|  |
| --- |
| The ethics for this project is informed by the following relevant research ethics guidance on the use of visual images and working with potentially vulnerable and stigmatised research users and participants:   * the ESRC’s Framework for Research Ethics, <http://www.esrc.ac.uk/funding/guidance-for-applicants/research-ethics> * the International Visual Sociology Association (2009) Code of Research Ethics and Guidelines, <https://visualsociology.org/wp-content/uploads/IVSA-Ethics-and-Guidelines.pdf> * the British Sociological Association Visual Sociology Group's statement of ethical practice (2006); * the British Psychological Society Code of Human Research Ethics (2014) <http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf>; * Wiles, R., Prosser, J., Bagnoli, A, Clark, A. Davies, K., Holland, S., Renold, E. (2008), Visual Ethics: Ethical Issues in Visual Research, ESRC National Centre for Research Methods Review Paper, <http://eprints.ncrm.ac.uk/421/1/MethodsReviewPaperNCRM-011.pdf> * Association of Social Anthropologists of the UK and the Commonwealth (ASA) 2011. Ethical Guidelines for good research practice www.theasa.org/ethics.shtml * Salway et al (2011) Ethnic diversity and inequality ethical and scientific rigour in social research. Joseph Rowntree Foundation [www.jrf.org.uk/publications/ethnic-diversity-social-research](http://www.jrf.org.uk/publications/ethnic-diversity-social-research).   **Identification vs. Anonymity/Confidentiality; Beneficence/non-maleficence**  The researcher is aware of issues regarding anonymity, identification and confidentiality for research involving visual images (Crow & Wiles 2008; Wiles et al. 2012) in the ethical process. She will have in place an ongoing informed consent procedure: regular updates, ‘checking in’ to ensure participants understand the implications of visual research (Salway et al. 2011, 34 - 36).  During observation (i.e. at the workshop on using visual methods and creative methodologies for effective self-representations to be held in March 2019), as part of going through the participation information sheets with the participants, the researcher will first establish the ground rules for the workshop. Even though the main topic will be visual methods, methodologies and self-representation, it is possible that some participants may want to share personal information about themselves. That is why the researcher will emphasise the need for everyone to respect and maintain the confidentiality of the information shared during the workshop. Her ability to ensure anonymity/confidentiality will be contingent on group agreement and ethos as people in the group will be exposed to each other. In her previous experience of doing observation as part of her doctoral research, this agreement between each of the participants worked as each of the participants understood and appreciated the vital importance of having the information about themselves kept confidential and anonymous by others. To this end, the consent form for observation contains the following statement: ‘I agree to maintain the confidentiality of the information shared by all the participants in this observation.’ Additionally, the researcher will make clear to the research participants/users, both verbally and in writing, that if they are unsure about the other participants being able to keep their information confidential, they do not have to participate or they can share only the kind of information about themselves which they are comfortable with the others knowing about them. Realistically speaking, the researcher can control what she says/writes about the participants, but she will not be able to control what the research participants/users report about each other once they have left the group and/or if there is a fall-out between the participants, for example.  Some of the research participants/users may have concerns about anonymity/ confidentiality and the research interfering with their privacy. This may be true especially in cases where the person has outed themselves partially only and they may fear that someone else might out them, thus jeopardising their emotional wellbeing, safety and privacy. To minimise the stress, the researcher will seek to satisfactorily explain to the participant in detail the purpose of the study verbally and in writing by means of a participant information sheet (hereafter PIS), and, as a matter of principle, give them assurance about ethical principles, such as anonymity – where requested – and confidentiality throughout the research process. This will be done verbally as well as in writing in PIS prior to observation and the photo elicitation interview (hereafter interview), including during the recruitment process, and also during and/or after the interview. Before and during the interview, the researcher will seek to assure the interviewee that if research participants/users do not wish to be identified, they will describe the images in photo elicitation interviews; their faces will be pixelated; personal/geographical names will be changed and/or anonymised.  Some of the research participants/users may fear that the research will expose them to pressure from their family and/or community. This will be dealt with prior to the photo elicitation interview, including during the recruitment process. Also, to minimise the stress, prior to the photo elicitation interview, the researcher will provide information about the participants’ participation being entirely voluntary, and a detailed explanation of the purpose of the study and the principles regarding the protection of the participants’ privacy, anonymity and confidentiality. The research participants/users will be informed in advance that the interview will be audio recorded to allow the researcher to analyse the data in detail afterwards. Should they wish not to be audio recorded, they will be asked to indicate so ahead of the interview.  **Voyeurism vs. reality:**  Conducting research with members of a group that is considered stigmatised, marginalised or vulnerable (Luttrell 2010) may lead to participants questioning the researcher’s interest in ‘studying victims’ (Stoczkowski 2008, 349). In this specific case, LGBTIQ Roma may be seen as particularly vulnerable due to possessing two or more intersecting identities that are often perceived as stigmatised or stigmatising. The latest social science guidelines (some of which are listed above) will be adhered to, along with the researcher applying the principles of researcher reflexivity throughout the research project (Salway et al. 2011, Fremlova 2018).  **Exposure to sensitive topics related to sexual/gender identity**  Specific ethical issues pertaining to interviews are the potential interviewee’s experience of discomfort or emotional stress at discussing sexual/gender identity, especially where they are still closeted due to family/community pressures, something that may be and in fact still is perceived in some traditional Romani communities as a taboo. This will be partially addressed at the stage of recruitment (see consent forms, and recruitment strategy). Before the start of observation and the interview, the researcher will seek to check with the research participant/user whether they are still OK to discuss the topics. Additionally, the researcher will seek to draw upon her experiences and lessons learnt from discussing the same and/or similar sensitive topics previously during her doctoral and postdoctoral research.  The risks that sensitive topics (racism, sexism, homo/transphobia) may pose will be minimised by selecting those self-identified LGBTIQ Roma who are openly or partially ‘out of the closet’, some of whom participated in the researcher’s doctoral and/or postdoctoral research. The researcher will ensure research participants/users have understood the implications of being photographed and/or having their images used.  **Free, fully informed and valid consent**  Under GDPR (detailed in section 12.4), consent must be an active, affirmative action by the data subject, rather than the passive acceptance under some current models that allow for pre-ticked boxes or opt-outs. A record of how and when an individual gave consent, and that individual may withdraw their consent whenever they want must be kept by the researcher.  Taking into account the concerns regarding anonymity/confidentiality in a group (see above), wherever possible, all data will be anonymised, unless specific participants request to be named. Should participants wish to be named, they will be asked to specify whether they wish to be named by their whole name (first name and surname), only first name or surname; and/or pseudonym (pseudonymised data may be subject to GDPR if the individual is identifiable). This will be recorded on their consent form (see consent forms). The researcher will respect this by including their name in the format specified by the person in the consent form when participants are quoted. If research participants/users decide to use their own photographs, fully informed consent will also be obtained from the people who may be present in them.  As regards the issue of copyright, UK copyright law says that the person taking the image has the legal rights over the subsequent use of their images, which also applies to the archiving and reuse of visual data (Wiles et al 2008: 12). Willams et al (n.d., quoted in Wiles 2008: 12) notes that it is advisable to request the interviewees assign copyright to the researcher, as implemented in a research project by Tremlett (2017). Although the researcher being assigned the copyright by the research participants/users would be an ideal arrangement, it is not so straightforward in this case. Recognising that the photographic and/or other self-representations that are likely to be created at the workshop (March 2019) will be the products of a joint effort as part of this project that could be relevant to some of the research participants’/users’ own future work or artistic practice, the researcher will seek to obtain the research participants’/users’ agreement to use the photographic or other self-representations for research purposes. This is reflected in the consent form for observation under point 5: I understand that the data collected and the photographs generated as part of the workshop will be used as part of a research project. I understand that the data will be used in writing up and disseminating Lucie Fremlova’s research (including in two journal articles). I understand that only anonymous excerpts from the research will be used in this write up, unless I specifically request to be named. Additionally, the researcher will seek to obtain agreement from participants in the photo elicitation interviews to use the photograph(s) discussed. This is reflected in the consent form for photo elicitation interviews under point 9: I agree that the photograph(s) discussed during the photo elicitation interview can be used by the researcher, Lucie Fremlova, for research purposes. This will allow her to use the photograph in her research for the purpose of teaching and presentation at conferences.  **Recruitment of Participants**  The research participants/users self-identify as LGBTIQ Roma and/or Roma with multi-faceted, intersectional identities and are aged 18 or over. The prospective participants, whose names are kept anonymous for now in line with the researcher’s doctoral ethics approval, are unaffiliated individuals, as well as representatives of organisations, European cultural and intergovernmental institutions that the candidate has previously collaborated with\*. Most of the prospective participants are based outside the UK (US, France, Germany, Czech Republic).  Some of the research participants/users are vulnerable by virtue of being partially or fully closeted in their family/community.  Maximum levels of precaution and care will be taken by the researcher to ensure the safely (both physical and psychological) and wellbeing of the research participants/users. As suggested above, participants may experience feelings of discomfort or stress as a result of talking about sensitive subjects in front of people that they do not know, especially if they have not come out yet. Attempts at mitigating or minimising these feelings will be made prior to the person(s) taking part in the workshop and/or photo elicitation interview when explaining the purpose of the study to participants.  **Inclusion/Exclusion Criteria**  The inclusion/exclusion criteria is not relevant for this project as the researcher will be mostly re-engaging participants who are already known to her from her doctoral/postdoctoral research and her previous research, in which she tried to be as inclusive as possible by including different national groups and sub-groups of Romani LGBTIQ people (i.e. Rumungro, Vlax, Sinti, Romani Gypsies, Spanish Gitanos etc.), age groups, gender, sexuality, gender identity, class/social status  **Recruitment Strategy** (including details of any anticipated use of a gatekeeper in host organizations to arrange/distribute participant invitations)  The researcher is very well connected within the mainstream Romani rights and the LGBT Romani movement. This means that the research participants and users, some of whom participated in the researcher’s doctoral and postdoctoral research, will be recruited from within these networks. The participants will be recruited through my existing networks of contacts with Romani LGBTIQ people, with whom I have worked over the past 13 years, including as part of my doctoral research (2014-2017), the 2012-2014 Council of Europe study on Roma and multiple discrimination, the 2014 first LGBT Roma workshop and the 2015 and 2016 international Roma LGBT conferences in Prague and my ongoing involvement in the LGBT Roma movement.  Upon the approval of this ethics review, the potential research participants/users will be sent the enclosed generic introductory email inviting them to participate in the research study in English. If the reply is positive, the researcher will send them additional information with details of the study in the form of PIS. If a potential participant does not reply at all, the generic email will be resent once more. Those potential research participants/users who will have indicated they wish to participate will be contacted in the course of January/February 2019, confirming the date, time and venue (to be held in the UK in March 2019). The participants who confirm their participation will be contacted one last time a week before the workshop. There will be no advertising involved (i.e. posters or leaflets) and potential participants will be approached by the researcher herself.  **Payments, rewards, reimbursements or compensation to participants**  The research participants’/users’ travel, accommodation and subsistence expenses will be reimbursed by the researcher’s institution upon submitting valid invoices/receipts. The participants/users, some of whom the researcher has previously cooperated with, shall not be compensated for the time dedicated to participating in research: i.e. the photo elicitation interviews (approx. 60 mins) and/or travelling to and attending the workshop (approx. 3 whole days including travel). This is in line with the researcher’s experience of conducting doctoral research and previous projects and studies; with her principle of not offering financial or other compensation to research participants/users for their participation in research related to equality and social justice; as well as the conceptualisation of this research project, which is impact-oriented. (Please note that half of the potential research participants /users are based in the UK and the rest of the participants travel abroad frequently due to their work as prominent Roma rights scholars, activists, artists and performers.)  **What is the process for gaining *consent* from participants?**  The purpose of the study will be explained to participants both verbally and in writing (see the separate PIS for observation and photo elicitation interview) by the researcher beforehand. Only after the researcher has provided a satisfactory explanation of the purpose of the research in writing and verbally will research participants/users be given consent forms to sign. They will be told and reminded repeatedly that participation is voluntary and that they can withdraw from the study at any time in the course of conducting the fieldwork (before the research is written up, i.e. by autumn 2019 the latest) and without giving a reason, and that should they decide to withdraw at any time, or not to take part, there will be no adverse effects to leaving the study. Should they decide to withdraw, every record of their participation and/or comment they made will be removed and all information deleted.  As for electronic consent, if necessary, the researcher will seek to obtain informed consent by emailing a statement about the research study and the accompanying consent form as an attachment, or depending on length, by including them in the body of email to identified participants. Where written signature is still necessary, singed paper versions of consent forms may also be sent by conventional mail and/or scanned and emailed (Mann and Stewart 2000, 49-50). How this paperwork will be stored is addressed below in Section 12. Alternatively, oral consent will be sought before the interview (as this will be audio-recorded, there will be a record).  All data will be anonymised, unless specific participants request to be named. Should participants wish to be named, they will be asked to specify whether they wish to be named by their whole name (first name and surname), only first name or surname; and/or pseudonym. This will be recorded on their consent form (see consent forms). The researcher will respect this by including their name in the format specific by the person in the consent form when participants are quoted.  **Arrangements for translation of any documentation into another language (if applicable)?**  All the prospective research participants/users have good command of the English language, the researcher’s mother tongue is Czech; she is fluent in Slovak (Slovak is mutually intelligible with Czech), English and French.  **Outline how participants can withdraw consent (if applicable), and how data collected up to this point will be handled. Also stop criteria for specific tests (if applicable)?**  The research participants/users will be informed by means of PIS and reminded verbally several times before, during and after the workshop and the photo elicitation interview that should they change their mind, they are free to withdraw at any time in the course of conducting the fieldwork (by end of October 2019 the latest) without giving a reason, and that should they decide to withdraw, or not to take part, there will be no adverse effects to leaving the study. Should they decide to withdraw, every record of their participation in the interview will be removed and all information deleted.  In addition to verbal explanations and contacts, the consent forms and participant information sheets will serve as a main means of checking and verifying who has agreed and given consent to participate (and has participated) in the research.  **Description of data analysis**  After collecting all the data from observation at the 1.5 day workshop (note taking) and interviews, the researcher will transcribe all the audio-recorded photo elicitation interviews. Transcription has been hailed by some as ‘a key phase of data analysis within interpretative qualitative methodology' (Bird 2005, 227), during which the researcher familiarizes themselves with the data. Initial coding and categorisation will determine key preset, as well as recurrent and emergent constructs, patterns and themes that will be revised throughout the research process (Willms et al 1990; Miles and Huberman 1994), using different sources of themes (Bulmer 1979). This is a reiterative process, which allows the researcher to identify and continue to identify themes; to review themes; and to name and define them.  In coding the notes from observation, the transcripts of the photo elicitation interviews and the photographs themselves, the researcher will use the computer-assisted qualitative data analysis software (CAQDAS) NVivo 11: one of its features enables to process the labelling of the content of each photograph which can then be generated into broader ‘themes’, along with the transcripts and notes (N.B. The researcher will record impressions and take notes from observation and photo elicitation interviews in her reflexive diary).  The researcher will be identifying problems and concepts that appear likely to help in understanding the situations. As part of the analysis, the researcher will be regularly going through her data and notes recorded in her reflexive diary; and will be making frequent notes to identify important statements and to propose ways of coding the data, listing the concepts reflected in the notes and diagramming the relationships among concepts (Maxwell 1996, 78–81)).A robust, transparent, detailed, ethical data analysis is central to fulfilling the aims of this research project. It is required both to ensure ethical approaches are interwoven throughout the research project, as well as to render the data well to inform a wider audience as envisaged in the project’s pathways to impact (maximizing the impact of the research and making it available to academics, policy makers, NGOs and other stakeholders.) Thanks to its flexibility (Braun and Clark, 2006), the researcher will use thematic analysis at a latent level, sensitive to queer theoretical concepts. Latent thematic analysis looks beyond the individual themes by examining the underlying ideas, assumptions, ideas that are likely to emerge particularly during the photo elicitation interviews. This means that the development of themes is already interpretive, theorised.  **Personal Data – How will confidentiality be ensured?**  The researcher will seek to prioritise and make every possible effort to safeguard research participants/users’ confidentiality and anonymity at every stage during and after the study although complete anonymity cannot be promised and ensured.  Particular special ethical issues will arise around the use of visual data in research. Visual data can be problematic in both keeping to the concept of ‘anonymity’ of research participants, plus the likelihood of other participants appearing in the data who have not consented to being photographed or being in a research project (Crow & Wiles 2008; Wiles et al 2010). These concerns will be addressed as follows:   * The legal framework of visual data in the UK is outlined below. * Throughout the project, research participants/users will be asked for their views on having their pictures shown to a public audience. Potential academic publications and presentations will also be discussed. The role of the researcher and their views on public displays of their self- representations will be clearly evidenced in the writing-up of any of the research and forms an important objective of the research. * Informed oral and written consent from all research participants/users will be sought, including recorded discussions when the photo-elicitation interviews take place. * If other people appear in the photos, efforts will be made to gain their consent to have the images displayed in future publications and/or on the internet. However, this may not be possible. * All data collected about the participants will be anonymised, unless specific participants request to be named. Personal details included in the research will be anonymised regardless of if the participant wishes to be named. This will be recorded in their consent form. * In published work, images will be only shown when informed consent has been obtained. Place names and people’s names will be made anonymous and/or pseudonyms will be used and varied across publications in order to make it less likely that anyone’s visual images can be tracked across publications. Based on my experience of conducting my doctoral research, I am aware that some research participants/users may wish to have their real names publicised (in this case, this would be different, though, as in some cases, they may be publicised along with their images). * No images will be shown in the research without such ethical dialogues being clearly evidenced in the presentation of data. If necessary, certain photographs will not be shown in the research findings. If any ethical concerns are raised, photographs can be described rather than displayed and/or their faces can be pixelated.   Consideration of legal issues provides a framework of minimum standards that need to be adhered to and do not necessarily equate with ethical or moral practice, i.e. ‘not everything that is legal is ethical’ (Masson 2004, quoted in Wiles et al 2008: 11). General Data Protection Regulation (GDPR), which came into effect in 2018, superseding the Data Protection Act 1998, governs research ethics in the UK with respect to handling personal data, including sensitive data such as ethnicity, religion, sexuality, trade union membership, political views, mental and physical health, genetic and biometric data (as mentioned above, pseudonymised data counts as personal under the GDPR; **data that has been anonymised no longer falls within the GDPR requirements** <https://library.port.ac.uk/researchdata.html>). Specifically, data regarding the participants’ ethnicity, sexuality, gender identity etc. are key to this project. The ethical issues stemming from this – identification v. anonymity – are discussed above. |