


# Translational or translationable? A call for ethno-immersion in (empirical) bioethics research

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## Abstract

The shift towards "empirical bioethics" was largely triggered by a recognition that stakeholders' views and experiences are vital in ethical analysis where one hopes to produce practicable recommendations. Such perspectives can provide a rich resource in bioethics scholarship, perhaps challenging the researcher's perspective. However, overreliance on a picture painted by a group of research participants—or on pre-existing literature in that field—can lead to a biased view of a given context, as the subjectivity of data generated in these ways cannot (and should not wholly) be escaped. In response, we propose the implementation of a complementary approach of ethno-immersion in bioethics research. By positioning oneself in the context being researched, the researcher can better understand the realities of that context. The researcher's understanding will, naturally, be subjective too. However, it will act as a better developed and more informed outsider view, when considering the picture painted by participants and previous studies, thus enabling the researcher to introduce more nuance when analysing data. We introduce this approach after examining what we call the context detachment problem, whereby some bioethics scholarship—empirical or otherwise—fails to reflect the reality of the healthcare setting it concerns. Our proposed ethno-immersion (which differs from formal ethnography) is then explored as a response, highlighting its benefits, and answering the question of timing within a research project. Finally, we reflect on the applicability of our proposal to non-empirical bioethics scholarship, concluding that it remains important but may require some adjustments.

## KEYWORDS

empirical bioethics, ethnography, research methods, triangulation

## 1 | INTRODUCTION

So-called "empirical bioethics" has seen significant traction in recent years. Back in 2005, Borry and colleagues spoke of the 'empirical turn' in the field.<sup>1</sup> This shift to employ social sciences methods in bioethics scholarship was largely triggered by a recognition that the views and experiences of stakeholders are vital in ethical analysis where one hopes to produce practicable recommendations. Without rooting normative reasoning within practical realities, applied ethics might be thought of as having limited use in the real world. Empirical bioethics is not a descriptive enterprise concerned only with what is happening, but also how it is experienced by individuals. Stakeholders also invariably develop their own perspectives on lived ethical issues; they are, per Rapp's description, 'moral philosophers of the private'.<sup>2</sup> Such perspectives can provide a rich resource in bioethics scholarship, perhaps (usefully) challenging the perspective of the researcher.

In exploring these lived experiences, methods employed are often somewhat targeted, by which we mean that they seek to satisfy a particular purpose in a relatively efficient manner. For example, individuals may be asked to complete a survey or be invited to join a focus group. There is huge value in data generated in these ways, but its subjectivity cannot (and should not wholly) be escaped. Where individuals are being asked to share their views and experiences, events will be recounted through a lens of their own (un)conscious biases; an interviewee is not going to provide a wholly objective description of what happened even if they think that is what they are doing. Of course, these methods do not seek to gather objective data—subjectivity is recognised as inherent in qualitative research, both from the participant and the researcher. There is, however, a risk that an overreliance on a picture painted by a group of research participants (particularly where convenience sampling has been used)—or on pre-existing literature in that field—can lead to an inaccurate view of a given context, particularly where the researcher has no personal experience of that setting.

As a means of mitigating this risk, we propose the implementation of a complementary ethno-immersive approach (hereafter "ethno-immersion"). Through first-hand exposure to the context under investigation, the researcher can build their own understanding of how things play out. The researcher's understanding will, naturally, be subjective too. However, it will act as a better developed outsider view when considering the picture painted by participants and previous studies, enabling the researcher to introduce more nuance when analysing data. Importantly, what we propose is distinct from formal ethnography, as we will come to discuss shortly. We introduce this approach after examining what we refer to as the context detachment problem, whereby some bioethics scholarship—empirical or otherwise—fails to reflect some of the important realities of the healthcare setting it concerns. Our proposed ethno-immersion is then explored as a response, highlighting its benefits, and answering the question of

timing within a research project. Finally, we reflect on the applicability of our proposal to non-empirical bioethics scholarship, concluding that it remains important but may necessitate a few tweaks.

In the wider debate concerning translational bioethics<sup>3</sup>—which we acknowledge is not a conclusively defined concept, hence the special issue this paper is part of—our proposal contributes to what might be thought of as the translationability of bioethics research. Adopting ethno-immersion does not mean seeking to take on any sort of implementation role, but to aim to produce recommendations from research that have greater *potential* for implementation. It is concerned with bioethics scholarship making suggestions for policy and practice that those with lived experience of the pertinent context can recognise as speaking to that context, even if they disagree with such suggestions. Further, it dismisses a more linear view of translational bioethics that might result from a mirroring of translational medicine; we do not view ethno-immersion as a single stage to be tagged on at the end of a project, but as a long-term endeavour across the course of a research project (and possibly beyond that period).

## 2 | THE CONTEXT DETACHMENT PROBLEM

Researchers working in moral philosophy have long been criticised for their "ivory tower" pursuits, particularly for being overly concerned with esoteric questions with no relevance to real-world contexts. Yet, the suggestion that philosophers should be politically and socially engaged—and take on roles in both governing and transforming society—has been a recurrent theme in philosophical literature, dating as far back as Plato's *Republic*,<sup>4</sup> and as recently as output from the Frankfurt School.<sup>5</sup> Indeed, at its core, empirical bioethics seeks to address normative issues; an endeavour that requires social engagement, as it necessitates an understanding of the health and care issues prevalent in society. A European consensus statement on the standards of practice in empirical bioethics research also states that it should aim 'to bring about ethically defensible changes to practice', which includes policymaking.<sup>6</sup> This, Ives

