Plan Overview

A Data Management Plan created using DMPonline

Title: Associations Between Type 1 Diabetes, Sleep, well-being, internalising difficulties and cognitive variables in Twins.

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Affiliation: Royal Holloway, University of London

Funder: Economic and Social Research Council (ESRC)

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Project abstract:

We aim to utilise the Twins Early Development Study (TEDS) data, particularly that from the Year 16 (Child Behaviour/LEAP/LEAP-2 Study). The key contribution of the present study lies in the use of twin pairs discordant for T1D within the TEDS dataset, which enables a co-twin control analysis to provide preliminary data exploring whether associations between T1D, Sleep (insomnia severity, sleep quality and subscales), Wellbeing (life satisfaction, optimism and subjective happiness), cognitive/ educational variables (verbal and non-verbal cognitive ability, school engagement,) and internalising symptoms (symptoms of anxiety and depression) persist after accounting for shared familial and genetic influences. Although the number of discordant pairs is modest, this approach provides uniquely informative effect-size estimates that are critical for the design of future, adequately powered studies. Secondly, the dataset offers an opportunity to conduct population-level comparisons between young people with T1D and those without. These group-level analyses will provide initial estimates of whether T1D is associated with poorer sleep, well-being, internalising difficulties and cognitive variables.

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Associations Between Type 1 Diabetes, Sleep, well-being, internalising difficulties and cognitive variables in Twins.

Administrative Data

Please define an ID for your DMP.

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Which funder are you applying to?

What is the title of your project?

Associations Between Type 1 Diabetes, Sleep, well-being, internalising difficulties and cognitive variables in Twins.

Briefly describe your project.

Research Questions:

- Do participants with T1D and those without T1D differ in sleep, well-being, internalising difficulties and cognitive outcomes?
- Within twin pairs discordant for T1D, does the twin living with T1D report poorer sleep, well-being, internalising difficulties and cognitive outcomes than their co-twin?

Hypotheses

- H1: Participants with T1D and those without T1D will differ in sleep, internalising difficulties and wellbeing outcomes. Participants with T1D are expected to report poorer outcomes across the three domains.
- H2: The association between T1D, sleep, internalising difficulties and wellbeing outcomes will still be significant in the co-twin design, showing that this association is significant even after controlling for genetic factors. Within twin pairs discordant for T1D, the twin living with T1D is expected to report poorer outcomes than their co-twin.

Who is the primary investigator on the project? Please also name any co-investigators on the project.

Alice M. Gregory (PI), Beatriz Venâncio, Juan José Madrid-Valero, Jakke Tamminen, Alice M. Gregory.

Who is the project data contact?

Beatriz Venâncio - Beatriz.Venancio.2025@live.rhul.ac.uk

Data Collection

What types of data/ files will be created?

All data are derived from existing TEDS waves (primarily age 16 and health data from age 26). Use of these data is governed by the TEDS data access policy and data-sharing agreement. The dataset will consist of de-identified quantitative data, including

questionnaire-derived scale scores and standard demographic and twin-structure variables (e.g. family ID, zygosity, sex, age). In terms of data organization, data will be organised within a clear folder structure separating: (1) raw data, (2) cleaned/derived datasets, (3) analysis scripts, and (4) outputs (tables and figures). All data processing and analytic decisions will be documented in code and aligned with a pre-registered analysis plan.

What is the estimated total volume of data, number of items / files and largest individual file / items size?

How will the data be collected or created?

Data collection procedures can be found on the TEDS official website https://www.teds.ac.uk/ and corresponding references:

Haworth, C. M., Davis, O. S., & Plomin, R. (2013). Twins Early Development Study (TEDS): a genetically sensitive investigation of cognitive and behavioral development from childhood to young adulthood. Twin Res Hum Genet, 16(1), 117-125. doi:10.1017/thg.2012.91

Rimfeld, K., Malanchini, M., Spargo, T., Spickernell, G., Selzam, S., McMillan, A., . . . Plomin, R. (2019). Twins Early Development Study: A Genetically Sensitive Investigation into Behavioral and Cognitive Development from Infancy to Emerging Adulthood. Twin Res Hum Genet, 22(6), 508-513. doi:10.1017/thg.2019.56

Will any existing research data be used? If yes, describe any actions that will need to be taken in order to gain access to this data.

Access to the Twins Early Development Study (TEDS) data is restricted and granted only to researchers affiliated with recognised academic or research institutions, following approval by the TEDS Steering Committee. Before having access to the dataset, we have submitted a detailed data request form describing the study aims, hypotheses, and analysis plan, obtain agreement from a core TEDS team member to collaborate on the project (senior researcher AMG), and comply with all conditions outlined in the TEDS data access policy, which can be found here https://www.teds.ac.uk/researchers/teds-data-access-policy/ .

