APPENDIX A OF SPECIFICATION

IICSA Research Code of Ethics

1. The IICSA Research Code of Ethics has been developed by drawing on the London School of Economics research ethics policy and procedures (November 2014), the University of Bedfordshire Institute of Applied Social Studies ethics form (2015), British Sociological Association Statement of Ethical Practice and ESRC Framework for Research Ethics.

The Research Code of Ethics rationale

2. Research undertaken by the IICSA has responsibilities to society at large; to the safety and well being of people who take part in any research it undertakes; and to the safety and well being of IICSA staff, including the research team.

3. It also has responsibility to the wider academic and research community and to those contracted by the IICSA to undertake research on its behalf. Reconciling those responsibilities can be difficult and may entail ethical judgement. The IICSA research code of ethics exists to assist in exercising such judgement.

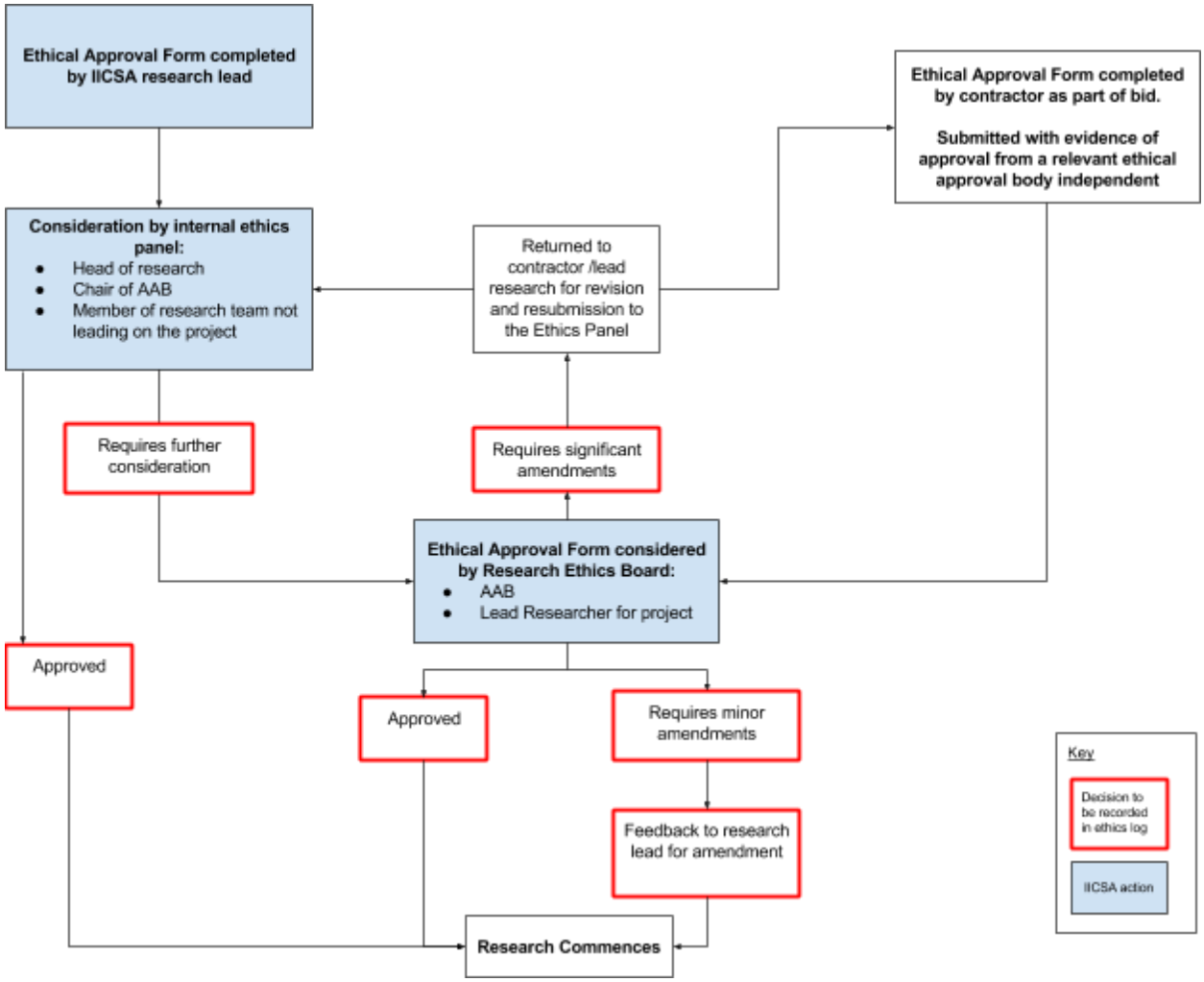
Principles of Good Research Practice

4. The code of ethics applies to any research undertaken by or within the IICSA, including research contracted out through ITT processes to external research providers.

5. The IICSA will conduct its research activity according to the following principles. Ethically sound research is:
    a. an essential component of research excellence
    b. pursued to facilitate, not inhibit, research and to promote a culture of research undertaken by IICSA whereby researchers conscientiously reflect on the ethical implications of their research. That is, consideration of ethical issues is an ongoing process.
    c. respects the autonomy, privacy and dignity of individuals and communities and enables inclusivity where possible
    d. maximises the benefit to research participants, and the benefit of research outputs
    e. prevents harm that could or may be caused through research activities
    f. ensures data is stored, shared, preserved and disposed of in an appropriate and responsible manner;
    g. provides clarity regarding confidentiality of data provided to the IICSA including consultation processes where confidentiality may need to be breached,
    h. maintains open and honest professional standards;
    i. follows best current professional academic and ethical practice as well as all relevant legislation.

Ethical approval process

6. Any research projects to be undertaken by staff within the IICSA, or by researchers commissioned by the IICSA must be approved through the process outlined below.



7. All research proposals must attach a completed IICSA Ethical Approval Form (see p4-13). This covers details of:
    a. access to research materials;
    b. access and engagement with research participants;
    c. risk assessment for researchers and researched;
    d. consent procedures;
    e. procedures for research participants to withdraw and/or retract information provided;
    f. a disclosure of harm protocol;