<sup>3</sup>There exists a (somewhat limited) literature on what is sometimes referred to as "translational bioethics". Broadly speaking, questions of the translation of bioethics scholarship into policy/practice (recommendations) in some manner. See, for example, Cribb, A. (2010). Translational ethics? The theory-practice gap in medical ethics. *Journal of Medical Ethics*, 36(4), 207–210; Bævre, K. (2014). Translational ethics: An analytical framework of translational movements between theory and practice and a sketch of a comprehensive approach. *BMC Medical Ethics*, 15, 17. Importantly, this is distinct from discussion of the ethics of translational sciences. Hostiuc and colleagues focus on this latter discussion rather than translational bioethics. Hostiuc, S., Moldoveanu, A., Dascălu, M.-I., Unnthorsson, R., Jóhannesson, Ó. I., & Marcus, I. (2016). Translational research—the need of a new bioethics approach. *Journal of Translational Medicine*, 14, 16. Translational bioethics more broadly—rather than our specific focus in this paper—is the subject of this special issue of *Bioethics*. As such, we will not claim to provide a definitive account here and allow the special issue as a whole to flesh out this developing concept.

<sup>4</sup>Plato. (2012). *Republic* (C. Rowe, Trans.). Penguin.

<sup>5</sup>Horkheimer, M., & Adorno, T.W. (2002). *Dialectic of enlightenment: Philosophical fragments*. Stanford University Press.

<sup>6</sup>Ives, J., Dunn, M., Molewijk, B., Schildmann, J., Baerøe, K., Frith, L., Huxtable, R., Landeweer, E., Mertz, M., Provoost, V., Rid, A., Salloch, S., Sheehan, M., Strech, D., de Vries, M., & Widdershoven, G. (2018). Standards of practice in empirical bioethics research: Towards a consensus. *BMC Medical Ethics*, 19, 68.

<sup>1</sup>Borry, P., Schotsmans, P., & Dierickx, K. (2005). The birth of the empirical turn in bioethics. *Bioethics*, 19(1), 49–71.

<sup>2</sup>Rapp, R. (2000). *Testing women, testing the fetus: The social impact of amniocentesis in America* (p. 306). Routledge.

and colleagues conclude, requires empirical bioethics research to be 'connected to the real world'.<sup>7</sup> Although there has been some debate over whether methods, borrowed from social sciences, are the right approach for gaining insight from the "real world",<sup>8</sup> the importance of contextual awareness in "good" bioethics research (whether it is empirical or not) is less controversial.<sup>9</sup>

Nonetheless, we suggest that use of certain social science methods alone is insufficient to produce recommendations that reflect the reality of the context being explored. By observing and drawing attention to research that has been done well, we begin to identify the various problems that can arise from context detachment.

First, research may have less potential for translation if the recommendations produced have not been grounded in some important features of the pertinent reality.<sup>10</sup> This is applicable to bioethics research regardless of whether it positions itself within empirical bioethics. For instance, a research project may conclude that use of a specific process/resource is an ethically justifiable solution to an identified problem. However, if this process/resource is not readily available, accessible, or implementable—even if it is identified as being the "gold standard"—this recommendation is unlikely to be helpful, as it does not reflect what is achievable in the context of the normative issue. This could result in reduced uptake of these recommendations and rejection of what could otherwise be valuable research for being "out of touch". By contrast, research by Fritz and colleagues on the development of a national approach to resuscitation decisions illustrates how research with realistic, functional recommendations can be transformative and widely adopted in clinical practice.<sup>11</sup> The research group produced and recommended a standardised form ('ReSPECT') to address the problem of poor discussion and documentation of do-not-attempt-resuscitation decisions. The lead researcher's close positioning—as a clinician—to the reality of the problem, and the frequent and extensive consultation with stakeholders in the ReSPECT development process, likely helped facilitate the development of a practicable solution with significant uptake.<sup>12</sup> Whilst we certainly do not expect that all bioethics research can, will, or should achieve similar heights (or that all bioethics research should be conducted by individuals directly professionally engaged with the issue being explored), this example demonstrates how *proximity* to context is essential to make research relevant and to produce pragmatic recommendations that benefit service users, professionals, and other stakeholders.

Context detachment may also lead to damage to the reputation of, and less engagement with, bioethics as a field. This may seem to be a lesser concern, as compared to recommendations that do not serve the public and professionals well, but it is important, given that bioethics research often aims to (directly or indirectly) influence medical and scientific practice. The concern, therefore, is that bioethics' credibility could be threatened by research and recommendations that do not satisfactorily consider the reality that professionals working in medicine and clinical sciences face. The scientification of literature review methods in bioethics exemplifies how researchers are keen to adopt a language that is readily understood and accepted by these professionals.<sup>13</sup> Further, as Chan notes, philosophical integrity has sometimes been compromised in favour of contextual appropriateness in order to influence policy and maintain credibility.<sup>14</sup> However, we are not suggesting that context detachment is only an issue where bioethics research has an empirical component or is policy-oriented. As the unfortunate example of the after-birth abortion paper showed, the public's perceptions of individual researchers, or of bioethics as a whole, may be harmed.<sup>15</sup> A more recent example of controversy in bioethics that gained media attention<sup>16</sup> caused one commentator to argue that 'bioethics, while it may sometimes be a platform for ideas we personally find repugnant, indeed remains an important field precisely because it is poised to debate a range of ethically difficult and complex matters'.<sup>17</sup> We do not mean to suggest that controversial ideas (and academic freedom) have no space in bioethics. However, we do consider it unwise to dismiss the impact and reputational damage that such 'controversial' work can have so quickly. The relationship between bioethicists and those working in policy and practice or developing new technologies can often be fragile. Thus, contextual awareness is needed even for purely theoretical research, as normative issues explored in bioethics research are sometimes socially delicate.

