Welcome!

Spring is in the air! Welcome everyone to this Spring 2016 edition of PFPS News. Despite the holiday period, the passion of our PFPS advocates, has continued to drive great advocacy efforts for safer, higher-quality, people-centred health care.

This newsletter features key projects from the WHO Eastern Mediterranean Regional Office, including the Patient Safety Friendly Hospital Initiative, the regional meeting on the principles and practice of health care accreditation, and reporting on meetings in Saudi Arabia and Jordan. The newsletter also features updates from Canada, Thailand, Australia and Malaysia.

Since January, the PFPS team in Geneva have travelled to Thailand, Austria, the United Kingdom and Sweden to promote the role of patient and people engagement and empowerment for safer and higher quality care. Updates from Geneva include exceptional support for the WHO Framework on integrated, people-centred health services, as it went through adoption during the WHO 138th Executive Board. Priority projects continue at WHO headquarters, including the scoping review on measurements and indicators for engagement, and the global report on perceptions of meaningful engagement. In December, we saw the launch of the WHO Safe Childbirth Checklist, and the PFPS programme’s collaboration with the WHO Department of Public health, Environmental and Social Determinants of Health has progressed in efforts to achieve greater medical radiation safety.

As patient advocates, we aspire to ask, “what do patients need to BE and STAY healthy”? As we strive towards achieving quality universal health coverage by 2030, patient advocates have an important role to play in engaging and supporting other patients and people in the community to play an active role in their own care. Actively engaged patients, not only empower patients, but they also help health professionals by motivating patients and people to have greater responsibility over their own health. Patients need not behave in a passive way, they need to ask questions, take control and ensure health care is personal to them. Congratulations on all the hard work so far.

As our colleague in South America says: “Many small people, in many small places, can collectively change the world”.

Please enjoy reading the newsletter, as we have so much to be proud of as a global network. We look forward to hearing your news and event updates very soon!

Wishing you all a happy and prosperous few months.

The PFPS team in Geneva.
WHO Global Action Framework on Patient, Family and Community Engagement

A key project under the WHO Patient, Family and Community Engagement Initiative is the development of a Global Framework on Patient and Family Engagement (GPFE). The concept of patient and people engagement and empowerment is well established in many developed countries, but less so in low-income settings.

Engaging and empowering people is a key junction of patient safety, people-centred health services and quality universal health care (UHC). It is expected that the Global Framework on Patient and Family Engagement will provide key guidance and ensure meaningful engagement of stakeholders, including patients, people and health professionals. This is critical as countries across the world move towards achieving UHC. The voice of patients and people will help ensure that equity of access and quality of care are recognized as fundamental to people-centred health services and quality UHC.

Engaging for Integrated, People-Centred Health Services

Most of us have come into contact with health care services, either personally as a patient, or through a family member receiving care or professionally as a health care professional or in another capacity. As a patient, we want more than safe and high quality and clinically excellent health care. We want health care providers to know what we need or value so they can address these things effectively and appropriately. As a professional, we want nothing less than the best for our patients. Advances in medical science and technology can help us to achieve clinical excellence. Never the less, we cannot resolve even the basic issues, such as getting patients to adhere to their medication regimen or using antibiotics rationally. The notion of patient and people engagement gives us an opportunity for the patient-and-provider to have a meaningful conversation. This is easier said than done, as effective communication requires both skills and attitude. Being able to engage and address any arising issues requires visionary leadership, supportive health systems and collaborative patients and the community. Therefore, strengthening people’s capacity and creating an enabling environment for meaningful relationships between health care professionals and those receiving health services is key to achieving safe, quality and people-centred health services.

WHO Framework on integrated people-centred health services (IPCHS)

The World Health Organization (WHO) has developed a Framework on integrated people-centred health services. This calls for reforms to reorient health services, shifting away from fragmented, vertical, supply-oriented models, towards health services that put individuals, families, carers and communities at the centre. One of the five strategic objectives of the framework is to engage and empower people, including patients, families, communities and health professionals. Concurrently, WHO is also developing a Framework for action on patient, family and community engagement. These two frameworks will be key resources for Member States, patients, patient advocates and health care professionals in their efforts to engage and collaborate for meaningful and effective patient-provider partnerships.
Lithuania), the Republic of Korea, the Philippines, India and Indonesia. There were many positive comments demonstrating strong support for the Framework, such as:

“The Framework is well written, well researched, considers similar initiatives and documents from all regions, is a comprehensive and good reference/guidance document for countries as they reform to be able to provide IPCHS; strategies, policy options, and interventions are sound and evidence-based” (the Philippines) or

“We urge Member States to move towards people-centred health systems run with warm hearts” (the Democratic People’s Republic of Korea).

The EB approved the resolution and recommended its adoption by the 69th World Health Assembly in May 2016.

WHO Patient, Family and Community Engagement Initiative: Priority projects in collaboration with WHO Integrated and People-Centred Services (IPCHS)

Scoping review on measurements and indicators for engagement

As stated by Dr Margaret Chan, "what is measured is what is valued”. And we want people to value engagement and empowerment. But how do we know if people are engaged? Are they empowered and what helps them to feel so? Despite the growing recognition of the importance of patient, family and community engagement in health care, consensus is lacking about how best to measure these concepts.

We have therefore embarked on a project to identify measures and indicators of meaningful engagement and empowerment in the contexts of quality, people-centred health services. These measures and indicators are important as benchmarks to evaluate current practices, as well as to promote accountability, and incentivize action for sustainable change.

This project aims to summarize key themes and identify gaps in the current measurement of patient, family and community engagement and empowerment. It involved a scoping review of over 13,000 journal articles focusing on engagement and empowerment, including the patient experience and measures of satisfaction.

Global perceptions report

Another project conducted under the WHO Patient, Family and Community Engagement Initiative is a global survey that explored people’s perceptions on meaningful engagement. More specifically, it sought answers to these questions:

- What does ‘engagement’ in health care mean?
- What makes ‘engagement’ meaningful to you?
- How can we measure if this ‘engagement’ is meaningful and/or effective?
- What attributes or characteristics should patients embody to make engagement effective and meaningful?
- What attributes or characteristics should health professionals embody to make engagement effective and meaningful?
- What are the barriers or challenges to achieving meaningful engagement?

There were 42 responses, from 18 countries. Key descriptions of “meaningful engagement” included the importance of partnership, communication, being informed, self-management, rights and entitlements, health literacy, trust, compassion and equity in direct care. Key themes from the organizational level included improved clinical outcomes, provider expectations, integrated care, family-centred care, organization and management issues and accessibility to services (linguistically, geographically, socio-economically and culturally).

