CENTRE FOR LONGITUDINAL STUDIES

UCL

CLS Data Access Committee

Terms of Reference

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Abbreviations

BCS70	1970 British Cohort Study
CLS	Centre for Longitudinal Studies
CLS DAC	CLS Data Access Committee
DAC	Data Access Committee
EGA	European Genome-phenome Archive
EUL	End User Licence
GENDAC	Genetic DAC
GDPR	General Data Protection Regulation
GIS	Geographic Information System
HES	Hospital Episode Statistics
HSC-PBPP	(NHS Scotland) Public Benefit and Privacy Panel for Health and Social Care
MCS	Millennium Cohort Study
NCDS	National Child Development Study or 1958 Birth Cohort Study
NHS	National Health Service
PI	Principal Investigator
RDM	Research Data Management
SAIL	Secure Anonymised Information Linkage
SLSP	Security Level Systems Policy
UCL	University College London
UKDS	UK Data Service
UK LLC	UK Longitudinal Linkage Collaboration

1. Scope

This document sets out the responsibilities, membership, and mode of operation of the CLS Data Access Committee (CLS DAC, also referred to as the 'Committee').

2. Responsibilities

(i) **Data access policies and procedures**: to agree on policies and procedures for accessing all types of data collected by CLS, as set out in the CLS Data Access Framework. This includes mechanisms whereby CLS research data is available to researchers through designated archival services operating to approved standards of access and security, such as the UK Data Service (UKDS).

(ii) **Review of data access routes**: to ensure that all of the different CLS data access routes, such as the UKDS, other data sharing platforms, or CLS direct data release, are promptly reviewed, fully documented, and reported to the Committee on a regular basis.

(iii) **Data classification**: to apply the CLS Data Classification Policy to CLS research data, and review any changes to data classification schemas already applied.

(iv) **UKDS data applications**: to ensure that applications for special safeguarded data (tier 1b, Special Licence) and controlled data (tier 2, Secure Access) are reviewed equitably across studies in accordance with the criteria set out in the CLS Data Access Framework, and to provide advice and guidance where new issues arise.

(v) **CLS DAC data access applications:** to ensure that applications for survey data, paradata, or genetic data not available via data sharing platforms such as the UKDS, SAIL Databank, UK LLC or the EGA, are dealt with as described in the guidelines that accompany the data access application form.

(vi) **CLS DAC data linkage applications**: to review requests for novel data linkages to CLS studies that involve linkage with new geographical indicators or with new administrative data such as health, education, finance, etc. These applications will be dealt with as described in the CLS Data Linkage guidelines and application form.

(vii) **CLS DAC data enhancement applications:** to review requests for CLS data enhancements of CLS studies – either for new data collection from survey

participants, requests for additional questionnaire or survey time within an existing data collection instrument, or for novel legacy data projects that involve not transcribed or digitised legacy data. These applications will be dealt with as described in the CLS Data Enhancement guidelines and application form.

(viii) **Emerging issues**: to consider any emerging data access policy issues and to refer these to the CLS Strategic Advisory Board for advice.

(ix) **Assessment criteria**: to address the CLS assessment criteria set out in the CLS Data Access Framework in determining whether data access should be granted.

(x) **Specialist knowledge**: if appropriate, to take the advice of third-party specialist knowledge, particularly where an application has not already been through an established peer review mechanism.

(xi) **CLS Strategic Advisory Board**: the CLS DAC will provide regular updates to the CLS Strategic Advisory Board, including a summary of decisions taken, as well as any underlying issues or concerns that the members of the CLS DAC wish to report to the board.

(xii) **Register of NHS Digital applications**: the CLS DAC will publish information about any linked health data dissemination to which NHS Digital is the data provider on the NHS Digital Data Uses Register. This should include the name of the organisation the data was provided to, the purpose (summary of the project), and details of the data released.

(xiii) **NHS Scotland data:** any requests for NHS Scotland data that cannot be handled by the UKDS will need to be evaluated by the CLS DAC and referred to the NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP).

3. Membership

The CLS DAC meets once every month. The meetings are attended by a number of CLS staff and external advisors, as follows.

3.1 Required attendees

- CLS DAC Chair: CLS Senior Data Manager, Aida Sanchez
- CLS DAC Secretariat: CLS Data Sharing Manager, C. Yogeswaran
- CLS Operations and IG representative: Managing Director of CLS, Lisa Calderwood
- CLS Research representative: PI of MCS: Emla Fitsimmons
- Ethics advisor: Alison Hall
- UKDS representative: Cristina Madger and/or John Sanderson

3.2 Additional attendees

Other CLS staff will need to attend the CLS DAC meetings to advise on specialised research areas included in the agenda:

- Director of CLS: Alissa Goodman
- PI of CLS genetics data: David Bann
- PI of Next Steps: Morag Henderson
- PI of NCDS and BCS70: George Ploubidis
- CLS Records Linkage Manager: Karen Dennison
- CLS Genetic Data Manager: Gemma Shireby
- CLS GIS Developer: David Church
- CLS Research Data Manager: Silvia Mendonça

