Learning from international experience on approaches to social power and participation in health

International meeting report

October 19-21 2017
Aberdeen, Scotland

Training and Research Support Centre
With local hosts
University of Aberdeen

With support from a grant awarded by Charities Aid Foundation of America from the Robert Wood Johnson Foundation Donor-Advised Fund
Table of contents

Summary............................................................................................................................................. 1
1. Background......................................................................................................................................... 2
2. Opening and introductions.................................................................................................................. 3
3. Motivations and frameworks for social participation in health....................................................... 4
   3.1 Framework and motivations in Shaping health............................................................................ 4
   3.2 Accountable health communities in the USA.............................................................................. 6
4. Exchanges on international practice .................................................................................................. 7
   4.1 Identifying, engaging and supporting community actors/ activists............................................. 8
   4.2 Working in and taking health services into community settings.............................................. 9
   4.3 Formal and informal mechanisms and their interaction......................................................... 10
   4.4 Organising and sharing information between communities and services............................ 11
   4.5 Joint decision making and social accountability...................................................................... 13
   4.6 Community and service capacities for participation and co-determination............................ 14
   4.7 Plenary summary discussions on the round tables................................................................. 14
   4.8 Monitoring, evaluating and reporting on change.................................................................... 15
5 Reflections on transferable learning and practice ................................................................................ 17
   5.1 Synthesising the learning in Shaping health.............................................................................. 17
   5.2 Reflections from the US sites on managing change................................................................... 20
6 The Aberdeen site visit......................................................................................................................... 23
   6.1 The site visit............................................................................................................................... 23
   6.2 Exchanges on the work in Aberdeen......................................................................................... 24
7 Follow up actions and communication............................................................................................... 26
   7.1 Follow up actions within the local sites in the USA................................................................... 26
   7.2 Follow up actions within other levels of the USA..................................................................... 27
   7.3 Follow up action internationally............................................................................................... 28
   7.4 Key messages............................................................................................................................. 28
8. Communicating the learning.............................................................................................................. 29
   8.1 Follow up communication in the USA...................................................................................... 30
   8.2 Follow up communication internationally............................................................................... 31
9 Next steps and closing......................................................................................................................... 32
Appendix 1: Programme....................................................................................................................... 34
Appendix 2: Delegate list .................................................................................................................... 37
Appendix 3: Documents tabled............................................................................................................ 38
Summary
On 19–21 October 2017 in Aberdeen, Scotland, TARSC in dialogue with the University of Aberdeen as local hosts convened an international meeting to bring together participants in the Shaping health project to share learning and discuss follow up actions from the work. The meeting was attended by 32 delegates from the five US sites, the twelve international case study sites, TARSC and RWJF and delegates from US and international organisations. This report outlines the discussions and recommendations made at the meeting. It presents:

- In Section 3 (p4) the **motivations, contexts and models for social participation** in health, and the framework used for organising evidence in the project,
- In Section 4 (p 7) the **experiences in and potential transferable practices from the international case studies** in relation to key themes emerging from the work, and on monitoring, evaluating and reporting on change.

**Areas of practice raised in these exchanges seen to be transferable including for the US included**
- Mentorship and development of community members literacy and power as activists;
- Having short-term ‘wins’ and evident benefits that build participants’ sense of agency;
- Giving people a safe base (a drop-in centre, social enterprise café);
- Involving cultural values, appropriate stakeholders and local languages in communication;
- Involve community members in decision-making as central to meaningful participation;
- Being transparent on why those participating are ‘at the table’ and what value it brings them
- Providing training for people to be able to navigate formal spaces when needed.
- Making service evidence accessible and linked to resources on priorities communities raise.
- Being transparent about benchmarks and agreeing on criteria for decision-making;
- Involving community members in the development of websites and information media.
- Using roadmaps to set steps and active community assets for increased participation;
- Using participatory budgeting, social audits and certification of health system performance;
- Implementing audits of community assets and building capacities in other sectors.
- Using drama, sports and other fun, non-threatening, non-stigmatising approaches.

- In Section 5, (p17) **reflections on transferable learning** and practice, including the synthesis of the learning from Shaping health and the reflections from the US sites on their interventions

Some of the questions that remained unanswered after these exchanges were:
- How to ensure that systems value participation and do not adopt tokenistic forms?
- How to sustain practices through harsh periods and keep informal spaces invigorated?
- What support can be given to volunteers, and what role do payments play?
- How to spread and amplify from local work to wider scale?
- What role for financial incentives and what incentives can encourage holistic approaches?

- In Section 6, (p23) **the Aberdeen site visit** and the discussions on the work in Scotland
- In Section 7 (p27), the key messages and **follow up actions** in the USA and internationally
- In Section 8 (p29) the **proposals for communicating the learning**
- In Section 9 (p32) **the next steps**. Closing and words of ‘Freedom Came Ae Ye’

The follow up actions proposed across these sessions included:

- **Different planned actions specific to each of the 5 US sites, and in the US generally**
  - involving the community in planning follow up, directly or through or partner organisations,
  - strengthening cross sectoral work, building community leadership and CHW /promotora roles.
  - developing media (videos, one-pagers, slides, vignettes, individual stories, evidence sheets) using Shaping health work with language and messages aligned to the US context
  - exploring participatory budgeting, and supporting community representation on boards/ councils
  - developing stories of change.

**Internationally and for the Shaping health community,**
- Translating Shaping health texts, revising the synthesis and conceptual framework (TARSC)
- Setting up a public Shaping health web page, with case study stories linked to the principles.
- Collaborative work and/ or web platform discussions on follow up issues: eg the questions above, on evaluation, community needs assessment, on social power in contested spaces.
- Communicating findings and widening the community of practice through sharing in own networks and face-to-face meetings (such as the next Health System Global conference).
1. Background

Social participation in health refers to people’s individual and collective power and involvement in the conditions, decisions and actions that affect their health and health services. It can take many forms and levels and may be initiated from within the community or by outside institutions. It takes place within formal and informal, invited or claimed spaces and within different functions of health systems. It may be ad hoc and transient or sustained.

In 2016/17 the Shaping health project explored how local health systems in different countries have built social power and participation in health, and the challenges they face. In Shaping health we focused on those forms of participation where communities co-decide the actions and services for their health and wellbeing, through their awareness, their collective power and power to act. As a community of people and institutions involved in this field of work, we shared experiences and insights on how communities build the power, confidence and capacities to identify their health and service needs, to set priorities and participate in decisions on the actions and services that address these priorities. We focused specifically on local-level health systems and the communities that interact with them to promote population health. The project, led by Training and Research Support Centre, (TARSC) was implemented with partners from five sites in the USA and twelve countries internationally. It was supported by a grant from Charities Aid Foundation of America from the Robert Wood Johnson Foundation Donor-advised Fund.

On 19–21 October 2017 in Aberdeen, Scotland, TARSC in dialogue with the University of Aberdeen as local hosts convened an international meeting to bring together participants in the Shaping health project to share learning from the work. The meeting aimed to:

- Discuss learning from the international sites in Shaping health on the approaches, tools for community participation, power and decision-making in health, and the issues in their application.
- Identify learning and approaches that can inform and be adapted for US sites and more widely.
- Strengthen links and review products, processes and dissemination opportunities for communicating the work, including through the Shaping health web platform.
- Discuss plans for follow up work in the USA and internationally.

The meeting was conducted in an interactive and participatory manner to facilitate exchange between delegates. A site visit organised by University of Aberdeen also provided an opportunity for delegates to see first-hand the experiences covered in the Scotland case study and to interact with lead actors in this work (see programme, Appendix 1).

The meeting was attended by 32 delegates from the five US sites, the twelve international case study sites, TARSC and RWJF and delegates from US and international organisations (see delegate list, Appendix 2).

The conceptual frameworks and background information, US site briefs and International case study reports, a draft synthesis report and other supporting documents were circulated before the meeting to inform discussions (see Appendix 3 for documents tabled). These documents and further background materials and the meeting presentations were provided electronically to delegates at the meeting.

This report summarises the key points raised and discussed at the meeting. It provides only brief summaries of material already contained in the background documents, many of which are already available in public domain online as shown in Appendix 3. The report thus captures the discussions and recommendations arising during the meeting in more depth.
2. Opening and introductions

The meeting was opened by Susan Mende, Senior Program Officer, Robert Wood Johnson Foundation (RWJF), and Pamela Abbott, Director of the Centre for Global Development, University of Aberdeen (UoA). Susan chaired the session with Lucia D’Ambruoso, UoA.

Susan thanked delegates for travelling long journeys to be present. RWJF has been working to build a ‘culture of health’ and she observed that this exchange between people in the US and in different countries contributes learning for this. In the USA, people, regardless of location, education, ethnicity, class, and other social features should be as healthy as possible, defining health broadly. Where people live, their power – or lack of it - impacts on their health. She noted that this project addresses this and there is interest in the US in the findings, as this kind of critical, cross-cutting work, drawing on international experience, does not happen very often. She thanked Rene for her thinking, strategizing and work in the project and in organising the meeting and all who contributed in the project.

Pamela added her welcome on behalf of University of Aberdeen. She introduced Aberdeen, known as ‘The Granite City’ due to materials used in building many parts of the city. Aberdeen has been a settlement since the 11th century, and the university, one of the oldest in the country, was founded in 1495. Aberdeen has had a history of considerable wealth, but now has very deprived neighbourhoods, with social enterprises and other organisations serving people living in these areas, some of which were covered in the case study and would be shown in the site visit. She welcomed delegates and wished everyone a productive and enjoyable meeting.

The formal opening remarks were followed by delegate introductions. Susan asked each delegate to introduce themselves and share something they anticipated from the meeting. The delegate list (Appendix 2) and photo overleaf shows the delegates. The expectations they raised for the meeting were:

- Meeting others involved in the field:
  - Getting to know people working with similar motivations and values;
  - Exchanging with colleagues globally, sharing knowledge from different contexts and experiences;
  - Seeing the case studies ‘come to life’ by meeting the authors and practitioners that are involved in the projects;

- Discussing various issues, experiences, strategies and learning around social power and participation in health:
  - Exploring the intersection between formal and informal spaces for participation;
  - Exploring how to strengthen citizen voice, democratic processes, build community activism, and make participation meaningful and truly get people engaged in decisions that affect their health and wellbeing;
  - Exploring how community outreach can be achieved through Community Health Workers (CHWs);
  - Discussing the idea that ‘our culture cures us’ and how participation supports this;
  - Thinking about ways that ground-level and bottom-up approaches can challenge top-down determination of priorities;
  - Thinking about alternatives where people are not viewed as consumers, and health as commercialised;
  - Discussing founding notions of democratisation and participatory democracy, and how citizens, rather than ‘users’, can have more control and power.

- Drawing inspiration and energy for the work underway:
  - Being inspired by social participation and empowerment movements;
  - Strengthening momentum around this type of work and thinking.
Following the introductions, Rene Loewenson, Director, Training and Research Support Centre (TARSC) welcomed delegates, both those who had met in person and those who had met online. She noted that our health systems are a reflection of our social values, citing the example of the National Health Service in the UK and the social struggles to protect it as a tax funded, public service in the face of austerity. She noted the huge amount of work that has happened in the last year, since the initial late 2016 meeting in the UK brought the various US sites together with international colleagues to discuss the framing and design of the work in Shaping health.

She summarised the work produced in the project (as listed in Appendix 3). She outlined the meeting process, objectives, and programme to exchange and draw transferable learning from Shaping health, recapping the aims as outlined in the previous section. She was happy that the meeting would also enable more direct discussion between those involved. Rene thanked RWJF for their support, the project advisory group, the five US site leads and their teams, the leads and teams involved with deep scan case studies and focal points for short case studies, TARSC colleagues and consultants and other technical colleagues. She explained how the decision was taken to host the meeting in Scotland, drawing on choices made in the 2016 meeting. Finally, she outlined the meeting process, which was adopted by the meeting delegates.

3. Motivations and frameworks for social participation in health

3.1 Framework and motivations in Shaping health

Rene outlined the conceptual framework that was developed based on a review of international literature, and used to frame the work in Shaping health. The motivation for the project emerged from interest in the US, with a number of US sites engaged in strengthening social power and participation, five of which were included in the project. The framework developed by TARSC, listed in Appendix 3, was reviewed in the 2016 meeting, with its key features summarised in Figure 1 overleaf:
Rene noted that the US and case studies implemented in Shaping health pointed to a number of contextual factors motivating and affecting social participation in health systems, including:

a. Socio-political norms, values and rights, whether from culture, political struggle and activism or as framed in constitutions and law, that are central for active citizenship and health.

b. Social change bringing opportunities and challenges for health, with a convergence of social progress and social inequality raising engagement due to frustration over social injustice.

c. The multiple (preventable) health burdens that arise due to socially created and preventable conditions that indicate that beyond technical interventions, the role of social change in their prevention and management.

d. The challenge health systems are facing to develop more effective, equitable, less cost burdening approaches that respond to these conditions, in holistic, population health approaches that engage communities and other sectors.

