Taking it to the Next Level: How can we generate leadership and develop practice in engagement?

Wellcome International Engagement Workshop 2018

Image: Attendees of the 2018 Wellcome International Engagement Workshop | Minh Tan

Contents

Summary

The 7th Wellcome International Engagement Workshop took place from 9th-11th October 2018 in Ninh Binh, Vietnam. It was built on recognition that the field of public and community engagement (CPE) is constantly evolving. Strong leadership and greater capacity is required for CPE to reach its full potential and engage as many diverse communities and individuals with science as possible. The workshop brought together key practitioners, leaders and stakeholders from across Africa and Asia to examine and explore the different strategies, roles and types of leadership within engagement, as well as the success and challenges faced by the international engagement network.

The objectives of the workshop were:

- to explore what capacity in engagement means and how it can be developed to improve practice and create strong leadership in engagement
- to explore the elements of different engagement strategies
- to develop the international engagement network and foster collaboration, and explore how this can be done between meetings

Image: Workshop participants | Minh Tan

The workshop addressed key questions including, 'what makes a great leader in engagement?', 'what does the field of CPE require to grow?', 'what networks, systems and approaches already exist to help develop CPE leadership?', and 'what kinds of capacities are important for engagement?'.

Delegates included representatives from organisations such as Carers Worldwide, the Zimbabwe National Association for Mental Health, UNICEF, Wellcome's Africa and Asia programmes, and universities, among others.

1. Leadership

Leadership in the field of community and public engagement (CPE) was a key aspect of discussions at the workshop. Several of the sessions aimed to explore leadership: what it means to be a leader in public and community engagement, what characteristics a leader should have, and what the field requires from its leaders. Talks from CPE leaders, Lillian Mutengu and Bella Starling, featured alongside group discussion sessions to provide participants with the opportunity to reflect on what they felt the role of a leader in CPE should be.

Image: Workshop participants | Minh Tan

During the workshop, participants split into working groups to discuss the question '*what is leadership*?' Across the groups, elements or characteristics which are important in good leadership were proposed:

Inspiring and influencing others

To be a great leader you need to be able to visualise the change that is possible, communicate that vision effectively, then facilitate actions and actors needed to create that change. This should involve stepping outside of the traditional paradigm of 'institution telling community' and moving towards facilitating a two-way conversation. Leaders should also work to influence and motivate others to understand the intrinsic and instrumental value of CPE, rather than just 'scaring' them into including it by threatening loss of funding or scoring poorly on an assessment criteria, for example – although this can be useful to get engagement on the agenda in the first place.

Practising inclusivity

It is vital to appreciate that people can be leaders within different spheres of influence, and that they can all contribute to the common goal. Leadership operates at various levels, from grassroots to senior leadership, and each level is equally valuable and necessary. We must make space for this diversity in our ideas of what constitutes leadership. Another key leadership quality is being able to listen to and empathise with others, but then when necessary being able to step back and make a decision, having taken multiple perspectives into account. To facilitate these contributions from all spheres, leaders must also ensure that the language being used is shared, clear and inclusive to all.

Ensuring sustainability

CPE leaders must ensure projects and their impacts are sustainable in the long term. By investing in people, we can enable and nurture 'bottom up' leadership within communities. To achieve this, community leaders must demand accountability, express empathy, communicate well, and advocate for community interests. Leaders from other institutions must work with the community leaders to ensure they are empowered to do this.

Image: Workshop participant | Minh Tan

A key aspect of ensuring sustainability is assessment. Good leaders must be self-critical and always open to assessing impacts and outcomes throughout projects and schemes. They must recognise areas where the team needs support, and be resourceful and flexible to bring in external help if necessary. Exit strategies must be planned to ensure projects come to an end effectively and without causing any damage to the community.

Behaving authentically

Leaders must lead by example, developing leadership inclusively and co-creatively. This also includes knowing when to step back and always working with the community's interests at heart. Leaders must also have the humility to accept failure and persevere when things go wrong.

These group discussions also created a number of questions:

- What are the differences between individual and organisational leadership? For example, what is the role of an organisation such as Wellcome as a funder, compared to leaders in traditional institutions such as universities, and community leaders?
- Is the aim of a leader to drive the agenda forwards, to improve practice, or to shift the paradigm? All of these things? Or something else?
- In reality, what challenges do CPE professionals face in practicing these great leadership behaviours? How can they be overcome?
- How can we develop a strong body of evidence to persuade others of the value of CPE?

Alongside these discussions delegates heard from two keynote speakers on the role of leadership.

1.1 Bella Starling: Leadership and embedding engagement in research

Bella Starling, a Wellcome Engagement Fellow and Co-Director of Public Programmes at Manchester University NHS Foundation Trust in the UK, presented on 'people-powered research' and the role of leadership in community and public engagement (CPE) to attendees of the workshop. She argued that leadership and growth is about sharing, supporting and collaborating with others, which can sometimes go against the competitive nature of academic science. Bella proposed that public engagement leaders have the power to bridge gaps and help researchers share and support each other in all of their work.

For Bella, leadership is:

- sharing and supporting others
- collaboration as a mark of success
- having the confidence to tread your own path
- filling the space between formal and informal structures
- being authentic and exploring creativity

Image: Bella presenting at the workshop | Minh Tan

Bella also discussed how CPE practitioners operate at the intersection between formal and informal environments – the worlds of academics, healthcare professionals, and community and patient groups. She argued that there is no formal definition of leadership in this space, so it has to "tread its own path".

For growth in the public engagement sector to occur, there needs to be recognition that the separate paths – those of informal and formal workers in different sectors – work in parallel, interweaving and complementing each other. There is no hierarchy, and one is no more important than the other. Bella had in the past been referred to as a "jack of all trades", balancing many different skills; a sentiment many public engagement professionals will surely have felt. This flexibility is often not valued, and this negative perception contributes to the field still being seen by some as "fluffy". To combat this, Bella argues public engagement professionals must take pride in their skills, knowledge and attributes, and feel masterful at a number of different skills. CPE professionals must make the case that good research cannot happen without good engagement.

In her blog to accompany the presentation, Bella lists the following skills and attributes as examples of those held by CPE professionals:

- *"The ability to distil, and be crystal clear about, the purposes and potential outcomes for engagement (not always an easy task!) – often at the eleventh hour*
- *Strategic thinking and planning, often with very limited resources*

- *Relationship management and teamwork working with a huge variety of people and patients, academic and research disciplines, creative partners and cultural organisations*
- *At times, transforming conflict (or perceived conflict) into productive thinking partnerships*
- *Sensitive, skilled and precise facilitation skills*
- *Influencing skills, tact and assertiveness*
- *Emotional intelligence; people and social skills, working across the disenfranchised to the highly corporate, the enthusiasts and the nay-sayers*
- *Clear and accurate communication skills, with a healthy dislike of jargon*
- *Creative flair and talent to inspire and engage*
- *Mastery of an arsenal of engagement and involvement methods, and generally getting stuff done*
- *Resilience (in bucket loads)*
- *Incisive impact and evaluation skills at project, programme and strategic levels*
- *Passion, drive and commitment*
- *The ability to understand and unpick complex and wide-ranging areas of scientific research in order to understand how to do 'good' public engagement and involvement*
- *A thorough appreciation of research methodologies, ethics and governance processes…*

As a public engagement professional, leadership in this boundary space often involves storytelling, to gain buy-in from senior leadership but also to connect all the people you work with. Using storytelling skills allows you to tap into emotions, which are a critical part of engagement work; professionals should not be afraid of this. This includes your own emotions as a CPE professional, which means acceptance of failure and self-reflection. By being authentic with your own emotions, sharing stories with those you want to engage with, and knowing your own skills and strengths, you can become a great leader in engagement.

1.2 Lillian Mutengu: Leadership and embedding engagement in research

Lillian Mutengu, Community and Public Engagement Manager at the African Academy of Sciences (AAS) in Kenya discussed how to ensure researchers view community and public engagement (CPE) as a core part of their work. Lillian has over two decades' experience in public and community engagement with biomedical science and sexual-reproductive health, working in leadership roles to implement innovative engagement strategies in a number of settings, as well as contributing to national and global policy advocacy. Lillian was able to draw on her wealth of experience for workshop attendees and present methods for ensuring senior buy-in to engagement work, particularly from senior research leadership.

Lillian's current role involves influencing senior research leadership, doctoral trainees and postdocs, and working with those implementing engagement. She discussed how to exercise CPE leadership to influence institutional policies and practices, making the following suggestions:

- Research Funders could make engagement a required aspect of research practice by:
  - Including it in calls for proposals/grant applications;
  - During review of proposals/grant applications, allocating a reviewer(s) to specifically review aspects on public engagement.
- The AAS has an established 'Science Citizenship Policy', which seeks to support scientists to serve the interests of their wider community. In practice, this means that researchers applying for grants to the AAS are required to provide their public engagement plans alongside their research proposals. Other funders could implement similar policies.
- It is important to support young and early career researchers to plan for and implement CPE in their research projects. This will ensure they recognise the value of public engagement early on in their career. They can then act as public engagement 'champions/advocates' as they progress through their research field.
- CPE professionals should also act as leaders by developing strategic plans to guide implementation of engagement activities at their respective institutions. Strategic planning facilitates measuring of impact, and ultimately, making a strong case for public engagement based on evidence.

Image: Lillian giving her presentation at the workshop | Minh Tan

2. Capacity

Image: Workshop participants | Minh Tan

One of the key themes to come out of the 2018 Wellcome International Engagement Workshop was building capacity; that of engagement practitioners so that they can achieve as much as possible, and how engagement can be used to build the capacity of audiences and communities. A number of presentations on this topic were made at the workshop; find articles and slides on those further down this page.

As a group, workshop attendees were asked to work together on a visual illustration of important aspects of capacity for effective public and community engagement.

These sessions are designed to stimulate open dialogue; uncover differences and commonalities in understanding; and work towards shared ideas of the theme, in this case "capacity".

The idea of the exercise was not to reach consensus or make decisions, but some common areas did emerge across the six groups. These included:

- Whose capacity are we aiming to build? Capacity resides in multiple places and people in engagement including researchers, public engagement professionals, and the communities we are working with.
- How can we make projects and networks sustainable by building the capacity of different groups?

- How can we build evidence of the effectiveness of PE to get senior buy-in, to then grow our capacity?
- How can we ensure we're always being reflective and evaluative, to ensure we're using our capacity in the best way possible?

