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# **Reimagining institutional ethics procedures in research partnerships with young people across Majority / Minority World contexts**

Mary Ann Powell, Independent Researcher, mapowell903@gmail.com

Sukanya Krishnamurthy, School of GeoSciences, University of Edinburgh, UK,  
Sukanya.Krishnamurthy@ed.ac.uk

Loritta Chan, School of GeoSciences, University of Edinburgh, UK, Loritta.Chan@ed.ac.uk

Kay Tisdall, Childhood and Youth Studies, Moray House School of Education & Sport, University of Edinburgh, UK, K.Tisdall@ed.ac.uk

Irene Rizzini, International Center for Research and Policy on Childhood (CIESPI), Catholic University of Rio de Janeiro (PUC-Rio), Brazil, irizzini.pucio.ciespi@gmail.com

Roshni K. Nugehalli, Youth for Unity and Voluntary Action, India, roshni.n@yuvaindia.org

**Contact:** Sukanya Krishnamurthy, School of GeoSciences, University of Edinburgh, UK,  
Sukanya.Krishnamurthy@ed.ac.uk

## **Abstract**

While institutional ethical procedures are critically important, the relevance and applicability of these procedures on the ground create tensions that are sometimes at odds with what is considered 'ethical'. In this paper, we reflect on the dissonances between formal institutional ethics procedures and community-based research practices by drawing on our experiences of a project involving co-production with young people in India and Brazil. The project is an international collaboration between partners from both Majority and Minority World contexts, across universities, community organisations and government bodies. Young people were involved in advisory and co-researcher capacities, and played a vital role advising the project team, conducting research projects, and developing engagement and advocacy strategies. The project was planned prior to, but started during, the Covid-19 pandemic, and therefore required methodological adjustments.

In this paper, we situate the role of institutional ethics procedures to reflect on the tensions and power imbalances in: (1) research co-production with young people, (2) collaborative cross-country research with partners, as well as considering (3) the relevance of ethical guidelines in different research contexts. We problematise the top-down nature of these procedures, and highlight the importance of reflexivity, conversations, and relationships in ethics. With growing research in the Majority world (funded by the Minority world), there is an urgent need to recognise and build on the expertise of experienced local civic society organisations in ethical research and safeguarding, to work in genuine, respectful partnership with those we do research with.

**Key Words:** institutional ethics, young people, Majority / Minority World, research co-production

## **Introduction**

In research, great importance is placed on ethics and ensuring that research projects meet ethical standards. Ethical guidelines evolved historically in response to research that posed significant risk to participants, with processes developed by institutions in efforts to ensure that research participants are protected, and researchers and institutions are operating within accepted ethical parameters (Israel, 2015). However, meeting institutional requirements does not necessarily ensure ethical research. Challenges and dilemmas can arise regardless of the precautions taken and protocols followed in planning a research project (Graham et al. 2013). Researchers often find themselves making ethical judgement calls based on their ‘on the ground’ experiences and interpretation of institutional guidelines (Powell, Graham and Truscott 2016). This can be extremely challenging, as researchers encounter and attempt to balance the dissonance experienced when institutional requirements are at odds with cultural understandings, disciplinary knowledge and best practice, or an individual’s own beliefs; in short, at odds with what they consider ethical practice. This paper draws on our experiences from the project Shaping Youth Futures, focused on youth livelihoods in India and Brazil, and led by an UK institution, to explore some of the dissonance encountered between working in the field and satisfying requirements of ethics review committees.

The research project is an international collaboration between partners from different contexts, across Minority/Majority worlds,<sup>1</sup> and academic/community-based organisations, co-producing research with young people. We explore multiple sites, spaces and contexts in which ethical considerations and challenges were experienced and negotiated. These include tensions that arose at the intersections between the UK institutional ethical requirements and co-production with young people in India and Brazil. In doing so, we respond to the call made by

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<sup>1</sup> Majority and Minority World is an alternative terminology for Global South/Third World/Developing world and Global North/First World/Developed world respectively (Punch, 2016).

Cutting and Peacock (2021) in this journal special issue for researchers to speak openly about ethical slippages in research and identify the inadequacies of our current procedural ethics systems. Alongside this, we question and challenge the presumptions inherent in institutionalised ethics and reflect on how genuine partnership between institution-based researchers and local communities can best be supported. In doing so we can work towards a transformation that prioritises ethics in practice, rather than bureaucratic requirements.

### **Decolonising procedural ethics**

Comprehensive regulations exist, intended to ensure that research practices are ethical and that risks and threats to all parties involved are minimised. These regulations encourage reflection from researchers about the methods and impacts of their research, thereby supporting good research practices and strengthening the calibre of research as well (Brown, Spino and Quinton 2020). However, a growing body of literature discusses the challenges and frustrations experienced by social researchers as they navigate what are sometimes referred to as ‘procedural ethics’; the processes established by institutions regarding the ethical dimensions of research, which usually involve gaining approval from an ethics committee (Guillemin and Gillam 2004). These processes, requiring compliance, are distinguished by Guillemin and Gillam from ‘ethics in practice’, which they describe as “the everyday ethical issues that arise in the doing of research” (2004, 263). Despite a shared aim of ensuring that research practice is ethical, tensions and divisions between researchers and regulators, such as research ethics committees, have been well documented, including research involving children and young people (Daley 2012; Powell et al. 2020; Tilley and Taylor 2018) and cross-country research, including that undertaken in Majority World countries by Minority World researchers (Abebe and Bessell 2014; Asselin and Doiron 2016).