    g. confidentiality procedures;
    h. legal and data protection requirements (according to UK Data Protection Act 1998);
    i. health, safety and well-being of those researched and researchers;

j. data collection techniques; data storage and disposal.

8. External contractors must also provide evidence of approval from an independent ethics board.

10. All external projects will be submitted to the full Research Ethics Board for approval. The IICSA research lead will handle this process and inform contractors of decisions by the Ethics Board.

Consent

9. Where information is to be collected from individual participants, other than in very particular circumstances, consent will have to be obtained from those participants for any use of their information. Where the research exposes its participants to a risk of harm, the researcher has an ethical duty to consider these risks. Some participants will have diminished capacity to give consent and are therefore less able to protect themselves and require specific consideration

10. Research that does not entail the direct participation of living human persons may nonetheless indirectly but significantly affect living persons. Researchers may be assessing information about identifiable individuals, the publication or analysis of which may have ethical (and indeed legal) implications. For example, collection and use of archive, historical, legal, online or visual materials may raise ethical issues (e.g. for families and friends of people deceased), and research on provision of social or human services may impact provision for individuals and groups of service users who did not contribute or consent to, or were not consulted about the research. Researchers should so far as possible consider and describe the steps proposed to manage such implications.

Ethical Approval Form

When completing this form please ensure that you read and comply with the following:

Researchers must demonstrate clear understanding of and engagement with the following ethical principles :

- ***Respect*** for the autonomy, privacy and dignity of individuals and communities - maximising benefit and minimising harm, including providing appropriate support for those that wish to provide information to the Inquiry;
- ***Ensure*** that data will be stored, shared, preserved and disposed of in an appropriate and responsible manner;
- ***Demonstrate*** clearly the steps taken to ensure confidentiality of data provided to the IICSA and/or those working on behalf of the Inquiry and the circumstances in which confidentiality may be overridden; and

Ensure that information provided to the Inquiry is only used in published research with the informed consent of those providing the data.

Ethical Approval from other sources		**Evidence to be provided**
Has ethical approval for this research been granted by a Research Ethics Committee external to the Inquiry?	Yes ☐ No ☐	Provide copy of ethical approval or application documents, if awaiting approval and estimated date of approval.

