Summer Training at

World Health Organization

(April 8- June 8, 2013)

Engaging Patients in Patient Safety Tools and Evidence Used by Health-Care Organizations

By
Sehr Durrani

Under the guidance of
Prof. Ashok Kaushik

Post Graduate Diploma in Hospital and Health Management
2012-2014

Institute of Health Management Research,
Jaipur
2013

INSTITUTE OF HEALTH MANAGEMENT RESEARCH
1, Prabhu Dayal Marg
Sanganer Airport, JAIPUR - 302 011, INDIA
Tel. : 3924700, 2791431-32
Fax : 91-141-3924738
E-mail : iihmr@iihmr.org
URL : http://www.iihmr.org
Gram : HEALTHINST

Certificate

This is to certify that Dr Sehr Durrani, student of Post Graduate Diploma in Hospital and Health Management (PGDHM) from Institute of Health Management Research, Jaipur Batch 17th has undergone an Internship with the Patients for Patient Safety (PFPS) of the World Health Organization Patient Safety Programme at Headquarter in Geneva between April 8 and June 8, 2013

She worked as the member of the team that has been reviewing approaches and evidence on patient engagement by health-care institutions, which is part of a bigger project that aims to promote patient empowerment and participation for safety and quality improvements.

She completed a literature search for evidence of patient engagement and the tools used by healthcare organizations and presented the summary report to colleagues at WHO. Apart from this she was involved in all the ongoing activities of the Patients for Patient Safety (PFPS) department.

I wish her success in all her future endeavors.

Dr Ashok Kaushik

Dean, Academics and Student Affairs

IIHMR Jaipur

Dr Ashok Kaushik

Dean, Academics and Student Affairs

IIHMR Jaipur

World Health Organization

20, AVENUE APPIA – CH-1211 GENEVA 27 – SWITZERLAND – TEL CENTRAL +41 22 791 2111 – FAX CENTRAL +41 22 791 3111 – WWW.WHO.INT

Tel. direct: +41 22 791 3712
Fax direct: +41 22 791 4769
E-mail : prasopaplaiziern@who.int

In reply please
refer to: PSP/PFPS/SD

Your reference:

TO WHOM IT MAY CONCERN

27 June 2013

This is to confirm that Dr Sehr Durrani from the Institution of Health Management Research, Jaipur, India, has undertaken an internship with the Patients for Patient Safety (PFPS) of the World Health Organization Patient Safety Programme at Headquarter in Geneva between 8 April and 8 June 2013. She worked directly under my supervision.

Dr Durrani worked as a member of the team that has been reviewing approaches and evidence on patient engagement by health-care institutions, which is part of a bigger project that aims to promote patient empowerment and participation for safety and quality improvements.

Dr Durrani has completed a literature search for evidence of patient engagement and the tools used by health-care organizations and presented the summary report to colleagues at WHO. Dr Durrani has shown to be diligent and committed to her work. She has been keen networker and integrated well with colleagues in the Patient Safety Programme. She collaborated with other interns and members of the staff in a considerate and constructive manner.

I hope her experience working at WHO Patient Safety will be rewarding. I wish her every success in her study and future work. I would be happy to provide additional information if requested.

Yours sincerely,

Ms Nittita Prasopa-Plaizier
Programme Manager and Technical Lead
Patients for Patient Safety Programme

Acknowledgement

To my supervisor, Dr Nittita Prasopa Plaizier, for the vision and foresight which inspired me to conceive this project. She is a remarkable, thoughtful and kind woman to whom I would like to offer my sincerest gratitude.

I am particularly indebted to my teachers and mentor, Prof. Ashok Kaushik, Prof. Santosh Kumar, Prof. Nutan P. Jain, Prof. Shilpi Mishra Sharma at the Indian Institute of Health Management Research, Jaipur for inspiring me to this work.

It is also my duty to record my thankfulness to Sir Liam Donaldson, Dr Edward Kelley, Dr Itziar Larizgoitia ,Dr Shams Syed , Anna Lee, Elizabeth Speakman , Armorel Duncan and Sorin from whom I had been inspiring and helping me in undertaking this project.

To my mother for the unwavering love, faith and continued support and reassurance over the years .

By extension I'd like to offer my thanks to all the staff of the Patients for Patient Safety at the World Health Organization.

And finally thanks to all my friends who have offered tremendous support and encouragement throughout my project.

With warm regards,

Dr. Sehr Durrani

Table of Contents:

Introduction

I started my internship on April 8th, 2013 at World Health Organization at Geneva. On my first day I was issued the WHO ID card. I had my meeting with the supervisor on that day itself. We chatted for a while and then she gave me the presentation on Patients for Patient Safety which I found very interesting and challenging. One of the most remarkable features of the patient safety movement is the lack of attention paid to the patient's perspective. Recognizing the importance of the patients' perspective, The World Health Organization (WHO) has designated 'Patients for Patient Safety' as one of the six action areas of the World Alliance for Patient Safety. The other action areas are Reporting and Learning; Taxonomy; Solutions; Research; and Global Patient Safety Challenge.

During the first week of my Internship I was told to read about the Organization and in particularly about the Patients for Patient Safety programme which I found very interesting.

It is a programme that brings together patients, providers, policy-makers and those effected by harm, who are dedicated to improving health-care safety through advocacy, collaboration and partnership. Millions of patients around the world are suffering every year due to preventable harm in health care and PFPS believes that safety will be improved if patients are placed at the centre of care and included as full partners.

From the second week onwards I started working on my project which was literature review on engaging patients in patient safety and what are the tools and evidence used by the health care organizations. This led to the formulation of a research question which guided the study: What are the evidences and resources in developed and developing countries that encourage hospitals and healthcare facilities to engage patients for patient safety improvement?

