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The First In-Country Patients for Patient  
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15-16 August 2014



Multi-stakeholder meeting on the  
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Brussels, Belgium, 26 September 2014

## Welcome!

*Felicity Pocklington (on behalf of PFPS Secretariat)*



*From left: SeHee, Felicity, Nittita, Liz and Katthyana*

A sunny and warm welcome to you all in this 2014 summer edition of PFPS News! We are proud to share a lot of new activities, which we can celebrate amongst our global network!

This summer will be a very exciting time for us here in Geneva, as we are pleased to introduce to you two new interns in the team, Felicity Pocklington and SeHee Kim. Felicity is working on the PFPS 10 year report (she is conducting the qualitative interviews on PFPS champions' experience). SeHee is working on the Medication Safety Project, helping to create a communication tool to encourage patient involvement in medication safety to reduce preventable adverse drug events.

Around the globe, we have heard of so much recent progress and accomplishments as your work continues to positively spread awareness of patient safety issues with growing momentum and recognition. It includes Evangelina Vasquez Curiel's research about access to medical records, but also a workshop on Patient Safety for students of "Technology in Pharmacy Management" held in Medellin, Colombia. Congratulations to Said for being awarded for his contribution to several campaigns he organised on prevention, awareness and screening of chronic diseases in different cities in Morocco. In Egypt, Nawga has organised a patients' education programme on hand hygiene. Hussain Jafri attended the WHO Guidelines on Ethical Issues in Public Health Surveillance meeting, which took place in Geneva. In Asia, exciting developments include Malaysia officially launching the PFPS Malaysian Network on 29 April.

We would also like to say HUGE thank you to those of you who have participated in Liz, Felicity and Katthyana's interviews. Your stories and enormous commitment have touched our hearts. The interviews have provided not only a way for us to get to know you all better, but the information gathered, both the positive reflexions, as well as the challenges, are proving to be very constructive for us to move forward in way that ensures we can better involve your global voice and collective wisdom.

Best wishes for the upcoming summer months to you all, keep up the good work and please ensure you tell us about your movements and achievements.

## PFPS Geneva

### Service Delivery and Safety (SDS) Department of WHO

*Nittita Prasopa-Plaizier*



*From left: Qi Zhang, Edward Kelley, Neelam Dhingra-Kumar and Hernan Montenegro*

The restructuring of our department is now completed. Dr Edward Kelley, who had been acting Director for the past few months, has had his appointment confirmed as Director of SDS.

The Service Delivery and Safety (SDS) Department now comprises three units and the Coordinator for each has also been appointed, effective from 16 June 2014:

1. Patient Safety and Quality Improvement (PSQ)
  2. Service Organization and Clinical Interventions (SCI)
  3. Traditional and Complementary Medicine (TCM)
- (see next page for more detail)

### **Patient Safety and Quality Improvement (PSQ)**

Coordinator: N Dhingra-Kumar

- Institutional partnerships
- Tools for safety and quality, including checklists
- Patient and family engagement
- Global networks and core safety work in injection safety
- Infection prevention and control
- Patient safety education and training

### **Services Organization and Clinical Interventions (SCI)**

Coordinator: H Montenegro

- Health services continuum, including hospitals and primary care safety and quality and service delivery issues through the life course (with special concentration on care of the elderly)
- Health services integration
- Regulation and accreditation issues
- Blood safety
- Essential and emergency surgical care
- Transplantation

### **Traditional and Complementary Medicine (TCM)**

Coordinator: Q Zhang

- Structures and delivery models of TCM and integration
- TCM policy development and regulation issues
- Evidence, research and technical guidance in TCM
- Education and training in TCM
- Best practices and links with department resources on issues of safety, quality and people-centredness of TCM

In addition, there is a team that works on special projects, Global Challenges and other campaigns.

SDS will serve as WHO's focal point for work on areas integrated, people-centred health services, patient safety and quality improvement and in efforts to help Member States strengthen health services across the care continuum from prevention to palliation, from primary to hospital and institutional-based services, covering both modern and traditional and complementary medicines.

SDS will also work on universal health coverage (UHC) in collaboration with regional colleagues, other WHO clusters and several external stakeholders. Dr Shams Syed will lead the creation of a WHO Task Force on UHC and Quality to tackle this important area of work. The Department has also started work on a Global Report on Quality and Safety of Health Services, which is being drafted with an Expert Advisory Group led by Sir Liam Donaldson, the Director-General's Envoy on Patient Safety.

### **Emerging Areas and New Projects**

- Universal Health Coverage Service Delivery Task Force
- Global Campaigns

Patient, family and community engagement will be relevant to all these areas. The PFPS team in Geneva works closely with colleagues in all units and will actively contribute to any special projects or campaigns.

## **WHO PFPS in meetings**

*Nittita Prasopa-Plaizier*

The PFPS Team in Geneva has also participated in several key meetings during the past quarter, including:

### **March 2014:**

PFPS was invited to a workshop entitled "Patients's Needs Driving Innovation in Global Health", held in Brussels, Belgium, which was jointly organized by DSW (Deutsche Stiftung Weltbevölkerung), EPHA (European Public Health Alliance), EFPIA (European Federation of Pharmaceutical Industries and Associations) DNDi, Global Health Advocates and PATH. The session coincided with the EU's Innovation Convention.