These primary results are largely based on the Chinese and US contexts (41% of responses). The survey is being re-distributed to elicit more responses from other settings. We invite your participation to help make this survey more global. To access this survey please follow the link below. The report of the initial responses will be available on the PFPS website soon.

https://extranet.who.int/dataform/241271/lang-en
Aiming to improve the quality of care during childbirth, the WHO Safe Childbirth Checklist and Implementation Guide were launched in December 2015 to target the major causes of maternal and newborn complications and deaths. The Checklist is an organized list of evidence-based practices to help health care workers provide high quality care during birth in health facilities, from the moment the mother arrives to the moment she and her newborn leave the facility. The Implementation Guide helps health care leaders and birth attendants successfully launch and help sustain use of the Checklist. It covers how to introduce and ensure continuous use of the Checklist by engaging relevant stakeholders, and how to launch the Checklist formally. It also provides support for the implementation process through coaching and data-sharing. For more information and to download the Checklist and the Implementation Guide, please visit the WHO website at the following link: http://www.who.int/patientsafety/implementation/checklists/childbirth/en/

There are two key principles in radiation safety – justification ‘is the procedure necessary?’ and optimization ‘how to ensure the procedure is as safe as possible?’ This technical meeting held on 7-9 March 2016, in Vienna, Austria, aimed to address the ‘justification’ side of things by exploring ways to improve the appropriate use of medical imaging through effective and consistent implementation of the Clinical Imaging Guideline (CIG).

The meeting brought together 60 experts from 30 countries, representing health care professionals, policy-makers, and national and global professional societies. Chaired by Dr Michael Bettmann (American College of Radiology), the meeting was organized by the International Atomic Energy Agency (IAEA) with the leadership of its senior officials including Dr Peter Johnston (Director of Radiation, Transport and Waste Safety, IAEA) and Dr Miroslav Pinak (Head of the IAEA Radiation Safety and Monitoring Section) and Dr Ola Holmberg, Head of the IAEA Radiation Protection of Patients Unit, who provided a scene-setting presentation.

Nittita Prasopa-Plaizier and Dr Maria Perez represented WHO at this global event.

Dr Maria Perez from the WHO Department of Public Health, Environmental and Social Determinants of Health (PHE), provided a global overview of the current status of Clinical Imaging Guideline (CIG) projects. Nittita Prasopa-Plaizier representing the WHO Service Delivery and Safety (SDS) Department, delivered a keynote presentation on person and people engagement and empowerment in the contexts of radiation safety. She examined how engaging and empowering health care stakeholders could better contribute to the implementation of the clinical imaging guidelines for an appropriate, justifiable, timely and safe use of medical imaging. Nittita’s participation was a part of the on-going collaboration between the WHO Patient, Family and Community Engagement Initiative and the Global Radiation Safety programme, led by the WHO PHE Department.
Global report on Radiation Safety in Paediatric Imaging

Jenny Westad and Felicity Pocklington

The WHO Department of Public Health, Environmental and Social Determinants of Health (PHE) and the WHO Department of Service Delivery and Safety are publishing their new joint publication entitled ‘Communicating radiation risks in paediatric imaging: information to support health care discussions about benefit and risk’.

This report is intended for health professionals involved in the referral and services of paediatric medical imaging. It builds on the rationale that referring medical practitioners need sufficient information, skills and resources to communicate clearly and effectively about the benefits and risks of paediatric imaging procedures to patients and their families.

The report was developed by groups of experts, which included Dr Maria Perez as WHO technical lead and Nittita Prasopa-Plaizier and Margaret Murphy who represent the Patients for Patient Safety programme and network respectively. The report built on the contributions of many stakeholders. These included participants in the "Radiation risk communication in paediatric imaging" workshop, held during the “International Conference on Radiation Protection”, in Bonn, Germany, in December 2012, and the international workshop on Radiation Risk Communication in Paediatric Imaging, held at WHO headquarters, in September 2010.

WHO PFPS would like to say a huge thank you to the WHO PHE team, especially Dr Maria Perez, for strong leadership and collaboration on this exciting project. We hope to work closely with the PHE Department in the future, to build on this tool and produce more specific information and materials on the role of patients, families and communities in this context.

Engaging for Quality Universal Health Coverage

PFPS team

Quality is fundamental to safe health care and sustainable Universal Health Coverage (UHC). Globally, countries have made a commitment to achieving UHC and the subject has been placed at the top of the global health agenda, as demonstrated in Goal 3 of the Sustainable Development Goals (SDGs). While the original focus of UHC had been on financing systems, there is now an opportunity to improve population health outcomes and attain UHC though using quality driven, people-centred and integrated approaches.

Building on the successes of previous development goals and lessons learnt from recent global epidemics, there is now a real need for health systems to incorporate patient, family and community needs, values and preferences, to develop resilient and people-centred health systems, without which delivering quality UHC would be an empty promise.

Engaging for Quality Universal Health Coverage

The WHO Department of Public Health, Environmental and Social Determinants of Health (PHE) and the WHO Department of Service Delivery and Safety are publishing their new joint publication entitled ‘Communicating radiation risks in paediatric imaging: information to support health care discussions about benefit and risk’.

This report is intended for health professionals involved in the referral and services of paediatric medical imaging. It builds on the rationale that referring medical practitioners need sufficient information, skills and resources to communicate clearly and effectively about the benefits and risks of paediatric imaging procedures to patients and their families.

The report was developed by groups of experts, which included Dr Maria Perez as WHO technical lead and Nittita Prasopa-Plaizier and Margaret Murphy who represent the Patients for Patient Safety programme and network respectively. The report built on the contributions of many stakeholders. These included participants in the "Radiation risk communication in paediatric imaging" workshop, held during the “International Conference on Radiation Protection”, in Bonn, Germany, in December 2012, and the international workshop on Radiation Risk Communication in Paediatric Imaging, held at WHO headquarters, in September 2010.

WHO PFPS would like to say a huge thank you to the WHO PHE team, especially Dr Maria Perez, for strong leadership and collaboration on this exciting project. We hope to work closely with the PHE Department in the future, to build on this tool and produce more specific information and materials on the role of patients, families and communities in this context.

Engaging for Quality Universal Health Coverage

PFPS team

Quality is fundamental to safe health care and sustainable Universal Health Coverage (UHC). Globally, countries have made a commitment to achieving UHC and the subject has been placed at the top of the global health agenda, as demonstrated in Goal 3 of the Sustainable Development Goals (SDGs). While the original focus of UHC had been on financing systems, there is now an opportunity to improve population health outcomes and attain UHC though using quality driven, people-centred and integrated approaches.

Building on the successes of previous development goals and lessons learnt from recent global epidemics, there is now a real need for health systems to incorporate patient, family and community needs, values and preferences, to develop resilient and people-centred health systems, without which delivering quality UHC would be an empty promise.

