

Patients for Patient Safety News

November 2006



Welcome!

Hello and welcome to this last edition of PFPS News for 2006. This edition continues to highlight the work being undertaken by Patients for Patient Safety Champions around the world, with news on recent events, future activities and plans for next year. In this edition 'Champion Perspectives' focuses on the WHO Africa Region with news from Zambia and Uganda. We've also had contributions from external groups who are updating us on their activities.

Please remember if you have any news you want to share about your work and activities in patient safety please get in touch with Rachel Heath the Project Manager at safety@patientsorganizations.org

Lead, Patients for Patient Safety
World Alliance for Patient Safety

CHAMPION ACTIVITIES IN-COUNTRY

Canadian Patients for Patient Safety Set Goals and Created Networks in Conjunction with Halifax 6-The Canadian Healthcare Safety Symposium

- Ryan Sidorchuck, Patients for Patient Safety Champion, PAHO

In Vancouver, BC, Canada from October 16th-19th, patients and family members from throughout Canada came together for the first "in-country" workshop to be affiliated with the Patients for Patient Safety group of the WHO's World Alliance for Patient Safety Initiative.

We had a very ambitious agenda that was modified significantly throughout the 2 ½ days of 'formal' workshop time before the group joined the CPSI pre-workshop day, "Partnering for Patient II". Our tireless leader Sue Sheridan was the keynote speaker for this event, with yours truly providing the "backup" at both the beginning and end of the day. Many of the workshop participants found this day to be the most valuable, as it brought together many of the themes discussed in the previous days in a tangible way that they could relate to, a tough task in the midst of the workshop as any one of us can attest to!

At this point in time, the Canadian champions are communicating by email and utilizing a web community provided by Mitch Dvorak of CAPS, who along with Marty Hatlie, John Tuckwell, Ed Kry (PAHO champion), Sharon Nettleton, and Carolyn Hoffman came together with yours truly to finance, plan, and deliver a workshop of patients from across Canada in a little over 2 months! We learned a lot about the process, and about ourselves in the process...friends were made, healing was seen, and a heck of a lot of work was identified as needing to be done!

In addition to the Canadian champions who attended the PAHO workshop in San Francisco in May, our total "roster" in Canada is now reflected by the following individuals: Brenda Byrd, Francine Chisholm, Barb Farlow, Darrell Horn, Sandy Koropas, Kathy Kovacs-Burns, James Kreppner, John Lewis, Alice Little, Anne L. Lyddiatt, Theresa Malloy-Miller, Ed Mendoza, Sandi Pniauskas, Kim Poppel, Deborah Prowse, Sabina Robin, and Leslie Worthington, again in addition to Susan Shallcross, Durhane Wong-Rieger and Carol Kushner, who were unable to attend the meetings in Vancouver.

Planning for our next national workshop, to be held in conjunction with "Halifax 7" in Ottawa, Ontario in October of 2007 has informally already begun, with a more focused effort to be initiated in early January. At this workshop, we hope to be able to recruit even more "new blood" from across the country towards the building of our group.

We will keep you all posted as new developments emerge.



Exciting Progress in England and Wales!

In England & Wales there is a 'patients for patient safety project which aims to develop the role of patients in patient safety work in the NHS in those countries of the United Kingdom. The project is a joint initiative between the National Patient Safety Agency (NPSA) and the independent patients' charity, Action against Medical Accidents (AvMA). AvMA has been promoting patients safety and supporting people affected by medical accidents for nearly twenty-five years. There are links to the WHO Patients for Patient Safety initiative through NPSA director Peter Mansell and patient safety champion Ian Hayes, who is on a reference group for the project. The project seeks to develop patient and public involvement in local patient safety work by:

- Facilitating a national network for patients who are involved in patient safety work with their local health services. This will provide a means of sharing experience, good practice and providing mutual support.
- Developing training and support to give patients the confidence, knowledge and skills they need to get involved in this work.
- Gathering and disseminating examples of good practice in involving patients.