Nittita represented WHO on the panel of six speakers, which included Ms Ingelise Damkjaer (a TB patient), Dr Benedict Blayney (Sanofi), Mr Kevin McCarthy (European Commission, DG DEVCO), Dr Isabela Ribeiro (DNDi, a non-profit product development partnership), Joshua Wamboga Magawa (The Aids Support Organisation, an NGO in Uganda).

The panel presented current efforts and thoughts on how they involved patients in the innovation process in the field of poverty related and neglected diseases. The discussion centred on two questions:



1. How patients' needs are currently addressed in policy-making and research & innovation processes for global health?
2. What practical ways can be envisioned to increase patients' involvement and the consideration of patients' needs for global health R&D?

#### April 2014:

1. The WHO Service Delivery and Safety (SDS) Regional Focal Points Meeting was held at WHO/HQ in Geneva. Focal Points for the departments of Health Service Delivery from the African (AFRO), American (AMRO/PAHO), Eastern Mediterranean (EMRO), European (EURO), and Western Pacific (WPRO) WHO Regional Offices participated in the event.
2. SDS also hosted the Global Technical Consultation on the WHO Strategy on People-centred and Integrated Health Services at HQ in Geneva. The purpose was to provide technical input on how best to package the Strategy's strategic directions, to reflect priorities and needs at country level and on how it will be implemented in a practical way at country level. The consultation was attended by representatives from a range of stakeholders including Member States, civil society, patients' groups, professional associations, donors, bilateral and multilateral agencies and WHO.

#### May 2014:

5 May 2014: This year, PFPS again collaborated with the Clean Care is Safer Care team to issue relevant tools and celebrate the Global Save Lives: Clean Your Hands campaign on 5 May 2014. Jeanine Thomas (PFPS champion, USA) was the champion leading this work on behalf of PFPS and contributing to the "Hand hygiene and antimicrobial resistance - Information for patients and consumers" factsheet which was produced to mark the occasion

PFPS (Nittita and Katthyana) contributed actively to many departmental activities during the 67<sup>th</sup> World Health Assembly (WHA) from 19 to 23 May, including staffing the HIS Cluster stand, supporting side-events and participating in several meetings with stakeholders.

1. The HIS brochure showcases the work of all departments in the Health Systems and Innovation cluster (HIS) in which SDS is located. The PFPS programme is listed as one of the cluster's area of work.
2. Side-event: *"People-centred and integrated health*

*care: what is it and how do we get there?"* was hosted by the Government of Belgium. This is a very high-profile strategy from our SDS department that aims to ensure that safety, quality and patients/people are essential components of any efforts toward universal health coverage (UHC). PFPS in collaboration with IAPO (International Alliance for Patients Organizations), worked closely with colleagues who are leading this strategy. PFPS champions and IAPO members contributed by providing the Patient Testimonials.

3. Side-event: "Improving Safe Emergency and Essential Surgical Care and Anaesthesia", which was chaired by Dr Ed Kelley, SDS Director. PFPS is now collaborating with the colleague who leads this work, to develop a tool to facilitate patient-provider communication.
4. Side-event: "Community Health Clinics: Health care at your door", hosted by the Government of Bangladesh.
5. Side-event: WHO global disability action plan: 2014-2021", hosted by the government of Ecuador in collaboration with the government of Paraguay.
6. The "Health Dialogue: Patient empowerment and patient therapeutic education" organized as part of the Geneva Global Health Dialogue by the "Dialogues Geneva" and its Governance, Entrepreneurship & Development (GE&D) network.



#### June 2014:

SDS hosted a virtual meeting to discuss the scope and potential focusses of the 3<sup>rd</sup> Global Patient Safety Challenge, which will be concerned with medication safety. PFPS (Nittita and SeHee Kim) participated in this e-meeting at WHO. Helen Haskell (PFPS Champion, USA) who was invited as the patient lead on behalf of PFPS, also participated. The meeting, facilitated by Sir Liam Donaldson and Dr Ed Kelley, brought together core experts on the topic from five different institutions and relevant departments in WHO to advance the goal of medication safety.

# Medication Safety Project

*SeHee Kim*

The third Global Patient Safety Challenge will focus on medication safety as it covers a major and significant aspect of risk to patients receiving health care.



The medication safety target will be the safe use of medication to reduce preventable adverse drug events (ADEs). As medication errors may occur at any stage in the treatment process, it is important to have a tool that promotes good communication between patients and the health care providers who are involved in the process.

PFPS is currently working to create a communication tool to encourage patient involvement in medication safety, to reduce preventable adverse drug events. The tool will promote understanding and adherence to prescribed medication, as well as aim to reduce prescription errors. We hope the tool will encourage communication between patients and health care providers and empower patients to ask for vital information, as well as motivate them to actively participate in their care process. The tool is expected to encourage patients to ask their health care providers questions or request information, for better overall service delivery and quality.

## PFPS: 10 years of challenges and achievements

*Felicity Pocklington*

Felicity started to work on the PFPS 10-year challenges and achievements project and in her own words: "I would like to thank you for making me feel so welcome in the PFPS programme. I am thoroughly enjoying meeting a lot of you through the interviews, which are proving to be fantastic, diverse and in-depth discussions around both your professional and personal experiences in Patient Safety".

