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**Welcome!**

*Margaret Murphy, External Lead Advisor, Patients for Patient Safety (PFPS)*

Welcome to PFPS News Autumn 2015 edition.

When I scan the topics, the geographical spread of active PFPS advocates (champions), together with the range and quality of activities described in this our most recent newsletter, I cannot but reflect on the early days of PFPS in 2005. We had high hopes, an abundance of enthusiasm and a resolve to transform personal adversity into that catalyst for health care improvement. It has been said that “adversity can grind us down or polish us up, depending on what we are made of”. In our current newsletter we see shining examples of effort and achievement that span all WHO regions.



*Figure 1: Margaret Murphy*

Even more than that, we have seen PFPS evolve. We are becoming smarter and more strategic in how we engage, in how we maximize effort through the advisory group and in how we rise to the challenges of diverse experiences in developed and developing countries.

I am particularly delighted that Helen Haskell has generously agreed to co-chair the advisory group. Her commitment, drive and organizational abilities have helped put shape and structure to our meetings and follow-up actions – an invaluable skill which you possess in spades, Helen!

Our strength will always be our connection with our roots and our intrinsic identity – The London Declaration. We are witnessing an evolution in how patients and families are viewed by health-care systems, organizations and individual practitioners. In many ways, we have spear-headed that change. Through our efforts and the efforts of like-minded people, partnership, engagement and empowerment have become part of the vocabulary and essential ingredients in the provision of health care.

So enjoy the newsletter! It will take more than one reading. There is much to absorb and much material for reflection and imitation. And thank you for your commitment.

**Upcoming Events**

Jordan quality health-care conference and exhibition, 23 - 24 November

Uganda PFPS workshop, 3 - 5 November

Mexico PFPS workshop, 18 November

3rd World Congress on integrated care, Mexico, 19 - 21 November

# Updates from WHO PFPS in Geneva

## 1. ISQua international conference, 4-7 October 2015, Doha, Qatar

*Nittita Prasopa Plaizier*

A team from the SDS Department here at WHO (Nittita Prasopa-Plaizier, Shams Syed, Neelam Dhingra-Kumar and Nuria Toro Polanco) participated in the 32<sup>nd</sup> ISQua (International Society for Quality in Health Care) international conference, whose theme this year was ‘Building quality and safety into the healthcare system’. Collectively, the team organized and presented the work of WHO during three scientific sessions, entitled ‘*Quality and safety of health care in developing countries, in the context of Ebola*’, ‘*Towards people-centred and integrated health service approaches: how to better integrate the patients, families and communities’ perspectives?*’ and ‘*From engaging for patient safety to empowering for people-centred and quality universal health coverage: what will it take?*’ respectively. Additionally, the team organized an exhibition stand and held several side meetings with key stakeholders. Click here for more details of WHO sessions at ISQua 2015: [http://www.who.int/patientsafety/patients\\_for\\_patient/news/isqua2015/en/](http://www.who.int/patientsafety/patients_for_patient/news/isqua2015/en/).

Nittita, in her capacity as designated technical officer for WHO ISQua official relations, also represented WHO at the ISQua International Accreditation Council (IAP) and contributed to launching the report entitled ‘Guidance on designing healthcare external evaluation programmes including accreditation’, whose forward was jointly penned by the World Bank and WHO. The report is available for download free of charge: <http://isqua.org/accreditation/reference-materials>.

## 2. Global perceptions of engagement and empowerment

*Emma Scholar*

In September, PFPS launched a project which aims to create an advocacy tool for global engagement and empowerment, by defining what meaningful engagement is and to inform the development of the WHO Global Framework on Patient and Family Engagement. The PFPS team has disseminated a ‘call for contributions’ through the PFPS global network, other professional networks and across social media. Participants are being asked to complete a questionnaire and are offered the additional option of making a video ‘selfie’ of themselves, answering questions regarding their perceptions of meaningful engagement. The PFPS team encourages contributions from patients, family members, health-care providers, policy-makers and the general public from all around the world, some of whom will then be represented in the final advocacy video.

The project deadline has been extended to 31 October 2015, and the questionnaire has been translated into French and Spanish, to encourage more people to give their contributions. If you have not done so and are interested in being part of global engagement efforts, please contact Emma Scholar at [scholare@who.int](mailto:scholare@who.int) or visit [http://www.who.int/patientsafety/patients\\_for\\_patient/en/](http://www.who.int/patientsafety/patients_for_patient/en/).

