

Accounting for research fatigue in research ethics

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Abstract

How to account for participants' psychological and emotional exhaustion with research has been under-explored in the research ethics literature. Research fatigue, as it is known, has significant impacts on patients' well-being and their ongoing and future participation in studies. From the perspective of researchers and researched communities, research fatigue also creates selection bias and opportunity costs, negatively impacting the collective scientific enterprise. Institutional Review Boards should systematically consider research fatigue during the research approval process and strive to mitigate it.

KEYWORDS

IRB approval, over-researched communities, research ethics, research fatigue

1 | INTRODUCTION

I am often invited to be a participant in research studies because of my group belonging. So often, in fact, that I find myself unable to participate in all but a few select studies. But my inability to participate does not arise from time constraints, though time constraints exist. Rather, it is psychological and emotional exhaustion that makes me pass on important projects in want of participants.

Known as research fatigue, this kind of exhaustion is frequently reported by participants of small and/or marginalized communities and is beginning to attract increasing attention among researchers.¹ Although research fatigue raises epistemic and ethical concerns by

negatively impacting participants and distorting study results, the notion has yet to receive significant attention within the research ethics literature.

Research fatigue is likely to become a growing concern in the coming years, as the internet reduces the cost of many types of studies and facilitates increasing access to hard-to-reach populations. Addressing research fatigue is not only essential because of its impact on individual participants, but also because of its repercussions on our ability to continue generating socially valuable knowledge.

With this paper, I hope to initiate a conversation about research fatigue among marginalized communities and how the research community should respond to it. The second section offers an overview of the concept of research fatigue. The third section explores the impacts of research fatigue and highlights its ethical and epistemological relevance to Institutional Review Board [IRB] approval.² The fourth and final section explores how research fatigue should be taken into account during the IRB approval process.

Although conceptually applicable to all research, the nature of the factors identified in the literature makes my discussion of singular interest for social science and public health research. For this reason, much of the paper is drafted with such research in mind and my recommendations may be less helpful to other forms of research.

¹Patel, S. S., Webster, R. K., Greenberg, N., Weston, D., & Brooks, S. K. (2020). Research fatigue in COVID-19 pandemic and post-disaster research: Causes, consequences and recommendations. *Disaster Prevention and Management: An International Journal* (ahead-of-print). <https://doi.org/10.1108/DPM-05-2020-0164>; Boesten, J., & Henry, M. (2018). Between fatigue and silence: The challenges of conducting research on sexual violence in conflict. *Social Politics: International Studies in Gender, State & Society*, 25(4), 568–588. <https://doi.org/10.1093/sp/jxy027>; Koen, J., Wassenaar, D., & Mamotte, N. (2017). The 'over-researched community': An ethics analysis of stakeholder views at two South African HIV prevention research sites. *Social Science & Medicine*, 194, 1–9. <https://doi.org/10.1016/j.socscimed.2017.10.005>; Cleary, M., Siegfried, N., Escott, P., & Walter, G. (2016). Super research or super-researched?: When enough is enough... *Issues in Mental Health Nursing*, 37(5), 380–382. <https://doi.org/10.3109/01612840.2016.1163977>; Pagano-Therrien, J. (2013). Exploring research fatigue in HIV-infected youth. *Journal of the Association of Nurses in AIDS Care*, 24(1), 11–16. <https://doi.org/10.1016/j.jana.2012.01.010>; Clark, T. (2008). 'We're Over-Researched Here!': Exploring accounts of research fatigue within qualitative research engagements. *Sociology*, 42(5), 953–970. <https://doi.org/10.1177/0038038508094573>.

²The generic name for IRBs varies by locale and they are also known as research ethics committees, ethical review boards, etc.

2 | WHAT IS RESEARCH FATIGUE?

Research fatigue is a state of psychological and emotional exhaustion both towards and as a result of research participation. Terminologically, research fatigue is distinguished from mere tiredness when the individual becomes reluctant or refuses to participate in ongoing or future research as a result of exhaustion due to participation.³ According to Tom Clark, research fatigue primarily appears in two contexts: research involving participation over time and over-researched populations.⁴ The causes and solutions to research fatigue likely differ between the two contexts, despite overlap. This paper focuses on research fatigue linked to over-research, which is most associated with research on marginalized communities. Research fatigue among marginalized groups raises unique concerns about the distribution of benefits and burdens of research and exploitation. Perhaps for these reasons, the literature has primarily discussed research fatigue in contexts of over-research.

