

Unexpected Findings Policy¹

WORKFREE
ERC - 2018 - StG - 805425

¹ Adapted from H2020 Guidance, 'Ethics in Social Science and Humanities' (2018). Also adapted with permission from the institutional policy of the University of Kent, developed by Nicole Palmer, Research and Ethics Governance Officer, for previous ERC grants.

Introduction

Unexpected, unintended or incidental findings have emerged as an important area of concern in clinical and medical research, since these can have a bearing on participant health and wellbeing. Although different in nature and focus, social science studies can also unintentionally discover things beyond the scope of initial research questions which are relevant to participant health and wellbeing. This raises challenging questions around confidentiality and best interest determination.

Unexpected findings may include things such as participant illness, criminal activity, abuse, or indications of domestic violence. As researchers involved in a research project, our primary commitment is to protect our participants from harm, aiming to contribute to the improvement of their wellbeing. This means that we have a responsibility to act if we make such findings, which may in turn require us to compromise participant confidentiality.

In all cases, our actions must be guided by the best interests of the participants and in defence of their human rights. However, given the complexity of real life, it may not be immediately clear which action to take – ultimately, there is no one-size fits all ‘right’ thing to do in all circumstances. Our individual and collective responsibility, therefore, is to critically reflect with the support of our colleagues on which *situated* decisions to make in any given set of circumstances². This Policy provides a resource for guiding us through that process.

...

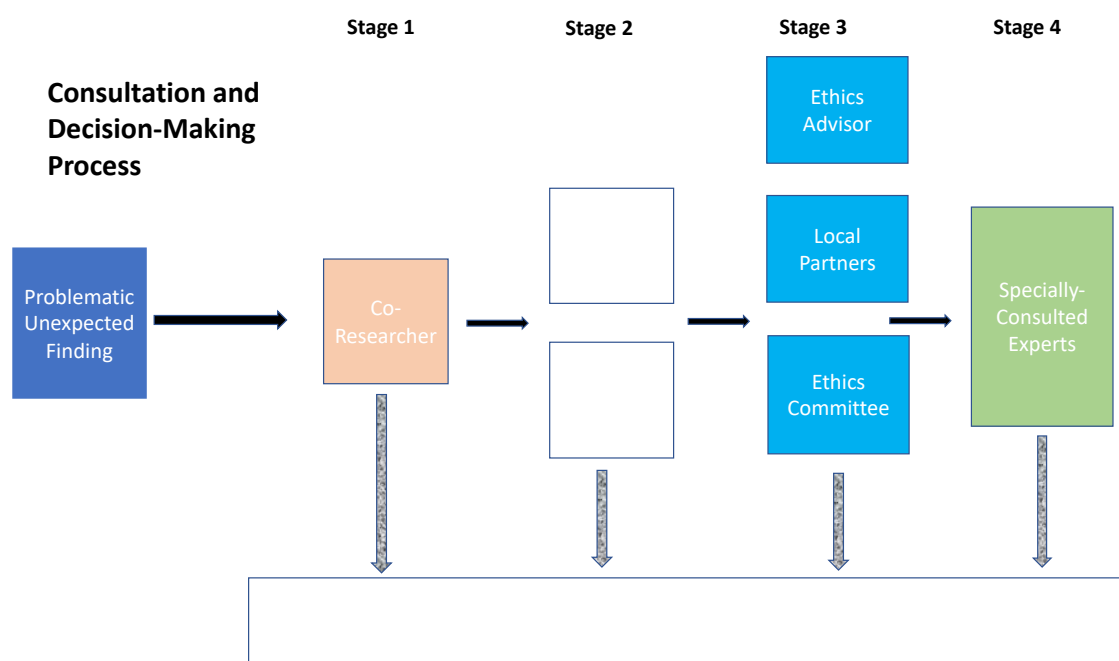
At the moment of obtaining informed consent, you will inform participants or their guardians about this Policy, explaining to them that, if we find evidence of harmful activity such as human and sexual trafficking, we will turn to the list of trusted networks of civil society support compiled by the WorkFREE Ethics Advisory Board. This explanation will be in terms and language intelligible to participants and sensitive to contextual norms. It will emphasise that the primary purpose of the Unexpected Findings Policy is to minimise harm to participants and give relevant examples of the kinds of harm that may lead to the policy being activated (such as sexual abuse). A list of locally-relevant examples will be provided to you before fieldwork begins. Time will be given for participant questions and all effort will be made to respond to them clearly and comprehensively.

² Cf. Ferdinand, J., Pearson, G., Rowe, M. and Worthington, F. (2007), ‘Tales From the Field: A Different Kind of Ethics’, *Ethnography*, 8(4): 519–543.

