Plan Overview

A Data Management Plan created using DMPonline

Title: COVID-19 IDD: A global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers.

Creator: Gail Birkbeck

Principal Investigator: Christine Linehan

Data Manager: Gail Birkbeck

Affiliation: University College Dublin

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ORCID iD: 0000-0002-9083-3457

Project abstract:

Background: This protocol outlines research to explore family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers. Evidence suggests that people with intellectual and developmental disabilities experience disparities in healthcare access and utilisation. This disparity was evident early in the pandemic when discussions arose regarding the potential exclusion of this population to critical care. Methods: An anonymous online survey will be conducted with caregivers, both family members and paid staff, to explore their perceptions of the impact of COVID-19 in terms of demographics, living arrangements, access to services, social distancing, and carer wellbeing. The survey will be developed by the research team, many of whom are experts in intellectual disability within their own jurisdictions. Using back-translation our team will translate the survey for distribution in 18 countries worldwide for international comparison. The survey team have extensive personal and professional networks and will promote the survey widely on social media with the support of local disability and advocacy agencies. Statistical descriptive and comparative analyses will be conducted. Ethical approval has been obtained for this study from University College Dublin's Human Research Ethics Committee (HS-20-28-Linehan). Dissemination: Study findings will be prepared in a number of formats in order to meet the needs of different audiences. Outputs will include academic papers, lessons learned paper, practice guidelines, reports, infographics and video content. These outputs will be directed to families, frontline and management delivering disability services, national-level policy makers, healthcare quality and delivery authorities, national pandemic organisations and international bodies.

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COVID-19 IDD: A global survey exploring family members’ and paid staff’s perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers.

Data description and collection or re-use of existing data

How will new data be collected or produced and/or how will existing data be re-used?

Guidance	Answer
Explain which methodologies or software will be used if new data are collected or produced and specify which community standards (if any) will be used.	Quantitative survey data of IDD (intellectual and developmental disability) caregiver experience using Qualtrics.
State any constraints on re-use of existing data if there are any.	Not applicable, existing data is not being reused.
Explain how data provenance will be documented.	Data is gathered using an online link to a Qualtrics survey. Participants are taken to a landing page created for this study where the desired language for survey completion is selected. On selecting to complete the survey participants are provided with information about the survey and how anonymised data will be used and stored. The survey proceeds once participants consent to participate. All of the survey data is stored securely in Qualtrics. It will be downloaded into SPSS for cleaning and data analysis. All stages will be clearly documented at the study, data and metadata level. In addition, in cleaning and preparing the data for analyses the syntax file contains a listing recording all amendments to the data (i.e., data recodes, computes and apportionment of any data as missing data).
Briefly state the reasons if the re-use of any existing data sources has been considered but discarded.	Not applicable, to our knowledge there is currently no existing data addressing caregiver experience in the field of IDD during Covid 19.

What data (for example the kind, formats, and volumes), will be collected or produced?

Guidance	Answer

Give details on the types of data – quantitative, qualitative; generated from surveys, interviews, medical records, clinical measurements, tissue samples, genotypic data, etc.	Quantitative data only from an online survey of adult family caregivers and paid caregivers in formal care settings. Two standardised psychological scales are also included in the bespoke survey: DASS 12 (Depression, Anxiety and Stress Scale) and the Coronavirus Anxiety Scale
Give details on the data format: the way in which the data is encoded for storage, often reflected by the filename extension (e.g. pdf, xls, doc, txt, or rdf).	Data will be saved in several different formats. Qualtrics will be used to gather data. Qualtrics uses Transport Layer Security (TLS) encryption (also known as HTTPS) for all transmitted data. All of the survey data is stored on Qualtrics and can be downloaded in different formats. In this study these are SPSS, .csv and Excel depending on need. SPSS portable (.por) or tab delimited format are proposed for sharing data file with a repository.
Justify the use of certain formats. For example, decisions may be based on staff expertise within the host organisation, a preference for open formats, standards accepted by data repositories, widespread usage within the research community, or on the software or equipment that will be used.	UCD School of Psychology has considerable expertise with Qualtrics and SPSS which are the preferred software for this type of study. The open format is the preference of the funding body who prioritise widespread dissemination of the dataset and have identified a range of reputable repositories which embrace quality standards within the field.
Give preference to open and standard formats as they facilitate sharing and long-term re-use of data.	The dataset will be made available to researchers for secondary analysis and re-use Users may need to submit a request form to access the data. The research team acknowledge the request form may limit the spirit of full open access but have selected this Archive as it is the most commonly used repository for quantitative data in the host country and following consultation was deemed acceptable to the funding body. In line with the principles and spirit of the Covid19 funding and the emphasis on rapid data sharing and making data FAIR the research team has also explored the use of a self-deposit repository alongside ISSDA. There are a number of Covid-related repositories and the ICPSR at the University of Michigan appears to be an appropriate archive for this dataset.