The overall prevalence of research fatigue is unknown and may be impossible to accurately estimate since people experiencing research fatigue are, by definition, hard to reach. In longitudinal research, loss to follow-up can be indicative of research fatigue. However, there are many possible causes for loss to follow-up, making it an unreliable proxy. Qualitative studies cannot establish the prevalence or incidence of research fatigue but can shed light on its gravity and ubiquity among given communities. Community representatives and individuals who have experienced research fatigue in the past may notably be willing to share their insights into the phenomenon.

The determinants of research fatigue include the concentration of research, its burdensomeness, its usefulness, and the psychosocial vulnerability of participants. These factors emerge from qualitative studies of researchers and community representatives and from the reflections of researcher-authors. The available evidence base being modest, I offer this quadripartite division on provisional terms, subject to revision as new evidence on the causes of research fatigue is gathered. Nonetheless, I would be surprised by any radical changes to the four proposed determinants, as they accord with intuition and conceptual reasoning.

The first determinant of research fatigue is research concentration. The greater the time investment relating to research per person over a period of time, the greater the likelihood and extent of research fatigue. All other things being equal, greater time commitments, whether within a single study or multiple studies, lead to greater fatigue. The relationship may not be linear, however, and how the time investment is spread over the period may plausibly influence research fatigue: studies that are too fragmented or involve too long sittings might have a larger impact on research fatigue. We have reasons to believe that the time spent in a study does not exhaust research concentration. Participants expend temporal, financial, emotional, and cognitive resources to choose whether and which studies to participate in, plan their schedule

around participating, and travel to the participation site [which can involve financial costs].⁵ These likely also contribute to research fatigue. Even if the person ultimately declines to participate, the mental load of choosing and planning may contribute to research fatigue and potentially impact future research participation.

Analyses of research fatigue must consider both the amount of research involvement of a studied population and the size of the population. The smaller the population, the more each study contributes to research concentration. Concerns over research fatigue often arise in relation to marginalized groups because of the convergence of small size and high interest to “humanitarian” researchers. Research fatigue has notably been discussed in relation to Indigenous populations, transgender people, homeless people, incarcerated people, people living with mental illness, people living with HIV, climate refugees, etc.⁶

The second determinant of research fatigue is the burdensomeness of research. The form and content of a study can make it more psychologically and emotionally tiring for some or all participants.⁷ Participants who are bored or stressed during participation may develop psychological and emotional exhaustion more quickly, whereas being entertained or experiencing pleasure may serve as protective factors. Questions and topics that don't interest the participant, repeated questions, overly difficult questions, distressing and/or sensitive questions, lack of pleasant social interactions, and research that involves little or no opportunity for introspection or learning seem to contribute to research fatigue.⁸ Antiquated and invalidating language can distress and alienate participants from marginalized groups—a potential source of emotional exhaustion and thus research fatigue.⁹ On the other hand, the risk of research fatigue may be diminished among studies that make use of methodologies that are novel to the participants, capitalizing on participants' curiosity and novelty-seeking.¹⁰

The third determinant of research fatigue lies in participants' perception of the usefulness of research. Altruism is a major motive of research participation.¹¹ When past participation fails to engender noticeable benefits, participants may come to see research as

⁵ibid: 963–964.

⁶Luetz, J. M. (2019). Over-researching migration 'hotspots'? Ethical issues from the Carteret Islands. *Forced Migration Review*, 61, 20–22; Glick, J. L., Andrinopoulos, K. M., Theall, K. P., & Kendall, C. (2018). “Tiptoeing Around the System”: Alternative healthcare navigation among gender minorities in New Orleans. *Transgender Health*, 3(1), 118–126. <https://doi.org/10.1089/trgh.2018.0015>; Koen et al., op. cit. note 1; Cleary et al., op. cit. note 1; Maar, M. A., Lightfoot, N. E., Sutherland, M. E., Strasser, R. P., Wilson, K. J., Lidstone-Jones, C. M., ... Williamson, P. (2011). Thinking outside the box: Aboriginal people's suggestions for conducting health studies with Aboriginal communities. *Public Health*, 125(11), 747–753. <https://doi.org/10.1016/j.puhe.2011.08.006>

⁷Pagano-Therrien, op. cit. note 1, pp. 11–12.

