Research Department of

BEHAVIOURAL SCIENCE & Health

**Requesting access of Gemini data** (2022)

The Gemini twin study is run as a resource for the research community. We encourage and facilitate data sharing by all researchers from all disciplines across the world to maximize use of the resource. Proposals to access Gemini data are requested through the Gemini Executive Committee in accordance with the Gemini Data Access Policy document below.

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**Data access policy for use of Gemini data**

1. We require that requests to use Gemini data are done in collaboration with a member of the core Gemini team who will oversee progress on the project, and who will be named as a co-author on any resulting publication:
* Dr Clare Llewellyn: c.llewellyn@ucl.ac.uk
* Dr Alison Fildes: A.Fildes@leeds.ac.uk
* Dr Alice Kininmonth: a.kininmonth@ucl.ac.uk
1. After obtaining agreement to collaborate from a member of the core Gemini team, complete the data request form below. A brief overview of measures and assessments points in the Gemini study can be found on p.5 of this document. More detailed information on collected data can be obtained by e-mailing gemini@ucl.ac.uk
2. The completed data request form must first be approved by the collaborating member of the core Gemini team. It must then be sent by the Gemini collaborating member of the core Gemini team to Dr Clare Llewellyn for final approval.
3. Members of the core Gemini team reserve the right to reject any data request, at any stage of the approval process. The Gemini dataset is not a public dataset made available to all who request access. We may also withdraw approval at any time if these guidelines are not followed, or if we feel that insufficient progress is being made.
4. If approved, you will obtain your working dataset via the Gemini collaborating member of the core Gemini team.
5. Because access to the Gemini data is restricted, and to comply with regulations concerning control of these data, you must not pass on your Gemini dataset to anyone not named in the data request form. All those involved in analysis of the data, including PhD students for example, should be named on the data request form.
6. Approval for the use of Gemini data is for **one year only, starting from the date of submission of the data request**.
7. To ensure timely completion of collaborative projects, we ask that collaborators do not submit a new data request if a previous project is unfinished. If you are planning to submit more than one paper from the requested Gemini data, please submit a second completed data request form with detail of the further planned publications at the same time as submitting the Data Access form.
8. When your project is finished you should contact us and let us know the outcome (see below for publication plans).
9. Under exceptional circumstances, if a project is not finished within the allotted year, then a six-month extension may be granted. This will **only** be considered if you can provide evidence that significant progress has been made, and the project is nearing completion.
10. In order to request a six-month extension, you will be asked to provide a progress update, by completing an **annual review** form. If an extension is not granted, approval will be withdrawn and others will be free to use the data for similar projects.
11. Any changes in the aims of the project, or in the focus of analysis (e.g. using variables differently from the description in the data request), or in the measures used, should be submitted for approval **before** you proceed.
12. Likewise, any intention to add collaborators or to change the researchers involved in the project should be submitted for approval first.
13. All changes mentioned above, including requests for extension, changes to project aims, or changes to personnel, must be approved both by the collaborating core Gemini member and by Dr Clare Llewellyn.
14. **Before submitting a paper** based on your data request, please send full publication details to Dr Clare Llewellyn. Dr Llewellyn will advise about grants that need to be acknowledged and about issues relating to open-access requirements.
15. You are expected to send copies of your paper and relevant correspondence when the paper is submitted, re-submitted, accepted and when published. Please send to your core Gemini collaborator.

**Gemini Collaborator Data Request Form**

Please read the guidelines above before completing and submitting this form.

|  |  |
| --- | --- |
| Date: |  |
| Provisional project/paper title:  |  |
| Name of Gemini ‘core’ collaborator (mandatory): |  |
| Name and email address of applicant (lead researcher): |  |
| Name and email address of other collaborators (if any): |  |
| Source of Funding/grant: |  |
|  |
| Planned submission date for paper (month and year): |  |
| Potential journals for submission: |  |
| Provisional author list for paper: |  |
|  |
| **Abstract**(Including aims/objectives, analysis methods, and potential implications of study) |
|  |
| Variables required \* |  |

\* Please specify accurately which variables or measures you want. For example, specify whether you want to include item-level data as well as scales; and specify the age and rater (some measures are available at various ages, rated by parents or twins). Upon request, Gemini core team members can provide further information on all measures and variables.