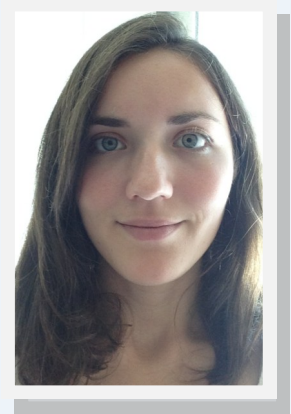


Figure 2: Emma Scholar

## 3. PFPS webinar: “Tips for patient and family engagement with health authorities to improve patient safety and quality of care”

*Katthyana Aparicio, Felicity Pocklington*

On 24 September, the WHO PFPS programme collaborated with PFPS Canada and the Canadian Patient Safety Institute (CPSI) to deliver a webinar. This interactive session discussed patient, family and community engagement with health professionals (including policy-makers, health-care providers and researchers), at the individual care, organizational and system levels. The session was designed by and for patients, families and PFPS patient advocates. It aimed to share examples, tools and guidance, to help patient advocates communicate more effectively with and build bridges between themselves and health authorities. Three themes were discussed during the webinar:

1) ‘*Patient engagement with authorities at the point of care*’ - Dr Jorge Cesar Martinez, PFPS advocate (champion), Argentina. This theme discussed the importance of meaningful



Figure 3: Collaborating teams who organised the webinar. WHO, PFPS Canada and CPSI

shared decision-making between health-care providers and patients and families in direct care. The importance of health professionals using non-scientific language that patients and families understand was discussed. Dr Martinez provided an example and guidance for engagement through his participatory programme named “An invitation for life”. The aim of this programme is to translate main health concepts into “mothers’ language” so mothers are empowered and enabled to engage in a friendly, informed and interactive learning experience.

2) *‘Patient engagement with authorities at the organizational level’* - Stuart Croall, Dennis Maione and Theresa Mrozek, from Manitoba, Canada. This theme considered the use of guidelines for sharing patient stories to ensure that both storytellers and health authorities participate meaningfully, to enable reflection, learning and improvement opportunities. The presentation explained the importance of patient representatives being equal members of committees and working groups to ensure that the goals and initiatives are focused on the values and needs of patients. The speakers provided an example and guidance from the Canadian ‘In-Sixty Initiative’ whose aim is to reduce the time to under 60 days, that a person needs to wait between suspicions of cancer and the start of active treatment being confirmed.

3) *‘Patient engagement with health authorities at the system level’* - Dr Nor'Aishah Abu Bakar, Senior official from the Ministry of Health and PFPS advocate, Malaysia. This theme looked at the importance of collaboration between patient advocates and health authorities. The technical and financial support from system level authorities to Patients for Patient Safety Malaysia (PFPS Malaysia) was described as essential for building interest, maintaining momentum and spreading engagement at the national level. Dr Abu Bakar provided an example and guidance of engagement at the system level by outlining the aims, objectives, milestones and projects in PFPS Malaysia.

Big thanks go to Theresa Malloy-Miller (PFPS Canada) for sharing the session and to all the speakers for their fascinating insights and discussions. Thanks also to all the global participants (nearly 200) who provided their questions and feedback to the discussions. For more information please follow the link below:

<http://www.patientsafetyinstitute.ca/en/toolsresources/pages/tips-for-patient-family-engagement-with-health->

[authorities-to-improve-patient-safety-and-quality-of-care.aspx](#)

## Update from AFRO

### Uganda

*Regina Kamoga and Felicity Pocklington*

#### **Moving towards people-centred and quality universal health care**

In Uganda, access to essential medicines remains low. Inequalities in access to medicine between rural and urban populations, and socio-economic factors between people using private and public services have added to these inequities. Engaging and empowering patients and people to be effective and knowledgeable stakeholders and partners in the endeavour of promoting people-centred and quality universal health coverage (UHC), would help to reduce this burden on health systems, and improve patient outcomes.

Regina Kamoga, a PFPS advocate (champion) from Kampala, Uganda and country manager for the ‘Community Health and Information Network’ (CHAIN), has taken various innovative approaches towards engaging and empowering people, patients and communities in Uganda. Key actions are summarized below. Established in 1998, CHAIN is an organization which promotes the empowerment of people living with and affected by HIV/AIDS. CHAIN promotes patient centered health-care and patient safety.