In Shaping Health participation was not only seen as a means to improve health service performance but as an end in itself. Beyond its role in improving the action on, and services for health, she noted that social participation and community empowerment is a right and a democratic goal of society. People are not seen simply as passive patients or individual consumers, but as active citizens, with rights and social power, who contribute to a culture of health.

She noted that this reflects how people see themselves, as one of the case studies points out: *People do not see themselves as mere recipients of state provided health services, in which they are claiming the right to participate. Rather, they see themselves as in control of their destiny.* This means that participation processes are rooted in history and culture, may arise from social activism and struggles that evolve over time, sometimes under harsh conditions, but are sustained by networks and driven by values and organisations that are trusted within
communities. She noted the time this takes, giving the example of Wan Smolbag in Vanuatu, where the growth of its work over 25 years was even reflected in a commemorative stamp.

She noted also that power is central to participation, with a social shift that is claimed rather than granted from the common forms of “power over” (domination, repression, controlling action) to “power to” (the ability to act and to influence conditions), driven by “power within”, or the internal capacity, self-confidence, and self-consciousness to support self-determined thinking and action and the “power with”, created through acting collectively. In Shaping health, the work has focused on those forms of participation where communities have built the evidence, voice, capacity and self-determined thinking and action to participate in, influence and co-determine actions and services for their health and wellbeing. Whether organic or externally induced, this involves a ‘bottom-up’ growth in the social power within affected communities.

She noted that while participation is expressed across different dimensions of health system functioning, it is supported by and elicits holistic, proactive, comprehensive primary health care and population health focused approaches. While health systems may thus provide enabling or disabling conditions for participation, she noted that social participation itself induces changes in health systems. Rene concluded by commenting that our understanding of the role of social power and participation can only partially be built from what is documented, and so calls for the sharing of experience and insights and learning from action. To that end she noted that while the project documented the case studies, the meeting intended to provide an opportunity for more direct and deeper exchanges on the learning from practice.

3.2 Accountable health communities in the USA
Alex Billioux, Center for Medicare & Medicaid Innovation (CMMI)/ Centers for Medicare & Medicaid Services (CMS), presented evidence on the wider US healthcare context for work on social participation in health, particularly the efforts to shift thinking from a health system that is producer-centred and incentivises volume, to one that is patient-centred, incentivising outcomes, as a means for more sustainable and coordinated delivery of care. He outlined the three areas that CMMI is focusing on for this reform: how providers are paid; how care is delivered; and how information is distributed between health services and from services to individuals. Three outcomes are envisaged: one, in which quality improves and cost stays neutral; a second where quality stays neutral but cost is reduced; and the best-case scenario where quality improves and cost is reduced. In thinking about the change, he gave the allegory of a rider on an elephant; the rider has difficulty changing direction of the elephant given its massive size, but laying a path that encourages the elephant can make it easier for rider and elephant to take this path.

He indicated that the efforts towards innovation are thus framed in terms of how payments are made to providers, with fee for service that has no link to value; fee for service linked to quality; alternative payment models building on the fee-for-service architecture and population-based payments. The Accountable Health Communities Model (AHCM) is at the forefront of efforts to build understanding that health happens outside of clinical care. He noted that a model such as the AHCM would act as a conducive “pathway” for the reform. The model tests, over a period of five years, whether systematically identifying and addressing the health-related social needs of Medicare and Medicaid beneficiaries impacts health care quality, utilisation and costs.

Alex illustrated the model using the figure adjacent. At its heart is a bridge organisation which gathers information about core needs of communities.
(housing instability, utility needs, food insecurity, interpersonal violence, transport), and their supplementary needs (family and social support, education, employment and income, health behaviours), from universal screenings which happen at clinical delivery sites. This information is then fed to community service providers to build a broader understanding of the social determinants of health. The model is being implemented with two separate 'tracks' for the bridge organisations. One track navigates services to assist high-risk beneficiaries with accessing services to address their health-related social needs. The other track encourages the alignment of partners to ensure that community services are available and responsive to the needs of beneficiaries. The model is innovative in:

- systematically screening beneficiaries to identify unmet health-related social needs;
- testing the effectiveness of referrals and navigation of community services on the total cost of care using a rigorous mixed method evaluation, and
- aligning partners at the community level and implementing a community-wide quality improvement approach to address community needs.

In the plenary discussion that followed, there were concerns about how ‘return on investment’ is defined and whether savings are re-invested back into communities to address broader health determinants. Delegates perceived this to call for community contribution to the thinking, to focus not only on savings, but also on health outcomes and inequalities in health. Alex noted that there is a policy focus on financial issues in the USA that needs to be engaged with, but that there are attempts to broaden understandings of what savings and lower costs mean and to reframe goals towards better health rather than just more health care, and that community voices should be heard in this. Delegates raised a query about how coordination between the different actors would be achieved (as it all seemed to depend on the bridge organisation). Alex noted that this is important, and that other models focus on cooperation within the broader health systems actors. Delegates observed encouraging examples of where such changes are occurring in the USA, albeit slowly, such as in Vermont, where an all-payer model agreement has been set up enabling the health system to invest in broader determinants, such as housing, for the first time.

4. Exchanges on international practice

In a session chaired by Patricia Gerrity, 11th St Family Health Services and Ranjita Mohanty India, Rene introduced the sites that the Shaping health project has involved. They are found all over the world, including the five US sites (Athens City County Health Department, Ohio; Blueprint For Health Department of Vermont Health Access; Centro Sávila Albuquerque; Stephen & Sandra Sheller 11th Street Family Health Services, Philadelphia; PIH Health, Whittier, California); six deeper case studies (in Brazil, Chile, Kenya, New Zealand, Scotland and Slovenia) and six shorter case studies (in Australia, Canada, Ecuador, India, Vanuatu and Zambia). These are shown in the adjacent figure.
Rene introduced the round table discussions on the experiences and transferable practices and learning from the international case studies. The round tables were set up on key themes emerging from the background documents and case studies, with countries assigned to specific themes based on their experiences. The round tables were:

1: Identifying, engaging and supporting community actors/activists
2: Working in and taking health services into community settings
3: Using/setting up formal and informal mechanisms and their interaction
4: Methods for organising and sharing information between communities and services
5: Processes and tools in decision making including on resources, and for social accountability
6: Building community and service capacities for participation and co-determination

In each round table the countries present outlined their experiences on the theme in focus, the features, practices, tools or methods that supported social power and participation, the challenges and how they were addressed and what may be transferable from the work. The round tables provided an opportunity for the US sites to raise questions on aspects of the work that they want to hear more about from the country site. A rapporteur at each table reported the transferable learning and unanswered questions in the plenary. The next sections summarise key features of these discussions. Case study reports are listed in the references in Appendix 3.

### 4.1 Identifying, engaging and supporting community actors/activists

This roundtable involved presentations by: Jo Dorras, Wan Smolbag, Vanuatu; Lucia D’Ambruoso, University of Aberdeen, Scotland; Deborah Howe, Central Coast Mental Health Service, Australia and Clara Mbwilli-Muleya, Lusaka District Health Office, Zambia.

Wan Smolbag began as a drama group, but now works across Vanuatu with plays that focus on issues affecting health in the community, such as domestic violence, rape and sanitation. The plays are scripted with community input and actors are employed full-time and a hip-hop group aims to engage youth. The element of enjoyment is important to this work. Jo emphasised key aspects that are important for engaging the community: firstly, activists have a base or permanent space to work from; and secondly, communities are engaged with on their own terms and in their own spaces, as you cannot expect communities to come to you unless you offer something that engages people, as for example the hip-hop group does for Vanuatu youth.

In Scotland, Social Bite and CFINE engage people through food, albeit in different ways and spaces. Social Bite is a social enterprise, where paying customers can pay for meals for homeless or impoverished customers and where commercial profits are re-invested in social dinners, signposting to social services, and employment and training opportunities. Social Bite aims to address short- and long-term insecurities, while de-stigmatising homelessness. CFINE is a social enterprise that runs fruit and vegetable sales and cooking classes for food insecure people, and a food bank, whilst noting that the latter is not transformative. Lucia observed that austerity in public funding results in a mismatch between mandates and resources, with non-state actors often providing small scale, variable practices that do not reach population scale, unless backed by law or in alliances. Actions targeting individuals rather than collectives may not build social power. She observed, in contrast, that food is an effective, accessible way to engage stigmatised and excluded people, as an entry point for referrals, training, supported volunteering and employment in practices that build respect and trust enabling people to overcome hardship.

Deborah outlined how the Central Coast Local Health District (CCLHD) has engaged young people in governance, planning and outreach through the use of paid youth consultants and youth peer workers. There have been challenges to this approach, particularly how to maintain this model in a sustainable way when working with young people who come in and out of the program. One employee is thus dedicated to supporting participation and outreach to maintain engagement, and the services try to be as flexible as possible to suit the needs of the youth consultants. Furthermore, funding is often project-based so money is not always available for longer-term commitments. She noted issues in avoiding the professionalisation of the youth consultants, while also remunerating them for their time and efforts.
The US sites asked Deborah for further detail on engaging youth. In New South Wales, online tools like Survey Monkey were used to engage youth in an anonymous way. Young people were consulted on simple things that would make them more likely to use mental health services, such as what a waiting room should look like. Mentor support for youth consultants was important, and useful for the mentors (clinicians) as well. Finally, flexibility was key; youth consultants attend a monthly mandatory meeting, but their engagement is generally quite flexible beyond that.

Clara reported on Lusaka’s District Health Office work using participatory methods to support changes in attitudes and behaviour in communities and health workers. Working at a community level and community volunteers were empowered through a health literacy approach, with a growth in trust in health workers in the community and health workers now sharing information with community volunteers. There were challenges around motivating community members to take part, and opposition from the central level due to unease over shifting power dynamics. Political support from the Minister of Health helped, leading to national roll-out of the work.

The four case studies highlighted key features of processes that engage community actors: Involving stakeholders outside health to build wide understanding of what is being done; building a natural and organic process, not imposing pre-planned top-down steps and taking advantage of windows of policy change. Various challenges were noted, particularly the demands on community members’ time; possibilities of tokenistic rather than meaningful, long-term engagement, and unanswered questions on how seed funding can be turned into sustainable financing, and where the balance between paid employee and volunteer lies.

Various ways of addressing challenges were seen to potentially be transferable:

- Determining and building peoples’ engagement around their shared interests;
- Having a common framework and participatory methods to foster engagement;
- Mentorship and development of community members as activists;
- Having short-term ‘wins’ and evident benefits that build participants’ sense of agency;
- Giving people a base of operations (a drop-in centre, social enterprise café); and
- Bridging distrust between community structures and formal structures.

4.2 Working in and taking health services into community settings

Cara Lee Pewhairangi-Lawton with Don Matheson on Ngāti Porou Hauora, New Zealand, Peter Beznec, Centre for Health and Development, Slovenia; Francisco Obando, Secretaria de Salud, Municipio de Quito, Ecuador; and David Musyimi Ndetei, African Mental Health Foundation, Kenya addressed this theme.

Cara Lee opened the presentation on New Zealand with a Maori prayer signalling the importance of cultural understanding in the work at Ngāti Porou Hauora. The indigenous population of New Zealand has a deep-rooted belief in self-determination, and the continuous relationship between the land and Maori people forms an integral part of their culture. These beliefs are recognised in the way Ngāti Porou Hauora services function as part of the community, with participation viewed as an entitlement rather than a utilitarian pursuit. Emphasis is placed on how the health workforce and community are meshed together, and on transparency between them.

Peter noted that despite high levels of health insurance coverage in Slovenia, inequalities in health exist. Health matters are predominantly decided by the national government. In the Pomurje region, a regional action group was established to promote health through an inter-sectoral approach that has linked the issues of agriculture, tourism, health and the environment together, through participatory approaches. For example, investments have been made in agriculture to help provide for schools and kindergartens.

David reported on the Kenya context where faith and traditional healers are often the first point of call for mental health disorders, but do not necessarily know how to manage such conditions. In trying to bridge the gap between traditional health practitioners (THPs) and modern medicine, a programme was established in Makueni County to support dialogue between THPs and clinicians.
in the health service. This dialogue aimed to address barriers to collaboration between the two groups, while mutually recognising the value and benefit of the other group of practitioners. It has led to the adoption of locally understandable names for various mental health conditions, joint training on how to identify and manage these and community engagement through CHWs.

