STUDIES INVOLVING ADULT REFUGEES IN THE UNITED KINGDOM

1. SCOPE

Several research groups in the University carry out studies of and with adult refugees. According to the United Nations (UN) Refugee Convention, the definition of a refugee is someone who “owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it.”.¹

For the purposes of this Approved Procedure, refugees are further defined as adults without serious mental or physical health conditions who:

- are not currently detained in a refugee camp (closed, waiting or detention camps);
- are not currently asylum seekers, refused asylum seekers or currently in the appeals process²;
- are not homeless;
- are being recruited as potential participants to the research study with the help of a supporting agency such as a Non-Governmental Organisation (NGO), charity, local government agency or community association;
- have been in the UK for at least 6 months;
- are not a patient detained under the UK Mental Health Act at special hospitals or other psychiatric secure units;
- are not aged under 18;
- are able to give voluntary and fully informed consent.

This Approved Procedure can be used by graduate students and researchers applying to the Social Sciences and Humanities IDREC and the Departmental Research Ethics Committees (DRECs). It should be followed in conjunction with the Ethical Guidelines provided by the Refugee Studies Centre, Queen Elizabeth House, University of Oxford.³

This Approved Procedure will not apply to research undertaken by undergraduate students. Applications must have a lead researcher at a minimum of postgraduate level with research expertise in the field. It is essential that researchers have the appropriate skills, knowledge and experience to be able to undertake the proposed fieldwork.

Because refugees may to be classed as “participants at risk” and/or “people whose ability to give free and informed consent is in question”, and because research studies dealing with these participants often deal with very sensitive issues, research studies in this category cannot be

¹ Article 1, 1951 Convention Relating to the Status of Refugees. Please also see the UN Refugee Agency’s definition of ‘refugee’ (both accessed 1 November 2019)
² Please see Habitat for Humanity UK’s definitions of the terms ‘refugees’, ‘asylum seekers’ and ‘migrants’ (accessed 10 October 2019)
approved purely on the basis of a CUREC 1A checklist completion. This Approved Procedure has been devised with the aim of specifying a set of procedures that will be acceptable to the SSH IDREC and DRECs to enable researchers to apply for ethical review and approval via the CUREC 1A process.

The applicable scope of this Approved Procedure is further dependent on the level of research risk, research setting, and types of research methods involved.

1.1 Level of Research Risk

The level of permissible research risk in order to apply this Approved Procedure is based on a risk analysis of a given research study at three levels:

1. Does the research cover a potentially sensitive topic – a field of research that may be ethically, emotionally or politically sensitive (e.g. gender issues, race relations, education, asylum seeking process, daily life, low to medium risk to participant’s wellbeing, associated with opening up discussion or making comments on sensitive/traumatic topics)? Could there be a risk of inadvertently influencing a participant’s decision-making when discussing the challenges they face? In analysing this level of risk, it need not be assumed that risky topics carry serious risk themselves, provided that proper safeguards are put in place, including secondary trauma training by researchers (see sections below).

2. Might the research present serious risks to or harm the participants (for example, but not exclusively: topics involving serious mental health issues, serious trauma, threats of or actual (sexual) violence, suicide, self-harm, serious communicable diseases; severe bullying, intimidation or harassment, involvement in current criminal activities)? Is there a serious risk of drawing negative attention to the participant and their circumstances as a consequence of taking part in the research study?

3. Might the research present serious physical or emotional risks to researchers?

This Approved Procedure covers situations that are assessed as carrying no serious significant risk (level 1 only). If the study classes as level 2 or 3 above, this Approved Procedure does not apply and approval must be sought by completing a full CUREC 2 application. In this case, the guidance given in this Approved Procedure document will still be helpful.

Examples given in levels 2 and 3 above are not exhaustive, so advice on whether a CUREC 2 application is needed should be sought from the SSH IDREC on a case-by-case basis.
1.2 Research Setting and Permissions

This Approved Procedure applies to research where participants are accessed through NGOs / charities and the research is conducted in safe premises convenient for both participants and researchers, with the prior permission of the NGO/charity, and the voluntary, informed consent of the participant. Researchers will need to ensure that they have assessed the participant’s capacity to consent.

The study can only start once CUREC approval and any necessary third-party permission (e.g. from NGO/charity) and safety clearance have been obtained.

NGOs/charities are likely to have their own policies that cover similar topics to those raised in this procedure. Researchers should read and adhere to those policies and raise any contradictions with the SSH IDREC or DREC when applying for research ethics approval.