*Figure 4: A patient leader, demonstrates the safe use of injection which involves handling, administering and disposal*



## Approaches of engagement and empowerment adopted by CHAIN:

- Organizing outreach programmes – delivering health services and medicines to vulnerable individuals with poor access to treatment services. Health professionals and patients meet at a central and convenient place, to reduce travel costs and other implicit costs, such as taking time off work;
- Working with village health teams (VHTs) – training and educating traditional birth practitioners about unsafe practices of which they may be unaware. Training is tailored to community-based needs, which are established through communication between CHAIN and community leaders;
- Working with local community leaders – raising awareness about available mechanisms that enable the community to participate in engagement and improved health-care delivery efforts;
- Empowering vulnerable people through education and raising awareness of unsafe childbirth practices;
- Organizing public hearings with question and answer sessions – facilitating communication between health-care professionals and the community. These public health hearings can facilitate learning from both sides and perspectives. Health professionals are enabled to learn about common misconceptions in the community;
- Introducing health literacy programmes in schools - by involving the teachers, support staff and the children themselves, CHAIN enables all members of the school to learn what their rights are (in non-technical language), and to be knowledgeable on common patient safety issues;
- Introducing health literacy programmes to orphans and vulnerable children through life training during their school holidays - This tailored training includes prevention of communicable diseases, sanitation and sexual and reproductive health.

We congratulate Regina on these fantastic initiatives and wish her all the best with this inspiring work!



Figure 5: Village health teams (VHTs) and Community health workers (CHWs) attending a one-day seminar organized by CHAIN to be sensitized on safe medicine use and injection safety.

## Update from AMRO/PAHO

### Canada

*Update from Patients for Patient Safety Canada (PFPS)*

The 70 plus volunteers from Patients for Patient Safety Canada (PFPS) have been hard at work over the summer, strengthening their internal processes and representing the patient perspective at all system levels, including when interacting with the global community.

#### Stronger internal processes

As a patient-led programme of CPSI, PFPS's organizational structure and its operations are led by members who are under the direction of two co-chairs. This group also receives coordination and support from dedicated CPSI staff. The PFPS membership group conducts interviews with interested candidates, orients new members to their role as patient champions and maintains engagement of all members. This summer, the group are updating its charter and the orientation package for new members, and the documents produced by PFPS are currently being reviewed. In addition, PFPS created a closed LinkedIn group that aims to make it easier for members to meet each other and share information.

#### Partners in improvement at all system levels

PFPS members participate in over 100 collaborations between themselves and health professionals each year. Recently, there has been a noticeable increase in requests to partner in system level improvement work in Canada. PFPS co-chairs Sharon Nettleton and Denice Klavano are members of the Steering Committee of the [National Patient Safety Consortium](#), a coalition of over 50 health organizations, governments, associations and groups. The groups co-chairs contribute to decisions and actions intended to advance safer health care in Canada. Furthermore, PFPS are leading and contributing to the work of the [Integrated Patient Safety Action Plan](#) across all specific areas of focus: medication safety, surgical care safety, infection prevention and control, home care safety, and patient safety education (see infographic video [here](#)).



Figure 6: PFPS logo

### ‘Never Event’

One example of PFPSC’s contribution to the Integrated Patient Safety Action Plan is [Barb Farlow’s](#) (PFPS champion) participation in an action team, which developed a list of [“Never Events”](#) for Canada. The list includes serious patient safety incidents that are preventable using organizational checks and balances. [Kapka Petrov](#), (a PFPSC member from Ontario) experienced a never event first-hand when she suffered complications from a surgical clip left behind in her abdomen. Her story was shared in conjunction with the report, increasing awareness of such events from happening, and hopefully action to stop these serious yet preventable incidents.



Figure 7: Denise Klavano



Figure 8: Sharon Nettleton

PFPSC contributed to knowledge transfer at the global level by designing and delivering webinars developed by PFPS champions for PFPS champions. The highlights from each webinar are publicly available on PFPSC’s website. The 24 July session moderated by PFPSC member Judy Birdsell focused on evaluating the [impact of patient engagement](#), and the 24 September session, organized and delivered in partnership with WHO PFPS and moderated by Theresa Malloy Miller, focused on [patient engagement with health authorities](#).



Figure 9: Barb Farlow

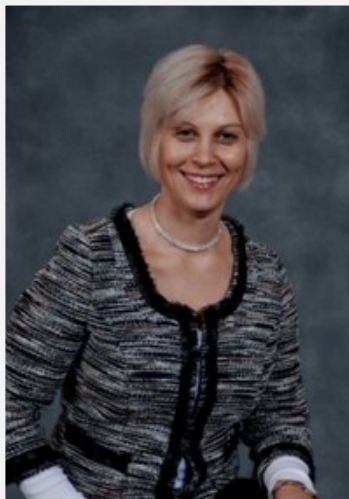


Figure 10: Kapka Petrov



Figure 11: Judy Birdsell



Figure 12: Theresa Malloy Miller

### Celebrating patients and organizations

PFPSC hold PFPS advocate [\(champion\) awards](#) that celebrate individuals and organizations that are excelling at partnering with patients to improve the quality and safety of health services and systems in Canada. Ed Kry, Sharon Nettleton, and Bernie Weinstein (all PFPSC members) and two organizational leaders judged the excellent applications received this year and selected winners in each category. The names will be unveiled on 30 October 2015 during [Canada’s Forum on Patient Safety and Quality Improvement](#). You can [register](#) to participate in this quality learning opportunity broadcast live from Edmonton across the globe, not only to see the winners but also to learn from other PFPSC members who will be speaking: Deb Prowse will present on patient engagement in incident management and Sabina Robin on communication for safety. Every day of the forum will open with a provider experience video. Participation in the forum is completely free.