The governance of social science research ethics has been shaped by the bioethical approach, which developed largely as a reactive response to questionable biomedical experiments and research misconduct involving human subjects (Israel 2015).<sup>2</sup> Debates have raged, within bioethics, about the application of ‘universal’ principles and dominant socio-cultural-moral constructs from ‘Western’ countries, that do not encompass the local belief-systems, cultural norms and moral values and tradition to guide decision making in other countries (Chattopadhyay and De Vries 2013). Ethical research guidelines in Brazil and India (where the Shaping Youth Futures project is situated) were developed by the national health authorities and relied heavily on the bioethical approach taken in Minority world countries.<sup>3</sup> While the ethical regulations in both countries have been subject to review and revision over the years, the bioethical approach continues to permeate ethical regulatory processes in institutionalised ethics (Israel 2015). Scholars in both countries question the adequacy of this for social research projects (de Albuquerque Rocha and Vasconcelos 2019; Nderitu and Kamaara 2018).

Scholars taking a decolonising approach emphasise the importance of respect, a term “consistently used by Indigenous peoples to underscore the importance of *[our]* relationships and humanity” (Smith 2021, 137), dialogue and critical reflection in cross-cultural research, in order to ensure that the research is ethically and culturally appropriate (Israel 2015; Keikelame

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<sup>2</sup> For example, the Nuremberg Code (1947), the Declaration of Helsinki (1964), Belmont Report (1979)

<sup>3</sup> The National Health Council in Brazil adopted Guidelines and Norms Regulating Research involving Human Subjects (Conselho Nacional de Saude, 1996, Resolution, 196/96). Subsequent adoption of Resolution 466/12 (2012) and Resolution 510 (2016) are more accommodating of qualitative and social research, however the default position and universal ethical approach in Brazil privileges positivist and medical research as outlined in Resolution 196/96 (Israel, 2015). The Indian Council of Medical Research (ICMR) published a policy statement on ethical considerations in 1980, followed by establishment of Ethical Guidelines for Biomedical Research on Human Subjects in 2000, subsequently revised in 2006, all focused largely on clinical trials. The most recent iteration includes the National Ethical Guidelines for Biomedical and Health Research Involving Human Participants (2017), however Nderitu and Kamaara (2018) note the seeming ignorance in the guidelines of what social and behavioural sciences constitute, and the lack of recognition of the breadth of social and psychological risks.

and Swartz 2019). While bioethics scholars have recently argued to reject simplistic notions of a Minority/Majority World, East/West dichotomy (Bhakuni 2022; Nie and Fitzgerald 2021), it is clear that ethical guidelines, based largely on bioethics and developed in Minority World contexts, produce particular spaces and outcomes, which may not be translatable and applicable in other sociocultural contexts (Abebe and Bessell 2014). We wish to emphasise that this paper is not a critique of existing institutionalised ethics procedures, as they have the capacity to offer constructive professional dialogue. Rather, it seeks to problematise the privileging of certain research paradigms, particularly westernised/ bioethical paradigms, and question taken for granted assumptions that these are the highest standard regardless of context. As Asselin and Doiron (2016) point out, ignorance of local values, principles and practices, can lead to skewed, biased judgments on practices of research ethics. Research ethics therefore needs to be reframed in a way that can foster active institutional commitments to shift resources and research practices to forms of knowledge that are anti-colonial (Sabati 2018).

### **Ethics procedures in research with young people**

There are numerous reported challenges that researchers encounter when gaining approval from research ethics committees for research involving children and young people (Daley 2012; Powell et al. 2020; Tilley and Taylor 2018). A literature analysis looking at institutional review processes for research involving youth, identified various issues: “incompatibilities with qualitative, interpretivist research and judged inappropriately; committee members assess research proposed from limited methodological perspectives; inaccurate judgement of degree of risk; stereotypical notions of vulnerability” (Tilley and Taylor 2018, 2192).

Operating within a risk-averse societal context, with increased surveillance and regulation of research ethics, Minority World ethics committees have tended to adopt a protectionist position which seeks to not only minimise risks to young participants but also to avoid any risks the

research might pose to the institutions involved (Graham and Fitzgerald 2010). Ethics committees often view young participants “as ‘incapable of protecting their own interests’, and classify children and young people to be homogenously ‘vulnerable’” (Cutting and Peacock 2021, 2). An overly risk-averse stance of research ethics committees can be seen in their having greater concern about perceived risks than the stakeholders who are directly engaged with the potential research participants do, such as teachers and practitioners, or the young people themselves (Allen 2009; Ruiz-Casares and Thompson 2016; Skelton 2008). The rigid attitudes of some research ethics committees can conflict with what researchers and young people themselves consider safe and ethical (Robson 2018). Furthermore, the exertion of power and formalisation of processes from ethics committees can also be felt as a lack of trust in the researchers’ capabilities to conduct research in an ethically responsible manner (Parsons et al. 2015). The requirement to satisfy stringent ethical regulations can impinge on academic freedom and exclude populations who would have benefited from participation in the research (Skelton 2008; Juritzen, Grimen and Heggen 2011; Powell, Graham and Truscott 2016).