Francisco described Quito Municipality's health promotion and disease prevention programs and the role of the community in implementing these. To support this, a steering committee has been established and meetings held with community members to facilitate the collection, organisation and analysis of health and determinants of health information to inform decision making. One example, was the community certification process that has been established for Quito's marketplaces. Francisco highlighted potentially transferable practice in the methods for prioritizing areas where the project is implemented; in determining who will be involved initially and later on in the process and in maintaining the momentum and follow through with commitments. He noted that it was important to identify common goals with community health teams, to show progress and implement changes quickly and to provide adequate incentives. It was important to follow through with commitments and use methods for prioritizing the issue that give communities a central role.

In response to US questions around how stigma and social support is addressed when working with communities, the sites raised the importance of being clear whose needs are being addressed through community engagement: of bottom up approaches drawing on the cultural values, existing structures and knowledge in the community; of taking holistic approaches, rather than silo efforts; of bringing community groups to the table to plan processes, using information from communities in policy setting and training community members to support their engagement in policy settings. It was observed that the willingness of stigmatised people to engage depends on how they are treated from the moment they step into services.

In terms of transferable learning, the roundtable summarised this as:

- Understanding embedded cultural values and that participation is intrinsic to identity;
- Understanding the roots of participation in political engagement and finding the right stakeholders and language for communication with communities;
- Understanding the relevance of the issue to the community and the health system;
- Approaching communities without an agenda; for people to determine their priorities; and
- Facilitating communication and feedback between communities and services.

Finally it was noted that political systems differ and affect how to navigate these measures and address the power chasms that exist, to affect change across different contexts.

4.3 Formal and informal mechanisms and their interaction

Ranjita Mohanty, an independent research consultant, India who worked with TARSC on the SSK Varanassi case study; Vera Coelho, Brazilian Center for Analysis and Planning, Brazil; Patricia Frenz, Universidad de Chile, Chile; and Sarah Simpson, EquiAct / TARSC, for Bridge for health, Canada presented their experiences on this theme.

In Varanasi, India informal spaces supplemented formal spaces. They provided spaces for women's groups to be empowered, in the form of community based organisations. Community members, especially women, used them to feed concerns and issues back into more formal spaces. Practices such as social audits, public hearings and forums for dialogue with local
authorities built the link between the two spaces. Where that link was seen to be strong, participation grew in informal spaces.

In Brazil, participation is mandated by law, and formalised through local facility councils. Anyone can attend the meetings, but only elected councillors can vote. Few councillors come from marginalised groups, potentially weakening their representativeness. There is thus a link between informal and formal spaces, in a two-way dynamic, and alliances between civil society organisations and health professionals were viewed as important in this regard.

In Chile, a biopsychosocial approach in health means that services work with community organisations to address public health. Participation is mandated by law. The system has embedded formal spaces for participation, such as elected health councils, opening up spaces for dialogue and action for communities and leading to a strong emphasis on social justice.

In Canada, Bridge4Health (B4H), as a social enterprise and cooperative engages in both formal and informal interactions. Its co-operative model has enabled organisational practices that are participatory, such as collective leadership and shared ownership, as well as processes that are accessible to communities, such as photovoice for digital storytelling by youth on the issues influencing their health and wellbeing. Representation is also a challenge here as some groups are more represented than others.

The discussions on these experiences raised questions of how to value and motivate participation so that it does not get abused; of how to overcome gender bias in representation and of how to ensure that informal and formal spaces stay dynamic and authentic.

In terms of transferable learning, delegates in the roundtable raised:

- The relevance and interaction of both formal and informal processes.
- The need to actively work to broaden participation, to avoid exclusion of certain groups.
- Ensuring transparency on and understanding of why those participating are ‘at the table’.
- Showing the value to and recognising participation for those involved; and
- Providing training for people to be able to navigate formal spaces when needed.

4.4 Organising and sharing information between communities and services
Cara Lee and Don, New Zealand; Deborah, Australia; Vera, Brazil and Francisco, Ecuador presented their experience on this theme.

Cara and Don described how Ngāti Porou Hauora services include other community services, with a meeting at the hospital every Monday morning for anyone to come and share experiences and concerns. The meeting lasts for an hour and always has participants. Patients are given space to feed back to staff, charting positives and where there’s room for improvement. A broad range of staff from all services also share their experiences. The meeting is a forum for discussion of issues and communication between patients and providers. It ‘levels the playing field’ and leads to inclusion in decision-making, while treating everyone as equals and with mutual respect. Issues brought up at previous meetings are re-visited to see if they have been addressed or if progress is being made, and to ensure that people are happy with outcomes. This community feedback process is already culturally established. It is not health specific and therefore engagement comes naturally and is expected. This is an example of the health system feeding into existing cultural processes.
The youth mental health services in New South Wales Australia emphasise dissemination and sharing of knowledge. As part of this process, benchmarks are established and shared. Surveys on experiences of care are collated from the community and youth who use the mental health services, and analysed off-site. Deborah added that the ycentral web platform provides information relevant to mental health workers and schools, carers families, and youth. It is updated regularly with information and links. Podcasts have been made by youth accessing services, as well as videos and other visual information. The website is the conduit for all this information.

In Brazil, the local facility councils, described earlier, meet monthly and form the link between the community and health systems. In Cidade Tiradentes, councillors have been successful in raising issues with health managers, but also mediate in ongoing or potential conflicts. The councils have a participatory approach, putting various actors at the same table, and seeking out community members rather than just waiting for patients to arrive at services. Vera said that CHWs form another link between community and health system, occupying both spaces and mediating between them by virtue of being part of the community and paid by the health system.

In Quito, the municipality focuses on prevention and promotion, rather than on treatment. The city is divided into "parroquias", and data and information from each is used and discussed in a comparative manner to help with prioritization. Different sectors bring different information, resources, and tools to identify, prioritize and address neighborhood issues that affect health. Francisco noted that providing the right kind and amount of information to avoid getting distracted is a challenge, as is bringing evidence from different sectors to the same process and marrying community perceptions with available statistics to support felt issues with data.

In discussion, delegates discussed the degree to which information is shared. In Ngāti Porou Hauora and New South Wales, for example, budgets are shared, but this raised a question of how community frustration with how budgets are allocated is addressed. There was a question of whether community-led prioritisation can lead to perverse incentives, where communities ‘game the system’ by describing their area as worse to obtain benefit. The experience of Quito, where equity is agreed as an explicit goal and criteria for decisions, was noted to assist in these processes. At the same time it was observed that there is need to understand the political contexts and processes to see who the data benefits.

As transferable learning, delegates identified that:

- Local contexts and cultures call for different ways and formats for how meetings are held;
- Information sharing should go both ways between health systems and communities;
- It is important to think about how evidence from services is brought to communities in an easy and accessible manner, what communities perceive of and do with it, how it links to resources or capacities to address issues raised in the evidence;
- Community knowledge is valuable and does not always translate into ‘data’;
- Processes that use evidence need to be transparent about benchmarks and agree on criteria for how evidence is used in decision-making; and
- Youth and other community members should be involved in the development of websites, podcasts, surveys and other information media.
4.5 Joint decision making and social accountability
Patricia, Chile; Ranjita, India; Peter, Slovenia and Lucia, Scotland presented their experience.

In Chile, various processes and tools have been used to facilitate joint decision-making and co-determination. Participation is acknowledged within the right to health and the biopsychosocial model is used for availability, accessibility, quality and affordability of health care. Patricia reported specific measures for co-determination:
- Explicit inclusion of people with disabilities, immigrants and other marginalised groups in intersectoral approaches;
- Links made with economic activities, such as eco-orchards that use recycled organic materials, eco-gardens in schools and the network of healthy food carts/kiosks in Santiago;
- Participatory diagnosis and budget proposals, such as Healthy Spaces in Santiago, to remodel public spaces;
- Co-design and co-production of health materials with communities; and
- Horizontal health team and community capacity-building processes, based on popular education approaches that value different forms of knowledge and expertise.

Ranjita noted that in Varanassi, India, social audits are community-driven processes used to hold the government accountable for its services. Pioneered first by civil society and later adapted for use in government programmes, social audits are now implemented by both state and non-state agencies, with public hearings used to check the activities undertaken and expenditures incurred. They are an effective tool to make government programmes transparent, and to promote joint decision making. She noted that SSK has facilitated social audit of health services in Varanassi.

In Slovenia, capacity building has been the most important process in improving participation in decision-making around health and co-determination of issues facing communities. Peter noted that the work undertaken has focused on promoting active citizenship and on building the capacity of all stakeholders who play a role in shaping social determinants of health. Capacity-building and training needs were determined by a capacity audit, designed to understand the available capacities and what resources were needed going forward. This capacity building was then supported by a technical health institution, the Centre for Health and Development (CHD).

In Aberdeen, Lucia explained the various tools used to increase co-determination and participation around food poverty, including: the paying-it-forward method to provide meals to those in need; the use of social media to engage with communities and encourage investment in the work in the local area; a strong people-centred approach around food and alliances across organisations concerned with food poverty. She described how participatory budgeting was used to involve communities in deciding on a share of local budgets backed by supportive national policy and tools; reorienting relationships between communities, political actors, civil society and the state, albeit without adequate evaluation yet of the outcomes.

In the round table it was suggested that participatory budgeting may be combined with social audits. Various issues were raised for further discussion, on the use of mapping tools to understand the structure of communities; on amplifying empowering aspects of tools used in co-determination; on building trust from authorities in community-led programmes and on evaluating the processes and outcomes of these approaches.
The round table identified the key transferable points of learning on this theme as:
- The value of legislation to support participation;
- Tapping the de-stigmatising potential of social enterprises;
- Using roadmaps to set steps and active community assets for increased participation;
- Using participatory budgeting as empowering communities in co-determination on resources, with social audits and certification of health system performance; and
- Building capacity horizontally, rather than top-down
- Implementing audits of community assets and building capacities in other sectors.
4.6 Community and service capacities for participation and co-determination

Clara, Zambia; David, Kenya; Sarah for Canada; and Jo Vanuatu presented experiences on this theme.

In Zambia, Clara explained that participatory reflection and action (PRA) methods have been used since 2006 to identify and address health needs and barriers to the use of health services. In PRA, community members and health workers identify shared priorities, problems, and ways to address these, in sustained participatory approaches that demystify and increases community involvement in planning and budget processes, building trust, transparency and accountability.

In Makueni County, Kenya, David outlined how capacity and co-determination was built through the development of a shared understanding and common language around mental health. The local community identified and adopted local names for common mental health problems and participatory approaches were used to promote dialogue between health workers, traditional health practitioners, community health workers (CHWs) and the community to improve health services and provide follow-up of patients.

Sarah described how Bridge4Health Canada focused its capacity building efforts on youth, through: Engaging the Leaders of Tomorrow work which facilitated youth to undertake participatory consultation processes for input to a 2016 Global Health Promotion conference; and photovoice with selected youth as a part of a wider health literacy initiative. Youth took photos of what health means to them, presenting them at the end of training to families and friends.

Wan Smolbag Vanuatu offers a range of activities for youth including music, sport, as well as useful work skills, such as computer classes and literacy work. A sizeable multipurpose sports field is adjacent to the youth centre. Jo explained how the activities offered at the youth centre were developed following consultation with youth and provide opportunities for the youth to develop skills that will benefit them when they enter working life, as well as capacities around health and co-determination. Offering activities that youth are interested in provides an avenue for exploring health issues, and with the clinics at the centres the youth can access educational workshops through nurses and peer educators who provide information and outreach on family planning and reproductive health. Likewise, the scripts for the plays performed by Wan Smolbag are developed using a participatory approach and involve youth and other community members.

In the discussions there were unanswered questions on how to recruit people to get involved in these processes and how to translate data in ways that speak to peoples’ lived experiences.

Delegates suggested the following potential areas of transferable learning:

- Being pro-active in inviting people you want to speak to; recognise existing processes
- Using drama, sports to engage people in a fun, non-threatening, non-stigmatising way;
- Preparing and training both professionals and community members/actors for processes;
- Embedding capacity building within person-centred processes and participatory reflection and action approaches; such as in facilitating and building capacities for planning;
- Co-exploring issues, accessing and addressing difficult issues in a sensitive manner; and
- Believing in people’s ability to self-identify their own needs.

4.7 Plenary summary discussions on the round tables

In the plenary discussion on the six round tables, further comments were raised:

- On what role external factors play in participation. For example the new law in Scotland has facilitated participation, but also builds on a long-standing social support for participation.
- On how to recognise ‘real’ community organisations and community leaders. It was noted that the ‘usual suspects’ taking advantage of systems is common, including in ‘democratic’ processes. One proposal was to split and decentralise participatory spaces into units and processes that are local enough ensure community involvement and voice.
- On finding a balance between professionalisation and authenticity of community actors involved in health processes, such as CHWs, community leaders and youth coordinators.
• On finding the shared interests that lead people to engage and participate.
• On approaches to amplify local empowerment, such as by local mentorship helping processes spread horizontally rather than vertically. For example in Lusaka, local level successes were picked up by other communities and the media. This process of horizontal mentoring and spreading of ideas was noted to take time, but also to build trust.

