

Guidelines for Compensation and Reimbursement in Disability Inclusive Development Research

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The PIRL Project

This document is for researchers. It tells researchers to think about compensation and reimbursement in research.

People who take part in research can have research-related costs. These costs can be things like travelling or childcare.

Researchers should cover these costs. This reimbursement could lead to more equity in research.

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Introduction

Research Participants should be fairly compensated for their time and expenses when they participate in a research study (unless they voluntarily agree not to be).

This document aims to guide researchers on providing disability inclusive research compensation and reimbursement of research-related costs to ensure as much equity as possible in research studies.

Who are these guidelines for?

These guidelines are primarily for researchers.

They are written from the perspective of teams who are engaged in international research but they can be used by all researchers in any setting.

Current situation

Current practice requires that participants are reimbursed for their expenses and given some compensation for their time. Recent studies show that only a small percentage of protocols include adequate consideration for compensation and reimbursement of costs related to participation, including lost work time (Gordon ¹et al., 2018). This lack of consideration can create challenges for both participants and researchers.

Disability and research

Disability inclusive development research involves participants who are persons with disability, living with the intersection of identities, and the impacts of disability and poverty. For women, trans, and gender-diverse people, experiences could also include gender-related discrimination. Other identities can also impact inclusion in research. This intersectional impact is evident everywhere in the world, including in lower-income communities and countries.

Research has important ethical considerations that researchers must consider (refer to, for example, COHRED, 2022; Mokgatla et al, 2017²;

¹ Stephen B. Gordon et al., "A Malawi Guideline for Research Study Participant Remuneration," *Wellcome Open Research* 3 (December 19, 2018): 141, <https://doi.org/10.12688/wellcomeopenres.14668.2>.

² "Council on Health Research for Development - COHRED | Making Health," Council on Health Research for Development - COHRED, accessed November 19, 2022,

Secretariat on Responsible Conduct of Research, 2016). In addition to the major considerations such as obtaining consent, autonomy, confidentiality, and doing no harm, additional considerations are necessary when involving vulnerable and marginalized groups, including persons with disabilities. For example, these groups include people with vision impairments, hearing impairments, intellectual disabilities, cognitive disabilities, and psychiatric disabilities. This document does NOT address all of the complexity of consent, confidentiality, and many other aspects of conducting good research.

Participating in a research project can involve sacrifices related to time and finances for those who are interested, and therefore researchers need to take all these considerations into account when providing compensation and reimbursement to research participants.

How were these guidelines developed?

The PIRL Project (Partnerships for Inclusive Research and Learning) considered research related compensation and reimbursement in discussions in several PIRL activities such as webinars, workshops, and online WhatsApp groups. We discussed the need to do no harm, to not coerce potential respondents, and to ensure research follows the required standards when involving persons with disabilities.

We also reviewed literature related to compensation and reimbursements in research projects. You can read more about the PIRL Project and other work related to the process used to develop the guidelines on the PIRL website.

Drafts of the guidelines were reviewed and discussed by over 30 people who are members of the PIRL Project and/or part of a research study conducted at the University of Toronto. After these discussions changes were incorporated, and these final guidelines were published.

<https://www.cohred.org>; Boitumelo Mokgatla et al., "Mapping Research Ethics Committees in Africa: Evidence of the Growth of Ethics Review of Health Research in Africa," *Developing World Bioethics* 18, no. 4 (December 2018): 341–48, <https://doi.org/10.1111/dewb.12146>.