Meeting the requirements of ethics committees can also involve considerable bureaucracy. Researchers recount multiple, complex, time-consuming rounds of application and amendments in institutional ethics review processes (Allen 2009; Collins et al. 2020). This can be significantly extended if more than one institution is involved (see work of Collins et al. 2020). These kinds of bureaucratic delays not only involve extensive paperwork, but also place additional burdens on stakeholders who facilitate participant recruitment causing significant delays in the involvement of young people in a project. The process can also be extended when research ethics committees grapple with methodologies that are not familiar to them. Allen’s (2009) study, for example, involved the use of visual methods and photo-diaries which were intended as a fun, youth-centred way of engagement, but led to a laborious, tedious process of paperwork, guidelines and consent. From this perspective, participatory research

methodologies that seek to prioritise the agency and competency of young people can be undermined.

What we ask here is how can we encourage ethics committees to identify, engage with, and challenge some of the assumptions and knowledge hierarchies that they are working with and within? In the subsequent sections, we turn more towards a discussion on reflexivity and ethical practices in research.

### **Ethics in research practice with young people**

As institutional ethics processes have become increasingly bureaucratised and formal (Parsons, Abbot, McKnight and Davies, 2015), researchers report experiences of dissonance between procedural compliance and ‘ethics in practice’ (Powell, Graham and Truscott 2016; Brown, Spino and Quinton 2020; King 2021). Cutting and Peacock (2021) argue that by focusing on specific, limited ethical aspects of research, “institutional ethics systems invariably contribute to the proliferation of slippages – between ‘what is’, ‘what should be’ and ‘what our organisational guidelines instruct us to do’.” (4).

Tensions between protection and participation of children and young people involved in research have been well documented (see for example, Collins, Rizzini and Mayhew 2021; Graham et al. 2013; Spencer, Boddy and Rees 2015). Despite the persistence of risk averse discourses, the focus for researchers engaging with children and young people over recent years has increasingly shifted from a protectionist discourse, to one that recognises children and young people’s right to participate, agency and voice, in being best placed to inform research about their own experiences and views (Kennan and Dolan 2017; Tisdall, Davis and Gallagher 2009). While the United Nations Convention on the Rights of the Child does not specifically address research with children and young people, researchers argue that a combination of four

articles underlie children's right to be properly researched,<sup>4</sup> as participants in research, with 'child-friendly' methods, and protected from harm, in research conducted by researchers who use quality, scientific methods and analysis (Beazley et al. 2009). The ethical lens has expanded beyond merely safeguarding, to a rights-based approach that involves a more comprehensive understanding of young people, acknowledgment of the sociocultural context and relations which they are positioned in, and respect for how this shapes their experiences, capabilities and perspectives. This shift considers relations and contexts, and provides greater relevance for ethics processes to be made reflexive, fluid and dynamic (Sherwood and Parsons 2021).

Importantly, there is an increasing need to move away from envisioning ethics as a one-off procedure, and instead, to conceptualise it as a negotiation of spaces and roles between all actors in the research project - from researchers and participants, to gatekeepers, ethics review committees and so on (Abebe 2009; Skovdal and Abebe 2012). Ethics is an ongoing process involving conversations about tensions, disagreements, power imbalances and ambivalences, respecting and acknowledging different experiences (Ebrahim 2010; Asselin and Doiron 2016; Sherwood and Parsons 2021) as well as working to develop trust between researchers and all stakeholders who are involved, including children and young people (Powell et al. 2020). Each encounter with the same group of participants and actors may differ each time, depending on the changes of needs, moods and expectations (Kaukko, Dunwoodie and Riggs 2017). Through her research experience, Morrow (2008) notes that even if a research project is designed to be participatory, ethical dilemmas will arise that may counter "common" practices of ethics, or what was envisioned at the beginning of the project. For example, according to ethics guidelines, pseudonyms should be used for names of individuals and places for anonymity and confidentiality purposes. However, some children wished to be recognised for their work, and

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<sup>4</sup> Articles 12.1 (freedom of opinion), 13.1 (freedom of expression), 36 (protection from harm and exploitation) and 3.3 (standards of care).

some used their own nicknames as a pseudonym, which presents a grey area. Reflecting on this, Morrow (2008) highlights the importance of seeing ethics as “situational and responsive” (56) to the context and diversity of individuals, rather than a generalised application and list of codified practices.

Researchers have considered the adult-centred construction of ethical practice and unequal distribution of power between adults and young people in research (Skelton 2008), with young people’s advisory groups increasingly involved in specific research projects (Collins et al. 2020). While there is a dearth of research that considers children and young people’s involvement in procedural ethics or views of ethical considerations in research (Spencer 2022), some recent publications have provided accounts of children and young people reflecting on ethics in research (Moore, et al. 2020; Spencer, Boddy and Lees 2015). These accounts point to the importance of developing approaches that are shaped by the perspectives of and engagement with young people. Young people involved in research have also been critical of the institutional ethical requirements, for example, in relation to procedures around informed consent (Collins et al. 2020).