John cautioned about making the distinction between ‘us’ and the ‘community’ saying that we need to make ourselves part of the community we are talking about as part of a service we are providing. This was evident in the New Zealand case study.

4.8 Monitoring, evaluating and reporting on change
In a ‘marketplace’ exercise, chaired by Beth Tanzman, Vermont and Peter Beznec CHD, Rene asked delegates to think about measures we can use to assess change from social participation in local health systems; what methods are used for participatory evaluation and strategic review; and how communities dialogue with services on such evidence. These three areas were put as questions on the wall. Delegates were asked to discuss and note their ideas on cards, to put them on the wall and to respond to others’ cards if they agreed, disagreed or queried them. Some added queries or disclaimers directly to the original cards. The cards under each question, recorded below, were then discussed in plenary, for what issues and conclusions they raised.

<table>
<thead>
<tr>
<th>What measures do we use to assess change?</th>
</tr>
</thead>
<tbody>
<tr>
<td>One set of cards under this question suggested specific measures, some contested:</td>
</tr>
<tr>
<td>• Happiness</td>
</tr>
<tr>
<td>• Change in participant self-confidence; Self-efficacy: how competent do participants feel?</td>
</tr>
<tr>
<td>• Change in public opinion, and impact on policy-maker or decision-maker views</td>
</tr>
<tr>
<td>• Number of connections/linkages (arising from convening partners to improve health)</td>
</tr>
<tr>
<td>• We can look at the experience of care from starting point to change</td>
</tr>
<tr>
<td>• Clinical measures (blood pressure, cholesterol, disease) and rates- this was debated with a comment added “What about quality of life? How do we measure this?” with a response “Use SF36 or SF12 quality of life scale”.</td>
</tr>
<tr>
<td>• As process – inclusion, dynamics, networks</td>
</tr>
<tr>
<td>• As outcomes – decisions, entry points in the policy process, changes in policies</td>
</tr>
<tr>
<td>Other cards also raised measures, but more generally:</td>
</tr>
<tr>
<td>• Goal attainment (were the person’s goals met)</td>
</tr>
<tr>
<td>• Local outcomes, locally defined: Participant reported experiences and outcomes; and Community feedback, process markers.</td>
</tr>
<tr>
<td>• Evidence from before and after surveys and photos</td>
</tr>
<tr>
<td>• Number of policy, system and environmental changes</td>
</tr>
<tr>
<td>• More people join the discussion and propose ideas, actions, issues</td>
</tr>
<tr>
<td>• Some quantitative, some qualitative but both towards or away from desired situation</td>
</tr>
<tr>
<td>• Subjective and objective. Participants, service ‘users’ and ‘providers’ perspectives;</td>
</tr>
<tr>
<td>• Move quickly from process to outcome/impact - How much are we doing? How well are we doing it? Is anyone better off?</td>
</tr>
<tr>
<td>Others however raised questions or cautions on the measurement of change</td>
</tr>
<tr>
<td>• How do we measure empowerment?</td>
</tr>
<tr>
<td>• Need to evaluate community participation not only program outcomes</td>
</tr>
<tr>
<td>• Can you use same standards in different settings? Don’t think so</td>
</tr>
<tr>
<td>• Is change in one direction? Who decides? Whose change?</td>
</tr>
<tr>
<td>• Unintended outcomes – good and bad (Who decides what is good and bad?)</td>
</tr>
<tr>
<td>• Depends on history and context</td>
</tr>
</tbody>
</table>
What methods for participatory evaluation and review?

One set of cards under this question suggested specific methods:

- Story-telling, case examples; most significant experiences
- Scorecards; Progress markers
- Social media; Citizen juries
- Network analysis – measuring strength and characteristics of organisation, and/or human relationships over time
- Realist evaluation; Formative methods; Theory of change

Other cards pointed to principles for the approaches:

- Agree on comparative benchmarks early on; It is the setting of goals that should be participatory – evaluation can be done by computer; It starts with participatory processes from the beginning; Participatory framing of questions; First, use participatory approaches to set targets, then evaluate!
- Community (‘user’) involvement in development of tools, collection of data, and interpretation, using qualitative methods as well as surveys
- Need to be built in from the outset as part of the community; Organise a community sing-along, and once people are tired of singing, talk health; Encourage a voice
- Ask community participants what they learned from being involved. What do they think they contribute? Were their voices heard?
- Participatory validation of findings

Some cards critiqued or cautioned about participatory evaluation and review:

- Often feels that evaluations are still ‘owned’ by organisations
- Community (health systems too!) get pissed off with constant evaluations (and surveys)
- If we spend all our time evaluating, will we be able to do any work? (Needs to be built in) (We need to recognise when we are asking too much of too few, and we need to resource and value better)
- Public health standards create expectation for community participation.
- Strategic review builds power; Connect to the means of power

What approaches to community dialogue on service data?

Here too one set of cards under this question suggested specific methods:

- PhotoVoice; Infographics
- Social reviews like Amazon or Yelp; user-driven
- Service data gathering could also include ideas about social support needed
- Comparative statistics as a starting point (but whose statistics?)
- Shared ownership of a results dashboard. Community decides what measures to prioritise, how to view those measures and translate them into action
- Book of complaints published (hard copy / online) and responded to (including in person)

Other cards pointed to principles for the approaches:

- Start with dialogue on what service data needs to be collected and analysed – what do communities want to know about their services?
- Allow input on which services receive funding (input requires education on issues first and asking the questions in ways people can understand)
- Community (user) feedback; Dialogue; Community involvement in findings
- Need to be accessible, relevant; Data analysed and responded to in a neutral space
- Bring different sectors to the table (be sure to have broad representation – need multiple tables), and facilitate their input to inform on the issue / solutions
- Treat all data as a testable hypothesis, not as a ‘fact’
- Demonstrate real value to dialogue, i.e. follow through with action

Again other cards raised cautions:

- There is a half-tacit assumption here that service data are a given
- Is there a real interest? What data are we talking about?

Following the exercise, delegates reflected on what had been written on the various cards, sometimes with strong debate on diverse views.
On the measures to assess change, the cards signal that process changes and changes in people’s perceptions and power are themselves important (and difficult to measure in a standardised way that is also accessible to diverse people), that what is assessed relate to what those involved in the process seek to achieve, in terms of both process and how conditions change, with a recognition that the processes are not unidirectional and may yield unexpected outcomes. It was noted the process of assessing change is very political; with power running through it. This means that there is no standardised approach to measurement of change and no simple answer on what measures can be used, as it depends on the context, the power dynamics, what the evidence is being used for and, most importantly, who decides on this.

In the discussion on methods for participatory evaluation and review of social participation in health, there was a caution on formal, external evaluation processes. This was not only due to the power issues noted in the previous discussion, but also as people are tired of being asked questions in processes they have no say over. There was a strong feeling that evaluation has been linked to funding in ways that disempower, divert energy and do not adequately understand the nature and timing of processes. External evaluations may not provide the important opportunity for those involved in processes to reflect on and review their work, building their power and knowledge in the process and building accountability of those involved to the wider community. On the cards and in the discussion this form of participatory reflection and review had more support, with participatory approaches for setting the purpose and goals and framing the questions and methods. The specific methods may be context dependent, whether scorecards and numbers, progress markers, or stories and narrative, and delegates noted that some triangulation of evidence from different sources and approaches can be useful. It could thus be useful to share information on approaches used to give people more information on the options to choose from depending on their local context. At the same time the question remained of how to engage with the evidence of outcomes called for by authorities or funders, given the reality of this demand in all settings.

In the final dialogue in the market place on approaches to dialogue between communities and services on their diverse evidence, it was noted that the approaches and measures need to be accessible, relevant and credible to both, and to build shared ownership and interpretation. In the discussion it was raised that it implies methods and respect for both lived experience and technical data as evidence; to triangulate evidence from different sources around shared criteria or principles for decision-making; and to not take data at face value or as fact or let it alone drive the way forward, recognising that what is collected and how it is understood is value-laden.

While some delegates raised the need for communities to be capacitated around the evidence that is gathered by services, others noted that people want ‘safe spaces’ where data is not used to define them. While the cards suggested various processes to address these challenges, delegates noted the need for transparency and openness to scrutiny and critique when services interact with communities on evidence to build trust in these processes.

5 Reflections on transferable learning and practice
This session was chaired by Vera Coelho CEBRAP and Alex Billioux, CMS/CMMI.

5.1 Synthesising the learning in Shaping health
Rene presented a synthesis of the learning across the diverse work in Shaping health and the principles of practice that emerge from the work. She noted that the principles are not intended as a prescriptive ‘toolkit’ for participation, nor a checklist to complete before initiating practice, but
rather a reflection on what works across contexts to support strategic thinking and foster participatory practice. Her presentation embedded short clips from videos from the international case studies. The draft report on the synthesis of the learning was provided as a hardcopy to delegates at the meeting and will be produced with revisions after the meeting so this report does not provide the detail presented in that document.

Rene briefly recapped the context for and understanding of participation informing the work, as outlined earlier, noting principle 1, that participation is both a means for health improvement and an end in itself based on values and rights, and that the social power involved in participation is claimed rather than granted, yielding stronger models than when organised primarily as a functional need of the health services.

Citing experiences from Varanassi, Zambia and Canada, with a video clip from Lusaka, she noted that the international case studies all initiate or sustain the work by building on community experience, with assets in a strong sense of community belonging, shared identity, history and values; a range of community health activists, including health literacy facilitators, local community leaders; community volunteers and teams; expert patients in peer to peer networks; elected CHWs that can act as health activists, linking with, complementing, supporting but not displacing other citizen leadership and processes that invest in and support citizen and collective leadership. The case studies highlight the role of voluntary community activism, but also the efforts by sites to recognise and provide benefit for this work, such as when the work provides pathways to employment. She captured this as the second principle: Community experience is a key entry point, and community activism and leadership are key drivers of participatory practice. She noted that this is consistent with Freirian participatory reflection and action approaches where ‘knowledge is built by systematising people’s experience, with communities directly involved in building learning from action.

There are many ways of doing this, including through the internet, with a number of the case studies using social media and communities co-designing their own websites to enable reach and inclusion beyond direct person to person approaches, providing a platform for narrating local experience and spaces where people can participate anonymously, where stigma and physical factors might otherwise discourage participation, and information to navigate and engage with services and resources.

She noted, citing experience in Vanuatu, Quito and Slovenia, the third principle arising from the work, that participatory processes and social power in health are more likely to flourish within community settings, such as schools, markets, workplaces, sports and traditional gatherings. In these settings the interactions are more likely to overcome power imbalances that inhibit communities in their interaction with service personnel, with processes centred on the community, rather than on the services. In Pomurje, Slovenia, for example, health promotion is embedded in schools, kindergartens, local producers, tourist sites, and restaurants, thus integrating health benefit in benefit to the local economy. A video clip from Kenya showed further how this has been key to addressing mental disorders in the community.

Rene highlighted, citing a quote from NPH New Zealand, that social participation promotes a more holistic vision of health, and is also more likely to be nurtured when health systems are organised around holistic, people-centred, population health and comprehensive primary health care approaches and when they work with other sectors on health, as for example is being promoted in Chile’s biopsychosocial service approach. Social participation is thus supported by and elicits more holistic models of health. International experience indicates that services can better prepare for this when they identify and employ health workers within communities; strengthen the orientation, capacities, readiness of health personnel and teams, and competencies to facilitate / respond to cultures, community roles and processes. They need to ensure and sustain management support and support mechanisms for shared planning and build shared indicators of success.
Rene highlighted the fifth principle highlighted in the work, that informal and formal spaces and processes both play key roles. The synergies and links between them enrich both. Formal spaces provide a means for joint decision making and for institutionalising participation, and she showed a video on how this is done in Brazil as an example. She noted, however, that informal spaces are more flexible, more inclusive, more able to use the processes, places and tools described in the report that are accessible to communities, especially to reach and involve groups often excluded from formal processes. They can build the collective power and confidence for formal interactions, as was demonstrated in a video clip on the work in Vanuatu. This makes the interaction between formal and informal mechanisms important. She noted for both that this is not just about the presence of the mechanisms, it also depends on whether the procedures and processes enable participation, to avoid bias against participation of particular groups, and making links with wider activities in the community.

As a seventh principle, she raised that sharing information and participatory processes to gather, analyse, discuss and use community evidence in planning are necessary (but not sufficient) for meaningful social participation. Sharing information is vital, and a video clip of young people in Yarnsafe New South Wales showed how information outreach is more effective when developed with the communities involved. She noted further that community evidence needs to be used in decision-making for more meaningful forms of participation, and that the case studies give various ways that this can be done, such as in Quito’s community market evaluation teams, and through participatory family and social mapping; community and online surveys, photojournalism and narratives and problems trees.