The project is funded for two years by the NPSA from 1st April 2006 to 31st March 2008, and the two project managers, Louise Price and Josephine Ocloo, are based at AvMA.

The project so far:

The project was launched at a highly successful conference in May – 'The Patients Agenda for Safety and Justice'. A network of patients' organisations involved in patient safety is being formulated, and around 40 individuals have so far joined the network. This network has already been used by the Department of Health to take soundings on part of its review of patient safety arrangements.

The project has also identified four NHS organisations, at which it is planned to pilot approaches at a local level and learn from experience at the frontline. These 'pilot sites' include an acute hospital, a mental health trust, a primary care trust and an ambulance trust.

For further information contact the Project Managers **Louise Price** or **Josephine Ocloo** who are based at AvMA.

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Denmark Plans for Patient Workshop

A Patients for Patient Safety workshop in Denmark is being arranged by Danish Society for Patient Safety in collaboration with WHO World Alliance for Patient Safety, Patients for Patient Safety programme.

It will be held 13–16 April 2007. The final day is the national conference for the Society where patient involvement is this year's special theme and where the patient safety champions will contribute with their stories and statements etc.

Patient Safety Update from Colorado, USA

– Jennifer Dingman, Patients for Patient Safety Champion, USA

The Colorado Patient Safety Coalition successfully held our sixth annual Do No Harm Conference on November 10. Doug Wojcieszak was outstanding as our Keynote speaker. His message, "Sorry Works, Making the Case For Full Disclosure", got right to the heart of the issue of silence that has been in the way of learning from errors and healing for far too long. Bear in mind that this state has had tort reform for years, yet disclosure has yet to become the norm. We have high hopes that his words will be taken to heart by the Colorado healthcare industry and changes will be made in the near future. The planning committee took a giant leap of faith by addressing the issue of disclosure here and must be commended for their brave and selfless dedication to patient safety. Dr. Michael Leonard, a pioneer in our state regarding full disclosure and prevention of medical errors, also gave an excellent presentation.

A patient safety award was given to two legislators in Colorado for the first time in the history of the CPSC. A bipartisan bill was passed due to the sponsorship of Rep. Bob McCluskey (R-Fort Collins) and Sen. Moe Keller (D- Wheat Ridge). My colleague and fellow advocate Kerry O'Connell, who as a patient, suffered terribly from MRSA several years ago and has since dedicated his life to the cause of patient safety, lobbied hard for the bill.

House Bill 1045 requires the analysis and reporting of infection data by health care facilities. "The bill requires facilities to collect data on infection rates for various clinical procedures including cardiac surgery, orthopaedic surgery and certain bloodstream infections. In 2008, the Advisory Committee established by this bill will consider adding abdominal surgery and other clinical procedures." <http://www.colorado.gov/governor/press/june06/healthcare.html>

Colorado now has a new Governor, Bill Ritter. Bill is the former District Attorney of Denver, and during his tenure as DA, he had several experiences that opened his eyes to issues of patient safety and health care quality issues. He is very concerned with the uninsured of Colorado and wants to do something about that issue as well. Far too often do those who are not insured neglect their health and not seek care early on in illness and disease. Governor Elect Ritter clearly sees the big picture of our healthcare system from several points of view and has made a part of his promise to Colorado to do all that he can to improve our healthcare system. It is very unusual for an individual in a leadership position to recognize this, as it is all too common that advocates are fighting separate agendas of access, quality and patient safety.

We have great hopes that much will be accomplished in our state in the next four years to address these matters, and perhaps make Colorado the healthiest state in the USA.

CHAMPION PERSPECTIVES

Experiences in the African Region (AFR)

Cosmas Kalwambo and Robinah Kaitiritimba both attended the first Patients for Patient Safety Workshop back in November 2005. Below they share with us some of their challenges and achievements over the last year.