Finally, recommendations from bioethics research may endanger vulnerable populations if context is ignored. There is a risk that these recommendations may be (even partially) adopted by policymakers, who are arguably further removed from some important features of the pertinent reality. This could result in problematic policies, which exacerbate (rather than solve) issues in health and care, and potentially alienate professionals and the public even more. For example, in an attempt to address the issue of higher perinatal mortality in pregnant people from Black and Asian ethnic minorities,

<sup>7</sup>Ibid: 9. We acknowledge that we are operating on a very European conception of empirical bioethics here, which is by no means the only one. Nonetheless, for our purposes, an understanding of empirical bioethics as that which seeks to engage with a given context alongside normative work is sufficiently broad.

<sup>8</sup>Herrera, C. (2009). Is it time for bioethics to go empirical? *Bioethics*, 22(3), 137–146.

<sup>9</sup>Chan, S. (2015). A bioethics for all seasons. *Journal of Medical Ethics*, 41(1), 17–21.

<sup>10</sup>Of course, this assumed that the research in question is seeking to produce practicable suggestions, which is not—and need not be—always the case.

<sup>11</sup>Fritz, Z., Pitcher, D., Hawkes, C., & Nolan, J. P. (2016). Development of a national approach to resuscitation decisions: The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). *Resuscitation*, 106(1), e73.

<sup>12</sup>Resuscitation Council UK. ReSPECT for healthcare professionals. <https://www.resus.org.uk/respect/respect-healthcare-professionals>

<sup>13</sup>Parsons, J. A., & Johal, H. K. (2021). In defence of the bioethics scoping review: largely systematic literature reviewing with broad utility. *Bioethics*, 36(4), 423–433; Birchley, G., & Ives, J. (2022). Fallacious, misleading and unhelpful: the case for removing 'systematic review' from bioethics nomenclature. *Bioethics*, 36(6), 635–647.

<sup>14</sup>Chan, op. cit. note 9.

<sup>15</sup>Levy, N., & Minerva, F. for *The Conversation*. (2015). *Talking about our work is important but it can land researchers in trouble*. <https://theconversation.com/talking-about-our-work-is-important-but-it-can-land-researchers-in-trouble-45781>

<sup>16</sup>Smajdor, A. (2022). Whole body gestational donation. *Theoretical Medicine and Bioethics*, 44, 113–124. <https://doi.org/10.1007/s11017-022-09599-8>

<sup>17</sup>Lee, J. Y. for *Journal of Medical Ethics Blog*. (2023). What's the big deal with 'whole body gestational donation'? On defending bioethics. <https://blogs.bmj.com/medical-ethics/2023/02/07/whats-the-big-deal-with-whole-body-gestational-donation-on-defending-bioethics/>

the National Institute for Health and Care Excellence (NICE) produced draft guidance that proposed inducing labour at 39 weeks in Black and Asian pregnant people. Although the process through which this guidance was produced was not clear, these blanket recommendations were heavily criticised by doctors and birth campaigners for being 'racist and discriminatory'<sup>18</sup> and for not sufficiently acknowledging that it is a complex range of social and political factors—not just biological factors—that likely lead to poorer maternity outcomes.<sup>19</sup> Furthermore, early in the COVID-19 pandemic, in an effort to produce guidance for triage of adults requiring critical care, NICE proposed that 'Clinical Frailty Scores' should be used to determine the suitability of all adults for hospital treatment. This suggestion was quickly revoked upon the realisation that it could result in discrimination against individuals with stable cognitive impairment (e.g., learning disabilities). This example further reveals that even national bodies may produce guidance that does not adequately consider the nuances or realities of clinical practice.<sup>20</sup> Superficial insight into the context of normative issues in health and care research may therefore adversely impact patients, professionals, and policy.

### 3 | MOVING TO ETHNO-IMMERSION

As a means of overcoming the context detachment problem, our central proposal here is that we should endeavour to employ ethno-immersion as complementary to a given research method. Much like ethnography as a research method in itself, the approach we propose is about *physically* positioning oneself in the lived reality of the context being researched.<sup>21</sup> In bioethics research, this may mean time spent in a clinical environment, a family support group, or even the homes of patients. We stress *physically* as it is about a more tangible immersion that cannot be achieved through methods such as interviews or focus groups.<sup>22</sup>

We do not suggest that methods such as interviews and focus groups are in any way poor choices. Indeed, that is why our call is for ethno-immersion as *complementary* rather than as a replacement. Nor do we suggest that ethno-immersion is a replacement for ethnography. Our approach and formal ethnography serve different

purposes and should be employed in appropriate scenarios. If an in-depth account of a given context to complement analysis of data generated using other qualitative methods is the goal, then ethno-immersion is unsuitable—although aspects of it may still be employed in the research planning stages. Neither approach is inherently superior, and we would similarly welcome more ethnography in bioethics.

Ethno-immersion is about gaining some first-hand experience that, we suggest, provides a level of understanding that cannot come from data generation alone,<sup>23</sup> whilst still leaving space for qualitative methods that generate important stakeholder perspectives. Incorporating ethno-immersion into a research project enables a more nuanced handling of any data generated, wherein things said are better understood and the researcher may be able to "read between the lines" more when developing an interpretation.

We are certainly not the first to suggest a broadly ethnography-like approach to bioethics research. As far back as 1990, Jennings discussed the benefits of ethnography to bioethics, exploring this value through the example of neonatal intensive care.<sup>24</sup> More recently, Parker has argued that 'ethnography offers the possibility of a bioethics better informed about the meaning and intersubjective significance of the situation under consideration'.<sup>25</sup> In a sense, then, we are simply trying to revive this discussion—perhaps of growing importance as empirical bioethics research becomes more common.