Figure 13: Ed Kry



Figure 14: Berrie Weinstien



The work of PFPSC volunteers will also be celebrated in the award-winning publication [Hands in Health care](#), one of the resources prepared to celebrate [Canadian Patient Safety Week 2015](#) (October 26-30) with 150 000 copies distributed across the country. Click on this [edition](#) to read and learn more about Sharon Nettleton.

Please feel free to contact PFPSC for more information at ([info@patientsforpatientsafety.ca](mailto:info@patientsforpatientsafety.ca)) or [www.patientsforpatientsafety.ca](http://www.patientsforpatientsafety.ca).

## Mexico

*Evangelina Vazquez Curiel*

Evangelina Vazquez Curiel, PFPSC advocate (champion) presented at the ‘Safety of a paediatric patient’ conference on 12-13 August 2015, which celebrated the anniversary of the Iztapalapa paediatric hospital’s bioethics committee. This conference was held at the hospital where her son, Uriel, was hospitalised after suffering multiple adverse events as a baby. Because of this location, Evangelina said that giving the talk was ‘a wonderful and rewarding experience’. The conference facilitated reconciliation between patients and health-care professionals and managers, to promote actions in support of paediatric patient safety.

Additionally, on 24 September Evangelina gave a talk on ‘Patient safety incidents’ at the congress on quality, patient safety and safe hospitals at the General Hospital of Mexico, one of the biggest hospitals in the country. The Mexican patient advocates are working on safety strategies with this hospital and are also considering creating a ‘Patients for Patient’s Safety’ network within the hospital.



Figure 15: Evangelina presenting at the General Hospital of Mexico

## Paraguay

*Perla Lovera Deolinda Martinez*

The first PFPSC workshop was held in Paraguay on 14 November 2014, supported by WHO and the Pan-American Health Organization (OPS). Since then, the PFPSC group has met to discuss their collective vision and possible strategies towards effective patient advocacy. Current activities of the network include focusing on recruiting new advocates and forming better cohesion within the group.

Some strategies and visions of PFPSC Paraguay include:

- Training patients and family members on patient safety and health-care systems. This has included the use of presentations and online training modules in non-scientific language;
- Spreading knowledge about patient rights through advocacy leaflets (see figure 16);
- Teaching medical students on the importance of the patient voice, through lectures and talks;
- Working in direct care. For instance in hospitals, designating patient representatives, helping patients and families navigate the care process more safely;
- Collaborating with leaders of patient associations;
- Raising awareness through storytelling and testimonials at community events such as world awareness days and weeks;
- Supporting health professionals through public campaigns such as “no violence against health professionals”.

Perla Lovera Deolinda Martinez commented: “The experience of seeing that, as patients, we can collaborate with the system to provide high quality and safe health-care, is what motivates us to carry on, come rain or shine!”



Figure 16: An advocacy brochure raising awareness of patients rights

## USA

### **1. 7th Annual World MRSA Day Kick-off event & Global C. difficile Summit**

*Jeanine Thomas*



*Figure 17: World MRSA day balloon release*

The Methicillin-resistant *Staphylococcus aureus* (MRSA) Survivors Network held its 7th Annual World MRSA Day Kick-off Event & Global *C. difficile* Summit on 26 September. 'The MRSA Epidemic – A Call to Action' was this year's global theme. The event was held at the community house in Hinsdale, Illinois. Participants attending the event included MRSA and *C. difficile* survivors and their families, patient advocates, the general public and hospital infection preventionists. The events' received support from local and national sponsors (see the link for more details) Presentations and talks were given by world renowned MRSA and infectious disease specialists. Dr William Jarvis was the keynote speaker and Dr. Michael Pulia spoke on CA-MRSA and *C. difficile*. Mr Lynn Utesch spoke about livestock-acquired MRSA (LA-MRSA) and its impact on the environment and community. MRSA survivors Jason Suci and Karen Hudson both shared their stories. The event included a question and answer session with questions from health professionals and patients. The event also involved an award ceremony with awards given to Dr Michael Pulia for 'Person of the Year' and Joseph Paz, the networks 'MRSA Youth Champion'. The uplifting event closed with a balloon release outside in the courtyard for MRSA survivors and their families.