Give details on the volumes (they can be expressed in storage space required (bytes), and/or in numbers of objects, files, rows, and columns).	This will be a single file. The number of questions, answer options and responses will determine the size of this file. The volume of data is unclear at this stage as responders self-select to participate. There are approximately 150 variables. Currently, this does not include any data transformation and new variables created in the analysis. There are considerably more variables now with the various data transformations created in preparing the data for analysis. [Final number of variables is being ascertained]
Consider and detail which data will have value to other research users and could be shared. We recognize that there are many reasons why data cannot be shared or made openly available. If you do not intend to make the data you've generated available to others, please provide justification for your decision.	The full dataset will be available to other researchers. Data transformations will also be included where appropriate, for example, the total score on two psychometric scales included in the survey. Data transformations will be documented and labelled in the codebook. The data will add value as, to the knowledge of the research team, it is the only source of data on the experiences of individuals with IDD during this pandemic, the data will be of interest to those developing policy and practice in supporting this population through a pandemic. The research questions are as follows: 1) What are the experiences of the Covid 19 pandemic for individuals with intellectual and developmental disability and their caregivers, for example, in access to healthcare and impact of restrictive practices? 2) Are there differences in experiences for those living in the family home, different residential service models, and different international jurisdictions?
The following information was added by the research team so as to streamline all of the information on data collection and to address targeted questions on all aspects of the study design, timeframe, study population and complete data gathering process.	
When is the data being gathered?	August – End September 2020.
Where is the data being gathered?	Caregiver data will be gathered in 19 countries. Australia, Brazil, Canada, Czech Republic, Germany, Greece, Hong Kong, India, Ireland, Israel, Italy, Netherlands, New Zealand, Norway, Spain, Sweden, Zambia, UK, US.
Who is the subject of the data gathering exercise?	A convenience self-selecting sample of adult family members and paid staff who provide support to people with IDD.

Why is the date being gathered?	To evidence the experience of this population during the Covid 19 pandemic. This population are evidenced to be poorly served in health promotion and access. Their experiences during the pandemic need to be captured so that lessons can be learned about how best they might be supported

Documentation and data quality

What metadata and documentation (for example the methodology of data collection and way of organising data) will accompany data?