4. Mode of operation

4.1 CLS DAC Secretariat

The CLS DAC Secretariat will deal with the administration and documentation of all DAC applications and DAC-related issues. Their responsibilities will be to:

1. Manage DAC-related queries from external and CLS data users.

2. Manage all received DAC applications, from receipt to approval, gather feedback for Committee members, and correspond with applicants on the CLS DAC decision and requests for additional information.
3. Design and maintain a database of applications and decisions.
4. Organise all DAC-related data releases and keep the database of applications up to date.
5. Generate the monthly UKDS data sharing report.
6. Organise the monthly CLS DAC meetings and write the minutes.
7. Design and maintain the DAC application forms and related CLS documentation.
8. Manage the content of the CLS data access webpages on the CLS website, in collaboration with the CLS Communications team.

4.2 Standing agenda items

The CLS DAC will consider at least the following items at each meeting:

- Monthly UKDS data sharing report
- CLS DAC applications
- Changes to data classification and the data sharing strategy

4.3 Changes to data classification

Decisions of the CLS DAC on data classification will be by majority vote. In the event that either a) a majority decision amongst Committee members is not reached or b) the majority view of the Committee and PI of the relevant study do not agree, the Chair of the CLS DAC will refer the decision to the CLS Strategic Advisory Board.

Any appeal against the CLS DAC's decision will be considered by the Strategic Advisory Board.

4.4 CLS DAC approvals

An application is completed by the individual/persons making the request. The CLS DAC has a dedicated email address, clsdata@ucl.ac.uk, for any queries. Applications to be considered by the Committee are sent to this address.

There are three types of DAC requests:

1. Data access
2. Data linkage
3. Data enhancement

Applications requiring a decision from the Committee will be considered at the monthly CLS DAC meeting.

DAC applications will be circulated to the Committee a week before the CLS DAC meeting to allow enough time for Committee members to read and evaluate the application in advance.

Decisions of the Committee on whether to grant access to applications, in light of data classification and other considerations, will be by majority vote. In the event that either a) a majority decision amongst Committee members is not reached or b) the majority view of the Committee and the PI of the relevant study do not agree, the Chair of the CLS DAC will refer the decision to the CLS Strategic Advisory Board.

If the applicant is a member of the CLS DAC, they will be able to present their DAC project at the meeting and will then be asked to temporarily leave the meeting. This will enable the rest of the Committee to discuss the project and ensure there is no conflict of interest.

Decisions about which requests will be approved will be based on the information provided in the application form and the criteria set out in the CLS Data Access Framework. The matters that will be considered are:

1. Bona fide research.
2. Appropriate access according to the potential disclosivity and/or sensitivity of the data.
3. Data minimisation.
4. Welfare of one or more of the study participants.
5. Impact on the public perception of the study or the future viability of the data collection.
6. Data security.
7. Data custodianship of linked data.
8. Sample depletion
9. Benefits connected with healthcare, adult social care, or the promotion of health for those projects which are applying to access NHS Digital linked health administrative data. The legal basis for processing these data must be 'public task'.

4.5 Approvals for genetic data

The criteria and considerations followed to review requests for genetics data are described comprehensively in section 6.5 of the CLS Data Access Framework.

Researchers may require access to use the genetics data in combination with survey data, biomedical phenotypes, linked administrative data, geographical indicators, etc. Access to genetic data linked to these additional data can potentially increase the disclosure risk, so such applications demand careful linkage of the relevant data to enable secure analysis at an individual level.

In order to achieve this level of security, DAC requests for genetic data (GENDAC applications) combined with survey data are subject to separate arrangements, which require the creation of a bespoke phenotypic dataset identified with specific project IDs.

Therefore, as part of the CLS DAC data access application, researchers need to submit a list of the exact variable names of the survey data they intend to use and provide a summary justifying how these variables fit within the scope of their project. The list of variables will be checked in detail by the RDM team in advance of the CLS DAC meeting.

Once an application has been approved by the CLS DAC a new ID will be created to identify the requested phenotypic and genetic data for every CLS DAC research team. This ID will always be different to any public IDs used on data sharing platforms.

The application and assessment criteria of genetics data requests are described comprehensively in section 6.5 of the CLS Data Access Framework.

4.6 Approvals for finite biological samples

The CLS DAC holds responsibility for assessing requests that involve the depletion of finite biological resources such as cell-line DNA or blood samples.

Upon receipt of the request, the CLS DAC will obtain a short report from the Bristol laboratory which will contain an up-to-date status of the samples and technical assessment of whether sample depletion will be an issue.

On a case by cases basis, the CLS DAC will request that the applicant provides a short external peer review document with regards to their proposed sample analysis.

These documents will be circulated together with the rest of the DAC meeting documentation. The application and assessment criteria of biological sample requests are described comprehensively in section 6.6 of the CLS Data Access Framework.

