Ethics and Politics of Community Engagement in Global Health Research

Trinity College, University of Oxford
20-21 September 2016
WORKSHOP PROGRAMME

TUESDAY, 20 SEPTEMBER

8:30 am – 9:00 am
Coffee and registration

9:00 am – 9:20 am
Welcome and introduction (Lindsey Reynolds and Salla Sariola)

9:20 am – 11:00 am
What makes engagement ‘effective’? (Discussant: Dorcas Kamuya)

Bipin Adhikari: Community engagement for Targeted Malaria Elimination in Nong District, Savannakhet Province, Lao PDR: design, implementation and critical reflection

Gill Black: Reflections on ethical considerations that emerge through working with visual methods to engage diverse communities in health and health science

Rochelle Burgess: Involving communities in “global mental health” research: The case for participatory action methods and community mental health competencies

Chimwemwe Phiri: Using participatory community engagement approaches to address severe illness in children in urban and peri-urban communities in Blantyre, Malawi

11:00 am – 11:15 am
Tea/coffee break

11:15 am – 12:55 pm
Production of knowledge (Discussant: Rik Wehrens)

Myra Parker: Addressing Epistemicide to Achieve Health Equity in American Indian Communities: Applications for Global Health Research

Sharli Paphitis: The Possibility of Addressing Epistemic Injustice through Engaged Research Practice: Reflections on a Menstruation Related Critical Health Project

Márcio Vilar: Contested legitimacy of regenerative vs. established biomedicine: Practices of engagement among immunostimulant-users for treating autoimmunity in contemporary Brazil

Saheli Datta: Legitimating the individual vis-à-vis the generalizable: the unstoppable growth of direct to consumer stem cell therapies.

1 As most papers are co-authored, we have only included names of those attending here, but please see full list of authors in the abstract list.
12:55 pm – 2:00 pm  
*Lunch*

2:00 pm – 3:40 pm  
*The relational dynamics of engagement (Discussant: John Manton)*

**Anthea Lesch:** Exploring the relational dynamics of community engagement in HIV vaccine research in a peri-urban community in South Africa

**Mackwellings Phiri:** Contradictory roles in community engagement: the experiences of community representatives in Malawi

**Siân Aggett:** Opportunities and Barriers to Engagement through Participatory, Community based arts practice with Community Based Biomedical Research in Patan, Kathmandu, Nepal

**Musonda Simwinga:** Who is answerable to who? Exploring the complex relationship between researchers, the community and community representative organisations in two clinical trials in Zambia

3:40 pm – 3:55 pm  
*Tea/coffee break*

3:55 pm – 5:25 pm  
*The relational dynamics of engagement, cont. (Discussant: Nadine Beckmann)*

**Justin Dixon:** Challenges of Interdisciplinary Collaboration in Community Engagement: Reflections from a Street Theatre Project at a TB Vaccine Trial Site in South Africa

**Deborah Nyirenda:** What counts as community engagement in health research? views on the purpose of community engagement among stakeholders in Malawi

**Daniel Reeder:** Engagement in Context: Practice, Research, Policy in Global and Public Health

**Magdalena Szafarzski:** Partnering with Faith Communities to Address HIV Disparities in Urban America

7:00 pm  
*Dinner at Trinity College*
WEDNESDAY, 21 SEPTEMBER

8:45 am – 9:15 am  Georgia Bladon  Introduction to the MESH platform

9:15 am – 10:45 am  Normative frameworks  
  Discussant: Ariella Binik
  Katharine Wright, Vicki Marsh and Dorcas Kamuya: Towards Partnership with children, young people and parents in exploring the ethical challenges of clinical research with children: experience in Kilifi, Kenya
  James Lavery: The Architecture of Community Engagement in Global Health Research
  Mark Sheehan: Justifying the co-production turn in research

10:45 am – 11:00 am  Tea/coffee break

11:00 am – 12:40 pm  Engagement as creating/managing people/groups  
  Discussant: Mwenza Blell
  Aaro Tupasela: Managing Expectations in Global Economies of Hope for Rare Disease Research
  Anna Versfeld: Unscripted responses: finding the unexpected in a harm reduction project evaluation in South Africa
  Kirk Fiereck: Community (Dis)Engagements: The LGBTQ Movement/Sector in South Africa
  Lieke Oldenhof and Rik Wehrens: 'Who is in and who is out?' The politics of participation of frail elderly in Dutch healthcare

12:40 pm – 1:30 pm  Lunch

1:30 pm – 3:10 pm  The Politics of engagement  
  Discussant: Javier Lezaun
  Decha Tangseefa: Place, People and Power: Basic Concepts of People’s Lifeworld in Community Engagement for Malaria Elimination
  Gift Trapence: Ethics without infrastructure?: Challenges of MSM research in Malawi
  Mangala Subramanian: Ignorance, Knowledge, and Information in HIV Prevention: Studying Women Sex Workers in India
  Nils Graber: Biotechnology and primary healthcare: community engagement in oncology clinical trials in Cuba
3:10 pm – 3:30 pm  
*Tea/coffee break*

3:30 pm – 4:30 pm  
*The politics of engagement cont. (Discussant: Elisabeth Hsu)*

- **Yan Long**: Brokering Engagement: Domestic Nongovernmental Organizations and Transnational Knowledge Production

- **Evans Gichuru**: Religious Leaders Become Allies within the Context of the HIV Epidemic in Kenya

4:30 pm – 5:00 pm  
Next steps and concluding remarks (Lindsey Reynolds and Salla Sariola)
Aaro Tupasela and Zainab Afshan Sheikh

Managing Expectations in Global Economies of Hope for Rare Disease Research

The extension of research networks to encompass broader and more far-reaching global collaborators and partners has become a mainstay of conducting global health research (Biehl and Petryna, 2013). In this paper we address research networks in the field of rare genetic diseases, where efforts to involve families and communities in both low and high income countries in order to collect human biological tissue are increasing. How do these efforts interact with the lives of donor families? How are the local communities managed? Based on ethnographic interviews, we compare and contrast whether and how researchers in Pakistan, Finland and Denmark facilitate research on rare diseases through engaging donors. We argue that the tacit, practical and explicit work around donor and family hopes and expectations are an important conduit through which patients, their families and the research they participate in are managed. Furthermore, we show how research goals and engagement practices are multiple and multi-faceted, whereby seeing engagement as either empowering or a type of buy-in is problematic.

According to Borup et al. (2006: 285-286), “expectations can be seen to be fundamentally ‘generative’, they guide activities, provide structure and legitimation, attract interest and foster investment. They give definition to roles, clarify duties, offer some shared shape of what to expect and how to prepare for opportunities and risks.” At the same time increased attention has been paid to the power relations between researchers and research subjects whereby practices of engagement are seen to play an important role in empowering patients. The Centers for Disease Control and Prevention (CDC), for example, sees the development of strategies for community engagement as central in improving public health, as well as improve the quality and applicability of population research (Haldeman et al., 2014). Different countries and institutions use different approaches to their engagement strategies with regard to the general public, as well as the research population from which they collect samples and data (Cañada et al., 2015; Tupasela et al., 2015).

Anna Versfeld, Shaun Shelly, Andrew Scheibe, Janine Wildschut

Unscripted responses: finding the unexpected in a harm reduction project evaluation, South Africa

The importance of community involvement in public health research processes is well established. The literature is, however, less forthcoming about processes of community inclusion in public health project implementation, especially when it comes to projects focusing on key populations. The Step Up project is the first multi-city harm reduction service provision project for people who inject drugs (PWID) in South Africa. Since inception, the Step Up Project has made concerted efforts to work with and alongside people who actively identify as PWID. This paper outlines two surprising features relation to project-beneficiary dynamics that emerged in a qualitative project evaluation. The first was that project “beneficiaries” comfortably expressed criticisms of both themselves and the project, and freely noted when their behaviour contradicted project ideals. This is distinctly different to anthropological accounts that have noted that beneficiaries of harm reduction programmes often position themselves as ethical actors by voicing harm reduction discourses while
expressing resistance through overtly contradicting the tenets of these discourses in their actions. The second was the extent to which engagement with the project was reported to be fostering a renewed sense of personhood and right to exist in the world. This was particularly marked for participants in the CAGs. These unexpected findings are, we suggest, partly related to the forms of community engagement exhibited by the project implementers, including multiple modes of care, consistent CAG processes, and a focus on human rights.

Anthea Lesch and Leslie Swartz

Exploring the relational dynamics of community engagement in HIV vaccine research in a peri-urban community in South Africa

Many biomedical HIV prevention trials are being conducted in settings with high HIV prevalence. In South Africa, efforts to develop a safe and efficacious HIV vaccine have been underway since the 1990s. The process of developing an HIV vaccine is a long term endeavour that involves multiple stakeholders, ranging from global to local role-players. Community engagement is a crucial component in the clinical research process, impacting the buy-in and support of local communities. In South Africa, clinical research to test candidate HIV vaccines is conducted in resource-poor communities where the risk of HIV-infection is high. While promoting community engagement in the HIV vaccine research enterprise has been highlighted as an ethical and scientific imperative (Newman et al., 2015), at the coalface it challenges researchers to balance scientific and operational goals with community capacity-building agendas in these resource-poor communities. Viewing HIV vaccine research as primarily a scientific endeavour in which researchers and their expert knowledge control and structure the process, whilst community members contribute their local knowledge to achieve scientific goals, produces a limiting view of the role of communities in the research process. Further, it ignores the fact that clinical trials are fundamentally about social relationships (MacQueen, 2011). Scientific research is social, political and deeply embedded in the social context in which it is conducted (Scott & Gibbons, 2001). When scientific research moves out of the laboratory into community settings it is transformed from a scientific experiment into a social process that is deeply rooted in the social, political and economic context of the local community. It becomes an integral part of the local community context and the complex dynamics and networks of social relationships that constitute it. Using the case of HIV vaccine research at one research centre in a peri-urban community in South Africa, in this paper I discuss the relational dimension of community engagement in HIV vaccine research. I locate my discussion in the community mobilisation approach outlined by Campbell and Cornish (2010). In my discussion I explore the network of social relationships that structure the participatory process and the roles, responsibilities and levels of participation available to those who are involved in the community engagement process. I present my exploration from the perspective of three key stakeholder parties who are involved in the process at the local community level, namely, community members who participate in HIV vaccine research, CAB members who represent the community and community outreach workers who are responsible for implementing community engagement activities. I reflect on how, in the research setting, community engagement continues to be reduced to the performance of a limited set of activities focussed on achieving operational and ethical objectives and recruiting large numbers of community members into HIV vaccine research studies.
Community engagement for Targeted Malaria Elimination in Nong District, Savannakhet Province, Lao PDR: design, implementation and critical reflection

Introduction:

Targeted Malaria Elimination (TME) involves a package of malaria prevention and control strategies, including the mass administration of antimalarials to entire communities. In light of concerns about increasing antimalarial resistance, TME is currently being evaluated across South East Asia. The effectiveness of mass drug administrations (MDAs) depends on high population coverage and adherence, and community engagement (CE) is recognized as crucial to promote this. Almost ubiquitous among MDA programmes, the process of designing and conducting CE is however, often left unreported. In this paper, I discuss the design of the CE strategy and the impact of CE activities for TME in Nong district, Laos.