Below are examples of the final illustrations.
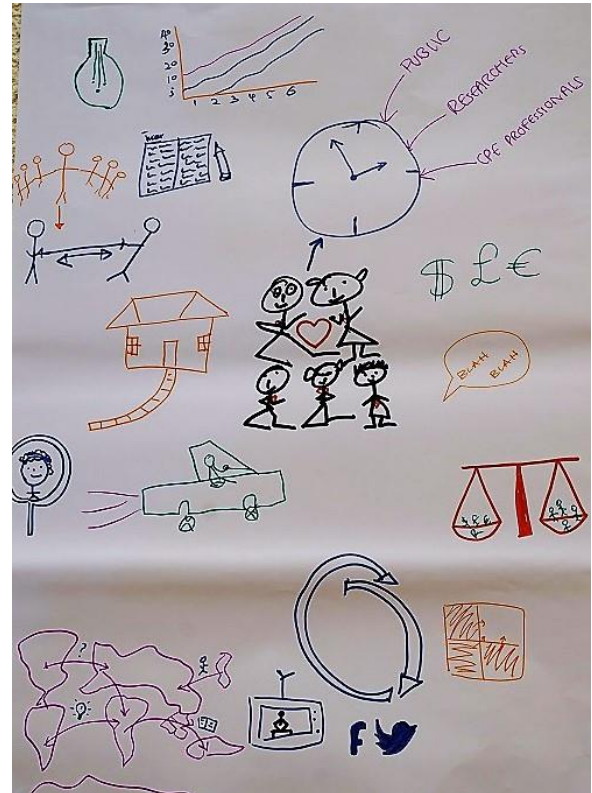
2.1 Abraham Mamela: Building ecosystems for sustainable engagement projects

Image: Abraham presenting at the workshop | Minh Tan

At the 2018 Wellcome International Engagement Workshop, Abraham Mamela, a Wellcome public engagement fellow and science engagement professional based in Botswana, presented on making engagement projects sustainable. Having just started his fellowship, Abraham told attendees about his ideas for developing the capacity of the field; he focused on how to build ecosystems and networks which will facilitate and nurture good engagement.

He posed a series of questions: How can we develop the capacity of communities to sustain projects? What relationships and resources could be put in place to support projects into the future? How can we build partnerships that co-own the proposal? How do other industries do this, and how can we work with others to raise the quality and improve the sustainability of projects? Abraham's answer to many of these questions lies within the creation of a 'project ecosystem', where different projects can be nurtured and developed at different points throughout their existence by actors with relevant skills and resources.

The way projects are currently managed in the engagement space are like planes in the sky - according to Abraham – as they progress they leave behind trails which might

intersect with those of other planes, but only briefly as the trails fade over time. An ecosystem, however, would be like the Nile river: it would support the entire community around it, and different streams of activity would feed into it, and some may dry up, but they ultimately work together to keep the river flowing. This is what we should be aiming for: by building a project ecosystem, the capacity of everybody working in the field would be stronger.

To help visualise how this would work, Abraham posed the 'ideal' project. A project which has ample resources and where the project team are so embedded that they have unlimited access to enablers within the community. 'Enablers' could include religious leaders, those involved in community groups, local employers, and more. Thinking this through, Abraham came up with a list of stakeholders who could form an ideal 'ally map'; institutions and organisations that each project should aim to engage with to ensure the range of access, capability and capacity required for a successful engagement project.

Image: Plane trails overlapping in the way Abraham describes

This 'ideal project' would be supported by those in the 'ally map': knowledge institutions, business leaders, funders and community groups. The idea for the project could come from any ally on the map, but it would be supported by every single one. The knowledge institutions can provide research and academic backing for a project, businesses could provide management and administrative support, funders would offer financial support and community groups would work to implement and guide the project. Communication between all stakeholders would be constant, meaning the projects could be updated and altered throughout the entire process to make sure it best fits its purpose.

In a more formal sense, Abraham also argued that, when a project comes to and end, there should be a facilitated workshop bringing together all beneficiaries and

stakeholders to discuss the value of the project and begin to design the next steps. Many engagement practitioners are doing something similar to this already, if not more informally - drawing on the help of those we know who are experts in particular areas and using their feedback to adapt projects in an iterative way. But Abraham argues that formalising and strengthening this existing network and making it accessible will create an economy of scale, through which this project ecosystem can be created.

This ecosystem could help to make working across many projects together more affordable. Practitioners could work collectively to make it accessible and break down barriers to projects starting and/or continuing.

Abraham argues that "ecosystems plus projects provide the best of both worlds", offering support to every stakeholder in the engagement project process to strengthen each ally's capacity.

2.2 Building communities of practice: MESH and The Global Health Network

The Global Health Network (TGHN)

[The Global Health Network](#) (TGHN) is a platform for communities of practice in specific global health fields that facilitates and enables researchers and health care professionals to work together across networks and between diseases, regions and organisations. Through these communities of practice, research outputs are amplified, and the process is made easier, faster and better.

Image: Leandro Abade, TGHN programme manager, presenting | Minh Tan

The platform supports health professionals to lead research in the world's most challenging settings and enables organizations to share best practice and know-how around the globe. If you are viewing this article on Mesh, then you are already within the network, which hosts Mesh alongside over 30 other communities of practice.

The platform is supported by a small Operations Team led by Professor Trudie Lang, Director of The Global Health Network. The team is based at the University of Oxford in the UK. Leandro Abade, TGHN's programme manager, presented the objectives and approaches of TGHN to attendees of the workshop.

The aim of TGHN is to bring people together to share expertise and knowledge, ultimately to make global health research easier, better and faster. TGHN members can share training and resources to help improve their research processes and capacities. Starting in 2011 with a single site on Global Health Trials, initiated to develop a knowledge sharing culture around clinical trials in global health, and funded by the Gates foundation, TGHN now hosts over 30 communities, where those working in specific areas of global health can network and share learning and methods.
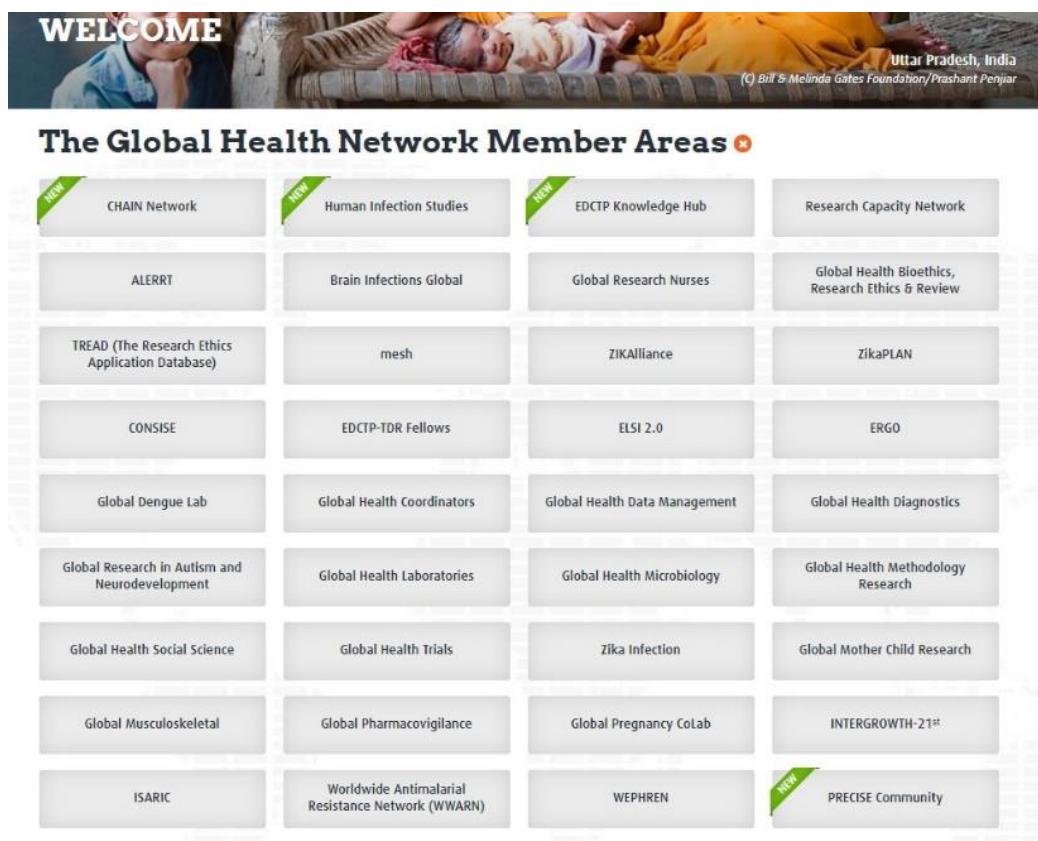

Image: The Global Health Network homepage, with all the current member sites.

This format allows those working in research to share materials and to meet ambassadors across different regions to feedback on these processes and outcomes via TGHN's various resources and tools such as the 'matchmaking' Sitefinder. Materials hosted on TGHN include:

Image: Some of the resources available through TGHN
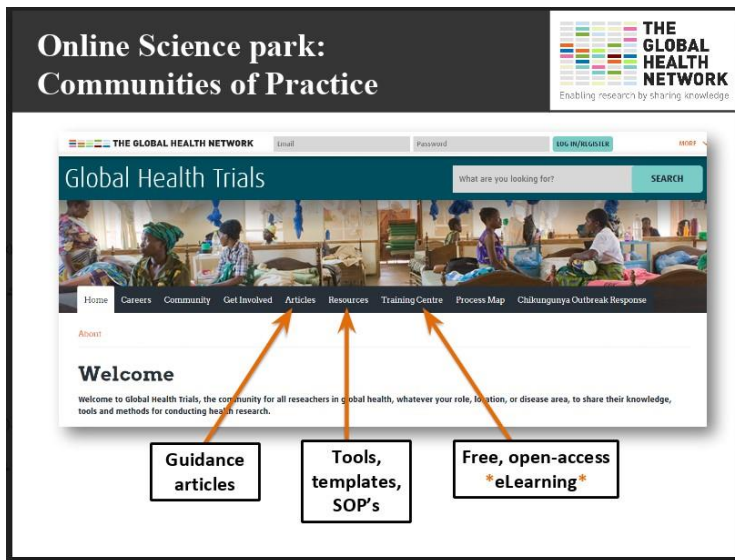
- Free, open access e-learning
- Guidance articles
- Tools, templates
- Live blogs and discussions with useful insights
- TGHN has an extensive global presence - since 2011, researchers, nurses, technicians and scientists working in low and middle income countries (LMICs) have accessed The Global Health Network over 11 million times, with many thousands of regular users.

REDe, the Research Capacity Network

Image: Nina Jamieson from TGHN presenting REDe | Minh Tan

One of the member areas hosted on TGHN is the Research Capacity Network, (also known as REDe). Nina Jamieson from TGHN presented REDe to the workshop attendees. REDe is a regional network, run across the three EU-funded Zika consortia (ZIKAction, ZIKAlliance and ZikaPLAN). The aim of REDe is to develop a network of research sites and build strong partnerships between all the research sites running Zika studies in Latin America and the Caribbean so that together, a sustainable

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platform for research develops that has the capability to respond effectively to future outbreaks. The pages are available in multiple different languages to make them accessible to researchers across the world.

REDe is currently undertaking a 'knowledge gap analysis' (KGA) study to establish the key knowledge and skills gaps in Latin America and the Caribbean, relating to clinical and laboratory research. The aim is to determine key training needs in order to support health facilities and laboratories in running high-quality health research studies. This KGA will inform the development of a training curriculum, and mentoring schemes that can be initiated between different study sites.