I started searching Pubmed and Cochrane together with the grey literature and stored the references via End note library. End Note library is a tool for publishing and managing bibliographies, citations and references on the Windows and Macintosh desktop for which I got the training from the Library during my library orientation which I participated in during the initial days. I was given a separate office for conducting the literature review on my project. At the same I was assisting my supervisor in all the on-going activities of the Patients for Patients safety department.

Advantages of Endnote

- Create a specialized library in your field;
- Produce reference lists for articles, reports, CVs, etc. in over 5,000 bibliographic styles using Word;
- Generate bibliographies in theses and dissertations using Word;
- Import references from major bibliographic databases;
- Import references for a BibTex file;
- Link references to full-text documents or to document retrieval services;
- Manage your personal book collection;
- Mac and PC compatible;
- Share data with colleagues;
- Create your Endnote Web library in MyEndNoteWeb.com

A Brief Overview of World Health Organization:

The World Health Organization (WHO**)** is a specialized agency of the United Nations (UN) that is concerned with international public health. It was established on 7 April 1948, with headquarters in Geneva, Switzerland, and is a member of the United Nations Development Group. Since its creation, WHO has been responsible for playing a leading role in the eradication of smallpox .Its current priorities include communicable diseases, in particular, HIV/AIDS, malaria and tuberculosis; the mitigation of the effects of non-communicable diseases; sexual and reproductive health, development, and aging; nutrition, food security and healthy eating; occupational health; substance abuse; and drive the development of reporting, publications, and networking. WHO is responsible for the *World Health Report*, a leading international publication on health, the worldwide World Health Survey, and World Health Day (7th- April of every Year)

More than 8000 people from more than 150 countries work for the Organization in 150 WHO offices in countries, territories and areas, six regional offices and at the headquarters in Geneva, Switzerland.

In addition to medical doctors, public health specialists, scientists and epidemiologists, WHO staff include people trained to manage administrative, financial, and information systems, as well as experts in the fields of health statistics, economics and emergency relief.

The WHO' s Constitution states that its objective “is the attainment by all peoples of the highest possible level of health**". [103]**

WHO currently defines its role in public health as follows **[104]:**

- Providing leadership on matters critical to health and engaging in partnerships where joint action is needed;
- shaping the research agenda and stimulating the generation, translation and dissemination of valuable knowledge;
- setting norms and standards and promoting and monitoring their implementation;
- articulating ethical and evidence-based policy options;
- providing technical support, catalyzing change, and building sustainable institutional capacity; and
- Monitoring the health situation and assessing health trends.

Its first major accomplishment was the eradication of smallpox, long considered the most deadly and persistent human infectious disease. Smallpox had caused millions of deaths and much suffering for centuries, but once the agency set out to eradicate it, WHO personnel traveled the world to conduct a massive vaccination program. And as a result, smallpox was eliminated in 1977. Since then, the WHO has turned its attention to other diseases such as polio and leprosy, which are now on the verge of eradication as well.

WHO Regional Offices

Region	Headquarters	Notes
Africa	Brazzaville, Republic of Congo	AFRO includes most of Africa, with the exception of Egypt, Sudan, South Sudan, Tunisia, Libya, Somalia and Morocco (all fall under EMRO).
Europe	Copenhagen, Denmark.	EURO includes most of Europe and Israel.
South-East Asia	New Delhi, India	North Korea is served by SEARO.

Eastern Mediterranean	Cairo, Egypt	Eastern Mediterranean Regional office includes the countries of Africa that are not included in AFRO, as well as the countries of the Middle East, except for Israel. Pakistan is served by EMRO.
Western Pacific	Manila, Philippines.	WPRO covers all the Asian countries not served by SEARO and EMRO, and all the countries in Oceania. South Korea is served by WPRO.
The Americas	Washington D.C., USA.	Also known as the Pan American Health Organization (PAHO), and covers the Americas

WHO Member States

Territories which are not responsible for the conduct of their international relations may be admitted as Associate Members upon application made on their behalf by the Member or other authority responsible for their international relations. Members of WHO are grouped according to regional distribution (194 Member States) [Appendix 1].

The Training:

1-Attended the WHO Library Orientation Programme

2-Attended the WHO Intern Induction Programme:

This session was designed to give the WHO interns an overview of the organization - how it is structured locally and globally within the UN system, where the funds come from and how they are spent.

Activities at WHO Headquarters

- Info Evidence Research (e health)
- HIV TB Neglected Diseases(Stop TB, Roll back Malaria, HIV)
- Family(Ageing, Gender-women, Pregnancy, Newborn, Maternal and Child Health, Child and Adolescent development, Reproduction ,Vaccines)

