'Telling Stories'

Wellcome Trust International Public Engagement Workshop

National Centre for Biological Sciences, Bengaluru, India

7-10 December 2009

Tinderbox Consultants Ltd

I am safely back in Kenya, sitting at home and watching the waves of the Indian Ocean rising and crushing on the shore. I am deeply in thought, wondering how to thank all the wonderful people I met in Bengaluru and how to put in words all the thoughts and experiences that I shared from across the continents.

I thought that maybe I could paint you all a picture of the thoughts inside my head but the picture would be of no justice. The colors would weep, for the thoughts in the picture would be too great for the canvas to handle. There are no colors on my palette that could ever compare to the experiences I carried from Bengaluru.

I thought maybe I could write you all a song and sing to you what Bengaluru brought to my world. The song would be one of silence, for there are no songs as beautiful as the sounds of the beautiful stories I heard. Your stories sang to my heart and created a song that is not meant to be heard in words but listened in the heart.

I thought maybe I could write you all some poetry but the poetess in me is lost in the story and the reality of the story. There is no sonnet, no poem that could ever explain what I learned from all of you. Poetry in motion is stopped by an engagement so deep that it cannot be expressed in rhyme.

I thought maybe I could pick up the phone and speak to you all about all these thoughts. But the problem with this is that I become speechless. My heart beats wildly and the butterflies flutter to the point of breathlessness. Still, the words cannot flow from my mouth. There is no language that can be spoken of the way I feel.

I thought maybe I could envision these experiences in my mind and you could all see what is inside, through some sort of telepathy. That way you would all see my picture, hear my song, read my poems and hear my voice. You would know the language in my mind because you're a part of it.

Please join me in holding these thoughts together and finding the artist in each one of us. Let us feel the art engraved in our hearts and free Simon Parry's parrot to go out to the world with the art of public engagement. Let us hear the words of silence, the wind of gender that blows across science and the translational agenda. We are the wind that blows the change, the sunlight, the moonlight, the ocean and the stars, the community of practice. Such life, such intense engagement, to be created by the power of science!

The journey ahead is long. We will continue to walk the path ahead. Together, united as a community, let us climb the mountain and experience the beauty of public engagement. Let us speak in silence, hear the symphony and see through our eyes. We will always know each other's song, for we sing the same tune. We will always know the words of the poet, for we all have written the poem. We will always speak the same language, for it is a language that is made out of our experiences.

I thought maybe I should share some of these thoughts with you. I gave it my best shot, but I have a feeling you all know what I think already!

Justa Wawira

Table of Contents

1.   Executive Summary

This report by Tinderbox Consultants Ltd gives an overview of the Wellcome Trust International Public Engagement Workshop, 'Telling Stories', which was held in Bangalore, India, in December 2009.

The report explains the background to the conference, traces its planning, development and research, gives details of delegates, speakers and partners, describes the event itself, and provides feedback received immediately afterwards from delegates, plus some reflections from attendees and organisers.

Official evaluation and documentation of the conference has been carried out separately by Wellcome Trust staff.

2.   Background

2.1   History and context

The Wellcome Trust International Engagement Scheme

The Wellcome Trust is the second largest charity in the world. They work both in the UK and internationally and spend over £600 million every year promoting research to improve the health of humans and animals. The Wellcome Trust has a long tradition of supporting public engagement with science in the UK and a long-term interest in the social, cultural and historical context of medical research.

The International Engagement Awards scheme, which extends Wellcome's public engagement work to low and middle-income countries around the world, is now in its second year. These awards aim to stimulate dialogue about health research and its impact on the public.

The annual International Engagement workshop is a relatively new initiative. The first such workshop was held at the Africa Centre in South Africa in December 2008. More than 60 delegates from 15 countries attended and the theme was 'Science and Community: Engage to Empower'.

The primary aim of the workshop is to build and strengthen international networks of practitioners working in public engagement with health research or science communication in developing countries.

The adviser for the International Engagement Scheme is Siân Aggett, who was the primary Wellcome Trust staff member in charge of organising the conference. Other Wellcome Trust staff who were closely involved in the conference were Zena O'Connor from the Meetings and Travel team, Jacob Leveridge (Bioethics), Laura Harper (Evaluation), and Ariel Retik, Operational Officer for Medicine, Society and History Grants. Dr Daniel Glaser, Head of Special Projects in Public Engagement, also took a leading role in the project.

Tinderbox Consultants Ltd

This year, the Wellcome Trust contracted us, Tinderbox Consultants Ltd, to help produce the workshop. We were contracted on the basis of previous work demonstrating commitment to and experience of public engagement with science, experience of working in India, and our backgrounds in the performing arts and humanities, combined with understanding of scientific issues and their societal implications.

Since 2002, Tinderbox has been developing innovative ways of bringing science and theatre together to illuminate and enrich both disciplines. Its primary objective is to cultivate curiosity, interest and understanding of science amongst general theatre audiences, and it has engaged with schools, communities, scientists and artists through a wide variety of initiatives.

As part of the Theatrescience project, Tinderbox have commissioned and produced biomedical science-based plays on subjects from bacteriophages in the River Ganges to post-traumatic stress disorder, organised workshops, festivals and exchanges in the UK and India, and planned, produced and evaluated many multi-disciplinary international projects. Recent examples include the Catalan-Wales Drama Festival, Drama Centrestage for the Wellcome Trust, and (with the

British Council and Apples & Snakes) the Speechless tour which brought five performance poets from South-East Asia to the UK.

Rebecca Gould, who co-founded Tinderbox with Jeff Teare, has worked extensively with theatre practitioners and scientists to develop new models for public engagement with biomedical science through the medium of theatre. As a theatre producer and director, Rebecca has led major projects for the Royal Shakespeare Company and has directed for the National Theatre, Made in Wales, and the Theatre Royal Plymouth, among many others. For this workshop, Rebecca took on the role of primary consultant and conference producer.

The Assistant Producer for this project was Dr Jessica Mordsley. Jessica holds a PhD in Critical and Cultural Theory from Cardiff University, and wrote her thesis on the boundaries between humans and other animals, and the construction of these boundaries within disciplines including palaeoanthropology, psychology, and linguistics. She has collaborated with Tinderbox on a number of projects as an assistant producer, copywriter, evaluator and administrator.

2.2 Location

The Wellcome Trust has funded research in India for over 50 years, and is currently expanding its involvement with the country. In September 2009 the WT-DBT Alliance Biomedical Research Career Programme in New Delhi was launched, with the aim of strengthening the research base of Indian biomedical sciences through a series of fellowship programmes. The new fellowships aim to build career pathways in India for scientists working in biomedical, clinical and veterinary research. 2009 also saw the launch of the MSD-Wellcome Trust Hilleman Laboratories, a unique research and development joint venture with a not-for-profit mission to develop affordable vaccines for diseases that commonly affect low-income countries. The Wellcome Trust also supports the schools debating competition 'Debating Matters India'.

Tinderbox also has extensive experience of working with theatre practitioners and scientists in India. Most recently, in January and February 2009, Rebecca Gould and Jeff Teare produced and directed a residency at the National Centre for Biological Sciences in Bengaluru. Tinderbox has also worked for a number of years in partnership with Artistes' Repertory Theatre, the resident company of Jagriti Theatre in Bengaluru.

For these reasons, it was decided to host this year's International Engagement workshop in India. After scoping and evaluating a number of possible locations, including Mumbai, Kolkata, and Bengaluru, it was decided that Bengaluru was the ideal location for the conference. The reasons were: its accessibility for speakers and delegates, its large international airport with direct flights to a range of worldwide and domestic destinations, and the availability of comfortable and safe accommodation close to the conference site(s) and amenities.

It was also decided to hold the conference in Bengaluru because of the presence of several local institutions undertaking cutting-edge biomedical research, and the high concentration of scientists, clinicians, press, and NGOs in the area who are interested in exploring and debating public engagement with science.

Finally, Bengaluru was chosen because of its cultural, ethnic, and religious diversity, as well as its good transport links. It was felt that delegates would be able to get a good sense of the region and of India as a whole, to learn about Indian culture and science, and to address the societal issues arising from biomedical scientific research.

3. Development

3.1 Findings from last year's evaluation

The Wellcome Trust's evaluation from the first International Engagement Workshop established that the delegates found the network building especially useful. Delegates also expressed a preference for a wide variety of more specialised sessions, as opposed to fewer, more general ones.

Delegates at the 2008 workshop were asked to suggest possible topics for future sessions. Their suggestions included:
- evaluation
- theory of engagement
- participatory methods (e.g. film making)
- developing strategic vision
- using storytelling
- examining media coverage of biomedical science

Delegates' suggestions for future workshop themes included:
- science festivals
- engaging young people
- evaluation
- dissemination

We drew on these findings when devising the programme for this year's workshop.

3.2 Aims and objectives

We set out to develop a programme for the workshop which would be intellectually rigorous, culturally aware, and inspirational and productive for all involved.

Our aims for the conference were:

i. Building community

One of the most successful aspects of the first International Engagement workshop was that it built links between many people working in public engagement; after the workshop, these links continued online via the D-group discussion network. We aimed to develop these links further by prioritising opportunities for delegates to network both formally and informally, by strengthening connections with existing networks in India such as WT grantholders, key stakeholders in public engagement, health researchers, and policymakers, and by disseminating the workshop findings as widely as possible. Ultimately, we hoped that the workshop would contribute to building a global community of active public engagement workers.

ii. Increasing participation and interaction

Tinderbox's experience in public engagement has demonstrated that the most productive results come when people are actively learning, rather than passively absorbing information. For this reason, we devised a programme that focused on enabling all delegates to participate as fully as possible.

iii. Working with metaphor and imagination

Successful public engagement means enabling people to grasp complex scientific concepts intuitively. While the media already understand how to employ

metaphor and imagery in a sophisticated and emotive way, scientific expertise does not necessarily equate to the ability to engage others (particularly non-scientists) with the issues at hand. We drew on our background in the arts, humanities and drama to design a programme which would help delegates to understand how to engage others through creative use of imagination and metaphor.

iv.   Enabling honesty
Finally, in order for the workshop to achieve its objectives, we considered that it was essential to create an open and non-judgemental atmosphere which would be a genuine forum for discussion. The workshop represented a unique opportunity for the delegates to share the challenges and difficulties, as well as the successes, of their work. We therefore set out to compile a programme of speakers and activities which would encourage trust and honesty.

3.3   Conference theme
When we began researching possible themes for the workshop, we realised that many of the ideas under consideration were related to the idea of story and narrative. Public engagement is about successful communication, and shaping that communication into stories that work is something that came up repeatedly in our discussions. We therefore decided to devise the conference programme around the theme of 'telling stories'.

Whether we are explaining biological processes which are too small to be seen with the naked eye or narrating our personal experiences, by telling a story we can make those events vividly real. A story is also crucially about the relationship between the storyteller and the audience. A good story can provoke a powerful emotional reaction in the listeners, and this makes them more deeply engaged intellectually and able to grasp complex ideas intuitively.

This power can be abused, for example when the media distort scientific facts in the pursuit of 'a good story'; this makes it even more important that those who are dedicated to public engagement with science also learn how to tell creative and persuasive stories.

Finally, with an invitation list that included potential delegates from over 30 countries, we believed that it would be especially useful and interesting to hear stories and experience forms of storytelling from many different cultures.

We decided to title this year's workshop: 'Telling Stories: Why narrative matters in public engagement with science'. We developed a programme to explore the question: when and how can we use storytelling properly in public engagement, and what are the potential dangers of misusing it?

3.4   Consultations and research
In developing the programme, we met and consulted with many people. Daniel Glaser chaired an initial meeting between Tinderbox and Wellcome Trust staff including Siân Aggett, Zena O'Connor, Craig Brierley, Kirsty Roach, Ariel Retik, Laura Harper, Lucy Evans, Michelle Jimenez, Jacob Leveridge, and Bella Starling. We also met other Wellcome Trust staff such as Derek Bell, Sara Candy, and Barry Gibb, with whom we discussed education, evaluation, and film-making, respectively.

We also met with Eleanor Lanyon from the Wellcome Library, who showed us fascinating selections from Wellcome's archive collection of material from India. Unfortunately it was not possible within the conference budget to bring any of this material to the workshop.

We presented an early version of our programme to the Wellcome Trust International Engagement Committee in July 2009. Their comments and feedback played a crucial part in shaping the development of the programme.

In September 2009, Rebecca Gould conducted a pre-visit to Bengaluru with Zena O'Connor from Wellcome's Meetings and Travel team, in order to assess possible venues for the conference and accommodation and to meet with various potential partners. Rebecca also visited Delhi where she met with, among others, representatives of the Public Health Foundation of India, HRI-DAY, and Plan International.

3.5   Partnerships

In order to deliver the conference successfully, Tinderbox and the Wellcome Trust formed partnerships with a number of organisations (in addition to the conference venue). Three organisations who played a vital important role in the workshop were:

i.   National Centre for Biological Sciences (NCBS)

We chose the National Centre for Biological Sciences as the conference venue because of its convenient location, its accommodating and attractive spaces, and the presence of many scientific researchers with a strong interest in public engagement and with the arts (as demonstrated by previous Theatrescience projects conducted there).

NCBS is part of the Tata Institute of Fundamental Research. Research at NCBS uses experimental and computational approaches to the study of molecules, cells and organisms. The aim is to understand biology at each of these levels to advance an integrated view of life processes. Collaboration and exploring new approaches are key parts of the NCBS ethos.

The main campus, where the conference was held, is in Gandhi Krishi Vigyan Kendra (GKVK) on Bellary Road, in the north of Bangalore. The campus provides accommodation and catering for some students, visitors, and faculty.

We also decided to partner with NCBS because they offered more than just a venue for the conference; they also provided consultation and advice on the programme. In particular, Dr Mukund Thattai of NCBS was closely involved with the development of the workshop. NCBS students were invited to attend the conference sessions and performances, and additionally Wellcome Trust staff gave a dedicated talk for students on the International Engagement scheme.

ii. Communication Initiative (CI)

The Communication Initiative network is an online space for sharing the experiences of, and building bridges between, the people and organisations engaged in or supporting communication as a fundamental strategy for economic and social development and change. It does this through a process of initiating dialogue and debate and giving the network a stronger, more representative and informed voice with which to advance the use and improve the impact of communication for development.

This process is supported by web-based resources of summarised information and several electronic publications, as well as online research, review, and discussion platforms providing insight into communication for development experiences.

CI submitted a proposal for a social networking and knowledge management platform dedicated to this workshop. The proposal was agreed by the Wellcome Trust and Tinderbox.

This platform was set up in September 2009 and was used to manage conference registrations. The Wellcome Trust's official conference invitations to delegates included instructions on signing up to the CI platform and explained that this was essential in order to attend the conference.

Once all of the delegates had become members of the CI site, the site was then used to distribute the official conference registration form, as a Word document to be downloaded, completed, and returned by email to the Wellcome Trust.

Two separate groups were established: one for discussing logistical and practical information about the workshop (membership of this group was restricted to conference delegates), and the other for broader discussions around issues relating to the themes of the conference and to public engagement work (membership of this group was open to anyone interested in these themes).

In addition, two groups were set up for Wellcome Trust, Tinderbox and CI staff to coordinate the management of the platform.

Maintaining the site did not form part of the original contract for services between WT and Tinderbox; however, it was agreed that that tasks associated with investigating and testing group management would be shared between CI, WT staff and Tinderbox. In the end this turned out to be a much bigger task than was originally anticipated.

iii. Madhyama Prasaran

We also worked closely with Madhyama Prasaran and Scientific Research Foundation (MPSRF), a charitable organisation based in Bangalore.

In partnership with various self-help groups, MPSRF has set up a craft-based, self-sustained, eco-friendly livelihood programme and has worked for the past 15 years with women and children affected directly or indirectly by HIV/AIDS, gender-based violence, homelessness, et cetera.

The objective is to provide a loving and healthy environment and avenues towards self-sustenance with confidence and dignity. MPSRF develop self-esteem, confidence and the use of creative methods, as well as acquiring skills. The women and children are trained to make contemporary handcrafted products. Their skills are combined with creative inputs arising from interactive theatre workshops.

MPSRF use only environmentally friendly, biodegradable materials such as elephant dung, korai grass, hibiscus, jute, wool, banana fibres, recycled cloth and newspaper. The product range includes fabrics, mats, table runners, coasters, window blinds, cushion and bolster covers, carry bags, greeting cards, pouches, picture frames, stationary, and traditional Indian games, among others.

We believed that it was extremely important to involve local, charitable, and environmentally conscious organisations in the production of the conference,

rather than producing all materials in the UK and then transporting these to India. We therefore asked MPSRF to produce the conference bags and notebooks, and also to organise printing of the conference programme.

The bags that MPSRF created were high-quality, strong and practical (complete with mobile phone pockets and hand-stitched conference labels), and were also aesthetically beautiful; each bag was handcrafted and unique. We were delighted with the bags and notebooks, and extremely grateful for MPSRF's work, especially as they were produced within a very short time.

4.   Delegates

The delegate list was drawn up by Tinderbox in close consultation with the Wellcome Trust. Wellcome Trust staff who were involved in the initial meetings about the conference were invited to submit lists of recommended delegates. All of the WT suggested delegates were invited. In addition, we researched other potential delegates, primarily from India but also from the UK and other countries.

The primary audience for the workshop was current International Engagement grantholders. Other groups that we wished to represent were Wellcome Trust staff (from the UK and Major Overseas Programmes), researchers funded by the Wellcome Trust, other scientists and science communicators, arts practitioners, and NGOs. We aimed to achieve a good balance of delegates in terms of nationality, area of work, demographics, and previous experience.

An initial list of approximately 170 potential delegates was drawn up to receive 'save the date' letters, which introduced the conference and requested recipients to register their interest in attending. A message about the workshop was also posted on the CI platform, from which we received a further 50 expressions of interest. We wrote back to these respondents asking them to give us more information about themselves, their work, and their reasons for wishing to attend the workshop, and then selected those whom we believed would benefit most from, and contribute most to, the conference.

Official invitations were then sent to 111 potential delegates. Further invitations, based on a 'reserve list', were sent out later once registration deadlines had passed. Delegates' travel and accommodation was organised and paid for by the Wellcome Trust.

84 delegates attended the conference, of whom 40 were male and 44 female. (These figures do not include the young people who participated in the conference and their chaperones, nor do they include the NCBS students and faculty who attended some of the sessions.)

