

# Research registration form for research studies that collect new data

All research projects collecting Personal Data must be registered with either the <u>UCL Data Protection Office</u> (only available if a UCL researcher is involved) or using this form and submitting to the IFS Data Controller before the data are collected.

This form should be completed if Personal Data is collected and used as part of the research project and, if relevant, before applications for ethics approvals are submitted to UCL Research Ethics Committee (REC). Once the registration is completed, you will receive a Registration Number which can be entered into the Ethics Application Form.

All sections <u>must</u> be completed before submitting this form to the Data Protection Officer. For more information, please see the GDPR information on the <u>intranet</u> and the <u>necessary steps for IFS</u> researchers collecting personal data. Please also refer to the ICO website: https://ico.org.uk/

For definitions, please refer to Annex I.

A. S1	UDY DETAILS	
1	Title of the Study	Evaluation of a pre-school program implemented at scale in Ghana
2	Proposed Start Date	1 <sup>st</sup> October 2021
3	Proposed End Date	1 <sup>st</sup> October 2024

<b>B.</b> M.	AIN CONTACT PERSON	
1	Full Name	Angus Phimister
2	Job Title	Research Economist
3	Email address	angus p@ifs.org.uk

	INCIPAL INVESTIGATOR fferent to main contact on)	
1	Full Name	Sonya Krutikova
2	Job Title	Deputy Research Director

3	Email address	Sonya_k@ifs.org.uk

# C. RESEARCHERS

# (Please list all other internal and external researchers involved in the <u>project</u>)

Name	Institution	Email address
Britta Augsburg	IFS	britta_a@ifs.org.uk
Orazio Attanasio	Yale	orazio.attanasio@yale.edu
E.Nketiah-Amponsah	University of Ghana	enamponsah@ug.edu.gh
Sharon Wolf	University of Pennsylvania	wolfs@upenn.edu

# **E. DETAILS OF PROJECT**

Please provide a brief summary of the project, including an explanation of the aims, design, methodology and plans for analysis that you propose to use.

Over 250 million children worldwide under the age of 5 years are at risk of not achieving their developmental potential due to poverty, poor health and nutrition, and deficient care and stimulation. The majority of these children live in low- and middle-income countries (LMICs), 1.6 million in Ghana. In Northern Ghana, the setting of this study, and where most families live on less than US\$2 per day, 20% of under 5s are stunted and 39% of 3-4 years olds are off-track cognitively.

In 2017/18, members of this team, partnering with the International NGO Lively Minds, conducted an efficacy trial of an Early Childhood Care and Education (ECCE) program through an RCT across 2 districts and 80 schools in Northern Ghana. This trial demonstrated that (1) the program is effective at raising child cognitive and socio-emotional skills and health; and (2) the hybrid features, which set Lively Minds apart from other ECCE intervention models, were key in achieving impacts. Both behavior change among the parents as well as activities within schools mediated observed impacts.

This program has now been adopted by the Government of Ghana (GoG), who partnering with Lively Minds are scaling it to reach over 4000 preschools over the next 3 years across

60 districts. This project is an evaluation of that scale up, measuring the effect of the larger program by randomizing the order in which districts receive the new program (i.e. a stepped wedge design randomized control trial).

Data collection will begin in study districts from December 2021, proceeding in groups of 6 districts at a time until the end of 2023. Within each district we will select a subsample of 3 to 5 schools, and then survey 10 to 15 children enrolled in these schools along with their household.

We will additionally analyze data on program delivery shared with us by Lively Minds, the program implementors.

# E. DESCRIPTION OF THE DATA YOU PLAN TO COLLECT AND THE INFORMATION FLOWS

Please provide the following information:

- details of any personal data being collected and any special categories of data
- details on who your data subjects are
- -the types of data you plan to collect (eg. quantitative, qualitative, testing and assessment data, observation data)
- the methods of data collection
- details of any partners involved in the study, eg other universities or organisationdetails of any processors being used, eg data storage providers, transcription services, fieldwork agencies
- a description or diagram setting out the information flows, which outlines who will have access to the data at different points in the process-which software and hardware you plan to use
- -whether you are planning to merge the data collected with other sources of data?
  -a description of the potential risks and mitigation strategies

This study will collect detailed identifiable information on children, their households, kindergarten teachers and district officials. The children's survey will include height and weight measurements, as this was a key aspect of improvement identified in the efficacy trial, and an important part of the trials impact. Most data collected will be quantitative, with qualitative data collected from district officials centered on interviews assessing problems with program scale up.