Experiences such as Youth Mental Health services in Gosford and community engagement in Scotland point to processes that need to take place for communities too have a meaningful role in decision–making, through elected and inclusive community representatives who are involved in community processes, feedback from communities; transparency on the procedures and principles that govern decision making, agreed with communities; and processes that are accessible to communities with measures to review step-wise progress, with short-term ‘wins’ to build confidence and decisions linked to resources, such as through certification, community grants, incentive funds and participatory budgeting. This raises the principle that accessible processes for co-determination link decisions to shared plans, actions and resources.

Rene noted that these features mean that deepening participation takes a consistency of presence, time and capacities, to let models evolve within community processes, and, that strategic individuals and institutions are important facilitators of participatory practice. A video clip of Social Bite flagged the many roles that these facilitators’ play, as organisers, catalysts, enablers and supporters of the processes. She pointed to the common features of these institutions from the case studies.

Finally, she gave examples from across the case studies to show how learning from action and evaluation tracks diverse forms of progress to support strategic review. She noted that processes building power and participation are often not evaluated, and that there is caution on what is evaluated and how and what can be transferrable. At the same time reviewing progress
builds confidence and learning and insights that can be shared. The experiences suggest that methods that test theories of change and enable participatory review, as done in Scotland using the outcome star or Zambia using progress markers.

In conclusion she summarised the 10 principles and asked for feedback and whether key features were missed that need to be captured,

In the discussion that followed, there was interest that so many sites are using participatory budgeting. Rene noted that further information can be found in a website that tracks this.

There was some discussion on who or what initiates the process of mobilisation. Ranjita noted that in Varanasi, women were initially mobilised to engage within formal systems of governance, and only later translated this into health interventions. It was suggested that it might arise from people getting angry about the status quo, but also noted that it is not always a bottom-up process. Peter raised that in Slovenia the process was enabled and initiated by the government. While government can provide an enabling environment, this was also seen to happen because of bottom-up mobilisation and claims on governments led by communities.

Jo highlighted that there is a need to find committed staff that are willing to do the work. They need money to survive so funding is vital to sustain their role. Others asked how we work with and relate to a health system that is focused on technical fixes to problems, with delegates suggesting that there needs to be consistent advocacy on and work supporting community roles so that progress can be made when windows of opportunity open.

While the synthesis was felt to generally reflect the experiences shared, Don and Sarah raised that ‘rights’ language sometimes does not capture indigenous understandings of health, where participation is intrinsic to their identity, and Patricia proposed that equity and social justice needed to also be profiled and power more explicitly referred to in the principles. There was a concern that we communicate with people that do not think like ourselves.

Rene thanked delegates for their feedback. She noted that the synthesis paper explicitly acts as a resource for the community of people involved with social participation in health, from which other communications materials can be developed, including for those that have different perceptions of the issue. Different audiences demand different ways of communicating the findings, and may have deeper interest in specific elements rather than all areas discussed in the paper. The final day will give more focus to this. Finally she asked US and international site leads if they would accept being named as co-authors in the paper and this was agreed to.

5.2 Reflections from the US sites on managing change

Presentations and a panel involving delegates from the 5 US sites, moderated by Sarah Simpson, consultant to TARSC, provided an opportunity to hear about how these sites were facilitating and supporting the communities they were engaging with in their sites, and changes they have initiated over the past year, in part informed by the exchanges and practices shared in Shaping health.

Patty Gerrity and John Kirby Jr, from 11th Street Family Health Services in Philadelphia described their longstanding community partnerships. The
Center’s Advisory Committee, comprised mostly of community and center members, provides input and direction on center services, patient care strategies; wellness promoting activities, such as healthy eating, mind/body practice and exercise; and other issues that are important to its members and neighborhood. Patty recounted that after the 2016 meeting she shared information on the work and case studies with community leaders and members. The New Zealand case study and the community- health service relations particularly resonated with the marginalised African-American community at 11th St. A small team of staff and community members deepened their knowledge of community leadership with an in-depth Institute for Healthcare Improvement (IHI) course focused of “Leadership and Organizing for Change”. In one project on Adverse Childhood Experiences (ACE), public health messages and ‘stories of self’ were developed by community members, reflecting messages they felt to be important.

Vanessa Ivie, PIH Health, Whittier, California highlighted that the tax-exempt status of PIH Health’s hospitals means they are obliged to give back to communities and must produce a three yearly community needs assessment report and an annual community benefit report. The latest assessment included broader social determinants of health as priority areas for the first time, and PIH Health holds events to sensitisise the public on the findings. PIH Health draws works with a Community Benefit Oversight Committee; Community Health Improvement Plan strategies; and with existing/emerging community collaboratives to facilitate participation, broaden representation in decision-making and engagement from underrepresented groups and to support and sustain community-led initiatives. The Health Action Lab coalition-building project was launched in 2017, with 30 actively engaged organisations that promote cross-sectoral collaboration on strategies that relate to youth, food insecurity, mental health and substance use, and chronic disease. The Health Action Lab project provides a way for all involved to engage with and discuss what was useful from the different case studies. PIH Health particularly learned from community education and empowerment processes in Shaping health related to mental health in formal and informal settings; to the involvement of CHWs; on how they used photovoice and health literacy (as in Zambia), youth involvement from Australia, community team building from Ecuador, setting up spaces for participation as Bridge for health has done in Canada and building citizen leaders in India. PIH Health is now applying these approaches with their communities, working with local promotoras (local CHWs), assessing environmental health, forming community teams to develop/implement plans and to find solutions for health needs. They have, for example, actively involved families in advocacy training, using photovoice. The use by WSB in Vanuatu of creative media to address health issues has also inspired PIH Health to explore these approaches to overcome the barriers people face in reporting their health problems.

Ruth Dudding, Athens City-Council Health Department (ACCHD), Southern Ohio noted that ACCDH has historically used social participation more as a means than an end, and often as an isolated activity. They lacked a formal infrastructure to engage communities, there was a low level of civic engagement, high levels of individualism and few public forums and public spaces for communities to interact. In the past year, ACCDH has learnt from and drawn on many useful practices from the international case studies. The team observed that laws and policies that create expectations for social participation are important; with processes like participatory budgeting; community competitions - as in the Ecuador case study – seen to be useful entry points into participation; and CHWs to be valuable intermediaries between the health system and communities. ACCDH has thus introduced a Community Improvement Challenge involving seven
multi-sector teams in a contest to address a specific health need. These teams engaged in participatory processes such as listening sessions and participatory budgeting, and share success stories with each other. They were surprised to find that rural organisations can be better positioned for social participation; and that communities get a lot done locally even without support from formal state and national structures. The Health Department now hopes to implement a community-based platform for information exchange; to establish CHWs; and to use its departmental power to advocate for the needs of communities.

Beth Tanzman, Vermont Blueprint for Health, talked about how they are dealing with the ongoing opioid crisis in the United States. The call for action on the crisis emerged from citizens and civic leaders, who demanded that the health system address the massive treatment gap and that there be a better support structure for people with opioid addiction. These demands for change led to the convening of a small task group, and the narrative from a person with addiction to the task force, on the accessibility of heroin and the inaccessibility of support led to a ‘tectonic plate shift’ in thinking, with discussion on and policy commitment to a rapid establishment of decentralised services to treat addiction and provide care. Blueprint for Health is yet to develop an approach to include affected people in planning services, including families of addicts and people who are involved in illegal activities, in part due to the stigma they face and hope to draw on the learning from Shaping Health on this, such as by creating and using informal spaces to involve addicts and their families.

Michelle Melendez from the EleValle collaboration in New Mexico that includes Centro Savila engage communities through CHWs drawn from and based in the community, linking health to other community activities like children’s football (soccer) training. They hold meetings in a park as people fearing deportation are often scared to attend more formal service providers. Various projects engage the local community, such as community gardening, communal meals, planting trees, hip-hop groups and art groups. Health services advocate on behalf of communities who cannot engage in protests, such as non-citizens. Michelle stressed that racism is central to these conversations in the United States, as so many of the issues and barriers communities face result from it. She indicated that they had drawn learning from the international case studies around how to co-create and co-design spaces and services. She suggested that with even local health services external to communities, for health to come from communities, clinics cannot be the driver of change.

In the discussions that followed delegates raised that there is need for processes to enable communities to recognise their power, while also noting that marginalised and voiceless people face barriers to inclusion, and that systemic factors such as racism have made people intentionally powerless. These conditions have led to distrust on the part of communities, and within service personnel, that processes need to negotiate and overcome, through different actors and levels of power, including local governments, community volunteers, activists and CHWs. Delegates identified the need to address what keeps CHWs and community activists engaged, whether through pay or other incentives, given the role they play. The experience of participatory budgeting was seen to be of interest in the US, given the power that comes from resources, but with concern on how to enlarge the currently small budget shares allocated to it.
Rene indicated that there was time the following day for follow up discussions on issues and questions raised from the meeting so far and for more direct interactions across the sites to follow up on some of the specific questions and interests raised. She summarised issues from the session that appear to remain as questions:

- How to ensure that systems recognise and value participation and do not adopt tokenist forms? How should those with power be engaged and included?
- How do people sustain practices so they survive through harsh periods? How to keep informal spaces alive and invigorated?
- What support can be given to volunteers, and what role do payments play?
- How to spread and amplify from local work to wider scale?
- What role do financial incentives play in this, and what financial incentives can be put in place to encourage holistic approaches?

Delegates proposed three round table discussions for the informal meetings the following day to explore this further together with one on one interactions: On addressing the power imbalances in the processes; on bringing other sectors into the conversation on health; and on spreading and amplifying practice.

6 The Aberdeen site visit

6.1 The site visit

Flora Douglas, University of Aberdeen, introduced the site visit involving the institutions and areas covered in the Scotland case study in Aberdeen. A bus tour of the city was guided by Chris Littlejohn NHS Grampian, Dave Kilgour previously of Aberdeen City Council, and Louise Nind of Social Bite. The tour took delegates through both wealthier and more deprived areas of the city, past Social Bite, and to the Community Food Initiatives North East (CFINE). In three groups delegates were shown around CFINE processes and operations by CFINE personnel - Dave Simmer, Fiona Rae and Graeme Robbie - including: its social enterprise activities selling fresh fruit and vegetables, with storage space for the fresh produce, and large refrigerators funded by the Scottish Government.

Parked in one area of the warehouse space was CFINE’s newest acquisition, the ‘Tuk In’ tuk-tuk van, which sells fresh bread, soup, and fruit pots at lunchtime to businesses across Aberdeen, to support affordable meals for those in food poverty. The idea for the three-wheeled van was conceptualised by university students who won a funding competition for it.

Delegates were shown the storage of food for FareShare Grampian, which distributes in-date, canned, frozen and fresh produce through food banks for people in food poverty, directly and through various charities and community organisations. The multiple processes involve management of people, logistics, volunteers, employees and finances and ensuring food hygiene and safety. Employees also help low income families with financial advice and with navigating welfare systems. Office space is rented out to
various organisations such as Sunrise, a charity that gives loss and bereavement support to children and young people. A newly constructed kitchen space, ‘Cook at the Nook’, is used to offer free cooking lessons and support to low income families, including on food waste and healthy eating; subsidised by cooking classes for paying customers like corporate teams. It was an enlightening visit, with the commitment of those volunteering and working at CFINE inspiring to delegates. It also brought the acute poverty and inequality experienced by many in Aberdeen into focus.

6.2 Exchanges on the work in Aberdeen

Following the site visit, delegates relocated to the University of Aberdeen’s Craig library building for further exchange in round-tables on the work of NHS Grampian, Aberdeen City Council, SocialBite, and CFINE.

Chris Littlejohn, Deputy Director of Public Health, NHS Grampian, presented the changing legal frameworks in Scotland that have integrated health and social care with a pooled budget to deliver against shared national outcomes. Underpinning these changes is a stated commitment to a publicly owned health service, delivered for, and owned by, the people, and therefore to be shaped and influenced by citizen participation. This principle has been further widened out to the entire public sector by the Scottish Government’s Community Empowerment Act, requiring all public authorities to work in partnership against locally shared outcomes. The challenge being taken up by public servants now is in genuinely implementing this policy. Chris noted that the work around food insecurity in Aberdeen provided an excellent case study of both the potential and the challenges in doing this. In the discussion it was observed that the civic engagement sparked by the independence referendum in 2014 helped to start widespread conversations about the future of Scotland. The community empowerment act has strengthened local determination within and across public services to embed co-production in routine practice, involving citizens in decision-making, design and delivery of services.