Engaging for Quality Universal Health Coverage

PFPS team

Quality is fundamental to safe health care and sustainable Universal Health Coverage (UHC). Globally, countries have made a commitment to achieving UHC and the subject has been placed at the top of the global health agenda, as demonstrated in Goal 3 of the Sustainable Development Goals (SDGs). While the original focus of UHC had been on financing systems, there is now an opportunity to improve population health outcomes and attain UHC though using quality driven, people-centred and integrated approaches.

Building on the successes of previous development goals and lessons learnt from recent global epidemics, there is now a real need for health systems to incorporate patient, family and community needs, values and preferences, to develop resilient and people-centred health systems, without which delivering quality UHC would be an empty promise.
emphasized the importance of engaging key stakeholders, including patient groups, health professionals and policy-makers, in implementing change and achieving sustainable outcomes. Dr Ken Taneda, former patient safety focal point at the WHO Western Pacific Regional Office (WPRO), and now works for the National Institute of Public Health, Japan, shared challenges faced by high-income countries, more specifically, issues related to meeting the needs of an ageing population.

WHO provided the final two scene setting presentations. Nittita Prasopa-Plaizier provided an overview of how patient and community engagement can help build better quality care within the context of UHC at global and local levels, focusing in on compassionate care as a key enabling factor for effective and meaningful engagement. Alison Macintyre presented the critical linkages between water, sanitation and hygiene (WASH) and quality UHC.

The ‘world café’, which followed the presentations, aimed to encourage discussion among the participants and to enable knowledge-sharing. The participants were systematically assigned into four groups to discuss the key questions in relation to Quality Universal Health Coverage. Each group reported the summary of their discussion at the end of the session. The full report is being finalized and will be available soon on the WHO website.

2. Announcement of the new SDS unit on Quality Universal Health Coverage (QHC)

Dr Shams Syed announced the new WHO QHC unit, following the opening plenary of the PMAC conference. Key points included:

- **UHC is the platform upon which we can build together to have an impact on the frontline;**
- **Target 3.8 of the Sustainable Development Goals focuses on achieving UHC, including financial risk protection, access to quality essential health care services, medicines and vaccines for all;**
- **Quality is relevant to WHO’s work in priority disease programmes, in reproductive health, in maternal and child health and in work on non-communicable diseases (NCDs). However, in recent history, there has been no centre of gravity on quality of care, yet it remains a critical but nearly “forgotten” part of the UHC agenda in our newly launched Sustainable Development Era. The new WHO QHC unit aims to fill that gap;**
- **The new WHO unit will work on three areas:**
  - (a) Country engagement and global frameworks;
  - (b) Health service resilience;
  - (c) Partnerships for improvement.

3. Panel presentation: ‘1.5 – Priority-setting and public health security: leveraging UHC reform for disease surveillance systems in a globalized world’

This panel session focused on how linkages between priority-setting and public health security can be achieved, with a specific focus on UHC driven processes. Key lessons have been learned from the Ebola, SARS, Avian Influenza, and Bird Flu epidemics, as well as the different elements of the global health security agenda. Multiple entry points to the subject were examined at the national, regional and global levels. At the national level, the focus of the panel discussion was on how communicable disease “shocks” to essential health services are seen within the context of a health system that is moving towards UHC. Recommendations included the need to better link health services with the health security agenda in terms of prevention, preparedness, response and early recovery. The significant experience secured during the work in Ebola-affected countries was examined. The link between strengthening surveillance, preparedness, disaster risk management and delivery of health services was explored within the context of UHC.

A full report of WHO SDS’ participation in PMAC 2016 is available on the PFPS webpage.
Other priority projects and events

International Alliance of Patients’ Organizations (IAPO) Congress

Felicity Pocklington

Nittita and Felicity, representing WHO PFPS, participated in the IAPO 2016 Congress in London on 9–11 April. This year, the theme was ‘Innovation improving sustainable access: how to boost your reach and impact’.

Nittita delivered the keynote address on “Where are we on the journey towards Universal Health Coverage (UHC)?” She considered the engagement and empowerment of people and communities, including patients’ organizations and groups, to be innovative in helping to deliver sustainable UHC. Kawaldip Sehmi, IAPO Chief Executive, facilitated the session. Other key speakers included Joshua Wamboga from the Uganda Network of AIDS Service Organizations, and Robert Johnstone from National Voices UK.

Nittita, Felicity and Hussain Jafri (PFPS advocate from Pakistan) coordinated an interactive workshop entitled “Meaningful engagement of patients and people in patient safety and health care quality improvement: The role of patient advocates”. The workshop gathered approximately 25 participants, mostly patient advocates and representatives of patients’ organizations.

Felicity opened with a presentation on “Safe and quality health care: The role of patient advocacy”. She described WHO tools for safer care as “hardware” in health service delivery, and described our responsibility to focus on the “software” for care to be delivered with quality and to be people-centred. She emphasized the importance of “compassionate care”, including communication, collaboration and trust. She presented the initial results of the WHO global survey on perceptions of engagement and empowerment (to participate please follow https://extranet.who.int/dataform/241271/lang-en). Hussain Jafri presented on the concept of Empowerment, outlining the challenges and opportunities based on community empowerment initiatives in Pakistan. He described improved health outcomes from locally-driven health initiatives, including increases in vaccinations, birth registrations, exclusive breast feeding, hygiene practices and attendance to antenatal check-ups.

The workshop received positive feedback for its practical approach, and for providing real-life examples and next steps for advocacy work.

Knowledge Transfer Webinar: Patient Engagement in Safety and Quality Committees

Ioana Popescu and Katthyana Aparicio

WHO PFPS, in collaboration with PFPS Canada and CPSI, hosted a webinar entitled “Does patient engagement in patient safety and quality committees advance safe care or is it a myth?” on 24 February. The webinar was attended by over 100 people from across the world.

The two presenters, Alethse De la Torre Rosas (Infectious diseases specialist, Mexico) and Malori Keller Kaizen (Continuous Improvement Specialist – Patient Engagement, Canada) shared examples of programmes, tools, data and lessons learned from their experience. Theresa Malloy-Miller (Patients for Patient Safety Canada Champion) as the moderator of the session, engaged participants in a conversation that resulted in further sharing and learning.

The slides and recording of the presentation are now available here and a document with tips for patient engagement in quality and safety committee have just been added (the tips are compiled from this webinar and discussions with members of the World Health Organization Patients for Patient Safety Community and the Institute for Patient and Safety Centred Care and the Patient and Family Advisors and Leaders Network).

