World Health Organization

GORDON AND BETTY MOORE FOUNDATION

Global Expert Consultation on the WHO Framework on Patient and Family Engagement

27-28 October 2014
WHO, Geneva
Switzerland

MEETING REPORT

Acknowledgements

This report summarizes the proceedings, presentations and discussions related to, or those that took place during the global expert consultation on the WHO Framework on Patient and Family Engagement. The expert consultation was jointly hosted by the WHO Department of Service Delivery and Safety (SDS) and the Gordon and Betty Moore Foundation (GBMF or the Moore Foundation), under the guidance of the WHO Framework on Patient and Family Engagement project Advisory Group, which includes Sir Liam Donaldson (Chair), Susan Baade, Dominick Frosch, Edward Kelley, Vivian Lin, Hernan Montenegro, Margaret Murphy and Nittita Prasopa-Plaizier.

The writing team for this report included Nittita Prasopa-Plaizier, Felicity Pocklington, Katherine Hayes, Katthyana Aparicio, Susan Baade and Edward Kelley and it was edited by Laura Pearson. Gabriella Garcia Castillejos and Sorin Banica provided administrative support.

Contributions in the form of presentations came from Kristin Carman, Peter Carter, Neelam Dhingra-Kumar, Susan Frampton, Dominick Frosch, Jonas Gonseth, Denice Klavano, Piyawan Limpunyalert, Vivian Lin, Kadar Marikar, Hernan Montenegro, Nittita Prasopa-Plaizier, Sue Sheridan and Shams Syed.

The facilitators and rapporteurs of the different working groups were Bruce Agins, Susan Baade, Angela Coulter, Dominick Frosch, Hussain Jafri, Kadar Marikar, Stephanie Newell, Luisa Pettigrew and Sue Sheridan.

The contents are based on the detailed transcripts of the Consultation and the existing information produced by WHO as part of the Consultation proceedings. Thus, the contents of this report represent the collective work of the Consultation participants , which included: Hanan Aboumatar, Bruce Agins, Ahmed Alamri, Katthyana Aparicio, JS Arora, Susan Baade, Sorin Banica, Sepideh Bagheri-Nejad, Abhishek Bhartia, Liesbeth Borgermans, June Boulger, Kristin Carman, Peter Carter, Angela Coulter, Neelam Dhingra-Kumar, Sir Liam Donaldson, Susan Frampton, Dominick Frosch, Gabriela Garcia-Castillejos, Jonas Gonseth, Rachel Gooden, Jo Groves, Katherine Hayes, Hussain Jafri, Manvir Jesudasan, Robinah Kaitiritimba, Regina Kamoga, Edward Kelley, Selma Khamassi, Denice Klavano, Zuzana Kusynova, Piyawan Limpunyalert, Vivian Lin, Kadar Marikar, Hernan Montenegro, Stephanie Newell, Sara Perazzi, Maria Perez, Luisa Pettigrew, Felicity Pocklington, Nittita Prasopa-Plaizier, Casey Quinlan, Ronen Rozenblum, Susan Sheridan, Ram Shrestha, Shams Syed, Ken Taneda, Nuria Toro Polanco, Tonny Tumwesigye, Lodewijk van Bladel, Suzanne Wood, Xuchun Ye.

Contents

Executive Summary

Engaging and empowering patients, families and the community is a key strategy of the WHO Strategy on People-centred and Integrated Health Services. The World Health Organization (WHO), Service Delivery and Safety Department (SDS), in collaboration with the Gordon and Betty Moore Foundation (GBMF) held the first global experts' consultation for the development of the WHO Framework on Patient and Family Engagement on 27 - 28 October 2014, at WHO headquarters in Geneva. The Gordon and Betty Moore Foundation's Patient Care Program aims to eliminate preventable harm and unnecessary health-care costs by meaningfully engaging patients and their families within a supportive, redesigned health-care system. This aligns with WHO's goal of empowering both patients and health-care providers in the implementation of universal health coverage which is safe, of high quality, and patient- and people-centred.

The Consultation discussed current evidence, practices, approaches, potential practical tools and proposed approaches that would inform the development of the WHO Framework on Patient and Family Engagement (PFE). This Framework aims to address the global need to empower and strengthen the capacity of patients and families, as well as health-care providers to collaborate and partner in efforts to improve health-care safety, quality and people-centredness.

The Consultation was organized under the guidance of the Advisory Group, chaired by Sir Liam Donaldson, WHO Envoy for Patient Safety. It gathered 18 internal experts from relevant WHO units and departments, as well as 37 external experts from government and non-government sectors from 16 different countries across all six WHO regions, and included patients, health-care providers, policy-makers, academics and representatives from non-governmental organizations.

On the first day of proceedings, experts shared their evidence, principles, strategies and activities for engaging patients and families in health care. The SDS Department presented four WHO programmes which incorporate PFE; 'Universal Health Coverage (UHC)', 'the WPRO Patient-Centred Strategy', 'WHO Strategy on People-Centred and Integrated Health Services' and 'the Patients for Patient Safety (PFPS) programme'.

The Moore Foundation's Patient Care Program and its 'Roadmap for Patient and Family Engagement in Healthcare: Practice and Research' played a large role as a catalyst and model for the application of PFE within health-care institutions. The Roadmap was used to illuminate the practical reality of the implementation of PFE in improving standards of care and it provided the participants with a template for exploration and discussion.

Three working groups were formed to explore important components of the WHO Framework, including 'the definition of meaningful engagement', 'the tools to measure PFE' and 'the roles, responsibilities and expectations of patients, families, health-care providers and policy-makers'.

On the second day, case studies of Patients for Patient Safety (PFPS) networks from Ecuador, Malaysia, Thailand and Canada were presented to showcase PFE in different sociocultural settings. The presentations from Planetree and the Patient-Centered Outcomes Research Institute (PCORI) demonstrated capacity-building for health-care providers and policy-makers respectively.

The preliminary proposal for developing the WHO Framework on Patient and Family Engagement, drawn from qualitative research of 110 semi-structured interviews with PFPS patient advocates from over 25 countries, was presented. The Consultation concluded with an agreed plan on the Framework and its dissemination.

Abbreviations

AIR	American Institutes for Research
APHM	Association of Private Hospitals of Malaysia
DALY(s)	Disability Adjusted Life Year(s)
FIP	International Pharmaceutical Federation
GBMF	Gordon and Betty Moore Foundation
HSD	Health Sector Development
IAPO	International Alliance of Patients' Organisations
IHF	The International Hospital Federation
ISQua	International Society for Quality in Health Care
MoH	Ministry of Health
MSQH	Malaysian Society for Quality in Health
PCIHS	People-Centred and Integrated Health Services
PCORI	Patient-Centered Outcomes Research Institute
PFE	Patient and Family Engagement
PHE	WHO Department of Public Health, Environmental and Social Determinants of Health
PFPS	Patients for Patient Safety
PSQ	Patient Safety and Quality Improvement
SCI	Services Organization and Clinical Interventions
SDS	Service Delivery and Safety
TCM	Traditional and Complementary Medicine
WHA	World Health Assembly
WHO	World Health Organization
WPRO	World Health Organization Western Pacific Regional Office
UHC	Universal Health Coverage

_____

Day 1: 27 October 2014

1.0   Welcome and Introduction

Sir Liam Donaldson, WHO, Ed Kelley, WHO and Dominick Frosch, The Moore Foundation

The expert consultation was opened by Dr Ed Kelley and Dr Dominick Frosch, representing WHO and the Gordon and Betty Moore Foundation (GBMF, the Moore Foundation) respectively, who each welcomed the participants and articulated the purpose and process of the Consultation and their vision for the goal and expected outputs. Sir Liam Donaldson gave a keynote speech, providing impetus and the redefinition of a common vision for patient and family engagement.

1.1 Rationale and purpose

Patient and family engagement is now at the top of agenda of many health-care systems. However, those who are involved in health-care systems and delivery, such as chief executives, managers and frontline staff delivering health services, are somewhat puzzled about how to implement this concept in practical terms. This is because health-care providers are traditionally educated and trained to have a particular view of their engagement with a patient, which is very much about establishing a clinical process – diagnosing the disease and treating it and may not really appreciate how a fuller or richer relationship with patients may help their recovery or support them over the long term.

Addressing issues about the paradigm of medical and nursing practices will be helpful in promoting a better understanding and the practice of meaningful involvement with patients and families in health care. This is an area where the Framework on Patient and Family Engagement can very much add value.

Experience at WHO with patient and family engagement began with the work that was developed and implemented with the establishment of the World Alliance for Patient Safety's patient safety programme, 10 years ago. The Patients for Patient Safety (PFPS) programme was set up as a core pillar of the World Alliance for Patient Safety and remains an important part of the WHO agenda. It has been a very successful approach to developing an understanding about the role of patients and families in preventing harm and promoting patient safety.

The Gordon and Betty Moore Foundation (GBMF) is very interested in how to implement patient and family engagement when delivering care on the ground. There is now increasing recognition that patients and families can contribute positively to health care if meaningfully engaged and encouraged to do so. The work of the Moore Foundation is focused on changing the way care is delivered in the United States, so that patients and families are meaningfully engaged within a redesigned, supportive health-care system. It is about transforming the way patients receive care, whether in an outpatient or acute care setting, so they are encouraged to contribute according to their preference and capacity.

The goal of the patient and family engagement work of the Moore Foundation is to achieve what in the United States are called 'the triple aim' namely: 1) better health outcomes, 2) an improved patient experience and 3) lower costs. The Moore Foundation has developed a roadmap aimed at facilitating patient and family engagement, which was shared with the participants during the Consultation.

The GBMF recognises that these concepts are not only relevant to the United States or developed countries, but they are relevant to countries all around the world.

WHO also recognizes that there are nowadays more opportunities open for patients and families to be involved, such as in the designing and shaping of services, not just receiving feedback on their experience but also through a more active involvement, and the whole agenda of self-care and the

self-management of chronic diseases, which is a big subject for all health-care systems. So patient and family engagement is a very rich territory and this collaboration presents an opportunity to produce some guidance and standards that will undoubtedly benefit patients as well as health-care systems.

The WHO Framework on Patient and Family Engagement project is a partnership between WHO and the Moore Foundation, with the anticipation of then welcoming other partners in its next phases of development. The overall goal of the expert consultation is, as a first step, to provide direction on the WHO Framework on Patient and Family Engagement project. It then aims to translate the vision and principles of patient and family engagement into a comprehensive, but practical framework that will enable people working on the ground to really make a difference in health-care delivery.

The specific purposes of the expert consultation were to:

- review, discuss and share current evidence on the concepts, approaches and practical experiences related to patient and family engagement;
- identify and propose the structure, key components, process and system requirements needed for meaningful engagement;
- discuss the direction and approach for the development of the draft Framework.

The agenda of the two-day Consultation was developed collaboratively by both partners. It started with some framing presentations to look at the work that has already been done, as well as working sessions that would examine and refine elements of the Framework. The two-day consultation was envisaged as the first step of the participants' involvement with this project. WHO and the Moore Foundation expected to achieve very solid products i.e. information and recommendations from the Consultation that will enable the work on patient and family engagement to move forward.

2.0   Engagement for Health: Defining a Common Vision

The morning sessions started with WHO and the Moore Foundation's presentations as the scene setting to provide an overview of current work of the two organizations on patient and family engagement for health.

2.1   Engagement for patient safety and quality improvement

Neelam Dhingra-Kumar, WHO

Dr Dhingra-Kumar provided an overview of WHO's work on patient safety and its evolution from being driven by harm prevention in the early stages, and then shifting to quality improvement in the present stage. Her presentation outlined the work on patient and family engagement, but also reflected on current and future WHO priorities in Patient Safety and Quality Improvement (PSQ).

Key messages:

- The complex combination of processes, technologies and human interactions that constitutes the modern health-care delivery system can bring significant benefits, but they can also cause harm. The majority of adverse events result from faulty systems and processes, not individuals being incompetent and careless.

- About one in 10 patients experience harm during hospital care. A recent estimate indicated at least 43 million injuries, nearly 23 million DALYs occur each year due to unsafe medical care.

- The three pillars of quality are: effectiveness, safety and responsiveness/patient centeredness.
    - There are three quality and safety building blocks: 1) 'framework and resources' - infrastructure, means of access and overall design; 2) 'culture and governance' -

leadership, management, standards, assurance and patient-centeredness; 3) 'process of care' – care pathways, procedures and skills.

- Patients for Patients Safety (PFPS), set up in 2005, is now under the umbrella of PSQ and serve as:
    - an approach to empower and capacity build patients and families as informed and knowledgeable health-care partners;
    - a platform to bring the patient voice to health care;
    - a mechanism to facilitate and foster collaborations with patients, families, communities, health-care providers and policy-makers.

- PFPS involved patients in the design, development and dissemination of information and tools such as the WHO Mother-Baby 7day mCheck[1] and the Patient's Communication for Surgical Safety[2].

Priorities of the patient safety programme at WHO:

- Improve medication safety
- Ensure safe blood and transfusion practices
- Create change that lasts through the use of adaptive tools and evidence-based interventions , and builds global standard and learning on clinical behaviour change
- Prepare the future health workforce: WHO Patient Safety Curriculum Guides
- Engage patients, families and communities: PFPS Programme
- Bring patient safety and quality improvement to the forefront by expanding and strengthening.

2.2   Engagement for universal health coverage (UHC) and quality of care

Shams Syed, WHO

Dr Syed began his presentation with a definition of UHC. What is UHC? Universal health coverage (UHC) can be defined as a concept for providing all people with access to the necessary health services with sufficient quality to be effective without imposing substantial financial hardship. The role of the WHO Department of Service Delivery and Safety (SDS) has been to ensure that quality of care and patient safety are front and centre of that discussion, with the recognition that improving access to health services without financial hardship is only part of the solution to creating an effective health service. Importantly, positioning the work of PFE, within a concept that has been described as the most powerful concept that public health has to offer, gives us some prioritisation of UHC and where PFE sits within this frame.

There are three dimensions of coverage: population coverage, service coverage and cost coverage. It is a useful guide for reflecting on options and priorities for expansion, to move towards a progressive realisation of UHC. Also, there are inevitably going to be some trade-offs within those dimensions of UHC.

There are three specific aims of UHC. Firstly, equity in access and service use, thus reducing the gap between need and service provision; secondly, sufficient quality to make a difference (to health outcomes); and finally financial protection so essentially no one should become poor as a consequence of having to pay for health services. The objectives: equity, quality and financial protection, that's what we want to achieve, and the instrument that we use to achieve them is the role of strengthening health systems. So investment in quality and safe health services, looking at human resources (HR), and also thinking about incentives to promote high quality care all contribute to this. Finally, reducing fragmentation in health services and building the role of the patient and family, of course, are critical and foundational to these efforts.

---

[1] A tool with pictograms which aims to empower a mother/family to recognize danger signs in the mother and the newborn baby during the seven days post-delivery, so that they seek necessary health care where needed.
[2] A tool which aims to empower patients to ask questions about preventing infections and complications following surgery.

When striving to achieve UHC, the roles of the patient and family are key, as UHC cannot be achieved without good quality care. For instance, when thinking about maternal mortality, it is estimated that in Southern Sudan 1 in 136 live births lead to the mother's death. To improve services, it is imperative to place people at the centre of the system throughout the continuum of care, from health promotion to palliation, and with the integration of services incorporated into that. Thus, the WHO People-Centred and Integrated Health Services Strategy, which incorporates concepts of engagement and empowerment, lies at the heart of UHC and quality. The SDS Department is taking this forward as a priority, focussing on three streams: 1) catalysing global change, 2) WHO taskforce on UHC and Quality, and 3) focusing on implementation to transform.

Another piece is quality and safety interventions. For example, the WHO Global Safety Challenges, like hand hygiene, surgical safety, and what has been envisaged as a third challenge on medication safety. These types of interventions have an interface with the actual system, to improve the quality of care as the systems move towards or have reached UHC.