We wish to congratulate all the participants for raising

awareness of MRSA through this uplifting and powerful event, and to the sponsors for making it possible. For more information, please see the press release at: <http://www.prnewswire.com/news-releases/world-mrsa-day--a-call-to-action-300152231.html>. For more information on the MRSA Survivors network, please see: <http://www.mrsasurvivors.org/>.

### **2. Patient summit on diagnosis to discuss patient response to the Institute of Medicine report 'Improving Diagnosis in Health Care'**

*Helen Haskell*

Helen Haskell, PFPS advocate (champion) and vice chair of the WHO PFPS Advisory Group, participated in a patient summit on diagnosis, which was held to discuss the patient response to the Institute of Medicine (IOM) report '*Improving Diagnosis in Health Care*'. The summit was held on 26 September, just four days after the release of the IOM report.

Getting the right diagnosis is a key aspect of health care - it provides an explanation of a patient's health issue and informs subsequent health-care decisions. An urgent challenge that needs to be addressed in patient safety and quality improvement is incorrect diagnosis of illness or disease error, which recent publications have estimated to affect as many as 12 million people annually in the United States alone.

The Institute of Medicine (IOM) of the US National Academy of Sciences, Engineering and Medicine, released its long-awaited report, '*Improving Diagnosis in Health Care*', on 22 September. The report concluded that most people will experience at least one diagnostic error in their lifetime, sometimes with devastating consequences. It emphasized teamwork and patient-centeredness as central to the prevention of diagnostic error and defined diagnostic error as "the failure to (a) establish an accurate and timely explanation of the patient's health problem(s) or (b) communicate that explanation to the patient." One of the report's committee members noted that this was the first definition of diagnosis ever to include the word "patient".

The patient summit was sponsored by the SIDM Patient Engagement Committee, which is co-chaired by Helen Haskell. It was associated with the annual "Diagnostic

Error in Medicine” conference in Washington, DC. Along with members of the SIDM Patient Engagement Committee, speakers included Baltimore Health Commissioner Leana Wen, author of the book, *When Doctors Don’t Listen: How to avoid misdiagnoses and unnecessary tests*, and cardiologist Roger Leonard, who discussed ways of improving teamwork and partnership in health-care organizations.

Recommendations in IOM reports are often both a blueprint and a springboard for action. The mixed group of patients, researchers, and health-care providers assembled at the patient summit explored ways patients could foster implementation of patient-centered IOM recommendations, while moving towards more patient-driven policy change. Some of the many topics discussed in the facilitated deliberation were the education of patients and health-care professionals in communication techniques and the different elements of the diagnostic process; teamwork centering on the patient and family; patient reporting of outcomes and errors; and policy initiatives such as payment reform, to improve health-care provider communication. The group’s suggestions will be used to help formulate the society’s national strategies for patient response to the Institute of Medicine report.

Attendees at the summit included a half dozen PFPS advocates (champions), among them former PFPS lead Sue Sheridan, who has recently joined SIDM as a member of the board of directors and Casey Quinlan (who live-tweeted the proceedings at @mightycasey). Further reading:

The Institute of Medicine report, *Improving Diagnosis in Health Care*, is available for download at <http://iom.nationalacademies.org/reports/2015/improving-diagnosis-in-healthcare>. An accompanying Institute of Medicine video featuring PFPS champion Sue Sheridan can be viewed at <https://www.youtube.com/watch?t=4&v=fStBWT6fa3E>. For patient resources on preventing diagnostic error, visit the SIDM Patient Engagement Committee’s webpage at <http://www.improvediagnosis.org/?page=PatientResources>.



Figure 18: Helen Haskell opens the Patient Summit on Diagnosis

## Update from EMRO

### Pakistan

#### A healthy lifestyle reduces the risk of dementia

Evidence suggests that a healthy lifestyle that includes regular exercise, a healthy diet and productive mental activity can reduce the incidence of dementia and Alzheimer’s disease. September was World Alzheimer’s Month and from 14 – 30 September, Alzheimer’s Pakistan, an NGO, organized a ‘grand quiz’ on Alzheimer’s disease and dementia for students in 12 medical colleges in Pakistan. The purpose of this quiz, which was called “healthy lifestyle reduces the risk of dementia”, was to create awareness amongst future health professionals that a healthy lifestyle can reduce a person’s risk of developing dementia.

Among the 12 participating medical colleges, the top five highest scorings students from each institution were selected to participate in the quiz finale. The Fatima Jinnah Medical University in Lahore won the quiz and the Army Medical College in Rawalpindi were the runners-up.