According to the post-session survey, more than 90% of respondents felt that the meeting objective had been met, which was to understand different approaches to patient engagement in patient safety and quality committees and how patient engagement has impacted patient safety and quality outcomes.
Kathy Aparicio, representing the PFPS team, provided technical support for two workshops - a capacity strengthening workshop for health professionals and a PFPS workshop aimed at empowering patients and advocates. Both events were held in Mexico City, on 19 November. The capacity-strengthening workshop was held as part of the WCIC 3 – the 3rd World Congress on Integrated Care, which was organized by the International Foundation of Integrated Care (IFIC), in partnership with the Pan American Health Organization/World Health Organization (PAHO/WHO), the Secretariat of Health of Mexico, the Secretariat of Health of the Federal District, the National College of Specialist on Integrated Medicine (CONAEMI) and Anahuac University.

The PFPS workshop was hosted at the Hospital de Ciencias Médicas y Nutrición and was co-sponsored by the Universidad Autonoma de Mexico (UNAM), through Dr Enrique Acosta. The workshop hosted 60 participants, the majority of whom were health professionals, patients, family members and PFPS advocates (champions) from Mexico (Lucia Aguilar Almazan, Evangelina Vazquez Curiel, Tomas Flores) and Costa Rica (Randall Madrigal).

Kathy Aparicio, with the help of PFPS Champions who participated in the workshop, has written a detailed report on the workshop. Below is a “taster” on key areas of the report:

1. Context: Information about how the Mexican and Pan-American PFPS networks were created, including their aims, general structure, common barriers and key solutions within the social context shared by many Latin American countries;

2. Patient safety:
   ⇒ The perspective of people from the Pan-American PFPS network – The perceived need of health literacy as a key to safe and quality care;
   ⇒ The perspective of health care professionals - The context of health-care associated infections in Mexico;

3. The role of government: Two examples of how governments can participate with communities and people to generate better outcomes;

4. Qualitative analysis of the main themes reported by workshop groups while discussing three questions:
   ⇒ What is a significant participation of patients in the health system?
   ⇒ What is required for you to feel empowered?
   ⇒ What can health care personnel do in order to make the patient and family feel part of the health system?

The report is currently in Spanish, but an English translation is being finalized. Both reports will be available on the PFPS website soon.
Sample snapshots from PFPS Spring 2016

Figure 14: Compilation of photos from PFPS Spring 2016
Overview

Felicity Pocklington and WHO Gender, Equity and Human Rights team

International Women’s Day (8 March) is a global day celebrating the social, economic, cultural and political achievements of women. Over the past century, vast improvements have taken place regarding the health and well-being of women and girls, including social and legal reforms of child marriage and sexual consent; access to safe abortion services (where legal), contraception, health technologies; and progress towards ending harmful practices such as sexual and gender-based violence, including female genital mutilation.

Yet, huge challenges remain. Health outcomes for women are worse when they face various forms of discrimination, oppression, and lack of opportunity for education and employment. Gender inequality also has negative consequences for women in the workplace, such as fewer opportunities for promotion and growth, and lower compensation. In fact, the World Economic Forum estimates that at the current pace, gender parity at all levels of decision-making will not be reached until the year 2133. That is 117 years from now!

A significant contributing factor to continued gender inequalities is unconscious bias.

“This (unconscious) bias erects powerful but subtle and often invisible barriers for women that arise from cultural assumptions and organizational structures, practices, and patterns of interaction that inadvertently benefit men while putting women at a disadvantage.”

Engaging women, men and children concerning the importance of gender equity through equal access to education and training, employment, health systems, science and technology, will empower them to observe how gender inequality directly and indirectly affects them, and to take action to reach their human right to health. For instance, education and training will equip people with the skills needed to protect their health, such as participation in health and education programmes often disseminated through online or mobile phone technology. If we are going to be innovative with health strategies, we must make sure that women and girls are not left behind because they do not know how to use or access these technologies.

WHO events

This year’s International Women’s Day (IWD) 2016 events were grouped under the theme “Planet 50-50 by 2030: Step It Up for Gender Equality”. It was not only a day to reflect on progress made across the world but also an opportunity to mark a call for action to address the pressing barriers that can prevent women from reaching their full potential. The Staff Association, the Gender, Equity and Rights team, and the Human Resources Management Department of WHO, organized a lunchtime seminar for all staff to hear Dr Michael Kimmel, a sociologist who specializes in men and masculinities, speak on equality. He touched on the subject of unconscious bias, to ensure the safety of both men and women, and organizational will for equity in access to clinical trials.

Jeanine, from her experience at CTTI, explained that clinical trials need to include a subgroup analysis to determine if the drug is appropriate for women. She stated how “research for drug and medical device development for women’s health issues have been lacking and lie far behind drugs specific to men’s issues and diseases”. For this, there needs to be political and organizational will for equity in access to clinical trials, to ensure the safety of both men and women, and all other underrepresented groups.

Jeanine concluded; “In the rush to get drugs on to the market, we must work even harder to ensure real diversity in clinical trials. People want to participate in trials and will do so with the right incentives, and women’s health and lives matter”.

PPFS advocate from the United States – comment on Gender Equity

Jeanine Thomas and Felicity Pocklington

Jeanine Thomas, PPFS advocate from the United States and founder of the MRSA Survivors Network, has been a patient representative for the Food and Drug Administration (FDA) since 2008. In her role, she attends hearings as a voting member on the Antimicrobial Resistance (AMR) Drug Development Committee and other FDA sponsored events. In recent years, Jeanine has also participated as a patient representative, in the FDA Clinical Transformation Trial Initiative (CTTI). This initiative promotes antibiotic drug development, using streamlined approaches to control emerging pathogens and provide better stewardship.

Jeanine highlight two important concepts in relation to gender equality and health research:

• Women aged between 18 and 65 must be included in clinical trials so that we can compare and contrast results with those of men;

• Gender equity of health research funds, in relation to allocations for drugs and medical devices, for male and female users.

Jeanine wrote; “Women, people of colour and patients over the age of 65 are under-represented in clinical trials making the safety and effectiveness of drugs difficult to measure in these groups”. Low representation of women in clinical trials compromises women’s health care safety from a lack of gender-specific information on dosing and use of drugs.

Jeanine, from her experience at CTTI, explained that clinical trials need to include a subgroup analysis to determine if the drug is appropriate for women. She stated how “research for drug and medical device development for women’s health issues have been lacking and lie far behind drugs specific to men’s issues and diseases”. For this, there needs to be political and organizational will for equity in access to clinical trials, to ensure the safety of both men and women, and all other underrepresented groups.

Jeanine concluded; “In the rush to get drugs on to the market, we must work even harder to ensure real diversity in clinical trials. People want to participate in trials and will do so with the right incentives, and women’s health and lives matter”.