However, there is an important distinction to elucidate between our proposed ethno-immersion and the use of ethnography as a research method in bioethics that others discuss. Ethnography—or participant observation—is an established research method originating in anthropology, which has since been exported to various disciplines.<sup>26</sup> Many ethnographies have been conducted in healthcare settings<sup>27</sup> and within bioethics more specifically.<sup>28</sup>

Ethnography as a research method in itself has as its end goal a rich written account of a particular context. The intention is to immerse oneself in a context to develop an understanding that is, to a reasonable extent, that of an "insider", given the long-term situating of the researcher in the setting. This account is the "graphy" in ethnography and is generally the final product of such a research project. Ethnographers do not ordinarily conduct ethnography to produce a data set for use in later ethical analysis—though a particular ethnography may later be used for cross-cultural examination.

<sup>18</sup>H. Summers for *The Guardian*. (2021). *Guidance to induce minority ethnic pregnancies earlier condemned as racist*. <https://www.theguardian.com/global-development/2021/jul/13/nice-guidance-to-induce-minority-ethnic-pregnancies-earlier-condemned-as-racist>

<sup>19</sup>Birthrights. *Inquiry into racial injustice in maternity care*. <https://www.birthrights.org.uk/campaigns-research/racial-injustice/>

<sup>20</sup>Parsons, J. A., & Johal, H. K. (2020). Best interests versus resource allocation: could COVID-19 cloud decision-making for the cognitively impaired? *Journal of Medical Ethics*, 46(7), 447–450; Scully, J. L. (2020). Disability, disablism, and COVID-19 pandemic triage. *Journal of Bioethical Inquiry*, 17, 601–605.

<sup>21</sup>Ethnography does not always entail physical positioning, such as where the context being researched is an online community. See Hine, C. (2016). Ethnographies of online communities and social media: Modes, varieties, affordances. In N. G. Fielding, R. M. Lee, & G. Blank (Eds.), *The SAGE handbook of online research methods* (pp. 401–415). SAGE. However, for ease of understanding, we will proceed on an understanding of such physical positioning as it is most likely in the context of research in a healthcare setting.

<sup>22</sup>It is important to note, however, that formal ethnographies do sometimes employ methods such as interviews and focus groups alongside the observation component.

<sup>23</sup>Unless, of course, the data generation is a formal ethnography.

<sup>24</sup>Jennings, B. (1990). Ethics and ethnography in neonatal intensive care. In G. Weisz (Ed.), *Social science perspectives on medical ethics* (pp. 261–272). Kluwer Academic Publishers.

<sup>25</sup>Parker, M. (2007). Ethnography/ethics. *Social Science & Medicine*, 65(11), 2248–2259. It should be noted, however, that Parker does highlight some reservations about the relationship between ethnography and bioethics.

<sup>26</sup>See, for example, Griffin, C., & Bengry-Howell, A. (2017). Ethnography. In C. Willig, & W. S. Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 38–54). SAGE; Halperin, S., & Heath, O. (2020). *Political research: Methods and practical skills* (pp. 339–363). Oxford University Press.

<sup>27</sup>See, for example, Tae, J. (2017). *The patient multiple: An ethnography of healthcare and decision-making in Bhutan*. Berghahn Books; Reblora, J. M., Dong, L., Lopez, V., & Goh, Y.-S. (2021). "The same but different": Triaging in primary healthcare settings: A focused ethnography study. *Collegian*, 28(1), 35–41.

<sup>28</sup>Moazam, F. (2006). *Bioethics and organ transplantation in a Muslim society: A study in culture, ethnography, and religion*. Indiana University Press.

In contrast, our proposed ethno-immersion is not research in itself. Indeed, it is not even a formal data generation process. It is not about producing a detailed written account of the context, but, rather, the researcher developing this insight in their own mind. It is about the researcher understanding the context being researched in detail through first-hand experience—that is, significant time spent in the context as an observer. Rather than relying on second-hand accounts of the context—whether from research participants, existing scholarship, or both—the researcher undertakes to build a detailed picture for themselves, recognising the subjectivity of their experience, their subjects' experiences, and the resultant limits of relying on the description of another. Of course, the researcher's own understanding through ethno-immersion will also be subjective, but this will better match the subjective lens they will apply to the interpretation of data generated through other research methods (such as interviews or focus groups)—something that can be reflected on in any reporting of results.

Ethno-immersion, then, is much the same as ethnography during the period of immersion. It is before and after that period that it differs. Ethnography requires the approval of an ethics committee, whereas ethno-immersion would likely only require the agreement of those being observed.<sup>29</sup> Ethnography requires the taking of detailed fieldnotes to aid in writing a detailed account, whereas ethno-immersion may not entail any note taking at all.<sup>30</sup>

### 3.1 | The value of ethno-immersion

The key benefit of ethno-immersion boils down to nuance. Incorporating this direct and sustained engagement with the context one is exploring can, if done properly, result in a rich understanding of the lived reality. Far richer, we suggest, than is achievable through other methods alone. In addition to improving the researcher's understanding of the environment in which they are undertaking their study, acquaintance with the types of people in this environment may improve the quality of data generated as well as the approach to analysis. Researchers will be better equipped to understand and then use language and phrasing that is familiar to potential participants, which may in turn help develop the rapport necessary for conducting successful interviews and focus groups. Demonstrating empathy during sensitive interviews may also feel more natural to both the participant and the researcher if the researcher has their own first-hand experiences of the study setting—albeit as an observer.