So far, 50 interviews have been carried out. Each interview has provided new insights, ideas, challenges and opportunities regarding working towards better patient safety, health-care quality and patient empowerment. It's expected that the interviews will be reviewed by the middle of July, leaving the rest of the month to compile visual

sources, write up my notes and analyse the information gathered. The information has presented multiple themes concerning health care safety, all interlinking into a "web" of knowledge.

The PFPS 10-year report is going to be a very useful tool for us all to learn from one another. "I have found from the interviews myself, that every patient champion has shown great knowledge and skills that need to be built on and shared in this global network, in order for us to move forward in a constructive, positive and useful manner".

## IAPO Congress

*Nittita Prasopa-Plaizier*

Between 29 and 31 March, Dr Marie-Paule Kieny, Dr Hernan Montenegro and Nittita Prasopa-Plaizier participated in the IAPO Congress entitled "Better access, better health: A patient-centred approach to universal health coverage. The Congress was attended by about 120 people from 48 countries. IAPO is a non-governmental organization (NGO) in official relations with WHO, and for which Nittita serves as a designated technical officer (DTO). WHO is collaborating with IAPO to promote and raise awareness about patients' roles, including in the context of universal health coverage. Dr Hernan Montenegro participated in a plenary session entitled "Breaking barriers to access" and Dr Marie-Paule Kieny, ADG/HIS, gave a speech during the closing plenary. Chaired by Nittita, WHO PFPS hosted a session to disseminate information on WHO activities and policy on patient engagement, during which four PFPS champions (see below) contributed as speakers. WHO also organized an exhibit stand during the Congress.

- Peter Walsh, Chief Executive, Action Against Medical Accidents (AVMA), PFPS champion, UK
- Hussain Jafri, PFPS champion Pakistan and IAPO Board Member
- Margaret Murphy, External Lead Advisor, Patients for Patient Safety (PFPS) Programme
- Jolanta Bilińska, PFPS champion Poland, and IAPO Board Member/President Elect.



*Hernan Montenegro, middle, at IAPO Congress*

# Update from AFRO

## Uganda - Medication safety

*Author: Regina Kamoga*

*Reviewer: Iren Hunyadi*

Unsafe medication and unsafe use of medication is a public health challenge in Uganda at both patient and systems levels. At the patient levels, these include non-adherence, self-medication, reliance on alternative health care and low literacy. At the system level, key challenges included poor quality or counterfeit medicines, leaky supply chains, weak regulatory capacity, medicines dispensed without a doctor's prescription and inadequately trained personnel to ensure the safe use of medication.

Unsafe use of medication contributes to patient morbidity and to adverse drug events. Patients are harmed and some lose their lives. It is also a burden to health systems.

Health services are provided to 96 000 people living with HIV/AIDS (68 584 on antiretroviral therapy) which represents 5% of the patients referred for hospital admission. Unsafe use of medication is the most frequent cited reason for treatment modifications and interruptions. A report on pharmacy systems performance (2011) showed increased access to newly introduced essential medicines, though there is an even greater need to monitor and promote their safe use.

There is a need to empower patients, consumers and health-care professionals to promote patient medication safety & patient-centred health care. Patients' awareness needs to be raised to ensure that they receive safe medicines and know how to use them correctly and safely.

The Community Health & Information Network (CHAIN), Uganda, worked on a campaign to promote the safe use of medication between November 2013 and May 2014.

We organized meetings with patients' organizations, the National Drug Authority (NDA), consumers, community leaders and health workers, to design medication safety messages.

Patients'/health consumers' mobile phone numbers were recorded and multi-angle messages were sent in themes to mobile phones with personalized medicine reminders, caller tunes, SMS, voice messages, multiple answers, interactive quiz questions, radio advertisements, sports, jingles and dramas. The campaign targets patient groups, including people living with HIV/AIDS, tuberculosis,

malaria, cancer and diabetes. The use of a caller center enabled any necessary follow-up.

Patient empowerment is an essential tool for improving the safe use of medicines, as it may help reduce hospital referrals. Mobile phone messages help promote public health information, including disease management, sexual health promotion, health education and medicine adherence. Addressing patients' safe use of medication requires multiple approaches, including patient access to appropriate information, appropriate prescriptions and dispensing, improved health practices that facilitate quick recovery. These enhance adherence and reduce adverse drug reactions.

Using web-hosted Short Message Service (SMS) is a cost-effective means of improving patients' medication safety in rural and hard-to-reach settings. Health-care service providers, in collaboration with website hosts and mobile phone networks, could quite easily offer technology as part of their corporate responsibilities.

## Uganda - Improving maternal mortality

*Robinah Kaitiritimba*

The Uganda National Health Consumers Organisation (UNHCO), with support of the Catholic Organisation for relief and Development Aid (CORDAID), is implementing a three year project aimed at reducing maternal mortality through the rights-based approach and Information and Communication Technology (ICT). The project is currently implemented in Kamuli, Luweero and Lyantonde.

Pregnant mothers are registered by Village Health Team members who avail the information to the Secretariat through their focal people. Mothers are sent reminders on going for antenatal check-ups and encouraged to deliver their baby at health facilities. In addition, messages also include health rights and responsibilities, health education, feedback and redress mechanisms. The community members are also given a chance to send their thoughts to the platform. Members register according to their districts which helps us to understand the issues arising from a particular district.



