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## Welcome!

*Helen Haskell*



Welcome to the Autumn 2016 edition of the Patients for Patient Safety newsletter! Our champions and the Geneva team have been as busy as ever this past quarter. We have reports on an important anniversary, updates from four of our six regions and several exciting new programmes at WHO.

Patients for Patient Safety Canada (PFPS Canada), one of our most active champion groups, this year marks its tenth anniversary. PFPSC grew out of the 2005 London workshop and the 2006 PAHO (Pan-American Health Organization) region-wide workshop held in San Francisco, which was attended by ten Canadian representatives. PFPS Canada was organized in a Canadian workshop shortly after San Francisco, and it has never looked back! In this issue, PFPS Canada celebrates its anniversary by featuring long-time member and co-chair Donna Davis, who reflects on the tragic death of her young son Vance and on the changes Canadian champions have been able to bring about thanks to PFPS Canada's existence.

Elsewhere in the region, Mexican PFPS champion Evangelina Vazquez reports on her activities promoting the patient's role in combating health care-associated infection; Jorge Martinez reports on children's nutrition in Argentina; and Leticia Gamarra, from our new PFPS Paraguayan network, discusses her work to establish safer surgical practices.

EMRO celebrated Hand Hygiene Day with enthusiasm. Egyptian PFPS champion Nagwa Metwally describes a memorable event involving cyclists and a well-known singer, and Said el Kharrasi reports on activities in Morocco including hand hygiene training for medical staff. JS Arora reports from India on raising awareness of thalassemia. From Australia, PFPS champion Brian Stafford discusses the links between physician burnout and patient safety, and Anna McMahon tells the sad story of her young son's death from prescription medications and the path it led her on to improve drug safety.

In other developments, members of the WHO PFPS Geneva team attended regional meetings on primary care in both the Eastern Mediterranean Region and Europe. At the EMRO meeting, the PFPS team held a workshop on patient, family and community engagement. At the WONCA Europe Conference, Felicity Pocklington and Shannon Barkley gave four presentations on topics around patient engagement and effective communication in primary care.

In May, the WHO Global Patient Safety Challenge on Medication Safety was introduced during a World Health Assembly side event, where Maryann Murray of PFPS Canada represented the patient perspective. The goal of the Challenge is to reduce harm from prescription medications by 50% over the course of five years. There will be considerable opportunity for patient involvement in both the design and fulfilment of this ambitious programme. Another important occurrence at the World Health Assembly was a resolution supporting the Framework on integrated, people-centred health services and the launch of the collaborative [IntegratedCare4People](#) web platform to allow the sharing of resources on people-centred care.

Stay tuned for more information on both of these exciting programmes! We have much to be proud of and much still to do as the concepts of patient safety and patient engagement push into new territory. I look forward to working with you all and hearing more about your accomplishments in the coming months.

### Upcoming Events

33rd ISQua Conference , Tokyo, Japan,  
16-19 October 2016



Patient, Family and community  
engagement and empowerment  
workshop, Muscat, Oman  
22-27 October 2016



World Health  
Organization

## Sixty-nine World Health Assembly: Medication Safety Side Event

Maryann Murray and Katthyana Aparicio

The side event on “Addressing the Global Challenge of Medication Safety to Improve Patient Safety and Quality of Care,” organized by the Patient Safety unit was held on 25 May during the 69th World Health Assembly (WHA69). The session was chaired by the President of WHA69, Dr Ahmed Mohammed Al-Saidi from Oman, and moderated by Sir Liam Donaldson, WHO Envoy for Patient Safety. The panel also included Dr Basia Kutryba from Poland, Dr Nor'Aishah Abu Bakar from Malaysia, Mr Ahmed Alharbi from Oman and Dr Sathasivam Sridharan from Sri Lanka. They all spoke of national experiences in medication harm reduction, and within this context Maryann Murray was invited to bring the patient's perspective.

Maryann lost a daughter due to an adverse drug reaction, so understands first hand how swift and deadly medication harm can be. She summarized the 10 years she has spent working to increase reporting of adverse drug reactions, as well as other patient safety initiatives. She spoke of work being done through Patients for Patient Safety (PFPS) Canada and brought an example of a recent Canadian initiative aimed at empowering patients: the ‘Five Questions to ask about your medication’ tool. Maryann came to this meeting with the goal of encouraging those present to take up this challenge and help create and share initiatives aimed at improving medication safety.

In the words of Maryann: *“What I had not anticipated was the effect this event would have on me. I was deeply moved by the level of understanding and motivation of those who spoke both during and after this meeting. The questions and comments were thoughtful and insightful and demonstrated strong desire to help reduce medication harm in a variety of ways. I left this event with renewed optimism, believing that the challenge of improving medication safety is being embraced, and soon we will be sharing ideas and actions that will significantly reduce medication harm.”*

As one attendee at the meeting stated, “feedback is the best reward.” We look forward to feedback and hearing of new initiatives that are reducing medication harm and improving patient safety around the world.