Methods:

The design and implementation of CE activities took place from November 2015 until May 2016. The implementing research team (including the lead author) documented the process of designing the CE strategy and the CE activities as field notes, audio recordings, videos and photos.

Results:

Designing the CE strategy started with the recruitment of two local social scientists. Drawing on the advice of the provincial Head of Malaria, the CE strategy began with consulting the Nong district authorities. A meeting was organized at district health center where community leaders were introduced to the study. A district health officer, fluent in Laotian (a non-written language spoken in the study villages) acted as a study coordinator and aided the TME team in introducing the proposed CE activities to community leaders. In each study village, volunteers were recruited and involved in implementing the CE activities, which included health education (leaflets, malaria guide book on TME, posters, power point presentation, drawing exercise, focused group trainings and mass meetings), audio-visual shows (a malaria documentary from provincial malaria control division and two videos made by the TME team), health care (from TME medics and the TME-funded health center), incentives (mosquito nets, kitchen materials, TME T-shirts, sweets & milk and travel allowance) and house-to-house visits (a meeting night before the MDA and house to house visits in the evening and in the morning just before MDA).

Conclusion:

Community engagement within TME was largely aimed at promoting coverage of and adherence to the MDA in the target villages. Preliminary results suggest that in those terms, it was a success. Nonetheless, particularly during the initial consent process, the TME team encountered rumours related to the blood sampling. Such stories seemingly had an impact on the levels of participation and, in response, CE activities (meetings with villagers and village heads, and house-to-house visits) were intensified and subsequently participation increased.
Using participatory community engagement approaches to address severe illness in children in urban and peri-urban communities in Blantyre, Malawi

Background:

Community based engagement has the potential to enhance a community's ability to address its health needs through improved treatment seeking. This paper explores the effectiveness of a collaborative community health intervention utilizing participatory theatre techniques to build relationships between research institutions and communities in turn empowering the communities involved. Community engagement that focuses on relationships between academic and community partners with principles of shared learning, collaboration, respect, mutual benefit and incorporates community knowledge is critical to achieving positive health outcomes in response to severe illness in children. We highlight the process of community engagement that took into consideration the social and political context of communities and the subsequent interaction of research institutions with various levels of community organization.

Methods:

The theatre for development intervention was implemented in peri-urban and urban communities in Blantyre, Malawi. The intervention was conducted in three phases 1. Situation analysis and baseline assessments to understand knowledge and practices relating to severe illness in children 2. In collaboration with community members the development and implementation of theatre performances 3. A mixed methods evaluation approach to assess the impact of the approach in communities.

Results:

An effective intervention was implemented that identified community contexts and incorporated community health needs. Individuals exposed to the intervention reported improvements in knowledge of severe illness in children and treatment seeking actions in response to a sick child. The intervention had notable empowering effects on community members involved in the play who implemented additional performances using their experience to share their knowledge in their communities.

Conclusion:

A crucial lesson from this case study is the need to incorporate local knowledge and to consider social and political contexts identified by community members throughout the engagement process. The success of the project is attributed to the initial identification of key social and political stakeholders and use of culturally informed strategies that fed into the intervention.
Gift Trapence and Crystal Biruk

*Ethics without infrastructure?: Challenges of MSM research in Malawi*

This paper, written from the collaborative perspectives of an anthropologist and an activist-researcher and director of Malawi’s LGBT-rights NGO, considers the effects of rising demand for statistics and data on key populations in sub-Saharan Africa—such as men who have sex with men (MSM)—that can inform “evidence-based” interventions and policy. Drawing on experience implementing a respondent-driven sampling (RDS) study of MSM in a number of districts in Malawi, we highlight how the push for timely data by foreign partners and local institutions such as the National AIDS Commission (NAC) can endanger the very communities these organizations aim to help. Indeed, such rapid research, often implemented in the absence of meaningful investment in infrastructure on the ground, can have the paradoxical effect of placing MSM at risk not only of the HIV and STIs the research seeks to measure, but also of becoming known in their local communities. The paper will examine the social and political context that shapes the ways in which this kind of research is carried out in a low-resource setting characterized by widespread homophobia.

Daniel Reeders

*Engagement in Context: Practice, Research, Policy in Global and Public Health*

This paper aims to locate public or community engagement and health research in relation to (a) governance of population health and (b) practice in community-based health promotion. It argues we need to identify what engagement – in different forms and on different occasions – does for government. This need arises because engagement is compatible with so many key ideas in neoliberal governmentality – in particular, Hayek’s notion that local markets have detailed knowledge that central government can never develop, which underpinned Thatcherite policies of devolution of planning to local communities. We can use Mitchell Dean’s theorisation of social governance to ask whether communities get ‘captured’ via engagement in the management of population health issues – which, as Foucault reminds us, includes knowledge practices like epidemiology, criminology, social psychology, etc. This poses important ethical questions: with Nancy Fraser, we might ask whether and how different modes of incorporating engagement in global health research ‘affirm’ or work to ‘transform’ the underlying generative framework of social inequities in health. Reflecting critically on my experience as a practitioner and researcher in Australia’s community-based response to HIV, I want to think through how practices of engagement in research might help to constitute *publics* that can bring weight to bear on political debate and policy-making processes – a missing ingredient in the discourse on the social determinants of health equity.
Deborah Nyirenda, Kate Gooding, Bertie Squire, Chiwoza Bandawe, Salla Sariola, Nicola Desmond

What counts as community engagement in health research? views on the purpose of community engagement among stakeholders in Malawi

Background:

Community engagement is increasingly promoted in international research guidelines to improve dialogue between researchers and communities in designing and implementation of research. There is however no widely agreed definition of community engagement leading to various interpretations: as a means of informing, consulting or actively involving communities in research. Limited evidence exists on effective approaches of engaging communities in two way dialogue particularly in settings with low health literacy. Our research seeks to examine views of various stakeholders on community engagement and factors that shape the engagement process.

Methods:

This paper draws from a wider study investigating the purpose, relevance and benefits of community engagement in health research using a qualitative research design. Three research projects were purposively selected as ethnographic case studies from two research institutions in Malawi. Participant observation was used to understand unarticulated aspects of community engagement in health research. In-depth interviews were used to understand community engagement as experienced by various stakeholders involved in research while focus group discussions were used to seek views of people on community engagement.

Preliminary results:

Although community engagement is promoted in the literature to support two way dialogue between researchers and communities, findings suggest that it is seen by stakeholders as a means of informing communities about research. Community engagement practices observed reflected deficit models of engagement which have been critiqued because of the assumptions that the public is ignorant and they need to be informed. Views on the purpose of community engagement however vary across stakeholders involved in research. We noted that community engagement practices were shaped by interactions between multiple stakeholders involved in research, their diverse agendas for engagement, communication approaches, interactions with other service providers in a given context, and other socio cultural factors. Despite having an aim of informing, a majority of research participants still had challenges to understand health research.

Conclusions:

We conclude that stakeholders understand community engagement as a means of informing communities about research which does not match the ideals in the literature. This understanding is shaped by a number of social and economic factors. An understanding of these factors will help to design community engagement approaches that will promote meaningful dialogue in a particular context.
The recent emergence of artemisinin-resistant P. falciparum parasites is of the highest concern. In the absence of more promising plans, it has been suggested to eliminate P. falciparum malaria from foci of artemisinin resistance. Part of a Targeted Malaria Elimination (TME) piloting project, this study investigated experiences of TME community engagement workers in four diverse villages along the Thai-Burmese border. As high participation is an imperative for TME, the purpose of this study was to maximize program participation of villagers through identifying basic concepts relating to people's lifeworld relevant for ethical and effective community engagement. During the study period of two years (2013-2015), semistructured in-depth interviews with community engagement workers (N = 17) of the Shoklo Malaria Research Unit were conducted regarding their experiences in four TME piloting villages. Furthermore, the researchers joined community engagement workers during their activities and occasionally also interviewed villagers. An additional source were experiences of malaria elimination workers from the multi-institutional Malaria Elimination Task Force, recorded during community engagement workshops. Based on transdisciplinary guiding theories of political theory, philosophy and anthropology, Place, People and Power were identified as three key concepts relevant to community engagement under the diverse, economically unstable, and politically fragile conditions along the Thai-Burmese borderland. They can facilitate as guiding concepts for community engagement for elimination interventions in post-conflict settings, contested areas, borders, and areas inhabited by mobile populations with a high diversity of peoples. Diversity, mobility, capitalization and crumbling social cohesion will be challenges to community engagement for malaria elimination in the future.

Evans Gichuru, Esther Adhiambo, Clifford Duncan Okoth, Salla Sariola, Monique Oliff, Eduard Sanders, Elise M. van der Elst

Religious Leaders Become Allies within the Context of the HIV Epidemic in Kenya

Background:

In Kenya, Men who have Sex with Men (MSM) are considered un-Christian and un-African. 15.2% of the new infections in Kenya are through male homosexual contact. Therefore, it is crucial to identify and engage supportive religious and community leaders to reduce stigma and discrimination and promote access to HIV services for MSM. Kenya faces deep tensions between religion and state on this matter. We tested a Community Engagement (CE) model that used a consensus-building community-based participatory approach. Here we report on phase 1, the formative work of this intervention.

Methods:

Thirteen religious leaders from a mix of religious groups and denominations (Catholic, Muslim, Adventist, Anglican and Protestants faiths) in Mombasa were recruited as "community engagement agents" (CEAs). Together with PEMA-Kenya - a LGBTI-led CBO in the Kenyan Coast - and members of the KEMRI-IAVI research group, a working group was formed to discuss, and challenge stigmatizing religious beliefs that often increase HIV vulnerabilities amongst MSM. Twelve training sessions were conducted, and offered the religious leaders
space to vocalize their fears and questions about MSM. Lessons learned from the 12 week working group are currently being used to develop a sensitization- and training intervention for religious leaders, whereby religious leaders’ CEAs will implement the training and be encouraged to form “community stakeholder allies”. Phase 3, will use pre-mid-and post assessments to evaluate the process and change in attitudes.

Results:

Based on the consensus-building participatory approach, which aimed to increase the level of knowledge about HIV (transmission, detection, treatment, risk) and sexuality, and reduce religious leaders’ level of prejudice, the following key outcomes were identified and will feature in the second phase: 1) developing an understanding of differences between people, lifestyles and the consequences of prejudice/discrimination/isolation; 2) a perspective of the out-group within religious frameworks, developing a multifaceted view of the situation for MSM and its complexity for the individual and the broader society; 3) empathy and compassion; 4) self-knowledge & self-disclosure; 5) finding a zone of comfort – despite residual ambiguity with regards to self and other; 6) initiation of trust, openness, and friendship in order to reduce anxiety about interacting with an out-group; and 7) the development of an ‘I can’ have a conversation with a gay man - ‘I can’ begin to contemplate tolerating the situation that previously I would have resisted. Moving to a group commitment, or ‘we can’ attitude within the group, this concrete and public step of linking the religious leaders psychologically to the out-group – is key to sustaining reduced prejudicial attitudes. A protocol is under development to conduct the intervention. Key indicators will be measured at baseline, midterm and at the end of the interventions to determine if this kind of targeted intervention can improve access to care for MSM (phase 2/3).