*Village health team members mastering the art of using SMS*



For those members who cannot use their phones to send SMS, voice calls are made every month to everybody who is registered on the platform.

Communities are appreciative of this initiative because they say that they get direct responses to their queries. In addition, the members welcome the calls because of the person-to-person contact, and are not afraid of expressing themselves. Male involvement in maternal health services is also promoted.

**“My wife does not have a phone but every time the messages come I make it a point of sharing them with her”.** Community member in Luweero district.

**“I share with my neighbours every time I receive a message from UNHCO. I know that at least every week I will receive a health tip which I can share with others who don’t have a phone. This information is very good, especially for us, the women”.** A community member from Luweero.

**“UNHCO has helped us a lot in encouraging mothers to come to hospital for ANC (Antenatal Care) Services and also to sensitize them on maternal health. Many women have not been attending ANC and we did not know the reasons why.”** Dr Okoth Obbo, DHO Lyantonde district.

The struggle for patient empowerment continues!

Link to the Civil Society policy paper on primary health care : <http://unhco.or.ug/2014/04/civil-society-policy-paper-on-primary-health-care/>

## Update from AMRO/PAHO

### Canada

*Kim Neudorf*

Members from Patients for Patient Safety Canada participated in the development of a Consensus Statement on Surveillance and Screening for Antimicrobial Resistant Organisms (AROs), held in Calgary, Alberta, Canada, on 18-20 June, 2014. The conference was the first of its kind in Canada to look at AROs. Kim Neudorf represented the patient voice as a presenter and Barb Farlow was a jury member charged with listening to two days of presentations, synthesizing the evidence and then collaborating late into the night with ten other jury

members. The expert jury’s goal was to prepare a consensus statement to inform a new standard for screening and surveillance and disseminate recommendations for policy and practice in Canada and other countries.



Kim Neudorf



Barb Farlow

It was an honor to represent the patient voice at this prestigious conference alongside the many accomplished scientists from the US, UK, Netherlands and Canada in the fields of microbiology and epidemiology. It is clear that patient representation is no longer an exception and is evolving as an integral part of the process of any comprehensive decision-making process. “Nothing about me, without me” is a patient engagement principle decision makers are paying attention to.

At the national and global levels, it is becoming increasingly important for patients to present not only their story, but to also provide evidence derived from robust research, so that definitive statements can be made on a patient safety issue.

Link to the 22 recommendations prepared at the end of the conference : [IHE Conference on Surveillance and Screening](#)

### Colombia

**Author: Andrea Areiza Bustamante**  
**Reviewer: Denice Klavano**

A workshop on patient safety was held in Medellin, Colombia on May 31, 2014. Andrea Areiza Bustamante, PFPS champion from Colombia, president of the Antioquia, facilitated the workshop together with Beatriz Grove, also a PFPS champion and a student on “Technology in Pharmacy Management”.

The audience was composed of students in their final year of the Technology programme of Pharmacy Management in the “Universidad Nacional Abierta y a Distancia” (UNAD) of the “Direcciones de Centros de Educación a Distancia” (CEAD) of Medellin. The purpose of the

workshop was to heighten awareness about the important role that pharmacists play in patient safety.

The workshop was well attended. Approximately 30 students were trained in person and others through web-conference. The workshop started with the introduction of the PFPS Antioquia-Colombia Network, its origins, the objectives of the network and the focus of patient safety. An institutional video was shown which illustrated the kinds of incidents that could be prevented. It was explained that the purpose of the network is to engage people, who may or may not have experienced a health-care related adverse event, as advocates for safer healthcare. It was recognized as important that those who have experienced an adverse event, need to be at a point where they are ready to move forward from the event, and are ready for an advocacy role. Several examples were presented and provided as illustrations.

The objectives of the Colombian National Policy on Patient Safety and Quality was also presented. It was stressed that the main purpose of the policy was to create and develop strategies to prevent adverse events.

All the basic concepts around patient safety, the role of PFPS, network objectives and the Colombian National Policy were covered. Ultimately, the important role that pharmacists play in patient safety was highlighted. That role is crucial as pharmacists provide assistance and advice to patients on the appropriate use of medications.

The UNAD expressed its interest in organizing this kind of workshops for other students and to continue its collaboration with the PFPS Antioquia-Colombia Network.



Andrea at the workshop

It is hoped that they can replicate this experience during the first meeting of the graduate students of Technology in Pharmacy Management of the CEAD Medellin to be held on 26 July this year.

Link to recording of the session: <http://conferencia2.unad.edu.co/p3cvh9wxadb/>

Link to the PFPS Antioquia-Colombia Network, institutional video: <http://www.youtube.com/watch?v=U0-WEQqEiKg>

## Mexico

*Author: Evangelina Vazquez Curriel*

*Reviewer: Denice Klavano*

There is arduous work being done in Latin America to ensure that health-care consumers have access to their own medical records. In some countries, this access has been achieved, but in other it is taking more time and effort. The right to access our own patient information, in a timely manner, remains one of the concerns of the PFPS Pan American Network.

Access to our own medical records remains an important part of patient empowerment and participation. Indeed, the medical record is a primary source of information. Our medical records contain important information regarding our health status, details of clinical tests, examinations, even specialist opinions. In order for patients to be able to ask informed questions or ensure guided and collaborative conversations, access to the health record is vital. With this access comes patient empowerment, engagement and active and equal participation across the health-care spectrum. It also comes with responsibilities for appropriate use of information.