All data will be collected in-person by International Poverty Action (IPA), who worked with us on the earlier trial. They have extensive data collection experience across LMICs, and a large country office in Ghana. IPA will be data processors (contracted via Yale, DPA agreement pending), with data collected via SurveyCTO, stored on a password protected SurveyCTO server. The password to this server will only be given to IFS and IPA researchers on the project. As district level data collections are completed this data will be deleted from

the server and stored in the IFS encrypted R:\ drive. Data will be stored and analyzed with Stata or R.

Other PIs and CO-I's are based in Yale University, the University of Pennslyvania, and the University of Ghana. These researchers will not have access to the SurveyCTO folder, but at a later date may be transferred data with directly identifiable information. Study participants are told of this during the consent process. No data transfer will happen without appropriate agreements with the IFS in place.

We may merge this data with publicly available district level information (e.g. unemployment rates).

### Risks

There is a remote risk that sensitive data might be compromised if the IFS, SurveyCTO, or IPA network is hacked into, if an unauthorised person gains access to the data, if an individual is identified in the data by an employee, or if a tablet is lost or stolen. There are several safeguards we can and will adopt to mitigate this. The IFS network has an extensive firewall, cyber essentials certification, and is regularly stress-tested. Access to the data will be restricted to named individuals only, who will use password-protected accounts to access the data. All access requests will be logged and frequently reviewed. Finally, enumerators will be extensively vetted and trained in how to minimise the risk of tablets being lost or stolen. All tablets will be password protected. The system for managing data collection we will use will have features to ensure that field staff are only given access to data that is completely necessary for their job and only for the minimum time necessary.

	F. INFORMATION ABOUT THE PARTICIPANTS		
1	Will the study involve children under 18?	Yes	
2	Will the study vulnerable participants (other than children)	No	
3	How are the participants selected?	Within each district, three to five schools will be sampled from the school census provided by the Government of Ghana. Kindergarten teachers surveyed will be those teaching in those schools. Community leaders will be identified through asking members of the community who village elders/chiefs are. We will then conduct a	

		household census of 100-120 households around each school to identify households with children enrolled in the kindergarten who will be enrolled during our study, and of these 10-15 will be enrolled in the study and surveyed. Enrollment will be done with replacement – i.e. if the closest eligible household to the school does not consent then we will approach the next closest household until either we enroll the required number of participants or we run out of households. District officials surveyed will be those in post and responsible for the program during its implementation.
4	How many participants will be involved in the study?	TBD based on funding, but maximum numbers are: 3600 children; 3600 primary care givers; 720 kindergarten teachers; 720 community leaders; 60 district officials
5	Where are your participants located?	Ghana

# G. PRIVACY IMPACT SCREENING QUESTIONS If the answer to any of these questions is 'yes', then a DPIA is required For further information on any of these criteria, please see this document I:\Data\GDPR\Data Protection Registration\background documents\DPIA checklist.pdf and this webpage SECTION A

1	Is this a major project that involves the collection of personal data?	Yes
2	Will the project carry out evaluation or scoring including profiling or predicting?	No
3	Will the project carry out automated decision-making with legal or significant effects?	No
4	Will the project carry out systematic monitoring	No
5	Will the project involve processing of sensitive data or data or a highly personal nature?	Yes
6	Will the project involve processing data on a large scale?	No
7	Will the project involve processing data concerning <u>vulnerable</u> data subjects?	Yes
8	Will the project involve <u>innovative technology</u> or organisational solutions?	No
9	Does the project carry out processing that involves preventing data subjects from exercising a right or using a service or contract?	No
10	Will the project result in you making decisions or treating individuals in ways which can have a significant impact on them?	No
	If the answer is yes to any of the questions in SECTION A please consider carrying out a DPAI.	
	SECTION B	
11	Does the project plan to use systematic and extensive profiling or automated decision-making to make significant decisions about people?	No
12	Will the project process special-category data or criminal-offence data on a <u>large scale</u> ?	No
13	Will the project systematically monitor a publicly accessible place on a large scale?	No
14	Will the project use innovative technology in combination with	No