The discussion that followed Dr Syed's presentation raised issues related to use of the cube, which is really a financing framework for UHC, to explain the UHC concept. WHO has pushed for the next paper to not be so financially focused. UHC has become a concept that people use interchangeably with other things without fully defining it or providing the context and political environment in which the services are delivered.

Another important point raised in the discussion was that people often believe that UHC would create a situation where everybody has free health care, but this is not the case. UHC is about making sure that people can have affordable health care that does not ruin them financially. This dynamic makes it an interesting opportunity for exploring more deeply the involvement of patients and families in the very fundamental discussions about the model of health care i.e. the way it is funded and how to create affordable and sustainable health care.

2.3   The Gordon and Betty Moore Foundation's Patient Care Program and a Roadmap for Patient and Family Engagement in Healthcare: Practice and Research

Dominick Frosch, The Moore Foundation and Kristin Carman, AIR

Dr Frosch and Dr Carman provided the background, rationale and the process they used to develop the Roadmap, as well as giving a summary of the Roadmap.

The United States still have a long way to go in terms of UHC, where everybody would receive high-quality care that does not impose financial hardship. There is still a lot of confusion about how to engage patients, to put patient engagement into implementation.

Patient and family engagement is a highly fragmented field, with many different players, and so currently lacks a common unified vision. Questions like `How do we pull all these strands together and turn that into reality on the ground?` underpinned the thinking for developing the Roadmap. It is about transforming complex ideas to workable tools on the ground that help and support patients to achieve the safety and outcomes of care, as well as lower health-care costs.

The Roadmap was built on a framework that Dr Carman, colleagues and patient advocates developed together. It recognizes that patient engagement occurs at multiple levels, including the delivery of care, the levels of partnering in organizational design, and in policy. In creating the Roadmap, 70 individuals, including health-care users from a variety of backgrounds, researchers, policy-makers, people in direct health-care delivery, such as nurses, clinicians and patients, were brought together. It was a multi-disciplinary group and with a collective rather than personal ownership.

'What are the desired destinations and milestones? If we achieve this then what does it look like? What are the strategies and tactics to get there?'. There were critical manifestations and the group

were asked to brainstorm ideas, discuss challenges, but not to be stuck on them. Then, they were asked about timing; 'what can we do today, tomorrow and the day after?' Feedback on the process was positive and the patients felt that their voices were equally heard in this setting.

This is not a new concept, but instead brings together available tools and turning them into a highly interactive document and presentation. It is organized into key four sections:

- Introductory material: How we did this?
- Vision for PFE in healthcare [video]: generated by the participants, describing for the patient what this is all about
- Five simple actions: what everyone can do <u>today</u> to make a difference for PFE
- Broader strategies for change, which each includes a number of tactics.

The heart of the Roadmap lies in the strategies that are the priority areas for practice and research. In each of these strategies, there are milestones and tactics; *what do we do and how do we achieve what we want to achieve, or are we at least progressing towards the desired outcomes?*

Prepare patients and families: Working to educate, prepare and empower patients to engage in their own health and health care. This helps provide patients and families with the skills, confidence, and authority they need to partner - to the degree that they want to – in interactions and health-care decision-making at all levels. Examples of tactics:

- Evidence-based support tools
- Increasing the use of peer education for patients and families
- Preparing them to partner in health-care organizations.

The Roadmap envisions patients and families being involved at every level of health care, so for each change strategy, the tactics are spread across direct care, engagement with health-care professionals, with organizations to participate in organizations design and governance and also at policy level.

Prepare clinicians and leadership to promote PFE: Change is not just about asking people to adopt new behaviour or do things differently. It is also about creating an enabling environment, such as systems that encourage or facilitate desired behaviour. This includes creating an environment where engagement is expected, welcomed, and facilitated –providing concrete opportunities for patients and families to engage and be active in their care; creating policies that emphasize patient and family partnership; and developing and implementing care processes that reflect patients' and families' self-identified needs.

Enabling environment: PFE is about creating a 'hospitable' environment for change to occur. One way to do this is through legislation and regulation – incentivizing desired behaviour (or penalizing undesirable behaviour) and developing legislation that creates the need for change.

Engaging at organizational and system levels: To design care systems that truly meet the needs of patients and families, partnerships are needed at the organizational level, where patients and families participate in decisions about how care is organized and delivered, how facilities are designed, how staff are hired and how to make critical improvements to quality and safety.

It is also about creating transparency and accountability in the system – through research, measurement, and better access to data that can inform health-care decision-making. When patients and families have access to clear, comprehensive information about quality, costs, treatment options and approaches, as well as their own medical records, they are better informed and better able to engage.

Measurement and research are critical to drive changes in behaviour and processes and to build relevant evidence. Measurement can provide patients and families with data to make more

informed choices and provide clinicians and health-care organizations with data to inform quality improvement efforts. Research can help assess whether, to what extent, and how engagement is occurring, along with identifying outcomes, and what is not supporting it.

Engaging at policy level: Working with patients and families to develop, implement, and evaluate national, state, and local health-care policy and programmes. Patients and families can collaborate with community leaders and policy-makers to solve community and social problems, shape health-care policy, and set priorities for research and the use of resources.

Five simple actions: These are tangible discrete actions [Fig. 1] that are important to help arrive at a system that involves patients, is high quality and cost-effective. The Roadmap has the same approach for each stakeholder: patients, clinicians, organizations, leaders, insurers, employers and researchers – 'five things you can do tomorrow'.

The Roadmap is a working document and the Moore Foundation asks people to share and use it and provide resources as appropriate to support its implementation. It is intended to catalyse efforts, by providing strategies, simple actions, and for people sitting on the fence, it could be motivating when they realize 'oh! I can do this'.

Figure 1: What can patients and families do?

1. Give feedback on your experiences. Complete any surveys you get from your health-care providers that ask about your experience during your most recent visit. Write a letter to your local clinic or hospital about the care you received or tell your doctors and nurses what went well and what could be improved. If you experience a problem with the quality or safety of care you get, inform your health-care provider and check back about what they have done to address it.

2. Look for information to help you understand your health and health condition. Look for information online or at your library to help you understand your health condition, symptoms, issues involved in your care, and treatment choices. Write down any questions or concerns to share with your health-care team. To find trustworthy information, ask your health-care provider about recommended websites or apps.

3. Get ready for your next health-care visit. Write down important health information, such as medicines you are taking and current health symptoms. Think about what's most important for your health-care team to know about you, your current problem, and your health history. Create a concise list of questions and let your provider know at the beginning of your visit that you would like to discuss these matters.

4. Keep track of and organize your medical information. Keep a record of your medical care for your files. Ask if your health-care provider uses electronic health records and whether there is an electronic patient portal. If so, use it to access your health-care information and look at your health records. After a medical appointment, ask for a copy of the visit summary and tests that were done.

5. Contact your local clinic or hospital and volunteer to be a patient and family advisor. Advisors share their experiences and provide input to help health-care organizations provide better care. If your local hospital or clinic does not work with patient and family advisors, ask them to consider doing so.

Key points from the discussion:

- *Global strategies, local implementation:* Although the process and setting of its development is US-centric, the Roadmap can be considered very global. It was shared with policy-makers, providers and patients in Latin-American settings and was well received. The Roadmap's principles are universal. The strategies can be applicable to any setting and people can adopt and adapt them to suit their own needs and context. Thus, its implementation must be local. Even in the United States, there will be variations in its uptake and application.

- *Understanding of patient-centred care: One* of the health systems issues around the world is that people do not know what patient-centred care is. So it may be worth building up this understanding. Perhaps, WHO can make the tools and educational resources available to educate policy-makers on what patient/people-centred care really means. Only then will they be able to implement strategies to achieve it. The Moore Roadmap is a tool that focuses on actions to help people implement them on the ground. This will help leaders see its potential and applicability and use it with their workforce to transform the system of patient and family engagement into a reality.

- *Empowering providers:* Providers also need to be empowered, not just patients. In Africa, patients and service providers are engaged through the community unit. Patient advocates and civil society help facilitate health-care providers to engage with the community as a group. Empowerment can then be incorporated into other areas like gender. For example, women and girls who cannot speak for themselves as individuals can speak through the community.

- *Empowering advocates:* Patient advocates need to be empowered in their own countries and there should be support from WHO, not financial but technical and facilitational support, such as making the role of PFPS champions more visible. This could help facilitate communication on the ground.

- *Organizational partnership:* The Roadmap addresses organizational partnerships, which are often overlooked. The focus on engaging patients and providers at the organizational level to foster a culture in the system to enable the possible implementation of these practices.

- *WHO involvement:* This Roadmap is also encouraging WHO involvement as it means initiatives and strategies can be widely disseminated and reach low-resourced countries. A user-friendly strategy like raising awareness of patients and families can bring about real change. One of the small steps that developing countries can adopt is patient engagement in information, education and the practice of informed consent. These should be implemented to demonstrate impact as part of routine patient care, not just as pilot studies.

- *Success factors:* Which elements of the Roadmap would be considered *the* critical success factors? Ideally, all strategies in the Roadmap should be implemented. In reality, it is unlikely that people will adopt the Roadmap in its entirety, implementing all strategies. Adoption is likely to unfold gradually, in part, because what it is about is culture change, which is not about changing the context, but about doing things differently and that people do them together. It is not going to be straightforward, implementation rarely is. Researchers may find it challenging as it may not yield tightly controlled research designs or reports that journal editors like to read. So barriers do exist, but the focus should be to get over them, around them or work with them to create a new system that works differently.

  One of the key underpinning success factors is a better understanding about and incorporation of the concept of systems improvement through behavioural change, individually and of the whole system. For example, patients are unlikely to a achieve changes if clinicians are not prepared to support them. For systems to improve, leadership is crucial. These are the reasons for having five simple actions and many tactics.

The term 'patient-centred care' and the term 'partnership' mean different things to different people. It will be helpful to describe words in ways that capture the concepts and illustrate how it would look on the ground. In Ireland, the Health Service Executive brought together people across the country to brainstorm matters that are important to patients and what they would look like This resulted in the 'National Healthcare Charter – You and Your Health Service', which promotes the importance of a culture of patient partnership in health care. The Charter outlines what matters most to patients, what they can expect and ways in which they can participate as full partners in their health care.

2.4 Patient and family engagement - approaches, challenges and opportunities: findings from the PFPS qualitative research

Nittita Prasopa-Plaizier, WHO

Nittita Prasopa-Plaizier provided an overview of the Patients for Patient Safety (PFPS) Programme and a summary of the patient interviews conducted as part of this project. Patient engagement was considered the flavour of the month. People wanted to have this as a component in their health-care systems and processes. The issue was how to ensure that it is meaningful and not just ticking boxes. The interviews captured activities that have been mentioned by our PFPS champions and sought to understand what they perceived as meaningful engagement as well as the challenges and opportunities they have identified.

Main points from the presentation:

- *PFPS Programme*: It was created in 2005 as a core pillar of the then World Alliance for Patient Safety. It began with a workshop in London in 2005 where 22 individuals from 20 countries gathered to share experiences and exchange ideas. Their collective passion led to the drafting of the 'London Declaration', the vision of safe health care that incorporates patients' and families' perspectives through positive engagement and empowerment. Ever since, participation in a PFPS workshop and a commitment to uphold the London Declaration have become the centrepiece of and a core principle for becoming a PFPS advocate (referred to as a 'PFPS champion'). To date, the PFPS global network has nearly 400 champions across 54 countries worldwide.

- *PFPS interviews*: WHO PFPS conducted semi-structured interviews with 60 PFPS champions to explore their perceptions and experiences of engagement and empowerment. The concepts and practices of engagement vary according to local contexts. Differences in cultural concepts between some countries made the term 'partnership' problematic. It is unclear to some patients what is meant by accountability. Providers have similar reservations, indicating close relationship created through partnership may make it difficult to provide objective advice or services for fear of offending patients. Cultural contexts need to be taken into account when engaging people in health care.

- *Meaningful engagement:* The interviews explored the perception of meaningful engagement. They indicated that tokenism engagement still exists. Patients may be included in many initiatives, but the roles and levels of engagement varied. For them, meaningful engagement means they participate fully; that they can have opinions, be listened to and responded to, etc.

- *Engagement experience:* PFPS champions have engaged or have been engaged in different levels of health systems - in individual care (own care or family), in policy, in organizational governance (services and processes), in community empowerment and education (grassroots level), in research and in peer support. One of the most common forms of engagement was presentations/speaking at conferences or meetings. They perceived themselves as quite knowledgeable and could be a resource to help connect with patients and with the community as a catalyst for change.

- Many PFPS champions worked as volunteers in their local hospitals. They provided insights into how the hospital handles complaints, reviewed internal processes and contributed to accreditation while also providing feedback and advice to health-care providers and patients. They emphasized the important point that not all patients can become a champion (due to knowledge gaps, availability, capacity, resources) and that not all wanted to be involved at the same level of intensity.

- They were the frontline and grassroots agents for empowerment. Some examples of empowerment quotes, on empowering people and changing the system:

  'Why do we line up in the sun, why can't we sit down? There is shade here. If you give us numbers, and I know that I am number 5'. Change happens when you start to question the system.

  'Empowerment is powerful – starts from something very little, by just giving them a voice, or a chance to ask questions. It has to be community-focused.'

Challenges:

- *Open disclosure:* lack of a process/mechanism for meaningful and respectful communication following an adverse event. This was mentioned by almost all participants in the interviews

- *Feedback mechanism/reporting system:* lack of mechanisms for feedback, complaints or reports, which not only limits patient engagement, but also prevents patients from having a voice. With no avenue to express opinions or raise concerns, the only way for patients to be heard was to take legal action.

- *Acknowledging harm:* patients sought appropriate acknowledgements when harm happened. They were not looking for revenge, but to be assured that learning had taken place and that actions would be taken to mitigate the problem or prevent future occurrences.

- *System issues:* they acknowledged that it was not about the fault of individuals, but weaknesses in the system. However, they emphasized that a system is managed by people, and therefore it can be changed by people.

Opportunities:

- *Engaging 'local heroes':* Create sustainability through engaging and empowering local leaders and organizations. WHO can offer technical assistance, but success depends on the capacity and ability of local people taking the lead and owning the initiative.

- *Capacity-building:* One of the WHO approaches to capacity-building is through awareness-raising and capacity-building workshops for patients, health-care providers and policy-makers. For example, a workshop in Shanghai, China, was conducted to gain the perspectives of health-care providers in order to develop ways to support their efforts to engage with patients and families.

Discussion:

Engagement for radiation safety: PFPS has worked closely with colleagues in the WHO Department of Public Health, Environmental and Social Determinants of Health (PHE), through Dr Maria Perez, who is leading the work on radiation protection. The notion of quality and safety, particularly patient and family engagement is applicable to work in this area.

Dr Maria Perez indicated that the timing of this expert consultation was in tune with radiation safety. PHE, together with eight international organizations have just published basic safety standards for radiation safety, which include a chapter on patient safety. These standards are

legally binding in many countries. When Margaret Murphy was invited to speak at the Bonn Conference in 2002, the result was a Bonn call for action, a policy document calling for decisions and actions to be implemented around radiation safety, with many new actions specifically focussing on engagement with patients. The work on radiation safety asks similar questions, includes reporting and learning and emphasizes on doing the right procedures correctly. PHE will take up and cross-fertilize the 'pollen' of patient engagement and cross-fertilize within radiation protection work. This WHO Framework on Patient and Family Engagement will provide a good starting point. The key message is join efforts at WHO, internal and country levels to engage patients towards safe and quality health care.

Patient and Family Engagement within Hospitals: Jo Groves shared information on the joint work between the International Alliance of Patients' Organisations (IAPO) and the International Hospital Federation (IHF), which surveyed their members to look at the different types of patient engagement institutionalised within hospitals. It comprised eight case studies from both a hospital and a patient perspective in different countries from Africa to the Asia Pacific Region, looking at engagement from hospital boards to self-management options and includes challenges and solutions. The Report, available on the IAPO and IHF websites, could complement and exemplify some of the principles and approaches in the Framework.

Inclusion of data from other sources: The findings of the interviews with PFPS champions were intended to serve as a starting point. The intention is to bring wider perspectives from providers, and various other stakeholders.