Maryann Murray and Sir Liam Donaldson



## Regional Meeting on Tools and Standards to Assess and Improve Quality of care at the Primary Care Level

*Jenny Westad, Felicity Pocklington, Nittita Prasopa-Plaizier*

The WHO Regional Office for the Eastern Mediterranean (EMRO) developed a set of quality indicators for primary care through in-depth desk review, surveys and a range of consultations with experts in the area of quality of care and patient safety during 2015. In total, 34 core indicators were selected under six well-established quality domains: Access/Equity, Safety, Efficiency, Effectiveness, Patient-Centeredness and Timeline. The indicators were piloted in ten facilities within the following four countries: Iran, Jordan, Oman and Tunisia.



*The PFPS Team and the participants of the workshop*

EMRO held a regional meeting from 30 May to 1 June 2016 in Amman, Jordan. This meeting focused on tools and standards and assessed the indicators used in efforts to improve quality care at the primary care level. The meeting aimed to help Member States generate a road map to assess and improve care at the primary care level and raise awareness among the national quality and safety focal points on patient engagement and empowerment. Objectives included:

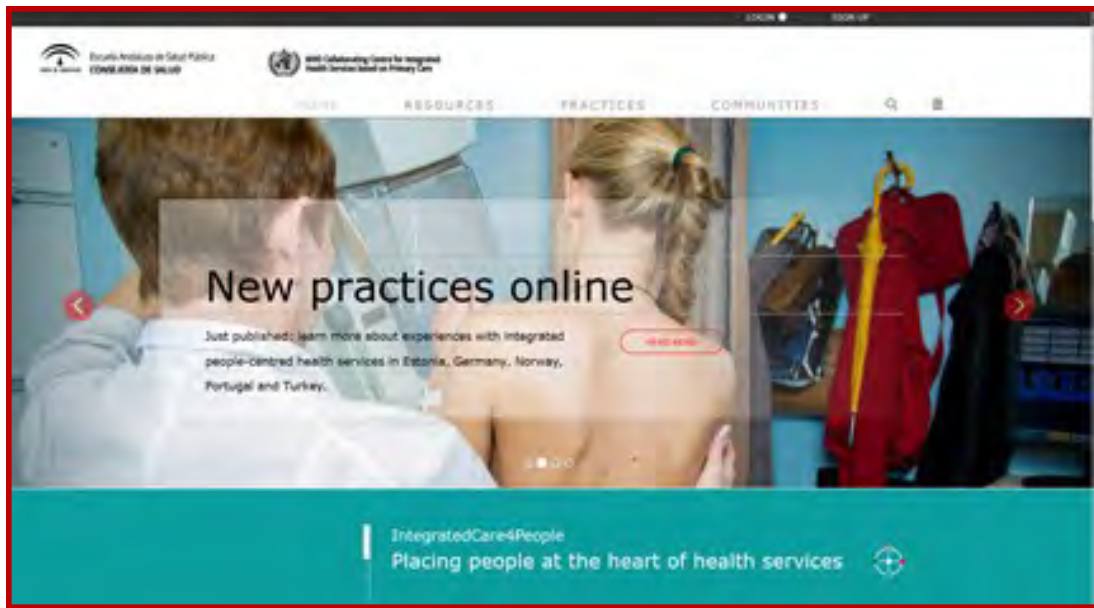
- To discuss the situation of the quality of care at the primary care level and identify challenges across the region;
- To share the quality framework for primary care developed by WHO and the experiences of piloting it in four EMR countries;
- To review and finalize the quality framework for primary care and its relevant indicators;
- To raise awareness among the national quality and safety focal points about engagement and empowerment.

The meeting gathered 49 people, including primary health care, quality of care and patient safety focal points from the ministries of health (MoH) of 19 countries across the Eastern Mediterranean Region, as well as global and regional experts invited to present evidence and best practices related to quality of care at the primary care level.

As a part of the meeting, the WHO PFPS team hosted a workshop on patient, family and community engagement, building on the initial review and discussion of the PHC quality indicators. The workshop aimed to raise awareness of the importance of engagement and empowerment and how it can help improve the quality of primary care services. International experiences of integrating patient and health professional engagement and empowerment into the national patient safety health-care quality policy agenda were shared. Patient advocates and representatives from civil society in the EMR region

