Welcome!

Welcome to the latest edition of PFPS News. We have lots of good news to share with you.

During the summer period, there is often a sense of wind-down and an opportunity for some rest and recuperation. However, the passion which drives the efforts of patient advocates means that we do not always take care of ourselves. For that reason, I hope you will take the opportunity to recharge your batteries and re-commence renewed, refreshed and re-invigorated in a few weeks’ time.

While not resting on our laurels, we can certainly be very proud of recent activities of the PFPS network and our new collaborations – all adding to our self-esteem as we are invited by others to take part in their work (the IAEA invitation to contribute to nuclear medicine safety and PFPS involvement in the 5 May Clean Your Hands campaign). These are but two examples. It is a real source of joy when individual champions are affirmed and recognised (the involvement of Mohammed Albaadani in the ISQua Fellowship programme). Other significant markers are: the increase in champion numbers, the critical Duty of Candour legislation in the UK, and our involvement at the World Health Assembly in a collaborative session on medication safety. I hope you enjoy reading this edition of PFPS News.

Look inside:
- WHA Session on Patient Engagement in Medication Safety
- PFPS Workshop in Canada

PFPS collaboration with SAVE LIVES: Clean Your Hands 2013 – Patient participation!

This year, once again, 5 May has been a great success, with increased hospital registrations for Save Lives: Clean Your Hands, new countries joining and new Member States pledging to combat health care-associated infections (HAI). PFPS has been collaborating to encourage action on patient participation in hand hygiene promotion in the run-up to 5 May 2013. This year’s campaign called for health-care facilities to work with their patients, patient organizations and local communities to promote hand hygiene in the prevention of HAI.

PFPS appealed to the network of patient champions and others to take action and encourage patient participation in hand hygiene practices. Below are a few examples of PFPS champions, advocates and patient organizations responding to this call for action.

Activities to mobilize action!
- Newsletter articles and targeted emails
- New webpages and resources
- Presentations and online discussions
- Educational workshops
- Videos.

The PFPS Mexico network led by Evangelina Vasquez, has been empowering patients and families. Workshops were held in collaboration with a health facility in Mexico City to educate patients on their role in infection prevention. The workshops involved sharing personal stories of the impact of HAI, showing videos on hand hygiene and patient involvement and lots of discussion. Patients also gave their own reflections and experiences of hygiene in the hospital.

PFPS Champion Nagwa Metwally in Egypt encouraged her local hospital to take action. A

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special ceremony was held at the hospital on 8 May 2013 on hand hygiene including a presentation by Nagwa on the importance of patient education.

In Canada, PFPS Champion Barbara Farlow joined the 5 May planning committee of the Canadian Patient Safety Institute (CPSI). The Committee developed a competition for facilities to showcase innovative ideas to promote hand hygiene that involved patients and families and demonstrated improvement - ‘a unique bottom-up approach.’ The winning entry was a personalized poster reminding patients, families and staff to wash their hands. CPSI will work with the winning facility to spread the learning from this strategy, across the country. Click here to view presentations from all the finalists.

Margaret Murphy, PFPS Lead Advisor, presented in the WHO teleclass on 6 May, on the added value of patient participation, highlighting efforts by PFPS to promote hand hygiene practices. Slides and the recording are available online to those who register.

The WHO Eastern Mediterranean Regional Office collaborated with Nagwa Metwally to interview patients for the production of a video for 5 May to encourage and inform others on the importance of hand hygiene.

In the United States, PFPS Champion Jeanine Thomas and the MRSA Survivors Network has been inspiring others to engage in hand hygiene and MRSA prevention through webinars and presentations to health workers, researchers and policy analysts.

In China, IAPO member, the Beijing Association of Alzheimer’s Disease, worked in close collaboration with the local community and medical staff to organize events to mark this hand hygiene day, by holding a workshop attended by over 100 community members. Participants were briefed on hand washing techniques and the danger of HAI.

PFPS Champions from around the world gave input into development of the WHO Tips for Patients document.

According to a recent survey conducted by WHO, in 260 facilities from 41 countries, patient participation is perceived as a useful strategy contributing to hand hygiene improvement.

