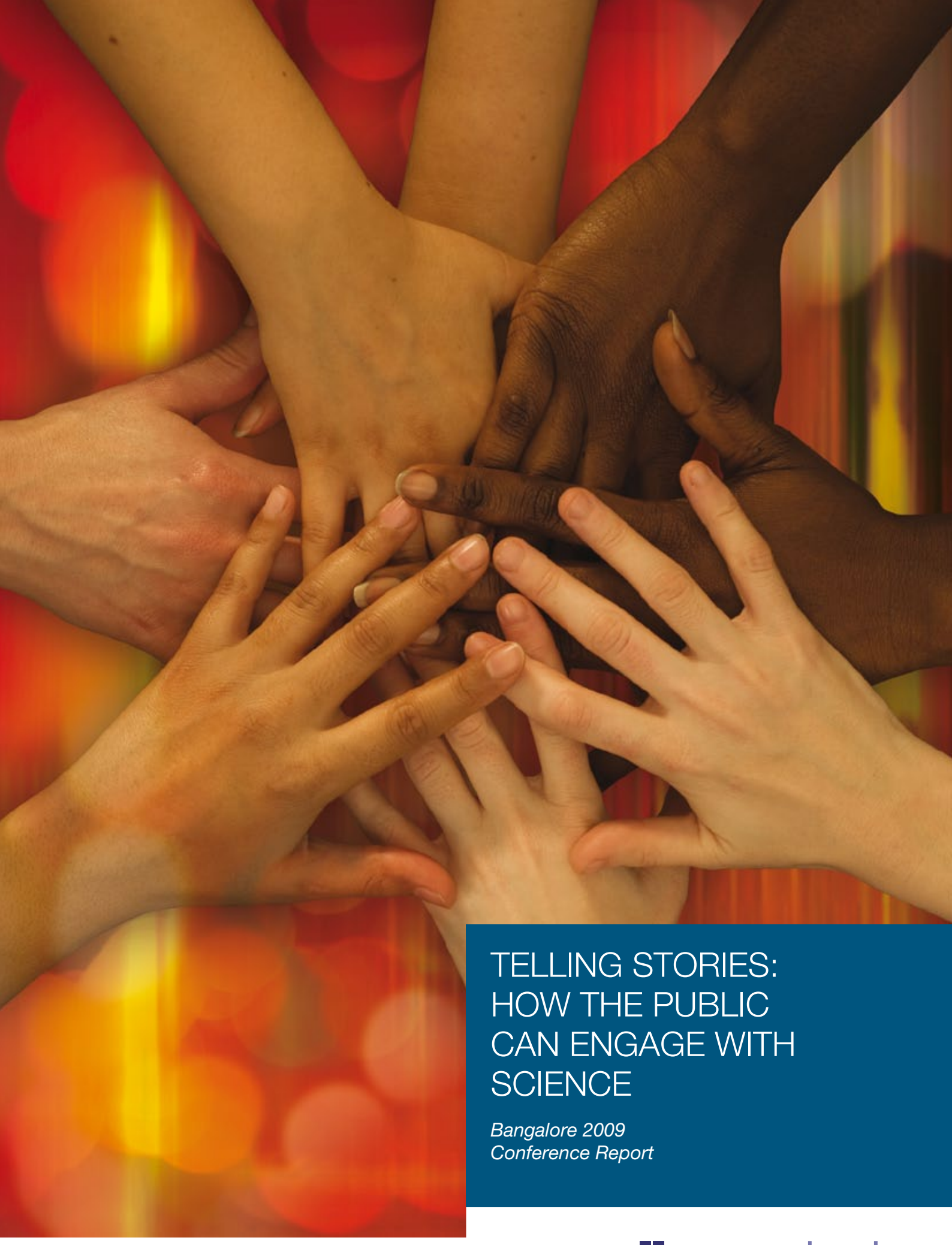

TELLING STORIES: HOW THE PUBLIC CAN ENGAGE WITH SCIENCE

Bangalore 2009
Conference Report

wellcome trust

TELLING STORIES: HOW THE PUBLIC CAN ENGAGE WITH SCIENCE

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Introduction

In December 2009 in Bangalore, India, 84 delegates from 22 countries participated in a conference about international public engagement organised by the Wellcome Trust. It was the second workshop on this theme, following 'Engage to Empower', held in December 2008 in South Africa.

Delegates came together to share their experiences and to discuss lessons and ideas about engaging the public in science. Many of them were and are holders of Wellcome Trust International Engagement Awards. The workshop was organised by Tinderbox Consultants Ltd.