© World Health Organization 2016. All rights reserved
Other updates from WHO—Eastern Mediterranean Regional Office (EMRO)

Mondher Lethaief, Kid Kohl, Felicity Pocklington

◊ The Patient Safety Friendly Hospital Initiative (PSFHI)

EMRO launched an initiative called the Patient Safety Friendly Hospital Initiative in 2006, which aimed to improve patient safety in health-care facilities, by encouraging them to meet a comprehensive set of patient safety standards. The initiative was launched with the support of a group of international and regional experts and was piloted in seven countries of the Region namely Egypt, Jordan, Morocco, Pakistan, Sudan, Tunisia and Yemen in 2009/2010 (See Siddiqi et al., 2012. http://intqhc.oxfordjournals.org/content/24/2/144.long). During phase two, Libya, Iraq, Iran and Palestine joined in (2010/2011); Afghanistan, Qatar (private hospitals) and Syria joined in 2014/2015. The initiative is currently being implemented in five general hospitals in the Sultanate of Oman.

The initiative consists of two pillars, the first deals with assessment, and the second provides support for improvement. PSFHI provides a set of standards for patient safety and guidelines for implementation. These guidelines include the engagement of the Ministry of Health, the development of a national task force, training for providers on the implementation of standards, and surveillance.

The assessment involves the use of patient safety standards, which are a set of requirements that are essential for the establishment of a patient safety programme at hospital level. The assessment of these requirements consists of 140 standards, covering five patient safety domains: leadership and governance, safe evidence based clinical practice, patient and family involvement, safe environment and lifelong learning. The standards are classified into three sections; critical, core and developmental. A manual comprising the standards and assessment tools has been developed (http://applications.emro.who.int/dsaf/ emropub_2011_1243.pdf). A second edition came out in 2016)

Following assessment, institutions have been provided with technical assistance to improve patient safety in the domains that have been reported as weak. Particular attention is given to the 20 critical standards which are absolutely essential for any hospital to be considered at the basic level of patient safety. A useful tool for this second part is the patient safety toolkit (http:// www.emro.who.int/entity/patient-safety/index.html).

Thus the PSFHI aims to implement safe practices in health-care facilities by assessing adherence to patient safety guidelines developed by WHO and partners. It also encourages the incorporation of all patient safety concepts and programmes (e.g. Patients for Patient Safety, Safe Surgery Safes Lives, the Safe Childbirth Checklist, and Research) as well as the participation of national health authorities, and medical and nursing schools to contribute to the process of safe health-care delivery.

There are challenges to implementing the initiative. Expansion to some countries/healthcare facilities has been delayed as it is not yet well institutionalized. Only a few countries have scaled up their efforts, like Iran, Palestine, Qatar (private sector) and Oman. There is an equivocal commitment by many countries, but initial enthusiasm has not yet materialized into action. There is a gap between the development of the assessment manual and the Patient Safety toolkit. Moreover, hospitals expect WHO to function as an accrediting body and deliver an accreditation certificate, which is obviously outside WHO’s remit.

Figure 16: Participants of the Eastern-Mediterranean meeting on the principles and practice of health care accreditation

◊ Regional meeting on the principles and practice of health care accreditation

The EMRO held a regional meeting on the principles and practice of health care accreditation in Cairo, Egypt, on 13-15 December 2015. The objective of the meeting was to discuss and provide guidance on setting up health care accreditation programmes, at both national and organizational levels. The meeting was attended by quality of care and health care accreditation focal points from ministries of health from EMRO’s 19 countries, as well as global and regional experts invited to present and share their experiences in health care accreditation and clinical governance.

The meeting focused on four technical areas;

- Policy issues around accreditation;
- Current health care accreditation programmes in the Region;
- Global and regional experiences in implementing such programmes;
- Alternatives to quality and safety.

Key issues discussed included accreditation in health care, the importance of common definitions of health financing and quality strategies at system and provider levels, agreement on what is good medical practice, measurements and comparisons between health-care providers, including benchmarking and external assessment.

The workshop proposed 20 recommendations. Recommendations to EMRO included the domains of organization and management; strategic development; and advocacy. Recommendations to Member States included the resource allocation and mobilization; methods of work; organization and management and policy development.

© World Health Organization 2016. All rights reserved
Following underpinning principles: 1) universal health cover

The tool has been developed based on the following domains: access and equity, safety, efficiency, effectiveness, patient centeredness and timeliness) and 3) regional priorities (health system strengthening, maternal and child health, emergency and preparedness, global health security and non-communicable diseases).

The quality indicators were selected based on three main criteria – 1) public health importance, scientific soundness and feasibility of implementation. A five-step approach has been used to define the final indicators:

1. Desk analysis and literature review – identify available quality indicators for primary care; 17 papers were considered;
2. Expert consultation - to establish a list of candidate indicators for inclusion in the selection process;
3. Delphi survey - experts ranked candidate indicators according to their amenability to public health interventions, scientific soundness and feasibility;
4. Pilot field test in five PHC facilities in two EMR countries (Egypt and Jordan) to refine the list of indicators;
5. Validation of the selected indicators through feedback from experts and quality primary care/focal points who are government officials in Ministry of Health in countries in EMRO.

The final set of 34 indicators has been validated by experts and further adapted after a first pilot test in five facilities in Egypt and by the United Nations Relief and Works Agency for Palestine Refugees, International charitable sector (UNWRA) Jordan (step 4). The two major objectives of this pilot study were to obtain feedback regarding the implementation of the tool and utility of the selected 34 indicators in measuring and monitoring the quality of care at PHC facilities.

In the next stage, the adapted indicator assessment tool was tested in 40 selected PHC facilities amongst four EMR countries (Iran, Oman, Tunisia, Jordan) to collect feedback regarding the challenges in its implementation and the indicator data.

These outcomes will be discussed during the regional meeting in Amman, Jordan in June 2016, which aim to finalize the tool and encourage its implementation in PHC centres throughout countries in the region.
Expansion of the network over the past 11 years....

"Ms X’s opening words were particularly poignant, as she highlighted the importance of *integrity, humility and compassion* factors which are often quickly forgotten in the world of medicine.... It was an absolute honour to hear Ms X talk. To turn such an *unspeakable loss into such powerful words* was so touching. As young medical students, our minds are malleable and eager to learn new material. We learn about the human body and diseases which afflict it, but how we *care for patients is not taught*. Last week, Ms X taught. She went where no other lecturer had been before. She taught us about emotion, about communication and about caring for the patient and their family. She taught us what it takes to become a great doctor.”