15	Will the project use profiling, automated decision-making or special category data to help make decisions on someone's access to a service, opportunity or benefit?	No
16	Will the project combine, compare or match data from multiple sources?	No
17	Will the project process personal data without providing a privacy notice directly to the individual in combination with any other criteria from SECTION A or SECTION B?	No
18	Will the project process personal data in a way that involves tracking individuals' online or offline location or behavior, in combination with any other criteria from SECTION A or SECTION B?	No
19	Will the project process children's personal data for profiling or automated decision-making or for marketing purposes, or offer online services directly to them?	No
20	Will the project process personal data that could result in a risk of physical harm in the event of a security breach?	No
	If you have answered YES to any of the questions in SECTION B, you MUST complete a DPIA.	
	Have you completed a Data Protection Impact Assessment (DPIA)? If not, please document in the box below your reasons why.	
	Reasons for not completing a DPIA (if applicable)	

H. D	ATA STORAGE AND TRANSFER	
1	Will the data be transferred from outside the UK into the UK?  If yes, please describe how this will be done	Pata will be collected on tablets using surveyCTO in Ghana. These will be uploaded to the surveyCTO server every night, and deleted from the device. Data will then be downloaded from the SurveyCTO server and stored at the IFS.
2	Will the data be transferred out of the UK from the UK?  If yes, please describe how this will be done.  If yes, please read the UCL guidelines on International Transfers which can be found <a href="https://example.com/here">here</a> .	While there is no planned data transfers in the short term, in the longer term the data may be transferred to project partners at Yale and the University of Pennsylvania. Participants are told of this transfer during the consent process and in the information sheet/privacy notice. Data sharing agreements will be written and put in place before any data transfer takes place.
3	Please list all the locations outside IFS where the data will be stored	N/A
4	Where are the data to be stored within IFS (e.g. standard network, encrypted network, enclave, dropbox)?	Non-anonymized data will be stored in the R drive. Analysis itself will be conducted on de-identified versions of the data, stored in the M drive
5	If your data are to be stored unencrypted at rest, please describe what other security measures will be taken. (e.g data will be de-identified)	N/A
5	If your data are to be stored in the cloud and the servers are outside the EU/EEA, please confirm that alternative data protection frameworks are in place (e.g. privacy shield).	SurveyCTO servers are in the EU
6	If your data are to be stored in the cloud, please confirm that you have ready the Information Classification and Handling Policy and the Data protection and GDPR guidelines for researchers working with personal	Confirmed

data understand the rules regarding storage or data in the cloud.

