It's Complicated: Navigating Scientific Complexity in Public and Community Engagement

Key Themes from the 2017 Wellcome International Engagement Workshop

Introduction

This workshop, held in Naivasha, Kenya, in March 2017 explored the theme of complexity in modern science and the challenges it raises when designing and implementing activities to engage the public with health research. Over three days a group of biomedical researchers, public and community engagement practitioners, social scientists and others from across Africa and Asia explored this complexity and some of the paths for navigating it.

Caption: Graphic representation of discussions from the 2017 Wellcome International Engagement Workshop

Introduction to Engagement

Engagement does not mean one thing to everyone, and this became clear during discussions at the 2017 Wellcome International Engagement Workshop. Practitioners and other parties involved in engaging communities with research had different views on how engagement should be defined, on why engagement should be executed, and on how engagement activities should look. Whilst these views may have differed, they rarely conflicted, and the key seemed to be to accept that engagement is a broad and diverse beast. For example, the purposes and goals of engagement cited in the room included the following with many projects working towards several at once:

- To make research more ethical
- To understand populations and get them to understand you
- To inspire the next generation of scientists
- To reduce stigma around certain diseases
- To make it easier to recruit and retain research participants
- To inspire healthy behaviours
- To show the relevance of research through the eyes and mouths of those it impacts upon so that they can act as advocates
- To give scientists the tools to explain themselves to patients, families and policy makers

Whatever the goals, defining them is an important first-step for anyone embarking on an engagement project as they should define a set of methods and approaches appropriate to the outcomes they hope to see and the communities they are working with. It is advice such as this, alongside varied case examples to show the breadth of engagement, as well as discussions of the broader definitions and history of engagement that frame these, that formed the Introduction to Engagement theme of the workshop.

Caption: Participants of the 2017 Wellcome International Engagement Workshop.

Below are summaries of two presentations that show the extraordinary breadth of engagement and the spectrum of activity, goals and approaches within it. The first is from the UK, and the second from Vietnam. Also below is an article exploring how to evaluate engagement effectively including case examples from Kenya.

Creative Engagement at the Crick Institute and Beyond

This keynote presentation from the Wellcome International Engagement Workshop describes a breadth of creative engagement work across the Francis Crick Institute, Guerilla Science Project and the Wellcome Collection, UK. It looks in depth at some key engagement activities across these organisations and explores the challenges and merits of engaging publics with science in unusual and creative ways.

The Spectrum of Engagement

This article explores a workshop session led by Mary Chambers from Oxford University Clinical Research Unit in Vietnam on the spectrum of engagement definitions, aims, and methods using examples from Vietnam.

Evaluating Engagement

Robin Vincent, Evaluation Consultant, UK gives an introduction to evaluating engagement with particular focus on "Theory of Change" as an approach to evaluation and how complexity in engagement can be navigated in evaluation. Dorcas Kamuya, KEMRI-Wellcome Trust Research Programme (KWTRP), Kenya, gives a detailed account of how and why KWTRP have evaluated their individual engagement activities and overarching programme of engagement to understand the impact it is having on knowledge and relationships.

Further Reading

National Coordinating Centre for Public Engagement - What is Public Engagement?

Mesh - What do we mean by Community Engagement?

Schools Engagement and Hands-on Science

Engagement, particularly in schools, can lack hands-on activity for a number of reasons: not having access to the materials needed; a lack of protocols on how to run a practical activity; a steer towards rote learning and written assignments as methods of teaching and assessment; and many more.

However, hands-on activity in engagement has a great deal of value and was one of the main topics discussed at the 2017 Wellcome International Engagement workshop. In particular, the value of hands-on science demonstrations, experiments and practical exercises in helping to explore and explain complex science ideas.

Science Engagement in Schools

One of the workshop's panel discussions focused on science engagement in schools.