- Woman, PAHO

“*The workshop helped me, if that hadn’t of been there I would have not have been working on patient safety*. It was motivating seeing fellow patients and people being there... hearing what they have gone through, and learning all their things that they are doing in their respective countries or regions... it was very motivating”

- Woman, PAHO

**Figure 20:** Compilation of photos from PFPS - The growth of the network over the last 11 years
Update from PAHO

Argentina

Jorge César Martinez

Following the webinar entitled “The Necessary Components to Governing Quality”, Jorge César Martinez, PFPS advocate from Argentina, received the following comment:

“Excellent presentations!!!! Structural and socio-cultural needs and values of patients are important, and we need to really understand these as healthcare professionals. As the people in charge of taking care of people, I think that the main objective should be to work on building a culture of safety, especially for the new generations.

...I absolutely agree that we need changes, great changes...We must emphasize that whatever our position within the health-care system, to treat others (patients) as you would like to be treated...

This needs cultural sensitivity and strong leadership...

CONGRATULATIONS for the work you are doing”.

It is always great to hear such positive feedback! Many thanks to Jorge for sharing this with us.

Canada

◊ Patients for Patient Safety Canada

Sharon Nettleton and Denice Klavano, co-chairs of PFPS Canada

PFPS Canada in-person champion workshop

PFPS Canada celebrated their 10th anniversary in March 2016, highlighting their past contributions and identifying ways to advance their mission: “Every patient safe in the ever-changing patient engagement environment”. Light and movement were two themes at the meeting as they reflected on where PFPS Canada are now in their journey. ‘Light’ symbolizing the importance of ‘seeing our way’ with each other, and in collaboration with leaders and providers, and ‘Movement’ to acknowledge the importance that PFPS Canada plays in keeping the patient safety agenda ‘moving forward’. PFPS Canada commented; “We won't stand still. We are partners in patient safety.”

In attendance were 27 PFPS Canada members, five programme staff members from the Canadian Patient Safety Institute (CPSI), including the CEO, Chris Power, and several guests: Marty Hatlie, WHO PFPS, Leslee Thompson, Accreditation Canada, Maria Judd, Canadian Foundation for Healthcare Improvement, and Andrew MacLeod, Ontario Hospital Association.

Marty and the guests inspired PFPS Canada to do more and challenged the group to take new and bigger steps by flagging opportunities to advance patient safety. Reflecting on PFPS Canada’s journey, many members spoke about how they feel much more confident as patient partners and noted how the culture today embraces their work far more than it did 10 years ago.
PFPS Canada contributions to the National Patient Safety Consortium

With support from the entire membership, 13 PFPS Canada members are contributing to the development and implementation of an integrated patient safety action plan. The plan is aimed at making care safer in medication safety, surgical safety, home care, infection prevention and control, and education. These members are: Johanna Trimble, Phil Bourget, Terri Szabo, Bernie Weinstein, Kim Neudorf, Phil Capone, Barb Farlow, Santiago Diaz, Carol Kushner, Anne Lyddiatt, Donna Davis, and Deb Prowse. PFPS Canada Co-chairs Sharon Nettleton and Denice Klavano are members of the Steering Committee of the National Patient Safety Consortium.

Figure 23: Patients for Patient Safety Canada members

Canada's Virtual Forum on Patient Safety and Quality Improvement (Forum) – October 2015

PFPS Canada members participated in many ways in this national virtual patient safety conference. The members were involved in planning the conference and co-hosting the three-day event (Sharon Nettleton), and were asked to deliver a key note speech (Deb Prowse on healing after harm, Sabina Robin on disclosure and incident analysis). In addition to the thousands of Canadian health-care providers, leaders, policy makers and planners who joined in over the three days, participants also connected from six other countries. The proceedings are available at no cost here.

Figure 24: Sharon Nettleton, Co-Chair Patients for Patient Safety Canada and Gord Wallis, Managing Director, Safe Medical Care, The Canadian Medical Protective Association

Champion Awards, presented by the Canadian Patient Safety Institute and HealthCareCAN, were announced at a Virtual Forum in October. The two awards recognize champions of patient safety – the volunteer work of patient and family members and organizations that achieve safer care through patient and family engagement. This year’s winners were the Price Family and Providence Health Care. Other finalists are listed here. PFPS Canada members Ed Kry, Sharon Nettleton, and Bernie Weinstein were part of the 5-person selection panel. Sharon facilitated the webinar celebrating the winners.

Figure 25: Left, Sabin Robin, PFPS Canada member. Right, Deb Prowse, PFPS Canada member

Figure 26: Sharon Nettleton co-chair Patients for Patient Safety Canada, and Chris Power, CEO Canadian Patient Safety Institute presenting the 2015 Champion Award (for organization) to Providence Health Care

Figure 27: Sharon Nettleton, co-chair Patients for Patient Safety Canada and Chris Power, CEO Canadian Patient Safety Institute presenting the 2015 Champion Award (for individual) to the Price Family
Update from SEARO

Thailand

◊ Patient’s Voice! Helping Healthcare Improvement

Piyawan Limpanyalert

Patients for Patient Safety Thailand (PFPS Thailand) joined a capacity-strengthening event hosted by the Healthcare Accreditation Institute (HAI), on 24–25 February 2016. Over 60 people from 13 health districts participated in the event, which aimed to share patients’ experiences of living with disease or illnesses, and to discuss effective communication skills and techniques between health care providers and patients, to improve the safety and quality of care.

The event was a great opportunity for patients with chronic diseases to share their life experiences with patient groups, and to raise awareness of the benefits of learning from patient experiences at the organizational level of health care. Patients shared examples of living with four chronic diseases; diabetes, kidney disease, cancer and haemophilia. Following this, the participants were divided into four groups, with one patient representative in each group. The groups were given the task of creating a key message for building effective communication and rapport to health care: straight, simple, and correct.

The event facilitated information sharing and interaction between health care providers and patients to develop key messages targeted at patients. The participants described how the “patient’s voice gave them the idea to create the message to raise social awareness about patient safety with all stakeholders”.

◊ Patients with Chronic diseases; Raising social awareness

The 2016 Healthcare Accreditation Institute held its HA National Forum, under the concept “Enjoy Quality Every Moment”, on 8-11 March 2016, at Impact Forum, Muangthongthani, Bangkok Thailand. Patients for Patient Safety Thailand participated in this event and took this opportunity to raise awareness about engagement for the management of chronic diseases.

More than 7 000 health care workers participated in this forum. PFPS Thailand had an exhibition booth to share information and held fundraising activities. The four patient groups, including diabetes, kidney, cancer and haemophilia, joined in this event. The groups not only raise awareness about the diseases, but also about prevention of these chronic diseases and about the patient group’s activities. Fundraising activities drew people’s attention to the booth with a smile and nice chat. We had a relaxing massage, healthy drinks and teaching clay work as well as sketched caricature drawings by a hemophilia patient. Our patients show a very good spirit: Though they live with a chronic disease, they are giving something back to the society. Compassion between patients and health care workers is a key success to engagement for patient safety.