Conclusion:

This formative work demonstrated religious leader’s willingness to be engaged on MSM/HIV issues, to raise awareness about HIV/AIDS, combat stigma, and provide a holistic approach for Kenyan MSM living with HIV to access health and social support. While some religious leader participants embraced the CEA’s concept others are still uncertain of how to move forward. KEMRI recognizes further work is needed to change attitudes.

Gill Black, Mary Chambers, Alun Davies, and Dalia Iskander

Reflections on ethical considerations that emerge through working with visual methods to engage diverse communities in health and health science

This paper reflects upon the extensive experiences of practitioners who have been working with visual participatory methods in four very different contexts to engage community members in public health and biomedical research processes. Over the past 5 years, we have explored an array of interactive engagement approaches including drama, photovoice, digital storytelling, video diaries and participatory video in Vietnam, Kenya, the Philippines and South Africa - and have worked with young children, adolescents and adults across these settings. The participants that we have engaged in these initiatives all live in under-resourced areas with high prevalence of communicable and non-communicable diseases. Our paper describes the challenges, successes and learning we have encountered in using participatory methods to build relationships and foster knowledge exchange between community and family members, health workers and biomedical scientists. We draw upon multiple and diverse ethical situations that have emerged through facilitating community-led processes and share our observations on the ways in which they can enable inclusion or be
unintentionally exclusionary. Many questions have arisen while we have been navigating these ethical landscapes; we explore the multiple purposes of producing participatory visual media, and look at how decisions are made regarding their dissemination and viewing. We consider intersecting matters of confidentiality, anonymity and vulnerability, the process of informed consent, decisions around content and editing, and discuss the sustainability of working with visual participatory methods for community engagement in biomedicine.

James Lavery and Emma Richardson

The Architecture of Community Engagement in Global Health Research

The conversation about community engagement (CE) in global health research has been shaped by a relatively narrow set of ideas and mechanisms. Although rarely articulated, the implicit value proposition for global health research funders and their implementation partners is that CE can facilitate the acceptance of their goals and strategies by host communities. This common understanding of the purpose and value of CE has important ethical and practical implications and represents a significant simplification of a very complex set of human interactions and consequences that are triggered by the introduction of research activities. The tacit acceptance of this conventional framing by the global health research community perpetuates CE strategies that are unnecessarily superficial and that discount opportunities for CE to improve the impact of global health research and make it more ethical, and more valuable for host communities.

In this paper, we present a model of CE for global health research that provides funders, implementation partners and host communities with a conceptual architecture to aid in the design, implementation, and evaluation of CE activities for global health research programs and projects. The model integrates the findings of 10 in-depth case studies of CE from 7 countries and a variety of disease areas and research strategies with conceptual analyses of the ethical and practical goals of CE.

The CE model describes the relationships among key aspects of global health research program design and how these shape specific requirements for the design and management of the associated CE strategies. CE design has both conceptual and operational foundations and these, in turn, shape the way the specific goals of CE are understood for any global health research program. The goals of CE have both ethical and practical dimensions and, when elaborated and carefully-articulated, illuminate a range of possible outcomes that should broaden and deepen our understanding of the implications and potential value of CE for all stakeholders.
Philani Sikhakhani, Justin Dixon and Amber Abrams

Challenges of Interdisciplinary Collaboration in Community Engagement: Reflections from a Street Theatre Project at a TB Vaccine Trial Site in South Africa

This paper explores a community engagement project run by the South African Tuberculosis Vaccines Initiative (SATVI), which has been running TB vaccine trials in the Breede Valley, Western Cape since 2001. The project, called ‘Carina’s Choice’ (CC), began its life in 2009 as a comic-cum-recruitment tool for a large infant vaccine trial, and was about a young Afrikaans woman’s ‘brave choice’ to enrol her baby in the trial. Subsequently, in anticipation of an adolescent trial, CC was adapted into a play and performed by local adolescents in high schools across the Breede Valley. Both comic and play were designed primarily to convey information, which could be measured and deemed a ‘success’ using pre- and post-intervention knowledge tests. CC’s latest incarnation, however, sought to do something different. Involving clinical scientists, actors, applied and academic anthropologists, it entailed a street theatre production which was explicitly funded to do ‘public engagement with science’.

But how democratic is the stage? We focus upon the diverging ways in which ‘public engagement with science’ was interpreted by the collaborators. The anthropologists saw it as an opportunity to discover and dramatize alternative versions of the ‘SATVI story’ to the rights/autonomy-centred one performed in schools. SATVI’s clinical scientists, by contrast, drew a distinction between ‘science’ (e.g. TB, vaccinology, participant rights) and ‘SATVI’ (the particular institute with whom people had considerable experience), favouring an abstract engagement with the former rather than opening up the stage to potentially damaging perceptions of SATVI and its trials. Moreover, conscious that the sponsor wanted to see its money had been well-spent, they continued to think of the street theatre performance as an ‘intervention’ whose effectiveness was to be measured. The result was a hybrid of both worlds: pre-‘intervention’ focus groups, fed into an open-ended play where the audience could choose the direction, and finally post-‘intervention’ focus groups intended to foster discussion and debate. Overall, we feel that this was valuable and productive with many lessons learned. However, the anthropologists especially were left with the feeling that the ‘need’ for demonstrable outcomes overly abstracted ‘public engagement’ from context, constrained community input and detracted from the critical potentials of the project.

Katharine Wright, Vicki Marsh, Sassy Molyneux, Dorcas Kamuya

Partnership with children, young people and parents in exploring the ethical challenges of clinical research with children: experience in Kilifi, Kenya

In 2015, the UK-based Nuffield Council on Bioethics published a report Children and clinical research: ethical issues, which challenged many of the ethical assumptions underpinning historic approaches to the regulation of research involving children. While written by an ‘expert’ working party, a fundamental feature of the working party's approach to this two-year project was its ongoing engagement and partnership with children, young people and parents, both within the UK, and in Kilifi, Kenya where two working party members were based.

Partnership methods included a standing ‘stakeholder group’ of young people and parents, online surveys for both parents and children/young people, school based projects in London, Brighton and Kilifi, adult community engagement in Kilifi, and input from ‘young people’s advisory groups’ (specialist groups developed to support children’s research) in England,
Scotland and the USA. Final outputs included a magazine-style summary of the main report, aimed at young people aged 14+ as well as adults, and a three minute animated film, itself produced as a result of a workshop of children and young people aged 10-18 (and now available with soundtracks in Spanish, Arabic and Chinese, as well as English).

Within the broad context of the UK-based engagement, this paper will focus on the input into this project by school children and adults in Kilifi. We will explore the practical elements of engagement (initial approaches, identification of participants, discussion methods, language used, analysis etc); the critical question of the role played by these contributions in the development of the thinking in the report itself; and the implications, both of involvement and of the report itself, for those participants, and other community members, in Kilifi.

Kirk John Fiereck

Community (Dis)Engagements: The LGBTQ Movement/Sector in South Africa

Scholars, globally, have noted the trends towards professionalization within LGBTQ social movements and specifically their partial incorporation within neoliberal economic and cultural rationalities in western contexts. Beyond these processes occurring in locales known as Northern, this paper argues that similar, yet distinct, processes are occurring in Southern contexts and examines these transformations as they are occurring in South Africa. The analysis will be based on more than three years of the author’s ethnographic field research that examines the present-day constitution of sexual politics around the question of “community” as it was addressed by a number of global health- and LGBTQ-focused NGOs in Africa’s most economically prosperous nation and the world’s largest HIV epidemic by examining material. Most LGBTQ South Africans who work at the intersection of community advocacy and global health initiatives describe that their work takes place in, and is constitutive of, what they refer to as the “LGBT sector” and/or “health sector.” This essay will explore a number of ethnographic sources, including key informant interviews and participant-observation data collected among individuals from NGOs that work throughout the southern African region. The analysis will chart the political and cultural processes that translate what was previously conceived of as an LGBTQ “community” or “social movement” into a market-based idiom: namely, what is now considered widely to be a “sector.” Such displacements raise questions regarding the Movement/Community/Sector’s simultaneous incorporation and marginalization within various flows of economic and cultural circulation and the implications of new forms of human and biocapital that are emerging in the global South.

Lieke Oldenhof and Rik Wehrens

‘Who is in and who is out?’ The politics of participation of frail elderly in Dutch healthcare

Community engagement is not only an essential topic in ‘global’ health research, but also an important domain of health research in general. This paper provides a critical analysis of the mundane practices of engagement in a Dutch health collective that aims to connect medical researchers and elderly to better align research to the needs of frail elderly (i.e. elderly with multiple, often chronic conditions). Many governments in western countries embrace patient engagement as a community ideal. A core underlying assumption of engagement initiatives is an active and vocally able patient. However, not all patients align with this image. For example, frail elderly constitute a marginalized group that is often overlooked in engagement
initiatives. To compensate for this, the National Program for Elderly Care (NPO) adopted as one of its core themes participation of elderly people in the articulation and evaluation of research.

Empirically, our paper analyses the problems of engagement in this program in two ways: as experienced by elderly themselves and by looking at the broader social and political contexts of engagement. For this purpose, we conducted interviews with frail elderly and their organizational representatives, doctors and project leaders, in order to capture the descriptive realities and everyday politics of engagement. In order to understand the broader contexts of engagement, we analysed policy documents and minutes of meetings.

On the basis of our analysis, we draw three main conclusions. First, despite ideals of democratic participation, practices of in- and exclusion are pervasive. Especially academically and verbally ‘able’ elderly (‘the chattering classes’) initially take centre stage, whereas elderly with underprivileged social backgrounds feel less inclined to participate or are discouraged during the process of participation. Second, socialization of the ‘less able’ elderly does take place via coaching, guidelines and reflective meetings with the aim of including the emic perspective of the frail elderly. This creates tensions however: while it shapes elderly people into ‘socially acceptable’ participants in the eyes of the medical world, it reduces the particularities of the original elderly perspective. Third, we show how dominant (biomedical) definitions of good research are materially embedded in existing power structures (i.e. academic positions, review procedures and distribution of research money). Nevertheless, frail elderly did exert agency by (partially) reshaping the definition of valuable scientific research beyond a strictly biomedical repertoire. This was done by prioritizing welfare research over medical-technical topics and by emphasizing the need for practical tools to improve elderly life in the here and now rather than long-term, fundamental research.