For more information please view the webpage or if you would like to share feedback on your activities on patient participation in hand hygiene promotion, please email pfps@who.int

Dramatic breakthrough on open disclosure in England

Peter Walsh, PFPS Champion, UK and CEO, Action against Medical Accidents (AvMA)

For many years now there have been calls in England (and elsewhere) for legally binding rules to ensure full open disclosure with patients or their families when things have gone wrong in healthcare and caused harm. The UK patients’ charity which I work for, Action against Medical Accidents (AvMA), which works for patient safety and justice, has led the campaign for what has been called a legal ‘Duty of Candour’. This had faced stern resistance from certain quarters of the health sector and some politicians. However, there has now been a dramatic breakthrough, which in my opinion represents one of if not the biggest advance ever in patients’ rights and patient safety in England. The Government has agreed to bring in a statutory duty of candour – a rule which would legally oblige every registered health-care provider in England to ensure that there is full and honest disclosure about incidents which cause serious harm.

This announcement follows the public inquiry into shocking events at Stafford Hospital in the UK. AvMA was a core participant in the inquiry, which provided us with the opportunity to advise the chairman and his inquiry team and provide substantial evidence ourselves to inform the conclusions and recommendations. The report, which was published in February, contained an unequivocal recommendation for a statutory duty of candour. The Government's initial response to the inquiry report has confirmed that it will now accept that recommendation. This represents a major u-turn in policy, recognizing
that voluntary guidance has not worked.

Why is this breakthrough so important? In my experience, health-care organizations which are prepared to tolerate unethical behaviour and incidents of avoidable harm to patients being swept under the carpet, will also be unsafe organizations, as they will not learn from error and be able to improve as a result. This was the case in Stafford, and has been recognised by patient safety luminaries such as Sir Liam Donaldson, who himself called for a legal duty of candour whilst he was Chief Medical Officer for England until two years ago. It has been my privilege to spearhead the campaign that has helped bring about this change. It has been born out of the experience of the thousands of people my charity supports each year, which shows that dishonesty after an incident causes untold further damage and distress to injured patients and their families. None more so than the family of Robbie Powell whose case became the symbol for our campaign “Robbie’s Law”.

My hope is that the example of England can be used to inspire a concerted international effort by PFPS to make open disclosure a reality around the world. No one is better placed to do this than us, and there is no greater prize than securing this for the advancement of patient safety.

For more information, please email Peter at chiefexec@avma.org.uk.

Patients for Patient Safety Canada meeting builds connections and designates PFPS Champions

Patients for Patient Safety Canada (PFPSC), a patient-led programme of the Canadian Patient Safety Institute (CPSI), held an emotional and engaging in-person meeting in March 2013 with 26 members participating. The meeting enabled members to share their perspectives about - and passion for - patient safety and reinforced that they are not alone in addressing issues in the health-care system.

The meeting goals were to build knowledge and understanding about the relationship between CPSI and PFPSC, foster stronger relationships with PFPSC members and to increase confidence as advocates for patient safety. A WHO workshop was held in conjunction with the meeting, where 11 additional PFPSC members qualified for the WHO Patients for Patient Safety (PFPS) Champion designation.

Hugh MacLeod, CEO of the Canadian Patient Safety Institute, kicked off the meeting relaying his personal experience as a patient and reinforced the important role patients and family members play in the health-care system. CPSI recognized the necessity for a strong and meaningful relationship with PFPSC.

“Hugh’s inspirational message focused on the importance of storytelling,” says Theresa Malloy-Miller, a PFPS Canada member since 2006. “He provided some great tips on how to stay focused and be clear about what you want to achieve when telling your story.”

Kim Neudorf, a PFPS Canada member since 2009, found Nittita’s presentation powerful and influential. “Nittita reinforced how the patient is the only constant, as they are present at every point in time during their care. It raised the question of, ‘How can the health-care system not involve the patient?’”

Barbara Balik, Principal of Common Fire Healthcare Consulting and Senior Faculty at the Institute of Healthcare Improvement, shared her insights about patient-centered care and safety. She referred to us as “disruptive innovators”, challenging the status quo in a positive way.

“Barbara’s inspirational message focused on the importance of storytelling,” says Theresa Malloy-Miller, a PFPS member since 2006. “She provided some great tips on how to stay focused and be clear about what you want to achieve when telling your story.”