2.5   Engagement for people-centred policy: the WPRO Patient-Centred Strategy

Vivian Lin, WPRO

In 2007, the World Health Organization's Western Pacific Regional Office (WPRO)'s Regional Committee adopted a policy framework - a systems approach that placed the patient at the centre of health care. At the beginning, there were a lot of debates about terminology. Some did not like the word 'patient', considering it patronising. The term 'client' did not resonate well within the health-care system. In some high-income countries, the term 'consumers' was used and there were ideological objections, because it made health-care provision sound like a transaction in the market place rather than a citizen's entitlement. In reality, especially within the Asian context, health care is not something that individuals do alone; it's about individuals, families and communities and so it was important to bring them together.

So people-centred care came out of that debate. It was recognized that, as much as individuals and practitioners wish to have a very patient-focused experience, health-care organizations are not often organised to do so. There are still places where people have to turn up at 8am for outpatient appointments and there are certain funding policies where doctors see patients rapidly for quantity rather than a quality experience. So it was important to look at how health-care organizations worked and responded to a whole series of drivers i.e. health-care delivery and policies that underpinned the health-care system.

A literature review showed that patient interventions were essential, but not sufficient. So it was imperative to look at a combination of all the different interventions:

- What were the policy underpinnings to support a people-centred health system?
- At the patient/family/community level, the aim was to ensure better informed and more empowered individuals, families and communities.
- At the health-care practitioner level, the focus needed to be on developing more responsive and competent health-care practitioners.
- For health-care organizations, it was about creating more effective and supportive health-care services and facilities; and

- At the health system level, the aim would be better system design, clear rules and better incentives to support people-centred and quality care.

The Policy Framework looked at the changes required, namely measures based on evidence-based research or current understanding of optimal practices that came from consultations across the countries involved. A range of evidence-based materials were used to guide the process, but it was also informed very much by the process of engagement that had been established in the four countries.

At the individual/family/community level, the focus was on increasing health literacy. The objective was to increase skills that would enable participation in decision-making, to improve self-belief in the capacity for improved self-care and to improve capacity of the voluntary sector to expand. So the efforts to engage went beyond the individual. Community participation was part of how the systems worked, with the objective of having supportive community leaders. This required quality assured information, multi-faceted approaches to community education, access to health records, self-management and self-help programmes, peer support groups, support and training for consumer organizations and representatives, as well as leadership development programmes. Thus, the team worked across multiple levels with individuals, families and communities.

There was a need to look at models of education and the content of the curriculum to address questions like 'how do we inculcate certain values through education of health-care professionals?', 'how do we enhance their commitment to quality, safe and ethical care?'; not only in terms of basic training, but also through continued professional development, codes of conduct and a range of other measures.

Moving towards health-care organizations, it was recognised that everything needed to be done from simple facility based issues, which remained significant (especially in rural areas), to the way health workers related as teams, to the way in which they engaged, their capability of engaging with patients and families and the different models of care that existed. It was also important to look at how internal management systems worked - the internal referral system, the payment systems, the performance-based incentives, the quality system and the feedback systems.

Buy-in from both managers and clinicians was needed. At the system level, primary health care was very poorly developed. Developing good general practitioners with appropriate payment mechanisms remained a big challenge. Professional registration and workforce licencing were still rudimentary in some countries and trying to move towards legal protection, monitoring of health system performance and monitoring of patient satisfaction was a substantial task.

Since this Policy Framework has been released, there has been uneven development across countries. Part of the integration agenda within the UHC framework was to bring those numerous vertical programmes, like maternal and child health, malaria, HIV, immunisation etc. together into an integrated health system. However, integrated health systems can still be provider-driven e.g. a health centre may provide everything, but the women may have to turn up one day for the hypertension clinic, come back another time for a pap smear, and the next day for her baby and so on. As UHC becomes a bigger agenda, it will be an opportunity to move towards more people-centred services.

Whether it is an individual-level or population-level intervention, it is important to ensure there is shared value between the community and the health-care providers/system and partnership that can be developed. Since this policy framework was adopted in 2007, many of the policy measures remain relevant. Perhaps, there are more theories about engagement, theories around deliberative democracy, and theories around community participation that need to be brought into practice so that this long-standing debate for people-centred care, that exists in some countries, can be addressed. Moving forward will need a systems approach and strong leadership.

The uptake was not uniform. In different countries, implementation happened at different speeds and on different issues. Countries have pursued developments in the specific areas, such as patient

safety, accreditation, education, i.e. taking up on the different elements of the strategy, rather than putting them together in a much more synthesised fashion. This is where UHC could become a wonderful opportunity to reintegrate many of these different pieces and help move forward on the issues of integration, people-centeredness and safety.

2.6   WHO Strategy on People-Centred and Integrated Health Services (PCIHS)

Hernan Montenegro, WHO

Dr Montenegro presented the WHO Strategy on People-Centred and Integrated Health Services (PCIHS), introducing its rationale, strategic analytical framework, strategic directions, as well as outlining steps required for its implementation.

Challenges in health care surround access, availability, acceptability and the quality of health services. In terms of health service delivery, there are huge gaps between countries. For example, while one-third of people with mental health disorders receive treatment in high-income countries (HIC), in lower-middle income countries (LMIC) the proportion is as low as 2%. An international survey of clinical practice for heart failure found that only 59% of quality of care indicators were achieved under clinical trial conditions. There are issues around condescension, intimidation and even physical abuse.

Achieving a perspective where providers interact with patients and families to better understand their issues beyond just the organ or the disease, is very much at the core of people centredness. Service delivery is challenging due to the complexity of health issues – multiple morbidities, fragmentation of services, inequalities and inequities.

The PCIHC Strategy is not about laying out the principles, but is about how to move from the current situation and realize the differences that would result from changing the system. WHO envisions that a people-centred framework would not be a luxury just for rich countries, but should speak to every country in the world and be applicable in every setting. It should bring together different providers and service sectors, for example, approaches to primary care need to encompass social care, home care, and hospice work.

Implementing and achieving the vision of this Strategy would be politically difficult as it would challenge current competing power interests. It would require special skills of visionary leadership to imagine and realize the changes. There would be many challenges including:

- Demographic and epidemiological transition
- Socio-political factors: concerns about health care costs and cost efficiency, increasingly active and organized consumers
- Technological advances: patient self-monitoring and self-management, linkages between health-care providers (e.g. electronic medical records)
- Globalization: export of unhealthy lifestyles and medical tourism.

People centredness is about organizing services around people's needs, demands and preferences rather than disease specific or organ-based services, and rethinking the systems to address issues due to globalisation. The Strategy would stress the importance of measuring service delivery around this approach and its progress. The Strategy proposes five strategic directions:

1. Empowering and engaging people
2. Strengthening governance and accountability
3. Reorienting the model of care
4. Coordinating services
5. Creating an enabling environment

Strengthening governance and accountability is a mutual exercise between the system and its structures with people and the community. How a decision is made and how to make it

participatory is about reorienting the model of care, coordinating resources and creating an enabling environment, which touches on many issues, like paying mechanisms, leadership, competencies, human resources and so on.

How do we bring together the notions of UHC and PCIHS? It is about achieving universal health coverage with people-centred and integrated health-care services. The PCIHS analytical framework is an interface between the community and the system, not like a traditional sector approach that centres around the governance and financing, but with the involvement of all the other sectors. It looks beyond the traditional lenses of health-care delivery systems and shift to health services that are coordinated and integrated, recognizing that education and social services are important components of such an approach.

So what can be done? Dr Montenegro illustrated the principles of the PCIHS approach (Figure 2) and explained the linkages between these principles. Some challenges are context-specific, which pose difficulties. Some countries are resource-poor, yet do very well in the area of patient centeredness. There are countries with the same levels of income, but people do not have access to health care.
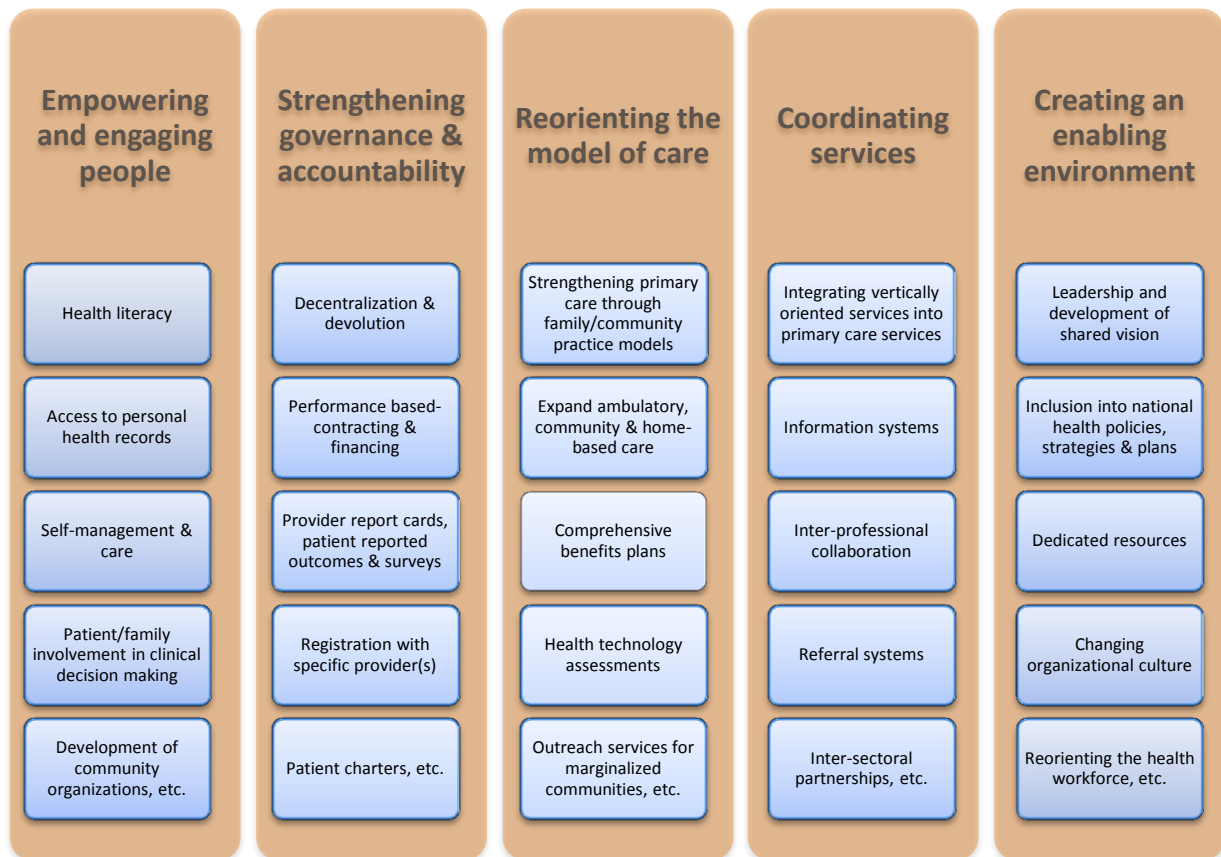
Strategy implementation will be country-specific, equity-focused, ensuring that people's voices are heard, recognizing interdependence, sharing knowledge and encouraging learning. There are many unknown factors. Even when we know a pilot study has been successful, scaling up will still be difficult to achieve.

Next steps: WHO will produce two interim reports and mobilise resources in support of the Strategy implementation. The rollout of the Strategy implementation will be collaboratively organized with other partners during the second semester of 2015 and will include the launch of a web-based platform on PCIHS.

Key points from the discussion:

- *Engagement improves patient safety:* Health-care professionals are expected to manage health-care complexity in their daily work, provide evidence-based health-care services, and maintain a safe environment for patients. Research shows that there are fewer errors when there is better communication between health-care providers and patients, and when patients are fully informed about their medication or treatment.

- *Traditional and complementary medicines:* There are challenges in addressing patient safety issues resulting from the interactions between traditional and complementary medicines (TCM) and western medicines due to fragmentation in the two systems of services. In many places, TCM may be seen as complimentary, but for some countries, they are primary and central to care. In the WPRO region, TCM is very important. In the countries where it is complimentary, such as Australia and New Zealand, research shows that many people are choosing complementary health care because they are not getting holistic support from the conventional health system. What this phenomenon points to is the lack of a people-centred approach, the lack of responsive practitioners, and points to room for improvement in the mainstream health system.

Figure 2: The Principles of the PCIHS Approach

Empowering and engaging people	Strengthening governance & accountability	Reorienting the model of care	Coordinating services	Creating an enabling environment
Health literacy	Decentralization & devolution	Strengthening primary care through family/community practice models	Integrating vertically oriented services into primary care services	Leadership and development of shared vision
Access to personal health records	Performance based-contracting & financing	Expand ambulatory, community & home-based care	Information systems	Inclusion into national health policies, strategies & plans
Self-management & care	Provider report cards, patient reported outcomes & surveys	Comprehensive benefits plans	Inter-professional collaboration	Dedicated resources
Patient/family involvement in clinical decision making	Registration with specific provider(s)	Health technology assessments	Referral systems	Changing organizational culture
Development of community organizations, etc.	Patient charters, etc.	Outreach services for marginalized communities, etc.	Inter-sectoral partnerships, etc.	Reorienting the health workforce, etc.

- *TCM and patient safety:* From a patient safety perspective, there may be herb-drug interactions and having a reporting system that captures an adverse event becomes critical. For places where there are both traditional Western medicines, there should be a series of mechanisms to ensure patient safety. The most important thing is to put traditional medicine on a regulatory platform so as to have certain standards under which practitioners operate as well as the quality assurance process for the products. People can really help systems and policy-makers in developing mechanisms to protect public health and safety.

  TCM is a unit within the SDS Department and a World Health Assembly resolution on the traditional medicine strategy has just been passed, indicating a need to recognize and integrate safe complementary and alternative medicines and services into health-care systems i.e. with western health care approaches. The PCIHS strategy recognizes these domains and work together with colleagues to ensure patient safety.

- *People-centeredness and integration*: When patients do not take prescribed medicines, there may be many reasons for this. They may disagree on the medication, or the consultation did not provide a safe environment for comprehensive discussion on available options or the patient's preferences. Patient engagement needs to integrate all those things. The ideas on integrating health care into the wider social determinants of health bring opportunities on two levels: health literacy and people-centredness. Improving health literacy is about education and the type of information given to patients, as opposed to interventions that induce behavioural change.

  Mainstream Western medicine may not be holistic in the way that care is provided. It is influenced by determinants such as conventional medical education and training, which place importance on specific outcomes that might not be particularly patient-centred. Thus, priorities should include more focus on supportive care, in addition to treatment, symptom relief, etc.

When communities feel abused and dehumanised, sometimes engagement is not enough. They need to know there is a mechanism for redress. That is, the system should be responsive. The community should be informed and knowledgeable about the resources available to health-care workers etc. so they understand the limitations and have realistic expectations. The community can understand that it is not about individual health-care workers, but that the government is accountable. This is another level of engagement.

Integration could be the buzzword of health care for the next few years, as was 'quality' in the past decade. Integration may be divided into strategic integration and people integration. Integrating care would be very costly as it would involve changing cultures, changing management, redesigning hospitals and changing the way medicine is taught. It would require the formalisation of professionals or experts or leadership groups to lead these changes. Evidence would be needed to support integration efforts as the costs would not be only in terms of monetary costs, but also political costs.

However, the cost of inaction could be worse, even in economic terms, due to health-care costs that would arise from fragmented and poor quality services. Countries that have had the leadership and the courage to invest in these already are already seeing the benefits.

Integration may have different focuses in different settings. For example, some research in the United States brought patients, clinicians and policy-makers together. The physicians came in and the integration was medically-based. The patients came in and the model was outcomes-based. So it is important to ensure that integration is based on both evidence and outcomes, which are central to patients' preoccupations.

The attitudes of health-care providers impact the delivery of care. Issues like staff burnout, staff shortages, lack of dignity at work, lack of support from managers and peers, all affect staff attitudes, which in turn, impact on the way they deliver care and this leads to depersonalised care. So health-care providers also need empowering.

