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A case study from Guyana of adapting engaged research design to promote 'fairness in knowing'

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Abstract

In this paper, we have combined ideas drawn from philosophy (epistemic injustice), critical theory (epistemicide) and practical approaches (engaged research design) with Indigenous knowledge to promote 'fairness in knowing' in a project called DETECT (Integrated Space Technology Vector Control for Enhancing community health and resilience against escalating climatic disruptions), an early warning system to support communities in identifying mosquito breeding sites using satellite, drone and ground-sensing technologies. DETECT used engaged research design to inform pre-award planning. We document how the project team, comprising Indigenous and other researchers,

re-imagined the plans in the light of the COVID-19 pandemic to allow project participants to meet safely and equitably, and reflect on some of the key challenges in engaging across borders and cultures in the context of rapidly changing conditions characterised by vulnerability, risk, complexity and uncertainty.

Keywords community-based research; engaged research design; epistemic justice; epistemology; Indigenous self-determination; international development; malaria; organisational change; planning; upstream engagement

Key messages

- Those planning engaged research with historically oppressed communities should aim to reduce epistemic injustice and promote fairness in knowing. Decision making should be based primarily on ethical principles, only shifting from this position *in extremis* to adapt for pragmatic reasons.
- Stakeholder groups and communities who have experienced forms of oppression, often over many years, have developed ways of understanding, representing and responding to change these conditions to promote empowerment. It is the responsibility of researchers both to learn about community histories and epistemologies, and to attempt to contribute positively to the futures of those with whom they engage.
- Engaged research involving historically oppressed communities requires long-term planning, support and adequate funding for community participation. Funding awards should be honoured in full; commitments should be underwritten by universities; funding for 'follow-on' activities and partnership working should be available.

Introduction

The politics of knowledge production is complex, multidimensional and often contested (Nowotny et al., 2003). This is not a new phenomenon. Researchers have explored the changing epistemological conditions of knowledge production (influencing both the processes and products of research) over many years (Hall and Tandon, 2017; Facer and Pahl, 2017; Rasool, 2017; Tandon and Hall, 2014; Nowotny et al., 2003, 2001; Gibbons et al., 1994). In this paper, we explore an example of these changing epistemological conditions in the form of a case study that addresses a huge health issue in the Global South: malaria. In so doing, we combine ideas drawn from philosophy ('epistemic injustice'; Fricker, 2007), critical theory ('epistemicide'; de Sousa Santos, 2007, 2018) and practical approaches ('engaged research design'; Holliman et al., 2017) with Indigenous knowledge to promote 'fairness in knowing' (Medvecky, 2018).

Engaged research design

In delivering a previous institution-wide culture change project (Holliman et al., 2015), researchers at the Open University, UK co-produced two key interventions that informed the planning and management of the DETECT (Integrated Space Technology Vector Control for Enhancing community health and resilience against escalating climatic disruptions) project. These were: (1) a definition of engaged research (Grand et al., 2015); and (2) an engaged research design framework to inform pre-award planning, project management and evaluation (Holliman et al., 2017, 2015).

In reviewing findings from surveys of staff and qualitative interviews with researcher leaders across the university, we identified a lack of shared tools of interpretation in how engagement was conceptualised across different academic disciplines and domains (Grand et al., 2015). To address this challenge, we co-produced a definition of engaged research, and secured approval from the University's Research Committee and Senate to adopt this as an institutionally agreed position: 'Engaged research encompasses the different ways that researchers meaningfully interact with various stakeholders over

any or all stages of a research process, from issue formulation, the production or co-creation of new knowledge, to knowledge evaluation and dissemination' (Grand et al., 2015: 14). In a qualifying statement to this definition, the authors argued that the involvement of stakeholders, user communities, members of the public and/or communities who come into existence or develop an identity in relationship to the research process should be explored strategically to consider questions of representation, utility and emergence (Mahony and Stephansen, 2017; Mahony, 2015).

Notably, the definition is deliberately generic and pragmatic. It applies to research conducted in any discipline. In seeking to apply this across all disciplines and domains at a university with a highly diverse research portfolio, the definition also draws on theoretical conceptualisations of engagement that do not assume a normative position of how engaged stakeholders should be in the context of a given research project (Irwin, 2008). As Morgan (2014: 1051) argues, 'Pragmatism shifts the study of social research to questions such as: How do researchers make choices about the way they do research? Why do they make the choices they do? And, what is the impact of making one set of choices rather than another?'

An obvious question follows from this approach in the context of engaged research: How can researchers and publics be supported in making decisions about the framing, contributors, methodologies and methods, outputs and so on from engaged research? In seeking to inform these decision-making processes 'upstream' (Wilsdon and Willis, 2004), the definition of engaged research was complemented by a similarly pragmatic design framework to inform planning, project management and evaluation across all academic disciplines (Holliman et al., 2017).





