WHO Patient Safety: The impact of patients on improving the quality of care

Chair:
Nittita Prasopa-Plaizier, Patients for Patient Safety (PFPS) Programme, World Health Organization

Speakers:
Margaret Murphy, External Lead Advisor, WHO Patients for Patient Safety (PFPS) Programme
Hussain Jafri and Jolanta Bilinska, IAPO Governing Board Members and Patients for Patient Safety Champions
Peter Walsh, Chief Executive, Action Against Medical Accidents (AVMA)

@IAPOtweets  #GPC2014

www.facebook.com/internationalallianceofpatientsorganizations
Aims of session:

This session will give an overview of how WHO engage patients, communities and non-governmental organizations in improving patient safety and quality of care. The session will illustrate the role of patients in improving patient safety and quality of care globally through the World Health Organization’s Patients for Patient Safety Programme.

The panel will share their experiences and their work in advocating and driving efforts to improve patient safety and quality of care in different settings. This session will contribute to the overall theme of the Congress by making the case for patient involvement in healthcare and demonstrating the overall value of involving patients in policies and strategies to implement and expand universal health coverage.
Session Outline

• Welcome and introduction to the session
• Presentations from four speakers
• Panel discussion and Q&A
• Summary, key points and closing remarks
Engaging Patient, Family and Civil Society for People-Centered Health Services

Nittita Prasopa-Plaizier

Programme Manager, Patients for Patient Safety (PFPS)
Technical Officer, Advocacy and Civil Society Engagement
World Health Organization

6th IAPO Global Patient Congress - Better Access, better Health: A patient-centred approach to universal health coverage
Ascot, United Kingdom, 29-31 March 2014
2002, WHA 55.18: "...Urging member states to pay the closest possible attention to...patient safety..."

2004 – the 57th World Health Assembly supported the creation of the World Alliance for Patient Safety
World Alliance for Patient Safety

2004 – launched of the World Alliance for Patient Safety
2009 – Became a WHO department and renamed "WHO Patient Safety Programme"
2013 – Incorporated into a newly created "Service Delivery and Safety" Department

Patient and community engagement has been a core priority since 2004 until today
Patients for Patient Safety

Partnerships for safer care

A global network

Telling “stories” to catalyse improvements and organizational learning.
Encourage partnership, empowerment and inspire action on patient safety worldwide.

A WHO programme

Aims to incorporate the patient voice in all levels of health care.
Empowers and facilitates patients and their families to advocate for change collaboratively.
From passion to innovation: The WHO Patients for Patient Safety Programme

From 24 champions at the first workshop in London in 2005

The most recent PFPS workshop in Ecuador in 2013, has seen 300 champions in 53 countries across all WHO regions.
PFPS Global network of patient advocates in 53 countries across all WHO regions
27 PFPS workshops, 300 champions, 53 countries
Some examples: PFPS Contribution to safer and improved quality health care

Education:
Presenters/lecturers

Systems & Policy:
Member of committees

Programmes:
Advisor/ partners professionals

Research:
Researcher Co-authors

Positive health care culture
Member of hospital board

Patients and community:
Leading advocate
WHO engages with a range of partners and stakeholders to bring the patience voice to health care

<table>
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<th><strong>PFPS Network</strong></th>
<th>• Strengthen interactions, communication, advocacy</th>
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<td><strong>Policy-makers</strong></td>
<td>• Collaborate with WHO, national, international organizations</td>
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<td><strong>Academic institutions</strong></td>
<td>• Create and share knowledge through research, education and training</td>
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<td><strong>Health-care providers</strong></td>
<td>• Facilitate patient engagement at hospitals and health-care facilities</td>
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<td>• Collaborate with NGOs and professional organizations</td>
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Australian Health Care Systems – "Partnering with Consumers" as one of ten national health care quality standards

- Standard 1: Governance for Safety and Quality in Health Service Organisations
- Standard 2: Partnering with Consumers
- Standard 3: Healthcare Associated Infections
- Standard 4: Medication Safety
- Standard 5: Patient Identification and Procedure Matching
- Standard 6: Clinical Handover
- Standard 7: Blood and Blood Products
- Standard 8: Preventing and Managing Pressure Injuries
- Standard 9: Recognising and Responding to Clinical Deterioration in Acute Health Care
- Standard 10: Preventing Falls and Harm from Falls