Further demographic information on those who attended is shown below.
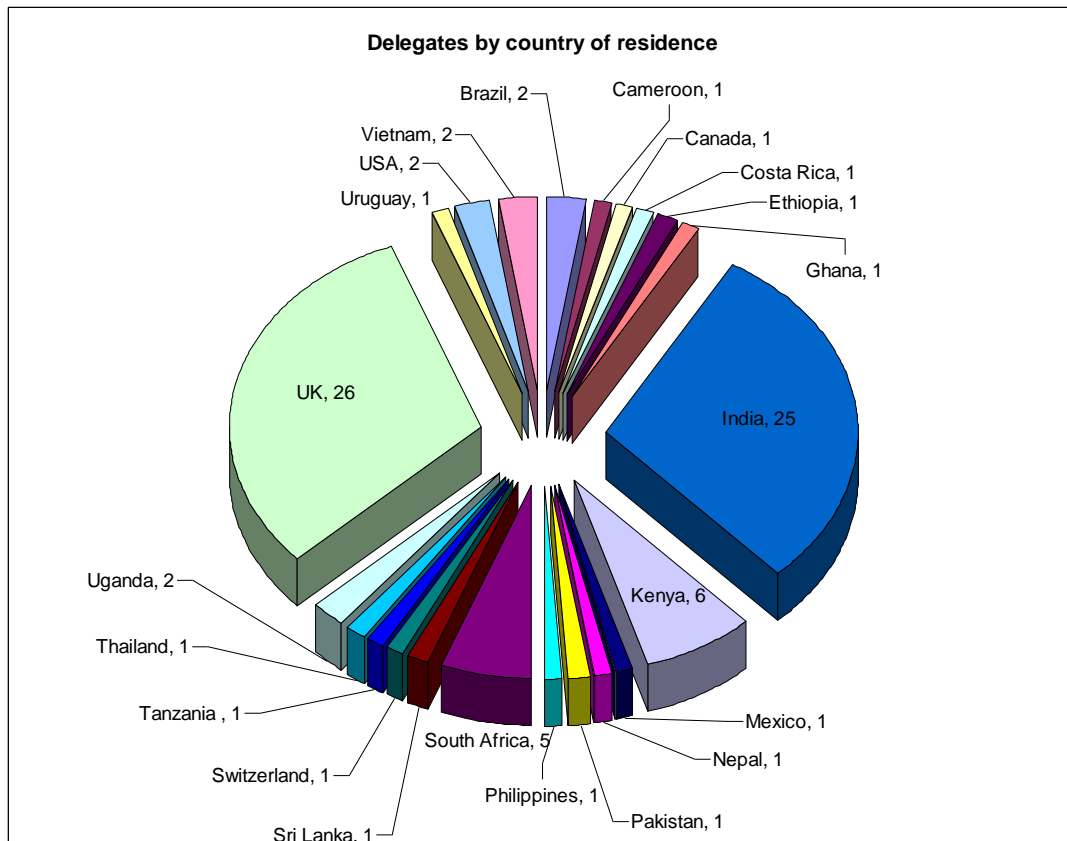
Figure 1: Delegates by country of residence

As Figure 1 (above) shows, there were delegates from 22 countries. 25 of the 84 delegates (29.7%) came from India, and another 26 (30.9%) from the UK. The remaining 33 delegates came from a wide range of countries in the Americas, Africa, Asia, and Europe.
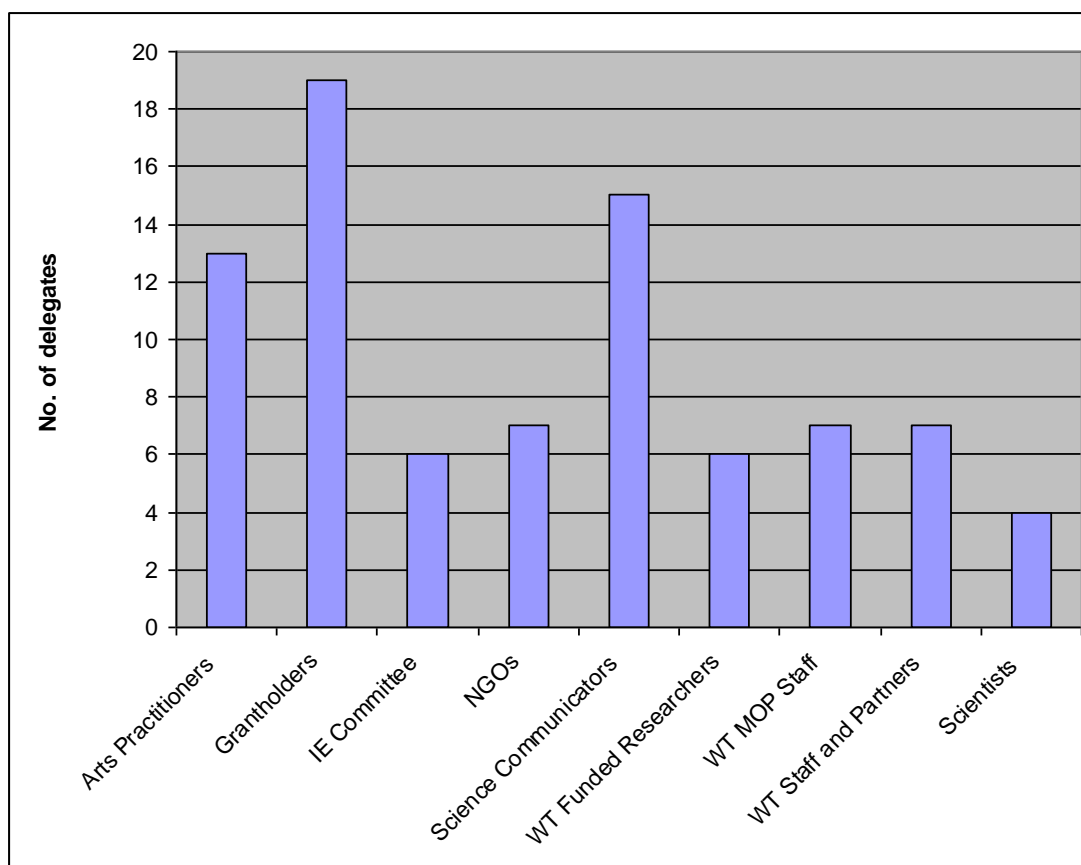
Figure 2: Delegates by group

Delegates were drawn from a wide variety of organisations and professions. We considered it vitally important to bring together a diverse group in order to enable cross-fertilisation of ideas and sharing of expertise. This was reflected in the final gathering, which drew together 19 International Engagement, Livestock for Life, Society and Arts grantholders, 13 arts practitioners from theatre, visual arts, music, et cetera, 21 scientists and researchers, along with representatives of various NGOs, Wellcome's International Engagement Committee, and Wellcome's Major Overseas Programme staff, as well as core Wellcome Trust staff and partners who were involved in organising the workshop.

5.   Conference Programme

5.1   Strands

The full conference agenda and timetable is appended to this report.

We divided the conference theme into three main strands:
- Translations: Engaging with Different 'Publics'
- Creative Approaches: Participating in Engagement
- Gender in Public Engagement

i.   Translations: Engaging with Different 'Publics'

This strand focused on the notion of public engagement as translation between different groups of people.

The questions this strand set out to explore were:

- How can we achieve understanding between those who speak in different registers, disciplines, and languages?
- How can scientific research be translated in a way that makes it accessible to the public, to end users, to the media, to health practitioners?
- How can marginalised voices speak in a way that enables them to be heard by those in power, such as policymakers and researchers?
- Can successful communication be achieved between those with different agendas, and if so, how?

ii.   Creative Approaches: Participating in Engagement

The 'Creative Approaches' strand enabled delegates to explore practical ways to tell stories using the creative arts to engage the public with science. The sessions in this strand looked at the use of music, drama, visual arts, storytelling, and radio in public engagement.

Figure 3: Gurupada Chitrakar, traditional West Bengal 'patua' scroll painter (Photo: Enriqueta Valdez)

These sessions were led by expert practitioners, and were designed to be interactive and participatory. For the majority of sessions, delegates were presented with examples of projects which have used this approach successfully, and then took part in a hands-on workshop in which they began to put these skills into practice.

iii.   Gender and Public Engagement

This strand asked how and why gender and sexuality matter in public engagement with health.

The questions we began with were:
- How do gender differences affect access to health care, information, and legal assistance?
- How can public engagement workers create safe spaces which allow women to tell their own stories?
- In what ways do the stories we tell about women's health affect their chances of living and dying; for example, what difference could it make if we explained maternal death rates as a result of mental rather than physical health problems?
- What are the special issues affecting transgendered people and homosexuals, and how can their stories be heard?

5.2 Young People's Projects

In addition to these three core strands, the final day of the conference was dedicated to the topic of engaging with young people. In a meeting dedicated to public engagement, we considered it essential to incorporate some direct interaction with those being engaged, to avoid all discussions being merely theoretical. Rebecca has specialised in working with young people and believed that it would be especially valuable to involve them in the conference, in particular in terms of encouraging open debate and highlighting questions of translation for different audiences. We are grateful for the input of the International Engagement Committee, in particular Douglas Wassenaar, for encouraging us to include this part of the programme.

A full account of the young people's engagement sessions is appended to this report.

**Figure 4: Small group work with the young people
(Photo: Enriqueta Valdez)**

5.3   Wellcome Trust staff workshops and focus group

Wellcome Trust staff led dedicated workshops on Evaluation and Grant Writing.

There was also a focus group led by Warren Feek of the Communication Initiative to discuss the use of IT in public engagement and to gather feedback on the CI platform.

5.4   Buddy Sessions

Prior to the conference, we divided the delegates into 'buddy groups': groups of 'travelling companions' who would share their experience of the conference throughout. We aimed to achieve a good mix of nationalities, genders, disciplines, and experience levels in each group of three. The buddies were introduced to each other online via the CI platform before the conference, and were invited to begin discussion around some suggested questions. There were dedicated periods set aside during the conference for the buddy groups to meet informally and discuss their hopes, expectations, and experiences of the workshop.

5.5   Performances, readings and speeches

There were a number of performances during the conference:

Storytellers

At dinner on Day Two, there were performances by two professional storytellers: Kole Odutola from Nigeria, and Simon Heywood from the UK. Both Kole and

Simon told traditional stories from their respective cultures; this was important as it enabled delegates to see the common roots of stories from different parts of the world, and to reflect on how storytelling has been transformed, in particular in terms of film and other new media. As well as being entertaining, the storytelling session highlighted the bringing together of many different cultures from across the world at this workshop.

Theatre readings
Extracts from selected Theatrescience plays were read in the amphitheatre at NCBS, to an audience including delegates and NCBS students and staff. The readings were *Bad Blood Blues* by Paul Sirett, *Seeing Without Light* by Simon Turley, and *The Invisible River* by Gautam Raja. These plays explore scientific issues including HIV research and bacteriophages in the River Ganges.

The readings were introduced by the playwrights (except for Gautam Raja), and the directors Jeff Teare and Arundhati Raja. The cast was Sukhita Aiyar, Jagdish Raja, Pritham Kumar, and Paula Hamilton. Following the readings, questions were taken from the audience; there was a great deal of interest in staging these plays in different countries around the world.

It was very enlightening for the delegates to see the storytelling and the play readings as examples of how telling stories in public engagement can work in reality.

Dance performance
The charitable dance group Bhramari, under the direction of Artistic Director and Choreographer Sneha Nandagopal, performed a traditional Karnatakan folk dance at the NCBS dinner. Bhramari was established both to preserve threatened Karnatakan folk dances and also to bring young people from diverse backgrounds together to learn and collaborate.

Speeches
Finally, speeches were given at dinner by representatives of the Wellcome Trust (including Clare Matterson, Daniel Glaser, and Jacob Leveridge), Dr Megha from the Wellcome-DBT India Alliance, who spoke about the Alliance's new fellowship scheme, the strand chairs, and Rebecca Gould of Tinderbox.

5.6   Structure
Including the three main strands, young people's projects, Wellcome Trust staff workshops, and a focus group, there were 23 sessions with over 50 speakers/presenters.

Days Two and Three of the conference began with keynote speeches attended by all delegates. The keynote speakers were Shubha Tole, professor of neuroscience at the Tata Institute Mumbai, and Elizabeth Pisani, epidemiologist-turned-journalist and author of *The Wisdom of Whores*. Each keynote speech was accompanied by a practical session, in which delegates participated in activities designed to help them to actively learn about the themes of the speech. For Shubha Tole's session, delegates played 'the ribbon game' to learn about the way that messages are transmitted in the brain. Following Elizabeth Pisani's speech, delegates were given sets of data relating to HIV epidemics and worked in small groups to construct different 'stories' using these data.

The remainder of the days were divided into parallel sessions, with three sessions running simultaneously. Apart from the workshop on Evaluation which was compulsory for all International Engagement grantholders, delegates were free to

choose to attend any of the sessions, with no prerequisites or requirements to commit to a particular strand. For those sessions with restricted places available, delegates were asked to sign up at the beginning of the day on a first-come, first-served basis.

We wanted to give delegates this opportunity to plot their own path through the workshop programme for two primary reasons: first to allow everyone to gain the maximum possible benefit from the sessions on offer, and second to encourage mingling among delegates from different backgrounds.

This was also the reason that we divided the strands in a conceptual way, in terms of the questions and ideas that would be explored, rather than along more traditional disciplinary or practical lines. In this way we hoped to take people out of their 'comfort zones', so that those present in any given session would represent a broad cross-section of people working in very different fields.

In practice, delegates took individual approaches to the choice of sessions; some preferred to attend all or almost all of the sessions in one particular strand, while others attended as many different strands as possible. The only complaint we received about structuring the programme in this way was that it was difficult to choose between simultaneous sessions ("there's so much I want to go to!", "I want to go to all of them", and similar comments).

We understand that this may have presented difficult choices for individuals, but we consider this strongly preferable to the reverse. We also hope that the rapporteurs' notes which are appended to this report, along with the lively discussions that were held both at and after the conference, will enable delegates to get a good sense of the content of the sessions they could not attend.

5.7   Speakers

We chose the speakers through a mixture of recommendations from Wellcome Trust staff and others, personal knowledge, and research. We also wanted to ensure that the choice of speakers was well-balanced in terms of gender, nationality, area of work, disciplinary background, level of experience, and so on. Guidance was provided to speakers through online contact in advance of the conference. There were also meetings on Day One for all speakers and workshop leaders to meet each other, their strand chair and rapporteur, in order to plan the development of the strand in more detail.

As outlined above, we also wanted to focus on interactivity and participation and to encourage all delegates, not only the speakers listed in the programme, to contribute to the content. We believe that this was successful and that very few, if any, sessions, consisted of official speakers lecturing to a passive audience; especially as the conference progressed, the contributions from delegates formed a vital part of each session, so that there was not a sharp dividing line between 'speaker' and 'audience', but rather a sense of an open forum where all contributions were listened to and respected.

Holding many of the sessions wholly or partially outdoors, and thus away from the conventional crutches of technology and multimedia, also contributed to achieving this aim. While Powerpoint, for example, is obviously very useful for presenting information, it can also stifle discussion and prevent discussions developing in an organic and fully participatory way.

5.8   Documentation

Tinderbox employed three rapporteurs to ensure that the conference was fully documented, each of whom was responsible for the sessions in one of the three main strands. The rapporteurs' notes are appended to this report. We also commissioned a podcast, which is available from the Theatrescience website *http://www.theatrescience.org.uk*. The report will also be available on the Theatrescience site.

5.9   Venues

The main conference sessions were held at the National Centre for Biological Sciences. NCBS provided lecture halls, seminar rooms, and a teaching lab, and supplied all of the necessary technology (PCs, projectors, speakers, et cetera). The Herbal Garden at NCBS was also dedicated to the conference, with a 'Market Place' set up where delegates could display material and provide information about their projects. Tea and coffee breaks were also held here, making it an ideal location for discussion and relaxation.

Several of the sessions were also held outside on campus, instead of indoors in the seminar rooms, and delegates were free to wander around the campus, for example when they were asked as part of a session to work in small groups. NCBS has a large and very green campus, with many trees, lawns, and ample outside space, as well as the amphitheatre and herbal garden. As outlined in the notes on these sessions (see Appendix 2 of this report), this contributed to the informality, honesty, and enjoyment in these sessions.

NCBS hosted lunch for the delegates, and dinner with NCBS faculty on Day Three.

All of those attending the conference (except a few residents of Bangalore) stayed in the Lalit Ashok Hotel, in Kumara Krupa High Grounds, about 20 minutes drive from NCBS. The sessions on Day One, and dinner on Days One and Two, were held at the hotel.

Dinner on Day Two, along with the storytelling session, was held on the lawn outside at the hotel, next to 'the Gandhi tree' (where Mahatma Gandhi held a prayer meeting in June 1927). Experiencing stories from Africa and the UK in such a beautiful location, lit by strings of fairy lights and in the warm Bengaluru evening, contributed to making this something more than a straightforward 'conference'. These events should not be seen as simply additional or extracurricular to the main sessions, but as key parts of colouring the overall experience and seeing very diverse forms of engaging with an audience.

**Figure 5: The 'Gandhi tree' at the Lalit Ashok Hotel
(Photo: Jessica Mordsley)**

We believe that the spaces in which the meeting took place were vital to creating a positive atmosphere and contributing to the successful bringing together of the sciences and the arts, the personal and the professional, and many different cultures from around the world.

6.   Reflections

6.1   Feedback from delegates

Following the workshop, a number of delegates sent feedback to us. Some selected comments from delegates are included below. (Comments have been edited for spelling, grammar, punctuation, and length.)

> *Dear Rebecca - I'm just back from India (I went to work in Delhi after Bangalore) and wanted to thank you and Jess again for all your incredible*

hard work for the workshop. I found it an incredibly stimulating gathering - so, so different from the "stuff" I usually attend!

I am just back from India and want to let you know how much I appreciate the opportunity you gave me. It was a privilege to be a part of the "Telling Stories" event.

I learned a lot about others delegates' work in the field of public engagement. The range of projects that were presented and the presenters, themselves, opened for all of us a great opportunity for future collaborative projects.

Thanks for making the conference such an enjoyable and educational experience. It has been really good to meet you all and find out a bit about your work.

The conference was wonderful and I learned so much from the different projects that you are doing. I would like to thank Rebecca, Jessica, Sian and all the other team members who put everything together. I'll certainly be contacting some of you as agreed to follow up on what we (APHRC) can learn from what you are doing.

I had such a wonderful time in Bangalore, I think the organizers managed to put together a really interesting. sensitive and connected group of people and the whole experience was very special. It was a privilege to be a part of it, and I feel very grateful for that.

Let me thank each one of you for making these meet so special. The informality and the way in which the sessions were unstructured helped a great deal in making the discussions rich and informative, as somebody said in the conclusion session we can always go back to theory and our books for knowledge but the quality of discussions we had because of the way in which sessions were conducted was of great help. Let me also thank all the people in the organizing committee for their efforts in making these meet flow so smoothly. Personally for me I felt empowered enough to engage with communities and policy makers in more ways than one.

The proverbial dust is finally settling and the jet-lagged bodies getting untangled. Slowly biological clocks are catching up and the stomachs temporarily attuned to the wonderful Sounth Indian cuisine are settling to more mundane stuff. It was a wonderful three days; there were light moments and intense deeply intellectuals ones - all engaging all blended so well. The level of engagement was simply great. The usual dilemma of desire to attend parallel sessions led to some frustrations; why can't somebody research on how to split the human being? Congratulations to Rebecca and her jolly team for a wonderful fete and thanks to the Indian hosts, they did not disappoint. The wonderful young people who so gallantly shared with us their wonderful work must all be profusely thanked by Dayaprasad in Telugu, Kannada, Marathi, Hindi, Bengali, Tamil and any other linguistic feat the man demonstrated. I doff my hat to you. The National Centre for Biological Sciences also deserves thanks for playing hosts and someone please send a great thank you to the bus drivers who were ever on time and drove soberly and ensured we had no incident to report back home of a traffic nature.