The engaged research design framework acts as a series of prompts or questions (Figure 1). It is designed to assist upstream planning for engaged research through the exploration of a series of 'dimensions': preparedness, people, purposes, processes, politics, participation and performance. Here we offer a series of simple questions that can inform decision making about each dimension:

POLITICS

- Politics: Do all the constituencies involved understand the wider 'political' context for engaged research?
- Preparedness: Is there shared understanding about how to plan for, manage and reflect on the engaged research?
- People: Who are the 'constituencies' (publics, stakeholders, community groups, end-users, institutions and so on) who could engage? What forms of support, including financial payments, do constituencies need to be able to meaningfully engage?
- Purposes: What are the aims and objectives of the engaged research? What outputs or products could be delivered?
- Processes: How will the engaged research involve people, and when and how often will these constituencies be involved?

- Performance: What measures are proposed for exploring how wider constituencies participate in practice? Has the need to adapt to changing circumstances been considered? How will the learning be shared to improve future practice?
- Participation: What were the changes, effects and/or benefits for the constituencies? Were the Purposes met for everyone?

We argue that actively involving different forms of expertise and experience in the design, management and reflective phases of engaged research requires flexibility. Those involved also need to be aware of, and to accept and welcome, the opportunity to work under bespoke epistemological conditions of increased indeterminacy. Put simply, if you agree to open the research process to wider constituencies, you should also accept that others bring forms of expertise and experience to those discussions, and that they should have influence over the direction and outputs of that research. In this paper, we explore how this process of opening research to the 'unexpected' must be underpinned by ethical considerations about what needs to be prioritised and for which purposes.

Fairness in knowing

In introducing the definition of engaged research, and the engaged research design framework, we have emphasised the underpinning pragmatism. Pragmatism obviously has its limitations. For example, the definition and framework lack an ethical dimension. This limitation is highlighted by Medvecky (2018: 1393) in the context of the decisions that science communicators can make:

whether science communicators acknowledge it or not, they get to decide both which knowledge is shared (by choosing which topic is communicated), and who gets access to this knowledge (by choosing which audience it is presented to). As a result, the decisions of science communicators have important implications for epistemic justice: how knowledge is distributed fairly and equitably.

Medvecky (2018) calls for researchers to (re)think how they communicate to promote 'fairness in knowing' in how, why, when and with whom they communicate. By doing so, he argues that they can help to counter 'epistemic injustice' (Fricker, 2007). Following this view, communication and collaborative science-making similarly need to account for inequalities built into the systems and channels of knowledge used to achieve their objectives.

Fricker (2007: 44) offers a definition of epistemic injustice when she argues that 'there is a distinctively epistemic type of injustice, in which someone is wronged specifically in their capacity as a knower'.

Two key concepts underpin Fricker's (2007) conceptualisation of epistemic injustice: testimonial and hermeneutical injustice. Testimonial injustice comes in two forms: credibility deficit, 'owing to identity prejudice in the hearer' (Fricker, 2007: 28); and credibility excess, 'a speaker who is overly esteemed in her capacity as a knower' (Davies, 2016: 486). The concept relates both to who is given a voice in engaged research, and to the forms of expertise and experience that are, or are not, routinely valued.

In applying these concepts to engaged research, we argue that they should relate both to those who routinely gain access to the processes of knowledge production and dissemination, therefore potentially experiencing credibility excess, and to those who experience deliberate and unconscious forms of exclusion from knowledge production and dissemination, therefore experiencing credibility deficit.

Hermeneutical injustice refers to a gap in our shared tools of interpretation (Fricker, 2007). In applying this concept to engaged research, it relates to whether and how parties to engaged research: (1) have encountered the issue(s) under consideration; (2) have any prior experience of processes of engagement; (3) have experience or desire to be involved in the production of outputs/products; and (4) have experience of working together under equitable conditions.

Put simply, have all the parties developed shared ways of engaging that are both meaningful and equitable?

Fricker (2007) argues that to understand and address issues of epistemic injustice, we should take account of the distribution of social power, placing this concept within broader patterns of social injustice.

We argue that, in applying Fricker's (2007) and Medvecky's (2018) philosophical concepts to engaged research in the context of communities that have experienced historical oppression, an ongoing lack of meaningful access to processes of knowledge production has, in part, perpetuated that oppression. Those planning engaged research should therefore seek to 'flip' the concept of epistemic injustice in practice to promote epistemic justice and 'fairness in knowing'. It follows that there is a very practical application in drawing on these philosophical concepts. The ethical dimension of research discussed here is not about institutional governance or professional guidelines for research processes; rather, it is in dialogue with Fricker's (2007) idea that there are distinctive forms of injustice that can be redressed by focusing on the ethics of knowing. As such, we are focusing on the accountability of researchers to different communities, and on other ways in which research is imbricated in asymmetric relations and historical injustice. (The DETECT project and the programmes with which it is associated, namely AstrobiologyOU, have developed a theoretically grounded ethical framework that highlights how ethical considerations need to be factored in decision making about the use of resources, ownership and use of data, as well as relationships within and outside the project team [Chimakonam, 2017; Ndlovu-Gatsheni, 2018; de Sousa Santos, 2018]. Considerations about relationships include explicit reference to power dynamics and addressing epistemic injustice, whenever possible.)