The Process of Deciding What to Do

As a staff member engaged with WorkFREE, you have been provided with a resource pack listing trusted service providers in the vicinity of participant communities. This includes the contact details and location of governmental and non-governmental services related to health, gender, education, pastoral care, legal support, financial planning, and security. Please consult and offer this resource pack to project participants at any point.

In certain instances, unexpected findings will be simple to deal with and you will only need to consult your nearest available colleague. For example, if a parent wishes to send an unschooled child to school but is unsure how to proceed, details of the relevant local resource can be provided by you or by partners. However, other circumstances will be more complicated, and further consultation will be required. For example, if you suspect that you have found cases of inter-personal violence and are unsure how to proceed without jeopardising participant wellbeing. In these cases, the decision-making process will unfold as illustrated below:



In the event of any problematic unexpected findings, staff should proceed through the four Stages outlined above, with each stage a step of escalation relative to both the severity/complexity of the unexpected finding and the support that should be sought in making a decision. At all stages, the principle against which action decisions should be made is the best interests of participants.

To be clear, in the event of any problematic unexpected findings (dark blue box above), researchers in the field should first consult each other over what to do (orange box above – Stage 1). If the matter is simple and resolvable, they should act, always guided by the best interest of participants. If the matter is more complicated, they should escalate to the Research

Manager and PI (purple boxes above – Stage 1). The latter will also consult with each other. If a suitable course of action is available, it may be taken at this point. If further support is needed, the matter can be brought to the Ethics Advisor, to our project partners and, in serious cases, the Ethics Advisory Board (light blue boxes – Stage 3). After these consultations, if still a clear course of action in the best interests of participants is still unavailable, the PI will seek external expert advice before a decision over action will be taken (green box – Stage 4). One of the project or partner’s senior staff may also consult the individual concerned by the unexpected finding, taking care to do so without in any way putting them at risk of harm. Alternatively, taking similar precautions, trusted members of the community may be consulted for advice.

Guidelines for Reflection

Project staff, up to and including the PI, will consult the following table when determining how to handle any specific unexpected findings.

QUESTIONS	CONSIDERATIONS
What is the nature of the finding?	<p>The nature of the finding will have a big bearing on what is done with it. It is important to reflect carefully on the issue and its potential implications.</p> <ul style="list-style-type: none"> - Is the finding simple or complicated? - How urgent is it? - How severe? - Are immediate responses available? Are these safe and likely to be socially acceptable? - What have participants expressed about the issue?
What is the context of the finding?	<p>The context of any finding will affect the potential benefits and harms to action and inaction. This must be considered before action.</p> <ul style="list-style-type: none"> - Who is implicated by the finding? - What are their social relationships? - Are services available and of good quality? - Who may be able to offer redress or support?
What is the nature of any existing consent?	<p>Consent is a vital platform for action and a critical consideration where confidentiality may be breached.</p> <ul style="list-style-type: none"> - Have participants given informed consent, including to the Unexpected Findings Policy?

	<ul style="list-style-type: none"> - Has any other consent been offered or implied in relation to the unexpected finding and its potential response? - Can the issue be addressed without compromising anonymity?
Are there established good practices in relation to the finding?	<p>Many of the challenges we may encounter will have been thought through by our partners or by other bodies in the field. Safeguarding approaches, for example, are well established and can provide important guidance.</p> <ul style="list-style-type: none"> - What relevant good practice guidelines exist? - Can these be used? - Can anonymous advice be sought from their authors?
What are the potential actions that can be taken in response to the finding?	<p>List the possible actions that could be taken, from the easiest to the most challenging, the simplest to the most complex. List them by actor and by which steps will be required to take them.</p> <ul style="list-style-type: none"> - Which actions are immediately available? - Which actions are available in the medium term? - Who acts? - How?
What would be the benefit to taking an action?	After listing the potential actions, envision the potential benefits to each one.
What would be the cost to taking an action?	Similarly, after listing the potential actions, envision the potential negative consequences that may arise from each one. Be as imaginative as possible – the more we are able to foresee at this point the less we leave to chance.
What would be the benefit to taking no action at all?	It may be that no action is possible without the chance of causing harm. Ask yourself: would doing nothing be likely to cause less harm? What positives would emerge from this choice?
What would be the cost to taking no action at all?	As above, imagine the scenario of taking no action at all: what might the negative consequences be?
What is in the best interest of participants?	Conclude this exercise with a cost-benefit analysis to determine which course of action is likely to be in participants' best interests.