Routing Questions	**Yes/No**
Does the study involve analysis of personal information, whether primary or secondary data? This would not usually include tertiary analysis, where only existing literature is being synthesised, for example literature reviews.	Yes ☐ No ☐
If YES: Go to Section 1 **If NO: Go to Section 6**	

Section 1 Recruitment and consent			
	Yes/No	**Information to be provided**	**Evidence to be provided**
1) Does your research involve human participants?	Yes ☐ No ☐	Confirm that informed consent will be obtained.	Consent forms and information sheets to be included.
2) Are participants volunteering to participate in the research?	Yes ☐ No ☐	Provide details of sample frame, recruitment, whether an opt in or opt out process, inclusion and exclusion criteria and your procedures for gaining informed consent.	Recruitment flow diagram/description; consent forms and Information sheets to be included.
3) Are vulnerable individuals or groups involved? *(Vulnerable individuals include: children and young people, elderly, offenders, those with illness (physical or mental cognitive) people at risk of exploitation, homeless people, victims/survivors of abuse)*	Yes ☐ No ☐	If no, please state why you do not feel your participants are vulnerable. Provide details on type of vulnerability. Provide details of recruitment, inclusion and exclusion criteria, steps you are taken to enable participation, and informed consent procedures. These must demonstrate appropriate efforts to ensure people are fully informed of the implications of participation.	Consent forms and Information sheets to be included. Information in relation to recruitment procedures to be included. Provide copies of NRES Committee approval (if applicable)
4) Are participants unable to give independent informed consent? (including children/young people)	Yes ☐ No ☐	Provide details of procedures for obtaining approval from guardian/legal representative and agreement of children. Provide details on measures you intend to take to ensure that there is	Informed Consent forms and Information sheets to be included.

		no coercion on participants and how consent from both the guardian and young person will be obtained independently.	
5) Will the research make use of gatekeepers or third parties to access participants?	Yes ☐ No ☐	Provide details of how third parties or gatekeepers will be involved and how they will gain consent from participants.	Provide copy of signed gatekeeper consent
6) Are participants children young people?	Yes ☐ No ☐	Provide details on age of children/young people. Provide details of children/young people assent procedures and parental consent. Provide details of measures intended to take to ensure welfare of children/young people.	Parental consent forms to be included. Information in relation to measures to protect and promote the welfare of children/young people to be provided.
7) Will information be gathered on participants from a third party?	Yes ☐ No ☐	Please give details of what will be gathered from the third party and how consent issues will be addressed.	
8) Will it be necessary for participants to be involved without consent? (e.g. analysis of o[pen source online material, covert observation in public places)	Yes ☐ No ☐	If Yes: Provide details of how you will access the data covertly and any safeguarding processes to prevent harm to participants.	
9) Will the research investigate/ potentially uncover any illegal activity/ identify children at immediate risk of abuse/neglect?	Yes ☐ No ☐	Provide a disclosure protocol that sets out detail of when and how confidentiality agreements may need to be breached and procedures for reporting illegal activity to the relevant authorities. Please provide	

		safeguarding procedures for the protection vulnerable children or vulnerable adults uncovered during research.	
10) Will the research involve intrusive interventions? (e.g. provision of drugs to participants, hypnosis, physical exercise, blood or tissue sampling)	Yes ☐ No ☐	Provide copies of Ethical approval to undertake interventions	Provide details for obtaining informed consent.
11) Will any incentives or inducements be offered to participants?	Yes ☐ No ☐	Please provide details of type and amount of incentive.	
12) What have you done to make sure that all people in your research population can take part in the research (e.g. language issues, communication aids, out of working hours appointment times etc)?		Please provide details of steps taken to facilitate participants to take part in research.	
Section 2: Sensitive Topics and Information			
13) Will the study be exploring 'sensitive' topics? *[Please consult the list of what may constitute a 'sensitive' topic given at the end of this form]*	Yes ☐ No ☐	Provide outline what sensitive information you will be asking about and provide copies of ethical approval to undertake research.	Provide information in relation to supports that will be put in place for participants. We would anticipate coverage of: -arrangements in place to deal with any difficult dynamics (people who may become upset, uncomfortable, defensive or angry - any signposting/support offered to participants - a note on disclosure if not covered in the section above.
14) Could this research cause psychological stress or anxiety, or cause harm or negative consequences to participants beyond the risks in everyday life?	Yes ☐ No ☐	If yes, please describe the harm or distress that could be caused by taking part in the research and how you plan to deal with this.	