Theoretically, we analyse these conclusions with the use of various concepts inspired by critical sociology that allow us to grasp the inherent tensions and politics of engagement. By using the concept of governmentality, we are able to understand how elderly are being responsibilized and empowered as ‘good participants’. Empowerment, however, is also disciplining elderly to behave in ‘socially acceptable’ ways in a highly professionalized, medical habitus. Through the concept of ‘social capital’, we explain why frail elderly with underprivileged backgrounds have difficulties to become and stay engaged, while vital and highly educated elderly are better able to voice their perspective. Social capital allows for micro-advantages in the ‘participation game’ whilst the lack of social capital leads to various micro-disadvantages.

The mechanisms of in- and exclusion and related power dynamics we have identified in this research have implications that are also relevant for wider debates in global health. One implication is that our study shows some of the more mundane and subtle aspects of in- and exclusion practices, in contrast to more explicitly manifest examples of exclusion in global health. Another implication is that our study shows how the politics and ethics of community engagement play out in a high income country like the Netherlands. The ways in which a traditionally marginalized group such as the elderly have been able to exert their agency in this program can offer valuable new insights related to the empowerment of marginalized groups in other global health contexts.
Mackwellings Phiri

Contradictory roles in community engagement: the experiences of community representatives in Malawi

Background:

The study explored how community members engaged by research studies as both key informants and community representatives face potentially conflicting and contradictory roles. It examined an integrated community liaison system and community engagement strategy established within a large community-based HIV/TB intervention to enhance dialogue between the community and research team.

Methods:

The study was conducted in urban Blantyre, in Southern Malawi. Data collection drew on qualitative research methods combining in-depth interviews (IDIs) and focus group discussions (FGDs). Purposive sampling approach was used for recruitment of study participants. Themes for the interviews were generated inductively from preliminary analysis of the initial collected data and iteratively as understanding was developed.

Findings:

The engagement strategy created tensions within the community and impacted on trust between the community, community representatives and the research team. Power relationships between researchers and the community representatives affected the way community representatives understood and performed their roles. Their duties as community representatives created tensions between different kinds of representatives and community members, and this affected long-term social relationships within the community.

Conclusion:

The findings show how community engagement is affected by power relationships and can negatively shape social life within communities by damaging relationships.

Magdalena Szaflarski

Partnering with Faith Communities to Address HIV Disparities in Urban America

African Americans face the most severe burden of HIV among all racial/ethnic groups in the United States, accounting for half of new infections and all infections at all stages of disease. The racial disparities in HIV and the long time that it has taken for evidence to translate into practice have created a national urgency to design effective interventions that can be scaled up rapidly. Faith communities, especially black churches, have been suggested as a key partner to address HIV, but stigma and condemnation of homo-/bi-sexuality contribute to discrimination against people who are infected or perceived at risk and impede HIV prevention efforts. This paper will describe a community-engaged research program to address HIV disparities in urban America that involves faith communities in two urban locations -- Cincinnati, Ohio and Birmingham, Alabama. The overarching goal of this community-partnered program is to implement an effective HIV stigma reduction, prevention, and care strategy for African Americans through empowering and engaging local faith
communities. The specific aims of this research are: 1) To develop broad and sustainable academic-community coalitions to address HIV stigma and HIV prevention/care efforts, with a particular focus on faith communities; 2) To identify congregations in African American and other at-risk neighborhoods that are most suitable to provide needed HIV programs, using predictive multilevel modeling; and 3) To design and test a faith-community guided intervention to reduce HIV stigma and improve HIV education/prevention efforts in high-risk communities. This research is guided by the US federal community-engaged research guidelines and global HIV stigma conceptual frameworks. We have employed concept mapping and health impact assessment methods to conduct community HIV needs/resources assessments and to evaluate each city project. Our study’s significant innovation is a focus on religion and HIV and the use of CBPR with a rigorous evaluation component. Furthermore, a predictive model of congregation’s responses to HIV will guide and complement the CBPR. The study provides new evidence about strategies to enhance HIV prevention/care through community engagement and mobilization and reduce the HIV disparity in African Americans.

Mangala Subramaniam

*Ignorance, Knowledge, and Information in HIV Prevention: Studying Women Sex Workers in India*

Studying sex work, the exchange of sexual intimacy for money and support, present researchers with complicated issues to confront. Many scholars studying topics such as sex work and prostitution have relied on ethnography as the primary source of data which is sometimes supplemented with informal interviews. While ethnographic data can provide insights into the daily lives of marginalized populations of interest, interviews, although time-consuming, allow participants such as women sex workers (WSWs), to reflect and narrate in detail their struggles and in this study the access to resources key to HIV prevention. Engaging in conversations with WSWs involves not only relations of power between the researcher and the researched. These conversations are about information shared by the WSW and the ‘community’ - the community of the high risk group of WSWs. The researcher is compelled to engage with local structures of power within the community to unravel the research participants’ ignorance and knowledge of their rights and risks. How does the researcher navigate local politics and handle ignorance and knowledge to gather data about WSWs daily lives that are fraught with risks to health and life? I address this question by drawing on my research - conducting in-depth interviews with WSW participants in a community organization in Bangalore (India). Bangalore, the location of this study, is the capital city of the state of Karnataka.

Although India is a country with low HIV prevalence, it has the third largest number of people living with HIV/AIDS. As per estimates, in 2008-09, there are 2.39 million people living with HIV/AIDS in India with an adult prevalence of 0.31 percent in 2009. In India, most infections occur through heterosexual transmission. Almost 70% of HIV infections in India are concentrated in six states categorized as “high prevalence” and which includes Karnataka. WSWs who were heavily criminalized and stigmatized at the advent of HIV/AIDS, became increasingly visible, engaged in alliances with the state for peer surveillance in prevention and behavior change efforts, and also began to collectively organize for recognition and rights. The AIDS pandemic thus meant an upsurge in interest in WSWs in the developing world and at the same time also provided an opportunity for sex workers to organize. Such a community organization of WSWs in Bangalore is the focus of this study. There are no specific areas in Karnataka earmarked for sex work (commonly referred to as ‘red light’ areas such as
Sonagachi in Kolkata or Kamatipura in Mumbai or Budhwarpet in Pune). In Karnataka, after soliciting and negotiating, the client is taken by the WSW to a lodge/garden, open field or other space depending on his paying capacity. Moreover, as most WSW are 'home based' (and some are street based), non-disclosure of their identity in public or to their family is of paramount importance. This complex negotiation of identity between sex work and the family differentiates this study from others focused on the process of research to study WSWs and HIV prevention.

Márcio Vilar

Contested legitimacy of regenerative vs. established biomedicine: Practices of engagement among immunostimulant-users for treating autoimmunity in contemporary Brazil

From an applied and theoretical anthropological perspective, I explore the following question: To what extent do the forms of engagement of people with autoimmune diseases in supporting non-authorized immunostimulant therapies in Brazil impact the established biomedical approach of utilising palliative immunosuppressive drugs to treat autoimmunity?

By addressing aspects of everyday politics and forms of engagement of medical doctors and patients with autoimmune diseases (such as arthritis, lupus, multiple sclerosis, cancer etc.) in their search for cure or relief, I describe how some of them adopt and promote immunostimulant drugs that are still not fully legalized and that tend to be disqualified by established biomedical authorities. To do this, I report two regulatory case studies that involve different immunostimulant pharmaceuticals associated with non-authorised regenerative medicine: the 'vacina anti-brucelética' (anti-brucellic vaccine), and; the 'fosfoetanolamina sintética' (synthetic phosphoethanolamine). Both are largely used by patients against rheumatoid arthritis and cancer, respectively, and both refuse the conventional approach of immunosuppression in order to properly function.

Using a methodology based on multi-sited fieldwork (incorporating autoethnography and netnography), I follow these pharmaceuticals in order to re-trace associations and map the main relations that have constituted them as biotechnological innovative agents and, coextensively, as objects of judicial dispute and regulation. As part of it, I focus on the efforts of immunostimulant-users to overcome the legal constraints imposed to these two immunostimulant therapies, and highlight a set of actors (medical doctors, patients, governmental agents, entrepreneurs, activists etc.) engaged in the regulation of immunity. Analytically, I seek to understand how scientific innovation, established biomedicine and informal health care co-exist and interact in contemporary Brazil, and how their relations are mediated by legal institutions, for instance, through a judicialization of biopolitics.

By conceptualizing the bionetworking activities of immunostimulant-users in terms of life assemblages, I provide an anthropological reflection from a Global South perspective on their practices of engagement as acts of co-regulation of the immune system that conflict with the globally hegemonic therapeutic model of immunosuppression.
Mark Sheehan

*Justifying the co-production turn in research*

My paper will begin by looking at the distinction between the intrinsic and instrumental value of community engagement. I will suggest that although the instrumental justifications for engagement are clearly distinct from the intrinsic ones, they do have an important role to play alongside the justification of research generally. In the main part of the paper I will examine a number of the intrinsic justifications for community engagement, with special attention to the ideals of the democratization of science and the co-production of scientific knowledge. I will suggest that these models fail in their attempt to provide adequate justification for community engagement.

Musonda Simwinga, John Porter and Virginia Bond

*Who is answerable to who? Exploring the complex relationship between researchers, the community and community representative organisations in two clinical trials in Zambia*

Research is often initiated by researchers as powerful outsiders with skill, knowledge and funds. However, to be successful and ethical, research requires the active participation of people as individuals and collectives. Therefore, it has become a standard requirement for studies to engage in relationship building activities with different community groups to secure entry into the community; solicit input at different stages of the research; and to ensure ongoing dialogue. The extent to which community representatives effectively play their role depends on a number of factors including the nature of communication and power relations between themselves and researchers, and the ability to demand and enforce answerability from each other and in particular from researchers. This paper will explore the accountability relationships that arose between researchers, the community and community representative structures (namely Community Advisory Boards (CABs)), drawing on research carried out in two clinical trials in Zambia between 2010 and 2014.

Myra Parker and Maya Magarati

*Addressing Epistemicide to Achieve Health Equity in American Indian Communities: Applications for Global Health Research*

American Indian and Alaska Native (AI/AN) communities continue to experience a disproportionate level of disease burden across the United States, comparable with rates in Indigenous communities worldwide. Concurrent with the magnitude of poor health outcomes and the effects on AI/AN communities, indigenous communities in the United States continue to bear the effects of medical and research harm from ongoing mistreatment and ethics abuses by government and academic researchers. This paper situates the everyday community engagement practices on research conducted in a series of studies with AI/AN communities in the historical, social, political and epistemological context to achieve an equitable approach to alcohol research within these high--need, stigmatized communities, and suggests updates to the community-based participatory research (CBPR) principles for applications in Global Health research. Along with ensuring research protocols receive Institutional Review Board review and approval at the AI/AN community level, researchers
must meet community requirements for reports on research progress and obtain community input on a regular basis to formulate the study design, methodology, analysis, and dissemination of results. In the attempt to achieve both knowledge democracy and turn the tide of epistemicide, a major outcome of the community engagement process has been seeking research support for a series of joint sessions between academic researchers and AI/AN community members to review study results and plan dissemination. This paper will shed light on unique community engagement practices in research with AI/AN communities that aim for broader transformations in the politics and dynamics of research.