As we re-evaluate the purposes and processes of institutional ethics procedures, this leads us to question - how can the experiences of all stakeholders be productively included and respected in a conversation about ethical research practice?

### **Reflexivity in ethical cross-country research with young people**

Reflexivity has become increasingly important as a means of addressing ethical challenges and dilemmas in research with children and young people (Davidson and McMellon 2022; Powell, Graham and Truscott 2016). Reflexivity in research has been described as “the capacity of researchers to reflect critically about the impact of their research on participants and their communities, on researchers themselves, and on the body of knowledge under investigation”

(Graham et al. 2013, 176). Based on the foundation of respect, reflexivity involves understanding identities and the network of relationships which young people are situated in, how moral and ethical spaces are (re)produced, and also continually reflecting on the multiple relationships which exist throughout the course of the research. Davidson and McMellon (2022) warn that reflexivity too can assume a ‘tick-box mentality’, with reflexive accounts treated as an ‘add on’, rather than integral to the research process, and being somewhat ‘sanitised’ in the requirements for a ‘clean’ narrative. They observe that reflexivity is “too often concerned with the position and positionality of the researchers within the research setting... with less attention... given in reflexive research accounts of the relationships and relationalities created, navigated and sustained” (110).

This relational and situational approach to ethics extends toward studies in international contexts, highlighting considerations in research across Majority and Minority world countries. Ethics committees can be situated far away from the field and it is problematic for children and young people involved in participatory research in the Majority World, to adhere to Minority World practices (Abebe 2009). Reflecting on his fieldwork with young children in Ethiopia, Abebe (2009) shares there should be a “moral consideration grounded in respect for local, gendered and socio-spatial constructions of childhood, as well as the need to go beyond acknowledging such complexities to ask how moral and ethical spaces are (re-)produced and who they actually serve” (493). Returning to the principles of respect, justice and benefit, King (2021) suggests building on the principles of care that respects and acknowledges identities, relationships and experiences. Particularly in research involving different age groups and different sociocultural contexts, it is crucial to acknowledge the situatedness and particularities of ethics to address power disparities. This argument is especially relevant as we navigate a (post) Covid-19 world, which has led to new online research methodologies, practices, and safety protocols. Firstly, how can one negotiate and respect different understandings of ‘safety’

across cultures? Secondly how accessible and equitable are online methods? Taking restrictions, lockdowns and health and safety risks into consideration, institutions have gravitated towards online digital methodologies for their convenience and the low risks to infection they provide. However, these methods presume ease of use and access to digital infrastructure for all and fail to recognise specific contexts where online methodologies can carry their own exclusions.

The literature discussed above highlights several ethical tensions evident in cross country research with children and young people, which typical institutional ethics procedures either fail to adequately address or in fact exacerbate. How do institutional requirements support or hinder ethical research co-production with young people? More importantly, what has been institutionalised in these processes? What are the tensions in different approaches to ensuring ethical research between institutional and community-based partners, and how are they addressed? What sort of exclusions manifest amidst these dissonances? More broadly, how can these dissonances inform better practices of respect in ethics? In the following sections, we draw from experiences in our project to examine these questions.

### **Situating our project and its ethical dilemmas**

This section discusses the authors' experiences in co-researching with young people in India and Brazil as part of the British Academy-funded project, "Shaping Youth Futures," which ran from 2020 to 2022 (YF190041). The research partners worked with young people in marginalised urban areas to co-produce knowledge and conduct research on emerging livelihood options in response to rising inequalities in cities. The Indian partner was a non-profit development organisation that focused on poverty alleviation, environmental sustainability, and urban planning, while the Brazilian partner was a university research centre with strong connections to youth collectives and children's rights organisations. Both

these partners were experienced in youth protagonism and supporting young people to engage in self-determined and sustained collective action to address their rights and issues which impact them.

Each of the partners involved in the Shaping Youth Futures project had ethical procedures to follow and requirements to meet. The UK and Brazilian partners submitted ethics applications to their respective ethics committees before recruitment and data collection. The UK partner submitted a two-stage ethics determination form, which involved an initial full application to allow recruitment of young people as co-researchers, followed by a subsequent amendment once the youth co-researchers had developed their research plans, including recruitment, consent, and data collection processes.

The Shaping Youth Futures project was conducted during the Covid-19 pandemic, and as a result, the ethics application and amendments were submitted during a period when protocols and restrictions were being developed and altered rapidly in response to the pandemic. The pandemic significantly affected the research process, necessitating ongoing adaptations and alternative methodologies. Therefore, the application and amendments included protective measures to ensure the safety of researchers and participants during the pandemic.