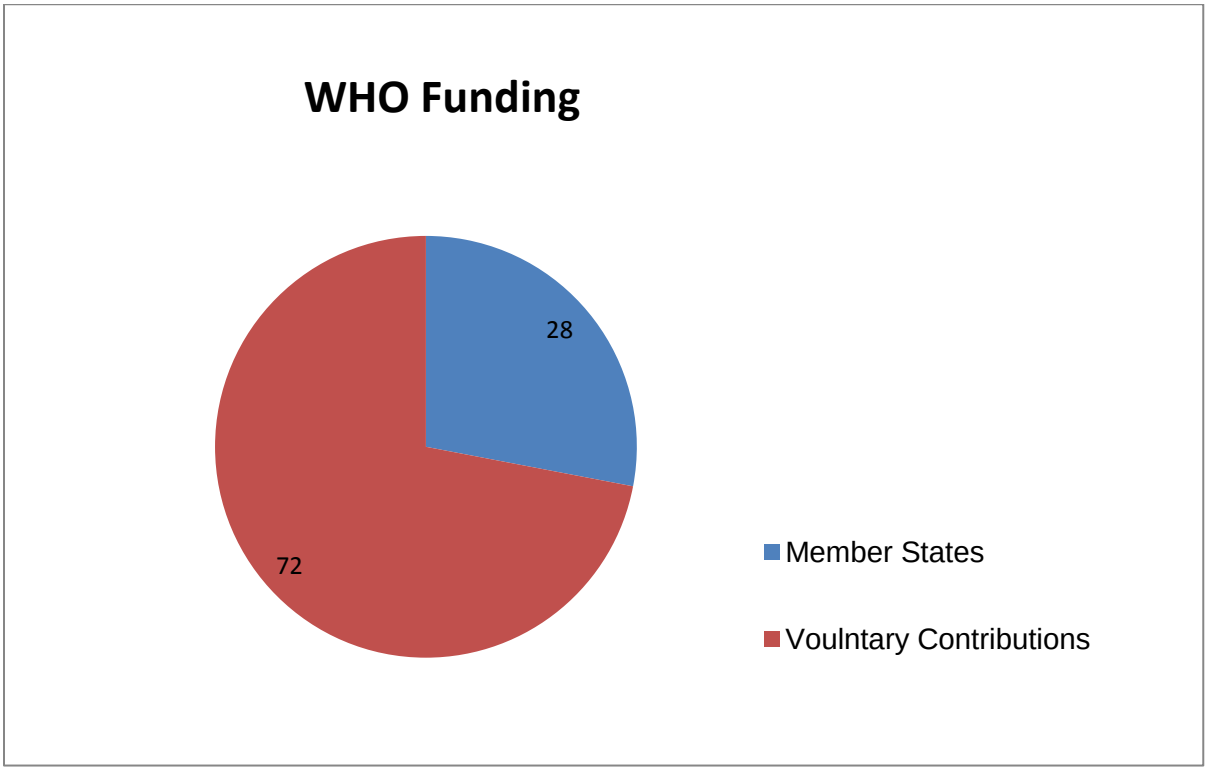
- Health Action in Crisis(Emergency, Policies)
- Health Secure Environment(Pandemics, Flu, Food, Chemicals)
- Health System Services(Health Policies)
- Non Communicable Diseases(Chronic, Mental, Nutrition, Injuries and Violence)

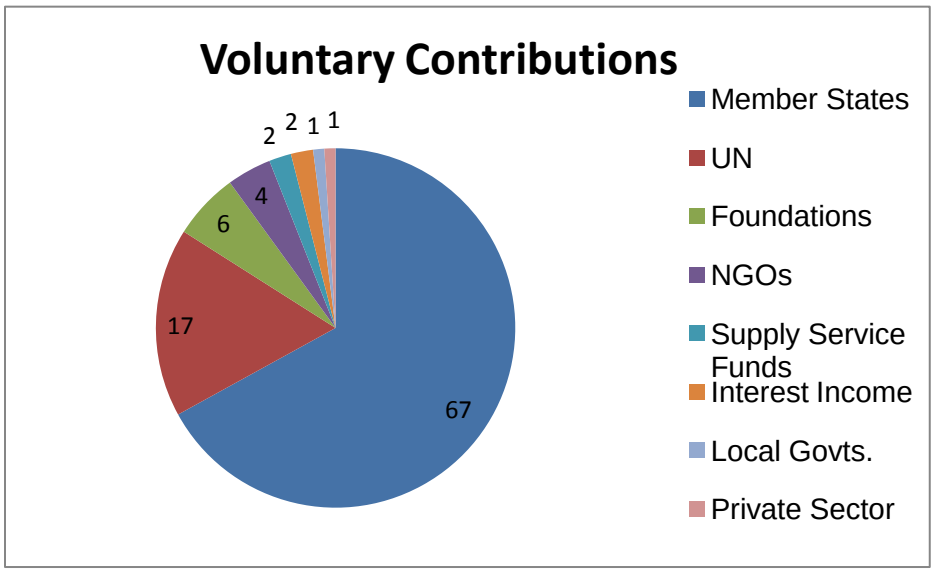
Source: WHO Intern Induction Programme

Work with other Organizations:

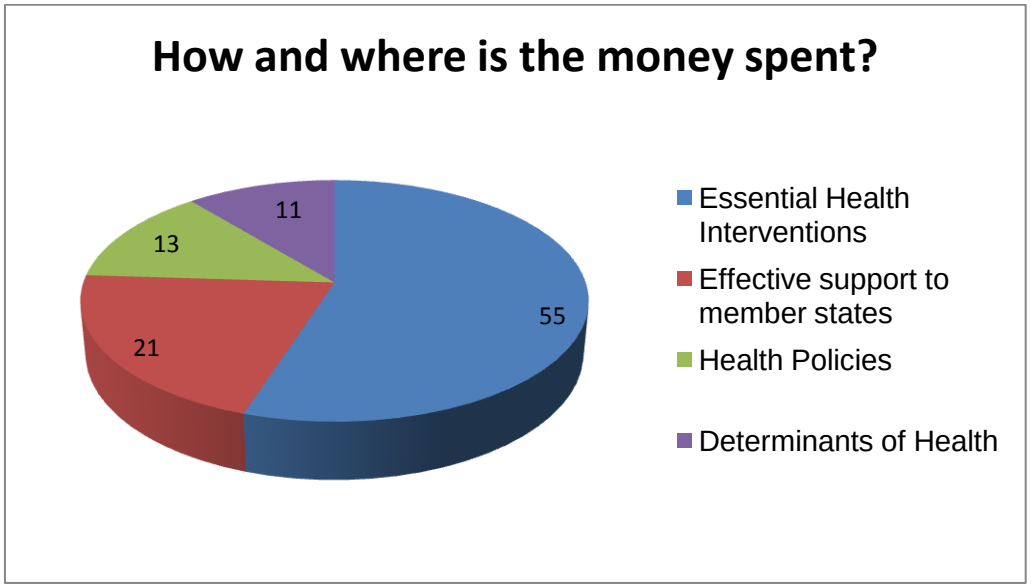
- UNAIDS, the Joint United Nations Programme on HIV/AIDS,UNITAID,raises money through innovative financing to shape markets for HIV/AIDS, tuberculosis and malaria in low-income countries,UNICEF(United Nations International Children's Emergency Fund)
- Global Health Initiatives: GAVI(Global Alliance for Vaccines and Immunisation) , Global Fund
- NGOs