Combining Fricker's (2007) conceptualisation of epistemic injustice with Medvecky's (2018) ideas about 'fairness in knowing' adds an important ethical 'lens' to decisions made in relation to how engaged research is planned, who shapes and frames what will be studied, who routinely engages with knowledge production, and who consumes the outputs from research and in what forms. In effect, these decisions influence who routinely gets a voice in research and who is excluded, and how those voices are enabled to engage fairly and equitably. If we explore the dimension of engaged research design with an ethical lens, several key questions need to be added:

- Politics: What is the historical context for the engaged research? Are there constituencies who have suffered oppression and/or exclusion from the processes of knowledge production?
- Preparedness: How can researchers gain deep contextual understanding of the challenges of engaging with different histories, value systems and knowledges on equitable terms? Have all constituencies been given genuine opportunities to bring relevant expertise and experience to the table?
- People: Who are the constituencies (publics, stakeholders, community groups, end-users, institutions and so on) who should be represented? What forms of expertise and experience should be included? Is anyone routinely excluded? Are there opportunities for wider constituencies to join as new issues emerge?
- Purposes: Have the constituencies been consulted about what they would like the outcomes or products of the engaged research to be? What processes could be proposed for consulting with these constituencies about the purposes and outputs of the research?
- Processes: How will the engaged research or knowledge exchange involve wider constituencies in meaningful ways? Where and how will the constituencies meet? Do different constituencies need different ways to engage?
- Performance: What measures are proposed for exploring how the constituencies have participated? Has the need to adapt to changing circumstances been considered? Will the findings be shared in appropriate ways for different constituencies to improve future practice?
- Participation: Were the objectives met for everyone? Were genuine opportunities and support offered to share learning in ways that are meaningful to different constituencies? How did researchers 'give back' to the wider constituencies with which they engaged?

Our argument is that an ethical imperative should underpin conceptualisations of engaged research. It is paramount that those planning engaged research with historically oppressed communities critically

interrogate the interplay between privilege and responsibility in relation to knowledge production (Raghuram et al., 2009; Jazeel and McFarlane, 2010). The Māori scholar Linda Tuhiwai Smith powerfully discusses the imperial legacies of Western knowledge, and points to the ways in which extractive methodologies continue to harm and exclude Indigenous communities (Smith, 2012). In striving for an Indigenous-led collaboration and engagement, we support foregrounding self-determination and sovereignty (Kukutai and Taylor, 2016). The DETECT project team includes Indigenous and non-Indigenous researchers. However, while the team carried out research *with*, not *on* Indigenous communities, we do not claim to enact decolonisation, which is understood by the authors as much more than just 'a metaphor' (Tuck and Yang, 2012).

As 'knowledge is politics in other words' (Jazeel and McFarlane, 2010: 110), our experience of collaborative practice suggests that when formulating a socio-technical, ethical and political intervention, one aim should be to reduce epistemic injustice and promote 'fairness in knowing'. Decision making should be based primarily on ethical principles, only shifting from this position *in extremis* to adapt for pragmatic reasons. By applying the engaged research design framework with an ethical lens to upstream planning (also management and reflection), we argue that all parties to engaged research can benefit from more equitable ways of working, as well as shared tools of interpretation.

Transforming theory into planning: the case of DETECT

DETECT used the engaged research design framework to frame its pre-award planning and post-award management. We combined the ethos of engaged research with theoretical concepts and practical approaches that allow team members to acknowledge the ways in which 'epistemic injustice' determines different starting points for project participants, and to structure their project activities in a way to promote 'fairness in knowing'.

Funded by the UK Space Agency, the DETECT project addresses a huge health issue in the Global South: malaria. The established international strategy for control of malaria is a top-down approach intended to break the transmission cycle (WHO, 2020). The strategy involves large-scale insecticide spraying, distribution of insecticide-treated bed nets draining bodies of water, or treating them with insecticide, and mass diagnosis and treatment of infected people.