Stephanie Newell, PFPS Australia, outlined (via video
Welcoming the new Irish PFPS Champions

Margaret Murphy, PFPS Lead Advisor, Ireland

In the current economic climate, the challenges related to holding face-to-face meetings for all groups and organizations has meant that we have all had to devise new ways to sustain our efforts and still encourage growth in numbers and quality of endeavour. Patients for Patient Safety is also impacted and consequently we have had to be more imaginative as evidenced by the first virtual workshop conducted in Canada.

The creation of the Irish PFPS group has, for me, been the fulfilment of a long-held dream. It was always important to me that champions and their work would be truly embedded in the Irish health-care system. The level of buy-in and support from our Department of Health and the Health Services Executive (HSE), the operational arm of Irish health care, at what is now an optimum time for patient engagement, should make such inclusiveness in the system a tangible reality.

The practicalities of ensuring that none of the elements of a three-day workshop would be lost, called for a mix of face-to-face gatherings and virtual input. Early in 2012 a steering group was formed – Mary Vasseghi (PFPS Champion), Orla Nugent (an educator), Tibbs Pereira and Loretta Evans (both patient advocate colleagues who have experienced harm in health care), John Crimmins (a consultant in organizational management), Greg Price, Mila Whelan (HSE Advocacy Unit), and myself.

A number of meetings were held in the Spring and Summer of 2012 to decide the communication and recruitment strategy, together with an articulation of what the work going forward would entail. Establishing and gaining support from the Department and the HSE as operational provider was important. Press releases were issued and the general public were invited to attend information evenings at three locations across the country. Presentations were made by Loretta and I. The meetings covered the PFPS philosophy of partnership and collaboration, the London Declaration and addressed any questions as well as inviting expressions of interest for attendance at the workshop.

The first full-day workshop was held on 26 January 2013. An enthusiastic group of 16 aspiring champions attended. They were both lay people and those working in health care, most of whom had a direct experience of preventable harm. Participants shared their experiences, Nittita Prasopa-Plaizier (WHO) provided an important presentation on the WHO Patient Safety Programme and how PFPS is positioned within that. Donna Davis (Co-chair of PFPS Canada) gave valuable live input (via video link) explaining the Canadian experience and took questions. Feeling better oriented to the process, group work then helped participants gain a greater understanding of PFPS, as well as discerning possibilities for their own involvement. All attendees gave very positive feedback and applied for PFPS champion designation.

A follow-up half-day meeting was held on 9 March following which the applications were approved at the next steering group meeting.

This has been ‘the easy part’. The real work now begins! The new Champions have to be provided with the opportunities to do what they do best – use their experiences as catalysts for change. We also have to ensure that they will have sufficient support to do that work to the best of their abilities. We issue a warm welcome – or as we say in Gaelic a ‘céad mile fáile’ (a hundred thousand welcomes) to the new PFPS champions in Ireland.

For more information please email pfps@who.int
Patient involvement in radiation safety

Nittita Prasopa-Plaizier, PFPS Programme Manager

Patients for Patient Safety (PFPS) was among three WHO programmes invited to participate in the "WHO - IAEA Coordination Meeting on Radiation Protection in Medicine: Areas and Mechanisms for Strengthening Cooperation". This was convened by the WHO Department of Public Health and Environment (PHE) to host the visit of a senior official from the International Atomic Energy Agency (IAEA) on 23 April. The purpose of the meeting was to discuss bilateral collaboration between WHO (represented by WHO PHE) and IAEA.

Nittita, Margaret Murphy and Liz Speakman (a volunteer working with Nittita) participated on behalf of PFPS. Margaret gave an impressive presentation, leading to discussion of potential collaboration and an eventual invitation for a patient champion to present at the Radiation Safety Standards Committee (RASSC) meeting to be held this July in Vienna, Austria.

Following the meeting, two potential collaborative projects have been identified 1) tools for communicating risks and benefits of radiation in medicine (e.g. medical imaging) for patients and health-care providers; 2) engaging patients in the promotion and dissemination of tools for the reporting and learning of adverse events related to medical imaging.

PFPS will collaborate through the coordination of Dr Maria Perez, from the WHO Department of Public Health and Environment (PHE).