Figure 28: PFPS Thailand members

Figure 29: From left,
**Update from WPRO**

**Australia**

Advocacy for a safer diagnosis, prescription and usage of drugs

Anna McMahon and Felicity Pocklington

The world is increasingly facing challenges in the prescription of drugs, with an increase in adverse events and mortality due to preventable prescription errors. Anna McMahon, a PFPS advocate from Australia, has been a patient advocate for the past 15 years, focusing mainly on safe and quality prescription and usage of drugs.

As Anna wrote:

“The prescription drug issue has become a complex problem. The issue can start at the first point of contact with the doctor during the consultation, therefore this is a good place to start to implement change and fix the problem. By introducing people-centred, integrated and streamlined processes across all areas of the health sectors(...), the benefits would be significant. More time will ensure patients get the correct dosages, the right medication, and that the doctor is able conduct periodic reviews for all patients’ medications including patients with long term health conditions. The change is small but the benefit is substantial, reduced patient addiction, reduced adverse events, fewer patients slipping through the cracks”.

In 2014, prescription drugs were involved in 82% of the 384 overdose deaths investigated by the Australian State of Victorian Coroner’s Court. This causes not only loss, but unquantifiable social and economic impacts from drug reliance.

Over recent years Anna has used advocacy methods to raise awareness of the significant impact arising from pharmaceutical harm. This advocacy has included meeting with government departments, health departments, private businesses and public groups, using statistical data to drive public awareness for change.

News and events:

2014:

- A state government parliamentary enquiry on specific impacts of Benzodiazepines – based on the continued prescription drug awareness campaigning;

2015

- Meeting with government representatives to consider the real time prescription drug monitoring system;
- Developing a real time prescription drug monitoring system and piloting the tool in a number of medical clinics. The system recorded 200 drug dependent patients in the first month;
- Raising awareness with the Health Department’s Drug and Poisons Regulations Office, – Anna demonstrated the real time prescription drug monitoring (RTPM) tool. Since this demonstration, Victorian Health was allocated a small amount of funding to establish a taskforce working towards the implementation of the tool.

A key challenge, Anna wrote, is that “we have lost the ‘CARE’ in health care”. For change to be sustainable, there “not only needs to be a RTPM tool, but also... improved streamlined prescribing processes and procedures to be implemented at the source, by all medical practitioners across the health sector”. There need to be tools and resources, and training for health professionals to improve communication skills. These skills must include meaningful listening of patients’ needs and empowering them to ask questions, and such efforts need to be supported by policy-makers too. Anna suggested “a national centralized repository for all patients’ medical information”.

**Malaysia**

PFPS Malaysia - Pilot project experience

Kadar Marikar and Rebecca John

Patients for Patient Safety Malaysia has conducted a pilot project researching the prevention of two common patient safety incidents in hospitals; patient falls and medication errors (see PFPS Autumn news for full details on this research [http://www.who.int/patientsafety/patients_for_patient/PFPS_Newsletter_autumn2015.pdf?ua=1]). The pilot project has been carried out so far in 14 public and private hospitals in Malaysia.

Objectives of the pilot project were:

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

- Awareness training on the two selected topics - fall prevention and medication safety - was conducted for both patient representatives and hospital representatives;
- Orientation for patient representatives and hospital teams, to provide information on the hospital processes in fall prevention and medication processes;
- Selection of pilot sites - identified the wards for the pilot project based on the number of incidents reported and patient type. The sample ward for falls was the orthopaedic ward, since it had the highest number of falls and medication errors;
- Intervention - identified activities for the pilot project which included monthly visits to the wards and regular meetings to monitor progress. The pilot project was implemented with support from the senior management team of each hospital as advisor to the project. Patients were interviewed using a Knowledge, Attitudes and Practices (KAP) questionnaire provided by the hospital, which aims to measure pre- and post-knowledge, attitudes and practices.

On 27 October 2015, health professionals and patient representatives who had participated in the pilot project were invited to a meeting to share their experiences. The meeting revealed enthusiasm between all stakeholders participating in the project. The hospital representatives’ experiences revealed initial resistance from the doctors and nurses who wanted to know why the patient representatives were on the ward. Over time and with better understanding, both the doctors and nurses accepted the presence of patient representatives and saw the benefits of the project.

The PFPS Malaysia committee members also supported the implementation of the project by making on site visits to the selected hospitals. A consensus decision was taken to develop a SWOT analysis on the reports presented by the hospital representatives and convert it into a survey questionnaire to support expansion of the project. A survey questionnaire had been circulated to the management of all the participating hospitals. Based on the findings from the survey questionnaire, the PFPS Malaysia committee will develop support evidence for the pilot project to be extended to other hospitals in the near future.

Completion of the evaluation and report of this project was delayed due to unforeseen circumstances, including illness and personal challenges of the selected representatives, and to changes in the management team of one of the hospitals. Analysis of the findings of the survey is currently ongoing and a report on the full project will be prepared and presented by the PFPS Malaysia committee at its next meeting in April 2016. This report will then be shared with the WHO PFPS community.

Future events

◊ **Primary Health Care Improvement – Global Stakeholder Meeting**

The WHO PFPS team will participate in the Primary Health Care Improvement Global Stakeholder Meeting, to be held in Geneva on 7–8 April.

The meeting on Primary Health Care (PHC) Improvement will engage Member States, partner organizations, international development associations, academic partners and WHO towards reaching a common agenda for PHC measurement and improvement. Stakeholder input is required to shape the concrete steps needed to advance the measurement and improvement agenda: (1) improved performance measurement (2) research and development for under-measured domains (3) performance improvement.

◊ **International Forum on Quality and Safety in Healthcare**

We are participating in the International Forum on Quality and Safety in Healthcare, to be held in Gothenburg, Sweden, 12 – 15 April. Nittita and Margaret Murphy, External Lead Advisor to the WHO PFPS programme, who is also a member of the Forum Strategic Advisory board, will work in collaboration with the Institute for Healthcare Improvement, which will be represented by PFPS advocate Helen Haskell, to deliver a workshop at the event. The workshop will be entitled ‘World Health Organization Workshop on Patient and Family Engagement’.