The Professional Development Scheme (PDS) is an online tool and a reliable mechanism to record a researcher's skillset, track career development and identify gaps in knowledge. It provides a step-by-step process to comprehensively document research experience and research competencies. The scheme can help plan staffing requirements for a study, carry out appraisals and direct training programmes. Measuring the acquisition of research competencies generates comprehensive data on the impact of capacity development, an essential requirement for conducting effective health research.
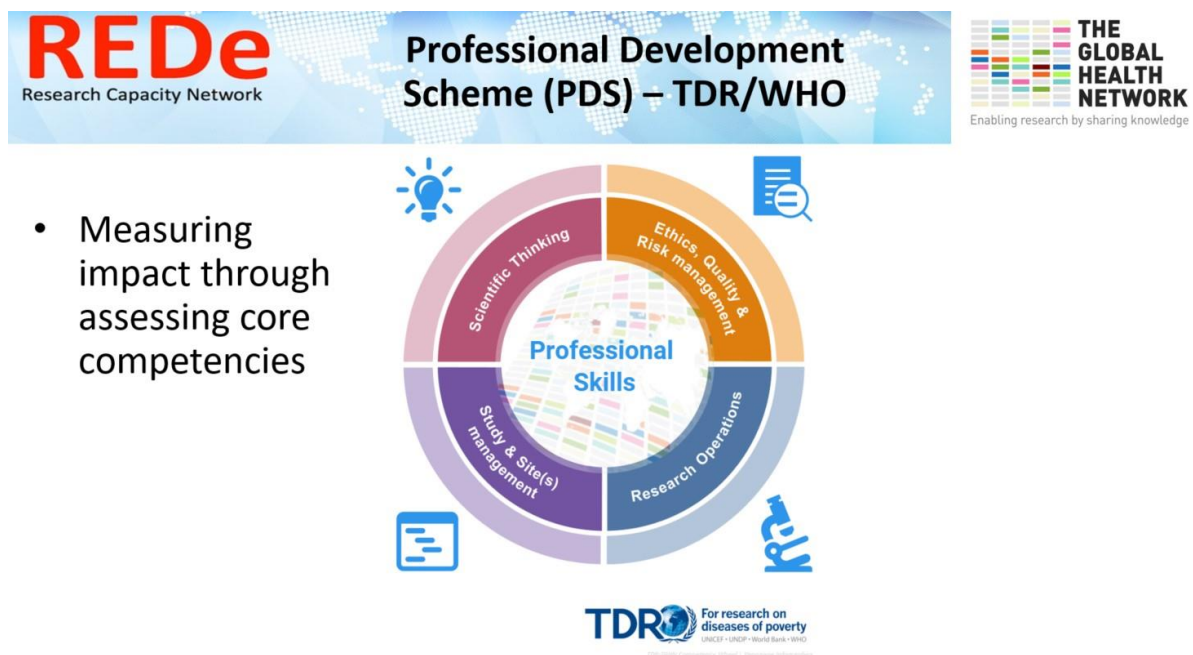
Image: Some of the resources available through REDe.

Mesh

Mesh is one of TGHN's member areas. Launched in 2016, it is a network for those working in community and public engagement (CPE), especially in low- and middle-income countries. It aims to support a community of practice around community engagement, which can help generate greater capacity and leadership, and evidence to support community engagement. It is a knowledge platform with information presented in a way that is accessible to a range of stakeholders. It is not currently set

up to serve communities themselves, but is instead focussed on how to incorporate expert knowledge of communities into engagement work.

Mesh includes:

- A repository of funding opportunities - which is open to contributions from the CPE community, if you know of any others!
- A list of relevant journal articles
- A repository of relevant project reports
- A repository of practical guides and tools
- A guide on project evaluation
- A map of other networks and organisations e.g. HELP, AVAC, and other places you could go.
- A list of training and funding opportunities

Currently in development is:

- A revamped matchmaking map
- A knowledge portal on engagement around epidemics
- An improved mechanism for discussion and debate

2.3 Career paths in engagement

The pathway to building a career in community and public engagement (CPE) is not well defined. The field is new and not valued equally by all organisations; some may pay less than others, some may expect different skills and activities than others. A group discussion at the workshop sought to address the issue of career pathways for engagement practitioners, particularly in the Global South. Participants thought about what people wanted out of a career in CPE, and compared the field with that of international development, which is much more established than CPE. In development you build capacity of community members to be the implementers. Are public engagement professionals willing to devolve engagement in this way? And what is the duty of care around empowerment, as we don't want to over-burden the community? Participants were also interested to know what training is currently available and whether it's possible to do a degree or PhD in engagement (see our list of courses here on Mesh).

As the group discussed what a career structure for an engagement professional might look like, it became clear that the role of CPE practitioners is very different in each context and therefore a single, defined career structure would not be useful. However, there was agreement that, even if roles and responsibilities for practitioners in different sites may vary, there are some key competencies that are common across the field. These included:

- Resilience
- Problem solving
- Strategic thinking
- Communication
- Relationship management

- Knowledge/understanding of health and research processes
- Applying evidence
- Project management
- Monitoring and Evaluation
- Facilitation

Image: Workshop attendees working on a task | Minh Tan

Potential actions to go forwards with developing career structures for CPE practitioners included: a sector-wide analysis of engagement professional job descriptions and the key skill sets asked for in different jobs, and the mapping of the engagement professional structures in different institutions. They also called for a scoping exercise to identify the training requirements in the field and the development of short training courses for CPE professionals.

3. Strategy

As the field of community and public engagement (CPE) continues to grow, it's important that engagement activities are not just seen as valuable as stand-alone projects. Instead, they should be part of a wider strategic plan which ensures every activity is contributing to larger aims and goals. At the workshop, how to develop a strategy and why it's important for CPE was one of the key themes presented on by keynote speakers.

Image: Workshop attendees discussing ideas | Minh Tan

In her talk on [leadership in engagement](#), Lillian Mutengu from the African Academy of Sciences (AAS) in Kenya highlighted key questions to ask when developing a strategy:

- What is the purpose of the strategy and its activities?
- What are the organisational vision and goals?
- What is the organisational capacity?
- What is the budget?
- What stakeholder attitudes will be faced?
- What previous efforts have taken place in this space?
- What sensitivities do you need to be aware of, e.g. cultural, ethical?
- What would success look like?

Lillian explained that it is vital to ensure the vision, overall goal and objectives all speak to each other – although it is not always as easy as it seems to make these align. She also stated the importance of setting yourself realistic expectations, but also challenging yourself get up to 100% buy-in from all stakeholders.

3.1 Imran Khan: Embedding Engagement in Research – Wellcome Trust

Image: Imran presenting at the workshop | Minh Tan

Imran Khan, Head of Public Engagement at the Wellcome Trust, presented Wellcome's public engagement strategy to attendees at the workshop. The Wellcome Trust is a charitable foundation based in the UK that funds research into health. The majority of its funding goes to UK-based researchers, but it also has many global investments, such as their Africa and Asia Programmes (AAPS).

Imran argued that traditionally, public engagement activities have been thought of as fitting into three camps: Transmit, Receive (or consult), and Collaborate.

People in public engagement have traditionally seen any shift from a 'transmit' model to 'collaborate' or 'receive' as a good thing and sought to promote that shift. Wellcome is now trying to break away from this model – and instead of valuing the mechanism of engagement, places more focus on the outcomes.
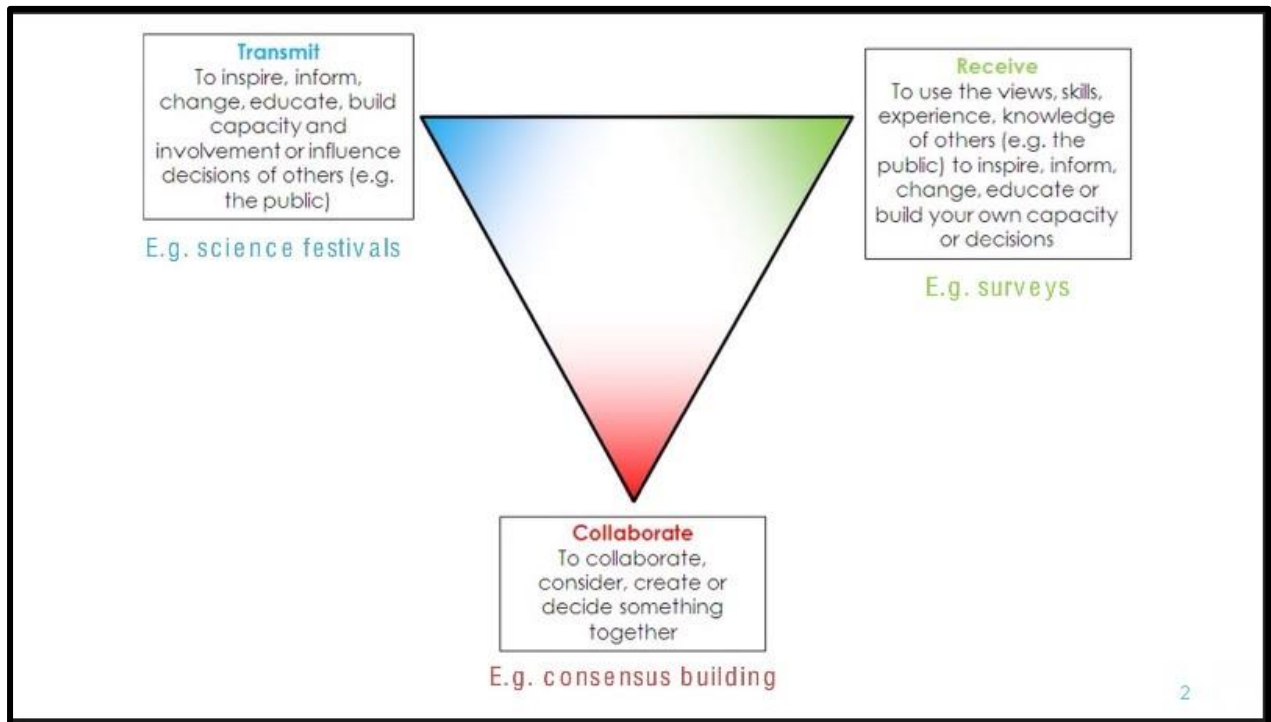
Image: The three traditional types of engagement activity | Imran Khan

In other words, rather than being values-based, Wellcome's new strategy encourages the view that engagement should always be oriented around solving problems, giving it a clear rationale that is easily rallied around and shared.

What's Wrong with Values-Based?

Working with a values-based, rather than problem-based, strategy came with challenges. It was very hard to measure the impact of activities, and as such difficult to get buy-in from others, as it meant other people had to share your implicit values in order for you to work with them. However, with the new problems-oriented strategy, there is a much stronger focus on outcomes and the problems being solved through engagement activities.

The new strategy has three main goals:

- Empowering people: helping people access, use, respond to and create health research and innovation
- People-centred health research: understanding people's experiences and using that knowledge to improve Wellcome's work
- Helping society value our work: bridging the gap between Wellcome and society so that research and innovation are trustworthy and valued by people, whether or not we work with them.

Since this strategy is new, Imran stated that Wellcome don't necessarily know how to achieve those goals yet. For that reason, the approach taken by Wellcome is agile, user-centred and focused on learning and adaptation. To do this, it is vital to get better

evidence on the research and activities being funded by Wellcome. By making the most of the institutions and relationships supported by Wellcome and the PE team, commissioning new research and data on the impact of engagement work, focusing on prioritisation of goals and a new global outlook, Wellcome is hoping to make a success of this new problems-based approach to engagement.

3.3 Ian Thornton: Strategy for Public Engagement

Image: Ian Thornton presenting | Minh Tan

Ian Thornton is a Senior Project Manager at Dalberg, a development consultancy. He is an expert on sustainable development as well as effective strategy production and project management. Ian presented an introduction to developing a strategy to attendees of the workshop. He emphasised that this is not the only way of developing a strategy, but this method draws on corporate strategy and can offer value to those working in engagement.

What is a strategy?