This strategy has been successful in many countries; for example, in 2016 the World Health Organization (WHO) declared that malaria had been eradicated from Sri Lanka (WHO, 2016). However, these successes mask ineffective and regressive situations in other countries, and the WHO has recognised there is an urgent need for appropriate technologies, better surveillance and smarter approaches that are tailored to local contexts (WHO, 2020). DETECT sought community-driven technologies to further local communities' interests without undermining their self-determination. The DETECT system is best summarised as a cost-effective community-based service. It uses satellite, drone and ground-based environmental data to identify, almost in real time and with a high spatial precision, where mosquitoes are breeding. The information derived from this equipment allows communities to deploy a 'sprayer drone' to high-risk areas to release biocontrol agents which kill the mosquito larvae without affecting other species.

Combining engaged research design with soft system methodology

Complex problems are rarely solved by a single intervention. DETECT built on the generic principles of engaged research design (Figure 1) through the use of soft system methodology (SSM), which 'acknowledges the existence of a variety of stakeholders involved in any project, and their distinct interests, and how this might impact on the design of any system' (Bannon and Ehn, 2012: 43). SSM was used to enhance participation of users and other stakeholders through a framework that aimed to resolve problems by assessing the overall situation, not just the specific technology challenge (Berardi et al.,

2017). Our human-centred SSM design strategy (see Figure 2) invited the active participation of a wide range of stakeholders, including the local communities, domain specialists, technicians, decision makers, funders and project coordinators in engaged exercises that allowed the learning acquired in every step to be put into practice in the next phases of the project.

Engaged research thus supported and fed into explicit consideration of social, economic, political and cultural issues which were fundamental determinants in the successful adoption of the system to be created at the end of the project.



Figure 2. Overview of DETECT's use of soft system methodology (Source: authors)

In what follows, we offer a detailed description of how engaged research design and soft system methodology were combined to co-develop socio-technical solutions to address malaria, with Indigenous communities, commercial companies, research organisations and government agencies.

Politics

DETECT required us to explore the *Politics* of malaria in Indigenous communities in Guyana (Figure 1) through a combination of 'needs assessment', 'political economy analysis' and 'operational cost/benefit analysis' (Figure 2). We argue that to engage with wider constituencies on equitable terms, those involved need to have a working understanding of the wider political context of the issue or issues in question. Further, planning to promote fairness in knowing requires background knowledge of constituencies who have previously held power, and those who have suffered oppression and/or exclusion from the processes of knowledge production. This requires careful consideration of those who have experienced epistemic injustice (Fricker, 2007), both in relation to 'credibility deficit' and 'excess', directing the attention of those planning engaged research to questions of representation. However, exploring issues of representation will not exhaustively address the complexity that underpins historical oppression. In exploring hermeneutical

injustice (Fricker, 2007), those planning engaged research should explore other related concepts that account for the distinctive ways in which instances of injustice have emerged and are experienced. In the context of DETECT, we explored the concept of 'epistemicide' (de Sousa Santos, 2007), which points to the ways in which colonial history looms large over modern inequalities, having enabled a destruction of Indigenous knowledge systems.

There are 113 officially recognised Indigenous communities in Guyana, which make up about 9 per cent of the country's population. DETECT focused on Yupukari and satellite villages in the North Rupununi, where the project team's Indigenous researchers live. While ensuring funded Indigenous representation in the project team and adequate support for the project plans from village authorities, the consortium had to account for other ways in which asymmetries of power affected project design, revision of its objectives and its implementation.

Wider contextual issues included disputed land rights, a lack of opportunities for employment and self-improvement, social problems (for example, alcoholism), over-extraction of natural resources and pollution, often carried out by international corporations, and the loss of traditional culture and customs. Due to the lack of investment in the region, young people were leaving their community to seek employment elsewhere (for example, in mining and logging), fracturing family and community life, and exposing communities to infectious diseases brought in by migrants returning home. Illness in family breadwinners was triggering downward cycles of ill health, malnutrition and poverty. (We have written this account in the past tense. We note that this wider context is largely unchanged.)

Culturally, understandings of malaria within Indigenous communities were mixed, combining a high awareness of entomological knowledge with other ways of knowing, such as seeing malaria as having been transmitted by curses and/or as a result of unethical practices. (Other researchers have reported similar complexities in how Indigenous communities combine different ways of knowing in their assessment of health and well-being [e.g. Davies, 2017].)

We cannot do justice to the complexity of Indigenous world views in this paper, other than to note that this issue could not be reduced to simplistic cause-and-effect (vector breeding sites > infected mosquito > sick people). To foreground Indigenous epistemologies, DETECT adopted a definition of health that accounts for deep interconnected relations between individuals, society and the environment. More effective disease-vector control would have wide family, community and environmental benefits, but previous policies had positioned Indigenous communities as passive recipients of vector-control measures. Many people were unable to consistently practise avoidance behaviours (such as use of bed nets), people with malarial symptoms did not always seek medical help and, indeed, medical help was not always available, and traditional remedies offered limited efficacy. DETECT sought to support communities' direct participation in controlling mosquito vectors by identifying and, if needed, acting on local breeding sites, but always under communities' control and being compatible with their traditional practices and knowledge systems.