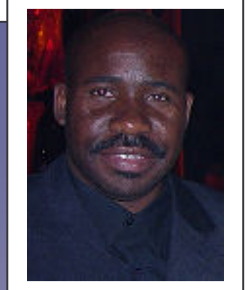
Cosmas talks about his work as a Patients for Patient Safety Champion and Robinah highlights some of the issues around patient safety facing people in Uganda.

Champion Profile – Cosmas Kalwambo (Zambia)

What did you gain from attending a 'Patients for Patient Safety' Workshop?

The workshop was an inspiration and a tribute to the work I have been engaged into

- It captured and highlighted the tragedy with accessing the healthcare system that I did not know of.
- The powerful moving footage, messages, recognition and experiences from my fellow patient's families from other parts of the world, changed my perception of Patient safety and made me realize how serious the issue was.
- Despite all the gripping images that have besieged me and that I have bared witness to I was made to feel and think about wider consequences and it summoned me into action with the others, into one common goal. I saw what could be done to reverse this trend.
- I have developed a network of colleagues with the same vision.



What did you find hard when you returned home?

I realized that the problem is actually more complex than I had known. Firstly I realized that even the minimum healthcare package is not being met in some areas. There is a complex problem of acceptance of the existing healthcare associated infections by health care workers and other stakeholders. The year 2006 has been an election year and as such any negative reports on healthcare issues have been very sensitive. Shortages include human resource due to the brain drain, logistics i.e. healthcare technology and infrastructure are not available and the HIV/AIDS pandemic has taken centre stage and is more complex than ever.

What were some of the first steps you took to bring about change after the workshop?

I sent an introductory recommendation and awareness campaign memo to the permanent secretary of our Ministry of Health and was given an audience. Since then a project proposal is on the way and is likely to be presented for funding in 2007. We have entered into dialogue with other patient organizations, professional bodies of healthcare workers and individual health workers and aim to sign a memorandum of understanding. Memos have been circulated to create an awareness, advocacy, knowledge and network with political systems, health care workers, professional bodies and other stakeholders. Few healthcare institutions have started strategies for mitigation and control of healthcare related infections, i.e. hand hygiene, sterilization of medical devices and proper waste management. Partnerships have been entered into, discussions are going on with all the stakeholders including nursing and medical schools to consider the inclusion of patient safety issues in the curriculum.

What are some of the lessons you want to share?

Patient Safety in Developing Countries requires a mixed approach with Government and NGOs. Government will always say we have no resources to provide the supplies that are required in order to meet patient safety standards. The current scenario where even the basic essential healthcare technological logistics are not available makes it difficult to discuss with stakeholders issues of patient safety. The concept of social marketing of some healthcare technology logistical supplies i.e. gloves, will improve the concept of hand hygiene and must be encouraged.

What activities have you undertaken so far?

- Created awareness, advocacy and developed a network at the Ministry of Health
- A project proposal is currently on the way.
- Due to an increased number of advocates and after attending the workshop in the UK last year a foundation has been formed called 'Patients Alliance Leading Safety and Risk Management Foundation'
- Patients rights are being dissipated and distributed to health institutions
- Patient Safety discussions during meetings and follow-ups are currently going on
- Discussions are underway with local researchers to consider carrying out a situation analysis of Patient Safety standards in Government and private health institutions with the hope of implementation of the safety recommendations
- There is a proposal for a safety Award for an outstanding health institution

What frustrations and barriers have you faced?

- The lack of support from health workers in the first instance is now fading away.
- Negative attitudes towards patient safety by all stakeholders and ignorance on the issues.
- The non-availability of resources and lack of interest.
- The lack of a reporting system for harm, foul language, physical abuse of patients, for patients and their conceived fear.
- There is a general lack of standards and principles of health management due to lack of supplies and knowledge
- The high flow of patients against very few health workers, little health care technology and infrastructure

How have you overcome difficulties and barriers?

Through Advocacy. Persuasion and campaigning on the importance and benefits of patient safety for health workers, the patient and the health care system as a whole. By knowledge, experience sharing and brain storming, examples from improvements in organizations that have satisfied patients, communication among individuals, groups and organizations.