Ongoing discussions with health care professionals and representatives of health systems have been interesting and the debate has centred mostly on the ability of patients to correctly interpret their records. There are concerns that many patients would not be able to properly interpret their medical records and that poor understanding or faulty interpretation of the records could lead to increased litigation. These parties feel that access to the medical record should only be justified in specific cases or particular circumstances.

An article about this important issue will be released soon and shared with the PFPS global network. It will provide a detailed analysis of the situation using legislation in Mexico and Costa Rica as examples.



# Update from EMRO

## Egypt

**Author:** Nawga Metwally  
**Reviewer:** Nasr Ali Ahmed

The PFPS champions in Egypt continue to work effectively toward patient safety improvement in many health-care settings in Egypt.

Plans for a Hand Hygiene (HH) campaign have been developed, to take place this time at Ein Shams University hospital. The campaign shall follow the related HH recommendations and guidelines from WHO & CDC which emphasize the patient and their families' involvement as being important in the area of HH.

So they decided this year to share with their partners in the process of providing health care and start "The Patients Education Programme for Hand Hygiene".

The main goal of the campaign is to improve hand hygiene compliance among different health-care providers in the hospital, including senior and junior doctors, nurses, housekeepers, laboratory and radiology technicians, staff of the auxiliary services and patients.



Nawga Metwally

Also, a number of specific objectives for the campaign were set as follows:

- Start hand hygiene training programme for patients and visitors;
- Launch an improvement plan for the infrastructure & required supplies for hand hygiene;
- Identify prominent physician and nursing leadership

in each unit to be a leader and role model for hand hygiene, as this is critical to success;

- Secure administrative support and keep them actively aware and up-to-date, with a mechanism to reward and to encourage good practices;
- Analyze the impact of hand hygiene in infection prevention and control with a special emphasis on multidrug-resistant organisms.



It is expected that this year the hand hygiene campaign will result in many positive and effective outcomes, raising awareness among health-care providers about the importance of HH and ensuring their commitment to better compliance with hand hygiene. It will also contribute effectively to improving the overall infection prevention and control activities in the hospital.

The campaign programme includes various activities and special focus will be given to having a one-day festival for HH in each hospital. A scientific forum for HH will be established to exchange experiences, ideas and related research.

Patients and their families' involvement remains the best outcome of this campaign as it will increase patients' knowledge about many infection control measures that should be considered while receiving health care.

## Morocco

**Author:** *Said El-Kharrasi*  
**Reviewer:** *Nasr Ali Ahmed*

Our PFPS colleagues in the International Federation of Kidney Foundations -FMAIRTO-(in French « Fédération Marocaine des Associations de Soutien des Insuffisants Rénaux et de Transplantation d'Organes) in Morocco are very keen to share their efforts in the area of health education and promotion for people with kidney problems, to minimize bad prognosis and complications. They have promoted partnership and collaboration in PFPS work as several activities have been conducted among civil society, health-care professionals, private and public health institutions to raise public awareness about the risks of chronic diseases and the leading causes of renal failure.

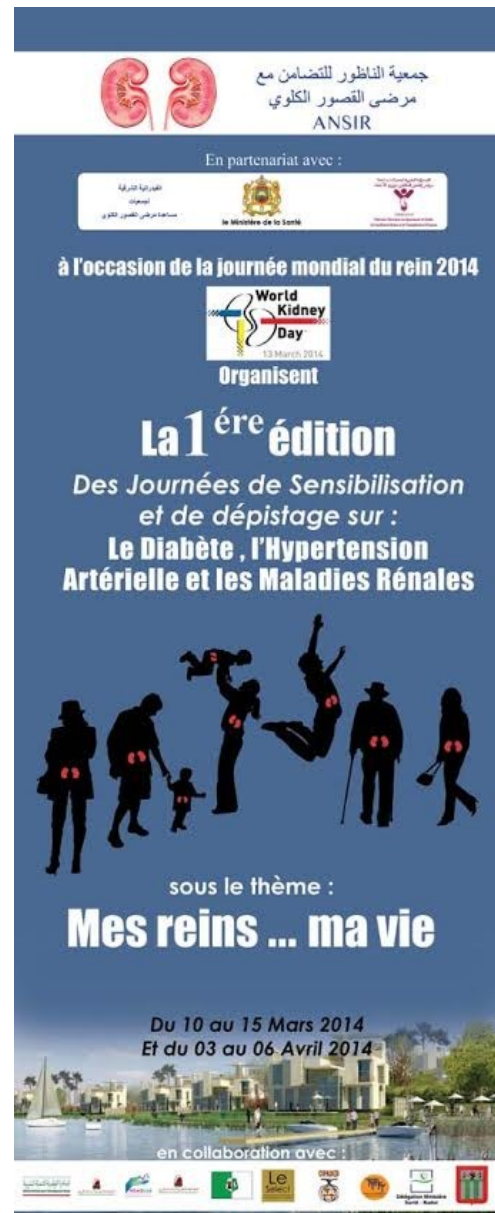
The Federation has developed a strategy to address the different aspects in renal failure, and launched national and local campaigns on screening, preventing and raising awareness among patients, families and the community. It has been an effective way to deal with such problem, and to sensitize populations in remote areas who have limited access to healthcare facilities and services, which are located mainly in the towns of Laayaoune, Guelmim, Berkane, Chefchaouen and Wazzane.