⁸Clark, op. cit. note 1, pp. 956–957, 962.

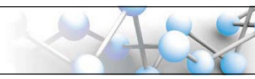
⁹Vincent, B. (2018). Studying trans: Recommendations for ethical recruitment and collaboration with transgender participants in academic research. *Psychology & Sexuality*, 9(2), 102–116. <https://doi.org/10.1080/19419899.2018.1434558>; Adams, N., Pearce, R., Veale, J., Radix, A., Castro, D., Sarkar, A., & Thom, K. C. (2017). Guidance and ethical considerations for undertaking transgender health research and institutional review boards adjudicating this research. *Transgender Health*, 2(1), 165–175. <https://doi.org/10.1089/trgh.2017.0012>

¹⁰Clark, op. cit. note 1, p. 962.

¹¹Peel, E., Parry, O., Douglas, M., & Lawton, J. (2006). “It's No Skin off My Nose”: Why people take part in qualitative research. *Qualitative Health Research*, 16(10), 1335–1349. <https://doi.org/10.1177/1049732306294511>

³Clark, op. cit. note 1, pp. 955–956.

⁴ibid: 956.



useless and grow apathetic and disinterested in ongoing or future participation.¹² After participating in research that does not yield tangible benefits, members of marginalized communities may even grow resentful of researchers and [often reasonably] perceive them as self-interested outsiders who only care to benefit their career.¹³ In other words, research fatigue may reflect exploitative dynamics, and refusing to participate may be a rational response.¹⁴ This would suggest that increasing the perceived usefulness of a study can motivate some potential participants to invest themselves notwithstanding fatigue.

The fourth determinant of research fatigue is the psychosocial vulnerability of participants. Participants' psychosocial characteristics can make them more prone to fatigue. Various mental health conditions are associated with a greater propensity for psychological and emotional exhaustion either in general or in relation to specific research methods and content. Marginalized communities also often have fewer available psychological and emotional resources because of minority stress, which results from oppression, and lack of social support: resources that would otherwise be available are used up in everyday life and fewer options are available to replenish them [e.g., access to adequate mental health services]. Psychosocial vulnerability is rarely homogeneous within researched populations, suggesting that the burden of research fatigue is not evenly distributed and that more vulnerable subgroups disproportionately experience it. This determinant of research fatigue significantly overlaps and intersects with burdensomeness and perceived usefulness. Notably, researchers that come from privileged groups are less likely to appreciate the experiences and needs of the researched population and unwittingly distress or tire marginalized participants.¹⁵

Significant parallels may be drawn between research fatigue and occupational burnout. Both involve context-specific exhaustion symptomized by disengagement and apathy. Like research fatigue, occupational burnout may differentially impact marginalized populations and people living with mental health problems. And both give rise to questions of exploitative dynamics and practices. It may be helpful to understand research fatigue as a form of research burnout. The link between research fatigue and occupational burnout should be further explored, as the literature on the latter could serve to complement the scant research fatigue literature.

Although tiredness is a natural byproduct of many activities, research fatigue as a social and scientific phenomenon cannot be understood without regard to study design, curiositisation,¹⁶ exploitation, and marginalization. A substantial portion of research fatigue highlighted in the literature and which I have observed in my communities arises because scientists from dominant groups turn to study "high interest" marginalized groups with little consideration for their needs or how to ensure the study will tangibly benefit them. Such an approach clashes with marginalized communities' expectations that research be responsive to their needs and priorities rather than indiscriminately add to scientific knowledge, paralleling some of the concerns over responsiveness in international medical research.¹⁷

3 | HOW IS RESEARCH FATIGUE RELEVANT TO RESEARCH ETHICS?