The initial (stage one) application to the UK university was submitted and approved in August 2020. This provided an overview of the entire project and details outlining the recruitment process for the Youth Expert Group (YEG)<sup>5</sup>. The recruitment process and planned engagement with the YEGs adhered to the institutional rules at the time, with online data collection

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<sup>5</sup> The Youth Expert Groups worked with adult researchers in each location, developing the project's local scope and focus, guiding and advising local youth-led research projects, facilitating trainings, establishing/connecting with community networks, documentation and disseminating findings, and participating in knowledge exchange events.

recommended, risk assessment to be carried out in each location, local guidance and restrictions regarding lockdowns and safety precautions to be followed. Following approval of the initial application, we recruited YEG members and set up the project in India and Brazil. The Brazilian partner, a university research centre, was also required to apply for ethics review to their local institution ethics committee. This included the submission of consent and information forms for participants.

An amendment (stage two) was submitted to the UK university in May 2021, outlining the research project developed by the young people in Brazil. This was approved following the submission of supplementary information, including evidence of approval from the Brazilian university, consent forms (in Portuguese), and clarification of data storage and collection platforms. The young people in Brazil conducted their trainings and data collection online, which was the institutionally recommended method for data collection during the pandemic.

A further amendment was submitted to the UK institution ethics committee in June 2021, outlining the research projects developed by the young people in India. Unlike the group in Brazil, young people in India decided to conduct their data collection in-person during the pandemic. Online methodologies were considered not feasible in the Mumbai location for various reasons, such as, lack of access to internet and digital infrastructure for both the young people and their research participants. At this point, the UK ethics committee requested that nine full applications be submitted; one for each of the young people's individual projects in India,<sup>6</sup> despite the approval of the overall project (stage one) and approval of Brazilian partner's amendment (stage two) without another full application being required. The Indian partner, a community based non-profit organisation, had ethics procedures internal to the organisation,

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<sup>6</sup> While the project in Brazil was carried out as a group of young people, in India the young people wanted to work individually in their communities.

that the adult and youth researchers were required to comply with. These procedures included recognition of and compliance with policies concerning safeguarding, child protection, sexual harassment, and obligations and responsibilities of researchers and young people working with the organisation. While these safeguarding mechanisms were acknowledged by the UK institution, the team in India were also compelled to comply with further UK institutional requirements.

Following email correspondence highlighting the terms of the initial application approval, the UK university ethics committee agreed to accept a single full application that incorporated details for all the young people's projects in India, rather than requiring nine separate applications. Multiple revisions of this application for research in India (stage two) were required, with at least five follow-ups to provide supplementary documents. These included details such as sampling, data storage, research training, and details of each individual project. It also included submission of forms concerning staff travel and off-campus risk assessment, even though no UK institution staff member was travelling or conducting research off-campus. Every step required multiple exchanges through email and phone with administrative staff in the UK institution, as well as ongoing correspondence addressing the issues under consideration with research partners in India. An online meeting was also held with committee and research team members in the UK and India. Over the course of this correspondence and review process, which took over two months with approval given in September 2021, the project itself was scrutinised again, as well as the evolving co-produced youth projects and amendments.

What should be stressed here is that this extensive process was not due to the obstructive objectives of the individuals implementing the institutional ethical procedures, who in fact were trying to ensure the research could ethically take place. However, it was clear from the outset that there were certain tensions between institutional ethics procedures and values of our

project. In such research, the design develops over time and brings together the expertise of different actors and stakeholders – young people, community practitioners, researchers, academic institutions and so on. The institutional ‘default position’ of gaining ethical approval, prior to engaging all the actors, creates a top-down rigidity, which fails to recognise and leverage the knowledge and experience of all who are involved. Rather, this process invests the lead institution with the power and creates a bias in which the institutional ethics procedures are positioned as the state of the art.

In the following sections, we highlight the presumptions of the institutional ethics procedures to shine a light on power imbalances and ethical challenges raised for our research project. Underpinned by epistemic privileging of Majority World, bioethical, elitist and adultist understandings of social relations, which appears to have been institutionalised in the ethics processes, the presumptions evident were that: it would solely be adult researchers in charge of the whole research process; it would be UK academic researchers who would be these adult researchers; and the context in which the research was taking place was similar to the UK. More broadly and in relation to the previous section, we explore how institutions can build productive partnerships in ethical practices with local community practitioners and gatekeepers, especially between Majority and Minority World contexts.

### **Situating ethics in research co-production with young people**

The usual institutional requirement for ethical approval before starting a project presents a challenge to co-production with young people, as it reinforces adult-centric research notions using non-youth friendly language and excludes young people from the initial development and design process. In the Shaping Youth Futures project, the initial conceptualisation was by adults, but they built on previous work with young people and sought to address issues raised by them. However, engagement with young people, even in an advisory capacity as YEG

members, could not take place until ethical approval had been obtained. This means that from the beginning, the adult researchers presented the project aims to the young people and sought their involvement.

Recognising the limitations of the institutional ethics approval process, the project was designed to provide young people with greater ownership of the research once ethical approval was obtained. The overall theme and broader research questions were formulated by adults, but the development of the project was dependent on young people engaging with and contributing to the process. Participants in India and Brazil were provided with research training to develop projects addressing key issues of interest to them, concerning livelihoods in urban areas.<sup>7</sup> The young people selected the focus, questions, and methods of data collection. After the training period, adult researchers took a more facilitator role, offering support, mentorship, and research training and tools to assist young people in their research projects. The young people took the lead in designing and conducting the research and developing a range of creative outputs. In subsequent knowledge exchange events, the young people expressed a sense of pride and ownership as they discussed bringing their research back to their local communities and government officials.