*Said El-Kharrasi during one of the campaigns*

The strategy also aims to prevent the most common risk factors such as diabetes, hypertension and cardiovascular diseases. Various training sessions such as seminars and conferences were organised within the campaigns.

For its positive and supportive efforts in patient safety advocacy and contribution to maintaining the health of citizens, the Federation was awarded first prize at the international level on this year's World Kidney Day 2014 celebration.



Link to the World Kidney Day: [www.worldkidneyday.org](http://www.worldkidneyday.org).

## Pakistan

**Hussain Jafri**

In early 2014, WHO established an international Guideline Development Group (GDG) to develop WHO Guidelines on Ethical Issues in Public Health Surveillance. The scoping meeting of this group was organized in collaboration with the Fondation Brocher, from 26 to 27 May, 2014, in Hermance, Switzerland.

Surveillance is one of the most fundamental activities of public health and raises multiple ethical issues for which appropriate national and international frameworks are required. There are currently no WHO Guidelines covering ethical issues in public health surveillance. Therefore, the objectives of the scoping meeting were to initiate the



development of the WHO guidance document that provides a standard ethical framework, which can be applied by governments, public health agencies and practitioners when designing public health surveillance policies and practices.

Mr Hussain Jafri, PFPS champion from Pakistan, was invited to attend the meeting on behalf of PFPS and gave a presentation on the patient's perspective on public health surveillance. Hussain stressed the importance of including patients in the planning and implementation of surveillance activities, particularly with respect to the protection of privacy and confidentiality. He pointed out that patients are often unaware of the objectives of surveillance activities or how the collected information will be used. Hussain explained that many countries collect sensitive information without consent, such as in outbreak investigations or in the context of laboratory tests or hospital visits. The option of opting out of information collection is often not provided, and when it is, may only be provided once, without any subsequent opportunity to revisit the decision. Moreover, patients are often unaware of the benefits and risks of surveillance.

Hussain argued that patients should be involved in all levels of decision-making regarding information collection and dissemination. In emergencies, alternative mechanisms, such as community consent, may be acceptable, provided that adequate safeguards are in place to protect privacy and confidentiality. The information must not be used to prejudice patients who are identified as having a particular disease or condition as a result of surveillance activities, and they should be guaranteed access to treatment. Measures should be put in place to ensure that they are not disadvantaged socially, economically, or legally. Hussain developed this presentation in consultation with other PFPS champions and Nittita at WHO.

Talking at this event, Dr Abha Saxena from WHO's Knowledge, Ethics and Research Department stressed the importance of ensuring that the guidelines that emerge from this project are developed with appreciation of the diverse social and political contexts in which surveillance activities are conducted. Other presentations and discussions during the meeting highlighted the importance of developing a broad definition of public health surveillance, to ensure that the guidelines are applicable as widely as possible. Furthermore, there was consensus that surveillance is a key component of universal access to health care. Transparency around how information is managed and used is critical. The public should have

access to all the required information, as well as an opportunity to participate in discussion and debate. Finally, information collected must be used to benefit the community.

At the end of the meeting, working groups were established on i) framing the issue, ii) core principles, iii) issues/problems/questions and governance. Hussain has been assigned to work with the group that is working on "issues/problems/questions". Dr Andreas Reis from WHO's Knowledge, Ethics and Research Department indicated that these working groups will work towards finalizing the Guidelines by the end of 2015.



*Hussain, the first on the left, and the other participants*

## Update from EURO

### Denmark

**Katrine Kirk**

On 25 June, Katrine Kirk spoke on behalf of Patients for Patient Safety at the International Radiation Protection Association's conference in Geneva. The invitation was secured by Dr Maria Perez from WHO, facilitated by Nittita. For many of the 400-500 participants in the audience, this was the first time they heard about radiation safety from a patient's perspective.

Katrine talked briefly about her own experience of how patients who become engaged in their own care can play an important role in making health care safer. Patients are the only constant in the continuum of care, and their experience of care can provide valuable insights into quality and safety in the medical use of radiation.



It must be ensured that health-care services across the world are driven by patients' needs. We need to improve the knowledge level of patients concerning radiation so they can contribute to ensuring that diagnostic tests and treatments are justified and optimized.

Katrine encouraged participants to establish collaborative partnerships with patients and their families, both at the individual level and at the policy level. Only through meaningful engagement and empowerment of patients can we ensure their optimal contribution to making radiation safer.



*Katrine at the IRPA 2014 Conference*

## Update from WPRO

### Malaysia

*Manvir Jesudasan*

Following last September's WHO workshop on Patients for Patient Safety (PFPS) in Malaysia, we have created a PFPS committee and launched PFPS Malaysia (PFPSM) with the help of the Malaysian Society of Quality in Health (MSQH), which has taken us under their wing. We got endorsements from the Director-General of the Health Ministry and the Honorable Minister of Health, which helped us to plan and launched the PFPS Malaysia network. MSQH guided us every step of the way.