Research fatigue is a significant concern for research ethics. The Belmont Report and its operationalization in the Common Rule [United States] and the Tri-Council Policy Statement [Canada] offer a framework for appreciating the relevance of research fatigue within research ethics.¹⁸ Three principles must guide the approval of research projects: respect for persons, beneficence, and justice. As I show in this section, each is implicated by research fatigue. In analyzing the ethical aspects of research fatigue, it is crucial to acknowledge the intimately intertwined nature of epistemic and ethical concerns. Research fatigue is ethically concerning both because it is a negative mental state in and of itself and because its impact on future research and scientific validity alters the balance of risks and

¹²Way, E. (2013). *Understanding research fatigue in the context of community-university relations* (Master's thesis). Clark University, Worcester, MA; Clark, op. cit. note 1, pp. 956, 958–961.

¹³Tagonist, A. (2009, December 10). Fuck you and fuck your fucking thesis: Why I will not participate in trans studies. Retrieved from <https://tagonist.livejournal.com/199563.html>; Clark, op. cit. note 1, p. 956.

¹⁴Tuck, E., & Yang, K. W. (2014). R-words: Refusing research. In D. Paris & M. T. Winn (Eds.), *Humanizing research: Decolonizing qualitative inquiry with youth and communities* (pp. 223–247). London, UK: SAGE Publications. <https://doi.org/10.4135/9781544329611>. Though they focus on refusal by researchers, the same rationales apply *mutatis mutandis* to refusal by potential participants.

¹⁵McKinnon, R. (2016). Epistemic injustice. *Philosophy Compass*, 11(8), 437–446. <https://doi.org/10.1111/phc3.12336>; Haraway, D. (1988). Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, 14(3), 575–599.

¹⁶Curiositisation refers to "the process through which people or groups of people become intensified subjects of curiosity" and, I would argue, intensified scientific interest: Marvin, A. (2020). Transsexuality, the curio, and the transgender tipping point. In P. Zurn & A. Shankar (Eds.), *Curiosity studies: Toward a new ecology of knowledge* (pp. 188–206). Minneapolis: University of Minnesota Press.

¹⁷Wenner, D. M. (2017). The social value of knowledge and the responsiveness requirement for international research. *Bioethics*, 31(2), 97–104. <https://doi.org/10.1111/bioe.12316>; London, A. J. (2008). Responsiveness to host community health needs. In E. J. Emanuel, F. G. Miller & R. Lie (Eds.), *The Oxford textbook of clinical research ethics* (pp. 737–744). UK: Oxford University Press. The requirement has been notably criticized by Wolitz, R., Emanuel, E., & Shah, S. (2009). Rethinking the responsiveness requirement for international research. *The Lancet*, 374(9692), 847–849. [https://doi.org/10.1016/S0140-6736\(09\)60320-2](https://doi.org/10.1016/S0140-6736(09)60320-2), though some of the critical arguments do not apply or are weaker in relation to local research on marginalized communities. First, the contentious requirement of making interventions under study reasonably available is tailored to clinical research, and the debate between reasonable availability and fair benefits is not readily transposed onto social science and public health contexts. Second, social science and public health research on marginalized groups typically does not purport to generate knowledge that will be directly useful to the dominant group and is most often non-responsive due to ignorance or disagreement with the community's priorities and understanding of its needs rather than by design. Third, the risk of some researchers abandoning research on the community is not as concerning since research fatigue arises in contexts of over-research and fewer, more responsive studies may be desirable.

¹⁸Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council. (2018). *Tri-Council Policy Statement: Ethical conduct for research involving humans - TCPS 2*. Government of Canada; Protection of Human Subjects, 45 CFR § 46 (1981); National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979, April 18). The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research. Retrieved from <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html>

benefits. Epistemic and ethical concerns raised by research fatigue should not be considered separately, as it risks obscuring their fundamental interdependence. Thus, I consider them side by side.