# I. PARTNERS AND DATA PROCESSORS (Please add additional third parties as necessary)

International Poverty Action (IPA)	
Status	Processor
(joint controller or processor)	
Location of third party	Outside EEA
(inside/outside the EU/EEA)	
Activity/purpose	Collecting and processing data
(e.g. storage, processing, analysis)	
Proposed method of data transfer	Upload to secure server and then IFS download encrypted data from server
Eg. AES-256 encryption with	
password.	
Is there an agreement/ contract in	PENDING Data processing agreement
place?	
For inite controllers a CDDD	
For <i>joint controllers</i> a GDPR-compliant Data Sharing Agreement is	
required	
required	
For data processors, a contract with	
GDPR-compliant clauses is required	
If the location is outside the EU/ EEA	All contracts with data processors will be GDPR
have you spoken to the Research	compliant.
Services Team about ensuring that	
the agreement/contract includes	
Standard Contractual Clauses?	
Lively Minds	
Status	Joint Controller
(joint controller or processor)	
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Location of third party	Inside the UK
(inside/outside the EU/EEA)	Applicate of the property of the state of
Activity/purpose	Analysis of program delivery data
(a a starage processing analysis)	
(e.g. storage, processing, analysis)	
Due wood weath and of data two wefers	
Proposed method of data transfer	Transfer of encrypted data using VeraCrypt software or via Boxcryptor
Eg. AES-256 encryption with	or via boxcryptor
password.	
password.	
Is there an agreement/ contract in	PENDING data sharing agreement
place?	
F	
For joint controllers a GDPR-	
compliant Data Sharing Agreement is	
required	
For data processors, a contract with	
GDPR-compliant clauses is required	
If the location is outside the EU/ EEA	N/A
have you spoken to the Research	
Services Team about ensuring that	
the agreement/contract includes	
Standard Contractual Clauses?	
Vala	
Yale	
	Joint Controller
Status	Joint Controller
Status (joint controller or processor)	Joint Controller Outside the UK
Status	
Status (joint controller or processor) Location of third party	
Status (joint controller or processor) Location of third party (inside/outside the EU/EEA)	Outside the UK
Status (joint controller or processor) Location of third party (inside/outside the EU/EEA)	Outside the UK
Status (joint controller or processor)  Location of third party (inside/outside the EU/EEA)  Activity/purpose	Outside the UK
Status (joint controller or processor)  Location of third party (inside/outside the EU/EEA)  Activity/purpose	Outside the UK
Status (joint controller or processor)  Location of third party (inside/outside the EU/EEA)  Activity/purpose  (e.g. storage, processing, analysis)	Outside the UK  Project partner, assisting in analysis of data
Status (joint controller or processor) Location of third party (inside/outside the EU/EEA) Activity/purpose (e.g. storage, processing, analysis) Proposed method of data transfer Eg. AES-256 encryption with	Outside the UK  Project partner, assisting in analysis of data
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Status (joint controller or processor) Location of third party (inside/outside the EU/EEA) Activity/purpose  (e.g. storage, processing, analysis)  Proposed method of data transfer  Eg. AES-256 encryption with password.	Outside the UK  Project partner, assisting in analysis of data  TBD based on what transfers are required
Status (joint controller or processor) Location of third party (inside/outside the EU/EEA) Activity/purpose (e.g. storage, processing, analysis) Proposed method of data transfer Eg. AES-256 encryption with password. Is there an agreement/ contract in	Outside the UK  Project partner, assisting in analysis of data
Status (joint controller or processor) Location of third party (inside/outside the EU/EEA) Activity/purpose  (e.g. storage, processing, analysis)  Proposed method of data transfer  Eg. AES-256 encryption with password.	Outside the UK  Project partner, assisting in analysis of data  TBD based on what transfers are required
Status (joint controller or processor)  Location of third party (inside/outside the EU/EEA)  Activity/purpose  (e.g. storage, processing, analysis)  Proposed method of data transfer  Eg. AES-256 encryption with password.  Is there an agreement/ contract in place?	Outside the UK  Project partner, assisting in analysis of data  TBD based on what transfers are required
Status (joint controller or processor) Location of third party (inside/outside the EU/EEA) Activity/purpose (e.g. storage, processing, analysis) Proposed method of data transfer Eg. AES-256 encryption with password.  Is there an agreement/ contract in place? For joint controllers a GDPR-	Outside the UK  Project partner, assisting in analysis of data  TBD based on what transfers are required
Status (joint controller or processor)  Location of third party (inside/outside the EU/EEA)  Activity/purpose  (e.g. storage, processing, analysis)  Proposed method of data transfer  Eg. AES-256 encryption with password.  Is there an agreement/ contract in place?  For joint controllers a GDPR-compliant Data Sharing Agreement is	Outside the UK  Project partner, assisting in analysis of data  TBD based on what transfers are required
Status (joint controller or processor) Location of third party (inside/outside the EU/EEA) Activity/purpose (e.g. storage, processing, analysis) Proposed method of data transfer Eg. AES-256 encryption with password.  Is there an agreement/ contract in place? For joint controllers a GDPR-	Outside the UK  Project partner, assisting in analysis of data  TBD based on what transfers are required