Strategy can be defined (in a 'science-y' way, according to Ian) as:

"an actionable plan to optimise for one or two variables within a set of constraints"

Ian broke down this jargon-filled definition as follows:

"Actionable" = feasible, realistic and achievable

"One or two" = focused on a realistic number of goals – a strategy cannot aim to achieve everything

"Variables" = Actions or audiences that can fit different sectors, organisations or challenges (as Ian calls it, "sector agnostic")

"Within a set of constraints" = The strategy should be grounded in real world challenges, as the context and circumstances surrounding an issue determines whether any strategy is truly actionable or relevant.

Why is a specific strategy important?

To highlight the importance of making choices in strategy development, Ian compared quotes from the CEOs of two competing computing companies, Compaq and HP, in the late 1990s/early 2000s:

> ## "We want to do it all, and we want to do it now"
>
> Eckhard Pfeiffer, CEO Compaq, 1998
>
> ## "Our game plan is to be an infrastructure technology company using our R&D resources to compete against Dell, and leaving IBM to focus on business processing"
>
> Mark Hurd, CEO, HP, 2005

Image: The quotes from CEOs | Ian Thornton

Both sold computer-related technologies and services. As you can see from their CEO's quotes, Compaq's strategy was diffuse and unfocused, whereas HP's was specific and direct. Compaq was bought by HP in 2002, and HP is still a highly successful computing company – demonstrating the importance of knowing your goals, your competitors, and not trying to spread yourself too thinly. Aiming to achieve everything, and trying to do it too quickly, may leave you like Compaq!

Ian emphasises that a strategy can only be truly valuable if discipline is exercised when creating it; for example a Theory of Change or strategy plan that is 'waffly' and non-specific offers no value. This means you might have to prioritise, but that's ok!

What is the difference between a strategy and a plan?

For Ian, a plan tells you what to do, while a strategy helps you make decisions about what – and what not – to do. Plans focus on individual aspects of the overall strategy. More specifically, the difference between a plan and a strategy comes down to a number of elements:

- Scale: a strategy is large scale and covers a whole scheme, whereas elements of the scheme will likely have specific plans.
- Specificity: plans will detail specific activities compared to a strategy which will look at the overall programme.
- Timeframe: plans will likely be shorter-term than the overall strategy.
- Uncertainty: strategies will have a certain amount of uncertainty, while plans will be specific and activity-focused.
- Focus – of outcomes or activities: the strategy will focus on outcomes of the entire programme and what each activity together will achieve. Plans will look at how to implement each activity effectively.

What can I use to start thinking about my own strategy?

Ian gave workshop attendees a number of questions, or prompts, that they could use to shape their own thinking around strategy development:

- What do you want to achieve?
- What are the barriers and opportunities to achieving these goals?
- What are the key assumptions underlying what you aim to do?
    - o Which are in your control?
    - o Which are in your influence?
    - o Which are out of your control?
- What relies on what? Do some elements depend on other things happening, or not happening, to come to fruition? Are some issues 'first order', and others 'second order'?
- What is the 'rate limiting step' i.e. which aspect could bring everything else to a halt, or allow for the greatest change?
- What are you going to stop doing, or not include in your strategy?
    - o What might you allow or encourage others to do instead?
- What do you need to do to test your assumptions?
- What if your assumptions are wrong?
- How can you test that you're on course and achieving your aims?

The exercise that Ian led encouraged groups to address these questions in turn. For many, this was a new way to approach developing a strategy. It is a straight forward and simple way to start thinking about your project, team, or organisation's unique offer in the field.

3.3 Engagement Strategies: The Development of Mahidol Oxford Tropical Medicine Research Unit's (MORU) Community and Stakeholder Engagement Strategy

Phaik Yeong Cheah, the Head of Bioethics and Engagement at the Wellcome Africa and Asia Programme (AAP), Mahidol Oxford Tropical Medicine Research Unit (MORU) in Thailand, presented on the process of developing MORU's community and public engagement (CPE) strategy at the workshop. She discussed the aims of a strategy, the value to community and public engagement professionals of working strategically, and how they are going about creating their strategy at MORU.

Image: Phaik Yeong Cheah presenting | Minh Tan

What is "Strategy"?

Phaik Yeong highlighted the history of the term 'strategy'. Coming from Greek, it is historically a military term, and in military and business settings generally refers to a plan of action for how to 'win'. But in the context of health research and community engagement, there is no simple 'win'; the logic of a CPE strategy will always be more complex, in particular because of the wide range of different interests affected by the conduct or outcomes of any research programme. Phaik Yeong argues that CPE is

about helping research programmes achieve their scientific objectives, while acknowledging and safeguarding the interests of stakeholders.

The Need for Strategy

The MORU team wanted community and stakeholder engagement to be more fully integrated into the organisation's planning and management processes for its research programmes. MORU's research programmes involve multiple stakeholders, institutions and communities across all of South Asia and parts of Africa, and a wide range of ethical and practical challenges. Having engagement embedded across the work of the whole organisation will help the Unit coordinate its research, which will provide critical new insights about how CPE works in research programmes and what value it can deliver for these programmes and for stakeholders, alike. To prepare to implement the new CPE strategy, the engagement team is mapping what engagement is happening already, what activities would fit each research area, and how to gain buy-in from MORU senior leadership.

Developing a Strategy

The MORU strategy is only part-way through its development. To begin building a strategy in this complex environment they have used a model created by the Human Engagement Learning Platform (HELP) for Global Health. This model states that a strategy needs:

- Conceptual foundations: what are the key concepts and aims of the strategy, and what are their implications for its design, management and outcomes?
- Ethical foundations: what are the ethical goals and commitments of the strategy, and their implications for its design, management and outcomes?
- Planning: what are the implications of the science programme for stakeholders? What budget and enabling conditions are in place to ensure effective CPE? What types of authorisation will be required for the various research programmes and what CPE will be required to support these?
- Design: how do the specific features of the research programmes and the contexts in which they are conducted inform and/or constrain the design of the CPE strategy?
- Management: how will leadership, human resources, and stakeholder relationship management be taken on? How will the CPE strategy be integrated into the research programme?

4. Approaches

There are many different ways of going about engagement, with different approaches best for different outcomes, public groups and circumstances. A number of different approaches were presented on and discussed at this workshop, from participatory approaches to human-centred design. Each of these different approaches are summarised in this section.

To find out more about approaches with a focus on inclusion and diversity, read section 6 of this report, focused on Inclusivity.

Image: Attendees at the 2018 Wellcome International Engagement Workshop | Minh Tan

4.1 Participatory, Action, Research: Make your engagement truly participatory

The word 'participatory' has been used in engagement and research to cover a wide variety of activities that involve any level of community involvement. But how should we really define participatory? Is it ok for activities that involve a very small amount of direct involvement to be called participatory? Praxis Institute for Participatory Practices, based in Delhi, India, argue that true participation means involving community members in every stage of any governance process, from research initiation – which should be based on priorities set by the community - to policy decision making. A representative from Praxis presented their work at the workshop, explaining how engagement practitioners can learn from their 'Participatory, Action, Research' principles to make their work truly participatory at every stage.
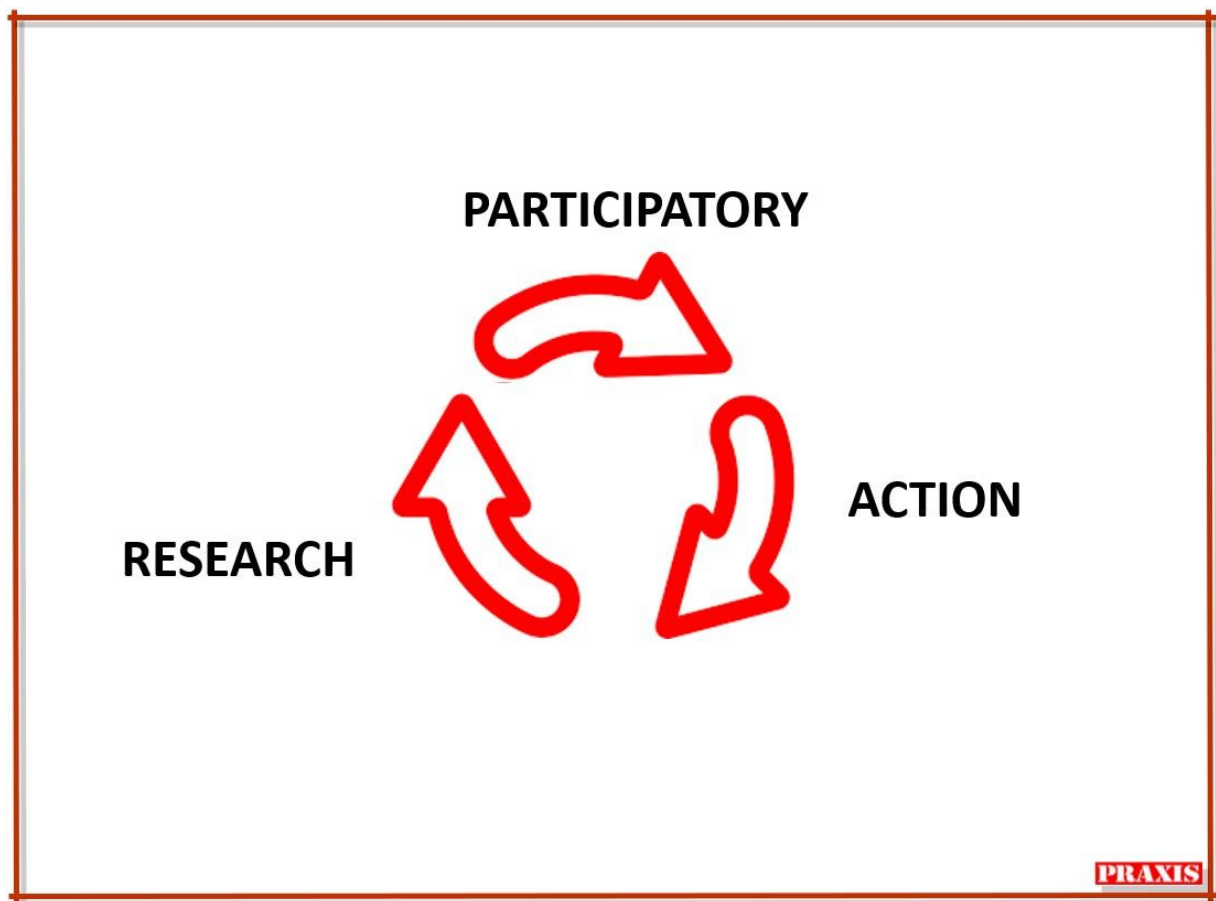
Image: The Participatory-Action-Research cycle | Praxis

As an engagement practitioner, how do you usually define the problem you are aiming to solve? Praxis suggested that when this problem is defined by traditional research and taken on by the engagement community, we are 'pre-fining' the problem; how can we be sure that this is truly a problem felt strongly by the community we are trying to serve, and that there are not other, more pressing problems we should be working to solve first?

This creates challenging questions for those working in engagement: what is our responsibility to enforce the health agenda decided by top-down processes? How do we balance this with a more progressive, community-led agenda, and what do you do when the two may not align? Can and should you influence the community's knowledge and understanding of a subject to shift their agenda?

Praxis argue that it is expected and normal for researchers to have an agenda – everybody working within a society has one. However, the important thing is to not be dominant in interactions; if you are, you will only reach those who already agree with you and you won't have the opportunity to learn from those with different experiences. Behaving like this won't prevent research from happening – after all, it is the way research has been done for centuries! But by not being truly participatory, any research outputs may not align with the needs of the community, making them difficult to implement and potentially damaging from the community's perspective. Praxis presents Participatory Action Research (PAR) as the way to avoid these struggles.