Nils Graber

*Biotechnology and primary healthcare: community engagement in oncology clinical trials in Cuba*

Since the 1980s, the national Cuban biotechnology industry is developing innovative biopharmaceuticals, in particular cancer immunotherapy drugs (monoclonal antibodies, cytokines, and therapeutic vaccines). Created in 1994, the Center of Molecular Immunology (CIM) is focusing on this oncological approach. As a “Socialist enterprise of high technology”, CIM is dedicated to undertaking basic and clinical research, production, marketing, and public health aspects of its pharmaceutical products. After having conducted many early-phase clinical trials to assess safety and efficacy of these drugs, CIM and public health authorities have recently started advanced clinical trials at the level of polyclinics, namely primary healthcare centers. In this research apparatus, family doctors and nurses have a central role, by following patients and providing data on the ground. It is considered as a public health intervention, which mainly aims to assess the impact of cancer immunotherapy at a population level in terms of ‘cancer chronicisation’. Building on an ongoing ethnography of primary healthcare oncology clinical trials, this paper will analyze how community healthcare is entangled and reshaped in this apparatus. While the clinical trials designers consider ‘community’ as a rather passive category, I will show how local practices are building a form of community engagement. These emerging practices are linked to both family doctors’ initiatives and to the spatial characteristics of polyclinics, which give a specific visibility of cancer patients. I will argue that this research apparatus contributes to transforming both the embodied experience and community awareness of cancer, which still constitutes a ‘taboo’ in Cuban society.

Rochelle Ann Burgess

*Involving communities in “Global mental health” research: The case for participatory action methods and community mental health competencies*

Within the field of global mental health, and global health more broadly, there is a legacy stressing the involvement of ‘the community’ in processes of research and delivery of interventions. However, the invocation of this term is complex, as intersecting notions of power, action and participation are seen within the varied designs of ‘community research’, carrying direct implications for how communities are seen, engaged with and, affected by research. Using the movement of global mental health as a case study, this paper interrogates the notion of ‘community’ involvement in research, and argues for an approach that places community driven action at the heart of its efforts.
Community based approaches within global mental health position actors into two broad categories: volunteers or low-skilled staff who participate within research studies on short term basis, (‘handmaidens’ of research); or targets, individuals who participate in studies and trials. Both of these positions are often viewed largely in terms of their benefits. For example, increasing local skills via training, the introduction of employment opportunities into settings with limited other options, and the creation of pathways to treatment and care in areas where little to no services are available.

However, the limitations to these forms of engagement are also becoming increasingly well known. For example, the emotional labour linked to delivery of care in complex settings by low skilled staff or volunteerism can carry negative impacts for individual and community wellbeing. Beyond this, there are concerns linked to the ethics of non-sustainable treatment options created through short term research trials that may not always be supported or taken over by formal service sectors at the end of research activities.

The use of participatory action methods alongside the establishment of community mental health competencies (Burgess, 2012; Burgess 2014), may provide opportunities to shift research-related engagements in global mental health into more equitable partnerships with communities. Through a focus on developing psychosocial resources that enable communities to support their own health and wellbeing in the long term, community mental health competencies emphasise the types of participation that enable more active engagement in research, interventions, and wider community life. Participatory action research carries a similar emphasis on empowerment and community voice, and provides tools to overcome the devaluing of community potential that can arise from mainstream engagements with communities as discussed above.

It is hoped that through the application of such an approach, global health research with communities can revolve around the aim of establishing more meaningful and long term improvements as an outcome of global health research processes.

Saheli Datta

*Legitimating the individual vis-à-vis the generalizable: the unstoppable growth of direct to consumer stem cell therapies.*

The literature on the ethical, legal and social issues surrounding global stem cell tourism is extensive with an overwhelming focus on ‘supply side’ analysis and sparse attention to ‘demand side’ (patient-based) needs (Salter et.al, 2014). According to Salter et.al, the ‘supply side’ comprises of key factors of production enabling the supply of stem cell based knowledge like researchers, clinicians, policy-makers, regulators etc. While health consumers or patients seeking stem cell therapies comprise the ‘demand side’ (ibid). The problem is that despite huge ‘supply side’ investments in stem cell research, statistics driven western models of bio-innovation have produced few of the ‘stem cell therapies’ promised by early breakthroughs in the late 90s. At the same time, a combination of media hype and internet-savvy, information-seeking, globally mobile health consumerism has steadily amplified demand for experimental stem cell therapies that are readily accessible in countries with developing regulations like China and India. The outcome is stem cell tourism. Literature about stem cell tourism provide an exhaustive analysis of the ethical, legal and social issues of stem-cell tourism to China and India but ultimately recommend ‘supply side’ changes grounded in strengthening compliance standards in medical and scientific innovation mainly through international pressure on countries with permissive regulations to raise standards as a precondition of global
collaborations. In contrast, the academic engagement with patients, patient-agency, patient choices are sparse. Thus the resulting overwhelmingly ‘supply-side’ discourse, constructed by the elite epistemic communities who contribute to respected peer-reviewed literature, not only assumes (a) a paternalistic attitude that assumes patients’ bodies as lacking agency to make rational health choices without state-intervention, but also (b) provides a distorted analytic of the ‘whole picture’– as it fails to consider the key dynamic relationship between supply-demand, supplier-consumer, clinical researcher-patient and the impact of internet and globalisation. On the other hand, findings of a handful of studies into the behaviour of stem cell tourists show that patients increasingly ii) draw trust from ‘experiential’ knowledge of stem cell treatments shared via social networks (mostly web-based) at the same time they reference repositories of ‘expert’ knowledge perceived as impartial e.g. the ISSCR guidelines, and iii) view the lack of agency suggested by bioethical positions like ‘trading on hope’ as ‘paternalistic’ and often reject expert knowledge in favour of the ‘experiential.’ Thus literature, however well-intentioned has little impact on patient behaviour. This paper draws on social media interactions of patients at the heart of the stem cell patient movements and individual patient interviews conducted in India, China and UK (from 2013 to 2015) to understand how epistemic communities’ overwhelming engagement with the ‘supply side’ not only marginalises the agency of the ‘demand side’ but in so doing reflects a ‘disconnect’ between epistemic communities and the ground realities that is unlikely to produce meaningful change.

Sharli Paphitis

The Possibility of Addressing Epistemic Injustice through Engaged Research Practice: Reflections on a Menstruation Related Critical Health Project

According to Fricker (2007), epistemic injustices are those which can be seen to dehumanize groups as well as individuals within those groups by delegitimizing them as ‘knowers’ – either in the eyes of society or the academy, or their own eyes - and through excluding them from taking part in the knowledge economy. Engaged research practices purport to stimulate the democratization of the knowledge production processes by being more inclusive of research participants within these processes, and in so doing to promote either testimonial justice (in which the standard and biased reception of testimony from groups or individuals which are given limited credence by hearers from dominant groups has been systematically disrupted) or hermeneutical justice (in which members of marginalised or oppressed groups are given opportunities, resources and platforms to interpret their experiences of the world for themselves and others and share these interpretations with hearers who give such interpretations credence), or both. There has been little research, particularly in a South African context, which examines questions of epistemic justice in relation to community engagement activities – either in relation to the effects within academia or in community partner organisations or sites. While it is purported that when academics and community members are involved in the co-creation of knowledge through a mutually beneficial exchange of resources and expertise, all participants are able to emerge as active stakeholders in the knowledge production process, little research has been done on how community partners in particular experience these processes from an epistemological perspective. Does the proposed process of repositioning research participants in community engagement praxis allows for a new power dynamic to emerge in research such that all parties genuinely feel like they share equal responsibility for determining the processes and outcomes of the knowledge production process? Do such activities allow for an epistemological shift away from the traditional knowledge construction paradigm which “characterises traditional scholarship...
where knowledge... [is] the preserve of universities” (Magaiza 2014: 68) to one in which the democratization of knowledge is prioritized? Does such an epistemological shift in the knowledge construction paradigm extend beyond simply the knowledge construction process to interpersonal relationships between academics – who no longer see themselves as simply detached and credentialed experts who generate knowledge – and community members – who are simply unskilled recipients of knowledge produced by those experts? In answering these questions I will draw on my own experiences working in a menstruation related engaged research critical health project, not only to discuss the complexities of whether the amelioration of epistemic injustices are being served through community engagement activities, but to make recommendations for improving community engagement practices such that they might better serve their purported aims.

Siân Aggett

Opportunities and Barriers to Engagement through Participatory, Community based arts practice with Community Based Biomedical Research in Patan, Kathmandu, Nepal

Engagement terminology rhetoric seems to have recently appropriated the work ‘creative’, perhaps as a way to distinguish engagement based on simple communications models from something which is less predetermined in outcome, open to being transformed by context and less constrained by assumptions of simple linear routes to change. However, how might such projects interface with the daily work of a resource poor, hospital based research environment in a country where the arts are not taught in the curriculum and creativity is not a quality nurtured in the local education system?

I propose to present a paper on two projects: - ‘Sacred Water’ and ‘Jeewan Jal’, which have attempted to use participatory community based arts approaches as a tool to address engagement needs between researchers at the Oxford University Clinical Research Unit-Nepal and people within their research area. Both projects centre around water, health and community: linked with the research unit’s work on enteric disease. ‘Sacred Water’, funded through a Wellcome Trust International Engagement Award found it very difficult to meet overarching objectives of ‘mutual understanding’, dissemination of research findings, informing research protocol and the inclusion of biomedical research knowledge into the creative processes. ‘Jeewan Jal’ is building on the lessons learnt through the experiences of ‘Sacred Water’, and is exploring the types of spaces and interactions where exchange between researchers and non-researchers might take place and what kinds of knowledges might be accommodated and created under the guise of collaborative arts. Both projects have highlighted structural and institutional barriers which, will be tentatively presented in this paper with the hope of gaining critical input from conference attendees.

Yan Long

Brokering Engagement: Domestic Nongovernmental Organizations and Transnational Knowledge Production

While lots of global health research is conducted in middle- and low-income countries, researchers from high-income countries often have to rely on brokerage as a transnational hinge to gain access to and communicate with local communities in the foreign context. By brokerage, I refer to the linking of previously unconnected global health research and local communities by a unit that mediates their relations with one another and/or with yet other
parties. Domestic nongovernmental organizations (NGOs) are increasingly becoming an important type of agents of brokerage especially in the authoritarian context where community engagement is much more challenging. In particular, this paper examines the formation of brokerage and its impact on community engagement by drawing on a case study of HIV/AIDS research in China.