Four points to consider: 1) it is much easier to say 'the what' than do 'the how'. 2) for the 'how', it is important to think about country specific roadmaps and articulate strategies that are specific to their context. 3) people-centred care needs to be considered as a journey rather than an end and that 4) change affects people. When someone takes control, someone else often loses it. So careful consideration must be given to all aspects: about people, about employers, about health-care providers and other stakeholders, as to how the changes may affect them.

3.0   Working Groups

3.1   Working Group 1 - Meaningful and effective engagement: what does it look like? How do we measure it?

Facilitators: Dominick Frosch and Stephanie Newell, Rapporteur: Bruce Agins

Dr Bruce Agins presented the summary of group one's discussions. The group began by acknowledging that patient engagement is complex, exists at various levels and involves many different 'actors'. Other domains explored included representation, satisfaction and loyalty, the journey experience, knowledge and information or expectations (indicators, inputs and outputs).

There 'is not one concept of patient engagement'. Each 'actor' has a different perception of meaningful engagement as the practice is influenced by socio-economic, political and clinical factors. It depends on whether care is short-term or long-term, and the setting in which such engagement occurs. There are different levels and types of engagement, including individual, organizational and at the policy level also. So context needs to be considered and it is important to capture the multiple and intertwined viewpoints of the different actors.

What is 'meaningful engagement'? Is it at the level of theory or at the level of actual experience?

- Meaningful engagement is an emotional commitment and involvement from both patients and providers. It has to be meaningful to all stakeholders involved and involve the patient's experience, which can be facilitated and measured through evidence-based tools and interventions.

- It refers to the development of a long-term and committed 'relationship' between the patient and provider

- It requires responsiveness from the provider *"not that you are doing everything I want, but that I feel you are responsive even if you don't solve my problem or heal my disease".*

- Responsiveness is very important - *"engagement is more like a state of mind",* involving listening and responding to what is heard *"just listening is not enough – I need to be able to respond to what I am hearing".*

Table 1. – Summary of characteristics and measures of meaningful engagement

Level	Actions to make it meaningful	Measurement and sustainability	Issues
Policy level	Patients/people as members of hospitals, councils or national boards Significant representation for patients/citizens/consumers Have a voice/able to influence decisions - depend on what level e.g. spectrum	*Measurement* Voting rights Ability/capacity to shape decisions *Sustainability* Process of selection Training for patient representation	Are they a <u>full member i.e.</u> do they have voting rights? How many is 'significant representation'? A minimum of two patients, for empowerment? Are they empowered? Was the selection process credible?
Organizational level	Wider network/panel of patient representation Transparent/credible selection Education/orientation and training for patient representation Dedicated person/team e.g. Chief of Experience/officers Feedback mechanisms Responsive to patient needs e.g. adverse events	*Measurement* Standards/ written terms of reference (TORs) for engagement Feedback/evaluation *Sustainability* Reflection on whether certain interventions work – a process that can analyse and reflect upon outcomes	Specific criteria and processes need to be in place to ensure significant patient's voice in each meeting.
Direct care	To have a voice - shared	Measurement	Important to measure patient experience and

Level	Actions to make it meaningful	Measurement and sustainability	Issues
	decision-making Sense of control over one's health and care – able to determine who is involved (family/carers); able to choose company/provider of choice (for those with private health-care cover) Patient/family member can be involved if have issues or concerns Information – relevant, evidence-based info for informed decisions Support for self-management, self-care, experiential leaning Awareness/mechanisms for staff feedback & recognition and job satisfaction	Patient satisfaction/ experience How often is experiential self-care education provided to patients? Self-management Sustainability Access to information and shared decision-making Training of HC professionals & awareness raising	satisfaction for benchmarking Available tools are not sufficient to assess patient and family engagement Patient experience vs. patient satisfaction
Community engagement	Voice, dialogue meetings Accountability, roles in supporting patients and families		

Key points from the discussion:

- Role of the patient, families and providers are the main determinants of PFE.

- Measurement is essential for improvement. Patient satisfaction measurement is not meaningful. However, if done differently and appropriately e.g. by measuring satisfaction with the experience and at different points along the care pathway, it may lead to a more in depth study of experience in different contexts and offer meaningful data.

- Satisfaction relates so closely with expectation. So it is important to map out very clearly what people can expect and what they should be responsible for. It is also important to look at safety, not just satisfaction.

- Patient experience measures are actionable and they resonate with the basics of care delivery. What is missing is the engagement measure to capture the contribution of informed consent or shared decision-making.

- Patient experience and feedback would allow expression of any concerns about safety. It is important to be clear about the purpose of such reporting. Gold standards for measuring real-time information can be very powerful tools, but it needs to be clear on the purpose for which it is serving.

- For example, a monitoring system through iPad/telephone app can be used in real time i.e. when the patient is still in the hospital and that the reports feed to the CEO/Director level, enabling them to monitor incidents and see whether they have been dealt with.

- For any measures, their concepts and definitions need to be clarified as there are huge variations in understanding of what these words mean, e.g. engagement, participation and involvement. It should be clear whether and how clinicians are really involved in this feedback process.

- Reward and recognition are important elements in dealing with experience at the organizational level.

- On the representation, it is important to ensure that disadvantaged patients/people e.g. those with particular disabilities, language barriers, or those who find it hard to speak up are represented and engaged.

- It is also important that patients and family members on boards, committees and government structures do not become 'insiders'. To address this, there should be a comfortable atmosphere for contribution where staff and patients can work together efficiently. Patients need to understand their roles and are aware for whom they are representing. Another practical approach is to set up a separate body of patients so that they are not intimidated by physicians at that table/board.

3.2 Working Group 2 – Roles, responsibilities and expectations: patients, families, health-care providers and policy-makers for facilitating patient engagement

Facilitators: Sue Sheridan and Kadar Marikar, Rapporteur: Angela Coulter

Dr Angela Coulter began her presentation by calling for recognition that patients and families faced with long-term or chronic illnesses provide most of the care; , and the time spent interacting with health care represents only a small fraction of the time they live with the and manage condition. Recognising the primacy of the patient's role may help reorient what providers and policy-makers should/could do to support patients.

Table 2. Summary of key issues re roles, responsibilities and expectations

Issue	Patient	Provider/Policy-Maker
Health literacy	Be critical consumers and recognize limitations. Understand the limitations of medicine/health care – benefits but also the inherent risks. Understand the health system and be aware of engagement opportunities Everybody is responsible for noticing any safety issues	Ensure patients understand health-care system Educate patients and providers on engagement, and providers to acknowledge patients Acknowledge that there is a spectrum – patient engagement to partnership – institutionally and individually Understand the limitations of medicine - only provide what is beneficial and not what is potentially harmful
Communication	Be honest - from both patients (what's happening) and providers (what we can/can't provide) Articulate patient's expectations,	Understand and deliver patient expectations, recognize that people have different expectations Manage expectations and perceptions of care

Issue	Patient	Provider/Policy-Maker
	recognize and communicate things that are important All parties are responsible for creating a welcoming invitation for participation Recognize that not every patient wants to be involved at the same level or intensity. Some may want to work alongside providers and researchers in policy-making. Others may just want to engage at the direct care level To get a buy-in from clinicians, patients should communicate 'in their language and in their voice' and show them the evidence	- spell out what patients can expect Have a strategy that outlines the roles and responsibilities of each member of staff at each level Clarify the responsibilities of the providers as people may perceive them as 'Hollywood school of medicine' – i.e. doctors are all-knowing and entirely responsible Ensure there is a point of contact for everybody who has a concern Advice and referrals – some rare diseases often don't have specialized services available within their own country
Resources and systems	For health systems and care to be understandable and accessible to everyone, the design needs to start at the ground level and the community has to be engaged from the beginning of the redesign	Develop the infrastructure that invites patient participation e.g. have an advisory council/report outcomes etc. Have patient engagement embedded within accreditation standards Include engagement in job descriptions so as to make it systematic. Inviting patient's participation to be part of clinicians' role. Then give _all_ staff training and education on how to invite patients to participate 'Train you, reward you, and support you' - the organization or leader should create an environment that supports engagement as part of the system/structure
Capacity-building	Get to know relevant policy-makers so as to approach the right people with the right message and approach Be aware that policy-makers need evidence - should give space for an engagement measurement that allows learning by doing Capacity build patients for engagement in research Capacity building through patient forums, access to information, reviews of the service Capacity build patients around innovations. Often this is left to the providers. But innovation to improve care is a critical role of the patients as well. Look at the community around the health facility and suggest mechanisms to better engage with them.	Encourage users, patient organizations, the community to give feedback Ask and inform patients about local community, support groups, patient organizations etc. and engage them for improvement, problem-solving, identifying and adopting appropriate solutions Learn about the patients, their community, their needs, their diseases outcomes which are important to them Hear patient stories, help them with how to best tell their story – capture the essence of it Changing the mindset of patients/community through innovative mechanisms, support them to innovate for issues within their community

Issue	Patient	Provider/Policy-Maker
Social determinants	*(June Boulger from Ireland shared approaches that incorporate social determinants of patients' health):* Access – ask patients to inform if they have any special needs, or if they could not make an appointment Dignity and respect – they need to also respect other patients and staff Safe and effective care – patients could wash their hands, could inform whether health-care professionals did not wash their hands, patients could ask about their early warning score, ask questions Information – access to health literacy. Providers could help direct them in terms of evidence-based material, health information and in terms of involvement in decision-making, feedback on experience. Expectations - patients are aware of what to expect and are aware that they can take part to drive those expectations.	It is important to understand social determinants of health, particularly at the policy level and what patients and families can do on the continuum The Five Simple Actions in the Moore Foundation Roadmap provide guidance related to health-care delivery interactions on different levels, not just self-management Consider the patient context, challenges, psycho-social factors and their capacity to affect their ability to fulfill their expected or assigned responsibilities, such as adhering to prescribed treatment. Be aware of the enablers for patients to fulfill their responsibilities. For example, when making appointments for follow-up, make sure to ask the patient if the time suits them or if they have transport to the hospital etc. Health systems have a responsibility to support and enable the patient and also to acknowledge when they are doing well. Patients don't just follow rules. They make the effort to get better and they need to be empowered to continue to do so.
Representation	Representing *all* patients/people - represent and advocate for the benefits of the whole community - not particular groups or those volunteers Be informed about patient's role in policy-making.	Include patients on boards, policy decisions about resource allocations, financing, approaches to health care Enable them to have input - even remote populations Speaks to patients to find the middle ground – something that works for both policy-makers, providers and patients.
Informed decisions Shared decision-making	Be more involved in information generation, development of decision tools Have a voice in research, be involved in priority setting, highlight things that are important to patients	Keep abreast with the 'cutting edge' technologies so as to provide patients with decision aids e.g. audio-visual materials to show risks and benefits of treatment Capture views of all patients across the spectrum - involve people from disadvantaged areas Ensure shared decision- making/ participation as part of the normal work ethic. Support shared decision-making, provide information/decision aids Where possible, alter work routine e.g. nurse bedside rounding to enable participation of patients and families.
Policy-making	Be knowledgeable about policy-making structure	Ensure equal/appropriate representation - patients who come forward to the role in policy-making or advisory groups tend to be

Issue	Patient	Provider/Policy-Maker
		the most advantaged, highly educated
		The organization is responsible for supporting both clinicians and patients and for aligning incentives to enable and/or empower parties to engage
		Ensure patients understand policy procedures
Accountability	Patient organizations should have policies and frameworks about policy making Patients understand their rights and responsibilities	Ensure patient engagement in policy making not to become a tick-box exercise – must evaluate and measure Ensures transparency and accountability Admit patients into policy and accreditation frameworks Provide effective leadership and support all leaders at the level of the system.

3.3 Working Group 3 – How to create an enabling environment for patient engagement?

Facilitators: Susan Baade and Hussain Jafri, Rapporteur: Luisa Pettigrew

3.3.1 Understanding an 'enabling environment'

An 'enabling environment': an environment where the engagement of patients and families with the health-care system at any level – local, national, regional, global – is expected, encouraged and facilitated.

- Holistic and informative: patients receive information, understand what to expect, feel comfortable and have space to talk and provide input and feedback.
- It may be created or encouraged. For example, a World Health Assembly resolution could encourage countries to make an enabling environment by taking collaborative actions with health-care providers, policy-makers, health minsters, the health system as a whole.
- It requires commitment from stakeholders who understand their roles and responsibilities.

3.3.2 Identifying and engaging stakeholders

Key stakeholders who can co-create 'an enabling environment' include:

- Patients, families, communities
- All health-care providers from frontline to leadership
- Government, Ministry of Health, regulators
- Payers of health care
- Civil society
- Private sector
- Universities/teaching institutions
- WHO and other global organizations
- The next generation

Obtain commitments from stakeholders through:

- Advocacy – through patient advocates, evidence-based relevant policy and sustainable practices.

- Shared practices, harmonized guidance and consistent policy across WHO – a joint initiative, to avoid duplications. It should not be just the initiative of the WHO headquarters or regional offices, all regions, and all country offices should be involved in its development and implementation.
- Shared vision and goals – consistent messages and approaches from national, regional and global levels.
- Clear definition of patient and family engagement from WHO.
- Shared accountability – all stakeholders understand their roles, expectations, the possibilities and clarity of how the engagement process will work.
- Commitment at different levels through a national policy – e.g. national policy on patients' rights, a patient's charter.

3.3.3   Supportive organizational governance, systems and policy

- Have a strong primary care system of family doctors for stability, continuity of care and develop patient-provider relationships.
- Develop or restructure health-care financing that facilitates engagement. Create a national policy on PFE; engagement to be part of health-care standards.
- Have a formal mechanism to engage and collaborate with patient groups, NGOs, civil society, volunteers; Have a clear and appropriate division of responsibility.
- Have a feedback system – staff are trained to be familiar with the system, part of regular work, clear responsibility and reporting lines, effective patient follow-up.
- Have health services complaints commissioners, with responsibilities to conciliate complaints, mediate conflicts, take disciplinary action where appropriate.
- Have patients as focal points/messengers for disease prevention and health promotion.
- Incentives – including non-monetary incentives; Recognize efforts – especially in the context of shortages of workers, reward achievements – celebrate success and promote positive attitudes and positive thinking.

Supportive environment for change management, care integration:

- Build institutions and practices that will create or motivate change. Changing practices will lead to changing of mind-sets. Then support this with legislation that involves stakeholders across the system.
- Demonstrate success and shared practices first, before trying to change policy, which is the key to creating an enabling environment.
- Involve patients, consumer organizations to represent the consumer voice in research and policy decisions, with training and financial support.
- Ensures true UHC - people's access to affordable, safe, quality and people-centred care.
- Remove or minimize geographical barriers and support people who are visually impaired or disabled or those with language barriers.

3.3.4   Capacity-building for engagement

- Improve health literacy by providing effective communication, appropriate information and relevant education.
- Train, motivate and facilitate patients' participation, and staff to be aware of patients' rights and understand their needs, preferences and circumstances.
- Build and strengthen their capacity to respond - engagement being part of professional training and continuous on-going learning.
- Identify needs or specific issues - asking patients and providers; support and training for junior or inexperienced staff.
- Train people on communication skills- all stakeholders must learn to listen, show empathy, love and understanding, share decisions, empower each other and deliver services or communicate with a smile.

- Recognize and address 'human factors' – doctors are trained to be 'dehumanised' and may prioritize clinical emergencies and requirements over patient centeredness. It is not easy for them to just make a switch.
- Foster leadership and dynamic civil society organizations to work with patients or community members - support them to spread and scale up.
- Establish patient/family advisory councils – communicating with clinicians in a coordinated way, able to mobilize resources; Foster people/community leadership; promote peer support, create a collective voice.
- Facilitate a patient's access to their patient records, information and tools.