The conference theme was 'Telling Stories: Why narrative matters in public engagement with science'. The programme allowed delegates to explore the following questions:

- When and how can we use storytelling properly in public engagement?
- What are the potential dangers of misusing it?

Two keynote speakers, Shubha Tole and Elizabeth Pisani, showed how people both absorb and present information differently. We cannot make assumptions about what others think, and we must be very careful when we create narratives, especially when using statistics.

This short report summarises the activities and discussions that took place during the conference. Questions that emerged as a result of the discussions are highlighted at the end of each section. This event was part of a bigger international discussion about public engagement with science, so please join our continuing debate online.

SHUBHA TOLE KEYNOTE ADDRESS

This keynote address opened unconventionally. What appeared to be a lecture about how the brain develops quickly moved to testing the reflexes of the audience's neural circuits: Tole and her team pelted the audience with (soft) balls. Some caught, some ducked, and some aimed them right back. The talk was about how these actions are the product of a complex but speedy decision-making circuitry, illustrated by a 'ribbon game' that Tole had designed for public outreach. The delegates became parts of the circuit and were interconnected with colour-coded ribbons. A giant spider web was wired up across the hall, and then the 'circuit' had to function properly. Tole then took delegates on an engaging exploration of the complexity of life, showing the steps an embryo takes from gene activation onward, to build a circuit that not only executes actions, but also is capable of learning new things. Delegates got a glimpse of the basics of neural circuits, and also how such a potentially complicated topic can be presented in a way that literally 'weaves' the audience into the story.

ELIZABETH PISANI KEYNOTE ADDRESS

Numbers rarely spur people into taking action; stories do. Since public health research is all about generating data that will lead to action, researchers would do well to learn how to turn numbers into stories. Pisani gave an example from the world of HIV, where effective storytelling transformed a neglected epidemic affecting politically unpopular minorities into the headline global health issue of our time.

It was not for nothing, though, that she subtitled her talk 'A cautionary tale'. In an effort to make HIV more politically palatable, the numbers were presented selectively to deflect attention from the sexual and injecting behaviours that spread the virus. The dominant narrative became that of 'vulnerability' and universal risk. This diversion from the truth sent prevention efforts off on the wrong path. The 'everyone is at risk' story increased resources for HIV prevention and care over 40-fold, but because it was essentially fiction, the money did not translate into effective programmes. In terms of new infections, we are where we were 15 years ago. Translating numbers into stories can certainly be compelling, but in the field of public health research, we are compelled to ensure that the stories we tell are non-fiction.

About the International Engagement Awards

This scheme has supported around 40 public engagement projects in low- and middle-income countries since its inception in 2008. It aims to build capacity for, and to stimulate dialogue about, health research and its impact on the public, in a range of community and public contexts.

Why public engagement?

Biomedical science is embedded in the cultural landscape. By its very nature medical research offers great promise, yet it can challenge cultural norms and personal beliefs and choices. Without engaging with the social, political and cultural fabric in which research is conducted and its results are to be implemented, health research can easily be seen as an endeavour of outsiders, unaccountable to society, misunderstood and mistrusted.

This is why the Wellcome Trust considers it vital to engage individuals and communities with science and health research. Public engagement activities should connect the research community with the general public, community groups, civil society organisations and any other groups or communities in the 'outside world' where research gains its relevance. Public engagement is not about getting public buy-in for a research programme or technology through lobbying or campaigning, and it is beyond simple health promotion. It is about really starting a two-way interaction between research and the worlds of public or policy.

True engagement should be more than dissemination of research findings, and challenges the traditional academic method of publishing in a peer-reviewed journal as a tool for making information accessible and useful to those that need it. The conference focused on telling stories and using creative approaches, because these are a powerful means to engage with communities in a genuine way.

Telling stories

"A story has the power to make something invisible become visible; whether we are explaining biological processes which are too small to be seen with the naked eye or narrating our own personal experiences, by telling a story we can make those events real." – Rebecca Gould, Tinderbox Consultants Ltd

Translation

Why does science require translation? How can we listen to marginalised voices? These two questions imply that translation is a two-way process. How, therefore, do we achieve understanding between people who speak in different registers, disciplines and languages? Translation can take many forms, whether it is between scientists and the media, patients and policy makers, or health workers and the general public.

Some key points from the session presented by Subhadra Menon were that translation is continuous, and that public stakeholders should engage with and be more accountable to marginalised groups of people.