Courtesy: Prof. Chris Baggoley
WHO's engagement with non-State Actors

Non-State actors

- Nongovernmental organizations (NGOs)
- Private sector entities
- Philanthropic foundations
- Academic institutions

Have to be managed in accordance with "WHO Policy and Operational Procedures on Management of Engagement with Non-State Actors"
WHO's engagement with non-State Actors

Types of Interaction

- Participation
- Resources
- Evidence
- Advocacy
- Technical collaboration
WHO's engagement with non-State Actors

Types of Interaction

• Participation
  • NGOs participate in WHO's meetings
  • The Secretariat participate in NGO's meetings

• Resources - Receiving/ providing fund

• Evidence – share info, experience in evidence generation activities e.g. research, scientific reviews
WHO's engagement with non-State Actors

Types of Interaction

- Advocacy
  - raise awareness of health issues
- Technical collaboration
  - product development,
  - capacity building
  - support to national policy development,
  - operational collaboration in emergencies,
  - implementation of WHO policies

WHO-IAPO collaboration on a side meeting at the WHA in 2013
WHO collaborate with the Malaysian Society for Quality in Health (MSQH)...

...and the Canadian Patient Safety Institute (CPSI) in the implementation of WHO policies on patient safety and patient and family engagement
PFPS Ireland supported by Health Services Executive

Health Services, Ireland

PFPS Canada supported by Canadian Patient Safety Institute (CPSI)

Health Canada

PFPS Malaysia supported by MSQH

Ministry of Health Malaysia
Patients for Patient Safety Champions

- **Raise** awareness of issues and **advocate** for innovative solutions
- **Tell** "story" and experience for learning and for behaviour changes
- **Partner** in setting **research** agenda and help **produce** evidence-based tools
- **Collaborate** in the implementation and **participate** in evaluation of impact
- **Share** experience and **promote** partnerships between patients and professionals
- **Strengthen** capacity and **empower** other patients
- Build bridges between patients, families, community and professionals

Only the patients' voice can tell if the policy is responsive, if the services are people-focused or if the care is patient-centred.
Patients for Patient Safety Programme

- **Empower** patients and **promote** patient leadership
- **Advocate** to bring the patient voice to health care, services and policy
- Collaborate with stakeholders and **facilitate** patient engagement
- **Provide** technical support - for local ownership and local capacity
- **Harness** contributions and **produce** evidence-based tools
- **Identify** gaps and **set** research agenda
- **Propose** innovation and **engage** in innovative solutions
- **Promote** connections and **create** partnerships among stakeholders
Connect with us

- PFPS Webinar series
- PFPS newsletters
- PFPS meetings or events

www.who.int/patientsafety/patients_for_patient/en/

Email: pfps@who.int
Patients for Patient Safety (PFPS)

Partnerships for Safer Care

A WHO approach for patient engagement
From passion to innovation: PFPS Who we are and Why we are

- PFPS – volunteer collaborative partners and co-producers of safe care
- Partnership as a key theme – patients, healthcare professionals, policy makers working together
- Patient Engagement – ‘Nothing about us Without us.
- The patient as the constant in the continuum of care with the greatest vested interest in the outcome
From passion to innovation: Motivation

- The negative experience as a catalyst for change
- Raising awareness
- Identifying shortcomings to highlight improvement areas
- Promoting open disclosure – not about blame – relates to integrity and true professionalism
- Using the past to inform the present and then influence the future, in partnership
- Empowerment of patients and families by enablers within the system
Taking account of the perspective of patients, their families and carers in planning and delivering care is…

- Central to the patient safety work of WHO
- Crucial to articulating the reality and identifying gaps in service
- Necessary to ensure services are driven by patient need and are authentically patient-centred
- A validation tool in relation to the implementation of guidelines, processes and protocols.
- Necessary to ensure the patient voice is heard
From passion to innovation: PFPS Core Values