Louise Nind, SocialBite, outlined the experiences of the social enterprise and what has been successful. As a brand SocialBite is carefully managed and has a high social and mainstream media presence. This has helped bring customers, raising revenue that is fed back into developing the enterprise and providing evening meals. SocialBite has begun a 12-week management training programme to support those in its workforce who have
been homeless progress to managerial roles. Beyond the social suppers and paying forward meals described in the case study, they are now organising a pop-up shop, an idea proposed by one homeless person to help those recently moving into homes with acquiring kitchen and other utensils. The pop-up shop collects incomplete sets of plates and other below threshold goods and provides them for free. Louise noted that SocialBite is in a good position as it has no statutory responsibilities and can therefore identify and fill gaps flexibly and quickly. In the roundtable discussion, delegates raised that being a commercial business generates income and that the flexibility and informality has enabled innovation. Louise noted that it takes time and trial to figure out what works: for example, women-only evening meals were poorly attended, but when they became mixed events women started attending.

**Dave Kilgour**, recently retired from Aberdeen City Council, outlined how participation is embedded in the public sector in Scotland. In 2011, the Christie Commission identified that different sectors were operating in silos and recommended a cross-sectoral move from crisis management to prevention. The Scottish government implemented a requirement for the public sector to fulfil a social economic duty, while the Community Empowerment Act requires locality plans to provide a holistic overview of community needs (within groups of between 500 and 1000 individuals), and to involve community input and participation. This is not starting with a blank sheet as there are a range of ways people already engage with local services. For example, participatory budgeting has been in place for about 10 years in Scotland and has proved to be a way to engage a wider range of people in health and social issues. In the discussion delegates discussed issues in implementing participatory budgeting, noting that people need to be well informed for it work effectively. Digital media was felt to be useful, but the barriers for some people need to be addressed. It was also felt that strategic ways are needed to engage the private sector. It was felt that local planning leads to engagement on smaller issues, but may leave people out of discussions on bigger issues; that there is need for approaches that break siloes across sectors, such as through shared resources; that elected representatives need to be capacitated for their roles and that communities need training to engage in formal procedures. The *Planning For Real* concept, where people build maps of places and identify where there is a need for regeneration of spaces or where infrastructure gaps exist was raised as an interesting concept.

**Dave Simmer**, CFINE, emphasised that culturally and in terms of mind-sets, there has been a shift towards participation and empowerment in Scotland. He too noted that there is already learning and experience of doing participatory work, and that the concepts are not new, but that there is a need to harness this learning better. In a context where inequality and poverty is on the rise, and where the welfare state is being gutted in a way not even seen in the 1980s under the Thatcher government, he asserted that community development is crucial as it involves those experiencing poverty and marginalisation as equals and contributors in key processes. Delegates raised particular areas of interest and learning from CFINE’s work, including: the range of actors involved, including local buyers, local government, local universities and students, oil companies and other local businesses and communities affected by food poverty. The role of volunteers was noted, recognising the need for them to benefit while observing the benefit they derive through their inclusion in social networks and links to other resources through the experience of volunteering.

Flora summarised the points raised, and expressed her appreciation and that of the meeting organisers and delegates for the time, support and exchanges from the colleagues from NHS,
CFINE, ACC and Social Bite that had given a practical lens on both the aspirations in and practical challenges in implementing policy commitments to social participation.

On the following morning, in a reflection on the site visit and presentations, delegates noted how much they gained in seeing the realities and exchanging with those involved, beyond what was documented in the case study. The link CFINE makes between information gathered in both formal and informal processes was interesting in how it gives a better picture of issues facing communities. The visit was felt to add significant value to the exchanges: it helped to give more insight on what had catalysed the policy process towards increased participation in Scotland, and how this might translate to the US and to learn about stages of progress and setbacks. People noted they draw strength from realising that others struggle with similar issues in various contexts and from seeing the different ways social progress can be made locally.

7 Follow up actions and communication
This session, chaired by Vanessa Ivie, PIH Health and Maryam Bigdeli, WHO involved round tables on
a. follow-up actions in the individual US sites, involving the site leads
b. follow up actions at other levels in the USA, involving other US delegates
c. follow-up actions internationally, involving international delegates
d. what should be in the key messages / principles, involving a mix of delegates.

7.1 Follow up actions within the local sites in the USA
The US site leads discussed the follow up actions they will take or would like to take in their work, following the meeting.

Patty and John observed that 11th Street is increasingly moving towards a health council approach that involves the community in decisions and supports participatory action by the community served. This is already underway, taking advantage of windows of opportunity, and they intend to enhance this. They will undertake an evaluation with the community members to find out whether their participation has been worth it for them and whether their goals have been achieved, to re-invigorate and sustain the processes underway. This will inform future work.

For Athens City Council Health Department, Ruth indicated that community engagement is a requirement for all health departments in Ohio, but there is still a lack of knowledge as to what that means. She will be presenting at a state-wide meeting on ways of bringing communities into decision-making and action. The Community Improvement Challenge teams are in the middle of their process, and the department is now working on making them sustainable. Work is also being undertaken to understand why Athens is the poorest county in Ohio. Focus groups are being convened on the issue, in a multi-sector, multi-stakeholder process. The health department also plans to continue to strengthen the development and role of CHWs.

Michelle said that for Centro Savila, participating in Shaping health has helped re-affirm the values that they and EleValle have and their work in engaging community organisations and being led by community voice. In the context of limited space for community organising, Michelle is taking home lessons on EleValle’s own role in providing that space and in avoiding public health ‘speak’ that communities do not relate to. She quoted the phrase used by many different groups shown in the adjacent figure, which in Spanish is "quisieron enterrarnos, pero se les olvido que somos semillas". She said that they will listen to the community to share further steps, work on local level leadership development to address upstream determinants of poverty, and build leadership in the community.

PIH Health will keep pushing to align prioritisation of participatory work, given their role as a convener and co-ordinator of coalitions. Vanessa indicated that they will try to bring representatives of affected communities into the coalitions, such as homeless people and food bank users, and identify leaders within communities and coalitions. They will also develop and
build on the use of promotoras (CHWs); and promote advocacy training in the community. Vanessa suggested that this is best done through the existing health collaboratives, as this will be better accepted by the hospital system.

Beth suggested that the parameters and systems within which Vermont Blueprint for Health operate in may be not flexible and forward-thinking enough to build genuine leadership among affected communities. The next steps may therefore be to help identify organisations that can engage in leadership development and are not so constrained by institutional parameters, and to be ready when policy windows and opportunities do present themselves.

Across the sites, there is generally an intention for discussion on the follow up to involve the community in planning follow up, or bring on board structures and organisations who can do this (outside the clinical services), to discuss the positive and negative features and effects from the community lens of what has been done so far, to build on or develop mechanisms for cross sectoral work involving communities that tackle specific prioritised issues, to build capacities for community leadership and to support the work of CHWs/promotoras.

In the exchanges on these follow up plans, delegates raised the issue of what resources and power needs to be availed for communities to be engaged. For example, in Vermont, there is no budget to support their inclusion, no decisions for them to make, so community groups can lose steam. Is it okay to convene people and take up their time if the avenues for them to affect change are not clear? This sparked lively discussion. It was suggested that rather than ‘giving’ communities power, we take it from the perspective that we need their power. In a Freirean approach people are given the tools and space to understand their own position and ask others what they need. This means that there is latent power in communities and that our roles are as facilitators to help people find this. This can come in different ways, telling ones story, giving people an opportunity to engage, and empowering people to find their own solutions. Others noted that it is important to be candid and transparent about where you are in the process: ‘I do not know if I can do anything about this, but I now know what you are feeling and experiencing and will take this forward’.

7.2 Follow up actions within other levels of the USA

The second discussion in this session was around actions to be taken at other levels in the USA, beyond the individual sites. It was observed that many current approaches can be tokenist, but that it is important to build from what exists, look at what is working well and support it, and what is not and improve it. There was interest in following up on participatory budgeting, on community representation on boards and councils, and on thinking about stories of change that describe process and outcomes. In the discussion it was noted that this means looking at how models, such as the Accountable Health Community, better support and incentivise community actions.

Participatory budgeting was viewed as one fruitful way of taking the learning from Shaping health back to the US. It would be fruitful to investigate sites that are using participatory budgeting and what the impact has been. Money saved from Medicaid Shared Savings plans could potentially be used for participatory budgeting. The amount of money saved through these is public information. However, finding the money for participatory budgeting in this way could risk it becoming project-based and unsustainable, rather than a mandated and consistent budget share. The view was that this is not just about a redistribution of money, but also a redistribution of power to avoid the process being tokenistic. The group felt that representation is not just a matter of numbers on boards but needs processes and structures to change to be more accessible to community members at the table. Delegates observed that this calls for transparency to gain trust and support and training to encourage those that engage.

The group proposed capturing and disseminating stories within the USA in ways that show how things were done and how processes have generated shared savings, noting that there is value in both process and outcomes. When telling such stories it is important to pay attention to particular population groups, such as people of colour, those with English as second language.
and indigenous communities to understand and act on the inequities. *One way of doing this was seen to be to continue to do case study work as was done in Shaping health to provide the stories of change that can empower communities and health professionals.*

7.3 **Follow up action internationally**

The discussion on follow up actions at international level began with a discussion of inspiration drawn from *Shaping health*. This included the recognition of diversity across communities, the role of the Community Empowerment Act in Scotland, the way participation takes place in practice and the way health councils interact with communities. It was agreed that it was important to stay grounded and avoid top-down processes in the follow up and to encourage processes that spread learning horizontally. It was suggested that key *Shaping health* documents be translated, into Spanish and if feasible Portuguese. *There were areas identified that would be useful to continue discussion on, such as the marketplace discussions on evaluation, the processes for community needs assessment, and also on how social power is strengthened in more dangerous environments and contested spaces. As a community of practice members within the group may take forward collaborative projects as subgroups, but it will be useful to share with the broader group and bring more people on board. This horizontal bottom up exchange could work by continuing to connect, working on specific themes and connecting face to face around specific events (such as the next Health System Global conference) and making smarter use of the platform to share information and analysis.*

7.4 **Key messages**

One group reviewed the summary statement of principles presented in the synthesis report tabled by Rene (presented earlier). It was felt that it should speak to both our own community and those not familiar with but interested in the ideas and work, understanding that different ways and forms of communication the information may be needed for wider groups. The group agreed with the broad content of the principles and messages, and suggested changes to wordings with these audiences in mind, especially to the bold statements in each of the principles. The group also suggested that how these principles related to key messages be clarified. The proposals made were for:

- Principle 1, to include identity, humanity, so that beyond being a right participation is integral to being human
- Principle 2, to emphasise that it is the lived experience and knowledge of individuals and communities that drives participatory practice.
- Principle 3, the word ‘thrive’ caused debate due to being seen to have different meanings, as did the focus on services going into community settings, rather than making it more directly the case that participation needs to take place in community settings to flourish.
- Principle 4, to make clear that holistic models of health actively support participation.
- Principle 5, to make clear that informal spaces and processes are of equal importance for participation as formal spaces and processes’ and clarify what is meant by informal’ spaces.
- Principle 7, to emphasise that community evidence is used for action, and the link to principle 8 that action needs to happen for participation to be meaningful, sustained and accountable’.
- Principle 9: to be worded as ‘participation takes time’.

Principle 6 and 10 were seen as not needing any input.

In the plenary discussion it was noted that list of principles should not be read as a list to be followed in a sequential manner, as some may need to be engaged with at different times and in different contexts. Rene noted if delegates had further comment they could email it in the coming week so that it can be integrated in the revisions to be made to the document arising from the meeting. She also noted that the document was a resource for communications, and that other forms of materials were needed, with other wordings, to speak to particular audiences. It was also suggested as useful, based on the work in Shaping health, to review and update the original conceptual framework.
The session chairs concluded by summing up their understanding of the key points across the four discussions on follow up: To stay grounded, make bold moves, aim for horizontal connections, keep looking at root causes and identify and facilitate the growth of power in those that have the least voice.

8. Communicating the learning
In a session chaired by Don Matheson and Michelle Melendez, Rene introduced the objectives of the communications strategy for the project, tabling a supporting brief. This was agreed in 2016 as:

a. Internally: To support the community of practice involved in the project, facilitating exchanges to inform/catalyse/inspire/strengthen practice.

b. Externally: To inform decision-makers and debates on meaningful forms of social power and participation in health and how to enhance it; sharing information and insights from the work; informing and reframing debates; and building support for practice.

The goal is to inform action and fortify, amplify and reframe the debate on co-determination, to move it from a ‘tokenistic’ and inconsistent pursuit to a more consistent, meaningful integration of social voice, power, participation and decision-making in health.