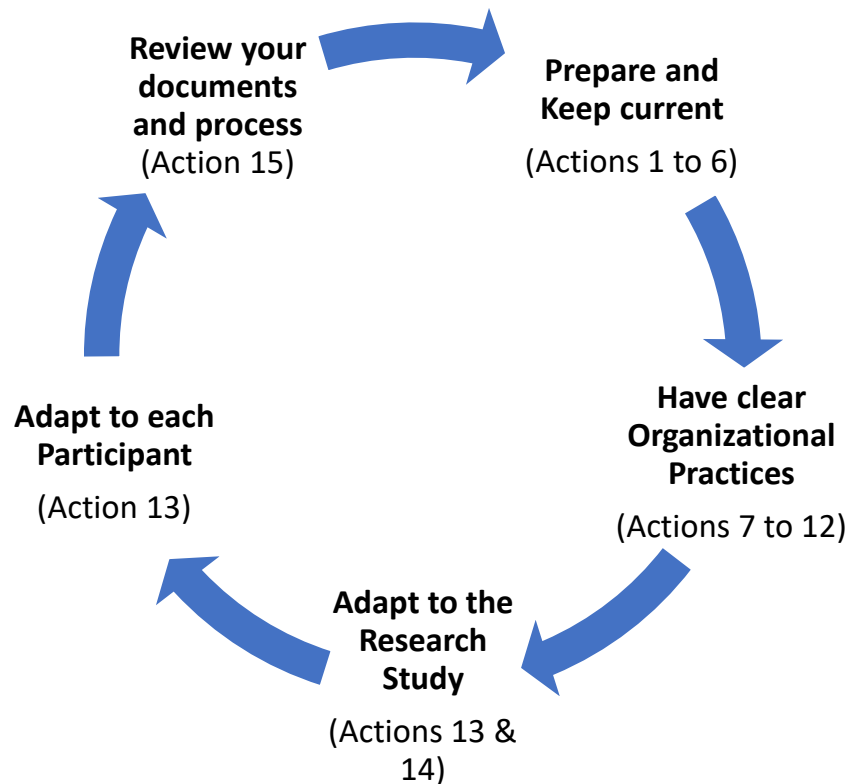
The Recommendations

There are 14 key recommendations in this document. In your organization you can decide which person or group of people will take on the work to implement the recommendations and where the information will be stored.

For example, you might want to use MS Teams or a Google Folder to have everything in one place.

In larger organizations, a Research Officer might lead the process. In smaller organizations, it might be a researcher who would lead the process.

Each of the recommendations is an action that an organization and team should take to develop and maintain their policies and practices about research-related compensation and expense reimbursement.



Outcomes from this Process

Using this process, there will be several documents to be used by your research team.

As a team, you can decide on which documents to share with the participants in each study.

Examples of each of these documents in the list below are included in the Appendices.

- A. A values statement for your organization about why and how you provide compensation in research studies.
- B. A list of relevant resources for your organization. These will be helpful for new team members as well as for everyone to refer to when making decisions.
- C. A compensation table and list of standard expenses for your context that includes disability related expenses.
- D. A glossary that is localized and can be shared with key people in your organization.
- E. A template for research compensation and expense reimbursement in your organization.
- F. Examples from specific research projects in your organization.
- G. A workshop guide for updating these documents annually or every 2 years.

Preparation and Keeping Current

It is important to be current on practices around you and globally to permit you and your organization to decide on your practices. That is why these key considerations should be considered before deciding on what reimbursement and compensation plan is most suitable. By staying current, researchers can implement the most up-to-date practices, ensuring that their studies are equitable and inclusive.

There are many guidelines about how to do research, and many of these must be followed to do research well.

However, in the past, and even today, people with disabilities were often not included in research and in research-related documents. Often, when they are included, their specific requirements are not well considered.

This current document does not cover all aspects of good inclusive research practice because it is focused on compensation and reimbursement.

For more information about terms used, please talk with colleagues and refer to the many good resources and glossaries available from funding bodies, universities, and research organizations³.

³ **Examples of Glossaries:** Glossary from Training and Resources in Research Ethics Evaluation <https://elearning.trree.org/mod/glossary/view.php?id=14>; Social Sciences and Research Council of Canada Definition of Terms <https://www.sshrc-crsh.gc.ca/funding-financement/programmes-programmes/definitions-eng.aspx> ; CIHR Glossary of terms used in accessibility and systemic ableism <https://cihr-irsc.gc.ca/e/53446.html>

1. As a research team, talk about who is going to be responsible and accountable for different roles, including the actions listed here. As much as possible, build the actions and the costs into your project plans.
2. Be aware of national, regional, and global guidelines and requirements related to how to conduct research. Examples of these documents are provided in Appendix 1.
3. Talk with others (and read) about how and why they are doing compensation in research. Compare what others are doing to your own organization's situation and guidelines.
4. Be aware of globally recognized guidelines related to the issues around compensation of research participants.
5. Be aware of the difference between compensation and reimbursement. Refer to Glossaries that explain these and other terms.
6. Commit to doing no harm and other basic ethical principles that apply to general research practice (Secretariat on Responsible Conduct of Research, 2016).