In describing the role of the participant observer, Fox details how '[i]t is through ongoing interaction and a developing relationship with

the individuals and groups who belong to the milieu being explored that the researcher enters ever-more deeply—psychologically and interpersonally, as well as intellectually—into its social structure and culture and the experiences, personae, and lives of those who people it'.<sup>31</sup>

It is this ongoing nature of ethnography—and our proposed ethno-immersion—that enables this depth of understanding. The snapshot that can come from, for example, interviews and focus groups, is limited in this regard. There are also relational and logistical benefits to ongoing observation. As ethno-immersion places an onus on the researcher to learn more about the realities of the study setting, it may build trust amongst those being studied, that the researcher is demonstrating a genuine interest in their lived experience and culture. As this phase of research is not, as yet, routine, it may show that the researcher has gone "above and beyond" in familiarising themselves with the environment. It may also help to rebuild trust in clinical research amongst marginalised populations who have historically been disadvantaged by unethical research practices and begin to rectify the damages to health and healthcare that have arisen from inaccurate research.<sup>32</sup> In addition, a regular or consistent presence in the research setting may break down barriers between the researcher and potential participants, thereby aiding recruitment. Informal interactions prior to the data generation process may put potential participants at ease and create opportunities for participants to learn more about the research study, whilst the researcher learns more about them. There are certainly parallels here with the problematic practice of parachute research, whereby the researcher in effect uses others as means to their own research ends in a somewhat exploitative fashion.<sup>33</sup>

A strong example of how ethno-immersion might be beneficial is a study conducted by Moazam.<sup>34</sup> Moazam explored conflicts between modern bioethics and the traditional societal practices of Pakistan, all through the context of organ transplantation. As well as interviewing practitioners, patients, and patients' family members, she spent time around the hospital observing interactions. She reflects on what she was told in interviews in relation to her own observations around the hospital, highlighting how the latter aided in her understanding of the former.

Moazam does characterise her approach as ethnography. As such, her time spent observing activity in the hospital was formal data generation with appropriate ethical approvals to then publish detailed descriptions. However, it still serves to highlight how ethno-immersion may add significant value to a bioethics project; it almost acts as a "showing your workings" to this effect. Undergoing a similar process to that of Moazam, just not formally using it as data

<sup>29</sup>An ethno-immersive approach at the outset of a qualitative research project may still require a form of research ethics committee review depending on local requirements. However, in most cases, it would be sufficient to take verbal consent from those present when observing, much like when prospective medical students shadow healthcare professionals.

<sup>30</sup>Of course, a researcher taking this ethno-immersive approach may choose to take notes for their own benefit, but they are unlikely to be as detailed as those of the researcher conducting an ethnography.

<sup>31</sup>Fox, R. (2004). Observations and reflections of a perpetual fieldworker. *The ANNALS of the American Academy of Political and Social Science*, 595(1), 309–326, p. 314.

<sup>32</sup>Wasserman, J., Flannery, M. A., & Clair J. M. (2007). Raising the ivory tower: The production of knowledge and distrust of medicine among African Americans. *Journal of Medical Ethics*, 33(3), 177–180.

<sup>33</sup>The Lancet Global Health. (2018). Closing the door on parachutes and parasites. *The Lancet Global Health*, 6(6), e593.

<sup>34</sup>Moazam, op. cit. note 28.



generation for publication, may provide those insights that, in effect, fill the gaps between qualitative data generated through interviews and focus groups.

To some extent, ethno-immersion may be considered as contributing to triangulation. Triangulation in the context of qualitative research is 'the observation of the research issue from (at least) two different points'.<sup>35</sup> Much like triangulation can help to pinpoint a geographical point by reference to its distance from several others, in qualitative research, it can be used to reach a conclusion by reference to its alignment with several data points (those data points being results from different research methods). It is about validating findings through a safety in numbers approach; if several methods lead you to the same conclusion, it is more likely to be accurate than if you rely on just one method.

Whether ethno-immersion could be considered one of the methods in triangulation may be a point of contention amongst some methodologists as it is, quite explicitly, *not* a formal data generation exercise—ethnography, on the other hand, would clearly be accepted for triangulation purposes. Nonetheless, the underlying intention of triangulation can be considered met using our proposed ethno-immersion, as it acts as a check on any data generation method (s) used.

These benefits stand regardless of who the researcher is. Whilst the benefits may be quite clear for someone from a non-clinical background with, at best, limited experience of what the context being explored is actually like, for the clinician researcher, it affords an opportunity to stand back and look on scenarios that may feel very familiar with fresh eyes and from a different perspective. Indeed, the clinician researcher may well come to a project with more preconceived notions of how things are and should be done, so this opportunity to look on without the demands of seeing patients may prove especially useful.

From a reflexivity perspective, the (pertinent) professional conducting bioethics research might be thought of as providing an insider account of the context. The researcher approaching a bioethics project from an alternative background—such as philosophy, law, or social science—and engaging in ethno-immersion will likely only ever be able to provide an outsider account. Both are of equal value, but in pursuing ethno-immersion, it is important that this is highlighted and reflected upon in any publication.

There is, of course, a risk that the researcher may become *too* close to the data and participants, and this may introduce more bias; the researcher may become inclined to side with, or advocate for, the groups of people with whom they have spent so much time. However, by using existing tools, such as reflexive journals, researchers should be able to reflect on how their own attitudes and views have changed as a result of ethno-immersion and discuss this in reporting.

Conversely, researchers may believe they have a deeper understanding of the context as a result of ethno-immersion than is realistically attainable. This is particularly relevant if, for example, their understanding of the context has influenced their own moral judgements. Where empirical bioethics bridging methodologies, such as 'wide reflective equilibrium',<sup>36</sup> rely on researchers moving (*inter alia*) between qualitative findings (i.e., the views of participants) and the researcher's moral intuition, researchers must be careful not to confer additional weight to their individual moral judgements simply because they have been informed by ethno-immersion. Indeed, the overall benefits of ethno-immersion rely on the individual researcher being genuine in their engagement and allowing this to be reflected in their work. It cannot—nor do we suggest it is desirable to—overcome the inherent subjectivity of both normative and qualitative research. It is similarly important that the individual researcher stays within the boundaries of ethno-immersion, without crossing over into formal ethnography. Not least because the latter would require research ethics approvals. Nonetheless, it is a limitation of our suggested approach that a researcher may find themselves placing too much confidence in the accuracy of their understanding of the pertinent context developed through ethno-immersion.