A big thanks to Rebecca, Jess, Daniel and all others at the Wellcome Trust for the opportunity to join the conference in Bangalore. It was inspirational

to meet so many highly motivated people who actually put what they say into action and deliver the results to prove these engagement initiatives work. Let's do it again sometime.

It was an absolute privilege being at Bangalore for this excellent event. I learnt a lot and am grateful to the Wellcome Trust, especially Rebecca, Jessica and Sian for the opportunity to participate in the event as also present our own work. I am not a Science person and the forum provided the perfect opportunity to see that perspective and also how best to engage the public. Our own work endeavours to bring the arts and public health on the same platform. From that perspective alone there was a lot to learn from the experience of fellow delegates. Meeting many like-minded people from across the world with diverse background and experience was a huge bonus. Indeed, this coming together may lead to collaborative opportunities. The event was seamlessly organised, everything worked with clockwork precision - kudos to the team that worked so hard to put it together. Congratulations once again to the team and I do look forward to being in touch with my fellow delegates.

What a great show!!!!!!!!! It was not only smoothly run but also an opportunity for all of us to learn more about others' work in the field of public engagement to which Bella had first introduced me followed by the Theatrescience group. It is not only the public but also my grandchildren & other children to whom I demonstrated Kole's way of story telling. The adults who saw it were also enjoying it. Given an opportunity I would love to take part in future plans so that we could use it for my organisation's work in the area of public health and ethics.

I want to give my ever-lasting gratitude to workshop organizers and our Indian host and all the participants for giving me a great experience. I could explore and have direct contact with all the new initiatives for engaging the public of every cultural and socio-economical background and ages with the science, as strategy to break the circle of ignorance, which in many senses is an important social determinant of health. Every single moment during the activity I could feel the spirit of solidarity with a fantastic diversity of cultural and geographical backgrounds and talented ideas. I have learnt many new approaches, tools and strategies for telling stories to a broad diversity of audiences that I am sharing with my team for including new components in our everyday work and mainly for improving our WEB Based Audio-Video Bulletin.

Firstly it was a great privilege and pleasure being a part of this incredible conference. Thank you to the Wellcome Trust, Rebecca and Jess for providing this opportunity. The experience of meeting so many people with such diverse yet interelated interests, though overwhelming, has given me an oportunity to look at my work in new light and explore new possibilities. It will take some time to put my thoughts together and articulate them.

I'm going to join Dayaprasad in thanking Rebecca, Jess and Zena for all they did to make the conference go so smoothly. It was certainly great to meet people from so many different cultures and to realise that despite our differences we had so much in common. The conference has opened my eyes to new things and given me several new ideas in my work sphere. I hope to keep you updated on progress […], thank you so much for this wonderful opportunity.

A POEM FROM SIMON PARRY'S PARROT
I was just about thanking everyone when Simon Parry's parrot gave me the following poem as a reflection. The parrot says we should consider the first letters of each sentence—WELLCOME TRUST.
We really had an enjoyable and meaningful conference.
Examples of excellent public engagement activities were showcased.
Levels of participation were very high.
Learning from our colleagues was a good exercise.
Children were given the chance to be active participants.
Objectives of the conference were really met.
Many participants from diverse backgrounds found a common goal.
Extending what we have learned should be our goal.
Time was our greatest enemy.
Researchers, artists, science communicators, and other experts were there.
Understanding public engagement took place.
Story-telling was really made alive.
Thanks to everyone who played a part in the success of the conference.

6.3 Assessment of intended outcomes

To reiterate, our aims for the conference, as outlined in section 3.2 above, were:

i. Building community

Aim: to further develop the links between those working in public engagement in developing countries and across the world.

Outcome: Before the conference, the CI group provided a platform for delegates to make contact with each other and to share their expectations and plans for the meeting. At the conference itself, there were many formal and informal opportunities for networking, and we received many positive comments about this from delegates during the meeting. Since the conference closed, communication on the CI platform has continued, although it is only used by a small proportion of the delegates. In conclusion, we consider that this aim was successfully achieved.

ii. Increasing participation

Aim: to enable all delegates to participate as fully as possible in the conference.

Outcome: As discussed in section 4 above, there was a great deal of participation and interaction from all delegates. In particular, as the conference went on and everyone became more comfortable with each other, all sessions contained lively discussion and interaction between delegates, both in small groups and in the group as a whole.

iii. Working with metaphor and imagination

Aim: to help delegates to understand how to engage others through the use of their imagination.

Outcome: We believe that this aim was achieved, both through the sessions that formally taught these skills (especially those in the Creative Approaches strand), but also through the storytelling, theatre readings, and so on, which demonstrated the use of these skills in action.

iv. Enabling honesty

Aim: to create an open and non-judgemental atmosphere which would be a genuine forum for discussion.

Outcome: As in ii above, we were pleased with the warm and open atmosphere at the conference, and feel that this increased as the conference went on. The buddy sessions, informal settings, and small group work all contributed to achieving this aim.

Appendix 1: Conference Agenda

MONDAY 7 DECEMBER 2009 *Lalit Ashok Hotel*

CONFERENCE OPENS
Delegates arrive at hotel. Conference registration. Welcomed by WT staff.

3.00pm	*Strand Chairs/Speakers Meeting, Hotel*
4.00pm	*Buddy Session 1, Hotel* Delegates meet their two conference 'buddies' to plan their journey through the workshop.
6.00pm	*Conference Introduction, Chanakya Hall, Hotel* Welcome Speeches **Clare Matterson/Daniel Glaser/Jacob Leveridge** Introduction to conference theme **Rebecca Gould**
7.00pm	*Buffet Dinner, Chanakya Hall, Hotel*
	After-dinner Speeches/Drinks Reception, Chanakya Hall, Hotel Introductions to three strands by chairs *Translations:* **Subhadra Menon** (co-chair with **Latha Sekhar**) *Creative Approaches:* **Simon Parry** *Gender:* **David Osrin** Host Speech **Mukund Thattai**

TUESDAY 8 DECEMBER 2009
NCBS

'MARKET PLACE' to run throughout Days Two, Three and Four of the conference. *NCBS Herbal Garden*

8.30am	Delegates depart hotel for NCBS
9.30am	*Keynote Speaker 1:* **Shubha Tole** *NCBS Lecture Hall LH1*
10.15am	*Practical Session:* **Ribbon Game** *NCBS Lecture Hall LH1*
11.00am	**Coffee Break** *NCBS Herbal Garden*
11.30am	*Parallel Session 1.* Delegates choose from 3 options. 1a. *Translations:* Hearing marginalised voices (advocacy) **Subhadra Menon/Rose Oronje** *NCBS Seminar Room II* 1b. *Creative Approaches:* Drama **Jeff Teare/Arundhati Raja/Paul Sirett** *NCBS Teaching Lab* 1c. *Gender:* Why gender matters in PE **Wasundhara Joshi/Vikram Patel** *NCBS Lecture Hall LH1*

12.45pm	**Lunch** *NCBS Lawn*
1.45pm	*Parallel Session 2* 2a. *Translations:* Telling stories to policymakers **Michael Devlin/Paul Nampala/Wendy Graham (chair)** *NCBS Lecture Hall LH1* 2b. *Creative approaches:* Visual arts **Rajeev Varma/Gurupada Chitrakar /Bernard Appiah** *NCBS Teaching Lab* 2c. *Gender:* Women's stories: Making a space for women to speak **Amar Jesani/Lindy Wafula/Justa Wawira** *NCBS Lecture Hall LH2* [This session will finish at 2.45pm]
3.00pm	**Coffee Break** *NCBS Herbal Garden*
3.15pm	*Parallel Session 3* 3a. *WT Staff Workshop:* Evaluation **Laura Harper.** Compulsory for all grantholders *NCBS Lecture Hall LH1*
3.30pm	3b. *Creative approaches:* Radio **Enriqueta Valdez/Amel Belay Yimer/Ashish Sen** *NCBS Teaching Lab*
4.15pm	3c. **Focus group on IT platforms in public engagement – Warren Feek/Dan Glaser plus 10 delegates** *NCBS Seminar Room S01*
5.15pm	Delegates depart NCBS for hotel
7.00pm	*Pre-dinner talk, Poolside Lawn, Hotel* **Dr Megha**, DBT India Alliance
7.30pm	*Dinner, Poolside Lawn, Hotel*
9.00pm	*Storytelling, Poolside Lawn, Hotel* **Simon Heywood/Kole Odutola**

WEDNESDAY 9 DECEMBER 2009
NCBS

8.30am	Delegates depart hotel for NCBS
9.30am	*Keynote Speaker 2:* **Elizabeth Pisani** *NCBS Lecture Hall LH1*
10.15am	*Practical Session* *NCBS Lecture Hall LH1*
11.00am	**Coffee Break** *NCBS Herbal Garden*

11.30am	*Parallel Session 4* 4a. *Translations:* Telling stories to the media **Arup Jyoti Das/Rajesh Parishwad/Daniel Glaser/Rebecca McCall** *NCBS Lecture Hall LH1* 4b. *Creative approaches:* Politics of participatory arts in PE **Simon Parry/Bella Starling/Siân Aggett** *NCBS Teaching Lab* 4c. *Gender:* Alternative stories: Women's mental health **Vikram Patel/Douglas Wassenaar** *NCBS Seminar Room 02*
12.45pm	**Lunch / Buddy Session 2 / Structured Networking.** *NCBS Lawn* *YOUNG PEOPLE ARRIVE*
2.30pm	*Parallel Session 5* 5a. *Translations:* Public outreach/Science Cafés **Duncan Dallas/Ana Vasquez Herrera/Juliette Mutheu** *NCBS Seminar Room S01* 5b. *Creative approaches:* Storytelling **Simon Heywood/Kole Odutola/Claire Heffernan** *NCBS Teaching Lab* 5c. *WT Staff Workshop:* Grant writing **Siân Aggett/Ariel Retik** *NCBS Lecture Hall LH1* YOUNG PEOPLE TO ATTEND SESSIONS 5a OR 5b
3.45pm	**Coffee** *NCBS Herbal Garden*
4.00pm	*Parallel Session 6* 6a. *Translations:* Listening to each other's stories: communication between health researchers and the public **Wendy Graham/Mayada Elsabbagh/Claire Heffernan** *NCBS Seminar Room S01* 6b. *Creative approaches:* Music **Jonathan Stadler/Ansuman Biswas/Luisa Massarani** *NCBS Teaching Lab* 6c. *Gender:* Transgender issues in PE **Dayaprasad Kulkarni/Elizabeth Pisani** *NCBS Lecture Hall LH2* 6d. YOUNG PEOPLE INTRODUCTION/ICE BREAKER SESSION **Paula Hamilton/Rebecca Gould** *NCBS Herbal Garden*
5.15pm	Talk for NCBS postgrads **Siân Aggett/Ariel Retik** with grantholders **Sisira Siribaddana/Anaclaudia Fassa** *NCBS Lecture Hall LH1* **Theatrescience performance** *NCBS Amphitheatre*

6.30pm	**Drinks**, *NCBS Lawn*
7.00pm	**Dance performance***, NCBS Lawn*
7.30pm	**Dinner with NCBS Faculty Staff and Young People** *NCBS Lawn*
9.30pm	Delegates depart NCBS for hotel

THURSDAY 10 DECEMBER 2009
NCBS

SPECIALIST TOPIC DAY: YOUNG PEOPLE'S ENGAGEMENT

8.30am	Delegates depart hotel for NCBS
9.30am	*Session 1. Young People:* Showcase/Presentation of excellent projects. Followed by Q&A/discussion with panel: **Paula Hamilton/Mirra Savara/Oby Obyerodhyambo/Rebecca Gould (chair)** *NCBS Lecture Hall LH1*
10.45am	**Coffee** *NCBS Herbal Garden*
11.15am	*Session 2. Young People:* Planning and pitching ideas for new projects. Small group surgeries led by: **Anaclaudia Fassa/Arundhati Raja/Simon Turley/Clare Heffernan** *NCBS Lecture Hall LH1* Free time for other delegates
12.00noon	*Plenary* Presentation of delegates' stories and showcase of work produced at workshop. Followed by Discussion *NCBS Lecture Hall LH1*
1.00pm	Closing speech **Daniel Glaser** *NCBS Lecture Hall LH1*

CONFERENCE CLOSES

Appendix 2: Rapporteurs' Notes

Strand 1: Translations

TRANSLATIONS: HEARING MARGINALISED VOICES (ADVOCACY)
Tuesday, 8 December 2009, 11.30 am

Chair: Daniel Glaser
Speakers: Subhadra Menon, Rose Oronje, Raj Panda

Subhadra Menon

Translation is continuous – literally and otherwise. Examples to be shared on getting key public stakeholders to engage with marginalised groups. There is currently not enough accountability among policy makers.

What is Advocacy: A set of skills and support necessary to mobilise on public issues

There are currently 2 groups: 'circle of concern' and 'circle of influence' – how do you influence positive change – what kind of support is necessary from the different groups involved.
Policy makers, health researchers, the media – building capacity at these levels of influence

Examples
Hyderabad, 2006, Bill and Melinda Gates Foundation
Police unable to handle marginalised groups at high risk – HIV/ AIDS, mired by ITPA, Section 377, Narcotics Prevention Act.

Core translational work required with the senior police in Andhra Pradesh, in a space that had proactive governance. How to support vulnerable communities within the existing framework?

Police force and marginalised, empowered sex workers.
DGP – initial attitude: so- called women who must be looked after.
Post session: Police force will commit itself to handling marginalised groups with sensitivity – always have an NGO present, etc.

September 2009: Public Health Foundation of India
Re-defining health communication and literacy
Collaboration between the Performing Arts and Public Health Intervention

Question: What is a marginalised voice wrt to circles of influence or concern?

Rose Oronje

Studies in Nairobi in the slums – running for this year and started late last year.

Enriching communities through research – 'liberative' sessions, community radio, folk media, participatory media

Liberative sessions
- Share research with community members – sensitisation for specific groups – young women , youth
- 5 sessions so far with different approaches – sharing some statistics to be able to facilitate dialogue
    o the importance of research – the community's perception

- maternal health – testimonies from the community and a dramatic representation of the stories heard through a skit
- child health
- marriage in the face of HIV/ AIDS – skit on STIs – this led to another session – community-driven for more information

Community radio
Looking for interaction
- Partnering with local radio to run 1 hour health programmes, involving Community Based Organisations
- Journalists gather public perspective to be aired
- Subjects: Cardiovascular diseases, maternal and child health

Participatory media
Get the community to identify issues that are important and then present material that provides information – they started with child health but found that information was demanded on rape, and had to revisit focus.

Folk media
Groups produce skits based on research conducted – HIV/ AIDS, maternal health – these groups get people talking – local connections, entertainment

Mobilisation of slum communities to engage with policy makers. Facilitate Community Voices Forum for urban marginalised to make presentations to ministers and donors – direct access to express what they did, and what needed doing.

Finding: Marginalised groups don't want us to talk for them – they require only facilitation and support – they have their own solutions

Comment: A conference is a control point on a trajectory. The process leading in to it is critical.

Raj Panda

What is a marginalised voice? Are they an indigenous people? They are people whose voices are not heard or understood – even a policy maker, a doctor – by the people in power. Cutting across hierarchies and systems (caste, class) to be heard

Health System Project, USAID
Technical assistance to operationalise first referral units in Jharkhand (District hospitals, community health centres)

- Faced by red tape at the admin level – Raj himself became a marginalised voice! - big challenge of trying to make people understand that a grass-roots approach is critical to success.

Worked with 12 hospitals – doctors, nurses, waste handlers, ward boys, stores – to look for solutions at the facility itself.

Reasons given for dysfunction didn't map to the reality. Gap analysis required for every situation – these are not replicable. A fundamental solution lay in accountability and decision taking at the facility level, facilitating daily interactions to bridge communication gaps.

DANIEL: What is a marginalised voice/ group?
Geography – by virtue of location do not have access to voice
Theme – indigenous groups
Social and political

A voice needs to be raised first in order to be heard.
Who is doing the marginalisation? Is it something that happens to people? Through policy that favours one group or another.

An awareness needs to exist first - people need to understand that they are marginalised

A definition doesn't exist – no agreed discourse, but very context-specific

How are people connected to be able to find voice?

DANIEL: Why is translation important in the context of marginalisation?

Translation acts as the intermediary in bridging gaps of language, material, education and culture.
How do you work with voices that don't speak the same language?
This is a huge responsibility – the need to avoid dependency is critical.

Why is there a need for an intermediary? Can't motives and messages be understood directly?
Whose interests dominate, and whose are marginalised?
Providing a prompt, prod or process to communicate.

When is the translator part of the circle of concern or the circle of influence?
Linking communication with advocacy and moving people from the circle of influence to the circle of concern.

Who is the translator? How democratic is the space? Sharing and learning to find mechanisms that create spaces.
The point is to get the community to push their own agenda, rather than getting scientists or researchers to do it – this also has an impact on the quality of the output.

Suggestion: Make the circles concentric – with radiating spokes. The community is the centre, with concern and influence radiating outward. The translator becomes one of the radii.

TRANSLATIONS: TELLING STORIES TO POLICY MAKERS
Tuesday, 8 December 2009, 1.45 pm

Chair: Wendy Graham
Speakers: Michael Devlin, Ruhi Saith, Paul Nampala

WENDY: Why are you here?

- To learn how to tell stories – techniques
- How to make the bridge to policy makers
- How to tell stories to people that don't want to hear
- Who is the policy maker?
- Who tells stories, and who should?
- What is all this about?

What is the relevance of your story – and how not to be intimidated by the context.

Wendy Graham
At the end of a project in West Africa, visiting the ministry of health:
Tell me what works, not what doesn't...
Evidence can be positive and negative. Where do the negative findings go? It's hard to publish bad news – an example of a translational challenge.

How can it be positioned and translated differently at the policy level? Policies are usually framed and the evidence to support is collected.
Decision making bodies that affect policy are getting more diverse
There is nothing (we) like so little as to be well informed; it makes decision-making so complex and difficult – Keynes

The role of the scientist is to use research to ascertain the effectiveness of innovative policies and programs. This is in contrast to (their) role as advisor in which the scientist can indulge in over-advocacy – Donald T Campbell

Michael Devlin
Approaches to communicating research in a research producer's setting: organisations that are producing research need to build capacity in how to, why, and how to organise it, and how to communicate what they find.

How to create relevant policy briefings that are more visible and have greater impact?

Strategic Communication:
What do we want to happen?
Which groups of people can we influence directly?
How will my users access and use my research evidence?
What benefits am I proposing to users?
What communication actions will help me achieve this goal?