Your Organization's General Guideline on Compensation and Reimbursement

Although there are documents from other places that you can use, you will probably want to clarify for your own organization why it is important to follow these recommendations and who within your organization will be using them.

7. Clearly state where your organizational guidelines are from, and what documents you used in the process. If your organization does research in different locations, develop specific practices for each country or location that is relevant to that location and that incorporates these recommendations. Often participants are not compensated for any lost potential earnings (Gordon et al., 2018) – consider if time for lost work is something that you want to include.
8. Have a good understanding of the various costs related to accommodations (examples include hearing loops or closed-captioning

services, offering flexible scheduling options, pictorial or simplified instructions) for different impairments and disabilities in your context.

9. Create a list of standard expenses for disability accommodations and update it regularly (e.g., annually). Examples are included in the appendices.
10. Develop a clear statement of your values related to equity, justice, and fairness in the type of research your organization is doing. Refer to the Glossary and refer to your values statement as a “living document” that can change as you gain more experience and knowledge.
11. Develop a template for research compensation and expense reimbursement in your organization. We have received feedback that ideally participants would like to have a choice in the options available for compensation, such a choice between a product (e.g., soap, food), or cash, or a gift card.
12. Adapt globally and nationally recognized guidelines and others’ recommendations for your organization in your local context, using a workshop approach with several people involved. Update it by having an annual (or every 2 years) workshop. Include specific guidelines or actions for:
 - a. National and local requirements for compensation, and how they will be handled by your group. For example, some countries require compensation, and others do not allow research participants to receive anything. Make sure you know your own context. While you might not know of local requirements, all countries do have research requirements and most local areas also have requirements. If you are not sure, talk with other researchers in your area.
 - b. Reimbursement of expenses. Have a list of typical expenses that need to be covered, and what the local rates are in your area. Remember this topic might require a lot of discussion to situate what the rates are in some contexts.
 - c. Compensation for time and burden should be discussed openly and not just decided by the key research team members.

- d. Incentives for participation without coercion. Include information from your local research ethics review boards about what they will and will not accept.
- e. Provide guidance on how to handle compensation and reimbursement for non-funded projects by including a statement in the document. Address how to accept research studies without compensation and how to inform potential participants. Determine if student projects are exempt and under what circumstances exceptions can be made. Develop a standard statement for the organization to use and establish expectations for student-led projects at various academic levels.
- f. Withdrawal and non-completion. Include statements about what will happen if someone leaves the project part-way through or does not complete the full study.
- g. When and how individuals, families, organizations, communities and/or villages/towns should be compensated for participating. Be explicit about who will receive the amounts, and at what points during the study.

Adapt the Guidelines for each project AND for each participant

To ensure that research projects are conducted in a fair and ethical manner, it is important to adapt your practices for each project and for each participant within each project.

Always keep accessibility in mind for documents and other materials that are created or used, and make sure that everything is as accessible as possible.

This section outlines some key considerations for adapting guidelines and compensation tables for individual projects and participants with disabilities.

By following the steps outlined below, researchers can ensure that their work is conducted in an ethical and responsible manner, and that the needs and rights of each participant are acknowledged and respected.

13. Adapt your local organizational guidelines for each specific project. Develop a compensation table for each study. Refer to examples in Gordon et al (2018) and on the PIRL website. The decisions related to

reimbursement should be documented in both the study protocol and participant information sheet.

14. Carefully consider the degree of complexity in your project when you consider compensation and reimbursement. (For example, refer to Massett et al, 2022, the CEDIL working paper on evaluation of projects⁴).
15. Reflect on and discuss what worked and what didn't in using the guidelines and related tools for your research study and make changes for the next project as needed.

Acknowledgements

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For questions about these guidelines please contact:

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Louis Mbibeh, University of Bamenda, Bambili, North West Region, Cameroon

⁴ Edoardo Masset, Som Shrestha, and Matt Juden, "Evaluating Complex Interventions in International Development," CEDIL-Centre of Excellence for Development Impact and Learning, May 2022, <https://cedilprogramme.org/publications/cedil-methods-working-paper-6/>.