Several ethical issues surfaced despite making attempts to address issues of power. One example is the institutional requirement for anonymisation of young people in research outputs raised ethical issues and prompted further reflection on institutional bias. This can be understood in terms of the ethical principle of non-maleficence, ensuring that research participants are not harmed or compromised through the dissemination of findings (Graham et al., 2013). Omitting names and identifying information to maintain anonymity, for example, is

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<sup>7</sup> The grant supported training and capacity building activities in India and Brazil. The young people did not receive any cash remuneration for their participation but participated in training and various knowledge exchange activities (nationally and internationally).

posited to protect the privacy of young people and ensure that they will not suffer negative consequences from other community members or powerful groups. However, such 'protection' raises far deeper epistemological questions concerning how knowledge is generated and recognised. Anonymising the contribution of young people may reflect a positivist, structural assumption that knowledge is generated by the (adult) researcher negating the wisdom of the young co-researcher. The 'default position' of anonymisation may also reflect a deeper bias towards those who are being researched.

The issue of choice regarding anonymity can only be considered when the researcher is willing to engage with and question the notion that blanket anonymity is the ethical thing to do. To illustrate this point, by way of example, one young person's project focused on livelihood opportunities for transgender young people in Mumbai. The project involved video-recording interviews, with the youth researcher, Tanisha<sup>8</sup> providing assurances of confidentiality to participants, that the video would only be shown to members of the research team. One participant was initially hesitant to engage, however, as the relationship between Tanisha and the young interviewee developed, the participant became more passionate and willing to share their story. Eventually, they decided that they wanted the video to be put on YouTube so that "many more people" could hear their voice. While pointing to the participant's ownership of the knowledge that was being generated, this example also points to the role of the relationship in building trust and creating the safe space for the participant to feel comfortable sharing, initially with the researcher, then more widely. The regulatory processes intended to address concerns about non-maleficence through information and consent forms does not always suffice to build trust and provide reassurance. In practice, ethical moments are woven through the research, and trust is developed through interactions, conversations, and building

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<sup>8</sup> "Tanisha" is a pseudonym used for the young researcher to protect their identity.

relationships. In another example, adult facilitators observed how young people were attuned to the anxieties and concerns that participants had in taking part in the research projects. Aware of this, they used their own words to discuss confidentiality and anonymity of identity in conversation, matching the participants' comfort levels to reassure them and build trust.

In these ethical moments, it is important to recognise and respect how everyday ethics is embodied by young researchers, where they have their own ways of practicing ethics even before institutional frameworks were introduced to them. Firstly, such an emphasis on relationships can contribute to an ethics process which is more fluid, conversational and dynamic, rather than imposed and rigid. Secondly and returning to the point on anonymity, is it still ethical if participants wish for their name and voice to be recognised and heard, yet institutional regulations complicate the possibilities of this, to 'protect' young people?

What this section highlights is the importance of involving those directly affected by institutional ethics procedures, such as young people and local communities, in the negotiation of ethical understandings and processes. Although the young people in the project had a direct role in practicing ethics within their own research projects, they were not involved in the discussions and bureaucracies of the ethics review committees at their own organizations or with the lead partner institution. Rather, it was a decision from adult facilitators to take this on themselves to avoid overwhelming the young people, based on experience of how tedious it can be, and secondly, considering other commitments that the young people had outside of this project. Post the project what we are now reflecting on is the dissonances and experiences of ethics in the project and questions how best to involve young people in these conversations on institutional ethics procedures. Ultimately, it requires time, active listening, and conversation between the different actors to ensure that this point of action is truly meaningful.

## **Respecting the ethical knowledge and practices of community-based organisation partners**

Tensions were also apparent in the imposition of institutional ethics requirements from the lead UK institution on partners in other countries, without acknowledgement or recognition of ethics procedures or strategies already in existence in those contexts. The power was skewed in favour of the UK institution, where the Principal Investigator and two other Co-Investigators who had submitted the application to the British Academy were located, and where the funds were held for disbursement in the project. There was little understanding evident in the institution forms requiring completion and submission, of how ethics procedures could vary amongst partners. The burden of completing paperwork and meeting the lead institution's ethics requirements became increasingly onerous for partners, adding to project management complexities and causing delays.

Our position, shared by many other researchers, is that local community organisations and practitioners who work with young people very often have the best sense of on-the-ground realities and ethical considerations, such as what is safe or not. Unfortunately, institutional ethical procedures often do not recognize this. In this project, the community-based partner in India was required to provide detailed information to the UK institution ethics committee, without acknowledgement of their existing ethical policies. This culminated in an online video call where the Indian partner organization had to prove ethical accountability to an external institution, which created tensions and stress and that goes against notions of equal and fair partnership.