What do you see are your next steps in your role as PFPS Champion in your region?

I see myself being part of and creating a fully developed functional local and regional patient safety network and project which will together with other regional champions in AFRO change the face of the health care industry in line with other industries i.e. aviation which have safety as their primary concern. I see myself and the future patients able to access infrastructure, health care technology and human resources, which will be safe and friendly to them.

Perspectives from UGANDA

Can you explain the general structure of the Ugandan Healthcare system?

The Ministry of Health is the overall government structure for policy formulation and monitoring. It provides overall guidelines and is responsible for providing a framework within which even the private sector operates. However, Uganda is operating under the decentralization structure (which was intended to enhance effectiveness, accountability and taking services nearer to the people). So the districts are largely independent but the centre remains with roles for supervision and regulation.

What is the overall state of Patient Safety currently in Uganda from your patient perspective?

As a member of the UN, Uganda has made considerable efforts to move towards WHO guidelines on safety. Specific efforts have gone into injection safety, the hand washing campaign, blood safety. However, very limited progress has been made to mobilize and empower patients to enable them to play their role and contribute to their own safety.

How would you describe the Doctor-patient relationship?

The doctor patient relationship has not changed much from the traditional – “doctor knows it all”. It is slowly beginning to change into a partnership and the draft patient’s charter we now have will facilitate a positive relationship with information on shared roles and responsibilities.

What current channels can patients follow to get their voices heard within the healthcare system?

Channels for patient’s voices exist in form of question boxes at health facilities and structures such as Health Unit Management Committees (HUMCs). However these are not very effective and do not to a large extent represent patient voices. My organisation, Uganda National Health Consumers Organisation (UNHCO) with support from Ugandan government and DFID is working in different health units to improve and strengthen both the question box and HUMCs.

What is the level of awareness of Patient Safety amongst the health professionals and Leaders?

Patient safety awareness for professionals, but especially for leaders, is very low indeed. This may also be because it is not streamlined and expressed as patient safety but appears generally among other issues of quality service delivery such as access and impact.

How are patients included in the healthcare system?

In the past there was no deliberate intervention to include patients. Now they are beginning to be included through structures such as the HUMCs (mentioned in no.4) but also the intention is basically to improve access rather than have the voices of patients addressed. Now as an organisation (UNHCO) we are looking into policy issues include patient concerns on almost all government committees.

What are the patient safety priorities for Uganda?

Safety priorities are safe blood (there is a national blood bank that is working to ensure safe blood), storage and transmission processes, and injection safety looking at taking advantage of technology of safer injection needles on the market and water and sanitation. Uganda with a few problems is doing well on all the three.

What are the biggest challenges to bringing about change in Uganda and making healthcare safer?

The biggest challenge is creating awareness and putting measures/and strategies in place to ensure safety. Patients/consumers need to know what safety is, what they can do to improve it, their rights and responsibilities. Health care givers need to be oriented to accepting patients as partners and share information and develop strategies together to promote safety. This approach would also solve the blame culture.



You can contact either Cosmas or Robinah directly at:

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Other Patient Safety News

News from Sufferers of Iatrogenic Neglect (SIN-UK)

- Gillian M Bean & Margaret Macrae Co-Directors & Founder Members

Sufferers of Iatrogenic Neglect (SIN) started in November 1998 to protect and promote the interests of patients who are the victims of serious medical errors. The UK has a very high standard of care, but medical errors are inevitable. Thankfully, medical mistakes are no longer a taboo subject, and health professionals are not expected to be infallible. A most welcome development is that the 'voice of the patient' is being heard.

An exciting venture has been the 'European Initiative' when SIN was invited to join several like-minded European Patient Support Groups, for the problems faced by damaged patients are similar throughout Europe. The Iatrogenic Europe Unite (IEU) Alliance was formed and the July Declaration 2005 was produced, incorporating the Aims & Objectives of SIN. This was presented to members of the Council and Parliament of Europe in March 2006. The IEU-Alliance was well received and seen as a further step towards a patient friendly Europe. A Teleconference with PFPS in September was a welcome and productive experience.