At the Quiz closing ceremony, Dr Hussain Jafri, Vice Chair of the WHO PFPS Advisory Group and Secretary General of Alzheimer’s Pakistan, presented on the impact of Alzheimer’s disease in Pakistan and what services are provided by Alzheimer’s Pakistan. He emphasized the need for the government to implement policies and legislation to provide a better quality of life for people with dementia, both now and in the future.

Dr Yasmin Raashid, Patron of Alzheimer’s Pakistan, explained in her closing speech that there are around one million people living with dementia in Pakistan, but this figure is expected to rise sharply in the future. She called on all stakeholders to develop programmes to raise awareness and improve access to early diagnosis and care. Mr Zia Rizvi, President of Alzheimer’s Pakistan added: “This quiz has helped to create awareness amongst the future generation of doctors about this growing problem. It has highlighted the importance of supporting people with dementia and their carers, and also encouraging healthy lifestyle changes which may reduce the risk of dementia”.



We congratulate Hussain and Alzheimer's Pakistan for this successful event. We are also delighted to learn that Hussain Jafri has been awarded the degree of PhD by the University of Leeds, UK, in the field of prevention of genetic conditions. The topic of his thesis was "Attitudes toward prenatal diagnosis and termination of pregnancy in Pakistan".

Hussain is part of the pioneering team in Pakistan that initiated prenatal diagnosis and fetal medicine services in the country in 1994 and has several international publications to his credit.

On behalf of the PFPS network, we offer our most heartfelt congratulations to Hussain Jafri for his fantastic achievements.

## Update from EURO

### Lebanese Society for Quality and Patient Safety conference

*Denice Klavano and Mary Vasseghi*

On 18 - 19 September, Mary Vasseghi and Denice Klavano, PFPS advocates (champions) from Ireland and Canada respectively, participated in the Lebanese Society for Quality & Safety in Healthcare's (LSQSH) 3rd congress, held in Beirut, Lebanon, to share their personal stories. The theme of the congress was 'Patient Engagement', and it was attended by over a hundred health professionals. Three national and eight international speakers also shared their knowledge and expertise around patient engagement. Both Mary and Denice shared information about the PFPS programme and the importance of patient and family engagement in providing safe, quality health care.

This event represented the first steps towards promoting meaningful patient and people engagement in Lebanon, where awareness of the importance of engaging and empowering patients and families is still in its infancy. Their presentations provided the audience with both theoretical and practical tools to move such an agenda forward.

It is always fantastic to see PFPS champions being active locally, nationally and internationally, and we congratulate Denice and Mary for bringing the patient's voice to this conference!

## Update from WPRO

### Australia

*Stephanie Newell*

The rise in the understanding, acceptance and knowledge of the importance of patient and family engagement in health care in Australia can be measured through increased PFPS advocate (champion) invitations to events.

Steph Newell has participated in many events this year, one of which was the Medical School Student Conference of Melbourne's University of Victoria, held on 30 June. The conference was organized by medical students for medical students, as a part of their medical curriculum. Steph Newell joined with panel members from Australia and the United Kingdom for an in depth discussion on patient advocacy. The discussion covered the role of patient and family advocacy and the doctors' role in advocating for patients to navigate the health system. The discussion also looked at the role of a doctor working with patients in shared decision making and discussed patients' goals, preferences and information provision. The aim is to help patients to make the best possible informed decision and choice that is meaningful and patient-centred.

Steph commented, "I left the day feeling buoyed that the future of patient care is in innovative and compassionate hands that value the importance of working with patients, their families and carers, in partnership".

### Malaysia

#### 1. Patients for Patient Safety Malaysia participation in international events

*Manvir Jesudasan*



Figure 19: From left to right, Dr Kadar Merikar, MSQH CEO; Dr Lim Chie Kean, CEO of Fatimah Hospital Ipoh; Dr Nur Asiah, Ministry of Health; Tan Sri Siti, Chair MSQH; Manvir Jesudasan, PFPS Malaysia advocate; Reverend Samuel, Patient Advocate for Heart Institute

Manvir Jesudasan, PFPS Malaysia advocate, participated in the Malaysian Society for Quality in healthcare's 2015 international conference and exhibition, entitled, "Measuring Performance: 15 Years of the MSQH Hospital Accreditation Programme: Achievements & Challenges". This took place on 8 September, with participation from hospital directors and nursing directors from across Malaysia's public and private health-care services.

The event included a training and awareness-raising workshop. PFPSM member Manvir Jesudasan was invited to this workshop to contribute to the panel discussion entitled, "Patient - Provider Partnership in moving the Patients for Patient Safety Agenda". The other panellists included an official from the Ministry of Health, the chief executive officer of MSQH, a doctor and a patient representative.