What is Participatory Action Research *not*?

In many ways, it is easier to explain Participatory Action Research by explaining what it is not:

- Research with no participatory or inclusive engagement activities at all.
- Extractive participatory research – where researchers use a community to get data and participants for their research, but offer nothing else.
- A project that begins as researcher-led, then shifts to community-led in its later stages – can it ever actually be truly community-led if the community wasn't involved at the start?
- Research that begins as participatory, then shifts to action research partway through – action research must be integrated from the beginning and must continually shape the process.

What *is* it?

Praxis see the PAR method as a cycle, where participation feeds into action, which feeds into research, which then leads to participation with the results, which then feeds further action, which produces more research, and so on. In PAR participation should be present in defining purpose; in research design, data collection, analysis, dissemination and use.

How is it done?

1. Mapping and Scoping

The first step is to understand the community, not as a homogenous mass, but understand the power dynamics, what is already being done and who you need to influence for change to occur. You will only ever be able to bring a small sample of people to the table, they won't always be "representative" and you will be working with deep seated power dynamics.

2. What Evidence is Needed

What evidence is needed by community? Decide in community meetings what data is relevant and what tools are needed to collect it. Also be aware of capacity issues for the community to collect and analyse data.

3. Tools

Develop tools with community to collect data.

4. Data collection and Analysis

Be flexible about what data looks like, it won't look like data researchers are used to seeing. Think about methods to synthetize knowledge for and with the community.

5. Dissemination and Communication

Any interventions resulting from the PAR process need to be community led. They also need to be confident in influencing and policy and action. As facilitator, you may need to harmonise if people in "power" in the research or influence roles decide on different intervention than the community. Or, if different sections of the community disagree.

6. Evaluation and Learning with Communities

Ensure there is resource to continue relationships where possible.

Key Components and Benefits

Relaying the problem onto the community and being merely a tool for them to conceive of a solution ensures ownership and means less need for incentivisation. In PAR, the action should be led by the community.

Challenges

If the action is led by the community, we need to adopt a do no harm approach to ensure there are not negative impacts. The session included extensive debate on the practicalities and ethics of the approach, some of these challenges are captured below.

Three levels of research buy in are required to absorb PAR into biomedical research:

Researcher (personal) – attitude

Researcher (professional) – data and methods

Institutional - supportive environment

How to we build relationships and break hierarchy between research and community?

1. Locate yourself on their level, allow them to present their knowledge first. Do not start with your own expertise, as it will become hierarchical and they will just listen.

2. Move from researcher/community questions to a group asking questions of each other. Respect the silence as a researcher or engagement practitioner, the community members will fill it with their own experience if given the time to do so.

3. Democratise the process so others get a chance to speak. As the conversation progresses, write comments down for all to see. If you want to ensure you are capturing stories correctly, or not misinterpreting points (which can be disempowering) you can validate each point as you write, but balance this with breaking up process.

4. Allow people to change their opinion and take back information if they want to. A survey misses this as it captures one point of time, but PAR reflects evolving mindsets.

Who is best placed to run PAR?

A good listener. There are pros and cons to different people running PAR.

Biomedical Researchers may not always have the skills, or may carry bias, but by being present the viewpoints of the community sink in much better.

Community engagement practitioners often have the skills but don't always have buy in at senior level in research institutions.

Community members, if they are bought in, can self-organise and run focus groups and research themselves.

Issues to consider in data collection

1. You will hear multiple differing voices and research has to choose one or synthesise
2. There are existing power relationship
3. Certain methods may be exclusionary (access, disability)
4. Be clear what you want – transaction or relationship (You give me X e.g data, I'll give you Y e.g government change, or analysis). If you only want to explore one research area, will you get pulled into wider areas that are not relevant?

Ethics

Consent is a difficult issue for PAR. Consent letters predominantly protect the institution, not the community. Consent can dis-empower as you cannot take back consent and own your own decisions. Who is able to be the gateskeeper to the community to sign consent? And what does ethics actually mean to that community? The red line may be different and needs to be discussed. Community Based Ethical Review Committees can be helpful.

Payments and Incentives

Payment can kill off the research that cannot afford to pay community and it can be argued that the community don't own problem when they are paid for the process. But, the power imbalance is strengthened by lack of payment as, inevitably, someone is being paid. What funding might the community apply for to support their contributions?

Timescales

How do you account for the timescale of impact? Often if the problem is solved, it won't be an immediate pay-off for the community, it could be many years or decades away. You can focus on the greater good vs immediate family and friends but is this what people have capacity to care about when living in difficult circumstances?

Other Barriers

How do you manage expectations or the community naturally seeing the researcher as a problem solver and defaulting to them?

How to you solve wider problems that arise in PAR beyond those related to your research? (e.g literacy, income generation)

Researchers can be scared to lose funding if PAR shows they need to change course.

Making Space for PAR

There are several things that could make PAR more realistic:

1. Space within biomedical grants to flex in response to PAR and/or a requirement to do so.
2. Institutions using other parts of it's machine to help solve problems that arise outside of the researcher remit.
3. Identify where you need community empowerment for research and impact to succeed and funnel PAR in those areas.

The process is important to disrupt the power relationship – even if nothing else achieved.

4.2 Avinash Kumar: Making Research More People-Centred

One of the key aims in the field of community and public engagement (CPE) is for people and communities to be involved in every stage of research. This means from the very beginning: finding the problems that the public need answers to and designing the entire process alongside these publics. Quicksand is an interdisciplinary consultancy that specialises in user-centred innovations. Based in India, its expertise lie in emerging economies, and it supports a wide range of organisations to design innovative and exciting practice with people at their core.

Image: Avinash presenting at the workshop | Minh Tan

Avinash Kumar, one of the co-founders of Quicksand, spoke to attendees of the workshop about their work on people-centred mental health research (MHR) in India. Commissioned by the Wellcome Trust Public Engagement department, Quicksand were given the brief of exploring the landscape of MHR in India from the perspectives of the public, with the aim of providing insights into how people get involved in MHR, who the people who do get involved are, why others might not be involved and what could be done to remove any barriers faced. By doing this, the Wellcome Trust hoped to have a clearer picture on how to make sure MHR in India, and indeed worldwide, as inclusive and accessible as possible, and to pave the way for truly participatory MHR.

Quicksand researched the topic of MHR in three main ways:

1. In-depth interviews with a variety of stakeholders.

Key stakeholders were identified through primary and secondary research, including medical practitioners, researchers, both early in their career and more experienced, community engagement practitioners, alternative therapists and people with lived experience of mental ill-health.

2. Facilitation of collaborative spaces

This involved providing a supportive and safe space and platform for young people with lived experiences, and grassroots organisations working on the ground, to share stories safely and sensitively.

3. Rapid prototyping and testing of ideas

As gaps in Indian MHR emerged during Quicksand's research, they were able to quickly develop ideas and concepts which could lead to the development of a new product or service, or a change in a system, that could go some way to solving the problems. Research participants played a collaborative role in this development and testing stage.

Outcomes

A number of key insights came out of this participatory, iterative process. For example, they found that there is a lack of awareness about mental health in some communities, and that some Indian languages lacked the vocabulary to adequately describe mental illness. This could impact the ability of an individual to seek help if they are suffering from a mental health problem themselves. Furthermore, if somebody did seek help, major gaps in the treatment landscape mean they may struggle to get meaningful support. On the topic of MHR, Quicksand found that researchers struggled to access those suffering with mental health problems, due to barriers such as geography, funds, language and literacy, as well as institutional bureaucracy.

The team decided to hone in on young people specifically, and through their research put together maps of stakeholders in the 'mental health ecosystem' of a young person, including their informal and formal support systems, technological platforms, public resources and community interventions. They also sought to understand potential causes of mental health problems amongst the young population of India, and possible incentives that could be used to involve young people in MHR.

All of this information is a vital resource for mental health researchers in India. They can now have a greater understanding of the needs of the young people they are seeking to access, the platforms they use, the things that might be causing their problems and more. Quicksand suggested a number of steps Indian mental health researchers could take to meaningfully engage with the youth population, which included the development of a research participation digital platform and awareness and research participation events.

This case study shows how human-centred design processes can help researchers and those working in engagement to understand their audience better and adapt their research and processes so that they are truly serving the needs of the population. It also allows them to involve the communities they seek to serve at every stage, from program design to ideation and output design.

4.3 Gill Black: Participatory Visual Methods

There are many different approaches to engaging non-researchers with research. The application of participatory visual methods (PVM) can enable non-researcher participants to work with researchers to actively shape an interactive science engagement process through the co-production and exchange of visual outputs. At the workshop, Gill Black presented Bucket Loads of Health, a recent public engagement project facilitated by the Sustainable Livelihoods Foundation (SLF) that took an innovative approach to working with PVM.

Image: Gill presenting at the workshop | Minh Tan

In recent years, South Africa has been facing severe challenges with its water supply. In mid-2018, the Western Cape Province was declared a drought disaster zone and its residents were subjected to unprecedented water restrictions. Saving and reusing water - already common place in some parts of the country - became much more widely practiced, making the associated health risks ever more pressing. The Bucket Loads of Health project was implemented during the height of the water crisis. It aimed

to bring non-researcher participants into a research engagement process with a team of water microbiologists at Stellenbosch University (SUN).

The SUN microbiology team, led by Professor Wesaal Khan, explore strategies for the treatment of rainwater that has been harvested from shack roofs in informal settlements. The goal of their research is to make the harvested rainwater safe for domestic use, and ultimately for drinking. Enkanini – an informal settlement just outside Stellenbosch - is the current setting for Professor Khan's research. Gill approached Wesaal and her team in 2017, to find out if they would be interested in engaging members of the Enkanini community in their microbiology research. They were delighted to have been asked and did not hesitate to take up the opportunity.

The scope and scale of the Bucket Loads of Health project was expanded by including a group of residents from Delft, a formal settlement in the northern suburbs of Cape Town. The settings of Enkanini and Delft vary significantly in water accessibility. Households in Enkanini have no running water. Residents of the informal settlement collect water from communal standpipes. As such they live with a perpetual water crisis. The majority of households in Delft do have access to running water, but this area of Cape Town was particularly hard hit by the enforced municipal water restrictions.

As part of the Bucket Loads of Health project, the SLF team held creative workshops with residents from both participating communities. During these workshops, participants shared their varied experiences of living with water shortage through art, music and narrative storytelling.

Bodymapping

One of the arts-based activities involved the participatory visual method of body mapping. All of the Enkanini (12) and Delft (15) participants created individual, life-sized body maps that captured their embodied experiences of living with water shortage, and their relationships to water in and around their homes.

Knowledge exchange workshops provided the community members with an opportunity to present their body maps to the microbiology team. They used their body maps as platforms for storytelling, giving detailed descriptions about the multiple ways that restricted access to water was affecting their health and wellbeing.

During the knowledge exchange workshops, while they were presenting and discussing their research with the Enkanini and Delft participants, the scientists referred to what they had noticed in the body maps. As part of the discussions, the Enkanini participants strongly expressed their opinions about the multiple research projects that had been done in their community over the past few years. The scientific team took the Enkanini and Delft participants on a tour of their lab and the SUN microbiology department, to involve them more deeply in their research and open up another space for questions and answers.