3.3.5   Accountability and ethical considerations

- Transparency about representation - who represents whom?
- Transparency about funders, public sector, corporate interests;
- Declarations of conflicts of interests

3.3.6   Advocacy & awareness-raising

- Patient Safety Year 2016 - The Group nominated 2016 to be a Patient Safety Year – to reinvigorate and give impetus to the work at global, regional, national and local levels. This is our vision and these are our strategies.
- World Health Day – feature patient.
- Have a day each year to be Patient and Family Engagement day.
- Explore the use of social media.

Key points from discussion:

- Dignity and respect are important components of PFE.
- Lack of engagement and non-responsive services are not always an attitude problem, but may be due to the provider's ignorance of the patient' s rights and needs.
- Incentives will play a big role on PFE – not just money.
- There should be procedures for the blame-free reporting of adverse events. There should also be a mechanism or channel for people to contact health authorities – to give feedback, share information e.g. on medicines they are taking, etc.
- Moving PFE from believers to the mainstream, there is an issue of measurement. UHC and quality will be an important point to consider when thinking of the next steps. There is a list of perhaps 100 core global indicators and there are also a lot of alternative indicators. What indicators we would be able to harvest from this framework, which can be refined over the years?
- There is another WHO effort on moving towards standardising health facilities assessments. How does PFE fit into that?

Sir Liam Donaldson offered three points for consideration:

1. The premise of all of this is that we have been thinking about health care developed in a conventional way by providers and we want patients and families to help shape it. Based on work in low-income countries, giving patients, with chronic diseases, budgets to manage would completely change the understanding of what we mean by PFE.

2. When it comes to producing a framework, generic standards will only take you so far. There are very context-specific ways of involving patients and families in various settings or illnesses, e.g. end of life care.

3. Roles of technologies - probably in the next two years, we will see an explosion of software for monitoring your own health/aspects of health. There is very little being done to assess the way the health-care system should relate to people coming along with that information.

- The importance of community health workers and fostering community engagement in LMICs is an area the developed world can learn from. There are ways that the Roadmap developed by the Moore Foundation could be adapted or modified to suit countries outside the US. It may be difficult to move from north to south, but the potential for adaptation is there. The ultimate goal is to put together a framework for action, for pilot projects etc.

Day 2: Tuesday 28 October

4.0   Key Partners in Engagement

4.1   Introduction to the Gordon and Betty Moore Foundation

Dominick Frosch, The Moore Foundation

Dr Dominick Frosch provided an overview of the Gordon and Betty Moore Foundation, a philanthropic organization based in California, USA. The founders are Gordon and Betty Moore. Gordon Moore was a co-founder of Intel and in the year 2000, the Moore family decided to take a considerable portion of its wealth and create a philanthropic organization.

The Moore Foundation's mission is to use bold ideas to create change. Its 'Patient Care Program' is domestically focused, growing out of what was initially a nursing initiative focusing in the San Francisco Bay area, which ran for around 10 years. The impetus for that was that Betty Moore, who, during a hospitalization, experienced an adverse event. This motivated the Foundation to be a part of efforts to prevent medical harm. The 'Patient Care Program' focuses on taking some of the learning that we developed from the nursing initiative on to a national scale. It also broadened the scope of the programme to focus on health-care systems re-design and systems engineering through supportive and meaningful family engagement. The Foundation believes that this will help to achieve what is often called, in the United States, the 'triple aim', namely: 1) better health outcomes (better care); 2) better patient experience of care; and 3) lower costs.

The Foundation also supports work around improving how intensive care units function. Two of the participants in the Consultation are working on projects supported by the Foundation, looking at how to re-design intensive care units to encourage more engagement with patients and families.

4.2   International Society for Quality in Health Care (ISQua)

Peter Carter, ISQua

The International Society for Quality in Health Care (ISQua)'s role is to inspire and support quality improvement and safety globally. ISQua works with over 100 experts around the world, fostering very strong networks. Its programme includes external evaluation and accreditation. They accredit accreditors, meaning that ISQua sets a global standard for the accreditation of accrediting organizations. Education is the 'new kid on the block' in many ways, because it is a programme that ISQua only started in 2011-2012. The education programme now has a fellowship programme which was initiated in 2012 and is taught online globally. ISQua is launching this as a global programme in collaboration with 15 universities around the world.

ISQua also focuses on innovation. Anticipating what lies ahead will initiate the thinking about how to manage health-care quality issues in the future. ISQua provides advisory services and collaborates with its networks, experts and other stakeholders for advice on the safety and quality of services. Concerning patients, ISQua tries to represent and incorporate the patient perspective into its work and has a patient representative on its board (Denice Klavano from Canada). There is also a group called 'Partnership with Patients'. In addition to having a patient on a committee, ISQua also has a global reference group. The ISQua annual international conferences attract around

1100 people from about 70 countries. They have just held one in Rio de Janeiro and will host the next ones in Qatar (2015) and Japan (2016).

Following The Moore Foundation and ISQua presentations, Dr Ed Kelley provided an overview of the day's agenda, which would feature key themes on empowering and capacity-building for patients and families, as well as for health-care providers.

Dr Kelley emphasized that for this particular work, WHO's ability to move forward with patient and family engagement and involvement would require support from Member States and that it has to resonate with their priorities. It is important to learn about how to get Ministries to shine a light on what they are currently doing well. So the morning agenda would include some of case studies as examples, starting with the WHO PFPS approach, then Canada, Ecuador, Malaysia and Thailand.

5.0   Empowering and Building Capacity for Engagement: Approaches and Experiences:

5.1   Patients for Patient Safety – a WHO approach for empowering and capacity building

Nittita Prasopa-Plaizier, WHO

Nittita Prasopa-Plaizier provided an overview of Patients for Patient Safety (PFPS), a programme within the Patient Safety and Quality Improvement Unit of the SDS Department. The PFPS Programme supports a global network of patient advocates of the same name (Patients for Patient Safety global network).

PFPS was set up as a core pillar of the World Alliance for Patient Safety. Inspired by Sir Liam Donaldson's vision, it aims to engage and empower patients and families to learn from their experience and involve them in initiatives aimed at improving patient safety. It began with a workshop in November 2005 in London, where participants jointly created the patients and families vision for engagement, known as the 'London Declaration', and formed a network of patient advocates to champion for patient safety. They have become known as Patients for Patient Safety 'champion'. Participation in a WHO-approved workshop and endorsement of the 'London Declaration' have been the centrepiece of the designation of PFPS advocates (champions).

From 2012, WHO's engagement approach changed from directly engaging and empowering individuals to empowering and engaging with local leaders and organizations through WHO regional and country offices, to support them to engage and empower patients and families. This model has been piloted (in collaboration with local partners) in Ireland (the Health Executive Office), Canada (CPSI), Malaysia (MSQH and MoH Malaysia), Ecuador (the Hospital de Especialidades Dr Abel Gilbert Ponton de Guayaquil) and Thailand (HA Thailand).

Working with national organizations is a more sustainable model as it offers opportunities to foster collaboration between patient advocates, policy-makers, health-care providers and WHO at the country and regional office levels. WHO's approach is empowering local leadership and promoting ownership through technical support for capacity-building of patients, providers and policy-makers. Each PFPS capacity-building workshop includes local policy-makers and health-care providers to share about the national health system and services. This enhances the patients' knowledge of their own health system as well as raising awareness of patient engagement among policy-makers and health-care providers.

Sir Liam Donaldson provided his reflections on the PFPS programme. PFPS was among the inaugural programmes of the World Alliance for Patient Safety as was the Global Patient Safety Challenge on 'Clean Care is Safer Care'. He provided insights on key lessons learnt on three key areas.

Technical support: Patients and family members who have suffered harm can bring their personal experience to share with the public e.g. at a conference. Their stories move the hearts of health-care professionals, whereas the data and the technical presentations move the minds. Thus, patient stories are immensely powerful. However, not all patients are instantly good at presenting their experience. They sometimes need support, feedback and advice to do this well. However, support from WHO was limited, partly due to no support mechanisms being set up/agreed to and partly due to a desire for the PFPS network to operate with a certain degree of independence. In hindsight, the PFPS network would have welcomed more direct input from WHO in the earlier stages.

Facilitation: WHO did not open the doors that the patients needed to access and to influence health-care policy. WHO should have used a more vigorous approach to facilitate patient champions access to other stakeholders.

Visibility: The lack of interface between PFPS and other programmes within WHO Patient Safety due to the absence of mechanisms to orient or link the PFPS group with other programmes. So for a long time, though they supported others, the PFPS advocates were left without any concrete projects or any flagship projects to call their own.

Sue Sheridan concurred with Sir Liam Donaldson's reflections and reiterated the importance of training and capacity-building for patient advocates to frame their story and deliver the messages effectively. She urged for a more strategic approach that encompasses capacity-building for health-care providers and policy-makers.

Nittita Prasopa-Plaizier reiterated that, despite its name, the PFPS programme's roles and responsibilities have expanded to embrace broader engagement and empowerment for health, working across SDS and departments, collaborating for engagement on UHC, on people-centred and integrated health services and towards better radiation safety. Many PFPS advocates also work with the communities, engaging civil society, the public and health-care providers.

5.2 Engagement and empowerment: the Canadian experience

Denice Klavano, PFPS Canada

Denice Klavano, representing PFPS Canada and the Canadian Patient Safety Institute (CPSI), provided an overview of the engagement and empowerment approach employed by PFPS Canada.

PFPS Canada is a patient-led programme within CPSI and is funded by Health Canada. CPSI is a not-for-profit organization that works to raise awareness and facilitate implementation of ideas and best practices to achieve a transformation in patient safety. PFPS Canada aspires to advocate for safety and health-care improvement to close the gap between 'the health care we have and the health care we deserve'.

PFPS Canada's vision is 'every patient safe' and the mission is to 'champion the patient voice to advance safe health care'. It has two co-chairs and its structure consists of four internal processes:

1) Recruitment, interview, orientation, retention; 2) Internal communication – newsletter, meetings; 3) Matching members with participation requests; and 4) Knowledge transfer among members.

A Brief background of the development of PFPS Canada:

In 2005, CPSI started supporting PFPS Canada, providing budget and project management support. The group was formed in 2006, following the first patient workshop, which was attended by 21 participants. Another meeting took place in 2007 in Winnipeg, at which the participants (25) endorsed the London Declaration. Between 2006 and 2009, the group engaged in speaking engagements, endorsements, sharing stories and strengthening internal processes (created charter, board of directors, co-chair model). In 2010, PFPS Canada decided to be a programme of CPSI, there

was no board, but it functioned through a co-chair model; committees became Working Groups; closer strategic and operational alignment with CPSI. In 2012, it convened the first ever virtual WHO PFPS workshop (19 attended), followed by an in-person PFPS workshop (27 of 52 members participated) in the workshop), which was also attended by a representative from WHO (Nittita Prasopa-Plaizier). Succession planning and new initiatives like knowledge transfer among members were created.

PFPS Canada has had a lot of successes in engagement, with 153 requests for partnership, contributions in the last twelve months, the majority of which have been consultations at local, provincial, national and international levels. PFPS Canada advocates are members of boards, building partnerships with other stakeholders. Other themes of activities in which PFPS advocates are involved include education, organizational governance, policy and research, speaking engagements with colleges, nursing students, medical students, and conferences, sharing personal stories in person and through video, participating in projects such as accreditation standards, and contributing to the development of the Canadian open disclosure guidelines. These guidelines have made disclosure mandatory in all provinces in Canada.

Some challenges:

- *Meetings:* As a big country geographically, meeting face-to-face is extremely difficult and conference calls can be a challenge with the time zones.

- *Under-represented communities:* It has been difficult to engage or provide capacity-building support to people from under-represented communities.

- *Consistency of messages:* The group has tried to address the above issues by holding webinars, conference calls and producing newsletters. The challenge is to ensure consistency of messages around patient safety.

- *Expansion of activities:* There are requests for PFPS champions' contribution to patient involvement and patient-centred care that go beyond patient safety issues. As the group is diverse, they are able to respond to requests from different people and alternative groups.

Four lessons learnt:

- Support members to continue healing and engage.
- Develop member capacity to be confident partners.
- Improve participation evaluation to learn and improve.
- Link to similar organizations to share and transfer knowledge.

Opportunities going forward: To continue to build on the expertise of members and create more partnerships with health-care professionals and researchers. The group tries to provide on-going support to members, which has been one of PFPS Canada's challenges and simultaneously an opportunity. A lot of our members, especially in rural areas, feel very underused, and there is no financial resources to facilitate their travel. It is important for the group to move forward and innovate ways to engage these members so that they feel involved and for them to have a purpose as well.

5.3   Engagement and empowerment: the Ecuadorian experience

Jonas Gonseth Garcia, Hospital de Especialidades Guayaquil "Dr Abel Gilbert Pontón"

Dr Gonseth shared his experience as a hospital director in engaging patients and communities in the transformation of the Hospital de Especialidades Guayaquil "Dr Abel Gilbert Pontón".

The hospital de Especialidades "Guayaquil" Dr Abel Gilbert Pontón hospital is located in Guayaquil, Western Ecuador. In 2012, the hospital was considered disastrous without any foreseeable opportunity to improve. The media coverage of the hospital prior to 2012 illustrated the extremely dire conditions, with over 50% of the coverage reporting bad news. The President of Ecuador had asked *"is it not against human rights to have a hospital with such conditions?"*. The hospitals challenges, as outlined by President Correa, included corruption, poor governance and a lack of respect and compassion to patients. It was political and many attempts to reform the hospital yielded 'no real solutions'. So they looked for someone from outside of Ecuador to lead the changes. Dr Gonseth was dubbed 'Jonas the 5th' because he was the 5th manager in a one-year period.

He leveraged the support of patients and the communities in overcoming political issues and made the case for the hospital's transformation. The initiative was facilitated by the already existing legal framework for engaging and involving the communities - the Ecuadorian legal and political framework on the citizen's revolution, from which there was legal support for patient engagement. The law states:

Art. 45. Different functions of the State establish mechanisms to ensure transparency of their actions, plans and programs to facilitate active involvement of citizenship in its management.
(…)
Art. 46. The Citizens in individual or collective processes are asked to control (…) all functions of the State and the different levels of government (…).

The collaborative approach changed the attitudes of the staff and communities, engaged them to confront and address the problems of the hospital. Community consultation was carried out to identify issues, concerns and priorities. It revealed that patient dignity came out as the main concern and that having physical space was important for improved patient dignity.

A hospital committee (Comité de Usuarios) was set up from the beginning in September 7, 2012 to carry out the hearing of people's voices, formally and informally. The communities were invited with the message 'we want to transform the hospital with you' to work on the hospital problems. This empowered formal and informal leaders, champions, and the Committee reached out to communities, schools and professional bodies to explain the new initiative. More than 1000 patients were trained in different areas.

Patients felt empowered as they felt they were involved in a global strategy. In 2013, a PFPS workshop 'the Convention of the Pan American Network of Patients for Patient Safety', facilitated by WHO was convened, conveying the message to the patients, 'you belong to something that is global'. They were part of the workshop, online training and virtual training with WHO resources. There were members of the hospital involved in medication safety. The medical students were also involved in patient engagement.

Engagement activities also extended to hospital government bodies, including: Executive Committee (the main body - There is a meeting every month); Ethical Committee (involved in research as well); Economic Control Committee (due to shortage of economic resources, prioritization was necessary and transparency really helps. The communities felt empowered and responsible for it); Safe Hospital and Emergency Committee; Patient Experience Surveys (asking the patients and clinicians about their experience); Patient Safety Rounds; Volunteers team; Hand Hygiene Promotion; Safe Surgery Check List; and Patient identification.

The hospital works with the community to organize an 'Annual Public Accountability Session' a forum where any member of the public can report back about any issue throughout the year. In the evening, there were round tables, where different stakeholder groups discussed issues or placed in the agenda items they felt was relevant.

In two years, the number of specialists in the hospital has more than doubled without increasing the budget, but through improving performance and using resources efficiently. To reform a system amid corruption, many barriers, and competing interests, patients and community engagement has

helped to give credibility and sustainability to the reform process. After the hospital reform, the amount of negative media coverage has reduced significantly. So the reality of the hospital has changed significantly in two years. This could not have happened had the hospital not engaged patients and communities. People feel proud of the changes and should be applauded for their efforts. They feel to be a part of the patient safety framework, feel proud of their hospital and also feel accountable.