Under the principle of respect for persons, research must respect the autonomy of participants. In practice, and due to how the notion is embodied in the Common Rule, this concept has been predominantly focused on ensuring that participants' free and enlightened consent is obtained. Informed consent is implicated by research fatigue insofar as participants are rarely informed of the risk of research fatigue even though it might impact their decision to participate. Equipped with understandable information about the risk and impact of research fatigue, some participants may have declined to participate in favor of future studies that they expect to be more useful. Even when disclosure does not impact the decision to participate, participants may wish to act on the information and take precautionary measures to mitigate the participation's contribution to fatigue.¹⁹

Under the principle of beneficence, the harms of research must be minimized and be reasonable in relation to the anticipated benefits. Research fatigue pertains to both the benefits and harms of research. On the harms side of the equation, research fatigue is a negative mental state that plausibly constitutes a harm in and of itself. As the parallel to occupational burnout highlights, psychological and emotional exhaustion, apathy, and frustration are negative mental states that should not be discounted from the ethical analysis. As negative mental states, disappointment and regret due to being too exhausted to participate in important future studies should also be acknowledged as ethically salient components of research fatigue.

Turning to the benefits side of the equation, research fatigue reduces the benefits derived from research by impairing the collective scientific enterprise. In longitudinal research, fatigue can distort results as participants begin answering mechanistically or in an unserious manner.²⁰ In non-longitudinal studies, the loss of benefit will typically be borne by future research. Human subject research is a collective enterprise that aims at perpetually generating new socially valuable knowledge.²¹ In furtherance of this goal, research ethics should concern itself with the negative impact of research projects on future studies. Impact on future research is not alien to research ethics, as the scientific value of exploratory research lies in its impact on future, confirmatory studies and some authors have suggested that entire research portfolios should be evaluated instead of individual studies to

better account for the relational aspects of studies' value.²² That the impact of research fatigue on future studies is indirect and far more diffuse does not offer an overriding reason to discount it. If a single study of negligible social value were to predictably foreclose all future scientific research, allowing it would be unethical and any IRB who did so would have failed in its supervisory role. Since this hypothetical differs in degree but not in kind from research fatigue, then we have good reasons to consider research fatigue in research ethics analysis. Research fatigue meaningfully impacts the feasibility and scientific validity of future research projects, some of which would have generated highly valuable knowledge. Studies may not only fail to generate valuable knowledge but may also frustrate scientific progress by hindering recruitment and distorting results through selection bias. As noted, research fatigue disproportionately burdens more marginalized subgroups and risks making future sample populations less representative due to selection bias.²³ This can significantly curtail the usefulness of study results since research on marginalized groups often focuses on participants' needs and experiences of marginalization, which are correlated with research fatigue.

Under the principle of justice, the benefits and burdens of research must be fairly distributed. Research fatigue disproportionately burdens marginalized communities and consideration must be given to how this burden will be offset by studies. This can be done by generating forms of knowledge that benefit the community commensurately to the greater burden of research fatigue on them, as researchers often purport to do. However, projects that aim at benefitting the researched communities may not be responsive to the community's self-assessed needs and priorities and it cannot be assumed that the overall distribution of the benefits and burdens of research is fair, especially if dominant communities have their needs and priorities met without the additional burden of research fatigue.²⁴ The distribution of benefits and burdens must not only be considered at the level of the group but of subgroups as well. As noted, research fatigue creates risks of selection bias due to differential impacts across the sample population. This can lead to some perspectives being underrepresented in studies and correspondingly less benefited by the results.

The opportunity costs of research fatigue are also germane to the principle of justice. Studies that generate research fatigue can slow or prevent marginalized communities from remedying existing social injustices through future research participation. Without generating knowledge that substantially contributes to social justice, such studies perpetuate and entrench prevailing injustices. Perpetuating and entrenching existing injustices is not a

¹⁹Ashley, F. (2020). Surgical informed consent and recognizing a perioperative duty to disclose in transgender health care. *McGill Journal of Law and Health*, 13(1), 73–116.

²⁰Koen et al., op. cit. note 1, p. 4.

²¹The Nuremberg Code expresses the justifiability of human experimentation in terms of social value: "The protagonists of the practice of human experimentation justify their views on the basis that such experiments yield results for the good of society that are unprocurable by other methods or means of study." See also Habets, M. G., van Delden, J. J., & Bredenoord, A. L. (2014). The social value of clinical research. *BMC Medical Ethics*, 15(1), 66. <https://doi.org/10.1186/1472-6939-15-66>; Emanuel, E. J., Wendler, D., & Grady, C. (2008). An ethical framework for biomedical research. In E. J. Emanuel, F. G. Miller & R. Lie (Eds.), *The Oxford textbook of clinical research ethics* (pp. 123–135). UK: Oxford University Press.