		If no, please explain why you don't think that there is a risk of harm to participants in the study.	
Section 3: Burden on participants			
15) How many times will an individual be interviewed, observed or asked to complete a questionnaire?		Please provide details of time frames for observations, interviews etc.	
16) How long will the total interview/questionnaire/focus group/observation take?		Please provide detail	
17) Please give details on the length of the interview/questionnaire/focus group. If it is longer than 90 minutes please outline what is being done to reduce burden on participants?			
18) Does this study follow-up people from a previous study?	Yes ☐ No ☐	If yes, please give details of participants' previous involvement and whether they have given consent to be contacted again.	
Section 4: Risk to researchers			
19) Have all staff involved in the research been properly trained and briefed about the content of the study e.g *(Research methods, Data Protection training, child protection training, procedures for dealing with disclosures of abuse)*	Yes ☐ No ☐	Provide details of training etc.	
20) Have all staff involved in undertaking this research been subject to appropriate checks i.e. • Staff involved in undertaking research directly with children or vulnerable adults must have DBS clearance.	Yes ☐ No ☐	Provide details/copies of checks	
21) Have appropriate personal and confidential support services been put in place to support research staff undertaking the research.	Yes ☐ No ☐	Provide details of supports in place for staff undertaking research.	

22) Could this study lead to an “above normal” level of psychological risk to researchers?	Yes No	If Yes, outline the risk and how it will be managed? If No, outline why you think this study is a normal level of risk for researchers.	
Section 5: Protection of Personal data			
23) Does your research involve personal data collection and/or processing?	Yes ☐ No ☐	Details on procedures for data collection, storage, protection, retention, transfer, destruction or re-use (including, collection methodology (digital recording, picture, etc.), methods of storage and exchange (LAN, cloud, etc.), data structure and preservation (encryption, anonymisation, etc.), data-merging or exchange plan, commercial exploitation of data sets, etc.). Details on your data safety procedures (protective measures to avoid unforeseen, usage or disclosure, including mosaic effect, i.e. obtaining identification by merging multiple sources). outline procedures for ensuring that participants anonymity is preserved in the publication of final reports. Confirm that informed consent has been obtained.	
24) Does it involve the collection or processing of sensitive personal data (e.g. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)	Yes ☐ No ☐		
25) Does it involve tracking or observation of participants (e.g. surveillance or	Yes ☐ No ☐	Details on methods used for tracking or observing	

localization data, and Wan data, such as IP address, MACs, cookies etc.)?		participants.	
26) Does your research involve further processing of previously collected personal data ('secondary use') (including use of pre-existing data sets or sources, merging existing data sets, sharing data with non-EU member states)?	Yes ☐ No ☐	Details on the database used or of the source of the data. Details on your procedures for data processing. Details on your data safety procedures (protective measures to avoid unforeseen, usage or disclosure, including mosaic effect, i.e. obtaining identification by merging multiple sources). Confirm that data is openly and publicly accessible or that consent for secondary use has been obtained (and details on how this consent was obtained (automatic opt in, etc.). Confirm permissions by the owner/manager of the data sets	

Section 6: Impact of publication of findings		**Information to be provided**	**Evidence to be provided**
27) Could the publication of findings from the research result in a negative impact on victims/survivors of Child sexual abuse?	Yes ☐ No ☐	Provide details of safeguarding procedures in place to deal with potential possible negative impacts.	

Appendix 1: Personal Data

This section concerns research which involves collecting or processing of personal data, regardless of the method by which they are/were collected (e.g. through interviews, questionnaires, direct online retrieval

etc.).

Personal data' means any information, private or professional, which relates to an identified or identifiable natural person (for the full definition, Data Protection Act, 1998).