Source: WHO Intern Induction Programme

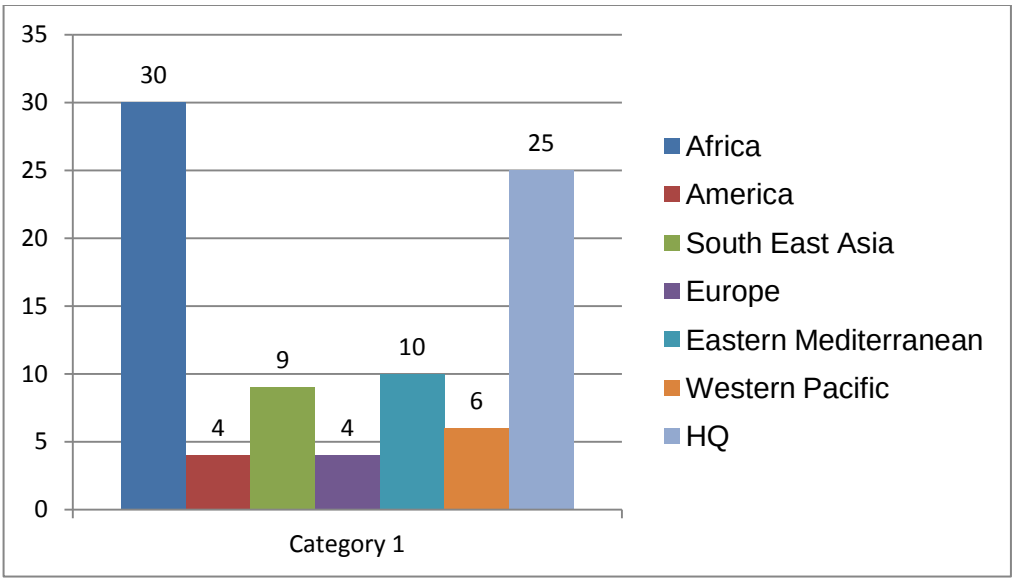




Source: WHO Intern Induction programme



Source: WHO Intern Induction Programme



Source: Budget 2007, WHO Intern Induction Programme

1- Attended the meeting with Sir Liam Donaldson and other PFPS members on Universal Health Coverage.

"Universal healthcare" or "universal coverage" refers to a scenario where everyone is covered for basic healthcare services, and no one is denied care as long as they are legal residents in the geography covered. WHO is providing support to countries to develop their health financing systems to move towards, and to sustain, universal health coverage.

2- Attended the meeting with Sir Liam Donaldson and other PFPS members on medication safety.

Recognizing that adverse drug events and medication errors cause significant health and economic repercussions both in developed and developing countries, the WHO Patient Safety Programme will launch in 2014 the *Third Global Patient Safety Challenge*, focusing on medication safety.

3- Webinar on Patient Safety Surgical Check list on May 8, 2013.

Dr Itziar Larizgoitia from Patient Safety Programme opened the session with a brief introduction of the outline of the seminar.

Dr Severin Von Xylander from the Department of Maternal, Newborn, Child and Adolescent

Health gave an overview of the major causes of maternal and child death. He then presented the background to the development of the Safe Childbirth Checklist and reviewed the items of the Checklist. The results of the pilot field test in one site in India were briefly presented and the next steps in the programme were highlighted. Harvard School of Public Health is currently conducting a randomized controlled clinical trial (Better Birth Trial) in 120 hospitals in Uttar Pradesh in India, with the strategic advice of WHO.

4- Webinar with Anna Lee at London about patient stories library project on April 10,2013
5- Met Margaret Murphy, one of the patient champions on her three days visit at the PFPS department
6- Attended the lunch time seminars on topics" Child Abuse Victimization in South Africa", Is law an essential part of public health practice?, Health care delivery and medicines donations after disaster in 2011 (tsunami/earthquake) in Japan.
7- Attended the department lunch time seminar African Partnerships for Patient Safety (APPS): It is a WHO Patient Safety Programme building sustainable patient safety partnerships between hospitals in countries of the WHO African Region and hospitals in other regions.
8- Participated in all the meetings held in advance for the WHA session on Patient engagement in medication safety.

11- Assisted in all the activities related to the WHA event on Patient engagement in medication safety. Contributed the photos for the newsletter.

12- Webinar with the Patient Champions: about the patient safety and quality from the perspective of the patients. How are patients becoming engaged in healthcare?