For this the 2016 meeting identified three key targets/audiences:

1. The community of practice working in local health systems in Shaping health
2. RWJF decision-makers and programme leads
3. Amplifiers who can spread the learning and reach or influence people who influence or make decisions or support practice that uses the learning

Identifying targets for communication in the 2016 meeting

The 2016 meeting proposed specific communications outputs for these target audiences, including powerpoint presentations, bullet-pointed summaries, brief videos; blogs, social media, FAQs, short briefs / infograms for communities; policy briefs on effective approaches from the international work for officials, and videos, fast-fact one-pagers, re-prints of articles, team biographies, media outreach, speech points, case stories, and ‘elevator pitches’ for top management levels. It was suggested in 2016 that in addition to the case study summaries and synthesis report, as a resource TARSC could prepare a generic powerpoint, on the learning that could be modified for local input (as prepared for the meeting), generic social media content and a brief on guiding principles of authentic social participation.

Following the introduction, delegates divided into two groups, one on follow up communications in the USA and one discussing communication of the work internationally.
8.1 Follow up communication in the USA

The discussion on follow-up communications in the USA was moderated by Susan Mende, and involved Jemma Weymouth from Burness on Skype. It covered the formulation of key messages, and ways of delivering them.

On the formulating key messages it was raised that:

- The language in communications materials in the US needs to be aligned to the US context and terminology.
- Having the deeper case study reports is useful. For certain audiences more concise and direct messaging needs to be used.
- The three key messages in ‘Communicating the learning: Brief’ tabled by TARSC could be more useful for US communications than the full set of ten principles, especially key message 1 which resonates with the ‘nothing about us without us’ concept that already has traction in the US. The last paragraph on Page 4 of the ‘Communicating the learning’ brief would resonate with CEOs and management, health commissioners and state officials, especially around notions of ‘possibility’, ‘opportunity’, and ‘cost-saving’.
- The framing of healthcare and the health system as ‘belonging to us’ and being made up of ‘our resources’ as applied in Scotland could be useful in the US context. As a counter-point, however, it was also noted that many already view the healthcare system as ‘belonging to them’ but cannot see how they have the power to affect that system. The international cases provide useful evidence in this case of how that community empowerment can be effected.
- There was uncertainty over using the language of rights and duties, in case there be some impression of blame being placed on disempowered people.
- In telling stories and formulating key messages, attention needs to be paid to particular population sub-groups, such as people of colour and indigenous people.

In terms of the delivery of those messages, several suggestions were raised:

- To help with the delivery of key messages, specific products may be helpful: eg videos, one-pagers, slides, vignettes, individual stories, evidence sheets. The next points were on their form and delivery.
- Know your audience. What does the CEO want to hear? What does the elected official care about? What does the community care about?
- When speaking to public officials, make their job easier for them so that they engage; using one-pagers with evidence and an explanation of what you expect them to do is useful. Furthermore, find different ways of holding them accountable, e.g. media coverage when promises are not met.
- Convince the community that getting involved can make a difference. Building trust over longer periods of time means that communities trust providers to take participation forward.
- Use informal spaces to approach people that do not, or would not, engage in formal spaces. But be aware that some people do not want to engage and/or view certain spaces as ‘safe’.
- People need to ‘feel something’ to engage. Videos have been really effective in this regard, as seen when meeting delegates broke into applause at the ‘Yarnspace’ music video.
- A note of caution was raised as well: there is a tendency with this messaging to fall into the trap of assuming that we know what the community wants, we should remember to continue going into the community and ask what they want. Equally, it’s important to also remember that we are part of the community as well. Similarly, think about how we, ourselves, like to have information conferred.

The group summarised the key messages they would be taking back to the US with them:

1. There is power and resources in the community that you might not know exist.
2. Participatory budgeting is a useful tool.
3. Policies that incentivise participation get results.
It was however noted that policy-makers and CEOs need to be prepared to hear the outcomes of participation. How do you get them to buy in? How do you hold them accountable when they do not take part? It was also seen to be important not to forget the systemic reasons that inequities exist and that communications and work also seek to alter these.

8.2 Follow up communication internationally
The group discussing communications at the international level worked in a series of buzz groups on key questions, facilitated by Rene. Delegates identified a wide group of people to reach out to in disseminating key messages from the work:

a. Like minded individuals and organisations, such as the delegates present.
b. Individuals and organisations who are receptive but not aware of the ideas and experiences in Shaping health, described as the ‘nodding group’ and as fertile ground to plant ideas.
c. Those who do not care about participation, but whom we need to engage and communicate with.
d. Those who actively oppose this work.

Delegates suggested that materials and processes that can be used to reach these groups include:

a. The numerous case study reports as a substantial body of evidence.
b. Translation of the summaries and key text into Spanish and Portuguese
c. Videos and visuals on the key findings and messages
d. Presentation of this work through delegates own networks, and in other forums.

More than the specific products, it was noted that dialogue and face to face meetings were important, and that there should be a consistency of dialogue and ongoing engagement with key audiences.

The group also discussed the future use of the web platform.

a. It was felt that the interaction in web platform around particular themes in the Forum has been useful, but has also faced challenges. In part this was because many people had not met, suggesting that it may be easier now that people know each other better. There were also some difficulties with logging in, with content not being saved when time outs take place and with making entries. It was also suggested that the platform be opened to new people.
b. It was seen to be important for the future of the platform to be clear about the purpose of its continued use. For example could it be usefully used to address unanswered questions from the meeting? This could be done setting a specific question and timing and place for the discussions.
c. Could it be used to add or share (further) stories of participation? While Rene noted that TARSC would sustain the site in the medium-term, it was noted that updating it as a repository could demand funding for time to do this. It was suggested that graduate students could be engaged for these processes or to prepare social media blogs.
d. One suggestion was to publish a story every two months related to one of the case studies through the website. This would not require a huge amount of work but would help get the Shaping health message to a wider audience. These stories could be linked to videos and tied to the principles of the project.
e. It was also agreed that a key next phase is to have an outward-facing public part in the Shaping health site.
9. Next steps and closing
The follow up actions proposed across the various sessions of the meeting included:

- Different planned actions specific to each of the 5 US sites, and generally
  - involving the community in planning follow up, directly or through partner organisations,
  - strengthening cross sectoral work, building community leadership and CHW/promotora roles.
  - Developing media (videos, one-pagers, slides, vignettes, individual stories, evidence sheets) using *Shaping health* work, using a language/terms and messages more aligned to the US context and audiences;
- At national level in the USA, follow up of participatory budgeting, support for community representation on boards/councils and developing stories of change.
- Internationally and for the Shaping health community,
  - Translating Shaping health texts, revising the synthesis and conceptual framework (TARSC)
  - Setting up a public Shaping health web page, with case study stories linked to the principles (TARSC).
  - Collaborative work and web platform discussions on follow up issues: A range of these were raised including following up on the discussion of participatory evaluation relevant to work on social participation, on implementing community needs assessment, on social power in contested spaces; on sustaining community in harsh periods and avoiding tokenistic participation; on amplifying work from local to wider scale, and on financial and other incentives for volunteers and for holistic approaches.
  - Communicating findings and widening the community of practice through sharing the information in our own networks and in face-to-face meetings (such as the next Health System Global conference)

There was a desire to keep the connecting in the Shaping health community of practice and to keep the conversations going! In a participatory exercise at the end, throwing a ball of string between us and sharing what we heard or learnt from each other, we could see visually the networks we have created between us that we wanted to sustain.

*I hold the thread at my end and marvel at the network we have created. Que broten las semillas (let the seeds sprout)*

Michelle Melendez.

Flora gave a beautiful rendition of ‘Freedom Came Ae Ye’, a song written by Hamish Henderson, the Scottish poet, songwriter, and intellectual in 1960. It is written in the Scots Language and describes a wind of change blowing through Scotland and the world at large, sweeping away exploitation and imperialism. It renounces the tradition of the Scottish soldier both as imperial cannon-fodder and colonial oppressor, and ends with a vision of a future global society which is multiracial and just. The English translation is overleaf, with the website for the original version.
It's a rough wind in the clear day's dawning
Blows the clouds head-over-heels across the bay
But there's more than a rough wind blowing
Through the Great Glen of the world today
It's a thought that would make our rodents,
All those rogues who strut and swagger,
Take the road and seek other pastures
To carry out their wicked schemes

No more will our fine young men
March to war at the behest of jingoists and imperialists
Nor will young children from mining communities and rural hamlets
Mourn the ships sailing off down the River Clyde
Broken families in lands we've helped to oppress
Will never again have reason to curse the sound of advancing Scots
Black and white, united in friendship and marriage,
Will make the slums of the employers bare

So come all ye who love freedom
Pay no attention to the prophets of doom
In your house all the children of Adam
Will be welcomed with food, drink and clean bright accommodation
When MacLean returns to his people
All the roses and cherry trees will blossom
And the black guy from Nyanga
Will break the capitalist stranglehold on everyone's life

http://unionsong.cm/u597.html

In the closing Rene thanked the all those who had played such valuable roles in the work, the US site members, case study leads and sites, the meeting delegates, the University of Aberdeen and Scottish hosts, Sarah, Andreas, Deena and others working with her at TARSC, and Susan, whose vision and interest gave support to the project. She and the delegates thanked also the staff at the hotel for their hospitality. Rene promised that TARSC would not ‘drop the ball’ in sustaining the connections and exchanges. Finally Susan Mende thanked all delegates for their thoughtful contributions, and the Scottish hosts for their hospitality. She expressed her appreciation to TARSC and all involved for all the work in the project, to all for the learning and insights shared in a rich three days and formally closed the meeting.
**Appendix 1: Programme**

**Thursday 19 October**

<table>
<thead>
<tr>
<th>TIME</th>
<th>SESSION TITLE</th>
<th>Presenter, facilitator</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.30-9.15</td>
<td><strong>SESSION 1: OPENING, OBJECTIVES AND INTRODUCTIONS</strong> Co-Chairs: S Mende RWJF, L D’Ambruoso U Aberdeen</td>
<td>Susan Mende RWJF, Pamela Abbott U Aberdeen, Delegates</td>
</tr>
<tr>
<td></td>
<td>Opening</td>
<td>R Loewenson, TARSC</td>
</tr>
<tr>
<td></td>
<td>Introductions</td>
<td>Alexander Billioux, CMI/CMMS</td>
</tr>
<tr>
<td></td>
<td>Overview, objectives and programme</td>
<td></td>
</tr>
<tr>
<td>9.30-10.45</td>
<td><strong>SESSION 2: MOTIVATIONS AND FRAMEWORKS FOR ADVANCING SOCIAL PARTICIPATION IN HEALTH</strong> Co-Chairs: S Mende RWJF, L D’Ambruoso U Aberdeen</td>
<td>R Loewenson, TARSC</td>
</tr>
<tr>
<td></td>
<td>Framing social participation and motivations for it.</td>
<td>Alexander Billioux, CMI/CMMS</td>
</tr>
<tr>
<td></td>
<td>Accountable health communities: Building clinical-community service partnerships to address health and related social needs at the individual and community level</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Discussion</td>
<td></td>
</tr>
<tr>
<td>10.45-11.15</td>
<td>TEA/ COFFEE</td>
<td></td>
</tr>
<tr>
<td>11.15-13.00</td>
<td><strong>SESSION 3a: EXCHANGES BETWEEN INTERNATIONAL AND US PRACTICE : Round 1: Organising social participation in local health systems Co-chairs: P Gerrity 11th St Family health service, R Mohanty, India</strong></td>
<td>R Loewenson, TARSC</td>
</tr>
<tr>
<td></td>
<td>Introduction and set up of round tables</td>
<td>Country site leads/focal points, US sites, delegates.</td>
</tr>
<tr>
<td></td>
<td>Round table discussions</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>ROUND TABLE 1</strong>: Identifying, engaging and supporting community actors/ activists</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Zambia, Vanuatu, Scotland, Australia + US sites</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>ROUND TABLE 2</strong>: Working in and taking health services into community settings</td>
<td></td>
</tr>
<tr>
<td></td>
<td>New Zealand, Slovenia, Ecuador, Kenya + US sites</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>ROUND TABLE 3</strong>: Using/ setting up formal and informal mechanisms and their interaction</td>
<td></td>
</tr>
<tr>
<td></td>
<td>India, Brazil, Chile, Canada + US sites</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5-7 minute summary from site leads, discussion on on the transferrable practices, strategies and learning on their theme.</td>
<td></td>
</tr>
<tr>
<td>12.30-13.00</td>
<td>Feedback from the round tables and plenary discussion</td>
<td>Round table rapporteurs</td>
</tr>
<tr>
<td>13.00-14.00</td>
<td>LUNCH</td>
<td></td>
</tr>
<tr>
<td>14.00-15.30</td>
<td><strong>SESSION 3b: EXCHANGES BETWEEN INTERNATIONAL AND US PRACTICE : Round 2: What processes and tools have been useful for building social power and participation in local health systems, Co-chairs: R Dudding, Athens County, P Frenz, University of Chile</strong></td>
<td>R Loewenson, TARSC</td>
</tr>
<tr>
<td></td>
<td>Introduction and set up of round tables</td>
<td>Country site leads/focal points, US sites, delegates.</td>
</tr>
<tr>
<td></td>
<td>Round table discussions</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>ROUND TABLE 4</strong>: Methods for organising and sharing information and evidence between communities and services</td>
<td></td>
</tr>
<tr>
<td></td>
<td>New Zealand, Ecuador, Australia, Brazil + US sites</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>ROUND TABLE 5</strong>: Processes and tools in joint decision making (co-determination) including on resources, and for social accountability</td>
<td></td>
</tr>
</tbody>
</table>
### Friday 20th October