Examples: name, address, identification number, e-mail, CV, bank account number, phone number, medical records.

There are various potential identifiers, including full name, pseudonyms, occupation, address or any combination of these.

Individuals are not considered 'identifiable', if identifying them requires excessive effort.

Completely anonymised data does not fall under the data privacy rules (as from the moment is has been completely anonymised).

'Processing of personal data' means any operation (or set of operations) which is performed on personal data, either manually or by automatic means.

This includes:

- collection (digital audio recording, digital video caption, etc.)
- recording organisation and storage (cloud, LAN or WAN servers)
- adaptation or alteration (merging sets etc.)
- retrieval and consultation
- use
- disclosure by transmission, dissemination or otherwise making available (share, exchange, transfer)
- alignment or combination
- blocking, deleting or destruction

Examples: creating a mailing list or a list of participants; managing a database; accounting records on personnel costs; time-sheets; project planning with names.

Processing covers normally any action that uses data for research purposes (including if interviewees, human volunteers, patients, etc. are not actively included in the research).

Data may come from any type of research activity (ICT research, personal records (financial, criminal, education, etc.), lifestyle and health information, family histories, physical characteristics, gender and ethnic background, location tracking and domicile information, etc.).

Your research must comply with:

- ethical principles
- applicable international, EU and national law (in particular, Data Protection Act 1998, and EU Directive 95/46/EC).

Under this Directive, personal data must be processed according to certain principles and conditions that aim to limit the impact on the persons concerned and ensure data quality and confidentiality. Certain categories of data are more 'sensitive' than others (e.g. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction) and these may only be processed according to specific rules.

The Directive is currently under revision. Any changes in the legislation will have an effect on your research, and must therefore be monitored.

You may collect and process data only if and insofar as it is really **necessary** for your research.

Collecting personal data (for example, on religion, sexual orientation, race, ethnicity, etc.) that is not essential to your research may moreover expose you to allegations of 'hidden objectives' or 'mission creep' — i.e. information being collected with permission for one purpose and being used or made available, including online, for another reason, without additional permission.

You must moreover obtain: the necessary notifications/authorisations for collecting and processing the data (including specific authorisations, if applicable) free and fully informed consent of the persons concerned ('data subjects') (see section 2).

Specific cases:
Secondary use — If you use secondary data in your research, it must originate from a public source or be authorised for use in your research (either specifically for your research or generally for any secondary use).

Recording of information — Recorded information (audio and/or visual) will need special consideration by your data controller, to ensure that privacy and personal identities are protected.

Sensitive data — If you collect or process sensitive data (e.g. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction), you may require a specific authorisation by the national data protection authority. If you collect or process health data, you should refer to the processes recommended in the Ilves report on e-health.

Tracking or observing of participants may require a specific authorisation from the national data protection authority.

Electronic data — Regarding the processing of personal data and the protection of privacy in the electronic communications sector, as well as the retention of data generated or processed in connection with the provision of publicly available electronic communications services or of public communications networks (e.g. cloud, big data, open data, cookies etc.), your research must comply with the relevant legislation (in particular Data Protection Act, 1998, EU Directive 2002/58/EC and 2006/24/EC).

Your research proposal must include the information indicated in the ethics issues checklist and any of the documents that are already available.
(For documents that are not yet available, provide an approximate timeline for their submission.)

Examples: If you are collecting personal information, interviewing, observing or tracking people, or recording data or audio/visual information, you need fully informed consent (see section 2) from your research participants and provide a clear description of the procedures that you will use for data control and anonymisation

Appendix 2: Sensitive topics

Research involving sensitive topics such as participants':
sexual behaviour;
their legal or political behaviour;

offending behaviour
their experience of violence, abuse or exploitation;
their mental health;
their personal or family lives;
their gender.
ethnic status;

Agreement Regarding Intellectual Property

All Intellectual Property Rights in relation to information and findings of research commissioned by the Independent Inquiry into Child Sexual Abuse (IICSA) shall vest in IICSA. As applicable, such information and findings will be subject to Data Protection Act requirements.

The terms and conditions of appointment for Researchers will contain relevant detailed provisions relating to Intellectual Property Rights.