Guidance	Answer
Indicate which metadata will be provided to help others identify and discover the data.	Background data to provide contextual information will include: *study-level* documentation: study context and history (e.g. recruiting the study team, the expansion of the team and the roll-out of the study in multiple countries); detailed methodology of the study design in order to address the project objectives ad research questions *data-level* documentation: a codebook of the variable names, value labels and missing data. Structured metadata will be provided from ISSDA when archiving the data, along with a commitment to long term preservation. Structured metadata may also be provided if/when data is self-deposited in an open archive.
Indicate which metadata standards (e.g. DDI, TEI, EML, MARC, CMDI) will be used and potential community standards available. Use community standards where these are in place.	It is proposed to use DDI metadata standard when depositing the dataset in a repository. The proposed archive, the Irish Social Science Data Archive (ISSDA) use NESSTAR Publisher for creation of Data Documentation Initiative (DDI).
Indicate **how** the data will be organised during the project, mentioning for example conventions, version control, and folder structures.	During the data collection phase all of the data generated will be on Qualtrics. Once data collection has concluded It is proposed to download a single file in SPSS for data cleaning and analysis purposes. This version will be clearly named in a folder on the study's Google Drive. A versioning process will also be implemented in order to identify a 'cleaned' copy of the dataset, and a dataset containing any transformations to the format, structure and values of data. Best practices in version control, folder structure and file naming conventions will be adhered to throughout the study.
Consider **what** other documentation is needed to enable re-use – methodology used to collect the data, analytical and procedural information, definitions of variables, units of measurement, and so on.	Detailed records will be kept on the all of the study components. An SPSS syntax file will be used to record all of the data transformations, new variables created, as well as all the analyses conducted. This will form the basis of a detailed codebook for this study. Best practice in variable definition and naming conventions will be adhered too.
Consider **how** this information will be captured and where it will be recorded for example in a database with links to each item, a 'readme' text file, file headers, code books, or lab notebooks.	A folder on all of the project documentation – study level, data level and metadata had been developed and includes a readme.txt file on the folder contents and versions. The Irish Social Science Data Archive provide a Data Deposit form, based on the DDI metadata standard, and this will also be used to collect study level metadata. This is will updated over the life of the study. Initially, this will be stored on Google Drive. A project website, where participants 'land' to participate in the study could also be used to share documentation as well as research products at a later stage.
When describing data, please remember that file and folder names as well as variables and metadata may contain personal or sensitive data. Even if your research does contain personal data, related metadata can be published if it does not contain identifiers which could be used to identify a study subject.	No identifying data is intentionally gathered in this study. There is no opportunity for participants to enter any data, instead only endorse closed questions as well as answer two standardised scales with fixed response options. The ethical approval for this study has been awarded following a review of the survey which was categorised by the researchers as anonymous. As there were a small number of replies for some questions it is proposed to run additional analyses to ensure no respondent can be identified in any way. Small cell adjustments will be performed should this arise. In addition, some countries with lower response rates may be excluded from the final dataset. Other indirect identifiers such as occupation, locality/province will also be reviewed and excluded from the public domain. Banding may also be applied to variables such as socio-economic status amongst others and this will be determined by the responses.

What data quality control measures will be used?

Guidance	Answer
Explain **how** the consistency and quality of data collection will be controlled and documented. This may include processes such as calibration, repeated samples or measurements, standardised data capture, data entry validation, peer review of data, or representation with controlled vocabularies.	During data capture there are pre-defined response options for each item of the survey minimising data entry errors. There is a limited chance of user error unless the incorrect answer is selected. In addition, simple language is used throughout the survey to aid comprehension. A back-translation process was also used to validate the translation of the survey into 15 languages to ensure the quality of the data collection (Note: The English-language version was not back-translated). The quality of the back translation process was tested by inviting a native speaker to answer the questionnaire.
Consider **how** data minimisation, pseudonymisation or anonymisation will affect data quality.	This survey is anonymous which means it will not be possible to revert to participants to verify the data. While a limitation, it is hoped that the benefits of anonymisation in terms of recruitment will outweigh the limitation. During the data cleaning process every effort will be taken to ensure anonymity is maintained and no potentially identifying information is contained in the dataset. For example, one question enquiries into family composition and number of children in the household. Hypothetically, a secondary user may be able to identify a large family in a specific country. In such a scenario data may be recoded into a categorical breakdown of the number of children (e.g., 1-2; 3-5; 6+) to protect privacy.
The following information was added by the research team	
When will the data and metadata be organised?	Study documentation will be ongoing during the data collection, data cleaning and data analysis stages of this study. Data level information regarding any data transformation or new variables generated as part of the analysis will be recorded during the data cleaning and data analysis stages.
Where will the data and metadata be organised?	The data will be organised in UCD. Structured metadata will be organised by the Archive where the data is being deposited.
Who will have responsibility for data documentation and metadata?	PI (Christine Linehan), Research Data Coordinator/Manager (Gail Birkbeck), Research Assistant (Adam Nolan). Structured metadata will be the responsibility of the Archive.
Why is data documentation and metadata recorded?	Documentation and metadata are recorded to enable the data to be understood and interpreted by future date users, as well as ensuring research integrity and reproducibility of the research.