# Communications Toolkit

Mart Leys and Katthyana Aparicio



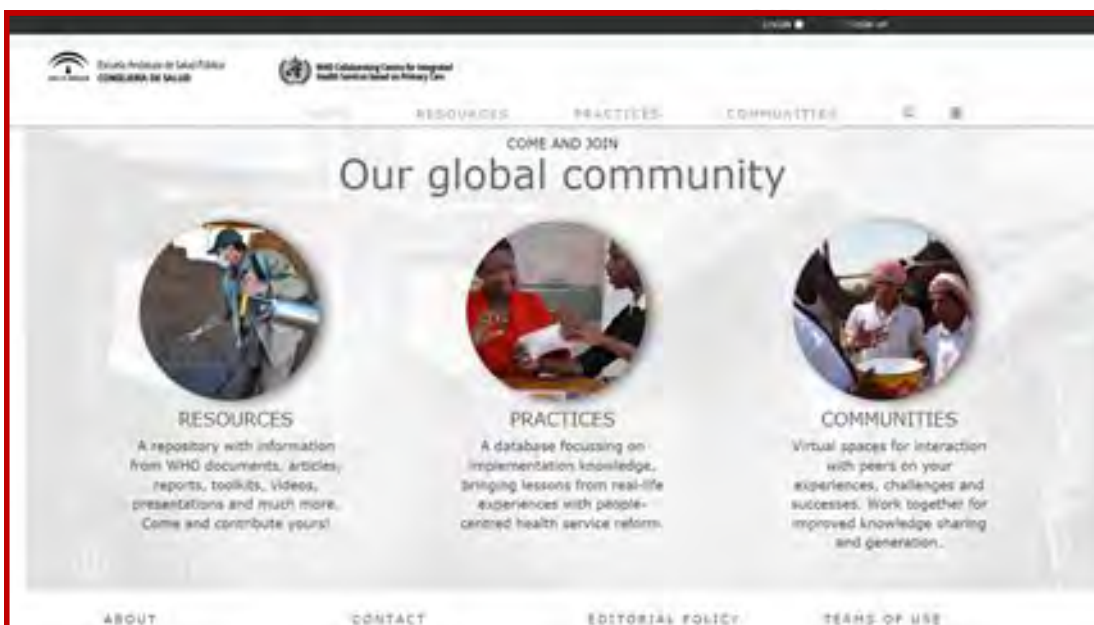
WHO have been working in collaboration with the Andalusian School for Public Health (a WHO Collaborating Centre) on the Framework for Integrated and People-Centred Health Services. On 27 May, they officially launched the [IntegratedCare4People](http://www.integratedcare4people.org/) web platform.

The platform includes a communication toolkit where people can find resources to support social media activities related to the strategy and its web platform.

This platform brings together knowledge, information and a global network of people and organizations working towards the goal of achieving integrated people-centred health services for all. Information is organized in a repository of resources, communities of practice and a practices database where technical insights and the operational know-how of health service delivery transformations are shared. The web platform for **IntegratedCare4People** is a collaborative platform. Everyone is very welcome to share their resources and practices and to participate in the various communities of practice.

We look forward to collaborating in building a truly global virtual network for stimulating and encouraging change towards integrated people-centred health services.

Link: <http://www.integratedcare4people.org/>





# WONCA Congress

*Felicity Pocklington and Shannon Barkley*

The WONCA European Conference was held from 15-18 June 2016 in Copenhagen, Denmark. The aim of the conference was to address five pertinent issues related to improving primary health care (PHC) systems and services in Europe: ageing Europe; making health care affordable; the future consultation; diagnosing – a vital task for family medicine; and inequalities in health. The conference brought together approximately 3000 international participants, mainly family doctors (otherwise known as “general practitioners”). Approximately, 1200 of these participants were young doctors.

Shannon Barkley, (WHO Lead on PHC) and Felicity Pocklington, (Technical Consultant to the patient, family and community engagement initiative) represented the WHO Service Delivery and Safety (SDS) department. They participated and delivered presentations in four events:

## 1. Presentation: “Measurements and indicators of patient, family and community engagement and empowerment”

The new WHO resolution advocating for Integrated People-Centred Health Services (IPCHS) was adopted at the 69 World Health Assembly last May. One of the five strategic objectives of this framework is to engage and empower people, including patients, families, members of the community and health professionals. Measurements and indicators of meaningful engagement and empowerment are important to evaluate current practices, ensure mutual accountability, and incentivize sustainable and people-centred action for change. Shannon informed the audience about existing measures and indicators of engagement and empowerment from a WHO scoping review carried out in January - February 2016.



*Shannon Barkley*

## 2. Presentation: “Meaningful engagement – the patient and family perspective”

The WHO Patients for Patients Safety (PFPS) programme, within the Service Delivery and Safety Department, recently conducted a survey exploring important actions that health care providers can take to make the patient feel meaningfully engaged and empowered. Felicity outlined the key findings of the survey, including seven actions considered most important for meaningful engagement from the patient perspective included showing respect and compassion, facilitating access to information, listening, providing quality consultation and discussion, and including family members.



*Felicity Pocklington*

## 3. Workshop: “Engaging for effective communication, collaboration and partnership between health professionals and patients”

Effective consultation requires effective communication and collaboration between health care providers and the patient. If engaged and empowered, the patient and family are more likely to access relevant health information, seek health care and services appropriately and better provide personal information. Furthermore, trained and skilled health care providers are able to better engage patients, ask questions in a culturally- and socially-sensitive manner, to collect data on the patient experience and protect patient's privacy. Shannon and Felicity outlined key strategies and tools for effective engagement and empowerment in consultations through a scene-setting presentation. Following the presentation, there was an interactive brainstorming session that explored key barriers and opportunities for engagement and empowerment of patients and families in consultations.