Gill argues that the value of participatory methods such as body mapping lies in their accessibility. During her presentation, Gill explained how the visual nature of these methods enables non-researcher participants to articulate their experiences and convey their opinions more easily than through the use of words alone. Gill also described how PVM outputs can be disseminated to, and understood by, a wide range of audiences. However, she also cautioned that working with PVM involves a large degree of openness and sharing. So that the researchers could understand the vulnerability that comes with telling personal stories, the SLF team asked them to create "hand maps" to outline their individual journeys into microbiology research. The scientists shared their personalized hand maps with the BLH community participants at the beginning of the knowledge exchange workshops, as a way of introducing themselves. Gill described how this process showed the scientists to be approachable people who are emotionally connected to their work, and how it provided a springboard for more engaged interactions.

Reflection

20 attendees at the 2018 Wellcome International Engagement Workshop discussed PVM in an open space exercise where a number of important questions were raised. Some questions related to practical aspects of PVM, such as the key practicalities to be thought through when making a decision about which method to follow. Other questions highlighted the possible ethical difficulties that may arise when using visual and storytelling approaches, e.g. as a facilitator, how do you deal with personal, sometimes difficult experiences that may surface through the use of these methods? Is it ethical to create visuals of very sick people? As the outputs of any PVM process are likely to be quite personal, what happens if a researcher misinterprets a visual i.e. presents it to other groups in the wrong way? How can complex medical health messages be conveyed in such a creative context? What happens if the needs or concerns that are uncovered by this process are beyond the reach of the researchers to address? How can it be ensured that other partners in a PVM process can respond so that exposed vulnerabilities are not left unhealed?

These are important questions to ask when deciding whether PVMs are correct for the context and issue, but the benefits of the approach are also many fold. Working with visual methods can be highly therapeutic for participants; they can allow them to voice themselves in ways they have not been able to before, and to convey complicated and personal experiences to those with power to change their circumstances.

Gill has created an email list for those interested to find out more about PVM; email Gill at gill.black@livelihoods.org.za if you're interested in joining. She is also currently working in partnership with Dr. Mary Chambers at OUCRU in Vietnam to develop an e-learning course for Mesh on the practice and ethics of working with PVM for public engagement in health and health science research.

4.4 Engagement with Human Infection Studies: A Panel Discussion

The development of new treatments and vaccines for disease can take years, or even decades to come to fruition, due partly to the difficulties of testing the reliability of such treatments in real-life infection scenarios. One innovative method seeking to speed up this process is known as Human Infection Studies. In a Human Infection Study for a vaccine, for example, participants would be given a dose of the vaccine being tested, before being given a dose of the disease the vaccine aims to protect against, in strictly controlled conditions. If they don't develop the disease, then it looks like the vaccine is effective.

There are strict guidelines surrounding Human Infection Studies; for example, they can only involve diseases with effective cures, such as malaria, and not chronic or otherwise difficult to cure illnesses such as HIV. Most of these studies have been conducted in high-income settings such as the UK and the US, but recently there have been increased interests to carry out these studies in low- and middle-income countries (LMICs) where the diseases are endemic, such that the vaccines are developed in a way most relevant to the people at risk. Human infection studies however can be ethically sensitive, and some of the issues may be particularly pertinent to studies in LMICs. For example, questions arise such as how to compensate people taking part – if the financial incentive is too large, does it become unethical? How do you ensure fully informed consent in communities where scientific literature levels might be lower? And how do you account for what these studies may represent in different cultural contexts?

Image: The panel speakers at the workshop | Minh Tan

Community and public engagement (CPE) is therefore a vital part of planning and rolling these studies out further. Funders such as Wellcome have been working to develop CPE strategies and guidelines for engagement with Human Infection Studies. A number of representatives working on this took part in a panel discussion on the topic at the 2018 Wellcome International Engagement Workshop. The discussion was chaired by Cecilia Chui, Project Officer on Vaccines at Wellcome.

Engagement and Human Infection Studies in Kenya

Noni Mumba, Head of Community Engagement at the KEMRI Wellcome Trust research program in Kenya, described their experience on developing engagement strategies for Human Infection Studies in their community. At first, Noni and her team struggled to get buy-in from policymakers and the ministry of health, but they were eventually able to begin studies using university students as participants. Engagement around these studies was fairly straightforward, involving just university administration and lectures for students. However, they later began a pilot study in the wider community in Kilifi, a coastal town in Kenya. This was the first Human Infection Study in Kenya outside of a university setting and aimed to test acceptability of a Human Infection Study amongst the community, while also developing protocols on who to engage with, how to best go about it, how to establish an effective feedback mechanism, what the community members would need in order to engage meaningfully with the process and more.

While there were no direct health benefits from this study, since it was only a pilot, Noni highlighted that for participants, the regular medical check-ups they were given as part of the process sometimes found other illnesses or health problems they were unaware of before. This medical attention could be one of the incentives for citizens of LMICs to take part in Human Infection Studies. Noni highlighted however that if another illness is found, treatment can't be offered as part of the study, but they can be referred elsewhere.

Noni and her team developed a strong feedback mechanism that can be replicated in future Human Infection Studies. The Community engagement Advice for Studies (CAST) committee was established for the research team with the aim of supporting implementation of engagement and ensuring constant feedback to the study team from community and study participants. The engagement team would then meet with the community and participants in the patient facilities to explain the institution and the process of the study. Participants would also be given a tour of the labs to get a better sense of how the research institution worked. Any feedback the community provided was passed to the research team via the committee. And finally a helpline, which was originally established for community members to call or text for help or information about any study being done at KEMRI-Wellcome Trust, also grew to offer advice on Human Infection Studies. This helpline also provides support for participants once the trial is over.

One of the difficulties of Human Infection Studies is dealing with media attention. It is easy to pick up on potential dangers of Human Infection Studies and sensationalise them, and so it is important to provide accurate and reasonable information to media outlets. Noni recommended tailoring your information to the type of outlet you're dealing with to avoid having things blown out of proportion, although she said that at

the end of their study, after media attention, they actually had more people wanting to sign up rather than negative responses. By working with social scientists the group were able to present the information in a way that was, and is, acceptable to the communities they were working in.

Human Infection Studies and Engagement in Vietnam

Mary Chambers, Head of Public Engagement at the Oxford University Clinical Research Unit (OUCRU) in Vietnam, told attendees about proposed Human Infection Study researching Shigella, a bacteria that can cause severe diarrhoea and fever in affected individuals, especially children, and dengue, a viral infection transmitted by mosquitoes. There are no legal or ethical frameworks in Vietnam for studies involving intentional infection of human subjects, so the team are starting a three-year project to engage government bodies to develop regulatory frameworks that would enable Human Infection Studies, and explore the public perceptions of these studies.

An initial stakeholder consultation was held in March 2018, bringing together 50 stakeholders, including researchers involved in Human Infection Stidies, representatives from the Ministry of Health, doctors, university leaders and more. Key themes emerging from this consultation include:

- Benefit vs risk to the community
    - What is the economic benefit to the community? Any longer-term impacts must be felt in the community, for example by making sure the vaccine is affordable. How much power do the researchers really have to do this?
    - What are the risks to the community? These could be serious, for example the risk of transmission of the studied disease into the wider community; in the case of Shigella this is especially pertinent as it is spread in water, so any waste water from the research facility would need to be specially treated.
- Benefit vs risk to the individual
    - Benefits to the individuals involved in a Human Infection Study include free healthcare and regular, in-depth health check-ups, as well as a financial incentive;
    - Risks from subsequent dengue infections;
    - Risks to the individual could come from certain cultural pressures in Vietnam. Young people are likely to need parental consent to be involved in this type of study, and from the parents' perspective, they may not want to put their child – who they have invested heavily in, as they are at university – in harm's way. Also, researchers had to think of their responsibilities to any participants who were severely affected by the illness.

Like Noni, Mary also was wary of public and media perceptions, and struggled with a lack of legal framework to support the study development.

Human Infection Studies and Engagement in India

Amrita Sekhar, from the Translational Health Science and Technology Institute based in India, described a study on engagement with Human Infection Studies in progress at the time of the workshop. India currently has no policy, regulatory or ethical guidance for Human Infection Studies, so the researchers had to start from scratch. They worked with a range of stakeholders, and communities in both urban and rural settings. Specifically, they spoke to groups from the student community and housewives. The latter threw up interesting points around the cultural complexities of carrying out this kind of research; it was found that wives needed consent from their husbands to take part in studies, but men didn't need any consent beyond their own. Ethicists and lawyers pointed out that in Indian law, it was not possible to legally consent to have harm done to you intentionally. A legal change was therefore required before Human Infection Studies could occur. However, this looks to be tricky; there is a lack of trust in the Indian media about clinical trials, so messaging will need to be improved to gain the necessary media support.

The biggest question Amrita and her team struggled with was how to ensure participants could give truly informed consent, especially non-scientifically literate communities. How could they make sure participants truly understood the risks they were signing up for?

This discussion highlighted many of the key challenges related to Human Infection Studies and engagement around them. However, the research shows these studies can be highly effective and can make the process of drug and vaccine development significantly faster, so the need for these studies to involve good and ethical engagement is greater than ever.

5. Landscape

The field of community and public engagement (CPE) is rapidly growing and changing. As a term, CPE covers a wide range of activities, and different actors in the field may have different perceptions of what CPE means and involves. It's therefore important to look at the whole landscape of CPE and understand where your own activities fit in. At the 2018 Wellcome International Engagement Workshop, a number of speakers and group discussions focused on mapping and analysing this landscape, as well as ideas and strategies on how the field can continue to grow.

Image: Attendees at the 2018 Wellcome International Engagement Workshop

5.1 Jim Lavery: Developing the field of community and public engagement

At the workshop, Keynote speaker Jim Lavery, creator of the HELP platform and professor of global health ethics at Emory University, Atlanta, USA, discussed the current state of community and public engagement (CPE) and how it can be developed in the future.

To understand the changes CPE may need to go through to develop as a field, Jim encouraged attendees to "think by analogy". CPE was compared with the field of health systems performance (HSP), which went through major development and reform in the 1980s and 1990s to become an established and successful field. It could be argued that the position CPE is in now is comparable to the position HSP was in a few decades ago.

Image: Jim at the International Engagement Workshop | Minh Tan

So, what can we learn from the development of the HSP field? Jim argues that many of the questions asked of HSP during its development can be applied to CPE now:

- What are the goals of CPE?
    - What are we trying to accomplish?
- What is the organising model of CPE?
    - What elements or components are necessary to achieve the goals?
    - What are their functions?
- How does CPE actually work?
    - What actually happens in CPE?
    - What are the active mechanisms?
    - What outcomes do these mechanisms produce or contribute to?
    - How does performance vary by context?
    - How does the perception of performance vary with perspective?
- What are the key measures of CPE performance?
    - What outcomes are associated with good performance?
    - Why are these outcomes considered to be "good"? And by whom?
    - What are the indicators of these outcomes?

- Are these indicators currently being tracked and reported and compared in different CPE strategies?

The development of health systems performance as a legitimate field of study, occurred over three main phases:

- Phase 1: Achieving clarity on the conceptual foundations of HSP
- Phase 2: Building the necessary data infrastructure to enable the collection and comparison of HSP data
- Phase 3: Managing the evolution of HSP to achieve impact in improving health systems performance and to improve the focus and responsiveness of health policy at local, national and global levels.