Storage and backup during the research process

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

Guidance	Answer
Describe how and where the data will be stored, backed-up and managed during research activities and how often the backup will be performed. It is recommended to store data in least at two separate locations.	During data collection all respondent data is backed up by Qualtrics using two methods: automatic propagation across servers (immediate upon collection) and daily complete off-site encrypted backups. Qualtrics backs up data for disaster recovery purposes only. It is also proposed to download a full, raw data file in MS Excel format and this will be encrypted and stored on Google Drive. During data cleaning and analysis an SPSS version will be backed-up on regular occasions. A procedure will be implemented for storing the data including who can access the data.
Give preference to the use of robust, managed storage with automatic backup, such as provided by IT support services of the home institution. Storing data on laptops, stand-alone hard drives, or external storage devices such as USB sticks should be avoided. If external servers are used please ensure that they are compliant with GDPR and any other legislation related to the data collected.	Qualtrics is GDPR compliant and CCPA (California Consumer Privacy Act) compliant. The PI, Research Data Coordinator and Research Assistant will work with the Chief Technical Officer in the School of Psychology, UCD to identify a server for data storage and backup for the SPSS version of the data.

How will data security and protection of sensitive data be taken care of during the research?

Guidance	Answer
Detail the key risks to the confidentiality and security related to human participants or other sensitive data and how this information will be managed.	Qualtrics is GDPR compliant and CCPA (California Consumer Privacy Act) compliant. However, as noted, this survey is anonymous, and no personal data is gathered.

Explain how the data will be recovered in the event of an incident.	Qualtrics has a back-up of the data for disaster recovery purposes. The full raw data file will also be stored in MS Excel format which will be downloaded from Qualtrics on a weekly basis and saved on UCD's servers and Google Drive while the survey is ongoing. The PI will work with an SPSS version of the file during the analysis stage and a versioning and backup plan will be implemented so that data can be recovered should there be an issue.
Explain who will have access to the data during the research and how access to data is controlled, especially in collaborative partnerships.	The Qualtrics administrator in UCD, the PI, the Research Data Coordinator/Data Manager and the Research Assistant will have access to the data during the research process. One study collaborator, based in UCD, will assist the PI with the statistical analysis. It is not proposed to share the dataset with the other study partners beyond that until after the study is concluded.
Explain which institutional data protection policies are in place.	Qualtrics complies with applicable data privacy laws in its role as a data controller of its own data and as a data processor of customer data. Specifically, Qualtrics is GDPR (General Data Protection Regulation) and CCPA (California Consumer Privacy Act) compliant and provides technology that enables our customers to be compliant as well. UCD Data Protection Policy:

https://www.ucd.ie/gdpr/t4media/UCD_Data_%20Protection_%20Policy.pdf

Legal and ethical requirements, codes of conduct

If personal data are processed, how will compliance with legislation on personal data and on security be ensured?

Guidance	Answer
Ensure that when dealing with personal data protection laws (GDPR and Health Research Regulations) are complied with.	This is an anonymous survey and no identifying data is collected including computer IP addresses.
Ensure that the preservation and/or sharing of personal data is fully consistent with the terms of the informed consent under which the data were provided by participants.	Participants are made aware prior to commencing the online survey how their responses will be used and that it will be made available. No personal data is gathered.
Consider anonymisation of personal data for preservation and/or sharing (truly anonymous data are no longer considered personal data).	Any potential identifying data evident in the dataset will be de-identified. A de-identification process is underway (Dec/Jan). The Data Protection Officer (DPO) at UCD has been providing guidance on anonymity. The DPO agreed that proposed data set is anonymous.
Consider pseudonymisation of personal data (the main difference with anonymisation is that pseudonymisation is reversible).	Not applicable
Consider encryption which is seen as a special case of pseudonymisation (the encryption key must be stored separately from the data, for instance by a trusted third party).	Not applicable
Explain whether there is a managed or governed access procedure in place for authorised users of personal data.	Not applicable

How will other legal issues, such as intellectual property rights and ownership, be managed? What legislation is applicable?