"There is a translator in all of us. There is a translator between a mother and her child, there's a translator between a teacher and a student, so it's a dynamic event which is happening all the time." – Subhadra Menon

A core theme to emerge was around inspirational stories and the power these have in the translation process between different target groups. Another major theme was about the 'circle of concern' and the 'circle of influence'. The more important and strategic intervention is about issues that lie within the 'circle of influence' – working with those people who can actually do something, make decisions.

Rose Oronje shared her experiences from studies of slums in Nairobi. Communities can be enriched through research, and ways of communicating research effectively are through 'liberative' sessions, community radio, folk media and participatory media.

Daniel Glaser raised some important questions during a session about translation and marginalisation. Translation acts as the intermediary in bridging gaps of language, material, education and culture. But the question arises: why is there a need for an intermediary? Cannot motives and messages be understood directly? Whose interests dominate and whose are marginalised? Who translates and how democratic is the space? Being aware of these power dynamics is critical in the process of translation.

During a discussion about telling stories to the media led by Daniel Glaser, the following points emerged. Relationships between journalists and scientists matter. Often, scientists would rather not be published in the media than get the wrong kind of publicity, so journalists need to be responsible in their reporting, appraising the context and the facts. The quality of reporting is better if journalists are trained in science journalism.

But what is the role of science in the media? Is it to entertain the public? To engage them in understanding science better? To encourage public trust in science? A more inclusive approach towards the media is needed to deepen relationships and understanding between the media and scientists.

Public communication and outreach is another key element of translating science and sessions on science cafés explored this further. Juliette Mutheu shared the experience of Kenya, where the science café is considered a place where you can get accurate scientific information. Ana Vasquez Herrera explained how the cafés had been adapted in Uruguay. The café is a forum to discuss and debate topical issues in a relaxed, informal and accessible manner in the presence of the media. No one is looking for behaviour change, but rather for a greater sense of awareness of scientific issues and how they affect our daily lives. Different types of people attend: unemployed people, school leavers, doctors, teachers and taxi drivers, for example. Cafés can be tools to shift power. A café strips the scientist of their traditional powers as they share the space with others. Duncan Dallas suggested that science cafés bring science back into culture. They allow for people to explore science in their own cultural contexts.

Another example of public communication, explained by Wendy Graham, was a project using local history in the UK to stimulate debate on maternal health and facilitate cross-cultural exchange between the culture of science and the public.

Key points:

- Translate scientific concepts and data in ways that audiences can understand and engage with.
- Reach audiences you would not normally reach, and think about marginalised people.
- Understand how knowledge flows at the community level so that researchers and community members can bridge the gaps that exist between them.
- Put the stress on what people are learning and why, rather than applying generic techniques and tools to engage with the public.
- Research communication should be evidence-based with inputs from policy, ethics, community needs, individual decisions and local capacity.
- When we try to influence social processes, we should not think that we will be in this position for ever. Our involvement is time-limited once change has been instigated.

"We all require translation, to differing degrees, but we should never forget the diversity of sources of information and knowledge." – Daniel Glaser

Questions for discussion: If translation and communication is a two-way process, how have you, as scientists, been influenced by the communities you try to engage with? Do you do anything differently as a result? Join the online discussion.

Creative approaches

This strand allowed delegates to explore practical ways to tell stories using creative approaches to engage the public with science. Sessions looked at drama, music, visual arts, storytelling and radio in public engagement. Delegates had an opportunity to explore how creative techniques can be used with a variety of audiences.

Jeff Teare, Arundhati Raja and Paul Sirett started this session by looking at the acting process, how you get a story on its feet and how characters express feeling in different ways. Paul Sirett helped delegates to understand the history of narrative structure in different cultures and countries, and explored the similarities. Then the delegates looked for themselves at how to create effective stories.

Key points to emerge were that stories should have a discernible shape and structure, moving dynamically with a twist or shift in power that keeps the audience engaged and asks them to question things. Different narrative models can help us to think through how best to tell a story. Delegates were particularly interested in how non-naturalistic elements, such as an inner voice or conscience, can contribute to telling a more complex story.

Visual arts can also be effective, as was shown by Rajeev Varma, who described the Patua-Plus project in West Bengal, India. This is an innovative HIV communication and stigma reduction initiative that uses scroll painting to communicate. Gurupada Chitrakar then sang a scroll of his own story of stigmatisation about HIV.

Singing and poetry can also be effective performance art forms.

Community engagement with an art form works best when:

- community engagement is sustained
- the art form is community-based
- there is a structured message or curriculum for learning and exchange
- artists work in tandem with community health workers
- communication about stigma reduction is backed up by local governance.

Bernard Appiah discussed how cartoons can be effective for public engagement work because they:

- lend themselves to open-ended questions
- stimulate thinking about issues in a non-threatening way
- provide important visual stimulus
- can make complex ideas much easier to understand
- make uncomfortable issues much easier to address.