**Overview of the measures and assessment points in Gemini**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Data collection wave** | **T0** | **T1** | **T2** | **T3** | **T4** | **T5** | **T6** | **T7** | **T8** | **T9** | **T10** | **T11\_C19\_1** | **T11\_C19\_2** | **T11\_C19\_3** |
|  | **Child age (months; years)** |
| **8** | **15** | **20** | **24** | **30** | **36** | **48** | **60** | **84** | **12-13 yr** | **12-13 yr** | **13 yrs** | **13-14 yrs** | **14 yrs** |
| **Child variables** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Anthropometrics a | X | X |  | X |  | X | X |  |  | X | X | X | X | X |
| Waist circumference |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| Eating behaviour/appetite – BEBQ (infancy: Llewellyn et al, 2011); CEBQ (childhood: Wardle et al 2001) | X | X |  |  |  |  |  | X | X | X |  |  |  |  |
| Food preferences, sensory experiences b |  | X |  |  |  | X |  |  |  |  |  |  |  |  |
| Eating and Feeding Concerns; Eating Disorders Diagnosis c |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| Development and well-being assessment (DAWBA) d |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| DEBQ – Restraint, Eating Disorder Inventory 2 (EDI 2), TEFQ-R18 d |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| Activity behaviour – IBQ, ECBQ, CBQ (Gartstein & Rothbart, 2003; Rothbart et al., 2001; Putnam et al., 2006) | X | X |  |  |  |  | X |  |  |  |  |  |  |  |
| TV watching (Anderson et al., 1985) and sleeping behaviour (Iglowstein et al., 2003) |  | X |  |  |  |  | X |  |  |  |  |  |  |  |
| Screen Time |  |  |  |  |  |  |  |  |  |  | X | X | X | X |
| Sleep behaviour c,d |  | X |  |  |  |  |  | X | X | X |  | X | X | X |
| Birth complications/illnesses/medical conditions b | X | X |  | X |  |  |  | X |  | X |  |  |  |  |
| Introduction of solid foods c | X | X |  |  |  |  |  |  |  |  |  |  |  |  |
| Three-day diet diary c |  |  | X |  |  |  |  |  | X |  |  |  |  |  |
| Temperament – CBQ (Putnam et al., 2006) |  |  |  |  |  |  |  | X |  |  |  |  |  |  |
| DNA collection using cheek swab / zygosity questionnaire |  |  |  |  | X |  |  |  |  |  |  |  |  |  |
| Formula feeding interviews |  |  |  |  |  |  |  | X |  |  |  |  |  |  |
| Allergies |  |  |  |  |  |  |  |  | X |  |  |  |  |  |
| C19: Thoughts and feelings about C19 c |  |  |  |  |  |  |  |  |  |  |  | X | X | X |
| C19: Activities, PA, Eating Habits c |  |  |  |  |  |  |  |  |  |  |  | X | X | X |
| C19: Home-schooling during C19 |  |  |  |  |  |  |  |  |  |  |  |  |  | X |
| C19: Personality and Mood c |  |  |  |  |  |  |  |  |  |  |  | X | X | X |
| Child Autism Spectrum (CAST) Short (Wiilliams et al 2005) |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| Strengths and Difficulties Questionnaire (SDQ) |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| Body Image (Stunkard et al 1983) |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| Weight- and Body-Related Shame - WEB-SG (Conradt et al.2007) c |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| Pubertal Developmental Scale – PDS (Peterssen et al 1988) c |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| Multidimensional Perfectionism Scale Brief (MPS-Brief) c |  |  |  |  |  |  |  |  |  | X |  |  | X | X |
| Negative Urgency (UPPS-P-C); Impulsivity (DERS-16); Emotionality (PANAS-C) c |  |  |  |  |  |  |  |  |  | X |  |  | X | X |
| Self-Esteem - The Self-Perception Profile for Children (SPPC) c |  |  |  |  |  |  |  |  |  | X |  |  | X | X |
| Loneliness c |  |  |  |  |  |  |  |  |  | X |  |  | X | X |
| Bullying c |  |  |  |  |  |  |  |  |  | X |  |  | X | X |
| Impulsiveness (Computer Go/No-Go Task) c |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| **Family variables** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Parental feeding style - PFSQ (Wardle et al., 2002), CFQ (Birch et al., 2001), PFQ (Baughcum et al., 2001) | X | X |  |  |  |  |  | X |  | X |  |  |  |  |
| Demographics, anthropometrics, health behaviours of both parents b | X |  |  | X |  |  |  | X |  | X |  |  |  |  |
| Socioeconomic status | X |  |  |  |  |  |  |  |  |  | X |  |  |  |
| Parental eating behaviour – DEBQ (Van Strien et al., 1986) |  |  |  | X |  |  |  |  |  | X |  |  |  |  |
| Parental activity behaviour – IPAQ (Craig et al., 2003) |  |  |  | X |  |  |  |  |  |  |  |  |  |  |
| Parental sleep behaviour – PSQI (Buysse et al., 1989) |  |  |  |  |  |  |  | X |  |  |  |  |  |  |
| Parental AEBQ – (Hunot et al, 2016)  |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| Parental diet – DINE (Roe et al., 1994) |  |  |  |  |  |  |  | X |  |  |  |  |  |  |
| Parental illnesses/medical conditions b | X |  |  |  |  |  |  | X |  |  |  |  |  |  |
| Parental Body Image (Stunkard et al 1983) |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Home stress – CHAOS (Matheny et al., 1995) |  |  |  |  |  |  |  | X |  |  |  |  |  |  |
| Home food, physical activity and media environment b (Schrempft et al., 2016, Kininmonth et al., 2021) |  |  |  |  |  |  | X |  |  |  | X | X | X | X |
| C19: Changes to Home Environment  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| C19: Vaccination status |  |  |  |  |  |  |  |  |  |  |  |  |  | X |
| Mental Health Diagnosis (Depression, Anxiety, ED) |  |  |  |  |  |  |  |  |  | X |  |  |  |  |
| Parental Impulsiveness (Computer Go/No-Go Task) |  |  |  |  |  |  |  |  |  | X |  |  |  |  |

a Anthropometrics include weight, length and head circumference as recorded by health professional in red book from birth. Electronic weighing scales and height charts with detailed instructions are sent at age 2 years for parents to measure their twins’ growth in 3-month intervals.

b Measures that are modified for use in infants or newly designed for Gemini. These are all intensively piloted in parents of young children (both singletons and twins). All other measures are based on validated questionnaires.

c Self-report by twins (in some cases from T9 onwards)

**N.B.**

**T9 –**Data collected via Parent and Twin Questionnaires 2019-2020

**T10**–Data collected via telephone HEI as part of Alice’s PhD (n=149). Nov 2019- March 2020

**T11** – All Gemini C19 data collection, including the following data sets;

* **C19-T1**– Baseline C19 data which includes data from T9, T10, or data from T9, T11 C19-2 asked retrospectively (for all families without baseline)
* **C19-T2** – data from C19 study HEIs and Twin questionnaires. August 2020- January 2021.
* **C19-T3**– data from C19 study HEIs and Twin questionnaires.  April 2021-July 2021.