4.7 Approvals for internal data access by CLS staff

CLS researchers do not have preferential internal access to CLS research data as a matter of course, so they must access the data via the UK Data Service or other data

sharing platforms, following the same procedures as the rest of the research community.

However, there are some scenarios under which CLS researchers can access CLS data internally from central UCL servers. This special internal access, which must be clearly justified to the CLS Data Access Committee, is only allowed for

i) QA/QC purposes (quality analysis/quality control);

ii) strictly methodological projects;

iii) policy-relevant research needed to raise awareness of how newly collected or linked data can shed light on important social or policy issues (aka “initial findings”).

4.8 Approvals for NHS Digital linked health administrative data

When reviewing applications to access NHS Digital linked health administrative data, the Committee will consider the NHS Digital requirements. These are explained in detail below:

a) **Data minimisation:** The CLS DAC will assess whether the Hospital Episode Statistics (HES) variables requested by the data applicant is adequately justified by the purpose stated in the project proposal. If the CLS DAC considers that the applicant has not justified the amount of data being requested, the Committee can request that the applicant either provide further explanation or re-select the variables that fit in with the scope of the research project.

   The NHS Digital data minimisation guidance is available here.

b) **Organisation security assurance:** The CLS DAC will verify that the applicant has provided evidence of having an organisation security assurance (e.g., a Security Level Systems Policy (SLSP), Data Security and Protection Toolkit assessment, or the international information security standard ISO27001), as outlined in the ‘*CLS Licence Agreement for Linked NHS Digital Data.’* Approval for data access will only be granted to organisations that meet the security assurance requirement. Failure to meet the organisational security requirements will result in the CLS DAC requesting the applicant to provide further evidence, and the project will only be re-submitted to the CLS DAC for approval when the evidence provided is satisfactory.

c) **Legal basis:** The CLS DAC will verify that the organisation requesting access to NHS Digital linked administrative health data has a legal basis for processing the data. Sub-licensees must have ‘public task’ as a UK GDPR legal basis.

d) **Expected measurable benefits to health and social care:** The CLS DAC will review the stated purposes of the application and how it benefits healthcare, adult social care, or the promotion of health and will decide whether it is satisfied with

the answer provided. If the CLS DAC is not satisfied with the statement provided by the applicant, the Committee can ask the applicant to provide additional information and the project can be re-submitted for approval at the next CLS DAC meeting or via Chair approval. Approval for data access will only be granted if the CLS DAC is satisfied with the proposed benefits.

e) **Public visibility:** CLS reserves the right to publish online the details of DAC-approved projects, including the name of the organisation/institution to which data was provided, purpose (summary of the project), and what data was released.

4.9 Fast-track approvals

The CLS DAC have delegated the action of evaluating and approving straightforward data access requests to the CLS Research Data Management (RDM) team. The RDM team will seek the advice and guidance of the CLS DAC where new issues arise.

This RDM team approval on behalf of the CLS DAC is referred to as CLS 'fast-track' approval.

Fast-track approval is used for:

a) Requests to access special safeguarded data deposited (tier 1b, Special Licence) and controlled data (tier 2, Secure Access).

b) Requests to access controlled data deposited at the UK LLC (tier 2).

c) Simple CLS DAC requests for direct release of safeguarded data (tiers 1a and 1b) not yet deposited at the UKDS.

d) Amendments to existing CLS DAC applications, such as changes to the research data users, or straightforward requests for additional data.

The RDM team will record the CLS DAC-approved applications accordingly and will report them at the next monthly CLS DAC meeting.

This additional approval system will free up time in CLS DAC meetings to allow Committee members to discuss more complex DAC applications and strategic issues.

5. Risks

The CLS Risk Register is owned by the CLS Senior Leadership Team (SLT) and is shared with the CLS Strategic Advisory Board so that the board can discharge its duty to provide assurance to funders.

In addition, data sharing risks are included in the CLS Information Governance Risk Register (owned by the CLS Information Governance Steering Group) and in the Records Linkage Risk Register (owned by the CLS Records Linkage Group).

The following risks should be monitored by the CLS DAC:

(i) Respondents and/or Policy Community withdraw support due to concerns over security of data, for example in relation to administrative data linkage aspects of CLS.

(ii) Respondents and/or Policy Community withdraw support because shared research datasets contain very disclosive or sensitive data of highly personal nature.

(iii) Respondents and/or Policy Community withdraw support the secure data sharing platforms chosen by CLS to onward share data don't conform to the necessary IG and security standards required to handle potentially disclosive or sensitive linked data.

(iv) There is a delay in the CLS DAC granting applicants access to data due to processing delays at partner organisations like the UKDS or other mechanisms.

(v) The access procedures become a barrier to wide use of CLS data. For instance, slow and/or complex application process for data available under the secure data sharing platforms chosen by CLS may result in loss of CLS reputation

(vi) The CLS DAC and/or the CLS Research Data Management team is overwhelmed by applications for access to CLS data and does not have the resources to ensure that data is made as widely available as possible in a timely manner.