	l
For data processors, a contract with GDPR-compliant clauses is required	
If the location is outside the EU/ EEA have you spoken to the Research Services Team about ensuring that the agreement/contract includes Standard Contractual Clauses?	Yes
University of Pennslyvania	
Status (joint controller or processor)	Joint Controller
Location of third party (inside/outside the EU/EEA)	Outside the UK
Activity/purpose	Project partner, assisting in analysis of data
(e.g. storage, processing, analysis)	
Proposed method of data transfer	TBD based on what transfers are required
Eg. AES-256 encryption with password.	
Is there an agreement/ contract in place?	PENDING data sharing agreement
For <i>joint controllers</i> a GDPR- compliant Data Sharing Agreement is required	
For data processors, a contract with GDPR-compliant clauses is required	
If the location is outside the EU/ EEA have you spoken to the Research Services Team about ensuring that the agreement/contract includes Standard Contractual Clauses?	Yes

# J. LAWFUL BASIS AND PRIVACY NOTICES

state which Article 9(2) special condition you are using to process these data?  Note: This will usually be Article 9(2)(j)-where processing is necessary for archiving purposes in the on child health which is special category data. To access this data we are using Article 9(2)(j)-where processing is necessary for archiving purposes in the	1	Have you written privacy notices to provide to your participants?	Yes
participants?  Please include the consent forms with this application  What legal basis are you using for processing the data?  Have you included your legal basis in your privacy notice in a way that is understandable to participants?  Note: this will usually be Article 6(1)(f) legitimate interests, where the processing is necessary for your legitimate interests or the legitimate interests of a third party unless there is good reason to protect the individual's personal data which overrides those legitimate interests.  In some instances it may be Article 6 (1) (a) consent—if you are unsure, please talk to the Data Protection Officer  4 If using legitimate interests as your legal basis, please complete a Legitimate interests Assessment (LIA).  A blank form can be found here and previous examples can be found here: I:\Data\GDPR\Legitimate Interest Assessments  5 If you are collecting Special Category data, please state which Article 9(2) special condition you are using to process these data?  Note: This will usually be Article 9(2)(j)-where processing is necessary for archiving purposes in the		Please include them with this application.	
What legal basis are you using for processing the data?  Have you included your legal basis in your privacy notice in a way that is understandable to participants?  Note: this will usually be Article 6(1)(f) legitimate interests, where the processing is necessary for your legitimate interests or the legitimate interests of a third party unless there is good reason to protect the individual's personal data which overrides those legitimate interests.  In some instances it may be Article 6 (1) (a) consent – if you are unsure, please talk to the Data Protection Officer  If using legitimate interests as your legal basis, please complete a Legitimate interests Assessment (LIA).  A blank form can be found here and previous examples can be found here: I:\Data\GDPR\Legitimate Interest Assessments  If you are collecting Special Category data, please state which Article 9(2) special condition you are using to process these data?  Note: This will usually be Article 9(2)(j)-where processing is necessary for archiving purposes in the	2	, , , , , , , , , , , , , , , , , , , ,	Yes
data?  Have you included your legal basis in your privacy notice in a way that is understandable to participants?  Note: this will usually be Article 6(1)(f) legitimate interests, where the processing is necessary for your legitimate interests or the legitimate interests of a third party unless there is good reason to protect the individual's personal data which overrides those legitimate interests.  In some instances it may be Article 6 (1) (a) consent—if you are unsure, please talk to the Data Protection Officer  If using legitimate interests as your legal basis, please complete a Legitimate interests Assessment (LIA).  A blank form can be found here and previous examples can be found here: I:\Data\GDPR\Legitimate Interest Assessments  If you are collecting Special Category data, please state which Article 9(2) special condition you are using to process these data?  Note: This will usually be Article 9(2)(j)-where processing is necessary for archiving purposes in the		Please include the consent forms with this application	
notice in a way that is understandable to participants?  Note: this will usually be Article 6(1)(f) legitimate interests, where the processing is necessary for your legitimate interests or the legitimate interests of a third party unless there is good reason to protect the individual's personal data which overrides those legitimate interests.  In some instances it may be Article 6 (1) (a) consent—if you are unsure, please talk to the Data Protection Officer  4 If using legitimate interests as your legal basis, please complete a Legitimate interests Assessment (LIA).  A blank form can be found here and previous examples can be found here: I:\Data\GDPR\Legitimate Interest Assessments  5 If you are collecting Special Category data, please state which Article 9(2) special condition you are using to process these data?  Note: This will usually be Article 9(2)(j)-where processing is necessary for archiving purposes in the	3		Legitimate interests
<ul> <li>interests, where the processing is necessary for your legitimate interests or the legitimate interests of a third party unless there is good reason to protect the individual's personal data which overrides those legitimate interests.</li> <li>In some instances it may be Article 6 (1) (a) consent – if you are unsure, please talk to the Data Protection Officer</li> <li>If using legitimate interests as your legal basis, please complete a Legitimate interests Assessment (LIA).</li> <li>A blank form can be found here and previous examples can be found here:         <ul> <li>I:\Data\GDPR\Legitimate Interest Assessments</li> </ul> </li> <li>If you are collecting Special Category data, please state which Article 9(2) special condition you are using to process these data?</li> <li>Note: This will usually be Article 9(2)(j)-where processing is necessary for archiving purposes in the</li> </ul>			
if you are unsure, please talk to the Data Protection Officer  If using legitimate interests as your legal basis, please complete a Legitimate interests Assessment (LIA).  A blank form can be found here and previous examples can be found here: I:\Data\GDPR\Legitimate Interest Assessments  If you are collecting Special Category data, please state which Article 9(2) special condition you are using to process these data?  The data will information on child health which is special category data. To access this data we are using Article 9(2)(j)-where processing is necessary for archiving purposes in the		interests, where the processing is necessary for your legitimate interests or the legitimate interests of a third party unless there is good reason to protect the individual's personal data which overrides those	
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state which Article 9(2) special condition you are using to process these data?  Note: This will usually be Article 9(2)(j)-where processing is necessary for archiving purposes in the on child health which is special category data. To access this data we are using Article 9(2)(j)-where processing is necessary for archiving purposes in the		examples can be found <u>here</u> :	
processing is necessary for archiving purposes in the processing is necessary f	5	state which Article 9(2) special condition you are	special category data. To
		processing is necessary for archiving purposes in the public interest, scientific or historical research	using Article 9(2)(j)-where processing is necessary for archiving purposes in the public interest, scientific or historical research
Have you included your separate condition in your privacy notice in a way that is understandable to participants?		privacy notice in a way that is understandable to	