Applying this model to CPE, Jim asked the group whether we have made progress on the goals and rationales for CPE. Have we defined the components of the field? Or created robust models and measures of performance and impact? . Jim argued that we are not yet able to answer these questions adequately for CPE, and to get there we will have to follow a development path similar to HSP. We need to forge consensus on the conceptual foundations of CPE and models of how CPE works. We need to build an evidence base that will allow us to measure performance and make comparisons across programmes to gain clarity on the value and purpose of CPE. And we need to manage the development of CPE to ensure it can have a positive impact on the ethics and performance of research programmes around the world. The field needs to develop gravity to attract more champions, especially within funding organizations. This will help to elevate the status of CPE from the current perception, by many, that it is 'fluffy', and not an integral aspect of many serious research programmes, and improve the intelligent integration of CPE into the design and management of research programmes.

This may seem like a daunting task – but Jim reassured attendees by highlighting that ten years of thinking and planning went into the first HSP report. The process will take time, and CPE is only in the early stages of its development. To get to the next step, we need sector leaders such as Wellcome to build strategic partnerships and bring others on board. Jim also suggested that we can learn from the private sector about how approaches such as human centred design and customer relationships management have improved the value of a wide range of products and services. Learning from other fields can help us broaden, and deepen our understanding of how CPE can add value in research and communicate this value to decision makers.

5.1 Understanding public perceptions of science: Wellcome Global Monitor

To engage effectively with communities, it is important to know how they perceive and relate to science, health and research. Many people working in engagement are already very good at finding this out within their communities, but across the world there is generally little understanding of how communities view the field we are seeking to engage them with. Wellcome, a UK funder of research and public engagement, is seeking to address this with a new project 'The Wellcome Global Monitor'.

At the 2018 Wellcome International Engagement Workshop this project was presented to attendees. The Wellcome Global Monitor takes the form of a survey, which has been asked to 140,000 people in 140 countries. The survey is delivered as part of the Gallup World Poll.

The project comes from the fundamental belief that science and its impacts must be understood in the context of culture, and so its objectives are:

- Improve and increase public engagement with science in countries around the world
- Help researchers to take account of the social and cultural context of their work
- Stimulate additional, often deeper and more localised research to increase understanding of public attitudes to science.

Image: Respondents being surveyed for the monitor | Wellcome Trust

There are four phases to the project: Create & Test, Fieldwork, Analyse, Launch & Reflect.

Phase 1 – Create & Test – involved a literature review of related research and surveys, and three rounds of testing and refinement of the questions in multiple countries. You can read more about that process here.

At the end of phase 1 a final set of questions was determined. These focused on the following topics:

- Knowledge and awareness of science
- Interest in science and health
- Trust in people and institutions
- Trust in science and the role of scientists
- Trust in medical and health practitioners
- Perceptions of science as beneficial for individuals and society
- Attitudes to vaccinations
- The compatibility of religion and science

Once the questions were developed, fieldwork began. This involved surveying an average of 1000 respondents in each of over 140 countries. This was adjusted for the size of the country; for example, 3000 people were surveyed in India due to its large population. Respondents were selected randomly to be interviewed in person or over the phone. This fieldwork, at the time of writing, is still ongoing.

Analysis will be done by Gallup as part of their larger World Poll. The results will be analysed in relation to the respondents' 'quality of life', which will include factors such as their education level, religion, health status, trust in government, socioeconomic status and their life satisfaction, amongst others. This will provide valuable insights into how these factors shape perceptions of science and research in countries across the world.

Once the analysis is done, there will be 4 key outputs:

- A report providing an overview of findings from around the world
- Two-page descriptors for each country's results
- A full dataset
- A questionnaire

These will be available on the Wellcome monitor site and elsewhere. Attendees at the Engagement Workshop were asked how they could use these results; as a Mesh reader, how could they shape your work as an engagement professional? What specific areas do you think will be valuable to you, your community or your work? What could Wellcome do to make it more useful, and what would you like to see included in the next round?

To give feedback on the monitor, please contact: Ethan Greenwood at e.greenwood@wellcome.ac.uk

5.3 Bridging the public-policy divide

The field of community and public engagement generally seeks to involve the public and community groups with the research that will impact their lives. However, they are often left out of the processes that translate research into policy and practice. If health research seeks to improve people's lives, then the policies implemented because of it

should also be shaped around the interests, needs and lived realities of the people it will affect. Integration of community and policy engagement is therefore vital.

Image: Attendees at the workshop | Minh Tan

How to bridge the public-policy divide was discussed by a group at the workshop.

Community engagement practitioners and those working on engagement at research institutions wanted channels to be created between themselves and policymakers, so that policymakers could be made aware of, and make use of, the findings of CPE practitioners as well as identifying research that could be transformative early on.

Attendees agreed that to be effective this should become a more systemic change to the nature of policy development, whereby communication between researchers, engagement practitioners, communities and policymakers should be regular and sustainable. For this to be effective, work needs to be done so that those in positions of power see learning that comes from the community as legitimate and valuable.

A meeting in June 2018 for delegates from Wellcome's Africa and Asia Programmes (AAPs) demanded more institutional support for policy work, and out of this came plans for a Policy Engagement Network. The network would aim to advocate for institutional support for policy work, and to understand that there is already huge expertise within communities; discussions between these groups and policymakers need to be facilitated. The Network plan has currently been put on hold, but the ideas and actions that came out of the workshops and the initial network scoping continue to inform Wellcome's strategic policy-public plans.

Members of this network and attendees at the workshop agreed that cultural context is vital in this field: in some countries, policymakers already work with communities,

whereas in others there is little to no infrastructure to support this. There will be no one size fits all solution. It is important to remember that researchers as well as funders often need to be politically neutral, and so by pushing too hard for specific policy changes, their impartiality could be at risk.

This discussion highlighted how much work there is to be done to involve the public in policy decisions, and how valuable this is, but also the complexity of changing such a system.

5.4 Minimum standards and indicators in engagement

Image: Rafael presenting at the workshop | Minh Tan

UNICEF Communication for Development (C4D) has long been a key player in embedding engagement in its work, which aims to realise the rights of every child, especially the most disadvantaged. Rafael Obregon, chief of UNICEF C4D, presented on the organisation's work in this area. For UNICEF C4D, community engagement is key in enabling communities to participate in humanitarian action, as well as for promoting healthy and protective behaviours. For this to be properly implemented, it was realised that a systems-strengthening approach needed to be taken; this takes into account the community networks that a child may come into contact with, such as social networks, education systems and justice systems. By strengthening the processes by which these organisations work, this can allow for strong, integrated system delivery by UNICEF.

When undergoing its strategy review and deciding to move towards this systems-based approach, of which community engagement is a key part, UNICEF C4D came up against a difficulty faced by many working in engagement: How can you define what 'good' engagement is? How do you define what success looks like for an engagement activity? Along with other charities, funders and non-governmental organisations, UNICEF C4D has therefore been working to solve this problem by developing a set of minimum standards and indicators for community engagement practitioners. This topic was discussed at the workshop, where some of those working to develop these standards attended.

The project initially came from the context of the Ebola outbreak, where CPE did not begin to be coordinated until a year into the response, although the organisers acknowledge that the challenges in the CPE field have been around for a lot longer than that. These challenges include the lack of evaluation, lack of agreed methods and rules and the perception that engagement is 'fuzzy' or 'soft'. Partners including Oxfam, the World Health Organisation, UNICEF and the Bill and Melinda Gates Foundation were convened to discuss developing a set of standard operating procedures and indicators to resolve some of these issues and help integrate CPE with policy and programmes.

Common principles that came up when scoping for the standards were participation/ownership, leadership, capacity and empowerment. The standards will be grouped according to level of desirability: minimum, intermediate and experienced.

Workshop participants discussed issues such as how the standards were developed and how they should be assessed and consulted on to make sure they are as relevant and applicable to as many people as possible.

The question of ethical standards in engagement also came up, which brings with it many issues: some engagement activities currently do not get ethical approval. If it was decided that they all should, then many non-academic organisations may struggle with the complex and time-consuming process of going through ethics approvals. How can we marry the importance of accessibility and community ownership with the need for stringent ethical guidelines?

Aside from this, participants stressed the importance of making sure the standards account for different budgets and capacities within different projects, as well as recognising that the standards may be different at project and programme level.

For more information about the minimum standards process, click here. At the end of 2018, Mesh ran an online consultation on behalf of UNICEF to gain further insights on the draft standards. You can see the draft standards and subsequent discussion here.

Jamie Bedson, an author of the Minimum Standards in Engagement document, presenting to workshop attendees | Minh Tan

6. Inclusivity

Inclusivity and accessibility should be at the core of engagement work, as by definition engagement should seek to involve as diverse an audience as possible. However it is evident that some groups are often left out of engagement activities, whether that's people with disabilities, diverse ethnic groups or others. At the workshop, inclusivity in engagement arose as a discussion topic, lead mainly by three speakers: Ed Young, Patrick Collier and Nabeel Peterson. Each have experience of engaging diverse groups in innovative ways. Patrick Collier is an independent arts producer and the executive director of Access All Areas, a UK-based theatre company that make urban, disruptive performance by learning disabled and autistic artists. Ed Young is a South African artist who worked on the Eh!woza engagement project in Cape Town. Nabeel Peterson is a Wellcome Engagement Fellow who develops inclusive collaborations and co-design processes with street arts to make biomedical science more accessible.

Image: Nabeel and Patrick at the International Engagement Workshop | Minh Tan

Ed, Patrick and Nabeel posed questions about the structures that prevent diversity around the world. What are the structures in society, in research, and in the arts that prevent us from including a diversity of voices? What can we do to change these structures? Patrick particularly asked why disabled voices continue to be so notably absent from all fields? Why was there not more focus on exclusion at this International Engagement Workshop? Why was there not more diversity in the leading presenters, more accessibility in the presentational style, and more diverse experiences feeding into the evaluation of the conference?

The lack of prominent disabled voices in engagement is reflected in society. Patrick pointed out that in the UK, 20% of the population is disabled, but only 5-6% of characters on TV and in films are disabled - and only 2% are played by disabled actors. To Patrick, this demonstrates how the population is being fed a skewed version of the world, where disability is less prominent than in reality. This leads to disabled voices being left out of the conversation too often. Patrick argues that the key to promoting disabled voices in the arts is co-production and co-design of work, with effort made to understand and support individual access needs, creating a level playing field. Patrick asked, what would it do to the conversation and to our work if presentations and activities were more accessible? What if disabled voices were equally represented, and equally heard?

Ed, Patrick and Nabeel all offered great insights into how they make their work as accessible as possible for different groups who may otherwise be left out of the discussion.

6.1 Nabeel Peterson: Participatory & Co-design collaboration between psychiatric youth patients, clinical staff & street artists

Nabeel Peterson, a Wellcome Engagement Fellow, was one of the speakers leading this session. After growing increasingly frustrated with the positionality of beneficiaries of public engagement and other programmes, Nabeel sought to explore alternative inclusive and participatory models. His unconventional methods seek to firstly establish a team and allow the team to co-design processes. This, by default, defies replicability and scaling. Nabeel relies on and strives to include community-relevant and sensitive approaches that are context specific.

Nabeel led the South African component of a Wellcome funded, multi-country, mental health public engagement initiative titled Arting Health for Impact. The Botswanan component was led by Abraham Mamela and the Indian component by Sarah Iqbal. Nabeel presented this project to those in the inclusivity group session.