### 3.2 | When to employ ethno-immersion

In terms of when one should be employing ethno-immersion within a body of research, we suggest the ideal answer is always. Our proposed approach is not intended as a one-off tick-box exercise, but a sustained exposure to the context in question. As such, there is no limit on how much time ought to be spent engaging in this process. This will, in reality, be guided heavily by practical constraints, such as availability of time and resources. Nonetheless, the focus should be on maximising the time spent in the context throughout the entirety of a project.

The benefits of ethno-immersion can be variable at different points in a project. Incorporating it as early as possible, it may become a central factor in framing the research question. Even with a rough idea of what you want to explore, engaging with the context can prove useful in nailing down a more precise research question. Time spent in a clinical setting new to the researcher may even result in them identifying an area in need of investigation that they had not previously considered, resulting in a drastic change to the originally anticipated research question. Later in the planning stages, if there is uncertainty over the best data generation method, a deeper understanding of the relationships between participants, and of logistical factors, may help guide decision making over the suitability of interviews versus focus groups, for example. Then, when setting up study sites for data generation, ethno-immersion may better ensure that the project as a whole is working towards ensuring practicable recommendations. To some extent, it reflects the role of a PPI group

<sup>35</sup>Flick, U. (2004). Triangulation in qualitative research. In U. Flick, E. von Kardorff, & I. Steinke (Eds.), *A companion to qualitative research* (pp. 178–183). SAGE. Though this may require you to disregard your concept of a triangle as having *three* rather than *two* sides/angles.

<sup>36</sup>Rawls, J. (1974–1975). The independence of moral theory. *Proceedings and Addresses of the American Philosophical Association*, 48, 5–22.

that may be established when planning a study. Nonetheless, it goes beyond the role of a PPI group and, as such, the use of a PPI group should not be viewed as a replacement for ethno-immersion—the two may, however, be used in the same project to really bolster any recommendations.

Where the project employs empirical methods, ethno-immersion may be especially useful during the data generation period. It is good practice to reflect after each instance of data generation—that is, after each interview or focus group—on the topics discussed and how they feed into the researcher's growing picture of the research area. This enables the researcher to adapt their approach as they continue with data generation if appropriate—such as amending a topic guide—perhaps recognising that certain points should be explored with participants that were not previously. Ethno-immersion enhances this by providing regular reflection on the researcher's first-hand experience observing the context, building a more in-depth picture. Indeed, the two could feed into one another. For example, an interview participant may mention something that the researcher then begins to notice when observing a ward round, something that had previously been taking place, but the researcher had not noticed until their attention was drawn to it. Again, the focus here is ultimately to see the researcher develop as realistic as possible a view of what things are like in the context being researched.

Finally, in the analysis and write-up stages of a project, continuing with ethno-immersion may again prove useful. It is at this point that the researcher is working towards conclusions and recommendations, understanding and making use of the information already gathered—whether formally through a particular research method or informally through ethno-immersion. As such, continuing to expose oneself to the context can guard against the researcher pursuing a line of reasoning that is unrealistic. It can be all too easy when sat at a desk most of the day writing to get somewhat carried away in this regard, so the continued ethno-immersion can help keep the researcher focused on practicability and perhaps further inform analysis.

It is worth noting some parallels here between our proposal and that of so-called embedded ethics. Embedded ethics is an idea that is currently gaining traction within the field of bioethics amongst those concerned with emerging technologies and engineering. McLennan and colleagues, for example, have recently proposed a framework for such an integration of ethical analysis into the development of artificial intelligence for healthcare.<sup>37</sup> Through embedded ethics, 'ethical considerations are integrated into development processes from the beginning, in order to anticipate, identify, and work to address any ethically significant issues that may arise at all phases of development',<sup>38</sup> ideally by way of an ethicist being part of the research team. Rather than an ethicist being consulted by a research team developing a new technology once or twice throughout a project—perhaps as nothing more than lip service—embedded ethics

sees that ethicist as integral to the project and there at all stages. By being present, the ethicist is then better able to identify ethical concerns in what is being developed and, from a largely pragmatic point of view, point them out earlier rather than later so that they might be addressed adequately.

Much like our proposal of ethno-immersion, embedded ethics recognises that it is through sustained engagement with a context that a researcher can build a better picture of that context and, as a result, provide better ethical input. Only whilst we are concerned with healthcare practice, embedded ethics is focussed on research and development.

## 4 | ON NON-EMPIRICAL BIOETHICS

Our focus thus far has been primarily on empirical bioethics. This is due to our underlying concern being one that empirical bioethics purports to overcome. However, it must be recognised that not all researchers in bioethics conduct empirical work—and nor would we suggest they necessarily ought to. Here, then, we reflect on how our proposal can also benefit those conducting non-empirical bioethics research.

A linear, top-down, translational, bench to bedside approach is one methodology used in philosophical (or theoretical) bioethics. The method, as Arras puts it, is that 'theory justified principles, that principles justified moral rules, and that rules justified moral judgments in particular cases'.<sup>39</sup> This method looks to moral theory to provide a fundamental justification for a course of action and applies this deductively to the case at hand. One need not always begin with what Arras called 'high theory' (such as consequentialism or deontology) however; mid-level principles, like those proposed by Beauchamp and Childress, can also form a starting point.<sup>40</sup> Wilson also considers how this linear model is supposed to follow science in attempting to bridge the gap between theory and practice.<sup>41</sup> He maps this onto a five-stage model based on translational scientific research to explain how philosophers move from different levels of abstraction. The model is as follows:

- 1) discussion of (pure) normative theory in the abstract (basic science);
- 2) working out what ought to be done in thought experiments (proof of concept);
- 3) working out what ought to be done in simplified but somewhat realistic cases (proof of efficacy);
- 4) working out what we should do, all things considered, in real-world situations (proof of effectiveness); and
- 5) policy changes (implementation).<sup>42</sup>

<sup>39</sup>Arras, J. (2017). *Methods in bioethics: The way we reason now* (p. 11). Oxford University Press.