The discomfort was heightened by several additional factors. First, the project was already well underway at the time the additional information was required. The requirement for a full application to be submitted, rather than the amendment as anticipated, resulted in a longer than anticipated pause on starting the research activity. The time pressure was already keenly felt due to the limited research timelines and project limitations, and partners did not have enough time to spend with participants to develop trust and buy-in for the ethics procedures (alongside Covid-19 restrictions). This led to a continuing skewed dynamic where the institution from the Minority world had to seek more information from local partners.

Second, the requirements for additional information differed for the different partners. Submitting an amendment was relatively straightforward for our Brazilian partner, whereas a full application was required for our Indian partner. A contributing factor to this difference was the different methodologies, in that the Brazilian young people decided to proceed with one single research project using online interview methods, whereas the Indian young people developed individual projects using a range of in-person methods. Ethics approval had been gained from their own university at the outset of the project in Brazil. However, the projects in India were intentionally delayed until local restrictions were lifted and risk assessment determined that in-person methods were safe to use.

Another factor to consider in the different requirements of each partner by the UK institution was the type of organisations involved. The Brazilian partner was a university research centre which had gained approval from their university research ethics committee at the outset of the project. This may have provided something akin to a ‘sponsorship’ of trust (Cree, Kay and Tisdall 2002), whereby the Brazilian university ethics procedures were familiar to and aligned with those of the UK university, and trust in this process was passed on to the partner,

even without the provision of corroborating documents. In contrast, the ethics procedures of the Indian partner were unfamiliar and followed a format that did not involve gaining research ethics committee approval. However altogether, this raises some uncomfortable questions for researchers in Majority world academic institutions concerning the different approaches to ethical research and presumptions of the ‘best’ way to achieve this.

These experiences point to some of the inflexibilities of institutional ethics during times of crisis like the Covid-19 pandemic, and also when working with community-based organisations in different parts of the world. This cannot be simply reduced to a Minority / Majority World dichotomy. Instead, it points to a lack of acknowledgement of the rich complexities, understandings and practices of ethics in diverse settings. As such, how can we build an approach to ensuring ethical research, that retains integrity and is more inclusive, respectful and flexible than compliance oriented procedural ethics? Could a broad framework be developed, which can be (re)negotiated each time a new partnership emerges? As we move towards decolonising ethics practices and procedures, how can we facilitate conversations for ethics committees to recognise, engage with and challenge the knowledge hierarchies within which they work? In creating these genuine collaborations that embrace the experiences of different actors, more conversations are called for, rather than simply filling out paperwork, so that institutional ethics procedures can be made more encompassing, adaptable and fluid. Regardless, negotiating ethics procedures and new ways of working takes time and conversation in order to foster inclusive, respectful research partnerships across different contexts.

### **Navigating ethics procedures during the Covid-19 pandemic**

A key dissonance experienced in our project was associated with conducting research in a different context to that in which the UK lead institution was situated. There appears to be a presumption that the ethical requirements and recommended methods will be relevant across any context in which research is being conducted.

This was clearly challenged by the varying impact of the Covid-19 pandemic across the globe. The Shaping Youth Futures fieldwork took place within communities in which people's daily lives were stressed and fractured by the pandemic in multiple unforeseen ways. Families and communities experienced sickness and death, hunger and mental health issues, with restricted livelihoods and diminished access to dwindling resources. Time was consumed as communities and organisations within these adapted to the circumstances, with individuals, including young people, shouldering additional caretaking responsibilities and increased work commitments.

The lead institutional response to research during the pandemic focused largely on the ethical challenges of face-to-face engagement from a methodological perspective. Online digital methods were promoted to navigate health and safety concerns associated with in person meeting, as well as travel and lockdown restrictions. While such methods functionally helped with geographical distances in international teamwork, varying exclusions occurred with different locations and contexts. Online engagement was not easy for young people or research participants in localities and communities with limited access to the digital infrastructure or necessary bandwidth to support this (Kustatscher, 2020).

The adoption of online and hybrid (a mixture of online and in-person) methodologies creates different spaces, relations and challenges to those of in-person research. Advantages to online research participation were evident for the young people in Brazil, who appreciated the convenience of virtual communication and being able to attend from the comforts of their own home. Participation was facilitated by the lack of commuting, which saved time and enabled a

more flexible schedule for them. However, there were also challenges to online participation, such as the cost of mobile data, stable Wifi and good quality devices. Many of the young people in Brazil were joining meetings and conducting interviews using smartphones, and with a small screen, it was very difficult to focus for a very long time. Other commitments young people had, such as studying and/or working, had also shifted online, contributing to exhaustion and screen fatigue, which could impact on their participation. In response to this, the young people suggested meetings be shorter (from 2 to 3 hours to 1.5 hours) and also shifted to Saturdays since they all had classes and some worked during the day.

In India, the research team considered that the limitations outweighed the benefits with online/hybrid methodologies and decided to pause data collection until it was safe enough to do so in-person. Like Brazil, limitations included lack of sufficient phone data or good quality access to Wifi and digital infrastructure, for youth co-researchers. This was also a concern for participants in the communities where young people wished to conduct interviews; many potential respondents could not read or write, were not well-versed with digital technologies, and indigenous communities, such as *adivasis*, lived in remote regions where internet access was sparse.