Techniques for translators:
- Short as possible with action points
- Summarise – with data, method and background
- Support recommendations with plans for implementation
- Provide as much information as possible

Evidence is useless if it is not communicated.

- What happens when all the institutes in my country are producing policy briefs?

- When to call for action?
- Who advocates?
- What is evidence?
- How to organise health research communication so it benefits the country

What about resonance? The resonance of people with policy makers who are responsible for the engagement

What is the researcher's contribution to engagement?

Paul Nampala

Convening activities to generate and offer evidence-based advice.
Consensus activities and peer reviewed reports.
Provide independent platform for scientists and policy makers.
Pair scientists with policy makers

Impact: increased engagement with scientists, continued collaborative work on the constituent level, generated debate in parliament

Context matters: policy makers are in a position to demand, they may be interested, but there is a gap in leadership, or they might be hostile to research.

TRANSLATIONS: TELLING STORIES TO THE MEDIA
Wednesday, 9 December 2009, 11.40 am

Chair: Subhadra Menon
Speakers: Arup Jyoti Das, Daniel Glaser, Rebecca McCall

SUBHADRA: How do we tell stories to a group of professionals who tell them better than we do?

Arup Jyoti Das

North East India – area of great conflict
Exploring approaches to communications research:
- Theatre performance based on conflict research
- Puppetry in rural Assam for health
- Audio access programme for urban and rural people
- Communicate research to translate English research into local languages, specifically Assamese

Currently, researchers and their research are obscure and inaccessible.

Support for Ishan – border issues, counter-insurgency, indigenous histories
Strong anti-dam movement, water and floods – comparative studies with Nepal, Bhutan, the Ganges

Daniel Glaser

It's not the job of the journalist to keep their sources happy.

Many scientists don't believe in a free press. They would rather not be published at all, than get the wrong kind of publicity.
Bringing the groups together is not enough – they aren't fundamentally interested in another perspective.
Mediated interaction is necessary.
Is there a correlation between the language that is used in a university press release and the journal in which the paper was published? No

An awareness of the processes on both sides is needed.
Appreciative inquiry/ positive interactions leads to culture change – individually the exchanges are positive, but the general view is that the media distorts.

Rebecca McCall

Focus on which public you're writing for – this will drive style and considerations
Scientist – Editor – Journalist nexus – what are the motives/ perspectives

The Journalist – Tim Rad/t/ford?
- You're not writing to impress the scientist you interviewed – it's all about the reader

What is the role of science in the media?
- Entertainment/ curiosity?
- Engaging the public to understand the goings-on and consequences
- Encourage trust in science?

How do you present information accurately/ present the whole picture, given restrictions of deadlines, column space, editorial interference, personal opinion/ agenda?

Tips for Scientists
In an interview:
- Think about how to summarise work/ findings
- Prioritise and then have examples to illustrate
- Sound bytes are interesting to encapsulate
- Make a checklist of what you want to say, including the details
- Research your audience and your media source

Discussion

In Uganda, research communicators lighten the pressure on scientists. The quality of reporting is better if journalists are trained. There needs to be a general shift in attitude and recognition that both groups have morals, modes and ethics.

One of the most important jobs is to maintain a relationship – the journalist has to have an interest in keeping you happy.
You are the best ambassador for your work
It reflects badly on you as a scientist in your own world if you are over-published – you are considered a media slut – which means most scientists shun the media

We need each other. While your sources are important, you must be careful to not compromise on the facts and the integrity of the piece just to keep your source happy.

Journalists need to be responsible in their reporting, apprising themselves of the facts and the context, before committing to a stance.

There should be a more inclusive approach to the media to deepen the relationship between the media and scientists.

The message is intended for the public – should journalists be responsible for their own research work to provide context?

You can be the best journalist in the world, but there are consequences to your work that you may not be able to anticipate – outcomes that can risk lives, economics, whole cultures

Scientists and journalists have to coexist – how do scientists expect journalists to behave/ how would they like to be treated?

Do briefings beforehand – the background stuff is important.
There is a shift in patterns of sources of information – from papers to the internet – now more scope for bloggers etc to act as a translation medium.
The lab next door theory: what is the guy next door doing?

TRANSLATIONS: PUBLIC OUTREACH/ SCIENCE CAFES
Wednesday, 9 December 2009, 2.30 pm

Chair: Hemalatha Somsekhar
Speakers: Duncan Dallas, Ana Vasquez Herrera, Juliette Mutheu

Juliette Mutheu
What is a science cafe?
A forum to discuss/ debate topical and thought-provoking scientific issues with the public, in a relaxed, informal and accessible manner in the presence of the media.

Origins of the science cafe in Africa

Kenya science cafes
An example of how scientists communicate science to the public.

Challenges of an outreach programme
Culture, class, language, do they want to engage, importance, time, geography, poverty, literacy, health issues, opportunity, understanding, context, communication gaps, how do you attract people to the cafes, conflict in priorities and differences in what is important

Solutions
- Contextualise the material
- Speak keeping your target audience in mind
- Engage in a process that is two-way
- Radio has been used to overcome geography – sound byte played

Ana Vasquez Herrera

Science Cafes: Changing Contexts and Challenges

Adapted in Uruguay – Challenges faced
- Setting the context of the situation in Montevideo and Uruguay - Had to travel to set up the cafes, so
- No continuity (so have to build an audience every time)
- Little chance of mouth to mouth
- More expensive

Public hard to reach, prior attitudes and mind sets a barrier – people who attend already are interested

Learning about science therefore focused on kids as a secondary target, to snare the primary target – their parents
- Children are captive audiences in schools
The science cafe is now an exhibition cum presentation – audience currently dinosaur fans and fossil hunters
New techniques used to attract wider audiences – theatre skits to put things in a wider context – good way to fill gaps in the education system
Presenters are the same (another departure from the traditional cafe) – how do we get professionals to participate?
Is this then a science cafe? Does this matter?
- Accept science cafe as a title
- Work with what you've got
- Let the evaluation do the talking

How far can you adapt it before it stops being a science cafe?

Duncan Dallas

The cafes provide individuals and groups to do things in their local setting – there is no formula.

Why has science communication grown?
- Cultural change: Science now provides many ideas that affects our lives both personally and globally
- A social change: people want to participate in the world around them
- Technological change: the reach of the internet

What part do the cafes play in this context?
They bring science back in to culture – it allows people to explore science in their own cultural contexts.
They are a barometer of social and cultural change, allowing people the opportunity and space to do this.
Cafes are independent networks...

The Bonds of Civility – if you have a group of people that are relative strangers (weak links), new communities are formed, and one of the ways in which society adapts.

Discussion
The word cafe is restrictive – was the original idea to raise a society's scientific temper, or push for larger, behavioural changes?
Science Cafe in Kenya is now synonymous with a place where you can get accurate scientific information – not looking for behavioural change, but a greater sense of awareness of scientific issues and how they affect our daily lives.

Who pays for it? How do you sustain it? Does the Bangalore Scientific Forum qualify?
Taking science out of a formal context and the lecture format makes it a cafe. A hat is passed round to meet travel expenses.

Appreciation for Ana's adaptation – it is more innovation, and therefore wonderful – varied media for greater engagement. You're reaching audiences that would not be normally considered. Were you able to reach the adults through their children?
Indirect targeting really works. Kids have returned with parents.

Like the use of evaluation as a tool to bring about the changes required.

Cafes can be viewed as a tool of empowerment – by stripping the scientist of traditional powers and sharing the space – the cafe is a space where normal power relations are temporarily suspended.

For Kenya – how do you sample the audience and how many experts are there in the bank?
Good media coverage draws audiences, as does the topic in question. There are also now hard-core fans.

Word of caution: all interventions also carry the possibility of doing harm. Science cafes would benefit from doing a risk assessment.

How many people here have actually been to one and what was the experience?
Good experience, but no publicity apart from the web

Who are the people that actually attend?

Kenya – unemployed, high school leavers, not from a scientific background, comparative to an auto driver in Bangalore coming to a cafe, professors, doctors
Uruguay – many science teachers – numbers are a challenge
London – local people, but recently given money by the government (Islam and science, street science, evolution of music)

If someone wants to set up a cafe, how do you go about it? Does the website articulate SC principles?

250 cafes in 40 countries.

**TRANSLATIONS: LISTENING TO EACH OTHER'S STORIES – COMMUNICATION
BETWEEN HEALTH RESEARCHERS AND THE PUBLIC
Wednesday, 9 December 2009, 4.00 pm**

Chair: Raj Panda
Speakers: Wendy Graham, Mayada Elsabbagh, Claire Heffernan

Mayada Elsabbagh

Is public engagement a rational goal for a scientist?
- It can be very strategy-driven, and good for research
- Learned from babies how to appreciate and seek mutuality of goals of scientific discovery and public engagement

2 examples from the British Autism Study of Infant Siblings
- Looking to predict autism in children of 3 yrs and below

A brief setting of context in the UK – costs, numbers

Autism as a scientific challenge
- A combination of genetics and environment
- Compounding issues add to the base combination
- Getting scientists to talk about their work to be able to learn from each other
- Advances in understanding of autism as a biological condition, but lack of understanding across scientific fields – genetics, neuroscience, clinical science

How and when is science good for public engagement?
- Ask a question – concepts and data must be measurable and easily understandable
- Collect the data
- Practice should be evidence-based, with inputs from policy, ethics, community needs, individual decisions, local capacity

Wendy Graham

3 part story of an attempt to engage the UK public on maternal death, to facilitate cross-cultural exchange (between the culture of science and the public)

Mid-1990s – 2000
- Presentations using photographs to organisations and schools to raise awareness of maternal mortality told through real stories – why did Mrs X die?
- Sometimes introduce numbers
- 2 split reactions – how can we help/ what can we do? I don't want to hear any more

From 2000
- Now millennium development goal-driven

Current usage
- Based on 4 weddings on a funeral – 4 Births and a Funeral
- Using history to appeal to the public – public engagement lowered mortality rates to almost nil, Local history and old photographs – localisation to appeal to the public, Relationship between mothers and babies, etc. – then using that as an entry point to issues in the developing world

The White Ribbon Alliance – www.whiteribbonalliance.org

Viewed a viral film – birth and death

In public engagement:
- History is a powerful tool
- Working with advocates enhances the effort

Need to be clearer about the role of scientists in engaging the public. What appealed to you? Mrs X photos, historical allusions, or viral film?

Claire Heffernan

Knowledge flows at the community level – bridging gaps are essential between researchers and the poor

How is knowledge now viewed?
- Shift from an intangible asset to a social construct – and now something that can be bought, sold or exchanged

Memes
- Method – knowledge change – transfer

Multi-media, pamphlets, learning videos to disseminate knowledge – multi-media most effective, with greater quality of assimilation
- For a meme to be successful it needs to be merged with local knowledge
- There needs to be a variation in the uptake
- There needs to be educational attainment

There needs to be a greater stress on understanding what people are learning and why, rather than applying generic techniques and tools to engage with the public.

Discussion

For Wendy:
The medium becomes the message and then a form of entertainment, which is a challenge.

Viral films are a reflection of today's generation – this is how they want to accept inputs.

What role do you play/ where does your responsibility lie when you don't have the answers? We need to give the public a more positive way to contribute.

For Mayada:
How much do you actually engage with the public? Do you merge two projects?
Sometimes scientific goals suit public engagement. This aspect is just an offshoot of the larger project, and not regarded as a separate objective.

Strand 2: Creative Approaches

The 'Creative Approaches' strand explored practical ways to tell stories using the creative arts to engage the public with science. Sessions on music, drama, visual arts, storytelling and radio offered examples of projects which have used this approach successfully and gave participants an opportunity to explore how creative techniques can be used to engage a variety of audiences.

Session 1
Creative Approaches: Drama
Jeff Teare, Paul Sirett, Arundhati Raja.

Warm-up led by Jeff Teare
The session started with some exercises (passing a clap around the circle and Zip Zap Boing) - the purpose being to introduce the group to working collaboratively and to heighten kinaesthetic awareness.

The group were then asked to create a series of statues as an immediate physical response to single words – for example *politician*, *celebrity*. The group were then asked to throw back single words in response to *artist* and *scientist*. Jeff commented that when this exercise was done with students or young people the words associated with science tended to be serious, whilst those associated with art were decidedly 'flouncy'.

The group were then asked to walk around the space, becoming aware of their body and trying to walk in a neutral way. They were then asked to think of an illness or pain and to experiment with walking around the space whilst experiencing symptoms or pain – but without overtly *acting* or *demonstrating.* The group then divided into pairs and watched each other walk the space whilst alternating between ill/well. Partners discussed what the illness might be and how it had affected and manifested itself in the body.

A short history of dramaturgy and narrative structure by Paul Sirett
Developing an understanding of different narrative models can help us to think about how best to tell and structure our stories for maximum effect.

A simple paradigm:

   ────────────────────── ****

                  Length of the Play

The Aristotleian Model**,** as described by Aristotle in The Poetics, is a play is in three parts:

   ─────────── **** ─────────── ****** ─────────── ******
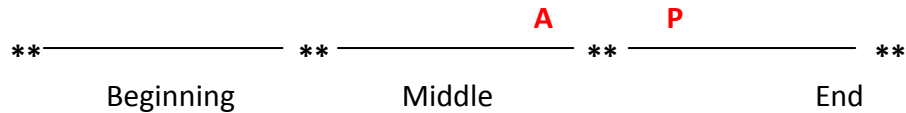
Beginning   Middle   End

Perhaps the most useful parts of Aristotle's model are the **anagnorisis (or revelation)** and the **peripeteia (or reversal)** which are placed thus:

<div align="center">

A   **P**

——————————————**———**———————**
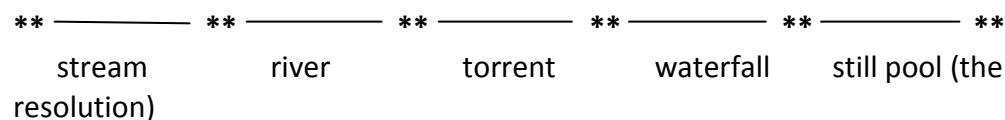
Beginning   Middle   End

</div>

The revelation, or *the best thing,* is reversed and becomes *the worst thing* (or vice versa) – this is extremely satisfying for an audience. For example, in *Oedipus* by Sophocles, the **angnorisis** (revelation) occurs when Oedipus is told that King Polybus, who he believes is his father, is dead. Oedipus is overcome with relief and thinks he has escaped his fate as the oracle had foretold that he would murder his father and marry his mother. The **peripeteia** (reversal) occurs when Oedipus discovers that Polybus was not his father and that he has indeed previously killed his father and married Jocasta, who is actually his mother. So the *best* becomes the *worst.*

Aristotle also introduced us to the idea of **catharsis** – which comes just after the **peripeteia.** In Oedipus it comes when Oedipus finds that Jocasta (who has realised the truth) has killed herself and in despair he plunges the pins from her dress into his eyes, blinding himself.

A more organic approach was taken by Bharata Muni in the Natya Shastra, an ancient Indian theory of the performing arts comparable to The Poetics. He lays out a five part dramatic structure thus:

** ——————— ** ——————— ** ——————— ** ——————— ** ——————— **

    seed   opens   sprouts   grows   bears fruit
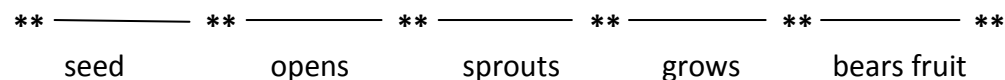
Zeami, who established the Japanese Noh Theatre tradition and wrote a huge number of plays, also describes a five part dramatic structure in his 15th century treatise:

** ——————— ** ——————— ** ——————— ** ——————— ** ——————— **

    stream   river   torrent   waterfall   still pool (the resolution)

In the 17th century, the Spanish writer Lope de Vega, who was a contemporary of Shakespeare and wrote prolifically for a popular audience, favoured a very simple three act structure for his cloak and dagger, love and honour plays:
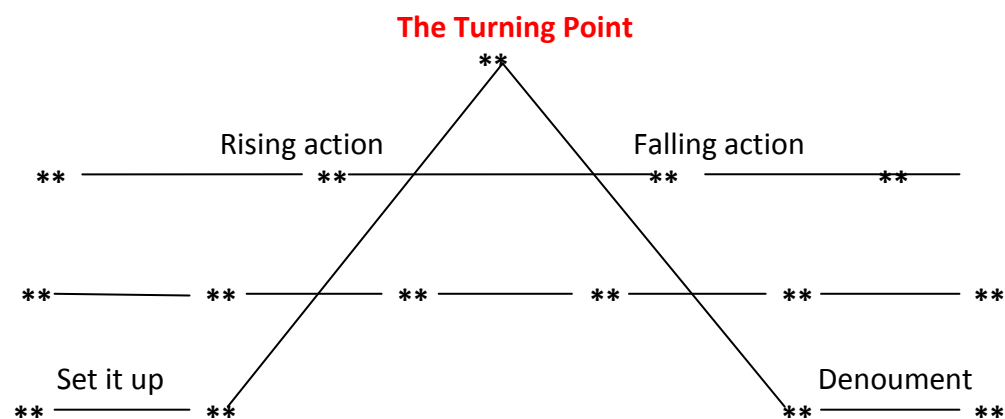
** ————————— ** ————————— ** ————————— **

    set it up   complicate it   sort it out
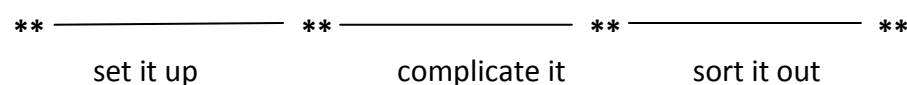
And if he was being flash, there would be a twist in the third act!

In the 19th century the German dramatist Gustav Freytag developed his *pyramid* to describe dramatic structure:

The Turning Point
**
Rising action   Falling action

Set it up   Denoument
** —————— **   ** —————— **
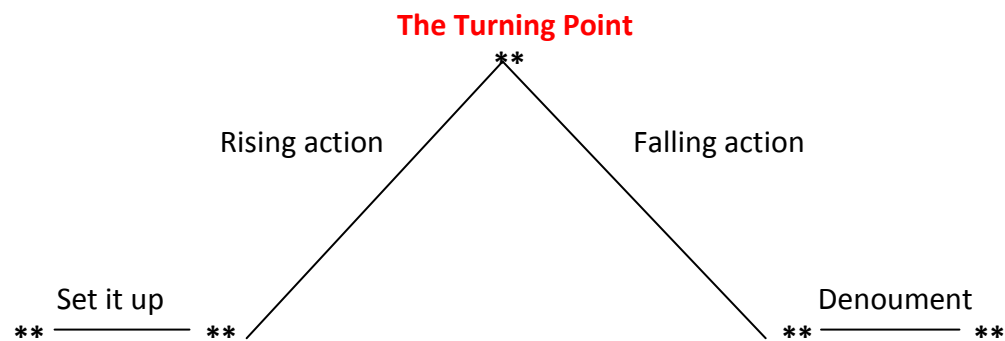
And in relation to a three act or a five act structure it looks like this:

The Turning Point
**
Rising action   Falling action
** —————————— **   ** —————————— **

** ——— ** ——— ** ——— ** ——— ** ——— **

Set it up   Denoument
** —————— **   ** —————— **

We looked at film theory – particularly the work of Hollywood screenwriting guru Syd Field. His, very rigid, model looks like this:

IC   MP
**   *   **   *
** ———————— ** ———————— ** ———————— **
set up   confrontation   resolution
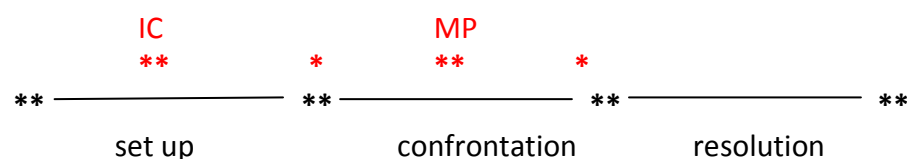
Midway through the first section (the set-up) an ***inciting incident*** occurs. For example, in Hamlet this would be when he meets the Ghost of his father. The inciting incident means that the story *has* to be told and it clearly sets up audience expectation, so that they absolutely know what they are watching.