Appendix 1: Relevant Research guidelines and resources

Global and Multinational

Research Ethics Web

<https://healthresearchwebafrica.org.za/en/api/start?keyP=marc> This portal has links to ethics related information for many countries.

Nuremberg Code (1947) https://en.wikipedia.org/wiki/Nuremberg_Code

Declaration of Helsinki (2000) <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>

3iE *Transparent, Reproducible and Ethical Evidence*

<https://www.3ieimpact.org/what-we-offer/Transparent-Reproducible-Ethical-Evidence> 3ie's Transparent, Reproducible and Ethical Evidence (TREE) Policy articulates this commitment to TREE best practices.

Keeyaa Chaurey, January 8th, 2020. Decolonising ethics frameworks for research in Africa.

<https://blogs.lse.ac.uk/africaatlse/2020/01/08/decolonising-ethics-frameworks-research-africa/>

Moodley, K., Kabanda, S.M., Soldaat, L. et al. Clinical Ethics Committees in Africa: lost in the shadow of RECs/IRBs?. BMC Med Ethics 21, 115 (2020).

<https://doi.org/10.1186/s12910-020-00559-2>

The US Department for Health and Human Services provides an International Compilation of Human Research Standards

<https://www.hhs.gov/ohrp/international/index.html>

TRREE TRAINING AND RESOURCES IN RESEARCH ETHICS EVALUATION has on-line training programme on the ethics and regulation of health research involving human participants, with several self study modules applicable to many countries. <https://elearning.trree.org/>

Listed below are *examples* of national guidelines – if your country is not listed here, please do look for them.

Cameroon

Ministerial Order No. 079/A/MSP/DS of MINSANTE (1987):

http://elearning.trree.org/pluginfile.php/34735/mod_folder/content/0/cm-arrete-079-MSP-CreationComiteEthique-1987.pdf?forcedownload=1

Cameroon - Operational Guidelines for Ethics Committees in Charge of the Evaluation of Biomedical Research

CAMBIN <https://cambin.org/>

Canada

Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2022) https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2022.html

India

The India Council of Medical Research
https://ethics.ncdirindia.org/ICMR_Ethical_Guidelines.aspx

South Africa

The National Health Research Ethics Council (NHREC) of South Africa has published several guidelines including Guidelines for Payment of Trial Participants in South Africa (2012) <https://www.health.gov.za/nhrec-guidelines/>

USA

- Belmont Report (1979)
- <https://www.hhs.gov/ohrp/international/ethical-codes-and-research-standards/index.html>

Appendix 2: Examples of Organizational guidelines

To be added

Appendix: Example Table for Calculation of Reimbursement

[\(Adapted from Gordon et al, 2018\)](#) Refer to the Explanatory Notes under the Table.

Please note that you should modify this table to meet the needs of your organization, and to include only the expenses that are relevant to your context and study. Add other expenses that are relevant.

You can include another column or indicate in some other way if an item is Not Applicable.

A completed example table is included under this blank template.

Disability Inclusive Development RESEARCH PARTICIPANT REMUNERATION	Rate (in your currency; add column(s) if additional currency is needed)	Number of Events and specify (e.g., focus groups, 1:1 interviews)	Total
Reimburse Expenses (in your currency)			
a) Transport – Refer to Note A			
b) Meals – Refer to Note B			
c) Childcare – Refer to Note C			
d) Personal Assistant/ Guide – Refer to Note D			
e) Accommodation – Refer to Note E			
f) Additional costs related to access/accommodations – Refer to Note F			
Compensation – Refer to Note G			
Direct time participating in the study			
Time traveling			
Additional time in Facility (e.g., waiting)			
Burden – Refer to Note H			
Procedure or Study Activity A			
Procedure or Study Activity B			
Procedure or Study Activity C			

Total for the Study			
When will people receive reimbursement and compensation? Refer to Note J			
Statement about withdrawal from study early: Refer to Note K			

Notes for Table 1

For all categories, refer to your organization's list of standard expenses, and adapt according to organizational policy.