Manvir also participated in an international patient safety seminar hosted by the Malaysian Ministry of Health on 9 September. The event was a one-day seminar supervised by the Deputy Director-General of the Malaysian Ministry of Health. The participants were largely hospital and nursing professionals working in Malaysia's public hospitals. Manvir Jesudasan represented PFPS Malaysia as a panellist in the discussion, "Patient Safety – Are we progressing?". The other panellists included a Malaysian Ministry of Health official, a renowned doctor from Indonesia and the managing director from Elsevier.

Manvir explained that both conferences held positive discussions between all health-care stakeholders present.

We wish to congratulate Manvir on his ability to represent the patient voice at these high-level events.



Figure 20: Reverend Samuel and Tan Sri Siti

## **2. Patients for Patient Safety Malaysia: pilot project**

*Rebecca John and Felicity Pocklington*

Patients for Patient Safety Malaysia (PFPS Malaysia) provided an update on their pilot project on Patients for Patient Safety in 14 public and private hospitals in Malaysia. This initiative was created following the in-country workshop on 30 September 2014, which was jointly organized by the Ministry of Health Malaysia, WHO Malaysia Country Office in collaboration with the Malaysia Society for Quality in Health (MSQH), PFPS Malaysia, the WHO Regional Office and the WHO PFPS. This update provides an overview of the objectives, methods and progress to date. Objectives of the pilot project were;

- to incorporate the patient, family and community voice into all levels of health care through engagement and empowerment;
- to identify a structure/mechanism where patients' experience and expertise can be engaged and integrated into and implemented within hospital quality improvement programmes.

Methodology:

- Awareness training on the two selected topics - fall prevention and medication safety - was conducted for both the patient representatives and hospital representatives.
- Orientation for patient representatives and hospital teams to provide information on the hospital processes in fall prevention and medication processes.
- Selection of pilot sites - identified the wards for the pilot project based on the number of incidents reported and patient type. The sample ward for falls was the orthopaedic ward since it had the highest number of falls and medication errors.
- Intervention - identified activities for the pilot project which include monthly visits to the wards and regular meetings to monitor progress.

Pilot project activities:

### 1. Fall prevention

- Falls are the second leading cause of accidental or unintentional injury and deaths worldwide.

- Each year an estimated 424 000 individuals die from falls globally of which over 80% are in low- and middle-income countries.
- Adults over 65 suffer the greatest number of fatal falls.
- Prevention strategies should emphasize education, training, creating safer environments, prioritizing fall-related research and establishing effective policies to reduce risk.

The pilot project involved patient representatives and hospital teams doing monthly ward visits to hospitals. Using a standardized questionnaire they would ask four questions to patients:

- What do you know about fall preventions?
- Do you know how to use the call bell?
- Did the staff provide education to you?
- What can we do to improve your understanding of fall preventions?

The pilot project was launched in March 2015, when no falls were recorded in the sample ward. In April and May, there were two falls and one fall respectively. There appeared to be a decline as no falls were recorded in the following months after the implementation of the pilot project between June and September 2015.

## 2. Improving medication administration safety

The PFPS Malaysia pilot project initiative for medication error prevention has involved three activities: 1) Pharmacy sharing session and tour, 2) Ward sharing session and tour and 3) Patient representative to create awareness to patients in the selected ward using a patient safety pamphlet.

Following the pilot project, the number of medication errors (administration) reduced between March and July 2015. The current patient representative, Mr Bulbir, a previous patient of this hospital, will continue to be engaged in patient safety initiatives in the hospitals.



Figure 21: Pharmacy sharing session and tour

We wish PFPS Malaysia all the best with this exciting project, and look forward to seeing the results, conclusions and recommendations after the project has come to a close.



Figure 22: Ward sharing session and tour

## Future events

### Jordan

The Jordan Health Care Accreditation Council (HCAC) will be hosting the 3<sup>rd</sup> quality health-care conference and exhibition in Amman on 23 - 24 November. The event is entitled, “Building Quality for Safer Healthcare”. WHO PFPS will be providing technical assistance through a pre-conference workshop aimed at raising awareness, and through a presentation at the conference too. This workshop will be titled, ‘Engaging and empowering for health: bringing in the voice of health professionals’ and will be a collaborative effort between the WHO PFPS programme, the Health System Development Department of the WHO Regional Office for the Eastern Mediterranean (EMRO), and the Health Care Accreditation Council (HCAC), Jordan.

The workshop aims to engage the participants in a discussion about how to encourage health professionals to involve the patient, family and the community’s voice into health care. It will provide an overview of WHO global initiatives on engagement and empowerment for patient safety and health-care quality, for people-centred and integrated health services and for quality universal health coverage (UHC).