Researchers need to bear in mind that refugees, NGOs and other organisations can suffer ‘research fatigue’, so research proposals should be tailored to the needs of refugees and these organisations as well as to the researcher’s own academic aims.

1.3 Research Methods

The following methods are permissible under this Approved Procedure with refugees and NGO/charity staff, as long as the NGO/charity has reviewed and approved the following:

- Semi-structured interview (including questions)
- Questionnaire
- Participant performs verbal/paper and pencil/computer based task
- Observation of participant
- Focus groups
- Online survey

The following require specific consent from the NGO/charity and the refugee (see section 6):

- Audio recording of and by the participant
- Making still images / photographs of and by the participant
- Video recording of and by a participant

If an NGO/charity is involved to the extent that a researcher is accessing participants as a result of its efforts, and/or the researcher is able to say that they are conducting the work with the support of the NGO/charity, then the NGO/charity may ask to see in advance the proposed questions/guidelines for the research. With regard to photos and recordings, some NGO/charity staff members may reserve the right to being present throughout and, in some cases, may intervene if they feel it appropriate. They may also reserve the right to check final versions.

IDREC and NGO requirements should be harmonised as far as possible as part of the initial negotiations between researcher and NGO, and researchers should alert their DREC or IDREC to any issues or amendments the NGO may request. Participant information sheets or oral consent scripts should reflect the possibility that NGOs may request to see some of the final data (including video/audio recordings), as long as the IDREC and DREC is content to allow this.

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2. TRAINING OF RESEARCH STAFF

All researchers working with refugees must be trained in the following before embarking on the research study:

- to use appropriate research methods
- how to deal sensitively with difficult issues and trauma (participants’ / secondary trauma)
- to recognise and address ethical issues
- to recognise and address situations where abuse and/ or serious risk is identified

It is crucial that senior researchers ensure that those working under their supervision are able to develop a good rapport with refugees and NGO/charity staff, and that they have appropriate safeguarding clearance.

Researchers must follow the guidance set out in the University’s ‘Safeguarding Code of Practice’, including completing the online training course ‘An introduction to Adult Safeguarding’ provided by the Oxford Safeguarding Board, as well as undertaking risk assessments of the proposed research.

Any risk assessment must include how researchers will ensure their own physical and emotional safety while conducting their research, in addition to complying with any security measures the NGO /charity advise. The University’s Social Sciences Division’s Fieldwork website provides information about resources available to support researchers who may experience secondary trauma or psychological distress as a result of their research. All researchers are strongly advised to follow CUREC’s Best Practice Guidance documents, including guidance around Prevent, security-sensitive materials, and Researcher Safety.

Researchers should also take responsibility for complying with safeguarding regulations and research practices that relate to the setting(s) of their research. As well as such compliance, researchers are strongly encouraged to consult guidance from relevant professional associations (see section 12). The issue of unequal relationships needs to be addressed. These will exist to the extent that refugee participants will be in a position of reduced power compared to the researcher. Hence, it is especially important that refugees are fully aware, at the information-giving stage and well before the study starts, that they need not volunteer for the study, that they can withdraw themselves and the information they provide at any time, without any consequences for them (including in relation to any services accessed through the NGO / other partner(s)) and without giving a reason. It is also important to emphasise that taking part (or not) in the study will not affect the refugee’s immigration status in any way. Researchers may want to consider including research assistants with a refugee background, or from the same culture, to mitigate potential risks of coercion or power differentials; however, it is important to be aware that they could also act as gatekeepers or might even amplify unequal relationships.5

3. METHODS FOR RECRUITING PARTICIPANTS

Researchers recruiting refugees through NGOs/charities should gain permission of the NGO/charity to conduct the study and, if applicable, gain ethics approval from the NGO/charity in addition to CUREC approval.

Researchers need to ensure that the following points are covered in the recruitment materials:

- University logo [for written information]

5 EC guidance note – research on refugees, migrants and asylum seekers, page 2, (accessed 10 October 2019)
• Department contact details
• Background and aims of the study
  o What questions the study hopes to answer
  o Names/departmental (not private!) contact details of the researcher (only if this is deemed appropriate by the NGO/charity)
• Why participants have been invited to take part
• That participation must be completely voluntary and taking part (or not) will not affect the refugee’s status or relationship with the NGO/charity in any way
• What the study will involve, i.e.
  o Purpose
  o Duration
  o Location (e.g. room)
  o Frequency (e.g. any follow-up interviews)?

3.1 ‘Opt-in’ research only

For the purposes of this Approved Procedure, refugees must actively agree to take part in the research, and ‘opt out’ approaches to recruitment and consent are not permissible. Refugees can be invited to participate but are under no obligation to take part. In all cases, criteria for inclusion and exclusion need to be specified.