Guidance	Answer
Explain who will be the owner of the data and who will have the rights to control access.	The data are owned by UCD. See
(https://sisweb.ucd.ie/usis/!W_HU_MENU.P_PUBLISH?p_tag=GD-DOCLAND&ID=157)	
Explain what access conditions will apply to the data? Will the data be openly accessible, or will there be access restrictions? In the latter case, which? Consider the use of data access and re-use licenses (e.g. CC-BY, CC-BY-NC, etc.)	Access conditions are dependent on the Archive. ISSDA has an application process to access the data. Data are made available for either research and/or teaching purposes and every application is reviewed prior to data being made available. If data is submitted to an open archive then it can be accessed by anyone, generally.
Make sure to cover these matters of rights to control access to data for multi-partner projects and multiple data owners, in the consortium agreement.	In this study UCD is the grant holder and the PI has responsibility for controlling access to the data. All collaborators have agreed to the publication of a paper addressing the research questions. A publication strategy is currently being drafted detailing additional publications planned once the commitment for this study have been fulfilled.
Indicate whether intellectual property rights (e.g. Database Directive, sui generis rights) are affected. If so, explain which and how will they be dealt with.	We have outlined our project and deliverables with HRB re our intellectual property situation and are advised that no IP is involved in this research (personal communication Sharon Kappala 04.11.20).
Indicate whether there are any restrictions on the re-use of third-party data.	Not applicable – there is no re-use of third-party data in this study

What ethical issues and codes of conduct are there, and how will they be taken into account?

Guidance	Answer
Consider whether ethical issues can affect how data are stored and transferred, who can see or use them, and how long they are kept.	Ethical approval from UCD approved open access. It is proposed that the data is stored indefinitely. The data is anonymous and can be stored and transferred.
Demonstrate awareness of these aspects and respective planning.	
Follow the national and international codes of conduct and institutional ethical guidelines and check if ethical review (e.g. by an ethics committee) is required for data collection in the research project.	*The study team also consulted with the following (as in the ethics application):* *HREC Guidelines and Policies specifically Relating to Research Involving Human Subjects:* *The UCD Data Protection Policy* *The UCD GDPR Policies & Procedures* *The General Data Protection Regulation* *The Data Protection Guidelines on Research in the health sector* *The Health Research Regulations.*
The following information was added by the research team	
What else has been implemented with regard to the conduct of the survey.	Should any participant become distressed as a result of completing the survey they are referred to the national support services in their respective country at the end of the survey. This was prepared by the research team member for each of the countries represented.

Data sharing and long-term preservation

How and when will data be shared? Are there possible restrictions to data sharing or embargo reasons?

Guidance	Answer
Explain **how** the data will be discoverable and shared (e.g. by deposit in a trustworthy data repository, indexed in a catalogue, use of a secure data service, direct handling of data requests, or use of another mechanism).	The data will be discoverable and shared in the Irish Social Science Data Archive, (ISSDA) Ireland's centre for quantitative data acquisition, preservation, and dissemination. The metadata will be available in ISSDA also. Currently, it is intended to self-publish the data alongside ISSDA and in that case data will also be discoverable there.
Outline the plan for data preservation and give information on how long the data will be retained.	It is planned to preserve the data and to make the dataset available indefinitely.
Explain **when** the data will be made available. Indicate the expected timely release. (For data related to clinical trials – specify how long the data will be made available for.) Explain whether exclusive use of the data will be claimed and if so, why and for how long. Indicate whether data sharing will be postponed or restricted, e.g. to publish, protect intellectual property, or seek patents.	Data will be made available with the first publication of the findings, or within a defined period to facilitate the archive to prepare the data. Documentation and other resources required to use the data will also be available via the repository.
Indicate **who** will be able to use the data. If it is necessary to restrict access to certain communities or to apply a data sharing agreement, explain how and why. Explain what action will be taken to overcome or to minimise restrictions.	It is intended that the data underpinning published research can be accessed by any interested party for research or teaching purposed.
We recognize that there are many reasons why data cannot be shared or made openly available. If you do not intend to make the data you've generated available to others, please provide justification for your decision. Restrictions should be minimized as much as possible.	Not applicable – the data will be shared.

How will data for preservation be selected, and where data will be preserved long-term (for example a data repository or archive)?