Four experts in delivering school engagement activities, in a panel chaired by Imran Khan Head of Public Engagement at Wellcome, presented their projects and discussed the key challenges and considerations when engaging school children in low- and middle-income countries with health research.

To see videos of the panel discussion and subsequent question and answer session, plus summaries of the key issues to consider when delivering science engagement in schools, visit the Engagement in Schools article on Mesh.

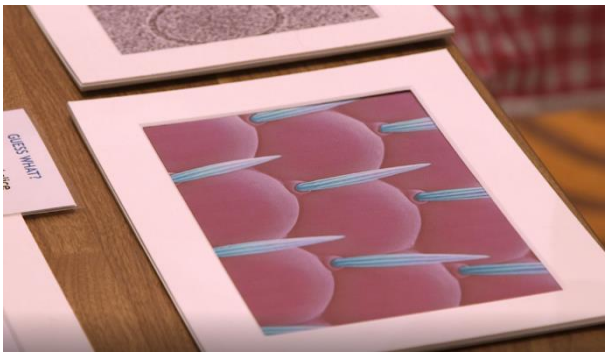
Caption: School Engagement panel from the Wellcome International Engagement Workshop. Left to Right: Frank Muzenda, Next Generation Bio-Medical Scientists, Zimbabwe; Hephzi Tagoe, GhScientific, Ghana; Imran Khan, Wellcome Trust; Duy Vu Thanh, Oxford University Clinical Research Unit, Vietnam Grace Mwango, KEMRI-Wellcome Trust Research Programme, Kenya.

Examples of Hands-on Activities

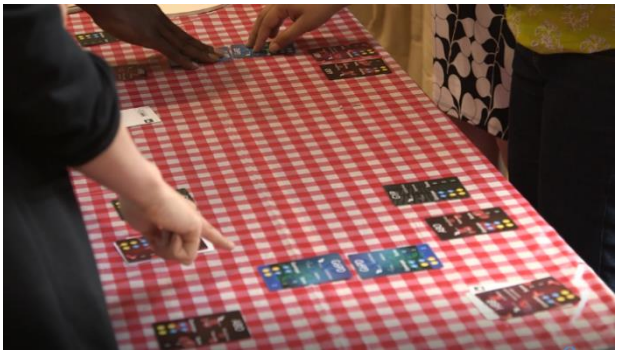
A Question of Taste: Bella Starling

Samala Moyo: Rodrick Sambakunsi

Hands-on at the Crick: Jenny Jopson



Cards Against Malaria: Brian Mackenwell



What Makes an Object Float or Sink? Alex Adadevoh

"From the perspective of someone who has no experience of engagement these activities have been very helpful - now I am thinking outside the box."
Workshop Participant, South Africa

"These tools really convinced me of the value of hands-on engagement as a model to generate interaction and mutual understanding between researchers and communities. I can see how it could work for many different stakeholders and look forward to exploring it in my own work."
Workshop Participant, Zimbabwe

Who are Hands-on Activities for?

The example hands-on activities were well received in the workshop setting and although many of them were designed with children and young people in mind discussions focussed on how activities like these can also engage adults whether they be teachers, community members, parents or even policy makers. The “A Question of Taste” exercise demonstrated by Bella Starling has been done successfully with policy makers, for example.

Often, policy makers and other decision makers are lay audiences when it comes to the science and it is engagement practitioners, skilled in translating science for all audiences, who can be best placed to explain complex concepts to them. As such, practitioners should feel confident in their ability to do so and should not be afraid of using hands-on activities as part of this.

Making sure Hands-on Engagement is Two-Way

Although hands-on activities like those showcased above create a great platform for researchers and other stakeholders to discuss an issue, and create an easier way for non-experts to understand it, it is important to remember that engagement is a two-way activity and to include space for challenge and discussion in the activity too.

"Some of the activities feel like scientists just showing science to the public. We need to make sure that the community get a chance to feed into and challenge the science as part of the engagement, it has to be two way" - Workshop Participant Abraham Mamela, Infers Studios, Botswana.