5.4   Engagement and empowerment: the Malaysian experience

Kadar Marikar, MSQH

Dr Kadar Marikar shared Malaysia's experience in creating a network of patient advocates. The PFPS Malaysia programme was initiated by the Malaysian Society for Quality in Health (MSQH), a not-for-profit NGO, which was formed through a partnership between public, private and professional bodies. MSQH is the national accreditation body for health-care facilities and services in Malaysia and it advocates for patient safety. MSQH is accredited by ISQua, the global accreditation body.

Before embarking on PFPS, MSQH already implemented some programmes related to patients and family rights as part of its accreditation activities. One of the requirements from ISQua involves ensuring that patient and family rights are addressed and that there is a patient representative in the MSQH governing body. At the same time, at national level, the Ministry of Health, Malaysia (MoH Malaysia), in responding to WHO policy on patient safety, developed the Malaysia Patient Safety Council and included patient safety goals as part of its national policy.

In 2012, MSQH sought support from WHO concerning the possibility of establishing a PFPS network with the aim to capacity-build patients to be members of the national accreditation body committee and of the Patient Safety Council. This was the start of the movement in patient and family engagement in Malaysia.

The first WHO PFPS In-Country Workshop was held in September 2013. The workshop participants were selected as per WHO PFPS guidance, which included an open call for applications through national media and MSQH website, followed by an objective and systematic screening and selection. Participants included a mixture of patients, health-care providers and policy-makers from both the public and private sectors. The workshop was financially supported by MSQH with technical support from WHO in Geneva and the WHO's Western Pacific Regional Office (WPRO). The workshop was presided by MoH and the WHO Country Office.

Following the workshop, participants met on 1 October 2013 to discuss ways forward and turn PFPS Malaysia into a nationwide network. The group formalized the team members, selected a chair person and created the PFPS Malaysia organizational structure and decided on activities in which members could be engaged. During the development phase, MSQH provided secretariat and logistical support for the group to function. The PFPS Malaysia network was formally launched on 29 April 2014.

PFPS Malaysia is supported by MoH Malaysia, the Association of Private Hospitals of Malaysia (APHM), as well as other professional bodies. It works in collaboration with the WHO PFPS at the WHO Service Delivery and Safety Department in Geneva, WPRO in Manila and the Malaysian WHO Country Office.

The second PFPS workshop was convened in October 2014 to explore quality improvement initiatives that would engage patients in implementation at hospital levels and to train and orient the participants in these quality improvement (QI) projects. Fourteen hospitals took part. A pair of representatives – one patient and one hospital leader or manager from each participating hospitals attended the workshop. The second workshop was supported by WHO (technical experts from WHO SDS and WPRO, funding support from the WHO Country Office) as well as the MoH Malaysia and MSQH.

Outcomes of the second workshop:

- A pilot project focussing on patient falls and medication safety was established with agreed action plans.
- All 14 hospitals (8 public and 6 private) agreed to participate in the pilot project.
- Hospital committees or governing boards where PFPS Malaysia members can actively engage with the hospital staff were identified.

PFPS Malaysia's 6-month workplan (first half of 2015) includes agreeing on a code of conduct, identifying disclosure issues and training patient representatives about patient falls and medication errors. PFPS Malaysia and MSQH would provide support to the hospital management and facilitate implementation.

Key opportunities:

- Patients and families are more educated nowadays, knowledgeable and informed, thus very resourceful
- Increasing acknowledgement of patients and families representing an invaluable untapped resource and available for voluntary contribution
- Strong government and policy-maker support and enabling environment for engaging and empowering patients
- Patients for Patient Safety network can further enable and facilitate engagement activities
- MSQH advocates for patient safety and will continue the health-care accreditation programmes with a plan to include a patient surveyor in the future
- A PFPS Malaysia representative as a member of the Patient Safety Council of Malaysia can be an agent/catalyst for PFPS activities.

Success factors:

- Commitment and support of policy-makers and leaders
- Internalization and institutionalization of safety culture
- Proactive and committed champions at national and facility levels
- Smart partnerships between public, private sectors and health-care professional bodies
- Top down and bottom up feedback system between policy-makers and implementers
- Implementation of existing WHO patient safety initiatives and Malaysian patient safety goals nationwide.

One of the key challenges is the lack of dedicated resources for on-going activities. Currently, PFPS Malaysia is under the guardianship of MSQH, but it is run independently. MSQH is able to leverage resources at the moment, but resources for long term programmes need to be identified.

5.5   Engagement and empowerment: the Thai experience

Piyawan Limpunyalert

Thailand has a reliable and accessible health-care system, with the Healthcare Accreditation Institute (HA Thailand) having a role in encouraging quality improvement, and a safety culture. The HA Thailand's mission is to encourage, support and drive quality improvement of the health-care system by using self-assessment, external surveys, recognition and accreditation, and knowledge sharing as leverage mechanisms. Collaboration, excellence and knowledge for change strategies are also opportunities to move the quality and safety agenda forward.

Engaging with patients in health care is important and provides added value to the public. HA Thailand realizes that working in isolation will not succeed, so incorporating the views of patients and families into patient safety efforts is the answer to sustainability.

A Brief History:

In 2009, HA Thailand developed the 'Thai Patient Safety Goals' known as 'SIMPLE' (Safe Surgery, Infection Control, Medication, Patient Care Process, Line Tube and Emergency Response) and encouraged all hospitals to use these guidelines to enhance safety practices in patient care.

In 2012, four communities of practice (CoPs) looking at the four main high-risk areas, (the emergency room (ER), the labour room (LR), the operating room (OR) and the intensive care unit (ICU)) were formed, inviting practitioners and professionals in those areas to share their experiences and good practices around patient safety. The 'Thailand Hospital Indicator Project' (THIP) was then established for tertiary care hospitals in the first phase, then further expanded to other levels of hospitals. THIP was used to benchmark the outcome of various quality and safety indicators. Finally, in 2014, the 'Engagement for Patient Safety Programme' was established with help from WHO.

HA Thailand has developed the umbrella 'Engagement for Patient Safety' Programme, which include Patients for Patient Safety (PFPS), Safety Hospital and Patient Safety Education for health-care students. It used the Thai Health Strategies known as the 'Triangle that moves the mountain' (figure 3), a three-pronged approach using knowledge, social mobilization and policy to drive the patient safety agenda through engagement.

Key concepts of the 'Triangle that moves the mountain' strategy:

- *Knowledge:* engage health-care education institutions to integrate the WHO Multi-professional Patient Safety Curriculum Guide into undergraduate and postgraduate training of health-care professionals
- *Social movement*: collaborate with WHO to established a network of patient advocates - Patients for Patient Safety (PFPS) Thailand
- *Policy link*s: engage volunteer hospitals to participate in the Safety Hospitals programme that follows the Minister of Public Health Policy named; 'Decades of the healthcare service for quality improvement and patient safety'.

Four approaches -***Share, Chain, Shape, Change*** – are used to engage all the stakeholders (including staff, professionals, patients, families, communities) to improving patient safety in Thailand.

- *Share:* create forums for experience-sharing and learning among leaders, health-professionals, health-care workers and patients through workshops, meetings and focus group discussions. This is about consulting and building relationships.
- *Chain:* encourage and facilitate collaboration through building networks among stakeholders, such as a patient working group for team-building and empowerment.
- *Shape:* encourage everyone to contribute to the shaping of 'shared vision' and purpose and create a process that is suitable for their context.
- *Change*: use research/evidence to facilitate engagement for change, empower people by promoting and recognizing people's ownership of their work.

Figure 3: The 'Triangle that moves the mountain'
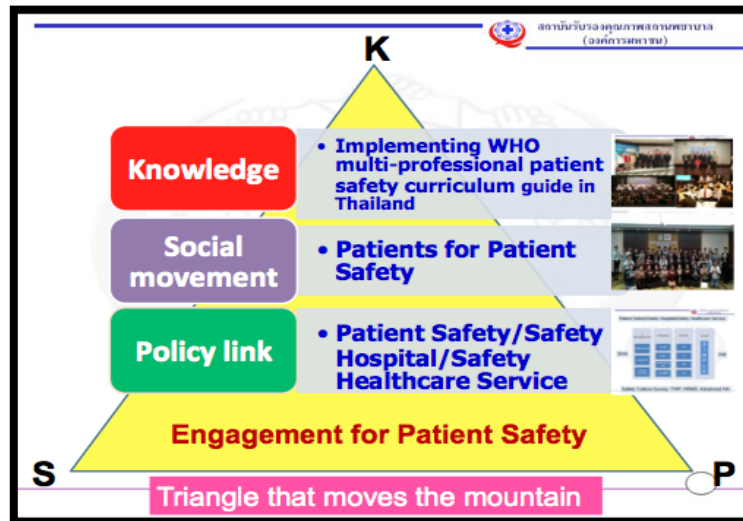
PFPS Thailand is building a patient-led, national network of patients and patient organizations to lead a patient safety movement. This 'Thai Pinkie Promise' hand gesture symbolizes collective efforts and shared commitments between patients and providers to engage for patient safety through collaboration, mutual understanding, love and trust. PFPS Thailand's vision is: 'Public participation in the health-care system's development for safety and equity, with evidence-based policies and common understanding of all partners'. The mission: 'To encourage collaboration between health-care providers, patients, families and the general public for the development of a standard, safe and equitable health-care system'.

Figure 4: Thai PFPS logo

Four strategic objectives of PFPS Thailand:

- To raise public awareness of rights and responsibilities for health and safety in health care
- To educate the public on health-care safety, and to promote better understanding between providers and users
- To promote safe health care both in health-care organizations and in the community
- To encourage collaborative movement among all stakeholders for safer health care.

HA Thailand aims to submit a resolution to the Thai national health assembly to formally establish a national network of advocates for patient and family engagement. A working group will be set up and members designated as 'Thai Public Envoys for Patient Safety'. They will be coached towards a role such as board member of health-care organizations, partners in implementing a health-care curriculum, and prospective training for health-care professionals i.e. having patient advocates

included in the teaching team. The aim is to raise awareness of the public, patients and health-care providers about patient safety.

Key points from discussion:

Patient advocates have done a lot of work in their own countries as well as internationally. The PFPS champions have planted significant seeds over the last ten years, and we are seeing the fruits now. The PFPS community is really growing in Thailand. WHO needs to measure, monitor and communicate the successes of individual patient advocates.

5.6   Empowering and building capacity for health-care providers

Susan Frampton, Planetree

"How we treat our health-care staff trickles down to how the staff treats their patients". Dr Susan Frampton argued that Patient and Family Engagement (PFE) means that we need to make a commitment to human relations and improving communication skills for health-care staff.

When talking about health-care providers, the focus tends to be on physicians, nurses and clinicians. Much of the research literature also focuses on these professionals. However, it must be acknowledged upfront that anybody who works in a health-care setting can have an impact on the patient and family experience. Staff in support services, such as those working in cleaning, food or finance, can also have an impact on creating a better experience for patients and families.

When considering a global health agenda, an important missing ingredient is often the communications and interactions between people - not what we do, but *how* we do it. When people are not treated with dignity and respect by their health-care providers, we are not providing the best possible quality care. Thus, the way people are treated impacts on their ability to access care. Health-care providers need to be sensitive to patients' and families' perspectives and consider these as opportunities for improvement.

Planetree International represents 6000 focus groups and approximately 50 000 direct family members and patients in direct care, who were asked these types of questions: 'what works well for you in this health-care delivery system? Where do you see opportunities for improvement? How do you want to be treated?'. Data over a 10-year period showed that these were the top care concerns:

• Absence of care and attitudes from health-care providers
• Not being listened to by health-care providers
• Lack of continuity in care.

Some of the most effective ways of building capacity of health-care providers and getting their attention around the importance of patient-centeredness and patient and family engagement has been in storytelling - sharing patient's stories, their care experience and in sharing the growing research literature. That is to illustrate that essentially it is their human relationship with patients that impacts the clinical experience of care and the medical outcomes of their patients.

Evidence indicates that the relationship and communication between a health-care provider and their patient forms a central part of the delivery of quality care. For example, the health benefits for diabetic patients were better under the care of doctors they rated as being empathetic. Patients suffering from diseases like flu had faster recovery times when being cared for by kind and caring practitioners.

What should professionals prioritise? Firstly, patient engagement needs to begin with role modelling from the top all the way down to the direct caregiver level. At Planetree, leadership is looked to as the role model, but 'the real power energy is generated through relationships'. The way that doctors treat nurses, has been seen to trickle down to the way that staff treat their patients.

Research findings suggested there must be:

- a commitment to staff education and training that includes human relation and communication skills;
- systems and practices that are more consistent with organizational values, focussing on fairness, pride, mutual respect, role modelling i.e. the way we want the care experience to have implications on patients;
- honest communication to and between staff;
- recognizing and rewarding desired behaviours.

For health-care systems to benefit from fully engaged patients and families, the issues about health-care culture that positions health-care professionals as 'all knowing experts' need to be addressed. That takes more than just tools and resources. It takes compassion in action. Policy-makers need to support the providers in their work so they can be the best role models possible. So the patient experience and the employee experience are intertwined.

The providers' awareness about how they can use body language and communication skills to improve the patient's feelings is both an art and a science. The power of relationship-focused training for clinicians improves patient clinical outcomes. Kelley et al (2014) looked at bedside manner and people's health. They found that the impact of a good bedside manner was more powerful than taking aspirin, or cholesterol lowering drugs for people with heart disease. It is the professionals' responsibility to ensure that staff are trained to help them improve in this area.

Furthermore, researchers have found the following acts convey compassion to patients and family:

- Staff going out of their way to acknowledge family members, such as shaking a relative's hand and asking them how they were, how they thought their relative was and if they had any questions;
- Staff taking the time to ask questions about what mattered—for example, finding out that a patient in their last few days of life preferred to lie on their right side:
- Staff taking the time to explain why the machine was beeping;
- Staff offering patients hand washing facilities after they had used the bedpan even if they had not wiped themselves.

These are just culturally appropriate common courtesies, but they often seem to be left at the door when people enter a health-care setting. Health-care professionals need to see that the patient in the gown is still a person and treat them with the same courtesy as in any other setting.

A key challenge is to align financial incentives that support clinician-patient communication. Unless the time spent on important and necessary communication is paid for appropriately, change is unlikely to happen. However, there is an interesting move in the correct direction. The American Medical Association has released billing codes for advance care planning services. This is a necessary step for Medicare to begin considering reimbursements for end-of-life discussions between physicians and patients. One billing code is for the first 30 minutes of face-to-face time with the patient, family member, and/or surrogate to explain and discuss advanced directives. An additional code is provided for each additional 30 minutes of planning. This is something that did not happen in the past. The more we can identify and align these incentives, the more we can build capacity in this important area.

There is also an opportunity to use new technology to support engagement between providers and patients; for example, bring a patient passport which contains documentation that a patient believes to be important and that the doctor should be aware of. There is also an opportunity to support innovative providers, organizations, and those champions of patient engagement, through implementing patient preferred practices to support providers. These initiatives can help to build provider capacity. Dr Frampton ended her presentation with a quote from Angelica Thieriot, an Argentinian woman; who spent some time in an American hospital:

"As a patient I rebelled against being denied my humanity and that rebellion led to the beginnings of Planetree. We should all demand to be treated as competent adults, and take an active part in our healing…we are human beings caring for human beings…" Angelica Thieriot, Planetree Founder, 1978.

For her (Angelica Thieriot), that meant she remained a competent individual in a hospital, taking an active part in her own healing. That is not something that a patient or a physician can do in isolation. We are human beings, caring for other human beings, and that recognition is very important in delivering the best possible and the highest quality care.