Before getting into more, let's see Malaysia in a nutshell. Malaysia is located in Southeast Asia, but is in the WHO Western Pacific Region. The country consists of

Peninsular Malaysia and East Malaysia, with Kuala Lumpur as the capital city. We have a population of 30 million with 40% living in urban areas, 55% are Muslim and the rest are Hindus, Christians and Buddhists. Our national language is Bahasa Malaysia with English as the business medium and a widespread use of Chinese and Indian dialects. We have better than average telecommunications and infrastructure, enabling us to travel to about 70% of the country. About 90% of the population use public health care and services, but the mushrooming of private health care sees more urban dwellers having access to faster services and many experienced government specialists leaving to join the private sector, lured by better pay and conditions.

PFPS Malaysia has Committee members who are health-care professionals from various strands of health care, and who have also experienced adverse events in their own lives. We also have an official from the Ministry of Health as part of our Committee, thereby ensuring that our ideas are achievable and implementable in public hospitals which are used by the majority of the population. Collectively, we are driven by a desire to improve the existing system. Our emphasis is on engaging health professionals and organizations to enter into dialogue with patients and patient organizations, NOT to see them as an adversary, but as collaborators to help improve patient safety.

We plan to kick off a pilot study with a few private and public hospitals to engage with professionals and patients, with a view of customizing seminars to help understand what are required by both parties. Malaysia has a multi-cultural and multi-religious populations so it is important to understand issues fully before spreading any ideas nationwide.

The launch of PFPSM was graced by the Honorable Minister of Health and its' closing by the Director-General.



*Participants during the PFPS Malaysian Network launch*

This enabled us to have more than adequate coverage in the media. As it was held in conjunction with a Healthcare Leaders' summit, speakers from WHO and from various countries in this region could join and share with us their experiences. Our launch had 217 participants and 30 guests representing major hospitals in the country. This enabled us to meet and share with them our vision for the organization and when we do eventually begin our programmes, we will have a starting point of contact. With the blessings of the Health Ministry and our fantastic committee, we hope to share with you more of our work soon.

## Malaysia

*Rebecca John & Ken Taneda*

The one-day National Healthcare Leaders' Summit and the Launching of Patients for Patient Safety Malaysia (PFPSM) was held on 29 April 2014 at the Marriot Hotel in the Federal Territory of Putrajaya. The Summit was aptly themed "Patients for Patient Safety". This national summit was the follow-up to the successful WHO Patients for Patient Safety (PFPS) Country workshop organized together by WHO (Nittita from WHO Geneva, Dr Ken-ichiro Taneda from WPRO, Dr Harrison from the WHO Representative's Office, Malaysia), Stephanie Newell, PFPS champion from Australia, the Malaysian Society for Quality in Health (MSQH) and the Ministry of Health, in September 2013.

A total of 217 participants from around the country including health care administrators, senior and middle-level managers, clinicians, nurses and allied health practitioners attended the summit. Around 30 guests representing the public and private health-care sectors and other related agencies attended the official opening of the summit and the launching of the PFPSM. The summit was held to raise awareness on behalf of health-care leaders in the country about patient safety and the importance of patient and community engagement in health-care services and quality and safety initiatives.

The official opening of the National Leaders' Summit and Launching of Patients for Patient Safety Malaysia was officiated by the Honourable Minister of Health Malaysia, Dato' Seri Dr Subramaniam in the presence of WHO Malaysia Representative Dr Graham Harrison, President of MSQH Datin Paduka Siti Saadiah Sheikh Bakir, MSQH CEO Dr Kadar Marikar and senior officers from the Ministry of Health, Malaysia.

The unveiling of PFPSM's own logo and the PFPSM Declaration read by the appointed first chairman of PFPSM, Mr J. Manvir took place during the launch ceremony. The PFPSM Declaration is a collective call and commitment to making patient safety a basic human right and the reduction of patient safety incidents a priority, to improve the quality of health care.



*Participants at the National Healthcare Leaders' Summit*

The National Healthcare Leaders' Summit was jointly organized by the Malaysian Society for Quality in Health (MSQH), Ministry of Health Malaysia and Patients for Patient Safety Malaysia (PFPSM) and the Patient Safety Council, Malaysia. The plenary speakers and topics presented were:

- Dr Ken-ichiro Taneda, Technical Officer (Patient Safety and Quality) Western Pacific Regional Office (WPRO), Manila - "WHO Patient Safety Programme and PFPS Network".
- Dr Alexander Thomas, Chief Executive Officer of Bangalore Baptist Hospital, India - "Healthcare Communication: The cornerstone to quality in healthcare industry".
- Mr Manvir, Chairman of PFPSM - "Can patients and families drive quality and improve patient safety in the Malaysian health-care Industry?"
- Dr Kadar Marikar, Chief Executive Officer of the Malaysian Society for Quality in Health - "Driving quality and patient safety in health care through the Patients for Patient Safety Network"
- Dr Nor' Aishah Abu Bakar, Deputy Director, Quality in Medical Care Section & Technical Coordinator Patient Safety Council Malaysia - "Enhancing Patient Safety through top-level governance, leadership and commitment".

The Summit was officially closed by the Director-General of Health, Malaysia, Datuk Seri Dr Noor Hisham Abdullah who said that health care is now driven by quality and it is important to engage and empower patients. Health-care leaders need to partner with patients and recognise them as an integral part of the process.

The Summit was followed by a one-day seminar on 30 April 2014 on “Medical Device Adverse Event Investigation and Management for Healthcare Leaders” jointly organised by the MSQH and ECRI Institute. The speaker for the Seminar was Dr Scott R. Lucas, Programme Manager, Engineering Accident and Forensic Investigation, ECRI Institute, USA. This post- summit seminar was attended by 106 participants.