Further Reading

Learning through Tinkering in STEM Education

This document from Relating Research to Practice provides practitioner briefs and links to four key pieces of research on the value and practicalities of engaging audiences with science through hands-on activities, or "tinkering". It comes from a USA perspective but there is useful learning to be found in it for any context.

Visualisation and Metaphor

Biomedical science and health are full of complexity - in terms of the complicated science concepts themselves and the cultural and ethical complexity that surround them.

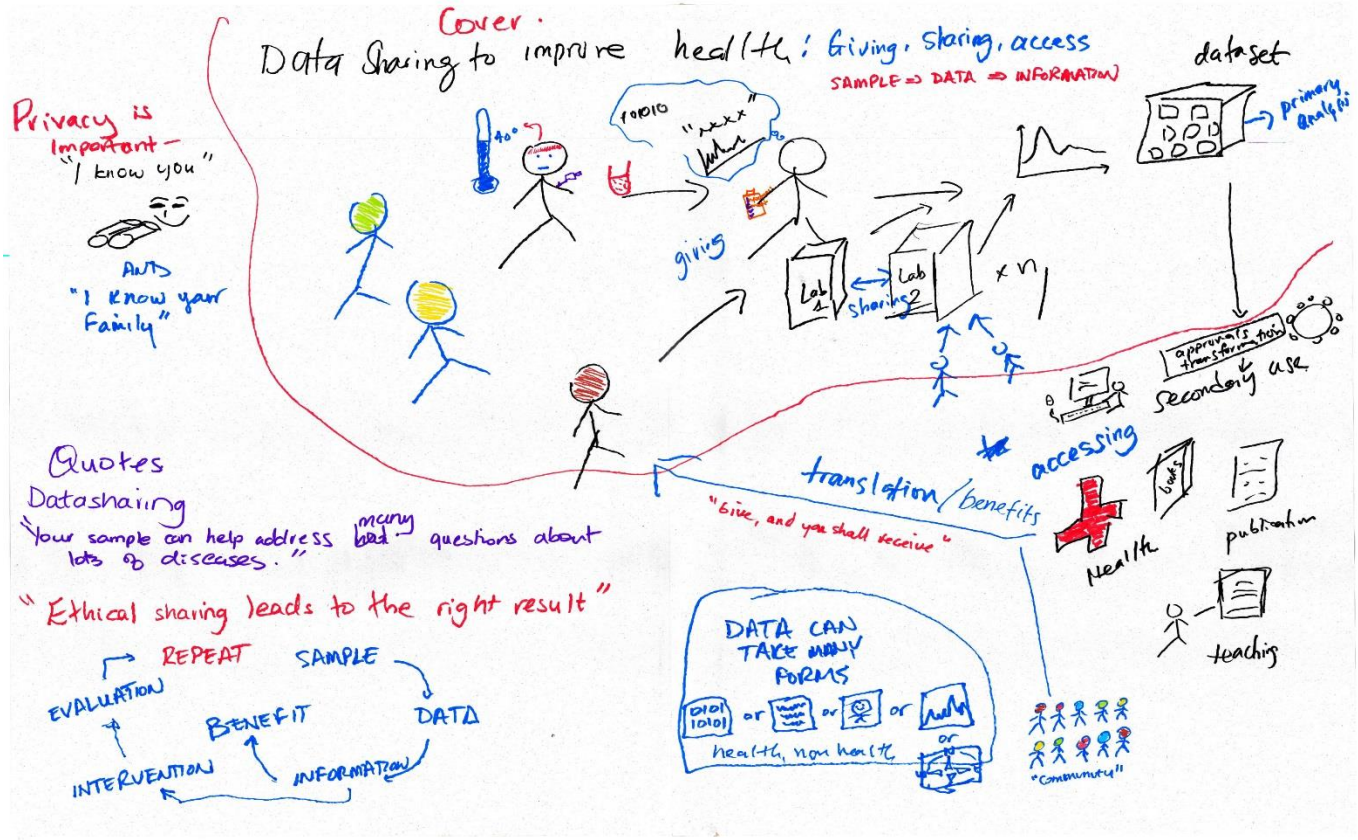
Engaging people with complex science issues when they have little or no background in science can be challenging. However, it is vital to do so to ensure communities can feed into the research that affects them, that research participants can give fully informed consent, and to raise science literacy in our communities.