The session will provide perspectives from different stakeholder groups, focussing on how countries can build on WHO’s approach to engaging for patient safety, particularly on the use of patient experience ‘story’ for professional and organizational learning. The session will engage experts in the area of patients, families and the community engagement and will employ a combination of approaches to stimulate information sharing and interactive discussions for brainstorming issues, ideas and experience sharing.
Lunchtime seminar on the Launch of the Radiation Safety

The WHO PFPS in collaboration with the WHO Radiation Safety team will jointly host a ‘soft launch’ of this report on 22 April 2016 at WHO headquarters in Geneva. The aim of the lunchtime seminar is to raise awareness about this new resource among WHO staff and strengthen cross-cluster, cross-departmental collaboration. The seminar will involve a panel discussion with key experts and key stakeholders. Helen Haskell, Co-chair of the PFPS Advisory Group, will represent the PFPS Network in this event. The session will be open to all WHO staff and to the wider public through a Webinar. Please register with the link below if you would like to join us!
https://who-meeting.webex.com/who-meeting/onstage/g.php?MTID=e9bd73e8f674eaf33507f561268a14402

Sixty-Ninth World Health Assembly (WHA 69)

WHO PFPS will be involved in two events at this year’s WHA, to be held in Geneva from 23–27 May. The first will be a technical briefing on Migration and Health, the details of which are still being finalized. The second is a side-event on the “Framework on integrated people-centred health services” (IPCHS). As explained earlier in the newsletter, this framework was discussed at the 138th session of the Executive Board (EB) last January. The EB approved the resolution and recommended its adoption by the 69th World Health Assembly in May 2016. This session will include the launch of the new IPCHS web platform. More details of these two events will be published in the PFPS Summer News.

Eastern-Mediterranean Regional Meeting on Tools and Standards to Assess and Improve Quality of Care at the Primary Care Level

Nittita and Felicity, representing WHO PFPS, and Shannon Barkley representing the WHO Primary Health Care (PHC) initiative, will participate in the Eastern Mediterranean Regional Meeting on Tools and Standards to Assess and Improve Quality of Care at the Primary Care Level, in Amman, Jordan, on 30 May–1 June 2016. Nittita and Felicity will provide technical support for a workshop on capacity strengthening for health professionals, aimed at raising awareness of patient and people engagement and empowerment for patient safety, health-care quality and people-centred health services.

The team will present the WHO Framework on Patient and Family Engagement, and will facilitate the discussion of how this can be adapted to different settings in EMR. The team will present case study experiences of engagement and empowerment across the world.

Symposium at the Association of Professionals in Infection Control (APIC) Annual Conference

Jeanine Thomas, founder/president of the MRSA Survivors Network will be presenting in a symposium at the Association of Professionals in Infection Control (APIC) Annual Conference on 11 June 2016 in Charlotte, NC. She will be speaking on MRSA and C. diff prevention, patient advocacy and also her personal journey with MRSA sepsis and C. diff.

WONCA Europe Conference 2016

Felicity, representing WHO PFPS, and Shannon Barkley, representing the Services Organization and Clinical Interventions Unit, WHO Service Delivery and Safety, will participate in the WONCA Europe Conference 2016, with the theme “family doctors with heads and hearts”, to be held 15–18 June, in Copenhagen, Denmark. The team has been invited to give three presentations and run one workshop.

Felicity and Shannon will coordinate the organization of, and facilitate the workshop entitled; ‘A WHO initiative - ‘Engaging for effective communication, collaboration and partnership between health professionals and patients: A path to future consultations’. The workshop aims to engage participants in a discussion on the importance of engaging and empowering patients and health care providers in future consultations. This includes exploring practical approaches to strengthening the capacity of patients and families as well as health professionals for effective communication that promotes mutual trust and respect in consultations.

Felicity and Shannon will give three presentations. The first is entitled; ‘A World Health Organization initiative: measurements and indicators of patient, family and community engagement and empowerment’. This presentation aims to inform participants of measures and indicators of engagement and empowerment based on the perspectives of health-care users, in efforts to ensure health systems and services are responsive to their needs, values and preferences, and are improving in a way that helps people have access to quality care.

The second is entitled; “Meaningful engagement – the patient and family perspective”. This aims to explore perceptions and encourage reflection on the concept of meaningful engagement from the patient and family perspective, and the important role it plays in delivering effective primary health care.

The third is entitled; “A WHO initiative - Health literacy - a way to engage and empower patients and families”. This aims to explore ways to engage people and the community to strengthen their health literacy, as well as to identify opportunities and key challenges.
PFPS advocate (champion) feature

Brain Stafford
PFPS advocate (champion)

Figure 32: Brian Stafford

Brian Stafford is a PFPS advocate, living in Australia. In his own words:

"I am a person with a personal experience of iatrogenic harm. At a time, I was in the maelstrom of trying to find my way through the health system, I stumbled upon the free website from the Cochrane Collaboration. I use Cochrane to evaluate better treatment options. As a consequence, the medical treatment changed in line with the Cochrane report. Out of gratitude to Cochrane, I am now one of their volunteer consumers. Cochrane publishes evidence-based findings for medical and lay people as a guide to the best possible treatment.

I found, from my own experience, that a great part of the stress of the situation came from the failure by the treating medical teams to fully and properly communicate with me. This has been a major issue for me. Since becoming a PFPS Champion, I have been a member of a select committee with Qualified Privilege looking at adverse medical errors where death has often been the direct consequence. I have also been a member of a committee looking at Open Disclosure in our State Health System. This is the opposite of Qualified Privilege.

In 2013, I was invited to represent the voice of the patient at an international patient safety conference organized by ISCOME in Switzerland. I learned more that I informed others at that meeting. After the meeting concluded, four members of the general public came up to the front – these were people who had been injured by medical treatment. It was a revelation to me to appreciate that the emotional injury inflicted on people by the denial and cover-ups of medical error was often more crippling to the person than the physical injury. A similar experience of the emotional trauma to a patient of iatrogenic harm followed in a keynote address given by Sir Liam Donaldson two years later at the ISCOME 2015 international conference in Italy”.

“...I have found that we do share a common humanity and increasingly a common pool of knowledge. How that knowledge is disseminated around the world, particularly medical knowledge to inform the lay person, has to be part of the effort to empower the patient and the family making decisions around informed consent”.

We wish to congratulate Brian on all his work, and wish him the best for the future.

Figure 33: Brian Stafford (middle) with family

Future PFPS News

Share your news with us!

PFPS team: Nittita Prasopa-Plaizier, Katthyana Aparicio, Felicity Pocklington

PFPS News: Contributions for the next PFPS News are invited. The deadline for submissions is 15th June 2016.

PFPS Community of Practice: You can also continue to ask questions, share experiences and learning on the PFPS platform at: http://ezcollab.who.int/pfpskop. If you have problems accessing the CoP, please contact Katthyana Aparicio at pfps@who.int.

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


Disclaimer
The information, comments and opinions expressed in this newsletter do not necessarily reflect those of the World Health Organization, nor have the incidents described been verified by WHO. The authors of the articles take full responsibility for the content of their contribution and the opinions expressed.