In order to manage expectations, it should also be made very clear that inclusion (or not) in the research study will not change the refugee’s immigration status in any way and will have no effect on their access to services provided by the referring partner.
4. INFORMATION PROVIDED TO PARTICIPANTS

The information provided should be appropriate to your specific research and presented in an accessible way. If there is not enough information, potential participants might not be able to make an informed decision. On the other hand, if the information sheet is too long or unclear (e.g. through using overly-technical language) they might not read it properly or it could deter them from taking part. Most word-processing packages provide readability statistics for a document, and one should aim for a 12-year-old (Year 7) reading level for adults.

The Information Sheet must be written in simple but non-patronising language, avoiding technical terms and jargon, and bearing in mind that for many participants, English will not be their first language. If there are literacy issues, an oral consent script will be acceptable.

If information has to be translated into a different language, the researcher needs to ensure that the translator/interpreter has signed a confidentiality agreement. The participant may be asked to assist with the selection of the interpreter to gain some control over who their information is shared with.6

Knowledge of the translator’s/interpreter’s background is important, in order to ensure they are acting with impartiality. This may be especially important if refugees are from areas of civil war.

Please see CUREC’s guidance on the informed consent process, including sample templates to be adapted.

5. CONSENT OF PARTICIPANTS (WRITTEN AND/OR ORAL)

After gaining a) permission and (if applicable) ethics approval from the NGO/charity and b) approval from the appropriate ethics committee(s) for the study, the participants need to be fully informed and have to give voluntary consent to take part in the study. Either written or oral consent (or a mixture of both) may be used for refugees and NGOs/charity staff (oral consent may be used e.g. in case of literacy issues or anxiety around form-filling). Consent is an ongoing process and may require renegotiation over time.7

Justification is required if NGO/charity staff are being used to select or approach suitable participants as it is acknowledged that this might bias the results of the study to some extent. If a researcher believes there may be some bias in the selection made by the NGO/charity, the researcher should raise this and try to resolve with the NGO/charity in the first instance. If this cannot be resolved satisfactorily, the researcher should state this in their research report.

“Whilst respecting gatekeepers’ legitimate interests, researchers should adhere to the principle of obtaining informed consent directly from the participants once access has been gained. They should be wary of inadvertently disturbing the relationship between participants and gatekeepers since that will continue long after the researcher has left the field.”8

If audio or video recordings (including still images or photography) are to be made, the consent form or script must include wording for the participant to sign or agree to, in order to give explicit consent to this. The information sheet or script will need to give a guarantee from the researchers that recordings will not be made available to those outside the research team without their written

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6 Case study: anonymity and consent in research with asylum seekers, ESRC website, (accessed 10 October 2019)
8 Ibid, p. 168
consent. If images or recordings may be used in a publication or scientific presentation then specific consent for this should be sought in the consent form.

5.1 Consent for audio, photographic or video data

Note that explicit consent must be obtained both for obtaining this type of data e.g. “I agree that I can be photographed/videoed” and for using this type of data for research purposes e.g. “I understand that any photographs/videos may be used in conference presentations/on a study website/in peer-reviewed journal publications”.

The consent form must be written in simple but non-patronising language. If there are literacy issues or anxiety around form-filling, an oral record of consent will be acceptable.

Researchers should only collect personal data that is essential for their research study, including audio recordings, videos or photographs in which participants are identifiable.

It is not uncommon for participants to withdraw their consent for use of their image at a later point. Please ensure all informed consent documents or scripts are very clear on a specific withdrawal deadline (well before publication) and on alternatives to identifiable photographs or videos (e.g. pixilation) and audio recordings (e.g. note taking only). If a participant withdraws their consent after the withdrawal deadline, please discuss within your department and with your DREC and IDREC how best to resolve the issue on a case-by-case basis.

Please see CUREC’s guidance on the informed consent process, including sample templates.

6. COMPENSATION

Researchers who are considering offering a small payment or reward to participants should seek the advice of the relevant IDREC/DREC and NGO/charity on its suitability and in particular if it may have any impact on benefit entitlements for participants. In some cases, even very small one-off increases in income can have a negative impact on entitlements.

Further guidance is available within CUREC’s Best Practice Guidance 05 on Payments and incentives in research.

7. POTENTIAL RISKS TO PARTICIPANTS/RESEARCHERS/OTHERS AND WHAT WILL BE DONE TO MINIMISE

The researcher should obtain a risk assessment form and safety guidance from their departmental or divisional safety officer.