<sup>&</sup>lt;sup>1</sup> In order to rely on this researchers must ensure that processing meets the public interest and that appropriate safeguards and technical measures are in place to protect data during collection, handling, transfer, storage, use and publication.

	J. CHECKLIST (State yes or n/a)		
1	Data Protection Impact Assessment	Υ	
2	Legitimate Interest Assessment	Υ	
3	Consent forms	Υ	
4	Privacy notices	Y (embedded within information sheets)	
5	Contracts with third parties	Pending	

DATA PROTECTION REGISTRATION	
IFS Data Protection Registration Number	Date issued
IFSDPR00010	01/09/2021

# **Annex I - Definitions**

Term	Definition
Personal data	'Any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.' <sup>2</sup>
	If it is not possible to directly identify an individual from that information, then it is necessary to consider whether the individual is still identifiable. You should take into account the information you are processing together with all the means reasonably likely to be used by either you or any other person to identify that individual.
Data subject	A data subject is any person whose personal data is being collected, held or processed
Human research subject	Research is considered to involve human subjects when an investigator conducting research obtains (1) data through intervention or interaction with a living individual, or (2) identifiable private information about a living individual. <sup>3</sup>
Data controller	A 'controller' means the natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data; where the purposes and means of such processing are determined by Union or Member State law, the controller or the specific criteria for its nomination may be provided for by Union or Member State law;
Joint data controller	Where two or more controllers jointly determine the purposes and means of processing the data
Data owner <sup>4</sup>	The individual or organisation who owns the data or who gives permission to access the data.
	It is possible to be a Data Controller, without being a Data Owner.