Ashish Sen, Enriqueta Valdez and Amel Belay presented information about their respective radio projects, for example, to encourage birth registration in India, or to reduce stigma about HIV in Ethiopia. Some key points to emerge were that radio programmes can provide a range of alternative platforms to engage listeners with issues that affect them. This can be done through poetry or drama, news items, interviews, vox pops, montage, a day in the life, folk or fairy tales, documentary, group debate, gameshows, diaries and phone-ins.

The session on participation, led by Simon Parry, Bella Starling and Siân Aggett, showed this to be a process that can be an effective driver for public engagement in science. The four dimensions of participation explored in this instance were time, space, language and bodies. Key points were that it is effective, but not simple or necessarily obvious, and that it is subject to constraints, depending on its nature and audience.

Simon Heywood, Kole Odutola and Claire Heffernan presented some critical issues about storytelling. Storytelling is universal: there is no culture that does not use stories and it is a tool that can be used in public engagement very successfully. It is interesting that stories from different parts of the world have common roots. Today, storytelling has been transformed, in particular in terms of film and other new media.

Storytelling is a widespread narrative pattern that can be described as 'problem–journey–helper' or 'test–confrontation–resolution'. A narrative can serve three functions for the human mind: cognitive (grasping cause and effect), empathic and imaginative. These allow us to understand the world, people and relationships, to understand that one thing leads to another, and to realise that there is more than one point of view. We couldn't understand a story without these things.

However, storytelling also has its problems and facts can be manipulated within narratives. This is demonstrated by how the story of 'poverty' in low-income countries has changed over the decades.

Key points:

- We locate our practices in who we are, where we are, and what we are doing, and then by locating them against other practices.
- Maps and journeys can be understood very well through storytelling.
- Hearing other stories helps you travel to other locations.
- Finding and understanding the roots of a community is important.
- Dramatic locations and characters work well.

Questions for discussion: Have you used, or are you considering using, a new creative approach as a result of the conference or the ideas described here? What is your experience of this so far? What challenges do you face? Join the online discussion.

Gender matters

David Osrin chaired this session and made his introduction by saying that this strand could have been interpreted in many ways. Does gender matter in public engagement? How do we engage with the public about the fact that gender matters? How do we engage with the public about gendered health issues? How do we do public engagement with gender groups? The group discussed the following topics: how gender differences affect access to healthcare and information, how stories about women's health affect survival, and how public engagement workers create safe spaces to allow women to tell their own stories.

Vikram Patel, in a session on why gender matters in public engagement, spoke about how he learned to shed his 'biomedical arrogance' and step outside of his trained assumptions by listening to women and allowing them to tell their stories.

In a session on making spaces for women to speak, Amar Jesani gave an example of women activists in India trying to tell a narrative of their experiences of accessing healthcare. Other health activists were present at the meeting, and demanded hard evidence, rather than stories. Should women have their own spaces in which to speak and be heard?

Delegates suggested that it depends on the context. In some countries, it is necessary for women to create their own spaces.

Gender matters in public engagement when you use media. Justa Wawira gave the example of parts of Kenya where there is 95 per cent penetration of radio in the community. Yet this figure disguises the fact that 95 per cent of listeners are men. The radio is a tool of status and power, and the man decides what to listen to – then passing, or not passing, information to his wife.

As Douglas Wassenaar pointed out, scientists can find themselves working in heavily gendered areas, such as mental health. There can be disconnection between clinical diagnosis of illness, academic research papers and the scientist's more personal and immediate view of women's experiences. There is also a tension between individual stories and large-scale data.

Elizabeth Pisani and Dayaprasad Kulkarni gave presentations about transgender issues in public engagement. Delegates discussed the specific challenges of public engagement of science with transgender people. The issues that were raised revealed the great lack of understanding and knowledge about transgender communities, how these communities function and even of their existence. This means it is difficult to get the public to understand who transgender people are and how they live.

Key points:

- Understanding gender issues among the public, including transgender issues, is a critical part of public engagement.
- Both physical and mental spaces are gendered. If storytelling is to be used in public engagement strategies, this gendered aspect cannot be overlooked.
- Different kinds of space and time are important to gender and storytelling: time to talk, to tell stories, bodily space, verbal storytelling space, social and sexual space.
- Moving into an alternative space can transform the engagement.
- Stories don't have to end; there is a function in the telling itself. We sometimes have a tendency to try to end the story, which can be detrimental.