## PFPS webinar series

*Katthyana Aparicio*

PFPS hosted a series of open webinars that started in December 2013 and finished with the 6<sup>th</sup> and last webinar in May 2014. These free technical webinars were for all interested in patient engagement and patient safety improvement.

**The fifth** webinar was delivered on 15 April 2014 by Peter Walsh, Chief Executive of Action against Medical Accidents (‘AvMA’), a UK charity for patient safety and justice, who is also a PFPS champion. Peter drew on the importance of open disclosure, both from the perspective of patients and natural justice, and from a patient safety perspective. Open disclosure is a communication process adopted in the UK between health-care providers and patients and families when things go wrong. Peter described the developments in England where this question was the subject of intense scrutiny and debate and has led to the Government promising to introduce a statutory (legal) ‘Duty of Candour’. He shared with the participants his passion for patient safety and experience in supporting people (patients or families) who have experienced health-care harm. The webinar was well attended and generated good discussion and interest among the participants.

**The sixth** webinar was delivered on 6 May 2014 by Perla Lovera, who became a new PFPS champion following the PFPS workshop in Ecuador in October last year. She is the head of the Medical Oversight and Quality and Safety

Department, Ministry of Social Affairs of Paraguay. Perla presented the case of Paraguay on how health-care delivery is moving towards people-centred health care. She emphasized the trend on integrated services and people-centred health care. The webinar generated a good discussion and questions around patients and care-givers engagement during the whole health-care delivery process. It is important to highlight that this topic is one of the major areas of work of the Service Delivery and Safety Department.

Link to the slides and recording of the sessions:

[http://www.who.int/patientsafety/patients\\_for\\_patient/pfps\\_webinars/en/](http://www.who.int/patientsafety/patients_for_patient/pfps_webinars/en/)

## Upcoming Events

### 20th International AIDS Conference

*Nittita Prasopa-Plaizier*



**STEPPING UP THE PACE**

The International AIDS Conference will bring together people working in the field of HIV, policy-makers, people living with HIV and other stakeholders committed to ending the pandemic. The conference will be held in Melbourne, Australia, from 20 to 24 July 2014. Nittita has been invited to join the panel of the Satellite Session: “Sustainable Community Health Systems: Opportunities and Innovations for enhanced ART outcomes”.

### 6<sup>th</sup> International Conference on Patient - and Family-Centered Care: Partnerships for Quality and Safety

*Bev Johnson*

The Institute for Patient- and Family-Centered Care (IPFCC) is delighted to welcome as a keynote speaker, **Sir Liam Donaldson**, formerly Founding Chair of the World Alliance for Patient Safety of WHO, launched in 2004, and past Vice-Chairman of the World Health Organization Executive Board. He is currently the World Health Organization’s Envoy for Patient Safety.



Sir Liam will discuss the role of patients and family members in the quest for safer health care worldwide and their incalculable benefit in the last decade. He will explain how their experience, wisdom and courage are fuelling a journey whose end-point is a coalescence of compassion and learning to eradicate serious harm from every health-care system in the world.



Joining Sir Liam in the opening plenary session will be **Leilani Schweitzer**. Nearly nine years ago, her son, Gabriel, died after a series of medical mistakes. Leilani will share her story and explain how she came to work in risk management at the same hospital where those errors occurred.

*The 6th International Conference on Patient- and Family-Centered Care ~ Partnerships for Quality and Safety*, 6-8 August 2014, Vancouver, Canada, will showcase exemplary programmes that promote collaboration and partnership with patients and families to improve safety, quality and the experience of health care.

Those who work tirelessly to improve the safety and quality of health care will come together in Vancouver, sharing exemplary programmes dedicated to fostering genuine partnerships and transformative change among patients, families, health-care professionals, and policy specialists.

In addition to these thought leaders, the conference will include more than 100 cutting-edge presentations and 60 posters presented by leaders in patient- and family-centered care from the United States, Canada, and other countries.

Link to the programme of the conference:

<http://www.cvent.com/events/the-6th-international-conference-on-patient-and-family-centered-care/event-summary-31f718a720e546c7a48870ac806d46f0.aspx>

## Thailand: First PFPS Workshop

*Nittita Prasopa-Plaizier*

The first PFPS in-country workshop in Thailand will be held in Bangkok on 15-16 August 2014 and will be hosted by the Healthcare Accreditation Institute, in collaboration

with the Ministry of Public Health. Nittita will facilitate the two-day workshop, representing PFPS.

## Multi-stakeholder meeting on the justification of individual exposures

*Nittita Prasopa-Plaizier*

The Association of Heads of European Radiological Protection Competent Authorities (HERCA) works to reduce patient radiation exposure in computed tomography (CT). Nittita has been invited to participate in a multi-stakeholder meeting on justification of individual exposures, to be held in Brussels, Belgium, on 26 September 2014.

## Future PFPS News

### Share your news with us!

**PFPS News:** Contributions for the next PFPS News are invited. The deadline for submissions is 10 September 2014.

**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 and Laura Pearson.

**Champions Editorial Group:** Denice Klavano, Nasr Ali Ahmed and Iren Hunyadi

### Disclaimer

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