- COLLECTIVE
- OPENNESS
- HONESTY
- COLLABORATIVE PARTNERSHIP
- MEANINGFUL ENGAGEMENT AND EMPOWERMENT
- REDUCTION IN HARM DUE TO MEDICAL ERROR i.e. SAFER OUTCOMES
PFPS is still a strong network with over 300 champions growing.
From passion to innovation: The ‘How’ of PFPS

- Providing Regional Workshops – building patient networks
- Providing Support to In-country Workshops
- Providing advocacy tools and communication support
- Guidance for holding workshops
- Producing Patient Voices videos
- Linkages with WHO Secretariat and with WHO Regional Offices
- Advancing Involvement/Engagement as a Patient Safety Solution
- Communicating expectations in relation to disclosure and learning from adverse events
- Engaging with other WHO work – e.g. Mother and Baby MCheck Tool
From passion to innovation: Champion Activities
- The Status Quo vs the Attractive Future

- Serve on patient safety commissions, task forces, committees
- Accept speaking engagements
- Act as advisers to various dedicated safety projects and research initiatives
- Engage with medical students and educators
- Partner with health providers at all levels
- Contribute to research
- Serve on Regulatory Bodies
- Connect with our country offices of WHO
- Establish our own patient safety organizations.
- Write in local or national publications and journals
- Empowerment of patients and families by system enablers
- Creating the pearl of healthcare improvement
Enablers within the System — Effective Partnerships

PFPS Ireland supported by Health Services Executive

Health Services, Ireland

PFPS Canada supported by Canadian Patient Safety Institute (CPSI)

Health Canada

PFPS Malaysia supported by MSQH

Ministry of Health Malaysia
From passion to innovation: The London Declaration

• We patients for patient safety will be the voice for all people but especially those who are now unheard. Together as partners, we ill collaborate in:

  ▪ Devising and promoting programmes for patients safety and patient empowerment
  ▪ Developing and driving a constructive dialogue with all partners concerned with patient safety
  ▪ Establishing systems for reporting and dealing with healthcare harm
  ▪ Defining best practices in dealing with harm and promoting those practices throughout the world

  e.g. IHI White Paper ‘Respectful Management of Serious Clinical Events – What’s your Crisis Management Plan?’
From passion to innovation: The Way Forward

- Building on lessons learned
- Pointing the way and removing barriers – a role for PFPS
- The importance of supporting and strategic linkages to enhance credibility
- Strategic Plan informed by grass-roots feedback and Impact Analysis findings
From passion to innovation: Themes of the Strategic Plan

- Increasing and consolidating membership
- Accelerating impact through greater collaboration with health authorities
- Expanding activities
- Reporting and Evaluation
- Resolving resource issues
- Addressing the challenge to translate aspiration to reality and the resolve to focus on the raison d’etre of healthcare – ‘the man in the bed’
From passion to innovation: 
The London Declaration

In honour of
those who have died,
those who have been left disabled,
our loved ones today,
we will strive for excellence,
so that all people receiving healthcare
are as safe as possible,
as soon as possible.
This is our pledge of partnership
We cannot change the past, but we can use that past to inform the present and in the present we can influence the future – and isn't it so much better if we do that together, in partnership?
Patients for Patient Safety Program

Jolanta Bilińska
Chair elect of IAPO,
President Patients Safety Foundation

How to involve patients?
Patients For Patient Safety Program

24 participants selected through an international call for applications from 20 countries from all six geographical regions of WHO

Achievements:
Formation of a global Patient Voice
Statement of Purpose – London Declaration
PSP Champion Activity

- Patients Organizations
- Training Courses
- Media Campaigns
- Networking
- Journal Articles
- Patient Materials

Presentations to
- Healthcare workers
- Medical Students
- Patients
- Hospital boards
- National groups
- Health Ministers

Committees
- Health quality and hospital boards
- Health ministries
- WHO expert committees
Improving Patient Safety

- Building an international network of patients and consumers
- To promote patient leadership and involvement in patient initiatives at all levels, through advocacy and open dialogue
- Develop and disseminate communication resources and tools to support the work of these networks
- Promote strong patient involvement in the program of patient safety
Patient – Doctor Communication