Two important mechanisms that can be used to communicate complex ideas in science are visualisation and metaphor and these were explored in depth at the 2017 Wellcome International Engagement Workshop. Materials, reflections and information from these sessions are captured in the pages linked to below.

Visualisation

Graphic Visualisation of Complex Ideas and the Art of Graphic Recording

An introduction to the concept of graphic recording and demonstration of a repeatable exercise on how to think about complex ideas visually.



Caption: This graphic was produced by a group at the 2017 International Engagement Workshop as part of a session on visualising complexity. The group chose to represent data sharing as their topic of interest and this was the result.

Metaphor and Analogy

Analogy in the Genome Adventures Comic Book Project

Exploring the benefits and pitfalls of using analogies in science engagement through the case study of the Genome Adventures project.

Metaphor as an Engagement Tool in Genomics

A presentation and repeatable participatory exercise exploring the role of metaphor in public engagement with genomics.

Narrative and Storytelling

Storytelling is an ancient human tradition and a well-established means of passing on knowledge; whether it be portraying moral lessons through fables and fairy tales, or giving an insight into other cultures or eras through tales set in other contexts. Good stories keep audiences compelled by creating situations that resonate with them. This connection to a story makes audiences more likely to engage throughout, to retain the information presented, and to relate to the behaviour in the story in a way that can translate to their own lives. For these reasons narratives can play an important role in engaging people with health and health research. This is especially true when dealing with culturally or ethically complex issues where the telling of real-life stories can garner empathy and understanding from an audience in a way that a simple telling of the facts could not achieve.

At the 2017 Wellcome International Engagement workshop some examples of narrative and storytelling as an engagement tool were presented, including:

The Lucky Specials

The Lucky Specials is a feature-length film that tells the story of a fictional young South African miner and his journey through Tuberculosis. Through storytelling, the film presents issues of drug adherence and the realities and risks of Multi-Drug Resistant Tuberculosis.

Fishy Clouds

Fishy Clouds, a puppet theatre show, was created to engage communities on issues of antimicrobial resistance and research with children in Thailand. The show uses visual storytelling to bring the research and behaviour around antimicrobial resistance to life for a broad range of audiences across different ages, locations, levels of education, and language.

Standing Voice project

The Standing Voice project, communicates facts about albinism through interactive performances, navigating the cultural complexity surrounding albinism in Tanzania.

Genome Adventures

Genome Adventures engages the general public and in particular school students in Botswana with genomics and biomedical research through a narrative comic book series.

Caption: A puppet and puppeteer from the Fishy Clouds project.

Making Telling Two-Way

Storytelling can be an intrinsically one-way process, which is not ideal when we think of engagement. But, there are many ways to integrate a two-way flow of information into storytelling to create a more dialogue focussed engagement tool. For example, the process of developing a story can be a valuable two-way engagement practice. The story can be written by integrating the voices of many different stakeholders who must listen to one another to shape a coherent narrative. This process requires dialogue, learning and compromise on all sides.