²²London, A. J., & Kimmelman, J. (2019). Clinical trial portfolios: A critical oversight in human research ethics, drug regulation, and policy. *Hastings Center Report*, 49(4), 31–41. <https://doi.org/10.1002/hast.1034>; Kimmelman, J., & London, A. J. (2015). The structure of clinical translation: Efficiency, information, and ethics. *Hastings Center Report*, 45(2), 27–39. <https://doi.org/10.1002/hast.433>

²³Maar et al., op. cit. note 6, p. 749.

²⁴Wenner, op. cit. note 17. Similar concerns have been discussed in the context of international research: London, op. cit. note 17.

fair distribution of the benefits and burdens of research. To ensure fair distribution, studies must be responsive to the needs and priorities of the researched communities. Studies should be sufficiently responsive not to slow or prevent communities from redressing their own marginalization.

Appreciating the relevance of research fatigue for research ethics requires us to take a holistic view of research. Studies are enmeshed within scientific research as a collective project.²⁵ IRBs cannot look at them purely in isolation. While some of the impacts of research fatigue can be appreciated in the context of an isolated study, many of its more meaningful ones cannot be understood without looking at the interactions between studies. Although IRBs cannot force teams to pursue more socially valuable projects, they can and should consider research fatigue when applying recognized principles of research ethics.

4 | HOW SHOULD IRBS ACCOUNT FOR RESEARCH FATIGUE?

The IRB approval process can incorporate consideration for research fatigue in various ways, many of which reflect good research practices with marginalized communities regardless of research fatigue. On the whole, IRBs should systematically consider research fatigue when evaluating and harmonizing the risks and benefits of studies including by placing greater weight on the perspective of the researched communities and ensuring that participants are adequately informed of the possibility and effects of research fatigue. While accounting for research fatigue during the IRB approval process may result in some studies being denied, my suggestions aim primarily at fostering researcher reflection and participant autonomy in the hopes of maximizing the production of socially valuable knowledge.

In studies involving a substantial risk of causing or contributing to research fatigue, informed consent forms should disclose the risk of research fatigue. Whether a study poses a substantial risk of causing or contributing to research fatigue should be evaluated by IRBs based on the submission materials and will often be the case for research on small marginalized communities. If the research project bears on a marginalized community, IRBs should also ensure that the consent form discloses the concrete benefits the study will or may generate for the community in terms that members of that community will readily appreciate. Since potential participants may not be cognizant of the pace of research, it may be helpful to estimate the time frame over which the benefits would be realized. Disclosing anticipated benefits to the community alongside the risk of research fatigue will help potential participants prioritize studies they partake in and can mitigate research fatigue by enhancing participants' sense of the usefulness of the

study for themselves and others in their community. Articulating concrete benefits to the community can also foster introspection among research teams and encourage studies that respond to the needs of the researched community. Community benefit statements should be drafted in plain language, included in recruitment material, and aim to reflect the community's understanding of what would be to their benefit.

When there is a substantial risk of causing or contributing to research fatigue, IRB submissions should aim to evaluate said risk and outline what mitigation strategies are proposed. Including this information supplies IRBs with the details necessary to consider research fatigue when applying criteria for ethics approval and encourages reflection among study teams. Evaluating the risk of research fatigue would typically involve applying the four previously highlighted factors of research fatigue, i.e., research concentration, burdensomeness, usefulness, and psychosocial vulnerability, to the researched population. The size of the researched population can often be estimated. Literature reviews and trial registries can provide some information on the quantity of recent research as well as similarities of topics and methodologies. In projects employing collaborative methodologies, the information can be complemented by asking community representatives directly. Submissions to IRBs should attempt to track how many studies were conducted on the same group and geographic area, and how likely it is that potential participants have participated in or were asked to participate in similar studies. Submission documents should outline proposed strategies for mitigating research fatigue, if any. These strategies may include [in no particular order]: incorporating members of the studied community in the research team, especially in leading roles; consulting and collaborating with members of the community before and throughout the study; tailoring research questions to a needs assessment to ensure responsiveness to the community's needs and priorities; ensuring accurate and sensitive language; adequately compensating participants for time management and traveling; providing for robust knowledge translation and dissemination; shortening questionnaires, including through skip logics; and adopting methodologies that are more stimulating to participants. Since research fatigue is related to the participants' and communities' perception that research does not yield concrete benefits for them, making the results of the research readily accessible and appreciable can meaningfully mitigate apathy and research fatigue. IRBs should strongly encourage teams to engage in robust knowledge translation and dissemination back into the researched communities and look favorably on proposals to do just that.