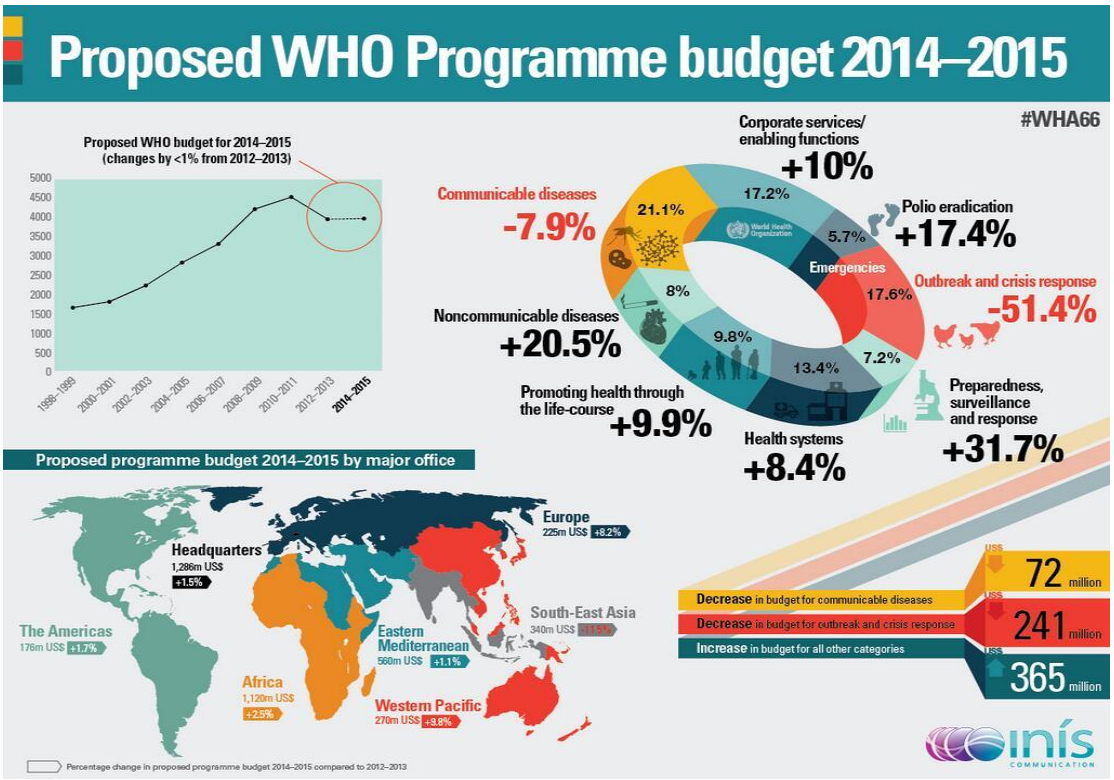
13- Successfully completed the literature review and presented the findings to the PFPS department on June 6

Sessions attended at WHA assembly May 20, 2013:

1. Opening of the health assembly May 20, 9:30
2. Address by Dr Margaret Chan, Director General Assembly hall May 20 14:30

3. Addressing violence against women: health impacts and the role of the health sector.Organizaed by the delegations of Belgium, India, the United States of America, Zambia, Mexico, Norway and the Netherlands. May 21 7:45-8:45
4. WHO reform, Programme and budget matters May 21 9:00
5. Technical briefings: Aligning for better results:IHP May 21 12:30-14:15 Room 12
6. Patient engagement in medication safety. Organized by the delegation of Australia and the International Alliance of Patient's Organizations. May 23 12:30-14:00
7. Promoting access to medical technologies and innovation-intersections between public health, intellectual property and trade May 23, 18:00-19:30
8. Maternal and child health: Millennium Development Goals and beyond. Organized by the delegation of Bangladesh. May 24 12:30-14:00
9. Ethical challenges of patients with chronic diseases and access to health systems. Organized by the delegation of Chile May 27 12:30-14:00

WHA Programme Budget 2014-2015



Source: 2013, WHA intranet

The budget was proposed to slash funding for communicable diseases and emergency response. In fact all items under “communicable diseases” will be cut, especially tuberculosis and tropical disease research, which will be reduced by 10.9 percent and 52.4 percent, respectively. In contrast, no communicable diseases will be boosted up to $318 million for the next two years, up from $264 million in 2012-2013.

Patient engagement in medication safety. Organized by the delegation of Australia and the International Alliance of Patient’s Organizations WHA May 23, 2013 [Appendix 7]

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 PFPS). Unsafe use of medication is a major issue in health care across the globe, 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. This meeting brought together global health-care stakeholders including a number of PFPS advocates. The session raised awareness about the

importance of patient engagement and empowerment in improving medication safety and to serve as a call to action to promote patient and family engagement in this area.

Patients for Patient Safety projects:

- **Save Lives: Clean your Hands:** PFPS collaborates with colleagues in the WHO Patient Safety Programme to promote patient participation in improving hand hygiene practices worldwide. This campaign is a flagship activity of the WHO's first Global Safety Challenge-Clean Care is Safer Care
- **WHO Mother –Baby 7 day m check tool:** A tool aimed at empowering mothers and families to identify danger signs in mother and baby during the first seven days after birth so that they can seek appropriate health care.
- **PFPS Patient Training Guide:** For the training and orientation of individuals wishing to join the Patients for Patient Safety network
- **Patient Engagement guide for Hospitals:** Review of ways in which hospitals can engage patients and their families in patient safety improvements
- **Patient Experience Library:** Patients for Patient Safety compiles patient stories' and experiences to illustrate the ways in which patients use their experiences to catalyze improvements in patient safety.