The PFPS presentation will be titled, ‘Bridging the gap between quality care and patient experience’. The presentation aims to engage the participants in a discussion about how to bring the patient, family and the community’s voice into health care. It will provide an overview of WHO global initiatives on patient, family and community engagement, which will encompass engagement for patient safety and health-care quality, for



people-centered and integrated health services and for quality universal health coverage (UHC).

## Mexico

The WHO PFPS programme will hold a PFPS workshop in Mexico on 18 November. The workshop will be hosted at the Hospital de Ciencias Médicas y Nutrición and will be co-sponsored by the Universidad Autónoma de México (UNAM), through Dr Enrique Acosta. This will be a great opportunity to expand the Mexican network and to train patients and people on patient safety knowledge, and patient advocacy skills, opportunities and techniques.

On 19 – 21 November, the 3<sup>rd</sup> World Congress on Integrated Care will be held in Mexico. On 19 November, PFPS will facilitate and organize a pre-conference workshop on family engagement. Evangelina Vazquez Curiel, a patient advocate and PFPS champion will work in collaboration with the PFPS programme to organize this event.

## Uganda

The Ugandan Community Health and Information Network (CHAIN), will be holding the first PFPS workshop in Uganda on 3 – 5 November. Regina Kamoga, a patient advocate and a PFPS champion, who works for the Community Health and Information Network (CHAIN), is the focal point for the workshop and has planned the event in consultation with the Patients for Patient Safety programme.

This workshop will focus on capacity-building for patients, families, communities and health professionals and is aimed at raising awareness of patient and people engagement and empowerment for patient safety, health-care quality and people-centered health services. The workshop will be supported by the Ugandan Ministry of Health and WHO HQ, who will provide technical support.

This is a great opportunity for the PFPS programme to provide technical support in the AFRO region, as currently the PFPS global network lacks AFRO patient advocate representatives. We are very much looking forward to it!

## PFPS advocate (champion) feature

**Mary Vasseghi**  
PFPS advocate (champion)



*Figure 23: Mary Vasseghi*

Mary currently lives and advocates in Iran, however her patient advocacy work began in Ireland following the preventable death of her mother in 2004 and her 18 year son in 2005, both due to medical misdiagnosis of different natures.

Having witnessed two preventable errors in hospital care, Mary explained how she had witnessed “unnecessary pain and suffering for the patient, the family and the health-care staff”. Since, Mary has worked passionately in the cardiac health field nationally and internationally, with a strong belief for patient and health professional engagement.

Mary set up a support group for families who had lost children to sudden cardiac death in 2006, with the aim of supporting parents and effecting positive change. The Irish Heart Foundation sudden cardiac death council was set up in 2008, which Mary chaired until 2011. This council included various participants, including policy-makers, health professionals, academics, patients and families. The aim was for all participants to work together to reduce the risk of sudden cardiac death in Ireland.

Mary accomplished an MBA (with a specific focus on health care) in 2009, furthering her ability to advocate with new knowledge and skills. She was awarded ‘Social Entrepreneur of the year’ in 2009, for her work in the cardiac area. Mary had trained as a nurse in the early 70s, and she said that “this training, the MBA and knowledge

of health-care systems is of considerable assistance when working as a patient advocate”.

Mary provided some insight on her own experience in health care and patient advocacy:

“The complexity of health care is extensive and medical practitioners can face many challenges, both professional and private, towards providing optimum care to their patients. I feel doctors set out and want to provide excellent care, however for a multiplicity of reasons they do not always succeed in doing so. Politics, power, agendas of agencies and individuals have had to be taken into consideration. A considerable amount of diplomacy, discretion and judgment is required in deciding what, to whom, where, how and when information can and should be shared. One must always be conscious of the potential effect of one’s involvement; therefore conscientiousness, diplomacy, discretion and a meticulous approach are necessary at every juncture. Knowing oneself, one’s strength, weaknesses and capacity and being open about it is very important when working as a patient advocate”.

The PFPS team congratulate Mary on her fantastic achievements and ongoing work in Ireland and Iran.

## Future PFPS News

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### Share your news with us!

**PFPS News:** Contributions for the next PFPS News are invited. The deadline for submissions is 15th December.

**PFPS Community of Practice:** You can also continue to ask questions, share experiences and learning on the PFPS platform at: <http://ezcollab.who.int/pfp scop>. If you have problems accessing the CoP, please contact Katthyana Aparicio at [pfps@who.int](mailto:pfps@who.int).

**PFPS Skype:** If you wish to speak to us interactively, our Skype name is pfps.geneva.

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### Disclaimer

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