<sup>40</sup>Beauchamp, T. L., & Childress, J. F. (2019). *Principles of biomedical ethics*. Oxford University Press.

<sup>41</sup>Wilson, J. (2021). *Philosophy for public health and public policy: Beyond the neglectful state*. Oxford University Press.

<sup>42</sup>Ibid: 45.

<sup>37</sup>McLennan, S., Fiske, A., Tigard, D., Müller, R., Haddadin, S., & Buyx, A. (2022). Embedded ethics: A proposal for integrating ethics into the development of medical AI. *BMC Medical Ethics*, 23, 6.

<sup>38</sup>Ibid: 3.

Wilson points out that, just as in science there is a distinction between internal and external validity, a similar problem could arise in relation to the linear model. Internal validity describes the quality of study design. In a randomised controlled trial, this might include factors such as: was it properly randomised; has the study been blinded; is there an appropriate control group; have important variables and confounding factors been measured and accounted for; are the end points appropriately measured; is there a suitable sample size; and so forth. This ensures a study is rigorous. Philosophers attempt to secure internal validity by clarifying concepts, defining terms, drawing distinctions, and considering counterexamples. External validity, on the other hand, is the degree to which the findings might generalise to other situations. There are problems with internal validity in philosophical bioethics, like disagreement over which fundamental moral theories are correct.<sup>43</sup> We will set this aside, however, and instead focus on the relationship between internal and external validity. The problem, as Wilson sees it, is that just as internal validity is no guarantee of external validity in science, the same is true of practical ethics. He raises two problems in support of this claim: 'normative contextual variance' and 'non-transferability of causal structures'.<sup>44</sup>

Normative contextual variance, according to Kamm, is the idea that a moral property can behave differently in different contexts.<sup>45</sup> This challenges the idea that we can infer external validity from internal validity. Non-transferability of causal structures is where, in moving through levels of abstraction, certain background assumptions fail to hold in the real world. In light of these problems, Wilson seems to advocate dispensing with the linear model and argues for a paradigm shift to other methods of applied moral theorising.<sup>46</sup> Whilst there is much to be said in favour of this, science has not dispensed with the randomised controlled trial because of problems with internal/external validity. Rather, evidence-based medicine has chosen to rethink the hierarchy of evidence, instead relying on contextually appropriate evidence.<sup>47</sup> Perhaps the linear model has its place amongst a plurality of methods in bioethics depending on what question is under consideration. This, however, will be of little comfort to those committed to the linear model.

Both normative contextual variance and non-transferability of causal structures suggest that real-world context matters. One simple solution to the internal/external validity gap is to improve one's understanding of the context and avoid recommendations being only internally valid by engaging with those with greater experience of the context. An appreciation of how a moral property might behave differently in various contexts requires one to understand *both* the moral property *and* the context. Minimising the risk that the

assumptions made in one's arguments do not transfer to the real world can be achieved by engaging with the real world perhaps through ethno-immersion.

Consider the following example. The distribution of ventilators was a critical question early in the COVID-19 pandemic. The concern was that supply would outstrip demand and critically unwell COVID-19 patients who might benefit from ventilation would not have access. Bioethicists discussed this extensively applying various theories of distributive justice and models of triage to ensure fairness. This may also have influenced how bodies like the British Medical Association and Royal Colleges, as well as local clinical ethics committees, developed their own policies out of the aforementioned trust in bioethical expertise. Regardless of what we make of the internal validity of this body of work, much of it made a fundamental error that severely limits its external validity. Many of these pieces are premised on the idea that allocating ventilators is like allocating organs: one available ventilator and a population of individuals who all stand to benefit.<sup>48</sup> The problem is that when it comes to critically unwell patients needing a ventilator, there is rarely a pool like this. These decisions are high stakes and time pressured, and so cannot wait for such a population to develop. Despite the pressure of COVID-19, the need for a ventilator arises sequentially rather than simultaneously. Even in an unusual case where there is simultaneous need for ventilation, there remains a possibility that another higher priority patient could arrive later. Sequential need is an inescapable fact of ventilator allocation and yet it is often overlooked by many well-intentioned bioethicists seeking to inform policy on fair ventilator allocation.

This example helps demonstrate the problems of normative contextual variance and non-transferability of causal structures. Truog describes how following a protocol for ventilator allocation based on an assumption of pooled patients could be particularly distressing for clinicians.<sup>49</sup> Knowing that a higher priority patient might arrive subsequently means that clinicians either hold a ventilator in reserve, denying it to a patient who is at imminent risk of death, or ventilate the patient in front of them and risk denying a higher priority patient who may arrive in the coming hours or days. The protocol operates differently in a real-world context, highlighting normative contextual variance, but, furthermore, can create a new dilemma for clinicians. This arises because of the non-transferability of causal structures. The background assumptions in ventilator rationing do not match those of reality. When working from theory down to practical recommendations for the real world, the picture of the real world being worked from is inaccurate. This is a particularly stark example, but it is easy to see how inaccuracies large and small can become baked into the model that one is working with. This also highlights one way these two factors can interact and compound one another; non-transferability of causal structures paves the way for normative contextual variance. Yet, these could have been corrected for by discussing the processes through which ventilator decisions are made in practice, minimising and perhaps even correcting for these. It is not enough to strive for internal validity;

<sup>43</sup>Bourget, D., & Chalmers, D. (2014). What do philosophers believe? *Philosophical Studies*, 170(3), 465–500.