The ***mid-point*** will bring the focus onto a particular threat – for example when ET decides that he must phone home.

At the end of each act there is a **_plot point_** which spins the action in order to move the audience into the next act.

With reference to his own play **_Bad Blood Blues_** (which questions the wider ethics of drug trials in Africa through the relationship between a scientist in an African hospital and a student whose sister has HIV), Paul Sirett deconstructs it thus:

** ——————————— ** ——————————— ** ——————————— **

    set up the science   explain the debate   conclude

or the five act version would be:

** —————— ** —————— ** —————— ** —————— ** —————— **

    set up   explain it   debate it   argue   resolve it

However, running in tandem with set up drug trials / explain / debate the drug trails / argue over ethics / conclude there is also the relationship between Clare (the scientist carrying out the HIV/AIDS drugs test) and Patrice (the young man whose sister has HIV/AIDS) which looks like this:

Two people meet / they become lovers / they fall out / they tear each other apart / it ends

Thinking about character as well as structure, we looked at the **_powerplay_** model:
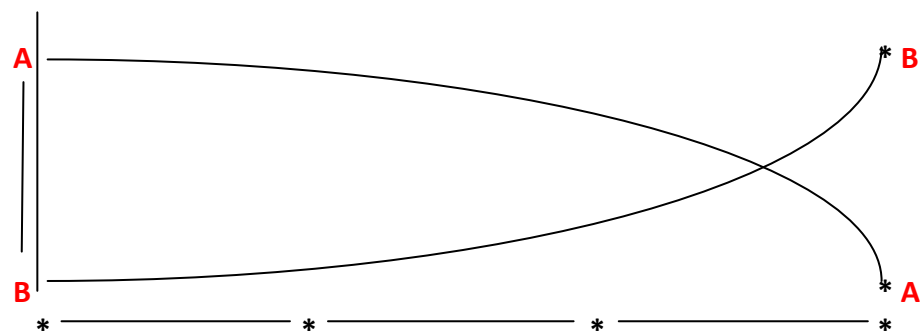
This shows the status of characters A and B at the beginning of the play and how, as the play progresses B becomes more powerful until, at the climax of the play they crossover and the balance of power shifts. This creates a compelling character journey and is very satisfying for the audience

It is important to remember that all of these structures are about **creating a narrative.** You would get quite a different, and circular, model if you deconstructed, for instance, a Beckett play!

Create your own narrative

In smaller groups, participants were asked to create their own short plays telling the story of a relationship between a clinician and a patient. The ground rules were to have ten *beats* – a beat could be a line of dialogue, or it could be action – and for the status of the characters to have changed by the end of the piece, in order to be succinct and to create dramatic impact.

Two examples (the first slightly more than 10 beats!):

A.
A patient enters a consulting room, dragging something behind him – it turns out to be a dead dog.

Doctor:	What seems to be the trouble?
Patient:	It's my dog.
Doctor:	Don't you want a vet then?
Patient:	No.
Doctor:	Why not?
Patient:	He's dead.
Doctor:	You want a spade then.
Patient:	No, I want a doctor.
Doctor:	For a dead dog?
Patient:	He died of rabies.
Doctor;	I still don't see what this has to do with a qualified medical practitioner who treats humans, living humans, not dead dogs. Do you hear me?
Patient:	(*weeping*) The last thing he did before he died ....
Doctor:	(*shouting*) What?
Patient:	He bit me ....

B.
A scenario for a Doctor A (female, 30s or 40s) and Patient B (female, 16)

- Doctor meets patient
- Patient explains situation – she is single, is pregnant (it is unplanned) and the father is married
- Doctor asserts moral authority – asks about identity of father
- Patient refuses to disclose any details about the baby's father
- Patient requests an abortion as she feels herself to be in a situation which would ruin her life
- Doctor questions morality of an abortion without the father's knowledge
- Doctor refuses to treat patient without name of the father
- Patient discloses that the Doctor's husband is the father of the unborn baby
- Doctor agrees to the Patient's request for an abortion

- They leave the surgery – the Doctor to sort out her husband and the Patient free to carry on with the rest of her life.

Both were performed with aplomb by the groups! In the first piece the group chose to have the dead dog in the scene (superbly played by Simon Turley – we could observe the rigor mortis setting in ...) and to have the rest of the group as patients in the waiting room – a chorus observing the action. In the second piece, they group staged it with a third person playing the inner voice of the patient.

All of the stories created had discernible shape and structure, moving dynamically with a twist or a shift in power that kept the audience engaged and asked them to question the relationship between patient and clinician. Participants were particularly interested in how non-naturalistic elements could contribute to telling a more complex story – e.g. the inner voice or conscience of the patient in the second piece.

End of session

Session 2
Creative Approaches – Visual Arts
Rajeev Varma, Gurupada Chitrakar, Bernard Appiah

Presentation by Rajeev Varma
Rajeev Varma is Director (India) and Associate Director (International) of **MAKE ART/STOP AIDS**, an initiative of the Art|Global Health Center at UCLA. An international network of scholars, artists, and activists committed to ending the global AIDS epidemic, MAKE ART/STOP AIDS seeks to capitalise on the vast potential of the arts by: (i) advancing an awareness and appreciation for the power of art to address crisis, and (ii) establishingartists as key partners in global AIDS interventions.

Art does have the power to save lives
Douglas Crimp

How can art and artists communicate and save lives?

The **Patua-Plus Project** in rural West Bengal is an innovative HIV communication and stigma reduction initiative. Using scroll painting – a traditional art form practised by a local caste of artisan scroll-painters known as Patua – the project aims to educate people in villages in West Bengal about the transmission of HIV and how to prevent that, as well as addressing the stigma for people living with HIV and AIDS. The Patua themselves are Muslim, but the scrolls use Hindu names and traditions. The scroll-painter comes to a village with a scroll he/she has painted in advance and sings the story of the scroll while unrolling it to reveal cartoon-like illustrations of the tale. The art form was on the wane prior to this project, but now these HIV scrolls have revived the tradition and they are also being used to respond to events, for example the Tsunami.

The other partners in the project are SPARSHA, a coalition of health workers, some HIV positive and some HIV negative who have helped to refine the content and design of the scrolls, and who amplify and clarify the message after the performance of the scroll .

When the project goes into a village there are always two Patuas – one male and one female – and two community health workers – one HIV positive and one HIV negative - to facilitate discussion and the Q&A session after the performance. This combination of male/female and HIV+/HIV- is an important part of addressing the issue of stigma, proving that you can eat and work alongside those with HIV/AIDS with worry.

The content of the scroll is designed to:
- Give clear information about transmission and prevention
- Reduce stigma through the story of people in the scrolls and personal testimonies
- Introduce ideas of love and sex with responsibility
- To provide information about access to services

Evaluation of the project so far has shown that it has been responsible for huge shifts in attitudes – regarding sharing food with someone who is HIV positive for instance – which therefore reduces stigma and encourages people to seek testing or treatment.

Will other art forms be as effective?
Currently in West Bengal there are other projects using Baul singers and Tarja which are proving to be equally effective. (Bauls are a nomadic group of composers, musicians, singers, dancers and actors all rolled into one. Their lyrics are simple and direct – and in the languages of the villages - and commentary on contemporary issues has always been part of their tradition. Tarja is a form of folk poetry contest from Bengal – often presented in the form of song)
However, for an art form to be effective you need to ensure:
- That community engagement can be sustained
- That it is a community based art form
- That there is a structured curriculum/message
- That artist work in tandem with community health workers
- That communication about stigma reduction is backed up by local governance

The presentation concluded with Gurupada Chitrakar singing a scroll of his own story. The pictures and his beautiful goose-bump raising singing tell how his father died when he was young and uneducated, and as he had three younger siblings and an ill mother to support, he went to the city to find work. His earnings were sent home to support and educate his brothers and sister, while he became more and more miserable and began taking drugs. As a result he contracted HIV and he tells how his family then ostracise him and make him live in isolation from them. He pleads with his audience:
Therefore I, Gurupada
Am telling you, please listen people

If you eat or sleep side by side, the virus does not spread
Therefore I, Gurupada
Am telling you, please listen people
If you eat or sleep side by side, the virus does not spread
Holding hands or kissing also does not give HIV
How can I express the anguish in my heart
My honest words are taken as lies, such is the situation
How can I express the anguish in my heart

For pictures of the Bengali scrolls -
http://www.makeartstopaids.org/photogallery/patuaPlus/patuaPlus01.htm

Questions from the group
Q   Would it be possible to digitise the scroll? Perhaps experiment with controls groups – one seeing it on DVD and one face-to face?
A   Make Art/stop AIDS have done this and have found that the impact is much greater with the live performance. The scrolls are a really credible medium and the audience know that they are based on true incident. Therefore they find the message has validity and know it is trustworthy and accurate.

Q   Why only in rural areas?
A   It is particularly pertinent in rural villages because of low literacy levels and because it is a traditional art form. They have seen it work in urban setting, but it is viewed as more of a novelty and may not have as much impact or credibility.

Presentation by Bernard Appiah
Bernard is a Ghanaian pharmacist and he has written a consumer-friendly books on medicines using cartoons, and scripts for a docudrama television series on medicines. Bernard has also presented a live TV programme to educate the public about medicine.

Bernard defines Public Engagement as any activity that stimulates any interaction between the public and those with specialist knowledge. He also clarifies that the cartoons he uses in his work are not animations, nor are they satirical cartoons. He sees them simply as a way to communicate humourously.

So - why use cartoons for Public Engagement?
- Cartoons lend themselves to open-ended questions
- Cartoons stimulate thinking about issues in a non-threatening way
- Cartoons provide important visual stimulus – particularly important when a book or leaflet is text heavy
- Cartoons can make complex concepts much more easily understood
- Cartoons make uncomfortable issues much easier to address

When Bernard first started using cartoons to illustrate leaflets etc he tried to source them from the internet – but this was a problem a) for copyright reasons, but mainly b) there were always elements not suitable for particular audiences. He now commissions and works closely with a cartoonist to ensure that he is meeting the needs of his audience.

Bernard showed a series of cartoon from *Medicines: Using Them Safely* to illustrate how communicate complex science.

Task for the group
In groups of 4/5 to come up with a cartoon concept (drawing not necessarily required!) to illustrate a scientific idea or issue. Two examples:

Example 1
How to communicate the idea of placebo in a clinical trial. After much discussion around whether the concept of double blind would be too hard to communicate through a cartoon the group came up with:
Two blindfold men
One saying – *swallow this*
The other saying – *what is it?*
The first saying – *I don't know*

Example 2
A cartoon strip entitled 99 ways to use a condom – using humour to make it easier to talk about condoms and also to illustrate how to put them on etc. Drawings would include things like someone buying and fitting a condom to fix a slowly leaking tap!

All groups were agreed that it was extremely hard to formulate ideas, but that the process of visualization did really commit the concept to memory.

Session 3
Creative Approaches – Radio
Ashish Sen, Enriqueta Valdez, Amel Belay

The three speakers each gave short presentations on the radio projects that they work on.

Ashish Sen is the President in India of AMARC (World Association of Community Radio Broadcasters) an international NGO serving the community radio movement.

These web links to articles by Ashish explain his approach further:

http://i4donline.net/interview/interview-details.asp?Title=Ashish-Sen,-Trustee,-VOICES,-India&interviewid=636
or
http://comminit.com/en/node/114735/306

How communities use audio and radio on the other side of the digital divide.
With reference to Namma Dhwani (means Our Voice in Kannada), a community radio station in Karnataka which cablecasts programmes made by the community on a daily basis.

2 pointers:
It is important not to look at radio in isolation from other media.
Radio's USP is the voice as the 'bridge' – but whose voice are we hearing? How do we bring peripheral voices to the centre? Community radio can go a long way towards addressing this if we think in terms of communities driving the media.

Looking at a project in rural Karnataka to promote legal awareness and to persuade people to register the birth of their child. (Universal Birth Registration campaign)

They recorded meetings/public hearings (Adalats) between local government and the community – these were then re-packaged into radio programmes and narrowcast to small community groups where there can be direct interaction. This is a way of bringing community issues to the front burner. For instance, the reason that people were not registering the birth of a child was because officials were asking for a payment (bribe) of 2 rupees which people couldn't afford. Made public through the radio programme the issue was resolved.

Narrowcasting uses loud speakers positioned in the tree tops, or a vehicle with loud speakers or audio cassette technology.

Sometimes these programmes made by, for and with the community have been picked up by public media, e.g. AIR – All India Radio which in turn connects those rural communities to the rest of the country.

The simplicity of this type of community radio disguises it efficacy.

Enriqueta Valdez studied medicine, then economics and did a post-doctorate on international policy of reproductive health. While living in California she started working on radio-dramas for a local community radio and since then has produced, written and supported the use of education-entertainment for social change through her work with Population Communication International: Media Impact.
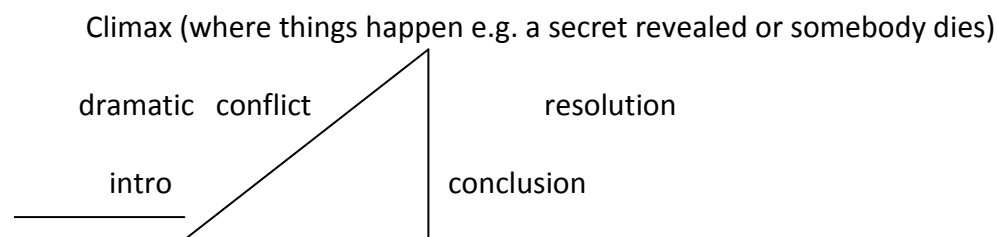
PCI-Media Impact's pioneering approach uses creative media, the power of storytelling and the reach of broadcast media to mobilize individual, community and political action in the areas of sexual and reproductive health, HIV/AIDS, environmental conservation and sustainable development, and human rights and democracy.

Enriqueta focuses on helping communities to produce radio drama in a magazine format in Mexico and throughout Latin America. The communities themselves make the programmes as they do not have access to professional actors.

The baseline is to collect stories from the community – the problems and difficult choices that they are facing in everyday life. These are used to create the drama, which will reflect what the community is thinking, will address their culture and their needs and will offer the possibility of changing behaviours and attitudes to improve and save lives.

Enriqueta describes what she means by education entertainment and how to create it.

Drama is a chain of events, a series of emotions + conflict. It is <u>dramatic conflict</u> that coverts a straightforward story to a DRAMA. Drama in turn is about appealing to the feelings and emotions of the audience, which therefore moves to <u>action</u>.

Climax (where things happen e.g. a secret revealed or somebody dies)

dramatic   conflict   resolution

intro   conclusion

What is dramatic conflict?
- A shock situation that the audience was not expecting
- A disagreement
- Permanent opposition to an idea/position
- Two characters or groups fighting

Dramatic conflict follows one of three models:
- A person against somebody else
- A person, or a community, against a natural power (e.g. an earthquake)
- A person against themselves – internal conflict

Types of characters:
- Positive – for example Snow White – the role model in the story
- Negative – the opposite of a role model
- Transitional – more realistic characters

In the stories/dramas, the positive characters are rewarded and the negative characters are punished. The transitional characters are most important in the drama as they move between positive and negative, and their experiences embody the difficult choices we all face in everyday life.

Prior to creating a new programme they will carry out Participation Research to discover negative and positive attitudes, practises, behaviours and conditions in the community. The subsequent radio drama/serial will explore the consequences of

the positive and negative behaviours, while promoting the positive. During the course of the drama, the audience begin to bond/identify with the transitional characters and when they begin to emulate the positive behaviours this has a huge effect on the audience.

An example – communities have knowledge about issues (e.g. HIV/AIDS) but are not putting this knowledge into practice. They will do a baseline assessment of knowledge/behaviours prior to starting the project to establish goals and a table for change, and then monitor what is happening to the audience during the series.

The community are the actors and also help write the script, in order to create a relevant and appropriate story for that particular community. Children also participate.
If the radio series is aimed at adults it normally has a 20 minute slot – but it is much shorter if it is aimed at young people. Music is also a vital component

For examples of programmes - http://www.mediaimpact.org/index.shtml

Questions from the group

Q   Can you explain more about the writing process?
A   Sometimes there is a single writer and sometime there are a number of writers who work closely with the community and pull all the material that they have come up with together.
Sometime Enriqueta will have script meetings with them via Skype and sometimes they will send scripts for comments. She is particularly looking to ensure that the science is correct and to ensure that the dramatic structure will be engaging for the potential audience.

Amel Belay works at the National AIDS Resource Center in Ethiopia where she is now Program Coordinator for a radio programme called **Betengna Diaries**, which tells the stories of people living with HIV. She has also trained radio producers in Ethiopia and Côte d'Ivoire who specialise in HIV and AIDS and other health programmes.

Betengna Radio Diaries presents a unique insight into what it really means to be HIV positive in Ethiopia.

Betengna is reality programming for positive social change. It engages heart as well as mind. It is:
- Non-fiction
- Education-entertainment
- Intimate – focusing on the voices of ordinary people
- Empathetic – listeners relate to the diarists and this creates an understanding of the similarities rather than the differences between them

All of the diarists are living with HIV, but their radio dairies do not simply focus on a life since HIV – that is not all they are. Many of the diaries go back much further than that and also deal with other subjects.

Objectives:
- Voices of PLWH to be heard by their communities and beyond
- To reduce stigma and discrimination
- To increase audience understanding of personal risk and vulnerability to HIV/AIDS

The Programme:
A programme is normally 20 or 30 minutes long. Of this approximately 8 minutes will be taken up by the diarist. The remainder of the programme will be made up of segments that highlight the theme the diarist is speaking of. For example if the diarist is talking about disclosure, the segments will look at this issues from a number of different angles and provide factual and legal information.