Guidance	Answer
Indicate what data must be retained or destroyed for contractual, legal, or regulatory purposes.	No data needs to be destroyed.
Indicate how it will be decided what data to keep. Describe the data to be preserved long-term and consider how this data will be curated and preserved beyond the lifetime of the grant. Indicate where the data will be deposited, preferably in a trusted repository.	It is intended to retain most of the data gathered, only data that potentially identifies a respondent will be excluded. ISSDA has been nominated as the main archive. The research team are exploring the self-deposit of data in trusted archives, such as ICPSR as it can point data from this study to an existing archive on disability. This would help promote this existence of this data to other disability researchers.
Explain the foreseeable research uses (and/or users) for the data.	The dataset provides a profile, albeit of a convenience sample, of the experiences of individuals with IDD and their caregivers – it has the potential to be examined using a number of core independent variables such as type and level of IDD, living arrangement, COVID 19 status etc. The data can be used to inform guidelines, practice and policy formation about the provision of care during a pandemic or similar health or medical emergency for people with IDD. Given that Covid-19 may be circulating in the future this will be an important data source for public health emergency teams in planning an appropriate response.
Indicate where the data will be deposited. If no established repository is proposed, demonstrate in the data management plan that the data can be curated effectively beyond the lifetime of the grant. It is recommended to demonstrate that the repositories policies and procedures (including any metadata standards, and costs involved) have been checked.	It is proposed to deposit the data in ISSDA. Requests to access the dataset will be handled by UCD Library. ISSDA holds a range of key Irish and international comparative datasets such as the Growing Up in Ireland survey, Quarterly Household Surveys and the EU Survey of Income and Living Conditions amongst others. ISSDA have to following policies: Collection Development Policy, Data Protection Policy, Data Acquisition Protocol and a File Format Policy. The study team will be mindful of these in cleaning and preparing the dataset for analysis and for deposit. For example, variables labels will be less than 60 characters so as not to impede the creation of metadata.

What methods or software tools are needed to access and use data?

Guidance	Answer
Indicate whether potential users need specific tools to access and (re-)use the data. Consider the sustainability of software needed for accessing the data.	Specialist tools and software should not be required.
Indicate whether data will be shared via a repository, requests handled directly, or whether another mechanism will be used?	The data will be shared via a repository. Requests to access the dataset will be handled by ISSDA/UCD Library

How will the application of a unique and persistent identifier (such as a Digital Object Identifier (DOI)) to each data set be ensured?

Guidance	Answer
Explain how the data might be re-used in other contexts. Persistent identifiers should be applied so that data can be reliably and efficiently located and referred to. Persistent identifiers also help to track citations and re-use.	See point above re the foreseeable research uses. It is intended that the data repository will issue a DOI for the single dataset.
Indicate whether a persistent identifier for the data will be pursued? Typically, a trustworthy, long term repository will provide a persistent identifier.	A persistent identifier will be pursued.
Who	The PI had ultimate responsibility for data preservation. The Research Data coordinator/manager will be responsible for liaising with the repository

Data management responsibilities and resources

Who (for example role, position, and institution) will be responsible for data management (i.e. the data steward)?

Guidance	Answer
Outline the roles and responsibilities for data management/stewardship activities for example data capture, metadata production, data quality, storage and backup, data archiving, and data sharing?	PI (Christine Linehan), Research Data Coordinator/Manager (Gail Birkbeck), Research Assistant (Adam Nolan) with have responsibility for data documentation, ensuring data quality and storage during the research project. Gail Birkbeck will be responsible for liaising with the data repository and planning for data sharing. Structured metadata will be the responsibility of the repository.
Specify who is responsible for the management of sensitive and confidential data as well as monitoring its implementation throughout the lifecycle of the data	No personal data is gathered in this study.
For collaborative projects, explain the co-ordination of data management responsibilities across partners	All data coordination activities will be coordinated in UCD.
Indicate who is responsible for implementing the DMP, and for ensuring it is reviewed and, if necessary, revised. Consider regular updates of the DMP.	Gail Birkbeck will be responsible for implementing the DMP and ensuring its reviewed and revised.

What resources (for example financial and time) will be dedicated to data management and ensuring that data will be FAIR (Findable, Accessible, Interoperable, Re-usable)?

Guidance	Answer
Explain how the necessary resources (e.g. time) to prepare the data for sharing/preservation (data curation) have been costed in.	The data management role was funded by part of the HRB grant.
Carefully consider and justify any resources needed to deliver the data. These may include storage costs, hardware, staff time, costs of preparing data for deposit, and repository charges	
Indicate whether additional resources will be needed to prepare data for deposit or to meet any charges from data repositories. If yes, explain how much is needed and how such costs will be covered.	Making enquiries into this currently in order to increase the findability of the dataset.