## 4. Presentation: “Health literacy - a way to engage and empower patients and families”

Health literacy goes beyond the transmission of information

and a person's capacity to read brochures or listen to instructions. Individuals should have access to health information relevant to their needs and be able to understand and use it appropriately. Felicity explained how patient and family engagement and empowerment can lead to better health outcomes, better care, a better patient experience and lower health-care costs. The presentation explained that one pathway to achieving this is to work to ensure that people are health literate so that they are capable of making informed decisions, choose appropriate care options and seek health interventions appropriately.

We congratulate them on their success in bringing the voice of patients, families and the community to the ears of doctors!

worked in groups in order to define the strategic direction of the Challenge and determine how to construct the Challenge Framework in order to achieve the goals and objectives of the upcoming Global Challenge.



*Participants of the Medication Safety Meeting*

## Global Patient Safety Challenge - Medication Safety (Working Groups Meeting)



Unsafe medication practices and medication errors are a leading cause of injury and health care-associated harm around the world. Worldwide, the

cost associated with medication errors has been estimated at US\$ 42 billion annually, which is almost 1% of total global health expenditure.

In order to address the global problem of unsafe medication practices and medication errors, WHO plans to launch the Global Patient Safety Challenge on Medication Safety, with the overall goal of reducing harm from medications, by targeting high-risk medications, polypharmacy and transitions of care.

Nittita Prasopa-Plaizier and Katthyana Aparicio are the secretariat to one of the five working groups – the patient and public group, which was co-chaired by Helen Haskell, (co-chair of the Advisory Group to the WHO Patients for Patient Safety (PPFS) programme). This 3 day meeting, held on 24-26 August, was hosted by the Patient Safety and Quality Improvement unit as the second preparatory meeting for the challenge. Medication and patient safety experts gathered at WHO headquarters in Geneva and

## China EPI (Expanded Programme Immunization) Communication Training Workshop

The National Immunization Programme in China has had to deal with several high profile events that negatively affected parental and public confidence in vaccines and health services. Within this context, being able to build trustful relationships, communicate and engage with parents, families, communities and a range of stakeholders on an ongoing basis, are critical matters.

Katthyana and Felicity joined the mission team to China to provide technical support and participate in a workshop, held on 31 August to 2 September in Beijing. They facilitated a specific session on lessons learnt from patient, family and community engagement and contributed to building full understanding of how communication and engagement processes work at the personal, collective and institutional level.



*Successful & challenging experiences*



## Multi-stakeholder consultation on patient, family and community engagement in Indonesia

*Nittita Prasopa-Plaizier*

WHO's Country Office in Indonesia, in collaboration with the Ministry of Health (MoH) for Indonesia and a not-for-profit organization 'Concerned and Caring Parents Foundation (Yayasan Orang Tua Peduli/YOP)', hosted a stakeholder consultation meeting on patient and family engagement on 21-22 September 2016, in Jakarta. Coordinated by YOP, led by Dr Purnamawati Pudjiarto, a PFPS Champion in Indonesia, the meeting was organized under the umbrella programme called 'Patient Engagement Programme in 2016'. The overall goal of the meeting was to promote patient, family and civil society engagement, with a view to establishing a patient network.

About 150 people participated in the first day of the meeting, which focused on raising awareness, gaining support and building collaboration. A smaller group of about 40 participated on the second day, which discussed the setting up of a patient network. Dr Kadar Marikar from PFPS Malaysia and Stephanie Newell from Australia also participated to share their respective experiences on patient and family engagement. The significance of this event was that it had the support of the Ministry of Health and facilitated by 'three WHO' – Dr Salma Burton from the WHO Country Office, Indonesia, Dr Sunil Senanayake, from the Southeast Asia Regional Office (SEARO) and Nittita Prasopa-Plaizier from WHO headquarters. The meeting ended with an encouraging sign that the participants had agreed to work together on a plan to set up an Indonesian network. We look forward to welcoming new PFPS Indonesia champions in the near future.

support mothers breastfeeding babies for at least six months and advocate continuing breastfeeding until two years of age, as per WHO advice. One of the activities organized by this programme is teaching mothers how to prepare safe and healthy food to improve organic and immunological development of babies in the first years of life.

This programme aims to expand its activities all over Argentina and spread the objective of Nutriacademia, which promotes using practical methods based on scientific knowledge on infant nutrition to raise healthy and children.

Jorge was invited to become advisor of Nutriacademia. At the launch event, held on 16 May which was well attended by families and professionals, he talked about organic and emotional development in the first year of life. The event was coordinated by a well-known TV host, Mariana Fabbiani, who facilitated the interchange and feedback from the audience. Nutrition expert Juliana López May led a practical session on safe and healthy food preparation. It was a great opportunity for Jorge to speak about what he thinks is crucial for childrens to have a healthy life. As final remarks, he mentioned that this kind of programme aiming to help mothers in their tremendous work should be supported and shared, so it can be imitated everywhere.

Jorge congratulates Nutriacademia for their efforts to support future generations and thanks programme coordinators Lucía Calogero and Belén Oliveira who are doing a great job boosting and developing new ideas to help early life nutrition.