5.7   Empowering and building capacity for researchers and policy-makers

*Sue Sheridan, Patient Centered Outcomes Research Institute (PCORI)*

Sue Sheridan presented a combined list of considerations for capacity-building of policy-makers and researchers, gathered through learnings from working with PCORI, an organization dedicated to patient engagement in research, and with WHO. She started by pointing out the Google language and principle that is to focus on the principles of the users and all else will follow. She encouraged policy-makers and all those involved in health care to adopt a customer-focussed approach like those of Google, when considering matters about the patients.

She showed a model of patient-centred health care systems (Figure 5) and shared her experience in engaging and partnering at each level of the model. As illustrated by the model, it is not just about patient-centred care, but about a patient-centred health-care system. To achieve patient-centred care in the top of the triangle, it must start from the very bottom by engaging patients, families and communities. PCORI has developed a research agenda that serves as a foundation for continued engagement throughout all the tiers working with policy-makers and others throughout the process.

PCORI engages with a range of partners including government (local and national), public health agencies, NGOs, hospitals, researchers, universities and research organizations.

PCORI was created by legislation, and the name was given by the government. To truly ensure that PCORI is patient-outcomes based, its funding criteria require proposals to demonstrate patient related outcomes and that there is patient-engagement throughout the entire research process. PCORI only funds research based on outcomes that matter to patients, making it very unique.

Figure 5: Patient-Centered Health-care System Model
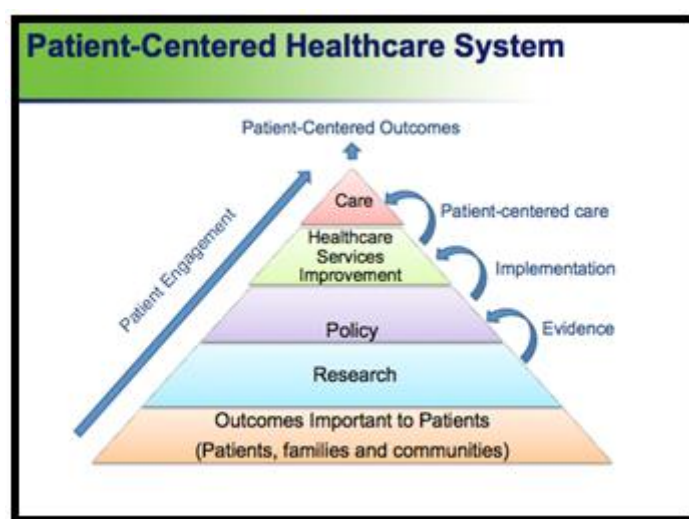
At first, it was very difficult for PCORI as it was criticised and confronted with such question as 'what do you mean you want to engage patients in research?'. This prompted it to realize a need for capacity-building. PCORI used the following steps in building the organization:

- It created a patient engagement advisory panel - reached out to the community of patient organizations for support. This panel helped define meaningful engagement from the perspective of patients.
- It created a framework for patient engagement in research based on data gathered through reviewing 150 research proposals, extracting relevant information on patient engagement, then packaged it in a framework and shared it with the research community. It was called the "patient and family engagement rubric", which outlined research by phases, and based on principles of trust, developing relationships, partnership and transparency.

PCORI now ensures that patients are involved in research at all levels, by:

- participating in research organization - prioritizing topics, proposal review and selection;
- participating in research as partners: in identifying research questions/outcomes; in planning, conducting and disseminating the research;
- donating to data/patient-powered research networks;
- re-writing consent forms and data-sharing agreements; and
- co-authoring manuscripts.

The framework enables opportunities to merit reviewers and capacity-build patients and researchers. Eighty-four percent of researchers reported having a clear understanding of patient engagement. PCORI also monitors and evaluates engagement, using data to drive research. Any contracts with the researchers incorporate both scientific and engagement milestones and PCORI Engagement Officers work directly with and capacity-build researchers and patient research partners on engagement.

Overarching opportunities for patient engagement work in policy activities include co-development of :

- practice guidelines, accreditation standards, performance measures, health campaigns, patient materials and decision-making tools;
- coverage and reimbursement strategies;
- presentations at conferences;
- approval process of drugs and devices.

Lessons learnt:

- Have leadership's commitment for engagement and their support for staff to implement
- Learn from others - use real life examples to demonstrate patient engagement in policy-making,
- Develop a strategy for engagement - create a framework for implementation, monitoring and measuring, provide capacity-building for engagement.
- Appoint patients to governance - include them in roundtables, conferences, incorporate them into other parts of the organization.
- Develop internal structure - a point of contact or department, an advisory panel.
- Develop an avenue for patients to tell their stories, listen to their stories, help them to tell their stories more effectively.
- Open doors to other policy-makers for patients.
- Celebrate and communicate achievements in patient engagement.

Sue closed her presentation by quoting a PFPS champion in Argentina:

"Do remember that many little people in many little places doing many little things can change the face of the world".

She reiterated that these little pieces contribute to changing the face of the world in patient safety and quality as well.

Key points from the discussion:

- Highlight the power of information, knowledge, evidence and research around the fields of patient-centred care and engagement. There is strong association between patient experience and patient outcome.

- More information needed about the key determinants of the patient experience. Many things affect the patient experience, but the main factor is the way physicians interact, communicate and tend to the patients. At the macro level, this conveys a message to countries with limited resources that improving quality of care through patient engagement does not require a lot of resources.

- One way to engage people for public policy is to bring patients, experts, professionals and policy-makers to discuss specific issues and thus contribute to policy.

- There is a need to have sufficient evidence that clearly demonstrates that engagement works, and a platform where patient advocates around the world can access such research evidence. They can then use this to advocate for the development of local policy.

- One way to measure patient engagement is to carry out a national survey, which was recently conducted in the US. This survey looked at engaging policy-makers in their decision-making about improvement and 52 of the highest performing hospitals had some strategies for engaging the leaders and staff in the process of improving care and patient-centred health delivery.

- It is important to create a system where leaders support health-care providers and reduce the gap between the high-level leaders and carers at the bedside. One of the key issues involved staff burnout because they had been trying to do work that cannot be done. Patient feedback may help to obtain attention from those leaders. Therefore, patient stories and data should feedback to directors of quality, as well as the providers delivering care at the bedside.

- A participant from Uganda (Regina) commented that Susan Frampton's presentation had taken her back eight years when she took her mother to one of the best consultants in the country. She had greeted him with a smile, but the doctor never smiled back. She really did not understand why clinicians found it so hard to practice the culturally common courtesies and what resources would be required to just smile or give a greeting? Her mother offered information, but the doctor did not take it down nor did he answer questions when asked. Her mother refused to go back to the hospital because she did not trust the doctor anymore. Susan Frampton's presentation brought back memories of the lack of trust, courtesy in the interactions and communication with health-care providers. How can we change this, especially in Africa?

- Angela Coulter pointed out the source of evidence related to patient engagement that could lead to improved health outcomes and other benefits. A British organization called 'National Voices', which is a collaboration of patient care-focused charities has many examples and testimonies. National voices - http://www.nationalvoices.org.uk/evidence.

- PCORI is able to specify important requirements for research as conditions for funding. But how does it influence other funding bodies to do the same? PCORI has three organizational goals, one of which is to influence patient-centred research in other institutes globally. The National Institutes for Health (NIH) and AHRQ pay a lot of attention to PCORI's work and have approved all the changes that PCORI has implemented. Work on measuring how PCORI's work impacts

other organizations has just began. In terms of measuring engagement, there is evidence that engagement in research improves trust, implementation, community engagement, but it is still limited as this is based on a model for community-based participatory research.

- It is important that staff have a role in the decision-making about health-care improvements along with patients, as only when these two parties work together do we achieve best outcomes. 'Planetree' has been working for patient-centred change for 36 years, and has developed a set of criteria with patients on how to make change in health-care organizations. There is a self-assessment survey that organizations can use to look at what they are doing and what they could be doing; the 'how to' in health-care settings. FIP commented that for every health-care professional, the welfare of their patients is their main concern. This ethical commitment can be supported by tools such as the Oath/Promise that FIP has developed for pharmacists. This is a means of further engaging pharmacists with their patients and supporting the profession's ideals and commitments.

6.0   Proposal on the WHO Framework on Patient and Family Engagement

Nittita Prasopa-Plaizier, WHO

Nittita Prasopa-Plaizier presented tables that showed grids of activities related to patient and family engagement as reported by the PFPS champions and stakeholders with whom WHO PFPS have interacted. Activities were put in one grid for descriptive purposes as the initial thoughts gathered from the data collected from the patients' interviews, from the observational data, from the PFPS workshops, and focus groups, as well as from literature reviews. To keep the thinking in line with the Moore Foundation's Roadmap, the activities were grouped in similar categories. The grids showed activities, instead of strategies, as the intention was to illustrate activities being carried out by patient advocates and health-care providers in different countries. The intention was to demonstrate what has been done already and what could be possible.

The grids were categorized into engagement at different levels of health-care interactions and from the perspective of different players (Table 3). At the level of individual care, for instance, what could be the actions for the patient/patient advocate, health-care provider, researcher, policy-maker and the community? For the community, this includes civil society, organizations and other professional groups. The table is not exhaustive as ideas emerged during this Consultation have not yet been integrated. Some items may be repetitive as sometimes actions may be applicable at many levels i.e. with policy-makers and health-care providers or individual patients and patient' groups/organizations.

Table 3. Patient and family engagement at each level of health care

	Patient and Advocate	Health-Care Provider	Policy-Maker	Researcher	Community
Individual Care					
Health-care processes	Examples of engagement practices at each level of care and for each actor				
Health-care systems					
Policy					
Research					
Community					

The idea was to generate discussion and to lay down a foundation on which the Framework could be built. Further input, more data and more evidence would be gathered. Displaying the activities on grids helps to visualize what engagement at each level would look like, who the stakeholders are, what the actions at each level would be and how we could package these actions to different stakeholders.

Nittita presented a proposal, which built on evidence gathered through literature about existing frameworks for PFE. Most of the existing frameworks, roadmaps, or strategies focus on the conceptual level, or the policy level, focussing on either the 'why' or the 'what' of engagement. Nobody talks yet about 'how' to do it.

The objectives: The document provides a concept on how the framework will be developed. It will be supported by a further and more complete review of the literature. The objectives of the framework are to provide Member States with a guide to implement and engage patients, to make it meaningful, objective and sustainable. It is something that will be actionable, something where WHO can provide support to Member States, so they can create and implement it.

The methods: The initial data used in the proposal were gathered from interviews with PFPS champions. Two concurrent interviews were conducted to avoid too lengthy a session. There were 63 interviews in the first group and 50 in the second group. The intention is now to collaborate with other stakeholders to expand to other patient groups and organizations to obtain a wider range of opinions and perspectives. The perspective of providers will also be sought with relationships that have already been established with collaborators in China, Ecuador, Malaysia and Thailand. Organizational groups e.g. NGOs in collaboration with WHO and other specialist groups will also be engaged.

The engagement activities gathered from the interviews were categorized under different themes, including individual care. This is not just about self-care, but also concerns activities related to patient advocates helping other people in their care i.e. activities that assist patients in their individual care. For example, some PFPS champions volunteered to help in their local hospital. They escort patients to the hospital, help them talk to doctors or lawyers and help them negotiate with insurance. They provide peer support, not just physical support, but also emotional and psychological support.

At the level of health service processes and health systems, in this context, health services are related to processes of service delivery while health systems are structures or governance mechanisms that underpin processes and procedures.

For research, a range of activities currently engaged by the PFPS champions span from setting research agendas (defining research questions) to dissemination of research findings. The implementation of research recommendations is considered to be part of policy implementation. In this context, policy is an action or a decision to take action.

At the population and public health level, we looked at the activities in which our patients have been involved, for example, surveillance, immunizations and outreach programmes. This is the domain of public health. An example of this is the involvement of our PFPS champion, Hussain Jafri, in WHO work on high level guidance for ethical conduct in public health surveillance. The patient voice reminds experts about how to differentiate individual from community consent and to make the population understand the difference between research and public health surveillance.

Community empowerment and awareness-raising are common activities of PFPS champions that encompass public speaking at events, engagement at the public level to raise awareness, and also outreach programmes to educate and empower the community. Examples include community forum or the outreach programme mentioned in Uganda. The activities shown are a snapshot of what interactions in real engagement could be. For each theme, one or two activities were shown as a highlight.

Key points from the discussion:

Dr Ed Kelley opened the floor up to a discussion and invited comments on the framework document.

- When looking at meaningful patient engagement, the concept can be divided into four levels. Three of these have been covered, however there is a need for more work on the organizational level that can enable the patient engagement to make changes inside an institution in two ways. Firstly, organizational design and secondly, organizational behaviour. This captures the culture, the change management strategies and the skills that have to be taught and learnt by staff. The organizational design incorporates the organization's structures, thinking about horizontal, vertical or even hybrid structures.

- It is important to flesh out policy goals so these are clear for policy-makers. It is also important to clarify the target audience of the document because deciding this will make a huge difference in the way the findings are presented As researchers, we are very fond of these overviews because they are very comprehensive, with all the levels and details. However, policy-makers will respond the best when the framework is straightforward and easy to understand.

- *Dr Ed Kelley acknowledged that* policy-makers and WHO's Member States are the first point of call. He asked to which target audience the Moore Foundation's Roadmap is intended as it is very action-oriented, includes actions 'what we can do right now' and touches on multiple audiences.

- *(Dr Dominick Frosch)*: The team gave considerable thought to who is the primary audience for the Roadmap really is. The approach was 'don't preach to the converted' they already get it. So the aim was for those 'sitting on the fence' i.e. stakeholders who were undecided about patient engagement concepts, so it is very deliberately action-oriented. *(Dr Kristin Carman added)* The Roadmap started on direct care, organization and policy-making, thus moving from consultation to partnership. There are real areas to expand, such as research, and involvement of the community. This is too much for one piece, so split it up into two pieces.

- The inter-relationship between all levels cannot be separated. For example, to support patients, you can't break this out from what health-care providers need to do. In the UK, one of the models that is gaining a bit of traction around conditions is the house of care model, it represents how inter-connected all of these elements are. There needs to be something within the framework that shows the inter-connectivity of all of the levels and themes.

- The community has to show up in all areas. There is a need to find some physical way of doing that. Underlying the discussion is what recommendations can WHO make after this framework? And with the recommendations, how are we going to find out if they are being followed? Where and how to find out if they are being implemented?

- Too many details and people may become overwhelmed. In Ireland, to support people's visualization, quality improvement plans were designed with long-term visions of where patients need to be. There were four levels. Firstly, what everybody should have, secondly, encouraging improvement, thirdly, improvement, and the fourth level was excellence. This ensures that people can see where it is all going.

- *(Sir Liam Donaldson)*: The first time Steve Jobs walked out to show the first generation of iPods, introducing a new portable music player, that weighed about 6.5 oz., that was the size of a sardine can, and had huge content and capacity life, with lightning fast transfer speeds. However, he did not state any of that. He said; *"we are going to give you a thousand songs in your pocket"*. Sir Liam's message is simplicity is very important or it will not have any grit or traction at all with health-care providers.

- Strengthening the links between the themes within the document would be useful so one can see how they are inter-related within the grid. In terms of the themes of activities, involving patients and families in finance systems in relation to service delivery would be something to consider, and how that would play out in the dialogue about UHC. How can patients or families receiving care be involved in determining or delivering health service payment mechanisms, and systems? How would this framework fit into the PCIHS Strategy? Having clinical relevance to clinician is key, within that context that patient and family perspective is incorporate into the health information system that is connected to the improvement agenda.

- This document represents the first thoughts and further refinement is needed. The Framework will not be one package, but will include a set of resources, similar to those of the hand hygiene multi-modal package. So the Framework will have similar concepts and there will be sub-groups. Further work is still needed to define those groups.

- It is vital to ensure that feedback from people who are less empowered and less educated is heard. In thinking long-term about how to create a culture change through engaging young people in shaping their thinking and instilling desirable values for culture changes. It is important to create a culture of equality where people can see health-care professionals as people. A hospital's logo (in Australia) says 'people caring for people', reminds us that it is about community and partnership.