• To achieve concordance, patients must receive:
  • Good verbal and written information from their health professionals
  • Information should be communicated in a two-way dialogue (patients have the opportunity to ask questions, discuss their expectations and concerns)
  • Patient should assess how their treatment will fit into the way they live their lives
  • Patient should have a chance to make appropriate decisions in partnership with their health professional, but also with family,
  • Patient should receive information according to their level of language, education level, cultural background via the family doctor, medical specialist, radio, TV, internet or friends
Including Patients in the care process

- During workshops, seminars and meetings with patients, the most important issue is to encourage patients to be actively involved in their treatment.
- Teach them how to start speaking-up, how to ask about dosage of a medicine, medical results of treatment etc.
- Teach them how to read leaflets about care, medicines and top diagnosis.
- Ask caregivers how to better reach particular needs of patients.
- Promote staff collaboration across all levels. Keep communication open.
- Promote discussions between health providers, pharmacists and patients on topics such as patient education and awareness.
- Promoting various forms of motivation (education, nurse care, telephone contact, knowing about biochemical tests) in order to ensure regular taking of medication and perserverence of treatment.
- Explaining all doubts about a medication at a given moment to the patient.
Advocate, educate, raise awareness

An advocacy Toolkit for Patients’ Organizations it is the best method of work with patients and patients organizations. There are in it information about: medical error, taking medicine correctly, hospital acquired infections, the quality and safety of medicines, injection safety, the reuse of single use medical devices, maternal and child health and safety, patient participation in clinical trials, advocacy and partnership and communication.
Counterfeit and substandard medicines – are those whose ingredients and/or composition do not meet required standards. Counterfeit may affect both branded and generic medicines, prescription and over-the-counter medicines, as well as medical devices.

Counterfeit medicines are a truly global issue and pose an increasing threat to patient safety.

Counterfeit medicines are also infiltrating legitimate medicines supply chains.

Counterfeit medicines may: contain the correct ingredients but have fake packaging or labeling, contain the wrong ingredients, not contain an active ingredient, or have too little or too much active ingredient.
Challenges / Possible Next Steps

Challenges

■ Reluctance for organizations to embrace change
■ Financial support
■ Access to influential individuals and organizations
■ Political Commitment
■ Low understanding of Patient Safety
■ Capacity of Healthcare systems
■ Lack of appropriate tools and resources

Possible Next Steps

■ Develop practical tools and materials
■ Widen community engagement
■ Develop innovative approaches to communication and activities
■ Provide evidence of external impact
Tools and Resources

- Newsletters
- Films
- Posters
- IAPO Toolkit
- Information Sheets

www.who.int/patientsafety
Working together …

Communication options:

- presentation
- press releases
- key messages
- talk to friends, colleagues about personal activity within PFPS
- sharing of personal experience (bad and good practice)

At press conference in Islamabad possibilities to show methods of collaboration between patients' activists and journalists were discussed.
Methods of campaigning for patient safety

Patient advocacy:

- letters to public medical institution
- phone calls to policy makers
- meetings with patients and consumers
- meetings with influential individuals on committee meetings, conferences, events etc.
- Public advocacy: publishing articles through media, organizing press conferences, presentations at conferences
Contact us

Please visit our website to find out more:

Jolanta Bilińska
Patients Safety Foundation

Tel.: 00 48 604 51 84 74
Email: jolabilinska@hotmail.com
Website: www.patientsafety.org.pl
Open Disclosure / Duty of Candour: a new era of openness and transparency?

Peter Walsh March 2014

for patient safety and justice
WHAT IS AvMA?

- The independent UK charity for patient safety and justice
- Provides advice and support to individuals affected by a medical accident
- Works in partnership with NHS, health professionals, Gov’t departments and lawyers
- I am ceo and also a ‘patients for patient safety champion’ with the WHO
SOBERING FACTS

- FOR OVER 65 YEARS OF THE NHS A HEALTHCARE ORGANISATION HAS NOT IN BREACH OF ANY STATUTORY RULE IF IT ‘COVERS UP’ A MEDICAL ACCIDENT

- THE CURRENT SYSTEM *FROWNS UPON* BUT *TOLERATES* COVER UPS
Lack of openness & honesty results in:

- Severe emotional stress and psychological harm to the patient/family
- Failure to recognise problems and improve safety
- For staff: “carrying a monkey on your back”; possible regulatory action
- Increased likelihood of complaints and litigation
Duty of Candour ("Robbie’s Law")?
What exists internationally?