The NGO/charity should have a Health and Safety Policy, Lone Working Policy, and a statement on professional boundaries, which both the NGO and the researcher should abide by (in addition to the researcher abiding by the relevant University policies and guidance). The NGO may be able to advise on whether participants have a history of violence or pose any other potential risks to the researcher.

All researchers will need to obtain complete training on safety, security and personal protection, and abide by any safety protocols provided by the NGO/charities. In addition, an internal/departmental risk assessment must be completed and University travel insurance sought if applicable. A copy of each should be submitted to the relevant IDREC or DREC with the research ethics application for information.
Any risk assessment must include how researchers will ensure their own physical and emotional safety while conducting their research, in addition to any security measures the NGO/charity might recommend. Please also see the Social Sciences Division’s resources available to support researchers who may experience secondary trauma or psychological distress as a result of their research. Safety measures might include researchers being accompanied, and/or NGO/charity security staff within sight.

A ‘risk of harm’ protocol should be created as the research study is planned, including guidance on how to respond if certain ethical issues or adverse events occur during the research study. These could include:

- Participant distress
- Disclosure of child abuse, neglect or exploitation (or any illegal activity)
- Disclosure of intimate partner violence or other forms of gender-based violence
- Intention to self-harm

The ‘risk of harm’ protocol should be submitted as part of the research ethics application. Please also see section 8 on how to deal with risks to participants and when/how to report adverse or unforeseen events, and section 10 on limits of confidentiality.

Electronic devices such as laptops must be password-protected and encrypted where at all possible; similarly audio recording devices should be PIN-protected or encrypted if possible. Please see Research Data Oxford’s guidance on data management and the Information Security webpages for further advice on this.

8. MONITORING AND REPORTING OF ADVERSE OR UNFORESEEN EVENTS

Researchers should be aware of the general levels of mental health of refugees. If a participant should become unwell or seriously distressed during the interview/session, the session must be terminated, and the event immediately reported to the nearest NGO/charity staff member, and at least to the supervisor.

Researchers should have a plan of who to speak to or refer to in case there are concerns related to the participants. It is best practice to be acquainted with the support services available to refugees and to have additional information about online resources/help lines and face-to-face resources to hand if needed (e.g. Rape Crisis, Listeners, Mind, etc.). Researchers may want to check, as part of their negotiations with the NGO/charity, whether the latter run their own advice services and what their protocol is in terms of reporting any issues or concerns the participants may express. Researchers should bear in mind that there may be situations where participants disclose concerns about the NGO itself, and should inform the DREC or IDREC at ethics application stage how they would resolve such a situation.

Researchers should handle appropriately any information discovered unintentionally (incidental findings) that are not related to the research aims, such as information on human rights violations, human/sexual trafficking, domestic violence, forced marriage, female genital mutilation, trading in human organs, child pornography, as well as any information that may affect the participant’s refugee status. There could be situations where the reason for the well-founded fear of persecution has changed, or where the participant is planning to voluntarily return to their country of origin, in which case this could lead them to lose their refugee status. It is important that the researcher shows in the ethics application a plan on how to deal with/help participants in these situations, i.e. by informing the responsible NGO/charity, the relevant DREC or IDREC, and the researcher’s Head of Department, and directing participants to relevant support services. Please also see section 10 on Duty of Care issues below.
Audio recordings should be wiped from the audio recorder between interviews (if there are multiple visits to the research site).

In refugee interview guides, it is a good idea to end on a positive and hopeful note, rather than ending with a question on e.g. barriers and challenges.

9. **COMMUNICATION OF RESULTS**

Information about participants should not be reported back to the NGO/charity, and this should be made clear within information provided to NGO/charity staff. It is up to the researcher to decide whether general feedback should be offered about the results from the study as a whole. Many NGOs/charities agree to collaborate because they would like to learn from the research results, so any potential issues around this should be discussed and resolved before the study starts (and made clear in the ethics application). Again, the role of any NGO/charity staff (e.g. interpreters) in the research study must be considered carefully, as they also have a responsibility to maintain confidentiality.

Conditions in the field should be reported on honestly, be they positive or negative. The researcher should anticipate at planning stage how to deal with any negative reflections on the NGO/charity that helps them conduct the research. If researchers have criticisms of the NGO/charity, good practice would be to discuss those with the NGO/charity in the first instance and to allow it to provide some explanation before reaching a final conclusion about what to publish. Researchers should bear in mind that NGOs/charities rely on their good reputation to generate funds in order to sustain services that are needed by refugees. There also may be instances where e.g. conditions in a refugee camp are better than expected, and NGOs/charities may feel that too positive a portrayal in research publications may equally harm their fundraising efforts. These situations should be anticipated and addressed by the researcher prior to the ethics application stage.