When considering submissions, IRBs should systematically consider the impact of research fatigue on participants, on the scientific validity of the proposed study, and on the feasibility and scientific validity of future studies. When evaluating proposals involving substantial risks of research fatigue, IRBs should strive to apply principles of research ethics from the perspective of the researched community, as it is the perspective most likely to reveal how the research project interfaces with research fatigue. Due to marginalized groups' historical and often ongoing exclusion from

²⁵While 45 CFR §46.111(a)(2) disallows IRBs from considering the potential risks of applying the knowledge gained in the research, it does not preclude taking a holistic perspective on the benefits of research or impacts of a study on capacity for future research.

science, their perspectives may not be readily accessible and understandable to those who research them.²⁶ Similarly, members of IRBs may lack the situated knowledge necessary to adequately assess the project's opportunity costs and responsiveness to community needs and priorities. Where doubts remain, IRBs should consult experts from the concerned community on an *ad hoc* basis to fill this gap.²⁷

Where a proposal involves substantial risks of causing or contributing to research fatigue in a marginalized population, IRBs should apply more strictly the requirements to minimize risk consistently with sound research design and that the risks be reasonable in relation to the anticipated benefits. I suggest a stricter requirement as a prudential measure because of the diffuse and unquantifiable aspects of research fatigue; because of the impact of marginalization on IRBs' ability to fully appreciate the impact of research fatigue; and because of the potential for causing or perpetuating social injustices through selection bias and opportunity costs [i.e., by *de facto* excluding more marginalized subgroups from future research and by making it difficult to conduct future research that responds to the group's concrete needs]. The proposal is consistent with the view that varying risk thresholds should apply depending on the vulnerability of the participants.²⁸

IRBs should also encourage collaborative methodologies and projects that include experts from the studied community as part of the research team. Collaborative methodologies [e.g., CBPR] and formal relationships between the research project and local community organizations can help curtail feelings of exploitation and unresponsiveness.²⁹ Communities' shared ownership and control over the research project mitigates exploitative dynamics and enhances responsiveness. However, the effectiveness of collaborative methodologies in these respects depends on the manner and context in which they are deployed, as they can also be sites of disempowerment and exploitation.³⁰ Besides collaborative methodologies, community representation among researchers [especially as principal or co-investigators] can also serve to counteract the feeling of

exploitation and unresponsiveness associated with research on marginalized populations, especially if the representation is disclosed in recruitment material. IRBs and study teams should however be careful not to indirectly pressure team members to publicly disclose private or sensitive information such as their belonging to a marginalized group. Disclosure should be free of pressure, manipulation, or coercion. However, many scientists from marginalized groups freely choose to make their marginalized identities public and may be comfortable disclosing it in recruitment material. Optimally, both strategies would be employed.

Graduate research by students who are not part of the researched communities tends to exacerbate research fatigue and has occasionally been the focus of ire among marginalized communities.³¹ Limited resources place collaborative methodologies out of reach for many graduate students and they are often too early in their career to have earned the trust of the researched community and been entrusted with extensive knowledge of its needs and priorities, resulting in elevated risks of unresponsiveness. Graduate students are less likely to publish the results of their research and to engage in knowledge translation and dissemination than senior scholars. Many abandon their studies partway through or change areas of research after graduation. These factors contribute to the impression of exploitation among researched communities. To limit research fatigue, graduate research proposals should be carefully scrutinized, especially but not only when submitted by non-community members,³² and looser standards should not be applied simply because it arises in a pedagogical context. On the contrary, graduate students may pose a unique risk when it comes to research fatigue and would do best to integrate larger research projects where risks can be better mitigated. Graduate student research posing a substantial risk of research fatigue should not be approved unless a senior scholar undertakes to complete the research, publish its results, and engage in knowledge translation and dissemination if the student is unable or declines to after initiating data collection.³³ The undertaking should be in writing to impart a stronger sense of obligation.