The UK government is discussing a Redress Bill that offers the opportunity for compensation to be paid without recourse to the adversarial legal process. SIN is delighted with this development because it reflects what we have advocated since our inception because patients are entitled to the truth.

We perceive there is a growing recognition of the need to register medical errors, to give open and honest disclosure, and to establish sensible compensation funds with genuine remedial care assured.

Thanks to the WHO World Alliance for Patient Safety, Patient Safety is now a global issue. Change is gathering pace.

Upcoming Events

Global

March - PATIENT SAFETY WEEK – Led by National Patient Safety Foundation, USA to promote activity around patient safety in the USA and globally.

April 18-20 2007 - The International Forum on Quality and Safety in Health Care Barcelona, Spain

Eastern Mediterranean

March 2007 – EMRO Patients for Patient Safety Workshop

Pan-America

April 30 - May 2 – World Conference on Quality and Improvement, American Society for Quality, Orlando, Florida

**“It is not the Kings and Generals
that make history, but the masses
of the people”
– Nelson Mandela.**

WHO WORLD ALLIANCE FOR PATIENT SAFETY

A Year of Cleaner and Safer Care

As a follow-up to the launch of the first Global Patient Safety Challenge "Clean Care is Safer Care" in October 2005, a one-year-on meeting was organized by the WHO World Alliance for Patient Safety on 10 November 2006. The meeting announced progress made worldwide since the launch of the Global Patient Safety Challenge.

The event aimed to:

- highlight the achievements of WHO Member States that have signed a statement committing to address health care-associated infection
- encourage more Member States to commit to addressing this problem.

A total of 22 countries representing 55% of the world's population have signed on to the Global Patient Safety Challenge since it was launched. On 10 November, 13 more countries — Australia, Belgium, Bhutan, Bulgaria, Costa Rica, Germany, Kenya, Finland, Luxembourg, Singapore, Sudan, Uganda and the United States—pledged commitment to the initiative.

The event, chaired by Sir Liam Donaldson, Chair of the World Alliance for Patient Safety, included keynote speeches by academics, WHO staff and thirteen Ministers of Health, or their representatives who presented signed statements pledging to support health care-associated infection in their countries. The high-level speakers were: Mr M. di Bartolomeo, Minister of Health, Luxembourg; Ms J. Halton, Secretary for the Department of Health and Ageing, Australia; Dr L. J. Singay, Minister of Health, Bhutan; Dr Yolande Husden, Ministry of Social Affairs, Public Health and the Environment, Belgium; Dr M. L. Avila-Agüero, Minister of Health, Costa Rica; Ms M. Caspers-Merk, Parliamentary State Secretary, Germany; Mrs C.K. Ngilu, Minister of Health, Kenya; Dr T. Botros Shokai, Federal Minister of Health, Sudan; Dr S. Mallinga, Minister of Health, Uganda.

Messages of support for the "Clean Care is Safer Care" initiative and signed statements were also presented by the Ms L. Hyssälä, Minister of Health and Social Services of Health, Finland and Dr C. Clancy, Director of the Agency for Healthcare Research and Quality, on behalf of the United States Department of Health and Human Services. In addition, Mr P. Draganov, Ambassador, Permanent Mission of the Republic of Bulgaria and Professor Chew Suok Kai, Deputy Director of Medical Services, of Singapore presented their country statements.

There were also video-links with sites in Hong Kong, SAR; Dhaka, Bangladesh; New Delhi, India; Riyadh, Saudi Arabia; Dublin, Ireland; Scotland, UK; Madrid, Spain; and Geneva, Switzerland.

For more information on the first Global Patient Safety Challenge visit: <http://www.who.int/gpsc/en/index.html>

Don't forget to visit our website at:

http://www.who.int/patientsafety/patients_for_patient