Based on ethnographic and archival data, this article demonstrates how China’s particular historical and political environment enabled Chinese NGOs especially those in urban areas to take on four kinds of brokerage roles as translators, coordinators, articulators and representatives in global health research. I illustrate how successful outcomes depended on domestic NGOs’ ability to leverage their networks, alliances, political and cultural resources as to help western researchers to operate at sites that were otherwise hostile to foreign actors. While this process channeled the voice of certain urban communities into the transnational networks of scientists and policy experts, it hindered people living with HIV/AIDS in rural areas in transnational engagement. Paradoxically, it is when mediating skills were most needed that they seemed to be hardest to accomplish for NGOs.
Presenter Biographies

Aaro Tupasela, University of Copenhagen
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Aaro Tupasela works as an Associate professor of ethical, legal and social aspects of biobanking at the Department of Public Health, University of Copenhagen where he is currently involved in a three year, interdisciplinary research project entitled *Global genes, local concerns: legal, ethical and scientific challenges in cross-national biobanking and translational exploitation*. Previously, he worked at the Department of Sociology, University of Helsinki, for fourteen years; the last year of which as an adjunct professor of sociology with a focus on science and technology studies (STS). As a sociologist with an interest in STS, his research has focused on the social aspects of biomedical use of human tissue sample collections and the information that can be gained from them in different contexts. He also has an interest in the work of population geneticists and the ways in which human populations are characterized and described.

Anna Versfeld, University of Cape Town
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Anna Versfeld is currently completing her PhD in medical anthropology at the University of Cape Town, South Africa. Her dissertation research focuses on the nexus of tuberculosis (TB) and substance use in patients accessing public health care facilities. This work builds on previous research on female methamphetamine users in Cape Town. She also consults for the Key Populations Programme of TB/HIV Care Association. Here she focuses on programmatic aspects of harm reduction approaches to care provision for TB patients and on service delivery systems for sex workers and people who inject drugs. Her background is varied and includes working in the NGO sector on conflict resolution, youth development, and on child and family wellbeing.

Anthea Lesch, Stellenbosch University
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Anthea Lesch is a lecturer and researcher in the Psychology Department at Stellenbosch University in South Africa. Anthea has completed Masters degrees in Industrial Psychology (Rhodes University, S.A.), Applied Social Psychology (Sussex University, U.K.), and Public Health (Johns Hopkins Bloomberg School of Public Health, USA). Her work is located in community health psychology and views issues of health and well-being from a social justice perspective. Anthea is particularly interested in exploring the impact of social inequality on health, and the role of processes of community participation, community engagement and community mobilisation in addressing threats to the health and well-being of at-risk groups in resource-poor communities. Anthea has been involved in conducting social science research on HIV vaccines since 2005, and has participated in a range of national and international events to promote the integration of social science research into the HIV vaccine research enterprise. Her PhD examined community engagement in HIV vaccine research at a research centre in a peri-urban community in Cape Town, South Africa. Building on this work, Anthea is co-investigator on a CHVI funded project that aims to evaluate the community engagement
activities at a research centre at which various biomedical HIV prevention technologies are being tested. Anthea has co-authored various articles in peer reviewed journals that focus on issues relating to HIV vaccine research and clinical trial participation.

**Ariella Binik, The Ethox Centre, University of Oxford**

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Ariella Binik is a postdoctoral fellow at the Ethox Centre. Her work focuses on philosophical questions arising in clinical trials with human subjects, especially clinical trials with children. Ariella's research aims to explain when and why it is permissible to enroll children—who cannot consent for themselves—in clinical research. She argues that children's inclusion in research can only be justified when the risks of a trial stand in reasonable relation to the knowledge to be gained, and she is developing a moral threshold for the degree of risk permissible in research procedures that do not offer children the prospect of direct medical benefit. Ariella's research also focuses on the concept of equipoise, a necessary requirement for the ethical justification of a clinical trial. She has written about challenges arising for clinical equipoise in cluster-randomized trials, that is, clinical trials that randomize groups rather than individual research subjects to different interventions. She is also interested in the justification of equipoise and its application in global health research.

**Bipin Adhikari, Mahidol University**

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Bipin Adhikari is a medical doctor from Nepal. He has a special interest in Tropical Medicine and Public Health. Besides, his career as a clinician in Nepal and in South Sudan for Medecins Sans Frontieres (MSF), he was always interested in exploring the broader aspects of illnesses, how people perceive and how that affects the health behaviour. Currently, he is working at Targeted Malaria Elimination (TME) project in Nong district of Laos under Mahidol-Oxford Tropical Medicine Research Unit (MORU). He is a prospective student for PhD at University of Oxford and his research focuses on the community engagement activities for Laos TME.

**Chimwemwe Phiri, Malawi Liverpool Wellcome Trust Clinical Research Program**

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Chimwemwe Phiri is a Research Scientist at the Malawi Liverpool Wellcome Trust Clinical Research Programme (MLW). She is leading in the evaluation of a community intervention that used Theatre for Development (TfD) as a behavior change tool. Her long term research interest is to explore intersections of medical and visual anthropology. Her research interests include ethnographic photography and film, treatment seeking and health-seeking behaviors, social impacts of participatory interventions and ethics of representation. Chimwemwe's background is in anthropology. Before joining MLW she was a graduate attaché at the British Institute in Eastern Africa, Nairobi assisting on various projects covering the social sciences.
Gift Trapence, Executive Director, Centre for the Development of People (CEDEP)

Gift Trapence is one of the Human activists in Malawi and a Graduate from the University of Malawi. He has done several Human rights courses with reputable Institutions. He is known by the sexual Minorities media column, which is published every week in one of the leading media newspapers. Through Trapence’s work different stakeholders including religious, traditional leaders and the media have been engaged. He has worked as a researcher since 2008 and has collaborated with several organizations including Malawi college of Medicine and Johns Hopkins University, Department of Epidemiology, USA. He coordinated the first ever MSM HIV prevalence study to be conducted in Malawi between 2008-2009. Trapence has also coordinated several behavioural and Bio medical MSM and HIV studies in Malawi. Trapence has also published over 12 papers with different International science Journals on MSM and HIV and AIDS and human rights issues including in one of the leading science Journals the Lancet. Trapence coordinated the much famous MSM population size estimate Study in Malawi in 2014 which influenced the inclusion of MSM HIV programing in the national HIV strategic plan 2015-2020 and Malawi’s Global Fund Concept for the new funding model which has just been funded. Trapence has also co-authored the first in history two Malawian LGBTI books namely Queer Malawi and Proudly Malawian where life stories of LGBTI and gender non-conforming persons are documented.

Daniel Reeders, ANU RegNet School of Regulation and Global Governance

Daniel Reeders is a PhD candidate at the Australian National University School of Regulation and Global Governance (RegNet). His PhD looks at how communicative disciplines like social marketing and strategic communication are used to manage the interface between administrative government and social governance of health issues, via an ethnography of how stigma is managed during the development of campaigns. He is the co-convenor of the Centre for Health Equity and Governance reading group. Before starting with RegNet he worked for ten years in social marketing in HIV, viral hepatitis, cancer screening and sexual health promotion with gay and bisexual men, migrant and refugees communities, and Aboriginal people. Daniel writes a blog called Bad Blood about stigma and public health strategy.

Deborah Nyirenda, Liverpool School of Tropical Medicine

Deborah Nyirenda is a PhD fellow from University of Liverpool and University of Malawi- College of Medicine joint PhD Program. Her doctoral research is funded by a Scholarship award from Wellcome Trust to investigate the purpose, relevance and benefits of community engagement in health research. She holds a Masters Degree in International Public Health from Liverpool School of Tropical Medicine, UK which was funded by a Scholarship award from Commonwealth. Previously, she took the lead on qualitative studies exploring health seeking behaviour in response to Acute Bacterial Meningitis, an assessment of a triage intervention in primary health centres and an evaluation of a public engagement radio programme. She has 10 years’ experience in community development and mixed methods research having worked for International Institutions such as World Relief Malawi and
Malawi Liverpool Wellcome Trust. Her career goal is to strengthen academic research within the fields of community engagement, bioethics and social science and the development of evidence based interventions to improve the practice of ethical research in Malawi.

**Decha Tangseefa, Thammasat University**
(tangsee@gmail.com)

Decha Tangseefa is an Assistant Professor at the Faculty of Political Science, Thammasat University, Bangkok, Thailand. His research and teaching interests lie at the intersection of political theory, cultural studies and critical international studies, especially in relation to migration and border politics. He has contributed to major anthologies and journals in Thai and English. Apart from teaching at Thammasat University, he has also been working with the Thai-Burmese borderland’s civil society. From 2008 to 2011, he was also teaching in a college in a refugee camp along the borderland. During the past few years, he has been working with the Shoklo Malaria Research Unit (SMRU), the Mahidol Oxford Tropical Medicine Research Unit (MORU) and their global scientist networks, helping with social science aspects of malaria mass drug administration (MDA). Currently, he is working on two English book manuscripts. The first is a co-authored book on the Mae Sot special economic zone. The second, which is a single-authored book, is titled Human, Animal, and Thing: Paradox of Security along the Thai-Burmese Borderland.

**Dorcas Kamuya, University of Oxford, UK and KEMRI-Wellcome Trust Research Programme, Kenya**
(DKamuya@kemri-wellcome.org)

Dorcas Kamuya has experience of working in diverse disciplines including health research (current), community development and Agriculture. In all these, engaging communities has been a core theme. She has multi-disciplinary skills including empirical applied ethics, social science, mixed methods. Dorcas has all worked with collaborative networks including Global Health Bioethics Network, H3Africa community engagement working group and the Pan-African Network on fieldworkers. Her work is grounded on realities and how these can feed into/ inform policy and practice. She has published over 16 peer-reviewed publications in the last six years, and been first author in 5 of them. Additionally, she has supervised and mentored a diverse range of staff; an adjunct lecturer at Pwani University, Kenya, and one of the research ethics lecturers at the Msc. International Health and Tropical Medicine class, at the University of Oxford.

**Elisabeth Hsu, University of Oxford**

**Evans Gichuru, KEMRI-Wellcome Trust Research Programme**
(EGichuru@kemri-wellcome.org)

Evans Gichuru has built up vast experience with community engagements of various stakeholders in Coastal Kenya, and in the last 5 years with the KEMRI-Wellcome Trust Research Program in Kilifi. He has particularly enjoyed the challenges presented through KEMRI-IAVI's
research with a focus on key populations, especially MSM and FSW engagements. His contributions with regards to community engagement included sensitizations of religious leaders, administrative people (e.g. chiefs, police), Kilifi Community Representatives, as well as LGBT groups, MSM, FSW and the SOGIE communities (Sexual Orientation, Gender Identity and Gender Expression).

**Georgia Bladon, University of Bristol**

(georgia.bladon@ndm.ox.ac.uk)

I have worked in public and community engagement for a variety of organisations; from the Wellcome Trust to the European Space Agency. This has included working with researchers, artists and the public to develop projects and funding applications; working within funding institutions to assess projects and their outcomes; and developing activities and outputs which increase research impact and improve the diversity of those engaged with, and contributing to, research. At present I run the public engagement programme for the Elizabeth Blackwell Institute for Health Research, University of Bristol, and manage community engagement network "Mesh", a web space for community engagement with health research in low- and middle-income countries.