Questions for discussion: In which ways do you take account of gender in your public engagement activities? What is the main lesson you have learned in terms of gender in relation to science? Join the online discussion.

Young people

For this strand, young people visited the conference to give delegates a first-hand account of public engagement activities in which they had been involved. Their experiences ranged from making animated films raising awareness of corporal punishment in schools, and drama tackling HIV, to large-scale political action that had led to the provision of clean water to areas affected by the 2004 tsunami in Asia.

Delegates then planned public engagement activities in collaboration with the young people, and pitched new ideas to them about future responses.

Key points:

- Consultation takes a long time. Building relationships with young people is essential to understanding what needs addressing, rather than jumping at the first idea.
- Young people should have the space to think about what they really need, without intervention.
- Have a board of directors of children to sit in on meetings with all stakeholders – media, scientists, policy makers – giving them a chance to drive the agenda.
- Don't create dependency of children on adults to get information.

Questions for discussion: How important is it for you to include children and young people in your project? How do you deal with the power imbalance between adults and children? Join the online discussion.

Looking to the future

If we are telling the story of international public engagement with science, we are far from the end. This conference was a single moment in a longer process. We need to continue to generate a community of practice, reflect on our activities, and think how we apply lessons in the future.

We don't want public engagement to be a token activity that is an add-on to the research process. We want it to infuse and inform the process of scientific endeavour, building on high-quality research and empowering people with understanding. Ultimately, public engagement needs to know how best to inspire people about the wonders of scientific research and its application.

There are risks with storytelling and creative approaches: risks of creating narratives that are not truthful, that do not accurately communicate the real story; risks to do with not fully understanding power relationships; risks of pushing agendas and interests. How to overcome these challenges is something we need to reflect on and share with each other.

Please ensure this international debate can continue and contribute online.

"It's been a really inspiring conference. When you come across practitioners, people from so many different countries and places, who share a passion for communicating science, and who do it in such different ways, it makes you think about your own work completely differently." – Daniel Glaser, Head of Special Projects, Wellcome Trust

MANAGING A GRANT: TOP TIPS

Laura Harper presented:
Top tips for evaluation

What is evaluation? Firstly, it is about learning and improving, which we call formative evaluation. Secondly, it is about making an informed judgement about the value or success of an enterprise, which we call summative evaluation.

What information is important to help us learn?

- Does this engagement format work?
- Were the objectives met?
- What did the project team learn from the experience?
- Are there learning points that would be of use to other current or future grantholders?
- How does this project contribute to the bigger picture of the public engagement field?

It is helpful to identify lessons when something goes particularly well, when you have to make a change to your plan, or when something doesn't work as expected. Think about why it happened.

You can capture lessons from delegates – observations/visitor books, from the team, meetings and record keeping. Don't wait until the end of your project to start learning.

When you plan for an evaluation, think about these things:

- Who are the audiences for your evaluation?
- What information do your audiences want?
- What are your project objectives?
- How will you know whether these have been met?
- How will you meet your reporting requirements?
- What do you have to do at the start of the project?
- What resources do you need?

Clarify the aims of the evaluation and set SMART objectives from the beginning (Specific, Measurable, Achievable, Relevant, Time-bound).

- Does everyone know who is involved and responsible?
- What will you see if you achieve the objective?
- Is there evidence that this is possible, in theory?
- Is it relevant or just easy to measure?
- Are the deadlines clear?

Siân Aggett and Ariel Retik presented:
Top tips for a successful grant application

A successful project first needs a successful grant application. Make sure you give your project the best chances by following this simple guide and checklist:

- Consult the application guidelines and make sure your project is eligible.
- Make it an engaging read, the tone should be interesting and exciting.
- Avoid abbreviations, acronyms and jargon.
- Answer the questions as accurately as possible without repeating yourself.
- Know who your target audience/stakeholders are – justify your approach with them in mind.
- Explain the context but be careful about information overload – keep it succinct.
- Make sure you have the relevant expertise in the project team needed for the project.
- Don't be overambitious with your project – be realistic about what you can achieve. Make the aims, objectives and rationale for your proposal SMART (Specific, Measurable, Achievable, Relevant and Time-bound).
- Make sure your evaluation plans are appropriate, and be imaginative with methods.
- Think about ways to disseminate what you have achieved.
- The project summary is probably the most important section – write it last.
- Show how the project is sustainable or how it is developing on a previous project.
- Have your application proofread by someone who has not seen it before.

Final checklist:

- Once you think you have finished, take a break and then re-read what you have written.
- Check the science content.
- Check the spelling.
- Ensure all co-applicants have read the proposal.
- Check that your budget adds up correctly.

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