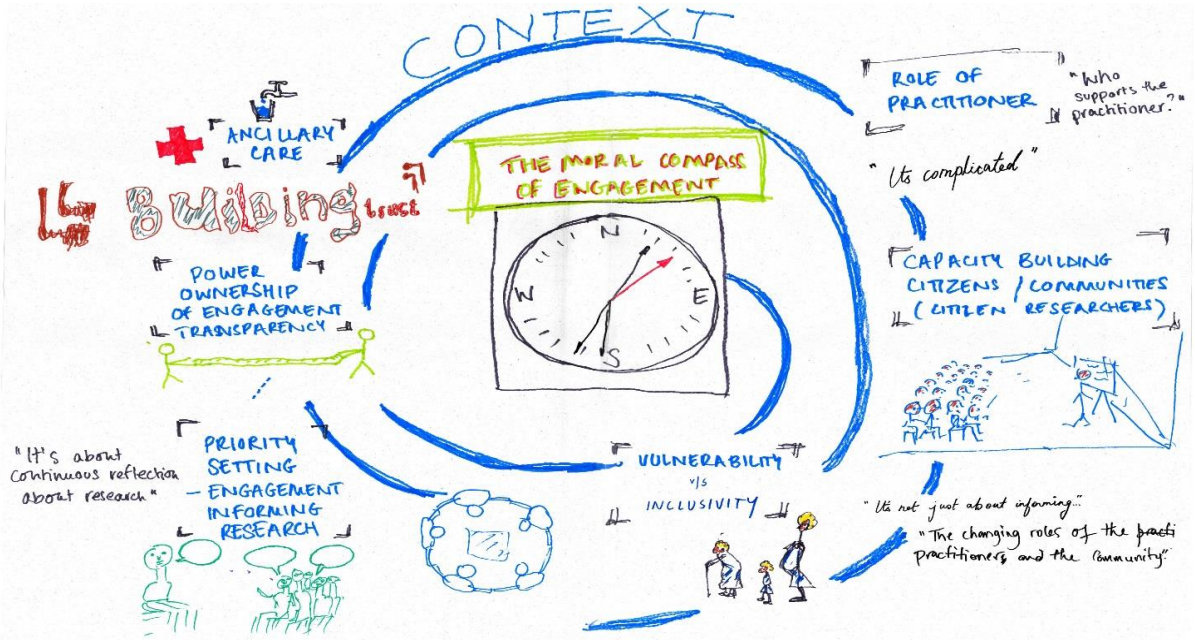
Once created, stories and narratives can be used to communicate information and stimulate discussions but this too can be made two-way. Presentation of stories can be paired with interactive engagement activities, online or in person, to ensure two-way engagement is core to the project.

Social and Cultural Complexity

There are many ways in which engaging communities with health research can be complex. The scientific concepts themselves are often rife with complexity. Engagement practitioners are regularly responsible for finding techniques to navigate this complexity and ensure the science is aptly understood to enable meaningful engagement to occur. Some of these techniques for engaging communities with complex science are explored in our Mesh reports on visualisation and metaphor, and narrative and storytelling. However, beyond the complexity of the science itself there is also a landscape of complexity surrounding the science. Science raises questions for society and the act of engagement requires delving deep into these questions.

Ethical Complexity in Engagement

Ethical complexity arises in many areas of engagement: reinforcing power dynamics through who we involve in engagement; incentivising participation in trials; creating risk for those participating in engagement activities where stigma exists; and navigating vulnerability and inclusion, to name just a few. A 2016 conference in Oxford, UK, explored the ethics and politics of engagement in depth and dozens of case studies and learnings from the workshop can be found on the ethics and politics of engagement workshop page on Mesh. There is a perceived disconnect between the social science research that explores ethics and engagement, like that presented in the aforementioned workshop, and the engagement practitioners. As such, there is work to be done to connect these groups and share learning between them to ensure practice represents theory when it comes to ethical engagement. This was explored in part by Katherine Littler in her presentation on social complexity, summarised below, and many practitioners agreed that a checklist for ethics in engagement, and markers for when official ethics approval should be sought, would be very valuable. Such a checklist does not, to our knowledge, currently exist.



Caption: This graphic representing ethics in engagement was produced by a group at the Workshop as part of a session on visualising complexity.