Note A - Transport Use the same amount for all participants in the study, based on your organization's travel rates (e.g., 5km = X; 10km = XX; 15km = XXX). However, these amounts can be adapted for people with specific requirements or needs. For instance, if a traveling companion is required for minors or some adults, double the sum allocated and make a note in the chart. Calculate costs based on usual transportation costs in your area. Include costs for additional support and transport related to disability. For example, in some places, people must pay extra for a taxi to carry a wheelchair. In other places, transportation for people with disabilities is free or low cost.

Note B – Meals Reimburse eligible meals that are directly related to your participation. This means that if the participants incur expenses for meals while engaged in study-related activities, they might/ will be reimbursed based on the guidelines that have been established prior to participating in the study. Meals that are incurred within the designated study period and directly related to participation would be considered eligible for reimbursement.

Note C - Childcare - Normally, childcare costs can be provided if the participant is the primary caregiver for children, and the study activities take place outside of normal daycare/school hours, where the parent/guardian needs to arrange childcare. Develop a policy/guideline for the number of children; who provides childcare; and any other specifics for your locality.

Note D - Personal Assistant/ Guide

Provide specificities on considerations for a guide. They are provided with transportation, accommodation (lodging, food) but you must decide if they need any extra pay for providing personal assistance depending on the context.

Note E - Accommodation (overnight stay)

When research participants are required to engage in activities outside of their regular homes, accommodations are provided to ensure their comfort and accessibility. These accommodations are arranged and funded by the research project itself. It is important for the project to collaborate with the participants to determine the most suitable accommodations that meet their specific needs. In certain cases, activities may be conducted in areas where the participants reside, necessitating the need for the research team to be present with them. There could be various reasons for this, such as ensuring a safe environment, availability of power or internet connectivity, addressing security concerns, or facilitating teamwork among participants.

Note F- Additional costs related to access or disability-related accommodations

Consider the normal rates, then evaluate the additional amounts according to context. For instance, while the PIRL project paid one seat on the bus for some participants to travel to a participate in research activities, in Cameroon they paid 2 spots for participants with disability who needed extra space or who traveled with a companion or guide.

Note G - Compensation - For compensation, consider the 1) rate for Direct time participating in the study; 2) Time spent traveling, and 3) any additional time in the facility (e.g., waiting) or related to the study, 4) time spent planning and actually holding meetings to prepare.

Note H - Burden/Personal Information

Acknowledging the burden in research studies is an important step towards creating a more equitable and respectful research environment. The research team needs to consider the burden placed on participants when they participate. Participants are critical to the success of research, and their involvement should be respected and valued. While it is important to ensure that the burden on participants is minimized as much as possible, it is equally important to acknowledge and appreciate that burden can exist, and the contributions to the research process.

Low burden would be studies that are “easier” to participate in – for example filling a simple form or responding to short interview questions that are not very personal. Burden increases with more time, more invasive procedures, more personal information, and so on. For example, a high burden study would be one where a person has to provide extensive personal information, be present in a hospital for over 24 hours and have several blood samples taken.

There also might be more than one study activity for a participant. Burden should be calculated for each discrete activity, and might also increase with more activities in a period of time. For each study activity, rate the burden placed on the participant and compensate for the level of contribution. Consider the time frame that the activities take place. For example 3 interviews in one week might be considered more burdensome than 3 interviews spread over 3 months.

Gordon et al (2018) used three levels of burden - your organization might want to consider fewer, more, or different categories. Consider other aspects such as risk levels, emotional content, stigma, and/or location of the study. Include your own rating of burden. For example, there is more risk when talking about trauma or highly stigmatized illness or experiences.

Note I: Total and Minimum remuneration. Recommendation is that for studies that require attendance at a location other than the person's home, there should be a minimum level set. For example, \$25, 7000 MK, or 20,000 CFA.

Note J: When funding will be paid. Be clear with participants if they will have to provide some funds out of pocket; if receipts need to be provided and for what; if there are staged payments. For example, in some studies, participants receive compensation after doing each interview. In other studies, they receive expense reimbursement at various points, and full compensation at the end of their participation.

Note K: What participants will receive if they leave the study early. In many studies, there is recognition that participants can receive a partial amount if they do not complete the full study. For example, if they are to engage in the three interviews, maybe they get X after Interview 1, X after Interview 2, and XX doing interview 3 and any other activities that are required for full completion of the study.