 $<sup>^2\</sup> http://www.privacy-regulation.eu/en/article-4-definitions-GDPR.htm$ 

 $<sup>^{\</sup>rm 3}$  Definition used by the US Office for Human Research Protections: https://www.hhs.gov/ohrp/

<sup>&</sup>lt;sup>4</sup> See IFS' Information Classification and Handling Policy

Data processor	A 'processor' means a natural or legal person, public authority, agency or other body which processes personal data on behalf of the controller	
Processing	'Processing' means any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction	
Sensitive and special category data <sup>5</sup>	Special category data under the GDPR is broadly similar to the concept of sensitive personal data under the 1998 Data Protection Act.  Under GDPR, processors must have a specific legal basis for processing special category data. They must still have a lawful basis for processing under Article 6 (Article 6: Lawfulness of Processing) in exactly the same way as for any other personal data. Processors will also need to satisfy a specific condition under Article 9 (Article 9: Processing of special categories of personal data).  Special category data is considered to be more sensitive, and need more protection. Examples of special category data include information about an individual's:  1	
	Although 'special category data' is specifically defined in the GDPR, it is important to note that this is not an exhaustive list of the types of data which may be considered sensitive by data subjects, and this may vary based on the context in which the data is being collected and processed.	

<sup>5</sup> https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/special-category-data/

## Anonymisation<sup>6</sup>

The GDPR defines anonymisation as '…information which does not relate to an identified or identifiable natural person or to personal data rendered anonymous in such a manner that the data subject is not or no longer identifiable'.<sup>7</sup>

This means that once the data has been de-identified, it is no longer re-identifiable as the identifiers have been permanently removed.

According to the UCL website:

Anonymisation is the process of removing personal identifiers, both direct and indirect, that may lead to an individual being identified.

An individual may be directly identified from their name, address, postcode, telephone number, photograph or image, or some other unique personal characteristic.

An individual may be indirectly identifiable when certain information is linked together with other sources of information, including, their place of work, job title, salary, their postcode or even the fact that they have a particular diagnosis or condition.<sup>8</sup>

The GDPR does not apply to anonymised information.

### **Pseudonymisation**

The GDPR defines pseudonymisation as "the processing of personal data in such a way that the data can no longer be attributed to a specific data subject without the use of additional information, as long as such additional information is kept separately and subject to technical and organisational measures to ensure non-attribution to an identified or identifiable individual" <sup>9</sup>

Pseudonymisation involves removing identifiers from the main dataset and replacing them with codes/unique IDs. The IDs are then stored separately and encrypted. This means that the data is potentially reidentifiable in the future.

Unlike anonymised data, pseudonymised data falls within the scope of the GDPR

# Data Protection Officer (DPO)

A DPO helps to monitor internal compliance, inform and advise on data protection obligations, provide advice regarding Data Protection Impact Assessments (DPIAs) and act as a contact point for data subjects and the supervisory authority

<sup>&</sup>lt;sup>6</sup> See the ICO's Code of Practice on Anonymisation for further information: https://ico.org.uk/media/1061/anonymisation-code.pdf

<sup>&</sup>lt;sup>7</sup> See Recital 26: http://www.privacy-regulation.eu/en/recital-26-GDPR.htm

<sup>&</sup>lt;sup>8</sup> See: https://www.ucl.ac.uk/legal-services/guidance/general-data-protection-regulation-gdpr/gdpr-anonymisation-pseudonymisation

<sup>&</sup>lt;sup>9</sup>GDPR: Article 4(3b): http://www.privacy-regulation.eu/en/article-4-definitions-GDPR.htm

Legitimate interests assessment (LIA)	Researchers may rely on legitimate interests as the lawful basis for processing personal data. A LIA is three-part test to assess whether legitimate interests applies. It is a type of light-touch risk assessment based on the specific context and circumstances. It will help to ensure that your processing is lawful. Recording the LIA will also help to demonstrate compliance.
Data protection impact assessment (DPIA)	A Data Protection Impact Assessment (DPIA) is a process which helps to identify and minimise the data protection risks of a project.  It is necessary to do a DPIA for processing that is likely to result in a high risk to individuals. This includes some specified types of processing. It is also good practice to do a DPIA for any other major project which requires the processing of personal data.