<sup>44</sup>Wilson, op. cit. note 41, pp. 57–60.

<sup>45</sup>Kamm, F.M. (2007). *Intricate ethics: Rights, responsibilities, and permissible harm*. Oxford University Press.

<sup>46</sup>Wilson, op. cit. note 41.

<sup>47</sup>Parkhurst, J. O., & Abeyasinghe, S. (2016). What constitutes 'good' evidence for public health and social policy-making? From hierarchies to appropriateness. *Social Epistemology*, 30(5–6), 665–679.

<sup>48</sup>Truog, R. D. (2021). Ventilator allocation protocols: Sophisticated bioethics for an unworkable strategy. *Hastings Center Report*, 51(5), 56–57.

<sup>49</sup>Ibid.



in adopting a linear model, an eye to external validity at the very least requires superficial engagement with the reality of practice.

As a final note, we reflect on an area of philosophical bioethics that might initially appear to have no capacity for external validity: speculative bioethics (ethical analysis of future technologies). Whilst there is a predominant focus in bioethics on contemporary problems, bioethics also 'understands itself to play a role in mediating between society and technoscience, in part by examining the implications of emerging and future biotechnologies'.<sup>50</sup> Thus, space is consistently made in leading journals for scholarship reflecting on technologies that are not yet with us (including some that may never be): artificial placentas,<sup>51</sup> cryogenics,<sup>52</sup> and sentient artificial intelligence<sup>53</sup> for example. Whilst normative argumentation need not always translate directly into an immediate 'measurable real world outcome in order to be of some practical value'<sup>54</sup>—and this might be particularly true of speculative bioethics—it is our contention that speculative research could have greater potential for impact where it is appropriately grounded. Much like how context matters for understanding the research environment or participants (and thus the suggested ethno-immersion is important in empirical work), and external validity is best achieved where normative argumentation is grounded in practical realities, the same should be said for (imagined) future biotechnologies.

Some factual realities still matter. Where novel technologies are in development, understanding the basic scientific concepts and approaches that lay the foundation of the novel technology is crucial. This can be the case even if the design is not final—the basic concepts and objectives in function are still important to understand. This is not simply a matter of providing background or enriching discussion, but is a prerequisite.<sup>55</sup> In the empirical bioethics literature, careful attention is paid to ensuring scholarship does not fall foul of the 'is/ought problem',<sup>56</sup> with researchers explaining how their methodologies plan to get around assuming what should be on the basis of what is. In speculative bioethics, we suggest, researchers should be concerned about the inverse issue. Researchers should be careful not to discuss what ought to be, without any understanding of what is or could be. Holm explains that relevant biological knowledge becomes 'straightforward empirical premises when a particular ethical argument needs an empirical premise of a particular kind'.<sup>57</sup>

Thus, which empirical facts are taken as a given will, in speculative scenarios as much as in contemporary ones (see the ventilator example above), influence what ethical issues are identified as pertinent, or more immediate, for examination. Researchers should think about which scientific facts they take to be material in this exercise, and they should be as open about the *subjective* nature of this stage of study design and be willing to learn from context—as those undertaking empirical methods must do as a matter of practice. In some instances, for example, this could involve ethno-immersion—though one imagines it is much harder to get access to an experimental laboratory than a hospital corridor.

## 5 | CONCLUSION

We are ultimately preoccupied with bioethics research speaking to the realities of the context it concerns. Whilst we recognise notable moves in this direction with the rise of empirical bioethics, we do consider that there is still room for improvement. Further, one need not be doing empirical work to achieve this practicability of recommendations. In the debate over translational bioethics, our suggestion is that we should instead think about ensuring our work is *translationable*—that it is *able* to be translated because it is rooted in an accurate understanding of the context.

Such translationability, we suggest, may be achieved through our proposed ethno-immersion. By positioning oneself in the context being researched, rather than relying solely on limited interactions and/or existing literature, the researcher can better understand what goes on. Something as simple as shadowing healthcare professionals for an extended period can strengthen understanding throughout a project, from conception to write-up. This applies to all bioethics research—not just that utilising empirical methods. The precise manner of ethno-immersion may vary depending on whether the research is empirical, normative, speculative, or a mixture, but the underlying concept is replicable across the board.

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<sup>50</sup>Schick, A. (2016). Whereto speculative bioethics? Technological visions and future simulations in a science fictional culture. *Medical Humanities*, 42(4), 225–231, 226.

<sup>51</sup>For example, Romanis, E. C. (2018). Artificial womb technology and the frontiers of human reproduction: conceptual differences and potential implications. *Journal of Medical Ethics*, 44(11), 751–755.

<sup>52</sup>For example, Moen, O. M. (2015). The case for cryonics. *Journal of Medical Ethics*, 41(8), 677–681.

<sup>53</sup>For example, Lawrence, D. R., Palacios-González, C., & Harris, J. (2016). Artificial intelligence: The Shylock syndrome. *Cambridge Quarterly of Healthcare Ethics*, 25(2), 250–261.

<sup>54</sup>Chan, S. (2015). A bioethics for all seasons. *Journal of Medical Ethics*, 41(1), 17–21, 18.

<sup>55</sup>Romanis, E. C. (2020). *Regulating the 'brave new world': Ethico-legal implications of the quest for partial ectogenesis* [PhD thesis, University of Manchester], p. 50.

<sup>56</sup>First articulated by David Hume: Hume, D. (1896). *A treatise of human nature* (Reprinted from the original edition in three volumes and edited, with an analytical index, by Selby-Bigge, L. A.). Clarendon Press (Original work published 1739).

<sup>57</sup>Holm, S. (2020). Bioethics and biological knowledge: A conflicted relationship. *Fra Forskningsfronten*, 62–65, 62.

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