- Issues of privacy and consent. Required to adhere to best practices:
 - obtaining consent, ensuring participants' anonymity, allowing options to withdraw & handling data securely
- Challenges:
 - UN3373 bags for special next day delivery through royal mail
 - Delays in ordering supplies – supply chain shortage

TwInduction provides an innovative, rapid and adaptive method for recruitment and data collection by using a remote based testing method.

Thank you and any further questions?

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