Social Complexity in Engagement

Katherine Littler, Wellcome, UK

Katherine Littler is a Senior Policy Advisor at Wellcome and you may wonder why she was present at a workshop on engagement. Her response to how social complexity presents in engagement answered this question almost immediately:

"The complexity associated with policy uptake issues is something that this community needs to grapple with", she began.

Whether it is social science or biomedical research, the pathways to uptake in policy are very complex. If we are to claim that engagement is part of those pathways the engagement community must start gathering case studies to show where it has happened and to demonstrate the spectrum of policy uptake work that engagement can play a role within. Much of Katherine's work is around emerging technologies, sample sharing and pandemic preparation, all of which have engagement at their core. "*Engagement"*, she says, *"gives you the social license to do this work."*

Aside from the policy question, Katherine broached the complexity of the ethical issues that flow out of engagement. To address these in practice the need for "rules of engagement" was highlighted. To highlight why such rules are important, we can use the example of marketing. Those in the marketing business have a very sophisticated evidence base for the work they do. Marketing, though we may not always think of it as so, can be a very two-way process with information gathered from the audience feeding back into the marketing process and the product that it represents. Marketing even has an ethical code of conduct. But it is important to recognise the difference, because we feel innately that there is one, between marketing and engagement. Engagement has at its core a mindfulness of the interests of the individuals and communities being engaged, and a transparency of the interests of those doing the engaging. There is much to be learnt from marketing conduct, but to separate itself engagement needs to define for itself a set of rules, principles, or an ethical framework, that outlines how we put these interests at the centre of engagement work, and how to ensure engagement is ethical.

These rules could encompass something overarching and applicable across contexts, research areas and activity types, but be layered to take variety and complexity into account. They might include principles of building trust, respect, transparency, of how to take the voices of many into account, and what your obligations to a community may be. These rules may not yet exist but the call to action for the community to develop them was well received and there is potential there for the future.

Image Caption: Graphic Illustration of Katherine Littler's talk on social complexity

Jim Lavery, Emory University, USA

"Stakeholders are all those who hold a legitimate interest in the conduct and outcomes of whatever it is you are doing. Engagement, is the act of uncovering those interests and gaining insights into the ways the interests of those stakeholders are effected by your work."

Jim Lavery asserted that uncovering stakeholder interests is not a simple task. Often, interests will be hidden and will be layered with complexity. There are welfare interests such as security, safety and livelihoods but overlaid on these are ulterior interests like personal ambition. These interests are not always easily articulated and this is made more socially complex when we, as researchers or engagement professionals, come with agendas and presumptions that can disregard or mask stakeholder interests.

Some key considerations for navigating the complexity of stakeholder interests are to consider what constitutes fair representation of a given interest; to be aware that interests are likely to conflict; and to understand how people align around interests (for example looking at how networks are evaluated). In community engagement, this complexity may also be abated by thinking of communities not as geographic, but as clusters of stakeholders who hold a similar set of interests.

Image Caption: Graphic Illustration on Jim Lavery's talk on social complexity

Case Examples of Cultural Complexity

Science, Art, Community: Building Interactive Understanding of Albinism in Tanzania
A case study on a project that seeks to understand and challenge stigma against albinism in Tanzania.

Cultural Complexity and Talking Trees

Talking Trees is a public health research project and forum addressing female genital mutilation among pastoralists' communities of Kenya.

Confluence of the Old and New: Understanding Resistance to New Born Screening in Nigeria
This project uses focus groups and a community radio project in an effort to better understand, and engage in dialogue about, the cultural beliefs that are opposing new born screening in Nigeria.