For more information email pfps@who.int

WHA session on patient engagement in medication safety

Liz Speakman, PFPS and Rachel Seal-Jones, IAPO

On 23 May 2013, at the 66th World Health Assembly, a session on patient engagement in medication safety was held, hosted by the Government of Australia and the International Alliance of Patients' Organizations, in collaboration with the WHO Patient Safety Programme, through Patients for Patient Safety (PFPS).

Unsafe use of medication is a major issue in health care across the world, harming millions of patients and costing billions of dollars to health-care systems. A global, concerted effort is needed to address medication safety and it needs the involvement of all health-care stakeholders, including patients. WHO has recognised the importance of medication safety, making it the third Global Patient Safety Challenge, to be launched in 2014.

This meeting brought together global health-care stakeholders including government, civil society and patients, with a number of PFPS advocates. Key messages from the session were that:

- everyone has a role to play in achieving medication safety and through collaboration and partnership, patients can play a role in ensuring access to safe medicine;
- patient engagement can be embedded at the national, hospital and individual levels and patient input is vital to ensure any health-care improvements are patient-centered;
- patient stories are a powerful resource to contribute to raising awareness and motivating change.

The session was enthusiastically received by a packed audience and PFPS is grateful to all participants for their valuable contributions.

For more information, visit the PFPS website here.

Patients for Patient Safety News, June 2013
Announcements

African patient safety conference with HUG, Geneva
Frank Mansour Adéoty, RIPAQS and Garance Upham, Strategy Group, PFPS

RIPAQS (the International Network on Planning and Improving Quality and Safety in Health Systems in Africa) and the University Hospitals of Geneva (HUG) are organizing a special session on June 27-28 2013, ‘Africa RIPAQS-ICPIC-2013’, to promote research conducted by African teams in the areas of patient safety and risk management. The session will:

- present the work, experiences and practices of African caregivers, as well as some experiences from other continents;
- identify current challenges concerning safety in health care, paying special attention to combating hospital-acquired infections (HAI) to achieve the MDGs;
- stimulate the undertaking of prevention and control of infection and improvements in patient safety in Africa and strengthen research partnerships.

This session will bring together the focal points for patient safety in Africa - professionals, researchers and managers of public and private health sectors, NGOs and international partners - and health authorities in the Region.

RIPAQS has conducted studies on patient safety in eight African countries as part of a partnership agreement with WAHO (West African Health Organization) as part of its collaborative agreement with that organization.

For more information: garance@safereobserver.org.

Interns supporting the work of PFPS

Sehr Durrani worked with PFPS from April to June 2013 to review evidence and resources that encourage hospitals and other facilities to engage patients for patient safety improvement.

Sehr has a degree in dentistry, a post-graduate degree in oral and maxillofacial surgery and is currently pursuing an MBA in hospital administration in India.

Liz Speakman is a qualified lawyer who worked for many years as a Claimant clinical negligence solicitor in London. She also has two Masters degrees in medical ethics & law and public health.

While working with PFPS, Liz will be drafting guidance and resources for the training and orientation of PFPS Champions.

Also, a big thank you to Hannah Sainsbury who has now finished her eight month placement. She has contributed to a wide range of activities aimed at strengthening communications. Hannah will be volunteering this summer as a project evaluator in India.

Next time...If you have any news on patient engagement in patient safety that you would like to share for the next edition, please email pfps@who.int.

Patients for Patient Safety News, June 2013

ISQua Fellowship
Mohammad Albaadani, PFPS Champion, Yemen

The International society for health care in quality (ISQua) aims to inspire, promote and support continuous improvement in the safety and quality of health care worldwide. Mohammed Albaadani has joined the ISQua fellowship programme for 2013/14 in order to improve patient safety outcomes in his country. The programme enables participants to record their ongoing achievements while building points towards an ISQua Fellowship - for established practitioners who want to be recognized as experts in their field. ‘I am a Quality Officer. We have a patient safety campaign with the theme Patient safety first & always. I shared in editing the leaflet and booklet for staff regarding the International patient safety goals (IPSG):

- IPSG1: How to identify patient correctly
- IPSG2: Improve effective communication
- IPSG3: Improve safety of High Alert Medication
- IPSG4: Ensure correct site, correct procedure, correct patient safety
- IPSG5: Reduce risk of health care-associated infection
- IPSG6: Reduce the risk of patient harm resulting from falls.

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