**Gill Black, Sustainable Livelihoods Foundation**

(gill.black@livelihoods.org.za)

Gill Black began her career as an infectious diseases researcher in 1993. Her experience as a field-based health scientist in Kenya, Brazil, Malawi and South Africa, and extensive interactions with research participants in each of these contexts, catalysed Gill's transition to the Sustainable Livelihoods Foundation (SLF) which she co-founded in 2010. In her capacity as director of Health Participation at SLF, she now works to engage with people living in townships and informal settlements about the public health issues and biomedical research activities that most affect their lives. Gill has developed a core interest in the use of visual participatory methods (VPM) as platforms for action research and to foster transformative health practice. Through partnerships with international experts she has gained experience in a wide range of VPM including the participatory design of health communication materials, digital storytelling, applied theatre, photovoice and collaborative video. Gill is currently leading a Wellcome Trust funded International Engagement project called 'Heart of the Matter' which brings together cardiovascular scientists from Stellenbosch University and residents from the township of Delft in Cape Town, to exchange knowledge and explore diverse perceptions of what it means to eat well. Dr Black has previously led several other health related community engagement initiatives that have focussed on tuberculosis and HIV. Gill received her qualifications and biomedical training at the Universities of Glasgow, Oxford, Cambridge, London and Stellenbosch. She has lived and worked in Cape Town since 2002.

**James Lavery, University of Toronto**

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Javier Lezaun, Oxford University
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Javier Lezaun is James Martin Lecturer in Science and Technology Governance at the Institute for Science, Innovation and Society, and Associate Professor in the School of Anthropology and Museum Ethnography at Oxford. He is interested in novel forms of public participation in science and technology. He has recently completed an ERC-funded project on the role of property rights in the evolution of biomedical research (BioProperty), and is currently working on a study of malaria drug discovery since the turn of the century.

John Manton, London School of Hygiene and Tropical Medicine
(John.Manton@lshtm.ac.uk)

John Manton is Assistant Professor in History at London School of Hygiene and Tropical Medicine, currently researching the history of health planning and development in Africa and Southeast Asia. He has worked extensively on the history and anthropology of disease control and medical research in West and Central Africa. He has collaborated with medical and cultural workers on articles and a broadcast on the history and legacy of community leprosy control programmes in Nigeria, and on an article and community presentations on local input into medical research in Cameroon.

Justin Dixon, Durham University
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Justin Dixon is a PhD student in anthropology at Durham University, funded by the UK Economic and Social Research Council (ESRC). For his PhD, he is conducting an ethnography of the work of South African Tuberculosis Vaccines Initiative (SATVI), a research institute based at the University of Cape Town that conducts large field trials on new TB vaccines in the Cape Winelands. The broad focus is the ethics of medical research in low-resource settings. Previously, he did his undergraduate and Master's studies at the University of Cape Town.

Katharine Wright, University of Oxford
(kwright@nuffieldbioethics.org)

Katharine Wright is Assistant Director of the Nuffield Council on Bioethics, and was responsible for the Council’s recent project on ethical issues arising from the involvement of children in clinical research. Her background is in health policy, law and ethics: before taking up her current post, she spent 9 years at the UK House of Commons, briefing MPs of all political parties on health issues, and then four years in the National Health Service, monitoring the effect of the Human Rights Act on health law in England. During this time she was also seconded to the English Department of Health to work on patient consent. Her work at the Nuffield Council has included consideration of ethical issues arising in dementia; the donation of bodily material for treatment or research; and the sharing of information in the context of donor conception.
Kirk John Fiereck, University of Pennsylvania
( kfiereck@sas.upenn.edu)

Kirk Fiereck is currently working on two ethnographic projects. The first is on “Ethnointimacies.” It explores the entwinement of ethnicity and sexuality when LGBTQ and gender nonconforming South Africans draw upon customary, constitutional, as well as biomedical sex/gender ideologies to enact hybrid forms of queer personhood. They do so by juxtaposing multiple sexual and gender identities across diverse cultural contexts. The second project is on “Biofinance,” and explores how these experiences are largely effaced by biomedical interventions based on new sexual finance technologies, such as pre-exposure prophylaxis (PrEP), hormone therapies, and plan-B. These biotechnologies enable practices that mirror the trading of financial derivatives whereby subjects are compelled to speculatively treat (or hedge) risk instead of disease. He examines how subjects inflect and are constituted by local gender and race relations while giving rise to new, global forms of sociality, what he calls derivative subjectivity, by indexing biofinancialized calculations of abstract risk, through the circulation of cosmopolitical categories such as “MSM” and “transgender.”

Lieke Oldenhof, Erasmus University, Netherlands
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Lieke Oldenhof is a qualitative health researcher, working at the boundaries of healthcare management, anthropology and history. She completed her PhD (cum laude) at the institute of Health Policy and Management, Erasmus University (The Netherlands). For her PhD research, she shadowed healthcare managers in their daily work. Her current research explores valuation practices in healthcare, re-placement of care to the local level, and community-based healthcare.

Rik Wehrens, Erasmus University, Netherlands
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Rik Wehrens is a qualitative researcher trained in Science and Technology Studies. He completed PhD at the institute of Health Policy and Management, Erasmus University (The Netherlands). For his PhD he investigated health collaboratives between researchers, policymakers and practitioners. His current research explores communication between clinicians and patients with a chronic illness using the imitation game method. He is also investigating issues related to new forms experimentalist governance.

Mackwellings Phiri, Malawi Liverpool Wellcome Trust Clinical Research Programme
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Mackwellings Phiri was from 2009 to 2013 part of a dedicated team of social science researchers within the University of Malawi holding the position of qualitative Research
Assistant in HIV and TB research work responsible for qualitative data collection and analysis. Since joining Malawi Liverpool Wellcome Trust Clinical Research Programme (MLW) in 2014, he has been directing his experience towards understanding and improving both community engagement as well as health research through qualitative research. In 2015, he conducted a study about trust and the roles of community volunteers in health research, funded by the Wellcome Trust. Currently, he is working on another Wellcome Trust funded study about data sharing, exploring research stakeholders’ perspectives on personal information being shared between research projects.

Magdalena Szaflarski, University of Alabama at Birmingham

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Magdalena Szaflarski has held teaching and research positions in sociology, public health, and medicine for over a decade. Her passion and career goal is addressing the health needs of vulnerable populations — the economically disadvantaged, minorities, stigmatized, and/or chronically-ill. She advances this goal through transdisciplinary research, education, and community engagement. Dr. Szaflarski has expertise in quantitative and applied research methods; she has published studies in health, medical, and social science journals on topics ranging from racial disparities in HIV/AIDS to quality of life in epilepsy and mental disorders. Her research has been funded by the National Institutes of Health (U.S.), state agencies, and private foundations. She has published expert reviews and served on national and international scientific review panels.

Mangala Subramaniam, Purdue University

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Mangala Subramaniam is Associate Professor of Sociology at Purdue University, West Lafayette, USA. Her research is in the broad areas of gender (and intersections with caste, race, and class) and social movements. Mangala’s current research projects focus on the role of community organizations for HIV prevention in India; interpretation of the law in judgments on violence against women; and the gender and social impacts of institutional arrangements for improved seed technologies. Since 2012-13, she has been studying the politics of HIV prevention and high risk groups in India by covering three major aspects: the ways in which high risk groups such as women sex workers demand rights as respect and dignity; the influence of the structure and leadership of ‘community’ organizations on risk reduction; and the mechanisms utilized by high risk groups to cope with intimate partner violence to reduce risk to HIV. She also studies the process of doing research about marginalized populations such as women sex workers. The papers from her ongoing project on HIV prevention shift emphasis from a clinical approach to the use of a social lens for understanding behavior that will reduce risks. Her most recent article on strategies for HIV prevention appeared in the Deccan Herald, a leading English daily in Karnataka, India. Mangala has served as Secretary/Treasurer of the American Sociological Association’s Sex & Gender section and is the current Treasurer (2016-17) of Sociologists for Women in Society. (https://web.ics.purdue.edu/~msubrama).
Márcio Vilar, University of Leipzig

(mcvilar@yahoo.com.br)

Anthropologist Márcio da C. Vilar was born in 1978 in Recife, Brazil, and actually lives in Leipzig, Germany. In 1996, he began his academic education as bachelor student at the Course of Social Sciences at the Federal University of Paraíba. In 2001, he defended his monograph on ‘Fear in the city’, based on ethnographic fieldwork among dwellers of Porto do Capim, in João Pessoa. Between 2002 and 2004, he attended the Master Course of the Graduate Programme in Sociology and Anthropology at the Federal University of Rio de Janeiro. As his final monograph he defended an ethnography on the experiences and perceptions of taxi-drivers related to violence, work conditions and daily life in Rio de Janeiro. In 2007, he initiated his ethnographic research as PhD candidate at the Institute of Ethnology at the University of Leipzig on ‘Mourning processes, personhood and exchange among Calon-Gypsies in Brazil as boundarization between minorities and majority society’, and submitted his PhD thesis this year. Since 2009, parallel to his PhD study and with support of his mentors at the University of Sussex, he investigates from an anthropological and historical perspective the co-production of medico-legal orders in contemporary Brazil by ethnographically focusing on the circulation of immunostimulant therapies as biotechnological innovations used by collaborative networks of patients and medical doctors to treat autoimmunity.

Mark Sheehan, University of Oxford

(mark.sheehan@ethox.ox.ac.uk)

Mark Sheehan is the Oxford Biomedical Research Centre (BRC) Ethics Fellow and Director of the Oxford BRC Ethics group within the Ethox Centre in the Nuffield Department of Population Health, University of Oxford. He is also a Research Fellow at the Uehiro Centre for Practical Ethics in the Faculty of Philosophy, University of Oxford. He is a National Research Ethics Advisor for the National Research Ethics Service, a member of NICE's Highly Specialised Technology Evaluation Committee, co-leader of the Ethical Analysis of Key Concepts GECiP sub-domain in the context of the 100K Genome Project and was recently a member of the Nuffield Council on Bioethics Working Group on research in children. His academic background is in philosophy with an emphasis on ethics. More recently, he has been working in applied ethics with a particular focus on normative problems that arise directly in practical contexts. His work is increasingly at the intersection of philosophy and social science and is mostly in the areas of research ethics and the ethics of healthcare resource allocation. He has a continuing interest in the ethics of commercialisation in healthcare and the ethics of new biotechnologies.

Maya Magarati, University of Washington (Indigenous Magar from Nepal)

(magarati@uw.edu)

Maya Magarati is a sociologist whose scholarship focuses on the social determinants of health as they affect the health, wellbeing and social mobility of indigenous, refugee and immigrant communities. Using mixed quantitative and qualitative methods, she both examines the science of Community-based Participatory Research (CBPR) principles and practices the art of CBPR on several research projects funded by the U.S. National Institutes of Health to investigate health disparities among American Indian and Alaska Native communities on one
hand and refugee communities on the other. She is increasingly interested in examining CBPR as a decolonizing methodology.