Nabeel is interested in alternative models of running public engagement activities to involve as diverse an audience as possible. As a means of exploring inclusive and participatory approaches to CPE, Nabeel initiated a relationship with the Lentegeur Psychiatric Hospital, South Africa, and its resident NGO the Spring Foundation. His intention was to design the project as a team, across the various organisations. The focus was to further explore the decision-making, outcomes and impact of co-designed events, activities and processes that hold all participants on an egalitarian platform.

The project began with meetings with a range of organisations and individuals working on Mental Health. After securing their interest and the participation of clinical psychiatrists, clinical psychologists, clinical nurses, clinical occupational therapists and clinic security he sought a similar approach to securing interested youth patients for inclusion. This process was guided by the clinical staff, while in-patients, out-patients and youth with learning disabilities were consulted. A key challenge was

attempting to disperse and reduce power imbalance within the team. Excursions were organised which allowed participants to be immersed in each other's worlds and the team visited both local street art exhibitions to gain an understanding of its potential as an engagement medium a science museum to understand more conventional engagement. This was followed by storytelling workshops, ahead of a participatory co-design process to design a mural and a public engagement event on the hospital premises.

Image: Nabeel at the International Engagement Workshop | Minh Tan

The team, including youth, clinical staff and artists co-designed the mural and its messaging, as well as all logistics concerning the event. The participants collectively decided on décor, refreshments, activities, invitation structure and took on specific responsibilities on the day. The event focused on mental health and managing mental health. The youth decided that it was necessary to avoid standard pedagogy and focus on management methods or techniques including yoga; a science museum exhibition; music; spoken word; meditation; mindfulness; flow arts; self-coping mechanisms; gardening and greater opportunity to talk openly to scientists researching mental health.

By providing youth with the opportunity and confidence to guide and lead these processes, their voices were central, elevated and amplified; their needs and wants were centre stage. The greatest success of the project was visible when compared with the hospital's previous attempts at engagement. In prior events focused on destigmatisation and rehabilitation, the hospital managed to secure a maximum of 15 people per event. By allowing youth to direct their own processes and co-design the event they secured the attendance of approximately 400.

Additional successes include: the continual interest by the hospital and clinical executive committee. The hospital now allows staff a finite number of days per month for engagement practice, which never existed before, and allows young people onto the government facility. Sharing between Nabeel's team and Occupational Therapists on arts methods was also a positive outcome as were the development of soft skills by youth and clinical staff. The output of a large public mural co-design by youth, scientists and artists can be seen from the outside of the hospital and will remain there for the long-term.

Nabeel credits the success of the project to a model which is focused on co-design, participation, inclusion and transparency.

Find out more about Arting Health for Impact here.

6.2 Ed Young: Giving Young People Control

Ed Young is the artist involved in Eh!woza (read our Mesh summary here), an engagement programme that seeks to engage with communities in South Africa that are significantly affected by tuberculosis (TB). Eh!woza brings together scientists researching TB, Ed, and young people from Khayelitsha in Cape Town. This partially informal township has a high proportion of the TB burden. Eh!woza aims to encapsulate the complexity of TB's impact on the area and people's lives.

Image: Eh!woza participants in scientific workshops | Ed Young

The Eh!woza model begins with scientific workshops, where young people from low-income South African homes participate in a series of workshops led by established biomedical researchers in various fields including TB, HIV, vaccines, and immunology. The young people are introduced to these topics and able to learn and

ask questions. After the workshops they are trained in videography, given high-quality video equipment, and tasked with producing films around topics of their choice using TB as a foundation for their research and development.

Despite using TB as a base, the films produced by the participants are not always directly linked with the disease. They often develop into stories about circumstances associated with TB and the societal hardships that often accompany it: gender-based violence, poverty, substance abuse and more. For example, one film worked with ex-miners to investigate their struggles to access the retirement and disease-related funds they are entitled to.

Another film focused on the life of Pamela Mala, a resident of the Khayelitsha township. Pam is an unemployed single mother living with HIV who has suffered multiple episodes of TB. The video demonstrates the complex ways in which disease interacts with poverty and other social issues, and the psychological trauma that can ensue.

A wide variety of community members were engaged in the project in a long-term way; for example, the young people producing the films relied on musicians from their neighbourhoods for the soundtracks in the films. These musicians were then invited to take part in a concurrent project run by international NGO Médecins Sans Frontières (MSF) and young survivors of TB. This has led to new projects, such as a video produced by a musician recruited through the scheme exploring the difficulties of a single-parent household in Khayelitsha.

Ed and his colleagues made the project inclusive and participatory by involving participants in the planning and organisation of the scheme, allowing them to affect changes and adaptations throughout the process so that it fit their needs and desires. Ed stressed that they wouldn't necessarily use the words 'participatory' and 'inclusive' to describe their work with Eh!woza; he is all too aware that participatory methods do not necessarily translate into inclusivity. Participatory methods can sometimes be used to raise the profile of a project while actually allowing little opportunity for genuine inclusion and diversity of production. Ed and the workshop participants agreed that if participatory methodology becomes too prescriptive, with a predetermined outcome, then this can prevent inclusivity altogether by being too inflexible.

6.3 Patrick Collier: Inclusion of disabled voices in engagement

Patrick is an independent arts producer and the executive director of Access All Areas, a UK-based theatre company that make urban, disruptive performance by learning disabled and autistic artists. These theatre and dance projects raise issues that are important to the broader disability rights movement.

A recent project was a collaboration between Graeae Theatre, La Fura Dels Baus, and 100 disabled artists local to Chennai, India. The show played to about 11,000 people in one night, demonstrating the scale of the audience that these types of open-access community-driven projects can reach.
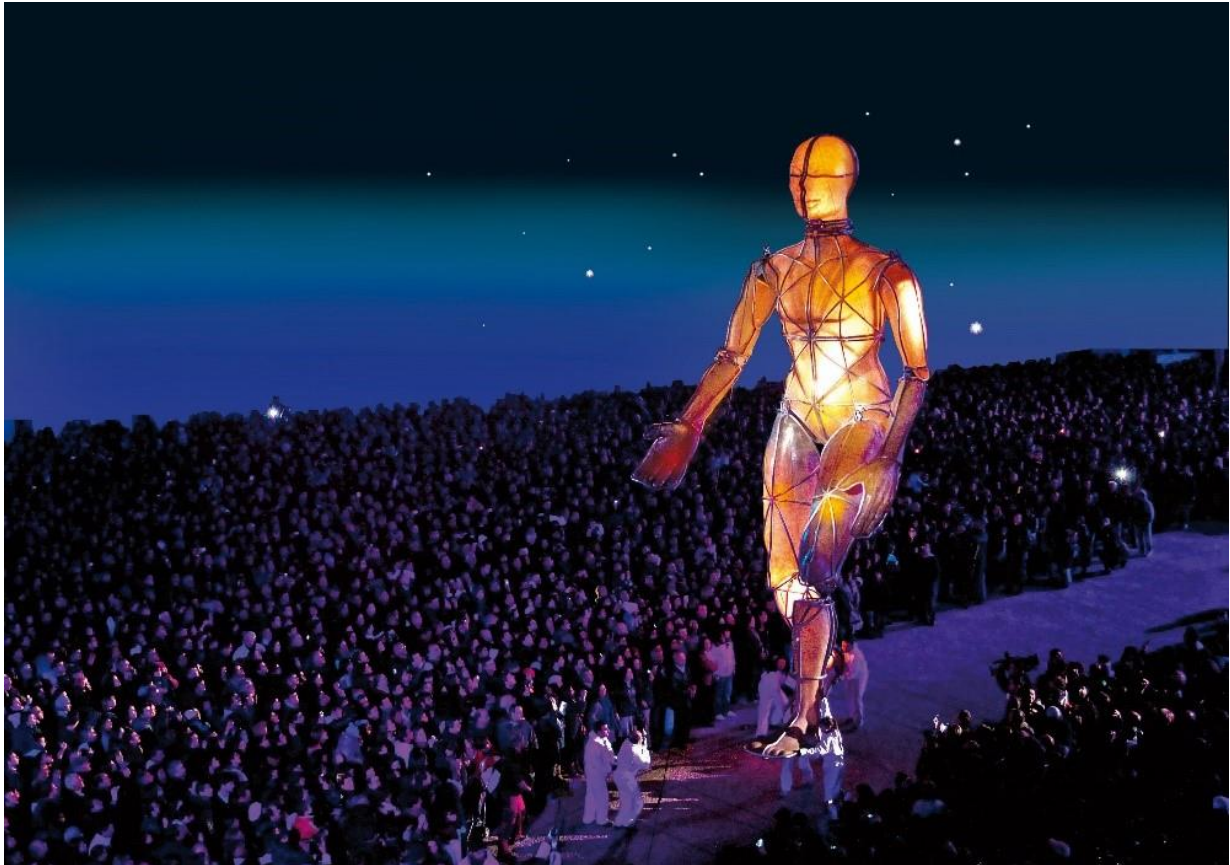
Image: a Prometheus puppet in the Graeae theatre production | Tia Lomas

The theatre project in Chennai was fuelled by a social consideration of disabled experience, which looks at the disabling factors of social context, rather than individual impairments. The social model of disability argues that it is social structures that disable people, rather than a perceived "difference" or medical diagnoses. For example, a wheelchair user is usually able to access a space that has ramps, lifts and even floor surfaces. When appropriate accessibility measures are not in place, however, a wheelchair user is disabled. This idea can be extended to people's attitudes, when social attitudes towards disabled people can often be as disabling as any physical structure. It is therefore the environmental and social factors – often encapsulated in society's lack of allowance for variety in people's access needs – that disables people. These conversations within the Chennai project led to the development of skills training workshops with local disabled people and local organisations, culminating in a large-scale production led by D/deaf and disabled artists. The performance involved 24-metre-tall puppets, a chorus of D/deaf dancers, a 'human net' operated by wheelchair users with performers suspended 50+ metres in the air, and other high-spectacle elements.

The project was directed by Graeae's Amit Sharma, who identifies as disabled. Involvement of disabled cast members moved the conversation away from a charity model that often disempowers disabled people by treating them as victims or unable to lead – and sparked debate and questions about the barriers disabled people face in getting involved not just with projects like this, but with other aspects of modern Indian society too. How are the homes they live in – sometimes low-quality shared accommodation such as hostels – adapted to their access needs? Why do buses and

other forms of public transport not have disabled access? Difficulties in these areas meant that participants sometimes struggled to get to rehearsals and performances, initiating high-profile public conversations in the media about how these structures could change in Chennai and beyond. The project also focused on the question of how Graeae Theatre and other western practitioners ensure these conversations are led by local people and appropriate specifically for India, and not an imposed version of western ideas around the social model of disability.

Image: Imogen Roberts in Access All Areas' 'Madhouse' | Helen Murray

Another project Patrick was involved in was MADHOUSE re:exit, a production led by learning disabled and autistic artists from the award-winning performance company Access All Areas. The production reflected on the history of people with learning disabilities being institutionalised – i.e., put into care systems run by the state – and how their treatment by society would often lead to 'secondary handicaps', as described before using the social model of disability. The full show was seen by over 2,000 people, but also received a lot of media coverage, and so is estimated to have reached around 1,200,000 people across the UK via national broadcasters and viral digital content. Patrick emphasised the value of working with high-profile theatre- and film-makers to achieve the kind of reach seen by this and the Chennai project, as well as their ability to emotionally engage audiences.