## Update from AMRO/PAHO

### Argentina

*Jorge Martinez and Katthyana Aparicio*

Jorge Martinez, PFPS Champion from Argentina, is the author of "An Invitation to Life." This programme promotes interaction and knowledge-sharing between parents and professionals about the advances of children's safe, organic and emotional development during the first years of life. He is now supporting the Nutriacademia programme, an Argentinian institution focused on providing guidance to parents on how to raise healthy children through the promotion of healthy nutritional habits. They also encourage and



*Jorge Martinez and Mariana Fabbiani*

## Canada

*Ioana Popescu*

For its celebration of 10 years of harm to healing, [Patients for Patient Safety Canada](#) featured Donna Davis' trajectory as an outspoken advocate for the patient's voice over the past nine years. Donna has been a member of PFPSC since 2007 and served as co-chair for 8 years. Donna has seen positive changes in the way health care providers collaborate with patients and their families.

"When we first started, we pretty much had to invite ourselves," Donna says of that initial founding group of Patients for Patient Safety champions. "We had to look for opportunities to say, hey, would you like us to come and talk to your group about patient safety? It has come a long way since then. Now we have so many requests coming our way that we can't fulfill them all." She reached out to the medical school at the University of Saskatchewan in those early days and asked if they had ever had a guest speaker address the topic of patient safety. They had not, so Donna said "well, I think I have a story that your students need to hear."

Fourteen years ago, [Donna's 19-year-old son Vance died in a Saskatchewan hospital](#) three days after he lost control of his truck on a rural road. Doctors decided Vance's head injury was minor, only a concussion. Donna, a nurse by training, felt otherwise but her growing concerns about his deteriorating health were dismissed. The family's ordeal was made even more tortuous by a series of miscommunications with health care workers. Five years of anger and frustration passed before Donna was contacted by the staff member who conducted the hospital's review of Vance's case.

"She phoned me and said Donna, we failed Vance in our care of him, and we failed you as a family," Donna recalls. "So I finally had validation that what I knew in my heart to be true was in fact true. Then I had to do something to try and make it right so no other family would go through what we had gone through."

Donna has been telling Vance's story ever since and believes it is that deeply personal perspective, just like those visceral experiences being shared by every one of the patient safety volunteers now active with Patients for Patient Safety Canada, that is the prime motivator for improvements in the health care system.

Donna says she is proud of PFPSC Canada's role in recent years in contributing to the development of a standardized method for investigating, disclosing and sharing information about accidental harm with medical professionals and the public. She is pleased that patient

safety and interacting with patients and their families is now a common part of the curriculum for many health care providers. She's also proud of her group's standing as one of the most active and credible patient safety advocates in the world.

When she started advocating for patients, Donna said she had no idea of how healing that work would be. "It has healed a piece of my heart that was broken, and I guess it's healed it because I know I'm honouring Vance's life and I'm making sense of his death."

Donna thinks the old paternalistic attitudes in the health system, where the patient and family views were often dismissed as largely inconsequential, are slowly changing but that there is still a long way to go. People's egos still get in the way.

It is certainly true what Donna says, "Talk is cheap. It's easy to say 'yes, we're patient/family-centred and yes, the patient family voice is important to us,' but when it comes down to it, where they have to put it into practice, it's really easy to fall back the old ways. We have to realize that culture can't be changed overnight. We have to celebrate the successes that we do have and we have to bring people on board, even if it is one at a time. We have to keep doing what we're doing and that's reaching out to partner positively with the health care community."

Link to the video of Donna Davis:  
<http://www.patientsafetyinstitute.ca/en/toolsResources/Member-Videos-and-Stories/Pages/Patient-Safety-Stories---Vance%27s-Story.aspx>



***Donna Davis honours her son's life by working as co-chair for Patients for Patients Safety Canada\* .***

**\*Credits: CPSI Website**



## Mexico

*Evangelina Vazquez and Katthyana Aparicio*

2016 has been a busy time for Evangelina who participated in several events.

The XI Refresher Training on health care-associated infections took place at the Infants Hospital Federico Gomez in Mexico City from 2-4 May. Evangelina was invited to deliver a speech on bacteremia at the V Seminar. The title of her presentation was *Patient and Family: Do we need them to prevent and fight nosocomial infections?* It was a great opportunity for Evangelina to provide rational arguments about the importance of involving patients and families to fight health care-associated infections. She mentioned that engaging patients and families brings a different perspective to designing policies to reduce nosocomial infections within a framework of integrated services. This event was also an opportunity for Evangelina to meet different stakeholders working on infection prevention and control, including the volunteer team from the hospital. They shared their initiative to engage with children on the hand hygiene campaign by using stories and a charismatic character who helps kids understand the importance of hand hygiene in hospitals and get engaged in this work.

Evangelina was invited by WHO to attend the meeting organized by the Infection Prevention and Control Unit (IPC) on Core Components of Effective IPC Programmes held in Geneva from 30 March to 1 April. The meeting focused on creating strategies within a Global Action Plan to mitigate the impact of future outbreaks and pandemics on populations. Within this wider context, the impact of health care-associated infections and the current strategies for their reduction were analysed with the aim of identifying evidence-based strategies to produce a new guideline. Thus, the recommendations stated in the 2008 IPC guideline were re-evaluated. Furthermore, topics such as surveillance and training for health care workers were analysed. The utility of the Microbiology laboratory as a tool for surveillance was discussed since there were only about 10 scientific reports as evidence of its relevance; however, it was approved based on solid arguments of previous experiences.