To supplement these efforts beyond the approval process, IRBs could produce written and audiovisual material to inform the public about research fatigue, how it can be mitigated at the individual and community levels, and how to carefully select and support research projects that are aligned with their values and altruistic impulses. This material could subsequently be linked or referred to in recruitment material for potential participants who are interested in learning more. Fostering conscientious research participation among marginalized communities is a crucial step towards mitigating apathy and improving marginalized communities' sense of benefiting from

²⁶McKinnon, op. cit. note 15, 440–441; see also Slovic, P. (1999). Trust, emotion, sex, politics, and science: surveying the risk-assessment battlefield. *Risk Analysis*, 19(4), 689–701. <https://doi.org/10.1111/j.1539-6924.1999.tb00439.x> on the differences in evaluating risk among different groups.

²⁷As encouraged by some guidelines, e.g., Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council, op. cit. note 18, p. 22.

²⁸Weijer, C., & Miller, P. B. (2004). When are research risks reasonable in relation to anticipated benefits? *Nature Medicine*, 10(6), 570–573. <https://doi.org/10.1038/nm0604-570>; see also 45 CFR §46.111(a)(3) & §46.111(b).

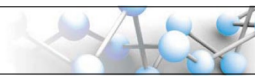
²⁹Travers, R., Pyne, J., Bauer, G., Munro, L., Giambone, B., Hammond, R., & Scanlon, K. (2013). 'Community control' in CBPR: Challenges experienced and questions raised from the Trans PULSE project. *Action Research*, 11(4), 403–422. <https://doi.org/10.1177/1476750313507093>; Tuck, E., & Guishard, M. (2013). Uncollapsing ethics: Racialized scientism, settler coloniality, and ethical framework of decolonial participatory action research. In T. M. Kress, C. Malott & B. J. Porfilio (Eds.), *Challenging status quo retrenchment: New directions in critical research* (pp. 3–28). Charlotte, NC: Information Age Publishing.

³⁰Travers et al., op. cit. note 29, pp. 411–416; de Schweinitz, P., Ansong, D., Manortey, S., Amuasi, J., Boakye, I., Crookston, B. T., & Alder, S. (2009). Evaluating international collaboration: Differential perceptions of partnership in a CBPR project in Ghana. *Journal of Empirical Research on Human Research Ethics*, 4(4), 53–67. <https://doi.org/10.1525/jer.2009.4.4.53>

³¹As an example, Tagonist, op. cit. note 13 is notorious among trans researchers and advocates.

³²Tuck & Yang, op. cit. note 14, p. 234.

³³Bauer, G., Devor, A., Heinz, M., Marshall, Z., Pullen Sanfaçon, A., & Pyne, J. (2019, August 1). CPATH ethical guidelines for research involving transgender people & communities. Canadian Professional Association for Transgender Health. Retrieved from <http://cpath.ca/wp-content/uploads/2019/08/CPATH-Ethical-Guidelines-EN.pdf>



participation, thereby decreasing research fatigue and empowering these communities as active collaborators in the collective scientific enterprise.

5 | CONCLUSION

Accounting for research fatigue in research ethics requires less a radical shift than a new sensitivity. Research fatigue can be understood both as a risk to participants and communities and as an opportunity cost for future research. As global interconnectivity facilitates an increasing amount of research and studies on hard-to-reach communities, research fatigue is all-but-guaranteed to grow as a concern for researchers. By accounting for research fatigue in research ethics, IRBs can help mitigate the impacts of research fatigue on marginalized and vulnerable communities and on science. While the IRB approval process is a fecund juncture for abating research fatigue and encouraging reflection among research teams, research fatigue cannot be comprehensively accounted for without sustained efforts and engagement by researchers, researched communities, and research ethicists.³⁴ The sooner these conversations bloom, the better.

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CONFLICT OF INTEREST

The author declares no conflict of interest.

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³⁴As Eve Tuck and Monique Guishard convincingly argue, research ethics cannot stop with the IRB approval process: Tuck & Guishard, op. cit. note 29.