Genetics and Genomics

Genetics and Genomics is a subject area which comes with many layers of complexity. The science itself is complex and the base level knowledge needed to understand its concepts can create a challenge for those engaging non-experts with it. But it also comes with other challenges, namely in the social, cultural and ethical complexities that it raises. Genomics defines families, and uncovering more about genetic disease in some contexts can lead to a marring of whole families with consequences for marriage opportunities or their integration into a community. Equally, understanding genomics can relieve social tensions, for example in removing the burden of blame solely from the mother when a child with a genetic disease is born to her. As such, when engaging communities with research in genomics great care has to be taken to ensure the context is understood and that the full effects of such engagement are anticipated. This page presents information and case studies on the work being done to engage communities with genetics and genomics. The focus is on Africa but the learning is applicable in many contexts.

Genomics Research and Engagement in Africa

Before 2000 there were very few genomic studies on African populations, research in genomics in Africa lagged behind only excelling in isolated centres of excellence. Since then, genomics research has leapt forwards and initiatives exploring African genetic diversity in health and disease have thrived. These include:

- The African Society of Human Genetics (AfSHG)
- H3Africa
- African genome variation project (Sanger Institute)
- MalariaGEN
- Biobank cohort building Network (BcNet)
- Bridging Biobanking & Biomedical research across Africa & Europe (B3Africa)

In all of these initiatives there are concerted efforts to engage communities with genetics and genomics research but there is still much learning to be done.

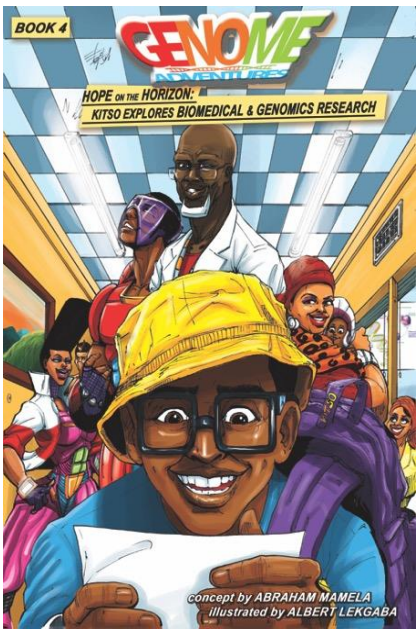
Case Studies - Engaging with Genetics and Genomics in Africa

Community Engagement across the H3 Africa Consortium, Africa-wide

The Human Heredity and Health in Africa (H3Africa) Consortium, a pan-African network which seeks to develop capacity for health-related genomic research in Africa, has identified community engagement (CE) as one of the key issues that need to be addressed to support the successful implementation of genomic studies in Africa. This article outlines the complexities of doing so.

Engagement in the TrypanoGEN Project, Africa-wide

This article outlines the key challenges and approaches of engaging communities with the TrypanoGEN research project - looking at genetic susceptibility to Human African Trypanosomiasis (HAT) or "sleeping sickness".



Genome Adventures, Botswana

Genome Adventures engages the general public, in particular school students, in Botswana with genomics and biomedical research through narrative and metaphor in a comic book series.

mGenAfrica, Africa-wide

mGenAfrica is an internet-based platform and mobile application designed to promote engagement between research staff in genomics and other health research fields with high school learners (16-19 year olds).

Case Studies - Engaging with Genetics and Genomics in the UK

Method in Motion, UK

Method in Motion from the Wellcome Trust Centre for Human Genetics, UK, is a project that translated researcher Irina Pulyakhina's work on understanding the mechanism of ankylosing spondylitis (AS) - a chronic inflammatory disease with strong genetic predisposition - into a piece of contemporary dance.

A Question of Taste - Hands-on Demonstration of Genomics, UK

A hands-on activity using DNA extraction designed to educate and engage people with key concepts in genomics.

Further Reading

Exploring the use of Metaphor in Genomics

This presentation and group exercise explores the role of metaphor and language in public engagement with genomics, using a creative group approach to reflect on the cultural contexts of genomics.

An Informal Learning Model of Genetic and Genomic Education

This paper explores the development and evaluation of a community model of informal genomic education that is culturally and educationally appropriate for low-literacy Latino adults born in Mexico and Central America (MCA).