Evangelina, bringing the patient's perspective, proposed to include patients and PFPS champions in discussions and policy-making whenever possible. She shared the experiences of the Pan-American and Mexican PFPS networks as an illustration of the importance of patient inclusion.

The working group thought it was a good idea in principle

but that further data and stronger scientific evidence were required. However, it was argued that even if there were no reports on the impact that PFPS champions can have on the control of healthcare-associated infections, there was information about their role for the improvement of other safety issues and thus it was a very promising idea. Therefore, the inclusion of PFPS champions was inserted within a multimodal strategy. We look forward to this guideline, which is currently being finalized.



*\*Credits: WHO Infection Prevention and Control Global Unit*

## Paraguay

*Leticia Gamarra and Katthyana Aparicio*

The PFPS Paraguayan Network, established in late 2014, has been working hard to promote safe practices at the hospitals in Paraguay. Leticia Gamarra, PFPS champion, is a very engaged nurse who has been advocating for safe surgery at her hospital. One of the major achievements has been the implementation of a coordinated team for each effective surgery, the presence of a paediatrician to receive the baby and the use of the WHO Safe Surgery Checklist.

She is now focused on having a stock of safe blood to react immediately in emergency cases. With the support of the National Blood Programme, Leticia is working in her community "Colonias Unidas Itapua" to raise awareness and encourage blood donation.

As Leticia says, "a lot remains to be done. The infrastructures are not yet optimal and only little changes have been effective so far". She hopes that the small steps she is taking will become bigger one day and lead to the implementation of a safety culture.

## Update from EMRO

### Egypt

*Nagwa Metwally and Katthyana Aparicio*

As is the case every year, Nagwa has been very active promoting the hand hygiene campaign. This year has been no exception! Nagwa organized a day of hand hygiene campaign on 20 May in collaboration with the Ain Shams teaching hospital in Cairo, and the Cairo Bike (a company promoting cycling and supporting different campaigns). The riders wore t-shirts and caps showing the logo of the campaign. The advocates stopped their ride in the street to discuss with people and raise awareness on the importance of hand hygiene. Following this activity, a celebration took place at the hospital with the support of the Dean and a very famous singer invited as ambassador of the event. The event was very welcomed by the community.

Nagwa is also working to spread good practices to other hospitals. With the support of Dr Samia, head of Infection Prevention and Control, seven hospitals have been conducting hand hygiene self-assessments and were asked to present their results to health care workers. Nagwa has noticed that materials such as water, soap or alcohol handrub are not really a constraint for improving hand hygiene, but attitude is.

Nagwa's aim for this year has been also to promote the implementation of the WHO Surgical Safety Checklist, for which she got great support from the senior management team of the medical school. She has started with the paediatric unit and emergency surgeries.

Nagwa will continue to advocate for patient safety, and she hopes to promote these activities at the national level with the support of policy-makers and the Red Crescent.

We wish all the best to Nagwa in these endeavours!



*Nagwa Metwally and the team at Ain Shams hospital*

### Morocco

*Said el Kharrasi and Katthyana Aparicio*

Our PFPS colleagues at the International Federation of Kidney Foundations (FMAIRTO, or Fédération Marocaine des Associations de Soutien des Insuffisants Rénaux et de Transplantation d'Organes) in Morocco were actively engaged in World Hand Hygiene Day. The programme of activities was ambitious and diverse. The focus was on safe surgical hands in order to prevent surgical site infections, which was the theme of the 2016 campaign.



*Said el Kharrasi and the team involved*

As part of the activities, a training for medical and paramedical staff was organized on 5 May at Ibn Sina Hospital in Rabat. Other trainings are expected to take place. The hand hygiene material campaign was distributed in different healthcare facilities.

Acknowledging the engagement of Said El-Kharrazi, President of FMAIRTO for safer care, he was asked by the WHO Regional Office to support this campaign and ensure the wide dissemination and promotion of hand hygiene.

This is an example of how patients can become partners in health care and help promote best practices to make care safer for all.

Link for the info graphic video:

[http://applications.emro.who.int/docs/media/infographic\\_World\\_Hand\\_Hygiene\\_Day\\_2016\\_en.mp4](http://applications.emro.who.int/docs/media/infographic_World_Hand_Hygiene_Day_2016_en.mp4)



## Update from SEARO

### India

*JS Arora and Katthyana Aparicio*

The National Thalassemia Welfare Society was involved in several events in 2016.

Encouraged by the Director of the Indian Council of Medical Research, who stressed the need for a nationwide Thalassemia Programme in late 2015, the society organized a massive awareness campaign on 14 February 2016. Since then, every Sunday in the heart of Delhi, the government has marked a place where no traffic is allowed and people are invited to participate in healthy activities mixed with fun to encourage good health. This is known as "RAAHGIRI." On 14 February there was a DJ, dance, songs, street plays, a walkathon, quizzes and prizes, all mixed with awareness on Thalassemia. Hundreds of people became aware of Thalassemia while having fun.