Betengna is an Amharic word which means a welcome guest who often visits one's home, a part of the family or someone to share secrets with.
This applies diarists to listeners and vice versa (as listeners are encouraged to respond and share their own stories and in some areas discussion groups have been set up)

The format is/has:
- Authentic tone
- Emotion and sincerity
- Features and variation – therefore engaging
- Context specific – one story for one region as behaviour patterns differ
- More than just HIV

The process:
- Personal interviews over many hours with each potential diarist to hear and explore their stories and decide which aspects should be communicated and how
- Training for each diarist in order to help them tell their story
- Developing the relationship between the producer and the diarist – this is vital as without a relationship of trust the process does not work

To hear some of the diaries: http://betengna.etharc.org/listenin

Questions from the group

Q   How do you find the diarists?
A   Initially we made contact with them through associations for people living with HIV, but after the diaries began to be broadcast people began to contact them independently

Q   How do you ensure that the process is not exploitative?
A   There is a long process before a diary would ever be recorded to ensure that people are totally aware of what they are doing and that it is not going to be

damaging for them. A contract is also drawn up for them to give their consent, and counselling is also available to them. Their experience is that many people find it very liberating – especially f they have been living with a secret for a long time.

The Task

In groups of 4/5 people create a radio programme that is 3 – 4 minutes long.
Possible formats:
- Poetry/drama
- News
- Interviews
- Vox pop
- Montage
- A Day in the Life
- Folk/fairy tale
- Documentary
- Group debate
- Game show
- Diaries
- Phone-in

The session leaders suggest that it would be unwise to use too many of the possible formats in such a short piece and suggest that the groups use no more than two.
They would be performed behind a screen so that we would hear only the voices.

Some examples of what the groups came up with:

- Based on a traditional song, a sung funeral eulogy for a mother who had died of AIDs.
  This was a very moving and engaged the listeners completely.

- A pitch for a radio programme to address issues of stigma around HIV/ASIDS amongst young people.
  Vox Pop with young voices intercut. We hear them talking about bands, singers, clothes, their social life and so on. What we don't know is that twelve of them are HIV positive and twelve of them are HIV negative. Gradually the odd comment makes on aware that something is going on. The V/O at the end asks us – *Could you tell the difference?*

- The 537th episode of *Life with our Family.* This is recognisable family situation with archetypal characters. – grumpy Dad, harassed Mum, stroppy teenager etc. In each episode an issue is explored through family

conflict. The group do their 4 minute drama around the refusal of the teenage to wear a bicycle helmet and what the consequences might be.

Session 4
Creative Approaches: Politics of participatory arts in PE
Simon Parry, Bella Startling, Sian Aggett

What is participation?
A participatory process is encouraged as a driver for public engagement in science.
It is effective, but not simple or necessarily obvious.
It is subject to constraints – depending on its nature and audience.

Is participation:
Inclusive/exclusive?
Empowering/disempowering?
Always a good thing?

4 dimensions of participation:
Time
- Is there a right time for participation?
- How long do you allow for participatory processes
- What role do memories of participants pley?
- How should participation relate to community histories?
- How can participation engage with the future?
- What are the power dynamics of the times of participation?

(Think about literal time – timescales and phases)

Space
- Where does participation take place?
- How are the boundaries of the space/s of participation set?
- Are there links to other (global/local) spaces/places?
- What gives the participatory process its particular sense of place?
- Is personal space important?
- What are the power dynamics of the space of participation?

Think about architecture and the constraints of the built environment
Think about a virtual environment

Language
- What languages are used and by whom?
- How can participation cross language barriers?
- Does participation depend on language?
- What are the power dynamics of the languages of participation?

Bodies

- How does gender influence participation?
- Who are the bodies/people involved in participation?
- How are relationships between participants constructed and how are they involved?
- Are there particular challenges for embodied participation?
- What are the power dynamics of the body in participation
- How do groups with differing abilities participate?

Each member of the group is given one dimension of participation and asked to consider the questions relating to that dimension while listening to brief outlines of the following participatory projects.

Project 1
Gabriel Harp
A project to look at water and its relationship to public health
Artifacts used as objects of participation – *cultural satellites* sent out and returned with data about what people are experiencing in their life.
For example – groups are given disposable cameras and asked to take ten pictures of something – perhaps their favourite places to play

Project 2
Ana Claudia Fassa
The project - Engagement of Rural Teachers in Pesticides Research: awakening a scientific way of thinking which aims to facilitate the engagement of rural teachers with research about pesticides and health and to support the development of methods to communicate its results and to promote
best practices when using pesticides.

It is known that pesticides have an impact on health – particularly teenagers' health - but this knowledge is not reaching the people it needs to reach and is not being used.
So – the project is to train teachers and to provide them with knowledge and skill to promote safe use of pesticides.
The chain looks like this:
Co-ordinators ➔ teachers ➔ other teachers ➔ students ➔ families and communities

They used science cafes and powerpoint presentations to work with teachers initially
Teachers were then ask to carry out research and interventions
Teachers were surprised initially to be asked to define the terms of their own research, but later evaluation found that this was highly satisfying for them

Project 3
Rose Oronje
A project in Kenya to stimulate discourse on slum issues
Discussion on disparity in health was not happening at local level

Project organised a series of meetings to highlight the issues – where a government minister would meet local communities. In order to spread the information they used community radio and one study community to produce a video.

Thought was given to the way the meetings should be set up and take place:
- Took place in community spaces
- Took place in Swahili – for presentation and discussion
- Seating arrangements – with the 'experts' sitting amongst everyone else- therefore anyone can ask a question on an equal footing
- Used entertainment groups from the community – eg a drama 'skit' on one of the issues for discussion
- Testimonies to provoke and encourage participation

Project 4
Sian Aggett
Wanted to work with a group of young women in South America to create a participatory video. The idea was that this would be empowering for them? But was it?

Things that needed to be thought about:
- How to support the group to find their own story – and then to make their own film from that story
- The uses for the video – Research? Therapy? Advocacy?
- Who would the audience be? Across communities? Or upwards to policy makers?
- Is the process as important as the product? Sian thought so, but the pressure to create an excellent product came early in the process when a high profile community screening was arranged
- Democracy, inclusivity, equality – it was important that Sian remained a facilitator and did not become a director

The challenges:
- Sian had little control over the process and the product, but also felt responsible. A difficult situation
- The young people had delusions of movie stardom that were difficult to work against
- They had extremely high hopes and expectations for what could be achieved through the workshops despite their lack of experience
- Most of the videos/films they had seen objectified women
- The 6 girls/young women were a friendship group with clear leaders which led to a power struggle as Sian tried to ensure all voices were heard
- Overcoming the assumptions she had arrives with – about collective working, about their education etc

There was a discussion on the different dimensions of participation.:

Space
- Importance of finding the best possible (spatial) relationship to create trust on an equal basis
- There is an assumption that it is always best to GO TO people – into their own community spaces? But is this always right? What about bringing people to an inspiring space? Or could people feel more free to speak outside of their own community spaces?
- What is the difference between place and space?

Time
- Importance of thinking about other people's time (ie not just those designing/delivering the project)
- How long for participation is key. Ideally long lasting – but where there are constraints it is better to keep projects short and intense
- Shifting timelines and deadlines are the biggest challenge
- Importance of an exit strategy and a legacy

Language
- There are many tools that can be used to communicate without language – but all were agreed that in the end some element of spoken language in vital
- Using the same language as the audience is vital – and not just in terms of spoken language
- No matter what – there will always be an element of 'translation'

Body/Bodies
- A great leveller
- Beware of making assumptions about participants
- An awareness of how engagement <u>feels</u> – as well as what has been communicated learnt etc

Final thought
It is about finding the right questions. If you can empower people to ask questions, then it is possible to bring about social change.

Session 5
Storytelling
Simon Heywood, Kole Odutola, Claire Heffernan

Kole told a story – won't attempt to document! In a nutshell, Mrs Budgerie – the gossip/scandal-monger/gross exaggerator - was finally proved to be right about something

Simon Heywood

Understanding the narrative and structure of stories

1. Problem
2. Journey
3. Helper or test
4. Confrontation
5. Resolution

This is a widespread narrative pattern – therefore we have to assume that it works (Structure of narrative in folk tales first analysed by Vladimir Propp in early 1900s and in later literary criticism/theory)

The story is a human universal
There is no community that doesn't have stories
If the story is a human universal – then is it biological?

Research suggests that narrative serves three functions for the human mind
1. Cognitive - cause and effect
2. Empathy
3. What is not present

Cognitive:
A form of practice/exercise for the mind and the imagination
Social cognition – to do with understanding the world, people and relationships – therefore necessary for survival

Cause and effect – we need to understand that one thing leads to another. This is the driving pattern of every narrative. There is nothing random
This governs our behaviour and our strategies for living our lives.
The pattern of reality

Empathy:
Theory of mind – the ability to realise that there is more than one point of view
This is not something we are born with, we learn it
If we proceed past the early years without theory of mind, this points to a learning disorder. E.g. autistic spectrum disorder
This is important in both friendship or in more aggressive acts (eg hunting)
We couldn't understand a story without it – we would not be able to think ourselves inside a characters head.
And both these skills depend on ….

What is Not Present:
Other realities
The ability to imagine/picture in our minds eye another place and another time

All of these things are a form of mental rehearsal for key life skills

Claire Heffernan:

What is Poverty?
How is poverty defined in literature?
The way the story of poverty has been told has changed at specific junctures – almost decade by decade
Development is now business – so to counter de-personalisation <u>poverty vignettes</u> are used

CH interested in the synergy between the definition of poverty and what the poor were saying about their lives. Do poor people consider themselves as victims?
Unlike the literature, poor people tend to talk about things in a measured and factual way
Hope – rarely expressed for themselves, but they have high hopes and look fr change for their children

Exercise – create a story about poverty.

People created stories in small groups. Some were based on traditional stories, others were based on true incidents (for example a story told in Elizabeth Pisani's book *The Wisdom of Whores*).

Strand 3: Gender

This strand asked how and why gender and sexuality matter in public engagement with health.

How do gender differences affect access to health care, information, and legal assistance? How can public engagement workers create safe spaces which allow women to tell their own stories? In what ways do the stories we tell about women's health affect their chances of living and dying; for example, what difference could it make if we explained maternal death rates as a result of mental rather than physical health problems? What are the special issues affecting transgendered people and homosexuals, and how can their stories be heard?

1.   Introduction to strand
David Osrin

All sessions in this strand were chaired by David Osrin. On the opening night of the conference, David introduced the strand to the delegates. This followed a meeting in the afternoon of the strand chair, rapporteur, and all of the contributing speakers, in which some of the themes and ideas were developed in more detail.

David described his experience of being invited to chair the strand by Tinderbox, and shared the reservations he had expressed at the time.

Firstly, he had had doubts because of his lack of knowledge of gender studies as an academic subject. Rebecca explained to him that he had been chosen for this reason: that he could be a fresh pair of eyes to bring a new perspective to the issues.

Secondly, David was concerned that it was inappropriate for a man, 'a representative of the patriarchy', to chair a strand on gender: a subject usually associated with women, or those of a 'third gender' (i.e. transgendered). Rebecca explained that this was a deliberate choice on the part of Tinderbox: to draw attention to the fact that men, too, have a gender, and have to deal with issues around gender – something which is often omitted from discussions.

David recounted how he had then sought the advice of his colleagues, and of his lesbian, gay, and transgendered friends. They responded:
David, I hadn't noticed you were a man
You work in women's health
You can identify the shop that my new clothes came from
You go to work everyday in an organisation of 200 women, run by women, and you do what we tell you
Or: they just rolled their eyes like I was a complete idiot who'd missed the point.
So I said yes.

David then introduced the four sessions in the strand:
1. Why gender matters in public engagement
2. Women's stories: making a space for women to speak
3. Alternative stories: women's mental health
4. Transgender issues in public engagement

He explained that each session would consist of telling stories; two or three panellists would each tell a story, and these would be used as 'nests' for other

stories. As one of the strongest ways of communicating is through personal testimony, he stated that those who have their own story to tell would be particularly welcomed at the sessions.

2.   Why gender matters in public engagement
Vikram Patel, Wasundhara Joshi

The chair, David Osrin, began by introducing the concept of gender.

He presented the World Health Organisation's definition of gender as the socially constructed roles, behaviour, activities and attributes that a particular society considers appropriate for men and women

He then explained that there are different ways of interpreting the title 'why gender matters in PE':
Does gender matter in public engagement?
How do we do public engagement about the fact that gender matters?
How do we do public engagement about gendered health issues?
How do we do public engagement with gender groups?

David outlined the style of the sessions, as discussed in preliminary strand meeting: the panellists will speak to spark discussions, but all present in session are invited to contribute by telling their own stories.

Vikram Patel [VP]
VP began by stating that he sees the challenge of public engagement as developing a better understanding of the public. In his work, he has learned the importance of listening to the public (not just talking to them).

VP's work has focused on health problems affecting women, specifically mental health. When he first qualified as a doctor, he was told to work in gynaecology, as so many women in India have gynaecological problems.

Very large numbers of Indian women were complaining of vaginal discharge, which were conventionally ascribed to STIs (sexually transmitted infections) and treated with antibiotics. However, the lab results for STIs were predominantly negative. The vast majority of women were being treated with antibiotics for non-existent illnesses.

So VP started talking to them about their lives; he discovered that they were overworked, and were spending all day looking after their families. Complaining of 'discharge' was a way of saying 'life is too hard'. Women had learned this (implicitly) from their mothers.

Therefore, VP carried out a Wellcome Trust-funded research study on 3000 women, to investigate the question: Why do so many women have gynaecological complaints? What factors are involved?

The findings of the study were as follows. There is no connection between STIs and gynaecological complaints. Instead, the factors that influenced whether or not women complained of discharge were social and psychological: in particular, a lack of choices in life: of who to marry, when to have sex, what form of contraception to use. All of these factors can be seen to fall within the idea of gender. In short, a constellation of factors, defined by gender roles, caused gynaecological complaints.

As a result of this study. VP learned that he had to shed his 'biomedical arrogance' and step outside his trained assumptions, by listening to the women and allowing them to tell their stories. These women didn't need to consider themselves 'diseased', but they did have problems that needed dealing with.

VP concluded that the primary audience for these findings was doctors and others who work with women's health, and that they needed to evolve alternative strategies (other than prescribing antiobiotics) for dealing with gynaecological complaints.

QUESTIONS/DISCUSSION

Q. Did the women actually have any vaginal discharge?
A. There is a proven connection between emotions and physical symptoms e.g. mental sexual arousal causes physical lubrication. Perhaps vaginal secretions could also be produced as a result of emotional problems?
Also, the interpretation of bodily functions must be seen in a specifically South Indian context, with regard to the belief system of Ayurveda. Ayurveda considers bodily secretions to represent a vital part of life. Semen is seen as the essence of vitality, and vaginal discharge in women may have a similar symbolic value. There are similar beliefs in Sri Lanka.
Finally, normal bodily functions may be interpreted as abnormal for cultural reasons.

Wasundhara Joshi made the point that complaining of discharge gives women the chance to sit in doctor's surgery, to take time out, have attention from doctor. She also suggested that there are issues with hygiene as there are no private spaces available for women to take a bath.

Q. Is it still appropriate to use 'syndrome' approach?
A. The syndromic approach has been revised. Unfortunately, there is no simple STI diagnostic kit available, and women won't come back to the doctor for a return appointment to get test results; there is a need for a bedside diagnostic kit. However, there is also a danger in the possibility of immediate diagnosis: if no illness is found, then the woman is dismissed as a malingerer.

Q. Did your experiences and discoveries alter policy in public health work?
A. VP said he considered himself and his colleagues the biggest beneficiary of the research. They are starting to treat testimonies as evidence, not just corollaries or appendices to physical symptoms. Patients' voices should not be seen as 'extra' information, but should be the first evidence that a doctor seeks.

Sisira Siribadanna questioned VP's interpretation of Tatt syndrome and the meaning of bodily secretions in South Indian and Sri Lankan contexts. Diffrerent possible interpretations were discussed.

Douglas Wassenaar stated that as a medical practitioner, one has to interpret every symptom as a metaphor as well as literally.

Mirra Savara argued that there is a danger of suggesting a woman's health problems are 'all in her head', and that it can be dangerous to put physical symptoms down to psychological causes. There are physiological causes of discharge: for example, the lack of public toilets for women in India means that they don't drink enough water, in order to avoid needing to use the toilet.
VP responded that 'medicalisation' of the problem is wrong regardless of whether you treat it with antibiotics or antidepressants. Instead we should look at

contextual/social factors, which would include way of living, hygiene, women's understanding of their own bodies, etc.

The issue of 'psychosomatic' illness was raised. Do people 'somatise' mental health problems, or is the physical symptom itself the distress? Is it pathological?

Ruchika Chanana commented on the depiction of women and their health in the Indian media: women are always depicted as caregivers, looking after family's health, but rarely their own.

Wasundhara Joshi [WJ]
WJ told a story of how storytelling can work to bring about change. She is an advocate of a technique known as Appreciative Inquiry (AI), which aims to bring about change using a positive, affirmative and appreciative approach.

In AI, people are encouraged to tell success stories. Instead of focusing on those things which have gone wrong or failed, the teller is asked to pick out those aspects which have been successful. These success stories create a 'buzz' and can transform the atmosphere and attitude of institutions such as hospitals; stories that say 'nothing works' are self-fulfilling.

Gender, if seen through lens of social constructivism, can be understood as the stories we tell about ourselves. In her work with women's groups, run by 'Asakis' (friends), WJ aims to create space for women to tell their own stories. When asked to tell the stories of their own lives, they tell these negatively, focusing on the bad events. WJ encourages them to tell the story differently: to focus on the positives, for example giving birth to a healthy baby. Changing the story in this way is a means of both effecting change and collecting data.

WJ described the way that the Asakis aim to change attitudes, for example to challenge fundamentalist attitudes in groups such as the breastfeeding promotion network, which is entirely managed by men.

QUESTIONS/DISCUSSION

Clare Matterson told her own story of how a support group became instead a pressure group. She described her own pregnancy with twins, and the problems she experienced towards end of pregnancy, such as pre-eclampsia, a difficult birth and postnatal difficulties. She was ostracised and berated by 'the breastfeeding mafia', and rejected by health workers, because she decided to switch to formula milk.

Amar Jesani pointed out that in an Indian context, we must bear in mind the intersection of gender with class and caste issues. As part of a media and ethics panel, he had examined a gang rape case from Bombay and how this had been reported on. They found that female journalists were much harsher in their judgements of the victim. Amar also stated that the stories we tell girls, when they are young, change their futures: for example, 'Brahmin girls don't become doctors'.

Further points raised were:

How can you combat institutionalised images of women as objects that we see in the media every day?

As it's not socially acceptable in India for women to protest publicly, should we perhaps involve men so the protest can be made public?

The relationship between stories and reality: are stories about reality, or do they themselves constitute reality?

The relationship between the story content, the storyteller, and the 'storytellee' (listener). Both physical and mental space are gendered. Areas to interrogate in order to use storytelling as a tool for research – listening is vital. Content and subtext must be attended to.

Q. Can you get the women to change the end of their story when they tell it, and in this way create change?
WJ replied that that would be going into the realm of therapy, and would go beyond the limits of appreciative inquiry.