10. **DUTY OF CARE ISSUES / CONFIDENTIALITY / LEGAL RESPONSIBILITY**

Researchers should be very cautious about managing participants’ expectations or offering advice to NGO/charity staff on the basis of research findings, particularly when the researcher is not qualified to offer assistance. On the other hand, the researcher does have a duty of care, and should not withhold information that could have serious implications for the participant. The question that the researcher needs to consider is whether drawing attention to a potential problem could lead the participant to gain access to services that might be of help.

For instance, if a researcher suspects the participant may have a treatable medical condition that has not been diagnosed, such as a hearing loss or visual impairment, then advice should be sought from a senior researcher. In such a case, it is likely that a decision would be made to inform the participant.

Researchers should be very clear about the limits of confidentiality they can offer to participants or NGO/charity staff, both in information sheets and when explaining the study verbally. The information sheet and/or script should include a statement saying that confidentiality cannot be guaranteed if the participant discloses anything of a criminal/illegal nature, previous behaviour against refugee camp rules, or if the researcher strongly suspects that the participant or others are suicidal or at risk of serious or imminent harm. Extra care needs to be taken to address the kind of information that can and cannot be disclosed to and by the researcher at information stage. Researchers may wish to ask participants specifically not to inform them of instances of illegal activity. The NGO/charity may also have its own policy for dealing with instances where
confidentiality might need to be breached, and researchers should be aware of this. If the researcher feels that it is necessary to break confidentiality, the “participant will normally be informed of what action is being taken by the researcher unless to do so would increase the risk to those concerned” (including the risk to the researcher).9

It is important to seek specific guidance, on a case-by-case basis, in the first instance from Legal Services and the Head of Department, as well as the relevant DREC or IDREC Chair. Legal duties of disclosure will be significantly different outside the UK jurisdiction. Any research conducted outside of the UK (not covered by this Approved Procedure) will be subject to different legislation, which researchers will need to be aware of when planning their studies.

11. DATA MANAGEMENT AND PROTECTION

Researchers should be careful about the type of information they collect, and only gather data that is essential for the specific research aims. Names, addresses, specific locations, date of birth, exact dates should only be collected if absolutely essential.10 Official reference numbers (e.g. Home Office numbers) should not be collected. Each participant should be given a code number or be given/choose their own pseudonym and this, rather than the name, should be used to label all data from the study, including any paperwork (e.g. completed surveys) the participant has created. If it is necessary to retain any personal information, the key linking codes to personal details must be kept separately in a locked filing cabinet or encrypted drive at the University department. It is important to keep completely anonymous any information that may endanger the participants’ personal safety or privacy.

Particular care should be taken to ensure confidentiality of audio and video recordings, where it is not possible to anonymise materials. These will be labelled with code numbers and date only, and kept securely, typically in an encrypted form. Researchers using video recordings should follow IDREC’s guidelines on procedures for storing such data, please see the Best Practice Guidance on Data collection and management (BPG 09).

The basic rule is that if researchers do intend to divulge results to anyone outside the research team, this must be made clear at the outset in the information sheet or script.

There is no time limit on retention of completely anonymised data. If non-anonymised data is to be retained, the consent form must seek consent for this retention.

University policy states that research data needs to be kept for a minimum of three years after publication, and funders may have additional data retention requirements. Please see the University’s policy on the storage of research data and guidance on funder requirements for full details.

Please also see the University’s webpage on data protection and research for further information about the General Data Protection Regulation.

Sharing of Data

Research teams will be encouraged to make their data available for reuse and validation. In all cases, the data will be shared as openly as possible and as closed as necessary in order to protect the privacy of participants. Online repositories will be assessed by research teams for their appropriateness with regard to:

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9 Statement of Ethics for Researchers in the Field of Criminology (2015), (accessed 26 January 2018)
• the required treatment and de-identification of unique brain and biometric data in line with UK GDPR;
• control of how the data are accessed and re-used, including terms to protect the ongoing privacy of participants;
• required attribution of the data to the originating research team, the University and funding bodies;
• management of data withdrawal requests made by participants.

12. FURTHER INFORMATION

Guidance from the Refugee Studies Centre, University of Oxford, European Commission, ESRC Framework for Research Ethics, the Social Research Association, the British Association of Social Workers and the Oral History Society should be consulted before the research starts. Other appropriate professional codes may apply. The University’s webpage on ethics guidance also has more information on professional associations.

13. CHANGE HISTORY

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