Appendix 3: Example of an Organization Cost List

For *Fictitious NGO* in Toronto

[We want to Include another example for non-Canadian organization – have asked colleagues in Cameroon for examples]

This policy shows how we calculate compensation and reimbursement for participants in research studies. We try to balance the constraints of research funds with respect to participants' needs.

Compensation - We start with the assumption that all research participants in Fictitious NGO studies that require interviews, focus groups, or similar kinds of participation will be compensated for all Direct time participating in the study at a rate of at least \$15.50 per hour (some studies might have higher rates), and at least 1 hour. Depending on the study, this hourly rate can be higher.

The minimum compensation for studies that require attendance at a location other than the person's home is \$25.

We also compensate participants for 1 hour of travel time if they are coming from the GTA at \$15.50/hour, and any additional time in the Facility (e.g., waiting) or related to the study, time spent planning and actually holding meetings at \$15.50/hr.

In general, we do not compensate participants for online surveys that take less than 1 hour to complete. In some studies, participants might be given an honorarium or entered into a draw for a prize for this kind of contribution.

Examples of calculating Compensation:

Mercy comes to our office to do an interview in person. The interview takes 33 min. She receives \$25 for her interview time because that is our minimum compensation amount for in-person time. She has no wait time. She is traveling from within the GTA, so she receives 1 hour of travel time, for 15.50. Her total compensation is \$40.50.

Sue does a screening survey online for 5 min, and an online Zoom interview that takes 1 hour. She is *not* compensated for the survey and is compensated \$20 for the interview. She has to wait for 30 min, and she travels to the interview from downtown Toronto (1 hour). Sue receives total compensation for her time of \$43.25 = \$20 + (15.50/2) + 15.50

Max does three online interviews over a period of 3 months, each one taking about 45 min. The study compensates them with 3 X \$15.50 = \$46.50 for time. They are not kept waiting, and Max does not receive travel time compensation or waiting time.

Jerry participates in one online focus group that takes 1.5 hours, and due to the nature of the study, participants receive \$30 per group (not by hour). The group starts late by 20 min, because two of the participants are delayed. Jerry receives \$30 for participation in the focus group, and \$4.65 for waiting time, for a total of \$34.65 for their time. There is no travel time.

Transport Costs

1. If the person usually takes TTC, we provide the usual roundtrip fare in cash, even if the person has monthly pass.
2. If the person drives, the amount to be reimbursed is based on mileage (currently \$0.60 per km) plus cost of parking in one of the approved parking lots.
3. If the person requires another form of transportation, we discuss it with the person. Generally, the maximum allowed is \$25.00.

Meals

Our policy is to provide refreshments and meals as part of the study. We do not provide cash in place of food to study participants. We often do plan that there will be extra refreshments for participants to take home.

Childcare - Normally, childcare costs can be covered if the participant is the primary caregiver for children, and the study activities take place outside of normal daycare/school hours, where the parent/guardian needs to arrange childcare. We discuss with each participant what is required. Generally, it is not more than \$20 per child per hour and will be less per hour if 2 or 3 children are being cared for by one person (for example \$30/hour for the care of 3 children).

Personal Assistant/ Guide

Personal Assistants will have the same refreshments and transportation costs as the participant. If extra pay is required for personal assistance, it is decided on a situational basis. Each project will establish an upper limit for these costs.

Accommodation

Depending on the research study, accommodation is only provided to research participants when they move out of their usual homes to participate in a study. The project coordinator (or their designate) will be aware of the requirements for accommodation, including that it should be accessible and agreed to by the participant. The project coordinator will decide with each participant what accommodation is suitable for them. The decisions of the project coordinator should be shared with participants and must be respected.

Additional costs related to access or disability related accommodations are determined on a situational basis. Fictional Organization maintains a list of usual costs. Typically, we do not provide hardware or software to participants.

Burden/Personal Information - Fictional Organization also considers burden and the type of study and builds these factors into our budgets. For each study activity, we rate the burden placed on the participant and we compensate addition amounts when for the level of contribution is rated Moderate or High discomfort or Long or complex procedures. We also consider other aspects such as risk levels, emotional content, stigma, and/or location of the study. The research Committee reviews these levels and processes annually. For example, there is more risk when talking about trauma or highly stigmatized illness or experiences.