The discussion was brought to a close, and it was decided to hold the subsequent sessions outdoors.

3. Women's stories: Making a space for women to speak
Amar Jesani, Lindy Wafula, Justa Wawira

This and all of the remaining sessions were held outside on the NCBS campus, with delegates and speakers sitting in a circle under a tree. This setting contributed to the informal, personal, and honest atmosphere of the sessions, in which all present felt equal and able to contribute their own stories.

Amar Jesani [AJ]
Amar told the story of a conference that was held in India in 1982. The aim of the conference was to discuss women's access to healthcare issues, but there was conflict at the meeting between health activists and women's activists (influenced by the 1970s feminist movement).

The women's activists tried to tell their stories, but were continually silenced by the health activists, who demanded hard evidence rather than narratives.

Ultimately, the women's activists decided to break away from the main conference and held their own, all-female meeting.

Following this, they conducted a number of studies, for example looking at evidence of bias in medical textbooks; they found evidence that nurses, for example, were represented both as female and as low-caste.

Amar suggested that this story highlights the question of whether, in order to reflect on their own specific issues, women require separate spaces, or should they attempt to debate these within the mainstream?

QUESTIONS/DISCUSSION

Helen Ngoh responded that in Cameroon, women do require their own separate spaces. The mainstream tells them 'if you seek to claim your rights, you are a bad wife, or not a real woman'; hence she believes that in a Cameroonian context at least, the answer is yes.

Rose Oronje suggested that, on the other hand, female empowerment has failed to achieve its goals because women are 'talking to themselves': does this disempower men? Perhaps the issue is not how to enable women to tell their stories, but how to get men to listen?

Lindy Wafula [LW]
Lindy then spoke about her work with women and girls in rural Kenya.
In her adult literacy work, for the majority of women, it is the first time they have ever held a pen – they are not even able to read or write their own names. As education is vital to health, LW sees this as a challenge for public engagement with health.

She told the story of the 'rafiki club' project. Rafiki is the Swahili word for 'friend'. This project began as a penpal scheme, part of literacy education, in which women would write letters to other women abroad. However, they were frustrated by the delays in receiving replies. Subsequently they began writing to women in neighbouring villages instead. However, even this was found to be too slow, so ultimately the women wrote directly to the rafiki club, posting anonymous letters and questions in a suggestion box. In this way, they identified the problems and issues facing them in their own community.

Once they had gained confidence to ask questions, they started to demand and receive answers from experts: health practitioners, MPs, and other authority figures. There are future plans to use the internet (Skype) to allow these women to question those in power directly.

This was then developed into a model of 'learning through doing and earning'. The rafiki club women have begun to produce their own textbooks, based on the questions they have asked and the information they have learned. They produce booklets based on their research, which they sell to other women in their own and similar communities for a small sum of money. They are thus disseminating vital information and also making a living for themselves.

These women have gained the confidence to set their own agenda. One woman stated: 'We are the researched… now we want to be the researchers'.

Justa Wawira [JW]
Justa told the group how, when she was a child, her mother had told her that if she had a story to tell and could find no one willing to listen, it was better to tell it to a tree or river than not to tell it at all.

While at university in the late 1980s, Justa worked with other women to collect women's secret untold stories. These were published in a book as Our secret lives (Phoenix, Nairobi: 1990)

Women told their secret stories, for example of being raped by family members.
Justa argued that by 'mainstreaming', women's own points are lost. By attempting to be heard within the system, they are made to 'think like the system'. for example, they are required to produce evidence of gender discrimination, rather than being allowed to tell their stories.

Justa argued that gender does matter in research; for example, if a researcher goes to an African village, if there are only women present but there is a male child, even if he is a baby, the researcher is required to approach the male child initially to ask his permission to speak to the women.

Another reason that gender matters is access to technology and who you can reach with different forms of engagement. For example, in parts of Kenya there is 95% penetration of radio in the community; however, what this figure disguises is that the 95% are all men. The radio is a tool of power and status – the man decides what to listen to, and what information to pass on to his wife. The women are generally busy performing tasks such as collecting firewood and cooking, and

do not have the money to buy batteries for the radio. This is something that must be borne in mind in public engagement work.

QUESTIONS/DISCUSSION

Oby Obyerodhyambo made the point that we are discussing making spaces for women to speak, but to speak to whom? to other women? to men? He suggested that it was necessary to engage with the mainstream to some extent to achieve change: 'if you are playing the game outside the stadium, no matter how well you play, you are not going to win'.

There was a discussion around the fact that women can often oppress other women, in some cases worse than men.

The point was made that gender is always a question of power.

Arundhati Raja raised the issue of selective gendered infanticide/abortion of female children in India. There was a discussion of how the status of female children could be raised to prevent this happening.

Ruchika Chanana suggested that it is vital that all people, not only women, have 'a space to vent', whether that is talking to friends, family, or professionals, the importance of having an outlet to express one's thoughts and emotions.

4.   Alternative stories: women's mental health
Douglas Wassenaar, Vikram Patel

Douglas Wassenaar [DW]
DW began by saying that this was his first presentation without powerpoint for fifteen years, and that this was a frightening experience. He also said that he had had doubts about three men leading a session on gender, but that 'I suppose, as I found out yesterday, I do have a gender'.

In his work, he has found himself repeatedly working in areas with 'heavy gender agendas': as a clinical psychologist, with eating disorders and suicidal behaviour, and as a researcher, with the question of voluntariness and consent in HIV research trials.

As a clinical psychologist, working with patients with eating disorders, he found there was a distinction between his clinical practice and his academic writing.

With his patients, he gave women a generous space to speak for themselves, to 'unpack their own narratives', and to find ways of developing their own agency as woman, to feel safer about being a woman and a person in the world, to help them have more creative ways of taking social action.

However, when he came to write papers, 'it was all graphs, numbers'. He experienced a 'big disconnect' between academic research, and the need for generosity as a clinician/psychotherapist.

The second main area he worked in was suicide. This is an area which is very skewed in terms of gender: 4 or 5 men commit suicide for every 1 woman. However, in the case of non-fatal suicidal behaviours, this proportion is reversed. He used therapeutic sessions to help women find ways of expressing their distress, by helping them to discover their interpersonal agency.

Again, he experienced a discrepancy here between his personal work and his published work. In publication, the 'richness of narrative that one is exposed to as a clinician' is lost.

In 2000, DW stopped practising as a clinician, and is now an academic investigating the ethics of health research. His focus switched from individual patients to public health, meaning a shift from personal stories to broad populations. He is involved in researching gender and women's participation in HIV prevention work. There is a problem with recruiting women into studies in sub-Saharan Africa, even though the incidence of HIV in young women is higher even than in men. He raised the question: can women authentically give consent to be in a high-risk study?

He has discovered a common theme of diminished personal agency in women across all three of these areas (eating disorders, suicide, and consent/voluntariness for studies).

DW stated that 'HIV has got everything to do with mental health' and argued that there should be less distinction made between mental and physical health.

He concluded by asking how can we put into practice the recommendation that we should hear women's voices? How can research be conducted so that women can participate as free and voluntary agents?

QUESTIONS/DISCUSSION

Justa Wawira asked why mental health stories should be designated 'alternative stories'? Why are they always considered secondary to physical health stories? Why should they not be the main agenda?

Mayada Elsabbagh asked DW what, in his opinion, is the reason that women are more likely to be anorexic, or to display non-fatal suicidal behaviour, or to refuse to participate in HIV research trials?

DW answered that with regard to EDs and suicide, he had avoided tackling that question. But he believes that with regard to HIV trials, it's a result of patriarchal society.

Vikram Patel made the point that not only is anorexia 'a women's illness', but it's also a white, Westernised, urban women's illness. He gave the example of Fiji, where they have traditionally preferred women of 'robust build'. However, within 12 months of US television being introduced, there was a massive increase in vomiting and dieting behaviours. He also mentioned the change in 'ideal shape' in India, as exemplified in the changing ideals of Bollywood actresses, who have become noticeably thinner in recent years. It was argued that you cannot decouple eating disorders from their cultural context.

DW argued that cultural differences in general are dissolving, and that television is just one index of westernisation. For example, in South Africa the population is moving towards urbanised living, and this has an impact on women's perceptions of their own bodies. There is research showing that women's body satisfaction decreases in line with their level of education and with their proximity to urban centres.

Self-destructive behaviour is also inflected by race: in SA, anorexia is the white woman's 'symptom of choice', while for Indian women it is self-harm.

There was a discussion about the issue of control over one's body and how this relates to EDs.

Wasundhara Joshi said that she has also experienced the disjunct between her work with patients/community, and her published academic work. She feels like 'two different people'. She suggested that this could be seen as the 'feminine' and 'masculine' sides of public engagement.

Jonathan Stadler described the differences in the work of early male and female anthropologists. The male anthropologists tended to write in a flowery and poetic style, while the women's writing was much more dry and scientific. He suggested this was because the women's accounts would otherwise be dismissed as 'over-emotional' – suggesting that women have to act more masculine than men in order to be accepted by the established.

Wasundhara linked this to the observation that women can often be more harsh to other women; perhaps this is because they are trying to be accepted in a predominantly masculine environment, and have to prove themselves?

Vikram Patel [VP]
VP told a story about suicide in India. Until 2007, India's recorded suicide rate was very low and remained consistent. Then it suddenly rocketed, especially in young people. Why was this?

Only half of deaths in India have their causes recorded. Richard Eagles' study 'Cause of death in South India' found that suicide was the #1 cause of death among young women. VP started to research why women were killing themselves. He found that domestic violence was a bigger predictor of suicide than depression. So suicide is a mental health issue, but is not solely a mental illness issue. There are also contextual and social factors that must be taken in to account.

Suicide and injuries are also a leading cause of death in young men. But this half of the story was missed: why are men being violent? It's necessary to look at the social construction of men's roles. Mental health issues are also gendered; in India, there is a tendency to see depression as 'a woman's issue', while alcoholism is more common in men. Why is there this gender difference? That is is not due to a biological difference between the sexes is demonstrated by the huge increase in female drinking in the UK over the past few decades.

VP concluded by saying that we shouldn't be too pessimistic about these stories; it is possible to intervene in the lives of individual couples and to change things for the better.

QUESTIONS/DISCUSSION

Amel Belay Yimer asked if VP/DW knew of any positive practices: how can you address suicide through the media without encouraging suicide?

VP: you can address it on a large-scale, public health, social level, not by addressing individual detailed cases.

DW described a systematic survey of appropriate and responsible media coverage of suicide. This survey concluded that there must be no focus on individuals, no detailed description of methods, no photographs of grieving bereaved family/friends, etc. The media must look only at neutral demographic facts and not the individual case details: not to be callous but to avoid dramatising and

encouraging copycat suicides. When he is asked to comment on a news story he restricts his comments to (1) saying whether or not this case fits the demographic data, and (2) recommending resources.

Helen Ngoh said that in Cameroon mental health is a taboo subject. Mental health problems are attributed to witchcraft, there are no mental health experts to call on, and only one mental hospital in the entire country. She asked how, in this situation, can one draw attention to this problem? How can you place an issue on the agenda?

Wendy Graham responded by describing the difficulties she had experienced placing issues on the agenda. There is a vicious cycle whereby, if there is no data to prove that something is a problem, it cannot be placed on the agenda; however, because it is not on the agenda, there are no opportunities to collect data.

Raj Panda raised the intervention model of public engagement; could this be used to tackle the problem of domestic violence in India?

VP answered that investigation into domestic violence has led to legislative solutions, e.g. the Domestic Violence Act. While this is useful, the problem is that it is only punitive; it only responds to the problem after it has occurred. There are also other difficulties with the legislative framework; for example, in India if a woman commits suicide within seven years of marrying, her husband's family are automatically culpable for her death. Therefore many Indian women disguise their own suicides to make them appear accidental (fires, etc.).

VP suggested that marriage would be an ideal opportunity to engage with young people about all aspects of health, social, life issues, to integrate mental health into this, and to tackle the stigma still associated with it (along the model of premarital counselling provided to those who marry within the Church of England).

The point was made that this would only be suitable for those societies, such as India, in which the vast majority of young people marry. In other societies, where marriage is less common, or happens later in life, other models would have to be found.

Justa Wawira informed the group of a new report published in Kenya which argues that the main area of violence is that perpetrated by women upon the male child. She sees this as trying to refocus attention and resources on men. How do you stop the gains that women have made being reversed in this way?

Wendy Graham made the point that for women, mental health, fertility, and mortality are all very closely linked. Many of women's mental health problems are driven by reproductive issues in one form or another, whether this is infertility, unwanted pregnancy, etc. This is a dimension that should always be considered as an extra risk factor for women.

Jonathan Stadler asked if there are gender differences in methods of suicide. He outlined a recent paper published in South Africa: 'Gendered Endings: Narratives of Sexuality and Suicide in the South African Lowveld'. This paper argues that while men tend to commit suicide in a 'quiet, solitary and ordered' way, women are more likely to choose a dramatic and public method of suicide: in effect, a kind of drama which they are performing, to send a message. He related some of the stories from this paper of specific cases of suicide.

DW responded that this highligts the tension between individual stories and large-scale data. In SA the data shows that there is no major gender discrepancy in terms of methods of suicide. The bizarre cases described as 'outliers'. However, while there is no major gender divide in methods of suicide, there is a major difference in terms of numbers.

VP outlined Emile Durkheim's classification of suicides into three different types (egoist, altruist, and anomic).

Paul Sirett told a story of a woman he had recently met who had just become an actress at the age of 74. This was something she had wanted to do her whole life, but had been prevented, first by her parents, and then by her husband. Now they had all died, she was finally able to pursue her ambition. After a somewhat dark period of discussion, this story uplifted the group's mood. Paul asked VP: do you have to have a mental illness to kill yourself?

VP replied: no, it can be a rational response to impossible circumstances. This is different from those with clinical depression whose perception of their circumstances is at odds with the reality.

However, he said that the more intriguing fact is all the people who live in terrible circumstances and don't kill themselves. Resilience, and coping, is the 'elephant in the room' in any discussion of public health. How and why do the vast majority of people manage to get through?

DW stated that psychiatric research is heavily influenced by pharmaceutical companies. No one has financial interest in investigating psychosocial or interpersonal solutions to suicide. Hence, the influence of the 'pharma funders' must always be borne in mind.

5.   Transgender issues in public engagement
Elizabeth Pisani, Dayaprasad Kulkarni

The final session began with a game. Everyone in the group picked a piece of card out of a bag; on each card was a sexual identity, for example 'female sex worker', 'transgender', 'gay man'. The group then played a kind of 'speed dating' game in which each participant had to say whether or not they would have sex with the others. Many lively and simultaneous discussions could be heard as the group circulated.

After the game, the session leaders Elizabeth Pisani [EP] and Dayaprasad Kulkarni [DK] discussed the cultural differences they had encountered in their work with transgendered sex workers in Indonesia and India respectively. For example, in India gay men regularly have sex with TGs, whereas in Indonesia this would never happen.

There are also differences within India itself. Each community is different and has its own rules.

The group asked many questions about the specific workings of these communities. Do all transgendered people ultimately want a sex change? For many, the answer is yes, but the difficulty is being able to afford it.

In India, each community is led by a guru. Acceptance into the 'inner circle' is generally dependent on having a sex change. However, as many TGs cannot afford to have this procedure performed properly, crude and dangerous 'sex

change' operations are widespread. The procedure is known as 'Nirvana' (enlightenment).

In Indonesia, TGs are legally recognised a separate gender: for example, they have their sex listed as 'transgender' on their ID card.

What are the specific problems when doing PE with transgender issues?

Who are 'the public' in this case? The questions asked in this group demonstrate the lack of understanding and knowledge outside of TG communities about how these communities function, and even of their existence. This means that there is great difficulty in getting the general public to understand who they are and how they live. Therefore 'mainstreaming' will not work as even the basics are not understood.

Instead, DK has sought to engage directly with TGs. Their 'health-seeking behaviour' is very poor. This is partly because they don't fit into the M/F categories, so there is difficulty with even basic questions such as which clinic they should attend. They also know from experience that they will be badly treated by medical professionals.

In response, DK has set up a 'gender clinic': a walk-in clinic open to all genders, providing health services and information. The challenge in terms of PE is getting the message out that this clinic exists and that these services are available.

Q. How about trying to engage the gurus?
A. In practice, this doesn't work, as they don't go back into their communities and spread the message.

Other PE initiatives which have been successful include a breakfast bar which has been set up in Tamil Nadu, staffed by TGs, which serves idli (traditional South Indian breakfast) to general public. Because they offer a professional service, the public (customers) don't comment on their gender, or abuse them. This demonstrates to the TGs that there are options open to them other than sex work.

There was discussion around the fact that, for many sex workers, this is the best, easiest, and most profitable occupation open to them. How can – and should – this be tackled?

6.   Plenary
David Osrin

At the plenary session on the final day of the conference, the strand chairs were given an opportunity to share their reflections on the strand as a whole, to describe how their views have changed over the course of the workshop. and why.

DO suggested that what has emerged over the conference is the need for different kinds of space and time: time to talk, to tell stories, bodily space, verbal storytelling space, social and sexual space.

'What happened under the tree was magic', he said. A series of stories were told. There was a feeling of space and relaxation. Things unfolded in a natural way.

We have learned that stories don't have to end. We have heard about different manifestations of distress, and explored ways of telling stories about your distress for better outcomes.

Gender strand: Speakers' biographies

Dr David Osrin, Wellcome Trust Career Development Fellow, UCL Centre for International Health and Development. David is a Wellcome Trust Career Development Fellow working on the health of mothers and newborn babies in Mumbai slums. He trained as a paediatrician with an interest in child health in low-income settings, lived and worked in Nepal for seven years and is now based in India. His academic base is the UCL Centre for International Health and Development at the Institute of Child Health. His primary research interest is in evaluating complex public health interventions for newborn and child survival. Areas of work include community-based strategies to improve home care and care-seeking, interventions to improve the quality of health services, measuring health indicators in underserved populations, and health equity. In Mumbai, he works in collaboration with the public, private and NGO sectors on novel strategies to address vulnerability and inequity. These include the potential of slum alley women's groups to improve the experience of maternity.

Professor Vikram Patel, Wellcome Trust Senior Clinical Research Fellow, London School of Hygiene and Tropical Medicine, and Founder of Sangath Centre Goa. Professor of International Mental Health and Wellcome Senior Clinical Research Fellow at London School of Hygiene and Tropical Medicine. Founded Sangath, a mental health NGO based in Goa which won the MacArthur Foundation's International Prize for Creative and Effective Institutions 2008. Leads a programme of public health research and capacity development with Sangath and others, focusing on child development, adolescent health and mental health. Honorary Professorial appointments: Public Health Foundation of India; Institute of Psychiatry UK; Dalhousie University Canada; University of Melbourne. Serves on advisory committees including WHO Expert Advisory Group for Mental Health and the Guideline Development Group for mhGAP; advisory boards of the Institute of Health Metrics & Evaluation (USA), Centre for Chronic Diseases Control (India), George Institute of International Health (Australia); publications Committee of the World Psychiatric Association. Serves on editorial boards of PLoS Medicine, British Journal of Psychiatry, the International Journal of Epidemiology and World Psychiatry. Fellow of the Academy of Medical Sciences UK. Awards include the Rhodes Scholarship, MacArthur Foundation Fellowship for Leadership Development, and, in 2009, the Chalmers Medal from the Royal Society for Tropical Medicine and Hygiene. His book Where There Is No Psychiatrist is a widely used manual for community mental health in developing countries. Editor of Lancet Series on Global Mental Health 2007, PLoS Medicine series on packages of care for mental and neurological disorders in developing countries 2009, and Lancet Series on Universal Health Care in India 2010.