Around the world, 8 May is observed as International Thalassemia Day. A panel discussion on a National TV Channel was held. The same day, a free camp was organized to screen Thalassemia sufferers for Hepatitis B and C infections and status of their liver. A subsidized treatment was proposed when required.

The society collaborated with a UK group to launch an app that records and monitors the health records of Thalassemia patients. It will have many advanced features including an emergency button to alert five people in case of emergency.

We look forward to knowing more about this app!

*explained this happened all the time, there was nothing we can do. I realized we need to highlight the prescription drug issue and improve and change this system. This is my journey for the next 15 years. I could not comprehend the lack of interest that a preventable death had occurred due to prescription drugs. This highlighted the first problem in the health care system."*

*"Initiating an investigation into my son's death, a case worker of the organization said to me 'don't pursue this and put yourself through heartache, as nothing will be done anyway.' He went on to say 'it is classified as not of a serious nature.' That comment was so hard to accept from an organization that is there to protect the public. After the hearing, the doctor and system were not implicated and no changes were introduced. I began to sit through many hearings where death had occurred due to prescription drugs. There were so many families who had lost loved ones in similar circumstances. Why are we accepting prescription drug deaths? I realized that more had to be done, my son is gone, but I could do something to prevent other patients and their families going through the same grief."*

We wish to congratulate Anna for her brave and resilient work on this important issue over the past 15 years. She is now a consumer member of many different health advocacy groups and non-profit organizations, through which she has provided presentations at conferences and master classes for health professionals; attended workshops, forums, and conferences; and has featured in various outlooks of the media. She has also joined consumer representative programmes in hospitals and is now very interested in participating as a patient advisor in the development of real time prescription drug monitoring tools. As she commented:

*"The real time prescription tool is not the total solution to these issues, but it's a small step in the right direction. I firmly believe that while we are training health professionals to use the tool, it's a great opportunity to improve their processes through patient reviews of drugs before prescribing, regardless of the patient situation."*

## Update from WPRO

### Australia

*Anna McMahon*

Anna has been a patient advocate for 15 years, since the preventable death of her son who was 23 years old. In the last PFPS Spring 2016 news, Anna explained her main roles as a patient advocate for improving drug safety, quality prescription and usage of drugs in Australia. This article is a heartfelt message from Anna, explaining how she became motivated to become a patient advocate:

*"I could not understand how my son died as a result of a broken leg and was prescribed morphine in large doses. Looking for answers lead me through a web of many different institutions, government and health departments for the next six years.....what a roller coaster. They*



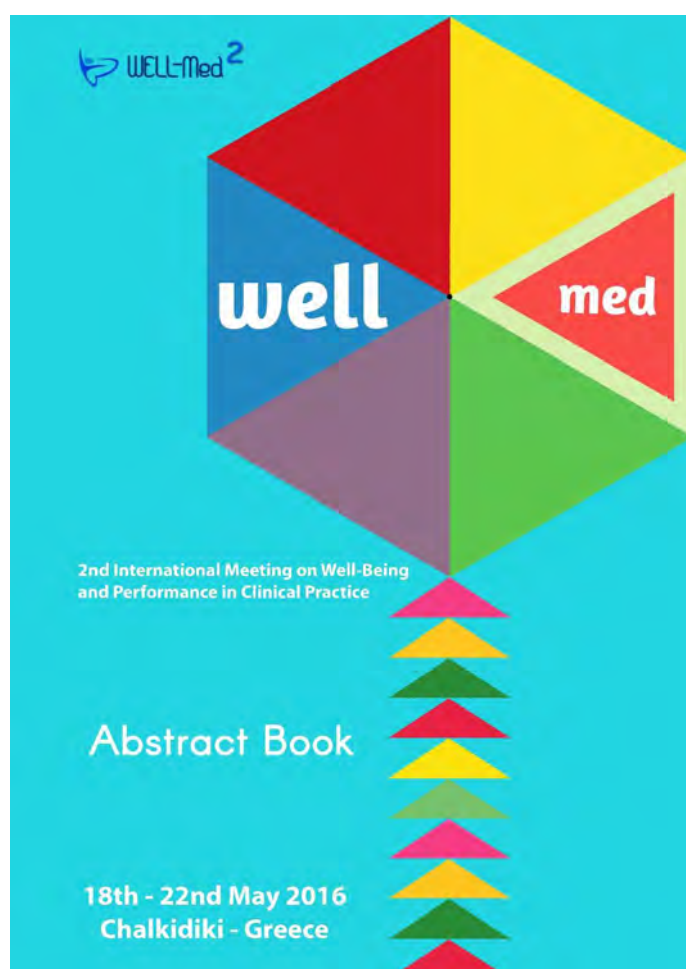
**Anna McMahon**



## Australia

*Brian Stafford*

Brian Stafford, PFPS Australia, was invited to attend the 2nd International Meeting on Well-being and Performance in Clinical Practice, WELL-Med2, held in Chalkidiki, Greece, from 18-22 May. This meeting intended to bring experts from different backgrounds to discuss innovative ways of linking physician well-being to patient safety and quality of care. An interesting aspect of that was to look at 'burn-out' of medical practitioners and its consequences. Brian was invited to bring the patient's voice. He presented a paper and chaired the session on Patient Involvement. It was to the credit of the conference organizers to have included a lay member of society to sit with them for the patient's voice.