In the light of this wider political context, DETECT started from the premise that a reductionist technocentric intervention would not be effective in controlling and eradicating malaria. Rather, any intervention would need to address complex interdependencies holistically. As a result, DETECT sought community-based solutions to malaria and underpinned wider interventions in Yupukari that dealt with a wider idea of health as well-being. For example, the project introduced infrastructure and resources to engage schoolchildren and teachers, and supported wider environmental and well-being initiatives.

Preparedness

DETECT required us to explore our *Preparedness* to engage in this context (Figure 1) through a combination of 'needs assessment', 'political economy analysis', 'operational cost/benefit analysis' and 'pilot activities' (Figure 2). Through these activities, we sought to bring relevant expertise and experience to the table, in combination with equitable ways of engaging in the context of different histories, value systems and knowledges.

Given the wider political context, in the initial phase DETECT sought to explore community needs and aspirations, and to develop shared tools of interpretation. Aiming to design the DETECT system *with* Indigenous end-users, rather than researchers designing the system for them, we created spaces where the need for new technology development was questioned while taking the wider socio-culturalenvironmental context into account.

Team members drew a 'context analysis document' to share knowledge of, and account for, structural and contingent issues relevant to the project. We drew our primary data to inform this document from community-level surveys and interviews with local, national and international decision makers. The document included political, economic and social factors (within and outside Guyana) that constituted opportunities and threats to the project's mission. (We note the interplay between documents that were 'mandated' by the funders, and the ways in which we used them to document our contextual analysis that foregrounded Indigenous voices.)

Purposes

DETECT required us to identify the *Purpose(s)* for the project (Figure 1), for example, through a 'needs assessment' (Figure 2). A key question for those planning engaged research is the degree to which the constituencies are consulted 'upstream' (Wilsdon and Willis, 2004), and through what processes. Guston (2014) argues that by building capacity in 'foresight' and 'engagement', wider constituencies can be offered meaningful opportunities to share forms of expertise and experience to explore and agree questions of need, priorities and potential outputs; to sense-check likely outcomes, but also to review potential unintended consequences. We argue that this initial process of exploring and agreeing shared purpose is also significant for surfacing issues of testimonial (who should have a greater voice, and who should listen more) and hermeneutical injustice (sharing epistemologies, knowledge and ways of working together).

The core purpose of the DETECT project was to collaboratively design, with Indigenous communities, an early warning system to identify mosquito breeding sites. The need to address malaria was first a practical issue: research teams involving Berardi in the 2000s were regularly affected by malaria infections that affected their abilities to conduct their work (Mistry et al., 2009). Following the publication of their paper (Mistry et al., 2009), the authors engaged with key Guyanese partners, including the North Rupununi District Development Board and the Iwokrama International Centre for Rainforest Conservation and Development, to develop a deep and long-term engagement with the Indigenous communities of the North Rupununi. In so doing, they co-designed research projects that directly addressed the priorities and well-being concerns of these communities, including helping to address their malaria challenge.

In planning for DETECT, we used interviews and desk-based literature searches, working with local community facilitators to 'translate' and apply our high-level questions and engagement approaches. Through mediated engagement, facilitated by 'boundary spanners' (Williams, 2002), we found that the pattern of malaria infection (and other vector-borne diseases, such as dengue) in Indigenous communities in Guyana is affected by the movement of infected people from mining areas (for malaria) and urban areas (for dengue), and a significant influx of Venezuelans and Brazilians seeking new livelihoods. We also noted increasing numbers of trained community health workers within Indigenous communities, enabling early diagnosis and treatment for malaria. Through the survey and interviews, we also found that mosquito net distribution and household fogging with insecticide were only initiated, if at all, during high levels of diagnosis, and that many Indigenous community members use traditional practices (such as setting smoky fires at dusk) to repel mosquitoes during times of high mosquito density. DETECT sought to add *proactive* biocontrol treatment of mosquito breeding sites to the established *reactive* practices of traditional customs, bed nets, household fogging, disease diagnosis and drug treatment.

People

In a similar vein to *Purposes*, DETECT required us to identify the *People* for the project (Figure 1), for example, through a 'political economy analysis' (Figure 2). Research has explored how publics are 'created' to engage (Mahony and Stephansen, 2017), and has proposed a strategic framework for supporting this process (Mahony, 2015). The framework calls on researchers to consider who should be represented; what forms of expertise and experience could and should inform the issues in question; and whether there are opportunities for wider constituencies to join as the research progresses (Mahony, 2015).