- Many resources around patient engagement already exist. The key is to tap into these resources. A lot of engagement is already happening and we may just not be aware of it all. So we need to start by mapping what is already happening in different parts of the world.

Concluding Discussion

Dr Ed Kelley drew the discussion to the conclusion, acknowledging the difficulties in capturing all of the thoughts, concepts and actions in just one tool and one table.

He reiterated that it was not WHO's intention to engage in multiple conceptual framework design efforts, but to build on the work of the Moore Foundation. There is a lot of work and potential to adapt this excellent Roadmap to an international context. This Consultation has begun it through case study presentations and through the feedback and the literature reviews, but there is still a lot more work to do. The value of a WHO document is in its inherent use. People in a country are able to say the framework is how WHO sees this particular slice of the health-care system's role, and we would like to engage in a process of locally adapting it. So producing a document around PFE would be valuable.

WHO has six core competency areas that were referred to earlier:

1. Providing leadership in global public health issues
2. Shaping the research agenda
3. Setting norms and standards
4. Articulating evidence-based and ethical policy options
5. Providing technical assistance
6. Monitoring and assessing health-care situations.

The case study presentations from Planetree and PCORI demonstrate that this concept of patient and family engagement works. However, there is not enough on this to convince policy-makers that patient engagement is not a 'nice to have', but something that has a real and positive impact on health outcomes and efficiency of health services. So the Framework would provide evidence-based guidance in this area.

We have also discussed the issue of a call to action, at the local, country, regional and global levels. This would involve creating a day, a week, or a month annually to raise awareness of family

engagement. There are other options on the world health day as well as a global report. Another topic that came out of the discussion was using the Framework as a platform for sharing experience tools at a global level.

Finally, the idea of innovation was mentioned repeatedly. This is probably the most interesting area, involving ideas such as hand-held patient and family engagement; patient reported outcomes, and patient tracking of services. There is also a whole range of issues of community engagement and community design of services that we have experimented with through the APPS programme, which has generated a lot of interest all over the world.

To consider looking at focus countries as pilots that could drive the research agenda, this would be extremely helpful. Additional thoughts will be needed on how this could be done, how it could be resourced.

The project team will be working on refining the document. In light of this feedback, looking at setting up sub-groups to work on different areas of the Framework in which people can express an interest, including people who have expressed interest during this Consultation. WHO will consider arranging regional meetings to get feedback on the draft Framework, with a follow-up of this Consultation with the Moore Foundation.

Dr Ed Kelley and Dr Vivian Lin gave the concluding remarks thanking the participants. *Dr Dominick Frosch* concluded by thanking WHO for giving a clear plan on how this would proceed and thanked all the participants for their contribution. He emphasized his view that the Framework would be critically important in creating a health-care system that meets the needs of patients and families, and which humanizes care.

Sir Liam Donaldson shared his 8-point action plan, which he wrote during the Consultation, which captured the essence of why it is very important to involve patients and family members:

1. You will be less likely to cause harm
2. Your research will bring greater benefits to society
3. Your health services will be better designed
4. You will save lives and improve the quality of life for thousands of people
5. You will reconnect to the passion that originally brought you into health care
6. Your institution will be less likely to have a scandal that puts you in the eye of a media or political storm
7. It will be much easier to improve quality
8. Others will come to learn from you.

Adjourn – Group Photo

Appendices

A1   The Advisory Group on WHO Framework on Patient and Family Engagement:

Sir Liam Donaldson, WHO Envoy for Patient Safety - Chair

Susan Baade, Program Officer, Patient Care Program, Gordon and Betty Moore Foundation- Member

Dr Dominick Frosch, Fellow, Patient Care Program, Gordon and Betty Moore Foundation -Member

Dr Vivian Lin, Director, Health Sector Development, WHO's Western Pacific Regional Office

Dr Hernan Montenegro, Coordinator, Services Organization and Clinical Interventions (SCI), Service Delivery and Safety

Margaret Murphy, External Lead Advisor to WHO Patients for Patient Safety Programme –Member

Dr Edward Kelley, Director, Service Delivery and Safety Department, WHO – Secretariat

Nittita Prasopa-Plaizier, Lead – Patients for Patient Safety, Service Delivery and Safety Department, WHO- Secretariat

A2.   List of Participants

African Region (AFRO)

Ms Robinah Kaitiritimba, Executive Director Uganda National Health Consumers' Organisation (UNHCO) Kampala, Uganda

Ms Regina Kamoga, Executive Director CHAIN UGANDA Kampala, Uganda

Dr Tonny Tumwesigye, Executive Director Uganda Protestant Medical Bureau Kampala, Uganda

American Region (AMRO/PAHO)

Ms Denice Klavano, Patient Relations Specialist Capital District Health Authority Halifax, Canada

Dr Jonas Gonseth, Gerente Hospitalario Hospital de Especialidades Guayaquil "Dr Abel Gilbert Pontón" Guayaquil, Ecuador

Dr Hanan Aboumatar, Assistant Professor Armstrong Institute for Safety and Quality, Johns Hopkins Medicine, Baltimore, MD, USA

Dr Bruce Agins, Director HEALTHQUAL International Medical Director
New York, NY, USA

Ms Susan Baade, Program Officer, Patient Care Program Gordon and Betty Moore Foundation Palo Alto, CA, USA

Dr Kristin Carman, Vice President, Health & Social Development Director, Center for Patient and Family Engagement American Institutes for Research Washington DC, USA

Dr Ram Shrestha, USAID ASSIST Project Senior Improvement Advisor for Community Health and Nutrition Maryland MA, USA

Ms Susan Sheridan, Director of Patient Engagement Patient-Centered Outcomes Research Institute

(PCORI), Washington DC, USA

Dr Ronen Rozenblum, Director of the Unit for Innovative Healthcare Practice & Technology Brigham and Women's Hospital and Harvard Medical School Boston, MA, USA

Ms Casey Quinlan, Mighty Casey Media and Patients for Clinical Research Richmond, VA, USA

Dr Dominick Frosch, Fellow, Patient Care Program Gordon and Betty Moore Foundation, Palo Alto, CA, USA

Dr Susan Frampton, President Planetree Derby, CT, USA

Eastern Mediterranean Region (EMRO)

Mr Hussain Jafri, Secretary General Alzheimer's Pakistan Lahore, Pakistan

Dr Ahmed Alamri, Associate Executive Director, Innovation & Corporate Integration (ICI) Director, Neuroscience Center King Abdullah Medical City Jeddah, Saudi Arabia

European Region (EURO)

Prof Liesbeth Borgermans, Professor of Chronic Care Vrije Universiteit Brussels, Belgium

Dr Lodewijk VAN BLADEL Senior expert in radiological protection Federal Agency for Nuclear Control Brussels, Belgium

Ms June Boulger, National Lead for Patient and Public Involvement in Healthcare National Advocacy Unit, HSE Kildare, Ireland

Mr Peter Carter, Chief Executive Officer, The International Society for Quality in Health Care (ISQua), Dublin, Ireland

Ms Sara Perazzi, Membership and Project Manager International Hospital Federation (IHF) Bernex, Switzerland

Ms Zuzana Kusynova, Policy Analyst and Project Coordinator International Pharmaceutical Federation (FIP), The Netherlands

Dr Angela Coulter, Director of Global Initiatives Informed Medical Decisions Foundation Healthwise Eynsham, Oxfordshire, UK

Ms Suzanne Wood, Policy Manager, The Health Foundation London, UK

Ms Felicity Pocklington, York University, York, UK

Dr Luisa Pettigrew, Family Doctor & Research Fellow World Organization of Family Doctors London School of Hygiene and Tropical Medicine London, UK

Ms Jo Groves, Chief Executive Officer International Alliance of Patient's Organizations (IAPO) London, UK

Ms Rachel Gooden, Consultant Community Engagement African Partnerships for Patient Safety London, UK

South East Asian Region (SEARO)

Dr JS Arora, General Secretary National Thalassemia Welfare Society, New Delhi, India

Dr Abhishek Bhartia, Director Sitaram Bhartia Institute of Science and Research New Delhi, India

Dr Piyawan Limpunyalert, Deputy Chief Executive Officer, The Healthcare Accreditation Institute, Nonthaburi, Thailand

Western Pacific Region (WPRO)

Ms Stephanie Newell, Patients for Patient Safety Champion Goolwa, South Australia

Dr Xuchun Ye, Professor, Nursing School Second Military Medical University**,** Shanghai**,** China

Mr Manvir Jesudasan, Chairman, Patients for Patient Safety Malaysia, Kuala Lumpur, Malaysia

Dr Kadar Marikar, Chief Executive Officer**,** Malaysian Society for Quality in Health (MSQH) Kuala Lumpur**,** Malaysia

WHO-HQ

Dr Sepideh Bagheri-Nejad, Technical Officer, Service Delivery and Safety

Dr Marie-Charlotte Bouesseau, Senior Adviser, Service Delivery and Safety

Dr Selma Khamassi, Medical Officer, Service Delivery and Safety

Dr Hernan Montenegro, Coordinator, Services Organization and Clinical Interventions (SCI), Service Delivery and Safety

Dr Maria Perez, Scientist, Interventions for Healthy Environments

Dr Shams Syed, Technical Officer, Service Delivery and Safety

Ms Nuria Toro Polanco, Consultant Services Organization and Clinical Interventions (SCI), Service Delivery and Safety

WHO-WPRO

Dr Vivian Lin, Director, Health Sector Development

Dr Ken Taneda, Technical Officer, Health Systems Development

Secretariat

Ms Katthyana Aparicio, Programme Officer, Patients for Patient Safety, Service Delivery and Safety

Dr Neelam Dhingra-Kumar, Coordinator, Patient Safety and Quality Improvement (PSQ), Service Delivery and Safety

Sir Liam Donaldson, WHO Envoy for Patient Safety

Ms Gabriela Garcia, Administrative Assistant (PSQ), Service Delivery and Safety

Ms Katherine Hayes, Intern, Patients for Patient Safety (PFPS), Service Delivery and Safety

Dr Edward Kelley, Director, Service Delivery and Safety

Ms Nittita Prasopa-Plaizier, Technical Officer, Advocacy and Civil Society Engagement & Manager, Patients for Patient Safety (PFPS), Service Delivery and Safety

A3.   Agenda

SERVICE DELIVERY AND SAFETY

Global Expert Consultation on

WHO Framework on Patient and Family Engagement

27-28 October 2014

World Health Organization HQ, Main Building, Salle D

20 Avenue Appia, CH-1211 Geneva 27

AGENDA

Day 127 October

8:30 – 9:00   Welcome and Introduction

- Welcome and opening remarks

   Dr Edward Kelley, WHO Service Delivery and Safety (SDS)

   Dr Dominick Frosch, Gordon and Betty Moore Foundation

- Introduction of participants - All
- Greetings from Chair of the Advisory Group on the WHO Framework on Patient and Family Engagement Project

   Sir Liam Donaldson, WHO Envoy for Patient Safety
- Review of meeting objectives, agenda, methodology

   Dr Edward Kelley

9:00 – 11:00   Engaging for health: Defining a common vision

   Facilitator: Dr Edward Kelley

9:00 – 9:20   Patients and family engagement for safety and quality improvement

   Dr Neelam Dhingra-Kumar, Patient Safety & Quality Improvement Unit (PSQ), WHO SDS

9:20 – 9:40   Universal Health Coverage (UHC) & Quality of Care

   Dr Shams Syed, WHO Service Delivery and Safety

9:40 – 10:20   The Gordon and Betty Moore Foundation's Patient Care Program and a Roadmap for Patient and Family Engagement in Healthcare: Practice and Research

   Dr Dominick Frosch

   Dr Kristin Carman, American Institutes for Research

10:20 – 10:45   Patient and Family Engagement - Approaches, challenges and opportunities: Findings form the PFPS Qualitative Research

Nittita Prasopa-Plaizier, Patients for Patient Safety (PFPS), WHO SDS

10:45 – 11:00   Q & A

11:00 – 11:30   Coffee Break and Group photos

11:30 – 12:30   Patient-Centred Care and People-Centred Health Services

Facilitator: Dr Shams Syed, WHO Service Delivery and Safety

11:30 – 11:50   The WPRO Patient-Centred Strategy

Dr Vivian Lin, WPRO HSD

11:50 – 12:10   WHO Strategy on People-Centred and Integrated Health Services

Dr Hernan Montenegro, Services Organization & Clinical Interventions (SCI), WHO SDS

12:10 – 12:30   Discussion

12:30 – 13:30   Lunch

13:30 – 15:30   Working groups/ Market Place

Facilitator: Dr Edward Kelley and Dr Vivian Lin

- Overview of the session: Objectives and methodology
  Nittita Prasopa-Plaizier

- Group 1: Meaningful and effective engagement – What does it look like? How do we measure it?
  Facilitators: Dr Dominick Frosch and Stephanie Newell

- Group 2: Role, responsibilities and expectations – For patients, family, health-care providers and policy-makers
  Facilitators: Sue Sheridan, Patient-Centered Outcomes Research Institute (PCORI) and Professor Dr Kadar Marikar, Malaysia Society for Quality in Health (MSQH)

- Group 3: Creating supportive environment for meaningful and effective engagement – What can we do to make the engagement meaningful, effective and efficient?
  Facilitators: Susan Baade, Gordon and Betty Moore Foundation and Hussain Jafri, PFPS Pakistan

15:30 –16:00   Coffee Break

16:00 – 17:30   Plenary Discussion, feedback on working group

Facilitators: Sir Liam Donaldson and Dr Edward Kelley

17:30   Adjourn

…………………………………………………

19:00   Dinner at "La Brasserie Genevoise", Boulevard Helvétique 27 - CH 1207 Genève

http://www.labrasseriegenevoise.ch/

....

Day 2   28 October 2014

9:00 – 9:30   Review of Day 1 and Introduction of Day 2 agenda items

Dr Edward Kelley and Dr Dominick Frosch

Brief Introduction to the Gordon and Betty Moore Foundation - Dr Dominick Frosch

Brief Introduction to ISQua – Peter Carter

9:30 – 10:30   Empowering and Building Capacity: Challenges, opportunities and Case-studies

Facilitator: Dr Neelam Dhingra-Kumar

9:30 – 9:40   Patients for Patient Safety – a WHO approach for empowering and capacity building

Nittita Prasopa-Plaizier

9:40 – 9:50   Engagement and empowerment: The Canadian experience

Denice Klavano, PFPS Canada

9:50 – 10:00   Engagement and empowerment: The Ecuadorian experience

Dr Jonas Gonseth, Hospital de Especialidades Guayaquil "Dr. Abel Gilbert Pontón"

10:00 – 10:10 Engagement and empowerment: The Malaysian experience

Dr Kadar Marikar, MSQH and Manvir Jesudasan, PFPS Malaysia

10:10 – 10:20 Engagement and empowerment: The Thai experience

Dr Piyawan Limpunyalert, Healthcare Accreditation Institute Thailand (HAI Thailand)

10:20 – 10:30 Q & A

10:30 – 11:00 Coffee break

11:00 – 12:30 Empowering and Building Capacity: Challenges, opportunities (Continued)

Facilitator: Dr Vivian Lin

11: 00 – 11:15 Empowering and Building Capacity for health-care providers

Dr Susan Frampton, Planetree

11:15 – 11:30 Empowering and Building Capacity for policy-makers

Sue Sheridan, Patient-Centered Outcomes Research Institute (PCORI)

11:30 – 12:30 Discussion

12:30 – 13:30 Lunch

13:30 – 14:30   Proposal on the WHO Framework on Patient and Family Engagement

Nittita Prasopa-Plaizier and Dr Ed Kelley

14:30 – 15:30   Shaping the Patient and Family Engagement Framework

Dr Edward Kelley, WHO Service Delivery and Safety (SDS),

Dr Dominick Frosch, Gordon and Betty Moore Foundation

- Agreeing on the contents and deliverables
- Agreeing on timeline
- Plans for dissemination and implementation

15:30 – 16:30   Next steps, summary and conclusion

Sir Liam Donaldson, WHO Envoy for Patient Safety

16:00   Adjourn