The move to online data collection brought both advantages and challenges for the research project. While online participation was convenient for the young people in Brazil, it also posed challenges such as the cost of mobile data, unstable wifi, and good quality devices, as well as screen fatigue. In addition, privacy and confidentiality concerns arose as many participants lived in small, shared spaces with their households. To address these issues, the adult facilitators organised a in-person workshops at their centre to provide a physical environment for the young researchers to focus on data analysis and discuss their projects.

More broadly, the constraints brought about by the pandemic led to reflection on the types of spaces that were created, and how these shaped feelings of access and inclusion. In Brazil, the young people already had established connections, providing a relational base for online engagement, whereas in India, it was a group that came together to participate in this project. In-person training and meetings were considered essential to create a sense of community and inclusion, especially given the diverse backgrounds of the young people involved (Wright, Tisdall & Moore, 2021). Online platforms provide opportunities for connecting, but facilitating feelings of inclusion is more challenging, and video calling can infuse inequalities in relationships (reveal elements of identity and reflect one's social, cultural, and economic background).

Adapting the methods to enable data collection online meets ethical requirements of protecting participants by ensuring their health and safety, at least in certain ways. However, these measures also are restrictive for both the young researchers and their respondents given the aforementioned reasons. Some topics may end up not being pursued, and these communities also lose an opportunity to participate and share their experiences. Exclusions extend beyond a digital divide, as the impacts of Covid-19 are not only to do with access to digital infrastructure, but also time, commitments in life, mental space and so on. It invites us to reconsider whether online methodologies – the institutionally recommended and favoured solution - are necessarily the best option to work with during the pandemic and at times of crisis.

### **Moving forward: how can ethics be reimaged?**

Meeting the institutional ethical requirements highlighted for us power imbalances and tensions at the intersections between adult and youth researchers, Minority and Majority world

contexts, academic institution and local community actors. The tensions outlined in the discussion above indicate that while institutional ethical requirements are important, these also contain presumptions that create dissonance in conducting ethical research. In particular, three elements of dissonance were evident in our experience with typical institutional ethics committee procedures, which are based largely on a bioethical, top-down model. These concern research that involves: 1) co-production, particularly with young people; 2) partners, who have the local knowledge and expertise, which is as relevant and important as institutional and academic knowledge, if not more so; and 3) different contexts to that in which the institution is located. This points to continued dissonances between procedural ethics and ethics in practice, but, more broadly, it highlights a need to decolonise knowledge and procedures on the ground. Ethical guidelines do not exist in a vacuum, and need to be responsive to context and location.

Our experiences have therefore given us cause to question the appropriateness and relevance of institutional requirements across contexts, and the extent to which these help achieve the goal of ensuring that research is conducted ethically. We share the concerns expressed by Cutting and Peacock (2021), who argue that “by submitting to our institution’s interpretation of ethics, we transform ethical processes that should be focused on morality, equity, justice and liberation, into bureaucratic ones focused on traceable decision-making, classification of risk, and legal compliance.” (9).

Beyond merely questioning the current standard institutional ethical procedures, we find ourselves drawn to wondering how ethics can be reimagined. Talking about the bioethical context, Nie and Fitzgerald (2021) argue that the world today “calls for moral imaginations and new paradigms of thinking and action” (348). We do not claim to have the answers to how this can be achieved, rather we see the need for raising questions about how we can approach ethics from a place of imagination, that recognises that social groups (such as young people), and

communities (wherever in the world they are) are not homogenous and that a blanket one-size-fits-all approach does not work.

Work has already been done on developing frameworks to support the application of ethical principles across multiple contexts in research with children and young people (see, for example Ethical Research Involving Children (ERIC) at [www.childethics.com](http://www.childethics.com)). The question remains of how institutions can integrate approaches like these into their ethics processes, so that researchers are no longer compelled to engage in parallel processes, which involve compliance with institutional ethics procedures on the one hand, and, on the other hand, simultaneously engaging with frameworks to ensure their research practice is ethical.

We believe that there needs to be a paradigm shift, such that the focus is moved from largely protecting the interests of institutions, to working in genuine partnership with those we do research with and building an ethical framework with them that is recognised and respected by the institutions. Such a shift represents a serious challenge to the bioethical foundations and institutional values driving ethics procedures (Cutting and Peacock 2021) and requires consideration of questions such as:

- How can we build an approach to ensuring ethical research, that retains integrity and is more inclusive, respectful and flexible than compliance oriented procedural ethics?
- What would it look like to have a broad framework, that is (re)negotiated each time a new partnership emerges?
- How can we ensure that those that are directly affected, such as young people and local communities, are directly involved in the negotiation of ethical understandings and processes?
- What ethical processes would allow for ongoing updating and revision, to be genuinely responsive to the needs of researchers, participants and communities?

While we have more questions than answers, we are convinced that a reflexive and collaborative approach needs to be part of the ethical ground-laying from the outset. It is essential that research ethics are inclusive of, and meaningful to, all those who are involved in and affected by the research process. This requires flexibility, imagination and, most importantly, trust in genuine partnership.

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