In adding the lens of testimonial injustice and credibility deficit (Fricker, 2007) to this framework, DETECT also explored whether, how and why specific constituencies had been excluded in the past, and what measures could offer them a meaningful voice in designing solutions. This also required DETECT to consider the dialectical tension with credibility excess (Davies, 2016): who had been given privileged access to debates, decision making, policy formation, knowledge production and research outputs about these issues in the past, and what measures could be taken to reduce this dominance. We were acutely aware that, as academic researchers, we could be in a position of credibility excess. As a result, in the engaged research process, we took measures to acknowledge the limitations of our knowledge and expertise, and to build the capacity of other stakeholders.

In the conceptualisation of DETECT and the initial phase of consultation with stakeholders, the project team produced a comprehensive stakeholder map. The initial stakeholder map was produced with communities as primary users and system co-designers, but it also included governmental agencies (from health to Indigenous rights) and actors involved in the management and treatment of malaria in Guyana (from the Vector Control Service to community health workers). We also explored stakeholders' expertise and experience in a capacity-building workstream by mapping stakeholders, their expertise, their agendas and so on, and completing a critical systems heuristics (CSH) table that documented expertise, agendas and so on. The idea behind undertaking a CSH exercise is that both the meaning and the validity of stakeholders' propositions always depend on boundary judgements as to what facts (observations) and norms (valuation standards) are considered relevant, and what other facts and norms are left out or considered less important. Such boundary judgements underpin the reference systems to which we refer our claims to knowledge; that is, stakeholders with different perspectives will recognise different systems of interest in the same context (Reynolds, 2014). In producing the stakeholder map and CSH table, we considered the authority, expertise and interest of the project team members and its stakeholders in detail. This included our own positions in the research, with a view to resisting the ways in which researchers can render themselves and their motivations invisible by claiming that positivist approaches deliver 'impartial' and 'objective' analysis.

Processes

Exploring *Processes* requires those planning engaged research to consider practical and ethical questions about how to engage. What are the methodologies and methods that underpin the engagement, and when, and how often, will different stakeholders be involved in the research cycle? Where are these interventions likely to take place, and through what mechanisms (for example, in person and/or mediated via tools and technologies)?

In selecting methodologies and methods, those planning how to engage with stakeholders should explore which 'order' (or orders) of engagement (Irwin, 2008) an activity can support (Figure 3). It follows that activities can support different levels of interactivity and active participation, ranging from informing, through consultation, to collaboration and co-production.

By 'flipping' Fricker's (2007) concept to explore how hermeneutical justice can be supported, those planning engaged research add another lens: how will the research involve relevant stakeholders in meaningful and equitable ways, and how has everyone contributed to ensure the processes will work for them? We argue that, by 'flipping' Fricker's (2007) philosophical concept in practice, those planning



Figure 3. A typology of engagement activities, categorised by 'order' (Source: NCCPE/Wellcome Trust)

engaged research should actively seek ways of engaging that are culturally sensitive to different stakeholder groups.

DETECT required us to identify the *Process(es)* for the project (Figure 1), for example, through 'pilot activities' and the use of 'co-produced tools' (Figure 2). We sought to embed an ethos of inclusivity in all processes, from intention to structure and evaluation (the latter encompassing *Participation* and *Performance*).

DETECT used the 'ladder of inclusive innovation' to identify the many ways in which our *processes* of technology production could be (or could not be) inclusive (Heeks et al., 2014). The steps in the ladder require participants to account for:

- Intention if the intention is to address the needs or wants of an excluded group
- Consumption if it is adopted and used by the excluded group
- Impact if it has a positive impact on the livelihoods of the excluded group
- Process if the excluded group is involved in the development of the innovation
- Structure if it is created within a structure that is itself inclusive
- Post-structure if it is created within a frame of knowledge that is itself inclusive.

We fostered inclusion through the following activities:

- 1. Refine needs assessment: we conducted workshops and interviews with academics, community members, non-governmental organisation (NGO) workers and government officials.
- 2. Co-define the intended impacts and measurement frameworks: we planned to use the evidence cafe methodology (Clough and Adams, 2017), but due to COVID-19 restrictions we had to rely on other methods (from interviews to storytelling) to draw and refine our theory of change, and to enhance the participatory nature of stakeholders' engagement.
- 3. Design and agree on the technological innovation to implement: (i) an expansion of the existing team with more expertise and new partnerships; (ii) use of an iterative agile prototyping methodology; and (iii) workshops to enable participants to feed back on the plans for technology development.
- Monitor/check processes against objectives: create monitoring and evaluation tools by foregrounding user needs and knowledges to monitor indicators underpinning the achievement of the project objectives.
- 5. Evaluate and learn from feedback: evaluating after every activity, taking stock of the responses received from consultations and data arising from the use of participatory methods, including workshops and participatory videos.

Performance

Performance (Figure 1) offers opportunities to reflect on the engaged research design and activity in practice, to review and adapt to changing circumstances, and to consider how to improve future engagement. *Performance* considerations can also be used to explore how outcomes and findings from a project can be distributed in ways that are culturally appropriate for different constituencies, to share learning and improve future practice.