The Two Patient Safety Global Challenges:

First Global Patient Safety Challenge

The goal of Clean Care is Safer Care is to ensure that infection control is acknowledged universally as a solid and essential basis towards patient safety and supports the reduction of health care-associated infections and their consequences. Clean Your Hands annual global campaign was launched in 2009 and is a natural extension of the WHO First Global Patient Safety Challenge

Second Global Patient Safety Challenge

The goal of the Safe Surgery Saves Lives Challenge is to improve the safety of surgical care around the world by ensuring adherence to proven standards of care in all countries. The WHO Surgical Safety Checklist has improved compliance with standards and decreased complications from surgery in eight pilot hospitals where it was evaluated. [Appendix 8]

Specific Project: Literature review

Background

The WHO PFPS (Patients for Patients safety) is a program promoting patient engagement which was launched in October 2004 as the World Alliance for Patient Safety with Professor Sir Liam Donaldson as its founding chair. In 2009, it was renamed as WHO Patient Safety Programme with Sir Liam Donaldson taking on the role of the WHO envoy in 2011.The objective of the program is to create awareness regarding how patients can act as partners in improving healthcare services. PFPS is one of the key areas of patient safety which recognizes patient engagement as a crucial factor in improving healthcare services .The WHO puts emphasis on patient voice in the form of stories to disseminate information to the others in a way of improving health care services .These stories are conveyed by " Patient champions" many of whom have experienced unsafe medical care and are willing to share their stories with others so that can lead to the improvement of healthcare services .Since 2007 it has achieved tremendous support from different healthcare stake holders from around the world. There are currently 250 champions from 52 countries. Some of them are active in advocating ,sharing their stories at various hospitals, conferences, webinars, students groups, academic institutions .The PFPS priorities for 2012-2015 are the PFPS network ,working with the policy makers, academic Institutions, healthcare providers and civil societies.

Objective:

The aim of the project is to review the literature on the efforts of healthcare organizations to engage patients or their families in promoting service improvements. This would help contribute to patient engagement resource project at WHO.

Methodology

Literature Review:

1- Database search for English language reviews and reports

1.1-Pubmed

1.2- Cochrane

2-Databases of reports, grey literature, e.g. Dissertation Abstracts, conferences

3-Patient safety organizations, e.g. National Patient Safety Agency, National Patient Safety Foundation.

4- Agency for Healthcare Research and Quality (AHRQ), US

5- Patient Centered Outcome Research Institute (PCORI), US

6- National Health Services (NHS), UK

Data	Keywords	Results
Pubmed	**Patient engagement**	**109**
	Patient involvement	**947**
	Patient participation	**547**
	Patient engagement, patient safety	**10**
	Patient engagement, medication	**1**
	Patient engagement, treatment	**11**
	Patient participation, patient safety	**8**
	Patient participation, medication	**2**
	Patient participation, treatment	**36**
	Patient involvement, safety	**19**
	Patient involvement, medication	**2**
	Patient involvement, treatment	**37**
Cochrane	**Patient engagement**	**16**
	Patient involvement	**135**

Results – 102 references were selected

Grey Literature

Agency for Healthcare Research, AHRQ

Patient-Centered Outcome Research Institute, PCORI

National Health Service, NHS

Inclusion Criteria	English Language	2002-2013

The Key Findings: The definitions of Patient Engagement

Barello et al identified 10 patient engagement definitions in literature 2002-2012. [1] These can be further categorized as:

1- Compliance related
2- Self-management
3- Better health outcomes
4- Cost effectiveness
5- Patient-centered
6- Shared decision making in health policy

Ten most cited publications from 2002 to 2012 by Barello et al [1]:

Number of citations	Authors	Title	Year	Source	Discipline	Definition of patient engagement	Categories
188	Lehmann et al.	Assessing organizational readiness for change	2002	Journal of substance abuse treatment	Medicine	Engagement as actions individuals perform in terms of adherence to drug prescription and a key component for high-quality healthcare services .	**1**
120	Simpson	A conceptual framework for drug treatment process and outcomes	2004	Journal of substance abuse treatment	Medicine	Engagement as a factor which enables patient alliance with clinicians and enhance recovery experience	**1**
119	Davis et al	A 2020 vision of patient-centered primary care	2005	Journal of General Internal Medicine	Medicine	Engagement as a key component to foster patient-centered medical approach	**5**
73	Hibbard et al.	Do increases in patient activation result in improved self-management behaviors?	2007	Health Services Research	Nursing/ social science	Engagement as a behavioral activation related to healthy behaviours and positive health outcomes	**3**
49	Roy-Byrne and Wagner	Primary care perspectives on generalized anxiety disorder	2004	Journal of Clinical Psychiatry	Medicine /psychology	Engagement as a crucial elements in health policy making to deliver effective and high-quality healthcare interventions	**6**

42	Casale et al.	ProvenCareSM: A provider-driven pay-for-performance program for acute episodic cardiac surgical care	2007	Annals of Surgery	Medicine	Engagement as behavioral activation that contributes to reduce resource abuse and improve health outcomes	**3**
41	Trotti et al	Patient-reported outcomes and the evolution of adverse event reporting in oncology	2007	Journal of Clinical Oncology	Medicine	Engagement as a measurable marker of patients' compliance to therapies and symptoms' management	**1**
32	Franklin et al.	Patients' engagement with "Sweet Talk"—a text messaging support system for young people with diabetes	2008	Journal of Medical Internet Research	Medicine	Engagement as a cognitive, behavioral, emotional, and social construct which foster patient's self-management	**2**
31	McCracken	Social context and acceptance of chronic pain: the role of solicitous and punishing responses	2005	Pain	Medicine /Psychology	Engagement as a behavioral activation useful to better control and manage illness symptoms and emotional-related alterations	**2**
30	Villagra	Strategies to control costs and quality: a focus on outcomes research for disease management	2004	Medical Care	Nursing/ Social Science	Engagement as a measurable marker of clinical results and organizational factor which contributes to reduce healthcare costs	**4**

Grey Literature

Agency for Healthcare Research and Quality (AHRQ)

AHRQ is one of the 12 agencies in the United States department of health and human services.