**Mike Parker, The Ethox Centre, University of Oxford**

(*michael.parker@ethox.ox.ac.uk*)

Michael Parker is Professor of Bioethics and Director of the Ethox Centre at the University of Oxford. His research focusses on the ethics of collaborative global health research. Together with partners at the Wellcome Trust Major Overseas Programmes in Viet Nam, Malawi, Thailand-Laos, Kenya, and South Africa he co-ordinates the Global Health Bioethics Network, which is funded by a Wellcome Trust Strategic Award. The Global Health Bioethics Network aims to build capacity and conduct research in ethics and engagement across the Major Overseas Programmes and beyond.

**Musonda Simwinga, London School of Hygiene and Tropical Medicine**

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Musonda Simwinga is a Senior Social Scientist working with the Zambart Project in Zambia. He is a holder of a Bachelor of Arts (BA), Master of Arts (MA) and a research degree PhD from the London School of Hygiene and Tropical Medicine (LHTM). He has over 10 years' experience conducting research in TB and HIV in high burden settings as a social scientist as well as a community engagement expert. His previous experience was in managing development and HIV/AIDS oriented projects including Monitoring and Evaluation. Recently, his research interests have been to assess and develop better ways of engaging the community in research. His PhD thesis was entitled ‘Exploring the Role of Community Participation in Clinical Trials: The Case of Two Community Advisory Boards (CABs) in Zambia’. Dr. Simwinga has been involved in the implementation of large community randomised studies including the ZAMSTAR study, a large two country randomised control trial of community level interventions aimed at reducing the burden of TB and HIV. He is currently the community and stakeholder engagement lead for another large two county community randomised HIV prevention study, the PopART (HPTN 071 Population effects of antiretroviral therapy) trial. Dr. Simwinga has also been instrumental in building capacity for Zambart research staff in conducting ethical research through facilitating research ethics as well as Good Clinical Practice (GCP) training. He is particularly interested in exploring the interface between community engagement and ethics. Dr. Simwinga has training in ethics from the Fogarty African Bioethics Training Programme (FABTP).

**Mwenza Blell, University of Cambridge**

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Mwenza Blell is a lecturer in Sociology at the University of Cambridge. Her work aims to generate interdisciplinary knowledge on the contested topic of the underpinnings of human suffering and flourishing. This includes exploring the impact of social inequality on bodies, taking seriously people's own interpretations and experiences of their biological processes in relation to conventional biomedical understandings. She has conducted anthropological
research in the UK, East Africa, Latin America and South Asia, on a range of topics including menopause, menarche, infertility. Her recent research centres on gender, intimacy and sexuality, as they relate to embodied experience and biological variation.

**Myra Parker, University of Washington**  
(*myrap@u.washington.edu*)

Myra Parker (Mandan-Hidatsa-Cree) is an assistant professor in the Center for the Studies of Health and Risk Behavior in the Department of Psychiatry and Behavioral Sciences, in the University of Washington School of Medicine. She also works at the Indigenous Wellness Research Institute at the University of Washington School of Social Work. Dr. Parker received her B.A. in Human Biology from Stanford University. She received a J.D. from the James E. Rogers College of Law at the University of Arizona in 2001, with an emphasis in Federal Indian Law. She received her M.P.H. from the Mel and Enid Zuckerman School of Public Health at the University of Arizona in 2002. Dr. Parker graduated with a Ph.D. in Health Services from the University of Washington School of Public Health in 2010. Dr. Parker has worked for over ten years on tribal public health program implementation, and coordination with tribal communities in Arizona, Idaho, and Washington, as well as with tribal colleges and universities across the United States. Prior to embarking on a career in research, Dr. Parker worked for five years in the policy arena within Arizona state government, in tribal governments, and with tribal working groups at the state and national level. Her research experience in public health involves Community Based Participatory Research, cultural adaptation of evidence-based interventions, and disparities research. As an enrolled member of the Mandan and Hidatsa tribes, she is aware of the historical health practices and misconduct perpetuated on tribes in the United States, as well as other minority and disenfranchised populations. Her background in law and policy has informed a broader understanding of the principles of ethics as well as honed her skills in identifying methods to address the disparities in research control and access through the use of formalized agreements.

**Nils Graber, Cermes 3, EHESS/INCa, France**  
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Nils Graber started his academic formation at the University of Lausanne with a bachelor in philosophy and social sciences, with a specific interest in ethics and medical anthropology. As he wanted to deepen his methodological and theoretical background in social sciences, he undertook a masters degree at EHESS in Paris. Here, he conducted some fieldwork studies on two topics. On one hand, he realized a research on assisting suicide in Switzerland, which focuses on the social trajectory and ethical positions of volunteers engaged in associations providing such assistance. On the other hand, he started researches on international aids in favour of the Cuban health system. For his PhD, debuted in 2014 at EHESS, he chose to focus on the local development of cancer drugs in Cuba, by exploring its social, (geo)political, and ethical stakes. Since then, he has been living between Paris, Switzerland, and Havana.
Rochelle Ann Burgess, London Metropolitan University

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Rochelle Ann Burgess is a critical community health psychologist who has worked globally exploring the role of communities in global health promotion. Her research and teaching are focused on applications of psychological theory to real world issues and the fight against global inequality in areas of health, gender and sexuality, race and economics. She is a Lecturer in Health and Social Care at London Metropolitan University, research associate at the Health, Community and Development Research Group, LSE, and the Health Economics and HIV/AIDS Research Group (HEARD), University of KwaZulu-Natal, among other affiliations. Her current research explores the feasibility of promoting community mobilisation within the space of brief-mental health interventions in resource-constrained settings. Her forthcoming book Re-thinking global health: Frameworks of Power will be published by Routledge in late 2017.

Saheli Datta, King's College London

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Saheli Datta is a final-year PhD Researcher at the School of Social Science and Public Policy, King's College London. Her PhD research is conducted as part of the ESRC funded Rising Powers Research at King’s Department of Political Economy jointly with King’s India Institute. Saheli’s research explores the evolving issues of transnational governance in the global bio-economy through the comparative lens of governance issues facing stem cell research and therapies in China and India. Prior to joining the PhD program at King’s, Saheli completed MSc with Distinction from King’s School of Social Science and Public Policy and a BA in Economics from Columbia University, New York. Since then, she has authored and co-authored several peer-reviewed articles, workshop reports and working papers. In the last year, she has been the recipient of various competitive awards and attracted individual research fellowship from the Newton-Bhabha Fund for research at the Indian Institute of Science, Bangalore under the supervision of Prof R Gadagkar, President of Indian National Science Academy (INSA).

Sharli Paphitis, Rhodes University

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Sharli Anne Paphitis is a South African philosopher and community engagement practitioner who received her doctorate in philosophy from Rhodes University. She has lectured in applied ethics, law, philosophy and community engagement at Rhodes University and the University of Fort Hare, and currently serves as the chair of the Rhodes University Ethical Standards Committee. Her philosophical research has largely focused on the ethical dimensions of human agency, identity, personhood and vulnerability. She has tried to bring this philosophical work to bear on her approach to community engagement, focusing on human development in engagement projects she has established and co-facilitated at Rhodes University. She was awarded the 2015 Rhodes University Vice Chancellor’s Distinguished Award for Community Engagement for her work in the critical health education project, Siyahluma, which addresses issues around menstruation in South Africa.
Siân Aggett, Sussex University

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Siân Aggett is a Wellcome Trust doctoral student and associate tutor in the Centre for Global Studies, and Media, Film and Music department at Sussex University exploring the use of participatory and socially engaged arts as a tool to engage biomedical research with local communities and publics. Her doctoral research is practice based and focuses on enteric disease and water in Patan, Kathmandu where over the last two years she has been working with epidemiologists, contemporary artists, local community arts organisations and community participants on two socially engaged arts projects linked to the work of the Oxford University Clinical Research Unit at Patan Hospital: www.sacredwaternepal.com/#intro and www.jeewanjal.com. Prior to this Siân worked for a number of years at the Wellcome Trust, a global foundation to support biomedical research, as the manager of the International Engagement Programme. This role saw her work alongside others to build and facilitate an international community of engagement practitioners and programmes across Global Health research programmes in East Africa, South East Asia and Latin America. With a first degree in Biology with Media, her career began within informal education at London’s Science Museum and later, The Natural History Museum where she worked in the learning departments and as a host and producer of public science events. Siân, also has a Masters degree in Sustainable Development, her thesis explored the use of participatory video as a tool for empowerment with young women in Honduras with whom she retains a committed relationship. Sian’s freelance work within the field includes illustration of research engagement materials, programme evaluation and hosting of public discussions at venues and events such as the Wellcome Collection, Brighton Fringe Festival and Latitude.

Vicki Marsh, Oxford University and KEMRI Wellcome Trust Research Programme

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Vicki Marsh is an Associate Professor at the Centre for Tropical Medicine and Global Health (CTMGH), Oxford University, UK and Senior Social and Public Health Scientist at the KEMRI Wellcome Trust Research Programme (KWTRP) in Kenya. At the KWTRP, her work within the Health Systems and Research Ethics department focuses on empirical ethics approaches to strengthening policy and practice in international research, particularly around ethical issues, including community engagement, informed consent, disclosure of genetic findings, benefits and payments, data sharing and concepts of vulnerability and agency. She is a collaborator in planned research on the development of clinical learning systems in Kenya, led by Professor Mike English at KWTRP/CTMGH; her contribution will involve research on ethics, public engagement and governance issues. At CTMGH, she coordinates, teaches and examines on ethics in research and public health for an MSc course in Tropical Medicine and International Health. Originally trained in medicines and general practice in the UK, Vicki has lived in Kenya for more than 25 years, initially as part of the team that established KWTRP in 1990. During this early period, her research on the role of village shopkeepers in malaria treatment was internationally recognised, and informed policy in the Kenya National Malaria Control Programme and the Roll Back Malaria strategy in the World Health Organization.
Yan Long is an assistant professor of International Studies at the School of Global and International Studies at Indiana University. After receiving a joint PhD in Sociology and Women’s Studies from the University of Michigan in 2013, she worked as a postdoctoral fellow at the Center on Philanthropy and Civil Society at Stanford University from 2013-2015. Her interests span the areas of global health, organizational studies, and community activism. Long currently focuses on the evolution of global AIDS governance and its impact on the political and social determinants of local health inequality. Her book project, Side Effects: The Transnational Doing and Undoing of AIDS Politics in China, demonstrates how transnational AIDS institutions’ endeavors to build community-based AIDS governance in China have alternately sustained, disrupted, and transformed the traditional forms of domination and resistance in public health. Long has received multiple national and international awards including a National Science Foundation Award, the 2013 ProQuest Distinguished Dissertation Award, and the 2014 American Sociological Association Best Dissertation Award.