DETECT reviewed *Performance* throughout the research cycle, in particular through 'consultation and reflection' (Figure 2). Here we focus on how the inclusive ethos of the project was translated into a practical methodology. In this light, we note that researchers have long argued that planning for 'upstream engagement' is important (Wilsdon and Willis, 2004). Less perhaps has been made of the need for these plans to adapt to changing circumstances once a project is under way. For DETECT, considerable uncertainties were involved in enacting the planning, amid the urgent need to adapt in the light of the COVID-19 pandemic.

The DETECT team planned to facilitate community-based decision making through a combination of evidence cafes, stakeholder workshops and focus groups (see 'Process' section and Figure 2). In practice, bans on international travel introduced to restrict the spread of COVID-19 made face-to-face interaction between the UK and the Guyanese teams impossible. Most of our planned processes had to be urgently rethought and re-planned according to stringent health and safety protocols. This resulted in a mix of locally organised and led face-to-face activities in Guyana and long-distance, digitally mediated interactions connecting UK stakeholders (researchers and commercial organisations) with Guyanese stakeholders (government agencies, NGO researchers, community researchers and community members).

The engaged design of the DETECT system with Indigenous researchers and users in Yupukari was only possible because it was led locally, following a process of rapid restructuring. The UK team and Guyanese team, which included NGO workers and Indigenous researchers, used online meetings to agree on the methods to use and the materials for the research. In effect, community researchers took leadership in co-designing and implementing research activities; Indigenous researchers carried out and often adapted the activities in the villages. To minimise travel between villages, one or more Indigenous researchers from each community were tasked with leading on village engagement.

We acknowledge the obvious damages that the COVID-19 pandemic has caused across nations and cultures. For DETECT, a positive consequence of the international restrictions and the subsequent

rapid restructuring was that it increased the decentralisation of power, prompted the redistribution of more resources to local partners, and increased Indigenous leadership of the engaged research process. In part, we put this down to upstream engagement that was informed by engaged research design and soft system methodology. Despite being an innovation programme, DETECT focused for its first eight months on addressing the marginalisation of Indigenous knowledge systems (*Politics*), learning about Indigenous health epistemologies (*Preparedness*), nurturing relations of trust with communities, and cocreating visions of the future that foregrounded community agency (*People, Purposes* and *Processes*).

Crucially, what we have learnt from this rapid restructuring will have longer-term consequences, by changing a research paradigm in which the Global North too often sets the agenda and project design, and research processes and outcomes remain extractive.

Participation

Participation (Figure 1) is a dimension of engaged research design where the requirements to report the outputs and impacts of engagement can be addressed, both in relation to the *Purposes* agreed by the various constituencies, and in relation to assessments such as the Research Excellence Framework (see REF 2020). Crucially, *Participation* should be assessed through the research cycle, and not just towards the final phases of a project.

In DETECT, *Participation* was assessed throughout the project (Figure 2). In the 'discovery phase', we collected data through three overlapping routes:

- 1. Assessing context and needs: the team gathered data on national malaria management through surveys, and on traditional practices of malaria control through interviews.
- 2. Imagining a solution through a forecasting exercise (Guston, 2014): households across the North Rupununi and Yupukari drew 'rich pictures' (Lewis, 1992) to imagine ideal community scenarios coming about in three years' time because of DETECT interventions.
- 3. Co-defining user requirements for the DETECT system through a back-casting exercise: storytelling was used to elicit Indigenous peoples' feedback on the proposed working of DETECT as a holistic solution, and on who should take major decisions about activating drones and use of biocontrol, as well as to understand what sort of specific user needs and requirements were being emphasised.

The sustained engagement through the discovery phase allowed DETECT to approach the complex challenge of vector control in Guyana in a way that 'provincialised' the technological aspect and questioned its very promise of 'better health' by asking what this phrase meant for Indigenous community members.

The plan was for the discovery phase to be followed by a three-year 'operational phase', in which local stakeholders would be trained in using the system, and it could be deployed, tested and revised *in situ* by Indigenous communities. However, the UK government's decision to drop a commitment to spend 0.7 per cent of gross national income on foreign aid (Amos, 2021) meant funding for the operational phase of DETECT was cut. This highlights another dimension of engaging with historically oppressed communities: precarity in funding. We argue that engaged research involving historically oppressed communities requires long-term planning, support and adequate funding for community participation. Funding awards should therefore be honoured in full, commitments should be underwritten by universities, and funding for 'follow-on' activities and partnership working should be available.