AHRQ defines patient engagement as "set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations." [2]

The enabling patient centered care through health IT is a AHRQ grant program and was launched in 2007.AHRQ puts emphasis on patient engagement and has conducted an environmental scan about the current literature, resources and tools available to engage patients for patient safety improvement. Based on the report, AHRQ has made a draft guideline that is undergoing pilot testing at three hospitals. The final guideline is expected to come out in mid may 2013.

"AHRQ uses two broad types of patient engagement strategies: [2]

Hospital-level strategies

The hospital-level strategies are grouped into four main categories:

Engaging patients and families as members of their care team.

- Bedside Rounds: The patients feel comfortable with the presence of the family member during the ward rounds. Also, the information can be provided by the member if in case the patient doesn't remember.
- Bedside change of shift reports: The nurse handovers the report to the next nurse in front of the patient and the family member instead at the nurses' station.
- Patient family-activated rapid response teams*.* Rapid Response Teams (RRTs).RRTs bring critical care expertise to the bedside (or wherever care is needed) to address the effects of early warning signs of health trauma affecting a patient. The patient is given access to an internal helpline number if his/her condition deteriorates and the current healthcare team is not responsive. This is known as The Condition H (Condition Help) program at the University of Pittsburgh Medical Center (UPMC) which provides an example of how RRTs have been implemented to encourage patient and family

engagement. The Condition H team comprises of an administrative nursing coordinator a physician, unit nursing staff, and a patient relations coordinator.

- Access to medical records by patients and families**.** Several hospitals have implemented strategies to allow patients and families to access medical records or online portals for information. For example, The Children's Hospital of Philadelphia provides patients with online access to shared care plans, allowing patients to collect information about providers and medicines in one place that they can share with their physicians. As another example, Plane tree hospitals have an open chart policy that allows patients to read and write in their medical records.

Other strategies in engaging patients:

One strategy is about the use of whiteboards in each patient's room to convey and share information among patients, family members, and members of the care team. In one study, nursing staff used whiteboards in each patient's room to help patients and family members identify who did what among nursing staff, including names, roles, and education level. Family members used whiteboards to enter their own phone numbers and leave messages for nursing staff about the patient's needs. Post-implementation evaluation results demonstrated positive increases in patients' ratings of nurses' promptness in responding to call light requests, making periodic checks without a request, and the positive manner of nursing care provided. Other strategies include providing written materials or posting information for patients and family members about staff names, telephone numbers, and other information about the hospital (such as visiting times, meal times, round times). For example, one hospital developed a "deck" of staff name cards, bound with binder rings, that was hung in the patient's room. Another hospital developed a business card to give to patients and relatives with information about the patient's location."

"**Involving Patients and Family Members at the Hospital Level**

These strategies include establishing patient and family advisory councils, introducing other opportunities for patients and families to be involved, and eliciting patient and family feedback. It is important to note that hospitals may adopt different models for the use of PFACs. At some institutions, PFACs have the authority to participate in the decision making process, which reflects a higher level of patient engagement. At others, the PFAC has the authority to collect information, provide input and feedback, and make recommendations to leadership. However,

the authority to make decisions remains in the control of leadership. Patients and family members also may participate on such committees as patient safety, patient and family education, or customer service and satisfaction. Patients and family members may also participate in safety rounds or "on the spot" satisfaction surveys, where patient volunteers can interview other patients and families about their concerns."

Eliciting patient and family member feedback. Eliciting feedback from patients and families is another hospital-level strategy to ensure that patient perspectives are incorporated into hospital policy and procedures. As noted in our discussion of organizational context above, patient satisfaction surveys such as HCAHPS can be important motivators for change at an organizational level and can also provide the opportunity for patients and family members to contribute feedback at the organizational level.

Individual-Level Strategies and Tools

As described earlier, individual-level interventions target changes in individuals' (patients, families, providers, leadership) knowledge, attitudes, or skills." [2]

Frameworks

An outline which supports a particular approach to a specific objective and also serves as a guide that can be modified as required by adding or deleting items.

National e Health Collaborative (NeHC framework) US, 2008 [Appendix 2]:

On November 19 via a webinar presentation, NeHC releases its patient engagement framework for the healthcare organizations looking for the information needed to engage patients. This framework advocates the use of e health tools and resources in patient engagement. [3]

It is divided into 5 stages:

Inform me: This is the 1st stage of the framework. The healthcare provider provides the patient with the all necessary information related to the condition in both the printable and electronic formats.

Engage me: The patients start using various e health applications such as EHRs (electronic health records) and PHRs (personal health records).

Empower me : At this stage, there is substantive use of health IT for communication purposes and health information exchange. For example there is secure messaging system between the provider and the patient.

Partner with me : At this stage there is a partnership relation between the provider and the patient. For example the provider provides the patient with the management tools such as home monitoring devices. The patient keeps the provider informed via e portal.

Support my e community:

Patients and providers at this stage are fully versed with the IT health resources. The patients are supported by the providers via online community support groups. There are opportunities for e-visits and cost comparisons. It is typical of a patient-centered care home model.

Limitations:

The framework might not work in developing countries where the concept of m health is still new. However the market is booming with the IT health these days everywhere and there is a capacity of scope for innovation in both the developing and developed countries.