- Doctor & Nurse codes of practice in most countries
- Canada
- USA
- Australia
- Ireland
The story so far (England):

- AvMA has campaigned for Duty of Candour for decades
- Recommended in Francis report. **Gov’t agreement with statutory Duty of Candour on organisations (in the CQC standards).** However….
- Original proposals were for duty of candour on organisations to be restricted to fatal or “severe harm” cases
- Dalton/Williams review recommends all *significant* harm covered. NOW ACCEPTED!
Effect of restricting Duty of Candour

- Legitimises cover ups of everything deemed less than “severe harm”
- Puts health professionals in impossible situation – follow professional code or employer’s instructions
- Ties up staff in assessing likely level of harm rather than getting on with explaining “something went wrong”
WHAT NOW?

- CONSULTATION ON DRAFT CQC DUTY OF CANDOUR REGULATIONS NOW OPEN
  Deadline 25\textsuperscript{th} April
- Guidance from CQC to follow
- Whatever statutory provisions are made, there is nothing stopping individual organisations developing best practice. For example:
What else is AvMA pushing for?

- Include requirement to train, support & protect staff
- Include requirement to take disciplinary action or refer individuals who deliberately breach the Duty
- Adoption across UK
Practical steps to take now:

- Prepare for new CQC regulations
- Raise awareness of *Being Open* guidance
- *Train staff* *(we can help)*
- *Audit incidents, complaints and claims* *(we can help)*
- *Take disciplinary action* where appropriate
- *Regulators to take firm and consistent stance*
Biggest breakthrough in patients rights & patient safety ever?

SUPPORT

ROBBIE'S LAW
Thank you! Any questions?

CONTACT:

www.avma.org.uk
advice@avma.org.uk
Twitter: @PeterWalshAvMA
@AvMAuk
PFPS – My Experience

Hussain Jafri

PFPS Champion
Former Chair, IAPO
Secretary General, Alzheimer’s Pakistan
Situation in Pakistan

- Population 180 million
- Low literacy rate
- Human right on low priority on government’s agenda

Rush at a free medical camp for women
Situation in Pakistan

- Health Support by Public Sector 25%
  (Minimal accountability in the Public Sector)

- Health Support by Private Sector 75%
  (No accountability & monitoring by the government in the private sector)

- Quackery

- Counterfeit medicines

- Over the counter sale of medicine

Three patients to each bed
Situation in Pakistan

- Patients have no awareness about their rights
- Minimal medico legal litigations

An operation Theater
My Experience

- Working as a genetic counsellor with genetic disorders like Thalassaemia (chronic illness) in Pakistan
- Carer for my grandfather, who is suffering from Dementia
- Founded Alzheimer’s Pakistan
- Informally worked as a advocate for patients centered healthcare.
- Joined IAPO
Patients for Patient Safety Workshops (London)

- Inaugural workshop – 21 patients from 19 countries, all 6 WHO regions were represented.

- London Declaration
Dilemma

- Coming back to the real world
- Totally Lost
- What to do?
- How to do it?
Issues faced by patients advocates in Pakistan

- Recognition of Patients advocates
- Where to start – what to do
- Lack of Advocacy Skills
- Fear of victimization
Partnership

- Patients
- Government
- WHO
- Medical professionals
- NGO’s
- Media
- Lawyers
- Social workers
Pakistan Patients Safety Initiative

- A group of dedicated social workers, doctors, patients, media personnel's, lawyers and social scientists have got together in Pakistan with an aim and objective to look after patients safety in Pakistan

- The group held its first workshop in 2007 at Pakistan Medical Association House in Lahore
Objectives

- PARTNERSHIP with strong non governmental organizations, government and individuals
- Create awareness of patients rights
- Carryout patient safety initiatives
- Attain knowledge of the medico legal system so as to help patients
- Recognition of the group by the government and the civil society as champions of patients cause
Patient Workshops