Our ethically driven approach to engaged research meant that we could not abandon the work undertaken in the discovery phase. Instead, the team leveraged alternative sources of funding (for example, Cobra Collective, 2022) to sustain the work of the DETECT team, and we adapted our research strategy. This strategy has been in place for two decades, and through it we have nurtured relationships, built our collective understandings and capacities (of both Indigenous and other researchers, including ourselves), and directly contributed to improving community well-being. Although we currently do not have funding to directly tackle malaria, we have established a mechanism in which malaria control is on the agenda. DETECT researchers are still sharing learning on the malaria situation, and how we should tackle it. Further, the systems for malaria management created through engaged research have been adapted to address other challenges, such as flood monitoring, which the communities face. In this way, social capital was maintained and built upon; further replacement funding is now being sought to conduct the operational phase in relation to malaria.

Conclusion

In this paper, we have reported a detailed process account of DETECT, a project that used an engaged research design to create a socio-technical system to empower Indigenous communities' mitigation of malaria in Guyana. We combined an ethos of engaged research with theoretical concepts and practical approaches to promote 'fairness in knowing' and reduce 'epistemic injustice'. We have shown how we embedded ethics in the context of cross-cultural engagement, aligned with systems thinking, to develop a principled approach to engaged research design. We were forced to review and revise plans following the emergence of COVID-19 and the introduction of restrictions, but in so doing, prioritised local communities' self-determination when addressing the conditions that give rise to malaria (and other issues, including biodiversity conservation, flood management and mental health). As a result of what we have learnt together through this work, we argue that engaged research involving historically oppressed communities requires long-term planning, support and a high degree of responsiveness to local demands for action and accountability.

We have argued that those planning engaged research should take account of the distribution of social power, and learn about the ways in which historical injustice has created and reinforced material and epistemic inequalities. In 'flipping' Fricker's (2007) ideas about epistemic injustice, we argue that those planning engaged research should seek to promote 'fairness in knowing' by surfacing shared territory on issues of representation, expertise, experience, history and culture, and actively seeking complementary ways of working together. While these issues are crucial, however, we also note that they are not sufficient to ensure that the structures put in place are truly open to dissent, nor that they will necessarily be successful in promoting fairness.

In the case of Indigenous communities, 'flipping' Fricker's (2007) concept was useful but not sufficient to fully capture the ways in which colonialism and its afterlives (the role of hegemonic languages, educational institutions, canons and so on) have undermined and subjugated knowledge diversity. De Sousa Santos's (2007) work on epistemicide added another powerful frame to address the centuries-long disavowal of non-Western knowledges, and provided us with an opening towards accounting for an ecology of knowledges – a dialogic method that includes processes of translation and negotiations in support of concrete social struggles (de Sousa Santos, 2018).

DETECT worked with a constellation of experiences and expertise. We foregrounded traditional Guyanese Indigenous world views on health and well-being, which presuppose the holistic integration of the environmental, the spiritual and the social spheres. In these world views, nature and the environment are not viewed as distinct entities, nor divorced from human thoughts and actions. Our aspiration to use engaged research to create an intervention that met community well-being needs, while safeguarding cultural and traditional practices, required the academic and industrial partners to question their epistemic practices and ways of thinking, and positively value Indigenous knowledges. Stakeholder groups and communities that have experienced forms of oppression, often over many years, have developed ways of understanding, representing and responding to change these conditions to promote empowerment. We argue that it is the responsibility of researchers both to learn about community histories and epistemologies, and to attempt to contribute positively to the futures of those with whom they engage. We primarily achieved this by recognising, supporting and promoting existing local agency and Indigenous leadership, and requiring non-Indigenous researchers to relinquish control over research processes and analysis. It is important to note that funding commitments to communities in the Global South and the

long-term sustainability of research projects must account for this proposed decentralisation. Inclusion, participation and sustainability require funds for diffused community-level work; confidence in funding commitments must be maintained. Decentralisation may be more costly than relying on the expertise of international consultants working in the monitoring and evaluation sector, but it allows for a shift in power relations and meaningful support for local struggles.

Finally, our thoughts turn to the transferability of the theoretical perspectives and practical application of the work undertaken through the different projects we have explored in this paper. Several of the authors of this paper are members of a Research England-funded research group, 'AstrobiologyOU'. In our planning for this multidisciplinary research group, our stated intention was to embed an ethos of engaged research across (and beyond) disparate academic domains and disciplines (for example, science, international development, governance and education). Supporting a group of stakeholders of different backgrounds, experiences and cultures into a community committed to ethically informed engaged research calls for continuing reflection and targeted support. A further aim of this paper is therefore to share what we have learnt about pragmatic and ethical approaches to the design, management and evaluation of engaged research by supporting a programme of collaborative workshops and targeted support. It is in this light that our final argument is that those planning engaged research with historically oppressed communities need to base decision making primarily on ethical principles, only shifting from this position *in extremis* to adapt for pragmatic reasons.

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Consent for publication statement

The authors declare that research participants' informed consent to publication of findings – including photos, videos and any personal or identifiable information – was secured prior to publication.

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