Are there any special tools and/or software needed to work with or view the data? If yes, describe any actions that will need be taken to access these tools or software.

Yes. The data will be analysed using R (open-source).

Documentation and Metadata

What documentation and metadata will accompany the data?

Ethics and Legal Compliance

Have you completed the University Ethics review process?

A DMP must be created and attached to the research ethics application. This process is only required after a project has been awarded or the research activity has been approved.

Yes.

How will any ethical aspects related to RDM and / or highlighted in the Ethics process be managed?

Ethical aspects related to research data management will be addressed through strict adherence to the TEDS data access policy, UK GDPR, data sharing agreements, and institutional ethics requirements. Any issues identified during the ethics review (e.g. data sensitivity, access controls, retention, or sharing restrictions) will be managed through documented procedures in the data-sharing agreements, secure handling practices, and updates to this Data Management Plan as required.

How will any personal identifying data be kept separately to responses?

Not applicable. All data used in this project are provided in de-identified form by the Twins Early Development Study, and no direct or indirect personal identifiers are accessible to the research team.

Who will own the copyright of the research data?

Copyright for the research output and documentation generated in this project will rest with all authors, Royal Holloway, and collaborating institutions. Any publications resulting from the project may be subject to publisher copyright transfer agreements.

Are there any specific copyright / IP aspects that need to be considered?

Question not answered.

Storage and backup during the research

How will the data be stored and backed up during the research?

Data will be stored and managed by each institution (Royal Holloway, University of London; University of Murcia) in accordance with their approved information security policies and the conditions set out in the TEDS data access agreements. Within the host institution, data will be stored and backed up on at least 3 encrypted drives. Keeping the data in 3 different location serves as prevention to data loss or corruption.

How will you manage access and security during the research?

Access to the dataset will be restricted to authorised researchers listed on the approved data request and governed by formal data-sharing agreements. All researchers will adhere to the conditions of the TEDS data access policy (https://www.teds.ac.uk/researchers/teds-data-access-policy/) and applicable data protection regulations, including restrictions on onward sharing and use of the data. Responsibility for secure handling rests with each participating institution under the terms of the data-sharing agreements.

Will the data be shared and accessed by other collaborators, colleagues etc during the research? If yes, how will this be managed?

Data will only be accessed by those identified in the data request form.

Evaluation and retention

Which data needs to be retained after the research ends?

In accordance with the TEDS data access policy, the original research dataset supplied by TEDS will not be retained by the research team after the approved project end date. All copies of the TEDS dataset will be securely deleted by each authorised institution, and confirmation of deletion will be provided to TEDS where required.

Where will this retained data be stored?

How long will the data be kept for?

Does any data need to be destroyed / deleted? If yes, how will this be managed and by who and when?

Deletion will be carried out by each authorised institution that received the data, under the responsibility of the local co-authors. All copies of the dataset, including raw and derived analysis files containing individual-level data, will be permanently deleted from institutional storage systems once the project end date is reached or earlier if access is no longer required. Confirmation of deletion will be provided to TEDS.

Data Sharing after research ends

Which data will need to be shared?

No individual-level data will be shared beyond the authorised research team; only non-disclosive aggregated results and analysis scripts may be shared in publications, pre-registrations, or supplementary materials, in line with TEDS data access conditions.

Where will this data be stored?

Question not answered.

How will the data be shared eg considerations around Open Access, terms of reuse and licencing?

Non-disclosive materials will be made openly available via the Open Science Framework (OSF) and, where appropriate, the Royal Holloway institutional repository, under standard open licences.

Where will the location of the data be recorded?

Question not answered.

Has consent been acquired /agreed from participants to share the data?

Are any restrictions on data sharing required?

Yes. Sharing of individual-level data is restricted under the TEDS data access policy and applicable data protection regulations; only non-disclosive materials may be shared, and access to the underlying data is limited to authorised researchers under formal data-sharing agreements.

Responsibilities and Resources

Who will be responsible for research data management?

Beatriz Venâncio.

What resources will you require to deliver your plan?

The project will use existing institutional resources, including approved secure data storage, standard computing facilities, and open-source statistical software (R). No additional funding, specialist infrastructure, or external services are required to deliver the data management plan.

State any identified costs and sources of funding for resources.

No additional costs are associated with the delivery of this data management plan. The project forms part of a PhD studentship funded by the ESRC through SEDarc, and all required resources are covered by existing institutional provision.

Please outline the actions that you will take to manage the research data when the project ends / before leaving the University

Question not answered.

Who will manage the research data after project end / after the PI leaves the University to continue to meet any requirements?

Question not answered.