<table>
<thead>
<tr>
<th>TIME</th>
<th>SESSION TITLE</th>
<th>ROLE</th>
</tr>
</thead>
</table>
| 8.45-12.45 | **SESSION 4: REFLECTIONS ON TRANSFERABLE LEARNING AND PRACTICE**  
Co-Chairs: V Coelho CEBRAP, A Billioux CMMS/CMI, USA |                                           |
| 08.45-10.15| Synthesising the learning: key approaches and principles on building social power and participation in local health systems  
Discussion | R Loewenson, TARSC                          |
| 10.15-10.45| **TEA/ COFFEE**                                                               |                                           |
| 10.45-12.20| Panel discussion and reflections from the US sites on managing change and strengthening social participation  
11th St  
Centro Savila  
Vermont Blueprint for health  
PIH  
Athens county health department | Moderator: S Simpson  
P Gerrity 11th St  
M Melendez Centro Savila  
B Tazman Vermont  
V Ivie, PIH  
R Dudding, Athens county  
S Simpson |
| 12.20-12.45| Site visit introduction  
Set up of follow up exchanges | F Douglas, U Aberdeen  
R Loewenson, TARSC |
| 12.45-13.45| **LUNCH**                                                                     |                                           |
| 14.00-18.30| **SESSION 5: SITE VISIT (A detailed programme and bios for the site visit will be provided)**  
Co-ORDINATOR: F Douglas, U Aberdeen |                                           |
| 14.00-16.15| Bus departs from Norwood  
Tour of key areas of Aberdeen  
Visit to Community Food Initiative North East and transfer to University | F Douglas, U Aberdeen  
Aberdeen City, Social Bite CFINE  
U Aberdeen assisting |
### Saturday 21st October

<table>
<thead>
<tr>
<th>TIME</th>
<th>CONTENT</th>
<th>ROLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.45-13.00</td>
<td><strong>SESSION 6: FOLLOW UP ACTIONS ON IMPLEMENTING PRACTICES</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Co-Chairs: V Ivie PIH, M Bigdeli WHO</strong></td>
<td></td>
</tr>
<tr>
<td>08.45-09.30</td>
<td>Meetings between sites.</td>
<td>Delegates</td>
</tr>
<tr>
<td>09.30-12.00</td>
<td>Reflections and feedback on the site visit</td>
<td>Delegates</td>
</tr>
<tr>
<td></td>
<td>Round table discussions on follow up actions in the US and internationally</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Four round tables: Follow up:</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Round table 1.</strong> What actions in the individual US sites?</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Round table 2.</strong> What actions at other levels in the US?</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Round table 3.</strong> What follow up in other countries, internationally?</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Round table 4.</strong> What should be included in a statement of principles/</td>
<td></td>
</tr>
<tr>
<td></td>
<td>key messages</td>
<td></td>
</tr>
<tr>
<td>12.00-13.00</td>
<td>Plenary report and review of conclusions of round table</td>
<td></td>
</tr>
<tr>
<td></td>
<td>discussions on follow up actions in the US and internationally</td>
<td></td>
</tr>
<tr>
<td>13.00-14.00</td>
<td>LUNCH</td>
<td></td>
</tr>
<tr>
<td>14.00-16.15</td>
<td><strong>SESSION 7: COMMUNICATING THE WORK</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Co-Chairs: M Melendez Centro Savila, D Matheson New Zealand</strong></td>
<td></td>
</tr>
<tr>
<td>14.00-14.30</td>
<td>Recap of the key targets, processes and products as identified in October</td>
<td>R Loewenson, TARSC</td>
</tr>
<tr>
<td></td>
<td>2016 and implemented to date</td>
<td>S Mende, RWJF, US delegates, J Weymouth Burness (on skype)</td>
</tr>
<tr>
<td>14.30-15.45</td>
<td>Reflections on communications opportunities and media</td>
<td>R Loewenson, Int delegates</td>
</tr>
<tr>
<td></td>
<td>Group 1: In the USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Group 2: Internationally</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Plenary feedback and discussion</td>
<td></td>
</tr>
<tr>
<td>15.45-16.00</td>
<td>TEA/ COFFEE</td>
<td></td>
</tr>
<tr>
<td>16.00-16.30</td>
<td><strong>SESSION 8: CLOSING</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Co-chairs: S Mende RWJF, R Loewenson, TARSC</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Participatory exercise on the network</td>
<td>F Douglas, U Aberdeen</td>
</tr>
<tr>
<td></td>
<td>Song</td>
<td>R Loewenson, S Mende, RWJF</td>
</tr>
<tr>
<td></td>
<td>Next steps on Shaping health, thanks and concluding remarks</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Next steps, concluding remarks and closing</td>
<td></td>
</tr>
<tr>
<td>16.30</td>
<td>Closing</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 2: Delegate list

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
<th>E-mail address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pamela Abbott</td>
<td>University of Aberdeen</td>
<td><a href="mailto:p.abbott@abdn.ac.uk">p.abbott@abdn.ac.uk</a></td>
</tr>
<tr>
<td>Maryam Bigdeli</td>
<td>WHO</td>
<td><a href="mailto:bigdelim@who.int">bigdelim@who.int</a></td>
</tr>
<tr>
<td>Peter Bezner</td>
<td>CHD MS</td>
<td><a href="mailto:peter.bezner@czr.si">peter.bezner@czr.si</a></td>
</tr>
<tr>
<td>Alex Billioux</td>
<td>Centers for Medicare &amp; Medicaid Services</td>
<td><a href="mailto:alexander.billioux@cms.hhs.gov">alexander.billioux@cms.hhs.gov</a></td>
</tr>
<tr>
<td>Vera Coelho</td>
<td>CEBRAP/UFABC</td>
<td><a href="mailto:verasp@uol.com.br">verasp@uol.com.br</a></td>
</tr>
<tr>
<td>Lucia D’Ambrosoo</td>
<td>University of Aberdeen</td>
<td><a href="mailto:lucia.dambruoso@abdn.ac.uk">lucia.dambruoso@abdn.ac.uk</a></td>
</tr>
<tr>
<td>Jo Dorras</td>
<td>Wan Smolbag</td>
<td><a href="mailto:jopet@vanuatu.com.vu">jopet@vanuatu.com.vu</a></td>
</tr>
<tr>
<td>Flora Douglas</td>
<td>University of Aberdeen</td>
<td><a href="mailto:f.douglas3@rgu.ac.uk">f.douglas3@rgu.ac.uk</a></td>
</tr>
<tr>
<td>Ruth Dudding</td>
<td>Athens City County Health Department</td>
<td><a href="mailto:rdudding@health.athens.oh.us">rdudding@health.athens.oh.us</a></td>
</tr>
<tr>
<td>Patricia Frenz</td>
<td>University of Chile</td>
<td><a href="mailto:patricia.frenz@gmail.com">patricia.frenz@gmail.com</a></td>
</tr>
<tr>
<td>Patty Gerrity</td>
<td>Drexel University / 11&quot; St. Center</td>
<td><a href="mailto:pg28@drexel.edu">pg28@drexel.edu</a></td>
</tr>
<tr>
<td>Maurine Gilbert</td>
<td>Vermont Blueprint for Health</td>
<td><a href="mailto:maurine.r.gilbert@gmail.com">maurine.r.gilbert@gmail.com</a></td>
</tr>
<tr>
<td>Renée Markus Hodin</td>
<td>Community Catalyst, Centre for Consumer Engagement in Health Innovation</td>
<td><a href="mailto:rhodin@communitycatalyst.org">rhodin@communitycatalyst.org</a></td>
</tr>
<tr>
<td>Deborah Howe</td>
<td>Central Coast Local Health District</td>
<td><a href="mailto:deborah.howe@health.nsw.gov.au">deborah.howe@health.nsw.gov.au</a></td>
</tr>
<tr>
<td>Vanessa Ivie</td>
<td>PIH Health</td>
<td><a href="mailto:vanessa.ivie@pihealth.org">vanessa.ivie@pihealth.org</a></td>
</tr>
<tr>
<td>Dave Kilgour</td>
<td>Community Food Initiatives North East</td>
<td><a href="mailto:dkilgour@aberdeencity.gov.uk">dkilgour@aberdeencity.gov.uk</a></td>
</tr>
<tr>
<td>John Kirby</td>
<td>Drexel University / 11” St. Center</td>
<td><a href="mailto:idk335@drexel.edu">idk335@drexel.edu</a></td>
</tr>
<tr>
<td>Chris Littlejohn</td>
<td>NHS Grampian</td>
<td><a href="mailto:chris.littlejohn@nhs.net">chris.littlejohn@nhs.net</a></td>
</tr>
<tr>
<td>Rene Loewenson</td>
<td>Training and Research Support Centre (TARSC)</td>
<td><a href="mailto:rene@tarsc.org">rene@tarsc.org</a></td>
</tr>
<tr>
<td>Don Matheson</td>
<td>Brisbane North Health Alliance</td>
<td><a href="mailto:donmathes@gmail.com">donmathes@gmail.com</a></td>
</tr>
<tr>
<td>Clara Mbwilli Muleya</td>
<td>Lusaka District Health Office</td>
<td><a href="mailto:cmbwilli@hotmail.com">cmbwilli@hotmail.com</a></td>
</tr>
<tr>
<td>Michelle Melendez</td>
<td>Centro Savila</td>
<td><a href="mailto:michelle@elevalle.org">michelle@elevalle.org</a></td>
</tr>
<tr>
<td>Susan Mende</td>
<td>Robert Wood Jonson Foundation</td>
<td><a href="mailto:smende@nwf.org">smende@nwf.org</a></td>
</tr>
<tr>
<td>Ranjita Mohanty</td>
<td>Research Consultant</td>
<td><a href="mailto:ranjitamohanty@hotmail.com">ranjitamohanty@hotmail.com</a></td>
</tr>
<tr>
<td>David Ndetei</td>
<td>Africa Mental Health Foundation</td>
<td><a href="mailto:dmndetei@amhf.or.ke">dmndetei@amhf.or.ke</a></td>
</tr>
<tr>
<td>Francisco Obando</td>
<td>Secretaria de Salud, Municipio de Quito</td>
<td><a href="mailto:francisco.obando@quito.gob.ec">francisco.obando@quito.gob.ec</a></td>
</tr>
<tr>
<td>Andreas Papamichail</td>
<td>TARSC / King’s College London</td>
<td><a href="mailto:andreas.papamichail@kcl.ac.uk">andreas.papamichail@kcl.ac.uk</a></td>
</tr>
<tr>
<td>Cara Lee</td>
<td>Ngāti Porou Hauora</td>
<td><a href="mailto:caralee.lawton@nph.org.nz">caralee.lawton@nph.org.nz</a></td>
</tr>
<tr>
<td>Sarah Simpson</td>
<td>EquiAct / TARSC</td>
<td><a href="mailto:sarah.simpson@equiact.net">sarah.simpson@equiact.net</a></td>
</tr>
<tr>
<td>Beth Tanzman</td>
<td>Vermont Blueprint for Health</td>
<td><a href="mailto:beth.tanzman@vermont.gov">beth.tanzman@vermont.gov</a></td>
</tr>
<tr>
<td>Deena Tissera</td>
<td>University of Aberdeen</td>
<td><a href="mailto:deena_lissera@yahoo.com">deena_lissera@yahoo.com</a></td>
</tr>
<tr>
<td>Godelleve Van Heteren</td>
<td>RGHI / WHO</td>
<td><a href="mailto:gmvanheteren@xs4all.nl">gmvanheteren@xs4all.nl</a></td>
</tr>
<tr>
<td>Rebecca Zapelli</td>
<td>Bridge for health, Canada (left early)</td>
<td><a href="mailto:gmvanheteren@xs4all.nl">gmvanheteren@xs4all.nl</a></td>
</tr>
</tbody>
</table>

**Apologies:** Silva Nemes, CHD Murska Sobota, Pomurje
Appendix 3: Documents tabled

Hardcopy versions of selected documents in the list below were tabled. A full set of all documents was made available electronically in a flash drive and further materials were displayed by delegates from their work.