- Organized Nine Workshops for Patients on Patients Centered Healthcare & Patients Safety
Patients Rights Campaign at Hospitals

- Run in collaboration with Pakistan Medical Association
- Provide awareness and training to healthcare providers on patient issues, rights, PCH, patient safety, etc
Fostering Human Resources Development - Project

Impart essential skills and training to the medical students and medical graduates to make them capable of dealing with managerial, political, socio-cultural, and public health issues in the field and professional settings.
• Need Assessment

• Curriculum Development

• Faculty Training (24 Trainers)

• Training of Medical Students & Graduates (Eight weeks course)

• Now Part of the Regular Training Program

Faculty Training Course
Patients Safety Awareness Trek

- Advocacy & Awareness
- Organized in collaboration with Patients Safety Foundation, Poland
Free Food Program at Hospital

- Government stopped providing food at hospitals.

- Started a free food program at Sir Ganga Ram Hospital, Lahore where more than 800 patients are provided free food every day.

- Enhanced our goodwill
Medical Camps

- Organize Medical Camps

Earthquake & Flood victims, Swat IDPs & Maternal health

More than 120,000 patients have been provided medical services so far
Social Mobilization on Health through Community Action Process (CAP)

- Rajanpur District
- 17 Union Councils
- Population of 676,984 people
Social Mobilization on Health through Community Action Process (CAP)

- Safe Motherhood
- Antenatal Care
- Skilled birth attendant
- Patient safety
- Hand hygiene
- Safe Medicines
- Patient Centered

- Family planning
- EPI vaccinations
- Promoting kitchen
- Breast feeding
- Infant Young Child Feeding Practices (IYCF)
- Birth registrations
Training of Master Trainers
Peer Counselor Sessions

Themes
- Safe Motherhood
- Medicine & Injection Safety
- Exclusive Breast Feeding
- Family Planning
- Child Health and Nutrition
Community Group Meetings

Mar 2013 – Feb 2014

- 5423 community group meetings
  (female groups meetings 2722 and male group meetings 2701)
Theatre & Puppet Shows
Poster and Declamation Contest

Theme
Health, Hygiene, and Immunization
Hand Washing Sessions
Advocacy with Policy Makers
International Involvement
Problems
Patient Safety Advocates

- Need to present our case with facts and figures
- No material to support our case
- From where to start
- No Plan of action
- The same problems were faced by other patients worldwide

- This is where IAPO decided to develop a patients safety toolkit for people like me to get us started in the right direction.
IAPO Patients Safety Toolkit

An Advocacy Toolkit for Patients Organizations
Objective: To Advocate, Educate & Raise Awareness

The Main Booklet provides:

- Basic information on a number of patient safety issues
  Medical errors, Taking medicines correctly, Hospital acquired infections, The quality and safety of medicines, Injection safety, The Reuse of Single-Use Medical Devices, Maternal and Child Health and Safety and Patient Participation in Clinical Trials
- General advice on how to advocate for patient safety
- Tips on communicating information to patients and with the media
PFPS

- PFPS Regional Representative for EMRO Region
- Presented for PFPS
- Assisted in the development of the WHO 7 Day Mother Baby mCheck Tool
WHO EMRO is currently developing the Patient Safety Friendly Hospital Toolkit

Have written the chapter on Patient Centeredness
Interventions at WHO

- Have been fortunate to participate in:
  - World Health Assemblies
  - WHO Executive Board
  - Regional Committee meetings
- Made several interventions on key health issues including PCH, patient safety, patient rights, counterfeit medicines, etc.
NOTHING ABOUT US, WITHOUT US

THANK YOU
Panel discussion and Q&A
Summary, key points and closing remarks
Contact Us

Please visit our website to find out more:

www.patientsorganizations.org

Tel: +44 20 7250 8280
Fax: +44 20 7250 8285
Email: info@patientsorganizations.org

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@IAPOtweets    #GPC2014
6th Global Patients Congress
Better access, better health:
A patient-centred approach to universal health coverage
29–31 March 2014 • Macdonald Berystede Hotel, Ascot, UK