Wasundhara Joshi, Executive Director of SNEHA (Society for Nutrition, Education and Health Action), Mumbai.
Wasundhara trained as a paediatrician in Mumbai, and then worked in the field of Neonatology, in the LTMG Hospital, better known as Sion Hospital. Around the year 2000, she became interested in behaviour change, organisation dynamics and behaviour, and have studied these extensively. She specialises in using the technique of appreciative inquiry. She was part of the founding team of the NGO called SNEHA in Mumbai. This organisation combines grassroot practice with community-based research and building innovative models in the fields of maternal and child health, domestic violence and mental health.

Amar Jesani, Managing Trustee/Consultant, Anusandhan Trust/ CEHAT/ CSER/ SATHI, India. Member of Wellcome International Engagement Committee. Amar is a medical doctor, involved in social science and policy research in health for last 30 years, and presently working almost exclusively in the field of bioethics. Most of his work is with NGOs, except for few years when he was faculty at a public health school. He has been a part of many public campaigns for policy changes, for improving public health and medical practices and for protection of human rights. He lives in Mumbai (India), where I am associated with the Indian Journal of Medical Ethics (www.ijme.in), and the NGO-based institutes, the CEHAT (www.cehat.org) and the CSER (www.cser.in).

Lindy Wafula, Founder/Director, Project Africa, Kenya. Founder/Director of Project Africa, a non-profit organisation that works to promote gender equality, equity and empowerment of women in rural Africa. She is also the Director of RESOURCE Africa, a consulting firm that specialises in building intercultural relations and cooperation between communities in the West and those in Africa. Lindy has pioneered many development projects and programmes in different parts of Africa. She has a background in international relations, communication for development, and media and communication, especially in TV and radio production. She has also trained in public relations and intercultural communications. Her background in event production has seen Lindy organise exhibitions, work camps and other cultural activities to promote social change, empowerment and development for women and for communities.

Justa Wawira, Head of External Relations, KEMRI Wellcome Trust Research Programme, Kilifi, Kenya. She is studying for an Msc degree in public relations, specialising in science communications with the University of Stirling, UK. She holds a Bachelor of Education degree in English language majors and a postgraduate Diploma in Public Relations and Human Resources Management (UK). She has substantial experience in the corporate, NGO and government sectors as an external relations professional, fundraiser and evaluator. She has worked with Christian Children's Fund as a monitoring and evaluation officer, with Del Monte Kenya Ltd and Castle Brewing Kenya Ltd as a Public Relations Manager, with Healthplan Services East Africa as a Group Operations Manager, with FIDA Kenya as a Strategic Team Leader in charge of Fundraising and Public Relations and with Practical Action, UK, as Head of Programmes Development and Fundraising for the Eastern Africa region, among others.

Douglas Wassenaar, Professor of Psychology, University of Kwazulu Natal, South Africa. Douglas is a clinical psychologist with primary current interests in ethical issues related to health research. He directs a research ethics training programme known as SARETI, funded by the US NIH/Fogarty Center, and related programmes for the UNAIDS African AIDS Vaccines Programme. He chairs two research ethics committees in South Africa: one for biomedical research and one for social science research.

Dr Dayaprasad Kulkarni, Vice-President, Madhyama Prasaran Foundation, Bangalore, India. Over five years of experience of working at the community level with vulnerable populations like commercial sex workers, transgenders, migrant labourers, street children, etc. in the field of HIV/AIDS and sexual health. Concentrating on making these populations aware of their rights and the importance of personal health and hygiene. Integrating theatre and science to develop tools to spread awareness and propagate various health- and education-oriented issues in the community. Worked as an actor in the Wellcome-funded TheatreScience 2009 project.

Elizabeth Pisani. An epidemiologist with a not very well-hidden past as a journalist, writing for The Economist, Reuters news agency and others. Her scientific work has focused largely on tracking the HIV epidemic and the behaviours that spread it, on planning HIV prevention programmes and measuring their effectiveness. She has worked for governments in Indonesia, China, the Philippines and elsewhere, and for WHO and other international agencies. In 2008 she published the book The Wisdom of Whores: Bureaucrats, brothels and the business of AIDS, which tries to explain the distortions of the AIDS industry to a general audience.

Strand 4: Young People's Engagement

The day began with presentations by young people from projects that had been recommended to us as examples of excellent public engagement work.

Each of the groups of young people gave presentations to the delegates. The work showcased was extremely impressive and moving, ranging from animated films raising awareness of corporal punishment in schools, to a drama piece tackling HIV infection, devised and performed by the young people, to examples of large-scale political action initiated by young people which had led to real effective change, such as the provision of clean water to areas affected by the 2004 tsunami. The young people ranged in age from 8 to 17.

After three days of intensive discussion and workshops for the delegates, the young people brought fresh energy and inspiration to the conference, and reminded all why public engagement is so important, and what it can achieve.

A panel of experts then responded to the presentations, providing comments and feedback, before the delegates, along with the young people, were divided into small groups.

These small groups, each of which included an experienced leader of young people's projects, were asked to go and devise a plan for a new young people's engagement project, before coming back and presenting their project to the rest of the conference and receiving feedback from the panel and the young people.

The three young people's projects which gave presentations were:

i.   REAL Nagai Nettilees Childrens Club, Tamil Nadu

ii.   Plan International Young Hearts project, Delhi

iii.   Madhyama Prasaran Young People's theatre group, Bangalore

Nethilees Children's Club

P Shobannath and M Pakya, Nagapattinam district, Tamil Nadu

Dedicated to those that sacrificed their lives – presenters are Tsunami survivors of December 26, 2004

There were many NGOs that worked with adults – REAL was among the few that listened to and spoke for young people.

Before the Tsunami, there was no organised children's grouping. They were named Nethilees after a fish, the young of which stick together...

They undertook a Social Equity Audit, conducted by the children – they were taught how to conduct a survey, speak to the villagers and see if relief had actually reached. Also taught photography to supplement reports – 20 children from 20 villages

Bhagya was 13 when she participated – didn't know anything about social equality – post-survey they were happy to have been engaged in something important...

Survey based on: access, relevance, timely provision, perceived value, prior consultation, preserving the dignity of the receiver.

They are now confident to be able to take on more surveys having learned as much from the first.

This was one of the last groups to conduct a survey – had to bear the brunt of the villagers' ire from the inaction of the previous visiting groups.

Conducted an SEA training workshop where they learned:
Day 1 – introduction to child rights
Day 2-3 – social equity, harmony and community development
Day 4 – 6 – vulnerable groups and resolving conflict between the groups
Day 4 – 12 – digital photography

The adults in the village had a Panchayat, but the children didn't, so the Nethilees Club was formed that produced a magazine as well.

They decided on the design of the houses that they would live in...

Currently 1587 members – taught many things on a professional level – music, dance, self-defense, martial arts

Nethilees Water Watch
250 children from 20 villages tested water from their villages to highlight levels of contamination to be able to improve conditions – questioned the source supplied by the government and demanded better water. 1500 children drew on a cloth spanning 2 km – district-level engagement.

Child Based Disaster Preparedness Team was formed, trained to handle disaster

Rural Education and Action for Liberation – REAL

Plan India, Young Hearts Project
Udit and Anshul

Using media tools to present issues at different forums

Training provided to children: news, story writing, making comics, developing radio programs, training of trainers

Issues discussed: child abuse – safer schools – prioritised issues, developed an action plan

Survey on the ground
- By observation, then interviews with children, teachers, parents, government officials
- Gathered and generated data
- Analysed reports, made individual presentations
Followed by discussions on which media tools were appropriate to which issues

At the village level:
- Tips and training on feature writing
- Training on creating comics
- Video animation and radio training

- Created all media tools and then conducted an awareness campaign for all stakeholders – aired radio programme telecast on AIR

A report was sent to UNCRC - As we see it - This report goes in every 4 years – recommendations on how the government can contribute to safer school environments

Film by Anshul on corporal punishment – Apni Paathshaala

Madhyam Prasaran, Bangalore

Children from GHS, Cox Town School, (8th and 9th standards) presented a skit on the transmission of HIV
Scenarios:
1. At a barber shop
2. Post accident blood transfusion

Trailer of a feature film – on adoption, poverty, Hindu-Muslim unity

Rebecca – amazing generosity to each other in the group – consider: what stories do you know that are told from a child's point of view?

Discussion

Panel: Paula Hamilton and Oby, Meera

Paula: energy, commitment, thoughtful, forward-looking – honest look at the world around them
Tsunami – how something appalling and disastrous can be turned into a triumph – a great legacy - All the work had the young people central to it. They would really like to pass on the skills they learned.

Oby: thanks to the young people for their generous sharing
Tsunami – sometimes from tragedy there can be energy, positivity and hope – this project empowered children – built confidence – very important – they were able to subvert the culture that says that children are recipients, helpless and need guidance. After this capacity building, do they still remain peers, or are they elevated to a position that makes them function differently? What is positive is that they are role models for other children to emulate.

Meera: proud to be Indian – concern – much of the agenda seemed to be NGO-driven – if we had spoken to the children about what they had wanted would have better empowered them for life.

To Young Heart: whose agenda was it to make schools safe, the children's, or was this NGO-driven?

Nethilees:
They wanted to do it; it was their idea – first for their village and then the others

To Madhyam Prasaran: very resonant – we should move to a position that HIV diagnosis does not make people collapse – empowerment is key – we should move away from blame. Representation of disclosure should be well thought-out.

Response on comment on HIV skit: negative reaction was a reflection of our current reality – the doctor's response is future-positive.

Tsunami: Subhadra - What is their opinion on the government's response to the Tsunami?

Govt was very supportive – both financially and logistically, and in the physical presence of Radhakrishnan.

What was the biggest obstacle they faced?
Tsunami: during the survey, they had to deal with the angry villagers
Young heart: from the govt in their not being able to give time – the elders in the village also did not cooperate.
Cox town: no problems

How did you come up with the script for the skit?
The children developed it themselves – they discovered through workshops that their knowledge was limited or fallacious – they wanted to rectify common perceptions – modes of transmission (mosquito bites)

How have aspirations changed?

Why were these groups selected?
Rebecca: Looking for models of best practice – less projects about informal education and young people in charge of the design and outcome, and more about formal teaching – the projects were selected for these reasons

Exercise: Planning and pitching ideas for new projects for young people

Delegates divided into groups of 6, with the children distributed between them.

Daya – 1
Consultation takes a long time. Building relationships with your community is essential to understanding what needs addressing, rather than jumping at the first idea. People should have the space to think about what they really need, without intervention.

(Did discuss water as a potential project)

Ana Claudia – 2
The children were asked for their ideas – they came up with Hospitals – corruption, poor care
My hospital story – identifying problems using drawings, and then identifying people that would provide solutions
Spoke about a project that did not have a theme but began with consultation with the children. Body mapping would keep the dialogue iterative, and encompass any hospital.
Children were asked to reflect on their own experiences and relate them over lunch.

Juliette – 3
From the children: Involve more children to develop relevant ideas.
Must be careful of children's rights – not use them as a medium to communicate
Have a board of directors of children to sit in on meetings with all stakeholders – media, scientists, policy makers - with them driving the agenda

Arundhati – 4

Done by young people – to develop a template for work of this nature to be conducted – to be able to get them away from dependency on adults for information – tools, multimedia

Claire – 5
Dare to Dream – young girls – 10 to 15 – from urban slums in Bangalore
Child labour, child marriage, illiteracy, abuse
I want to be a doctor, do I have a chance?
1. Community awareness and sensitisation – leaders, parents, govt officials, religious leaders – through meetings, seminars, skits scripted by children
2. Establish strong role models in the community
3. Entrepreneurship programme: Identify sources of economic empowerment for these children

Simon – 6
Misuse of prescription drugs
Children dictated the HOW to raise awareness
- Posters – images and words
- Street advocacy through leaflets, door-to-door visits
- Motor vehicles with hailers
  Calling meetings that contained drama, song - Invite govt official but only allow him to observe

WELLCOME TRUST STAFF WORKSHOP: EVALUATION

Tuesday, 8 December 2009, 3.30 pm

Speaker: Laura Harper

What is Evaluation?
The systematic collection and analysis of descriptive and judgemental information necessary to make effective decisions related to the selection, adoption, value and modification of various activities – Goldstein

Formative: To learn and improve
Summative: to make an informed judgement about the value or success of an enterprise

Evaluation has become:
- Justification vs learning
- Synonymous with auditing
- Important to justify funding
- A focus on learning lessons
  o Project level
  o Programme/ scheme level

Finding a balance between learning lessons and meeting objectives.

Why Evaluate?
Should be driven by the information needs of the audience, not because the funder requires it

The key audience for your evaluation is YOU
- How successful was your project?
- Was this worth all your time and effort?
- What did you learn?
- What could you change for any future work?

As a trust:
- Does the engagement format work?
- Were the objectives met?
- What did the team learn from the experience? Personally and practically
- Are there learning points that would be of use to other current and future grant holders?
- How does your project contribute to the larger PE field?

At Wellcome:
- End of grant feedback form – external evaluation in addition is welcome
  o Were objectives met
  o Audience numbers and profiles
  o Lesson learning
  o Project dissemination/ sharing experiences
- Clarify aims and set SMART objectives from the beginning (Specific, Measurable, Achievable, Relevant, Time-bound)
  o Does everyone know who is involved and responsible?
  o What will you see if you achieve the objective?
  o Is there evidence that this is possible, in theory?
  o Is it relevant or just easy to measure?
  o Are the deadlines clear?

Quantitative Data
- Should be representative of your audience
- Collection should be consistent
- Cost-quality trade-offs

Qualitative Data
- Cross-section of your audience

Learning Lessons
- From participants – observations/ visitors books
- From team – meetings and record keeping
What went well, what didn't, what did you have to change, and why

Share Experiences
- Project dissemination
- Plan audiences at the start, including media
- Identify specific audience interests

Who are the audiences for the evaluation?
What information do they need?
What are the project objectives?
How will you know if the objectives have been met?
What resources do you need?

TASK
- Groups of 5 – project story: context (political, cultural, background), aims and objectives, methodology and audience, outcomes (what went well, didn't go well, what did you learn from the engagement process)
- 1st person - 15 mins
- 2nd person – 10 mins – same structure but compare and contrast – focus on similarities and differences related to the first project
- 3rd person – 10 mins – drawing from 1 and 2
- 4th and 5th – 5 mins each

Feedback
- Summary of discussion
- What similarities/ differences were there between projects?
- What, if any, successes/ challenges did you share?
- What did you learn?

Juliette:
Paul, Dan, Bernard, Rose
Dan – research by institutions and its under-utilisation – training scientists to engage with the public, policy makers and media – the need for partnership between the different stakeholders
Rose – sensitise community to using research when addressing policy makers to be able to present a stronger case and for self-representation
Paul – MP-scientist pairing – shadowing for a year – scientists need to stop blaming MPs
Juliette – science cafes, to engage different stakeholders, placed in a context that people relate to

Daniel Peplow
Global representation – Suriname, South Africa, South Vietnam
- Find culturally appropriate ways to engage
- The need for adaptation

Mayada:

4 people using theatre to communicate concepts about complex conditions – workshops, working with schools and communities
Shared themes: even though you have specific objectives, you need to be open-minded and willing to adapt; the importance of listening to the audience because their solutions can be more targeted and effective; a good scientist is one that is able to change their mind based on the data collected, and looks at the underlying causes

Jonathan Stadler
Science cafes – Vietnam and Africa
Capacity building for health – Caribbean
Parallels: people's daily needs are more important/ pressing than the needs of the project; overall desire to have a greater awareness of science and its practice; HIV/ AIDS; range of participatory approaches
Barriers: change in currencies that re-shaped the budget and therefore impacted the range of activity; paucity of local scientists to engage in projects

Laura's agenda: evaluation of grants at Wellcome needs to be better. Looking at a new system of greater benefits – lesson learning frameworks, seeing whether the themes emerging from the discussion run parallel to Laura's ideas of themes for sharing perspectives

Plenary Session

Chair: Daniel Glaser
Strand Chairs: Subhadra Menon, David Osrin, Simon Parry

Need to continue to generate a community of practice – reflect on the projects funded, how can what we learned apply to future doings

Share the ways in which your views of your areas of expertise has changed post this conference?

Translations: Subhadra Menon
Thanked the Wellcome trust – for bringing together individual and isolated efforts in a commonality of purpose

1. We all require translation – to differing degrees – but should never forget the diversity of its source
   Dissenting voices that health researchers are not needed to translate or be trained – this was an eye-opener
2. Questioning the issues around policy makers
3. The need to build relationships – media-scientist-translator-public

As agents of change, we need to look for ways to remove ourselves from the path to social transformation.

Creative Approaches: Simon Parry
Very varied and diverse sessions – cannot do an overview or synthesis. Mapping is possible – to locate our practices to find out who we are, where we are, and what we're doing, and locating them against other practices
   - Finding roots – understanding communities
   - Maps and journeys are best recorded in the form of stories
   - Hearing other stories helps you travel to other locations
   - Dramatic locations and characters

Gender: David Osrin
Part of the experience of chairing is to reserve your own opinion.

1. Thought most about space and time – time to talk, tell stories
2. Moving into another space transformed the engagement – things unfolded naturally, without structure – stories don't have to end – there is a function in the telling
3. We have a tendency to try to end the story which can be detrimental
4. Stories were told to express distress
5. Structure is not necessary for good work – the point is to tell the story and not look to finishing it

Discussion

Warren – there are untold stories here –
   1. Questions of scale, different platforms – focus on certain aspects and leaving out others –
   2. Not much on theory

Kole
Is it possible to have country reports of what's happening on ground in each of the 26 countries – specific to telling stories and science and public engagement?

Laura
How can we learn more from the grants we fund? Is it a country focus we want, or engagement, or topic?

Runa
In response to Warren: Discipline is accessible to reinforce the creativity

Juliette
Could Warren create a map on the Communication Initiative locating all delegates?

Gabriel
Where do the next themes come from?
Daniel: the goals are clear – themes are not applied

Closing by Daniel: Presentations from Wellcome - Thanks to the grant committee and grant holders
Thanks to
1. Rebecca and Jess – Tinderbox
2. Hotel Lalit Ashok
3. NCBS – mukund and nidhi
4. Daya
5. Zena
6. Ariel, Jacob, Laura
7. Sian