Prior to the conference, WELL-Med2 ran a Master Class. The discussion focused on exactly what 'burn-out' meant when applied to a medical practitioner. There were extensive discussions around this. The evidence presented identified that 20% of doctors in hospitals have been, or were currently affected by burn-out.

This percentage is high when we consider that doctors are supposed to take care of patients. It is sad for any-one of us to become ill, but it is sadder if that illness is a direct consequence of our jobs. It is horrendous if that personal

injury is a consequence of working to care for the health of others in the community.

Drilling down on the evidence identified that the major cause of medical practitioners' burn-out is the working conditions, in particular the culture of competition and even bullying between doctors.

The discussions then addressed the cost to the community of training each of these medical practitioners who were then unable to fully utilize their medical skills. Thousands of doctors complete their training each year but cannot use their skills appropriately because of injury, and this potential healing skills are then lost. In Dollar terms, the cost is significant.

From a patient's perspective, we do not want to be treated by a doctor who has been psychologically harmed because he/she is less able to adequately empathize with the patient. There is also greater risk of unintended medical error occurs due to the high levels of stress. What this environment of corrosive harm doing to patients?

How does this contribute to medical error?

At the conference, there were discussions involving patients at other international conferences where medical practitioners spoke of the second victim. The second victim in this case was the medical practitioner. It was another excellent example of why it is time for medical practitioners and patient groups to work in teams to achieve mutual goals.

This is an area where the voice of the patient can be harnessed to improve the work conditions for all doctors. It is time we collectively start making the workplace safer for doctors and, in doing so, a safer place for all patients.

# Welcome Nicole to PFPS

*Katthyana Aparicio*

Nicole Gonzalez recently joined the PFPS team and will be working with us on patient, family and community engagement, in a volunteer capacity until December. Nicole will assist with the preparation and interviews of patients on the Story Project, on preparation of the database of resources on indicators and measures for patient & family engagement. She will also work with Felicity on the topic of Migration & health.



Nicole studied journalism but transitioned to public health after completing her undergraduate degree, first working as a research assistant at an epidemiology centre at Boston University. She worked on a case-control study examining possible associations between exposures during pregnancy and congenital malformations. She returned to school and earned a Master's in Public Health with a focus on maternal and child health and community health. While completing her degree, Nicole worked on several projects including a study examining group prenatal care and its potential impact on post-pregnancy outcomes (breastfeeding, postpartum depression, etc.). She also contributed to an evaluation of a case management programme aimed at helping families navigate health care and social service systems. Nicole has experience in the field and has worked on process evaluations, questionnaire and training material development, and technical report writing as well. Her interests are in maternal child health (MCH), health inequalities, and the social causes of disease.

I am sure you will all join me in welcoming Nicole warmly to our PFPS family.

## Future events

**ISQua International Conference:  
16 – 19 October 2016, Tokyo,  
Japan**

*Nittita Prasopa-Plaizier*

As in the previous years, Nittita, in her capacity as the designated technical officer (DTO) for the WHO – ISQua official relationship, will travel with the team from Service Delivery and Safety Department to participate in the ISQua conference in Tokyo. Nittita will coordinate all WHO activities, including three technical sessions and will be present as speaker and panelist in several other sessions. More updates will follow in the next edition.

## Patient, family and community engagement & empowerment workshop in Oman

*Nittita Prasopa-Plaizier*

The PFPS team will join Dr Mondher Letaief from the WHO Eastern Mediterranean Regional Office (EMRO) on a mission to Oman on 22-27 October 2016. The mission team will conduct stakeholder consultations (focus group discussions) and a two-day training workshop for health-care professionals and key stakeholders. The Ministry of Health of Oman will take this opportunity to launch the **'Patients Rights and Responsibilities' charter. We congratulate Oman on their leadership in taking this important step towards achieving greater patient, family and community engagement!**

## Future PFPS News

### Share your news with us!

**PFPS News:** Contributions for the next PFPS News are invited. The deadline for submissions is 30 November 2016.

**PFPS Community of Practice:** You can also continue to ask questions, share experiences and learning on the PFPS platform at: <http://pfps-communities.net>. 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.

**WHO/PFPS Editorial Group:** Nittita Prasopa-Plaizier, Katthyana Aparicio, Nicole Gonzales and Laura Pearson.

### Disclaimer

*The information, comments and opinions expressed in this newsletter do not necessarily reflect those of the World Health Organization, and incidents described have not been verified by WHO. The authors of the articles take the responsibility for the content of their contribution and the opinions expressed.*