PCPCC Patient engagement framework, US, 2006 [Appendix 3]

" The Patient-Centered Primary Care Collaborative (PCPCC) is a coalition of more than 1,000 organizations and individuals — employers, consumer and patient/family advocacy groups, patient quality organizations, health plans, labor unions, hospitals, physicians and other health professionals — that works to develop and advance an effective and efficient health system built on a strong foundation of primary care and the patient-centered medical home (PCMH) model, an approach to providing comprehensive care for children, youth, and adults." [4]

Funding Organizations:

Gordon and Betty Moore Foundation's Patient Care Program. [5]

Half a billion project aimed for the patient safety. The patient care program seeks to eliminate all preventable harms to patients. The program would initially focus on acute care settings and ICUs.

The program's first major grant of $8.9 million was for Johns Hopkins Medicine's Armstrong Institute for Patient Safety and Quality.

This Program means to harness the power of health information technology and

decision support to provide timely information to those who need it.

Robert wood Johnson Foundation: [6]

Based in Princeton, New Jersey is one of the largest US philanthropy organizations. The foundation's mission is to improve the health and health care of all Americans.

Funded through a $ 1.4 million grant from the Robert wood Johnson Foundation, Open notes Project got started this year. *Open Notes acts as an initiative to encourage doctors, nurses, and other clinicians to share their notes with patients as a way to improve health and health care. Clinicians can provide patients with access to visit notes electronically or in printable formats. According to the result of the pilot study of the project, Open Notes made the patients feel more in control of their care and helped them adhere to their medication regimens*.[7]

Various engagement tools [Source- National health service NHS UK, 8-25]

Providing Information

- Health education materials
- Leaflets
- Newsletters
- Email bulletins
- Display boards/exhibitions
- Texting
- Blogs
- Website-Frequently asked questions
- Webinars
- Podcasts/DVD
- Websites and social media
- Mass media campaigns

Receiving Information

- Surveys
- Patient advisory committees
- Questionnaire
- Comments cards
- Polling
- Telephone responses
- Electronic responses
- Email responses
- Video diaries
- Online consultations
- Suggestion boxes
- Comment slips

Patient stories/Journey mapping/Patient testimonials/Patient diaries [26-28]:

Patient stories are about patients who become patient safety advocates. They share their experiences of unsafe healthcare with other patients and healthcare organizations so that they can come up with better healthcare services.

The Aliki Initiative at Johns Hopkins Bay view Medical Center-a novel program [29]

It's a novel programme included in the curriculum of residents, interns and medical students. The programme is focused on patient-centered care where the residents engage the patients by friendly talk and making them feel at home. Sometimes they also make home visits as and when needed. And they call the patients on a regular basis once they get discharged for medication, post-discharge and follow up reminders.

E Health tools

Irody's MyPillSense, US, 2012 [30] [Appendix 4]: It enables patients to take better care of themselves, and the caregivers know in real time what, when and where a medication is taken.

- The pills are scanned by the person dispensing the medicines with a smart phone camera.
- The image is stored by MyPillSense with the time and location.
- Irody's algorithms recognize the medicine and compare it with the patient's scheduled medicines.
- If the medicine does not match with the patient's regimen, MyPillSense gives a warning.
- MyPillSense sends a copy of the pill consumed to the caregiver for their information.
- If a medicine was not taken as schedule, MyPillSense sends an alert to the patient or caregiver.

They are working in partnership with patient organizations, pharmaceutical companies and clinical research.

Ubitru, US, 2012 [3] [1] [Appendix 5]

A product from UbiCare sends patients quick text messages and emails reminding them of care updates.

They are working in partnership with healthcare, pharmaceutical and nonprofit institutions.

Glow cap electronic pill bottle [32] [Appendix 6]

It has the ability to transmit adherence data to the Way to Health (WTH) web portal. The investigators will measure adherence by counting the number of properly taken doses during the final four weeks of the study. Each time the pill bottle is opened, a date- and time-stamped wireless signal is sent to the Vitality server via the AT&T cellular network which will then be uploaded to the Way to Health portal for aggregation.

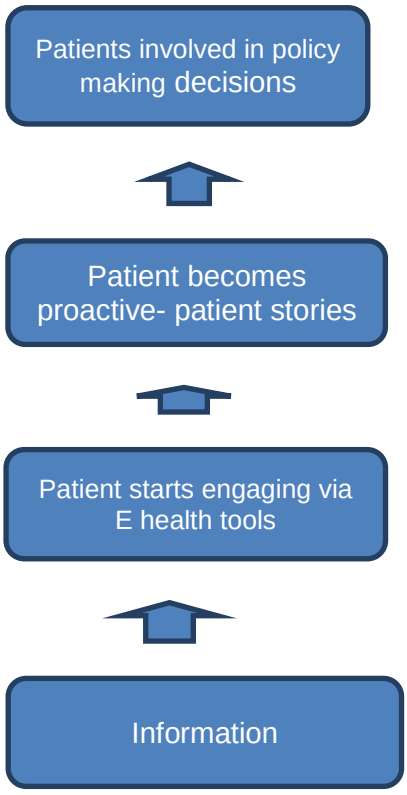
Limitations:

As the literature review was time limited and restricted to English language and to published documents/ End note, the results found were skewed to western countries such as United States of America, Canada, Australia and United Kingdom .With more time the search could have been widened with range of materials from low and middle income settings.

Conclusion:

Described by Forbes as the blockbuster drug of the century, patient engagement is certainly a hot topic of the 21st century. The interpretation of patient engagement varies from one healthcare stakeholder to another. The majority of literature found is related to compliance or, simply put, listening to the clinicians. The literature review found various definitions, frameworks and models for patient engagement. The majority of the literature found on patient engagement is about giving information to the patient and the use of e health tools such as EHRs by the patients. Only a few studies were found about the patients becoming proactive as patient safety advocates and participating in health policy decision making.

Different Levels of Patient Engagement



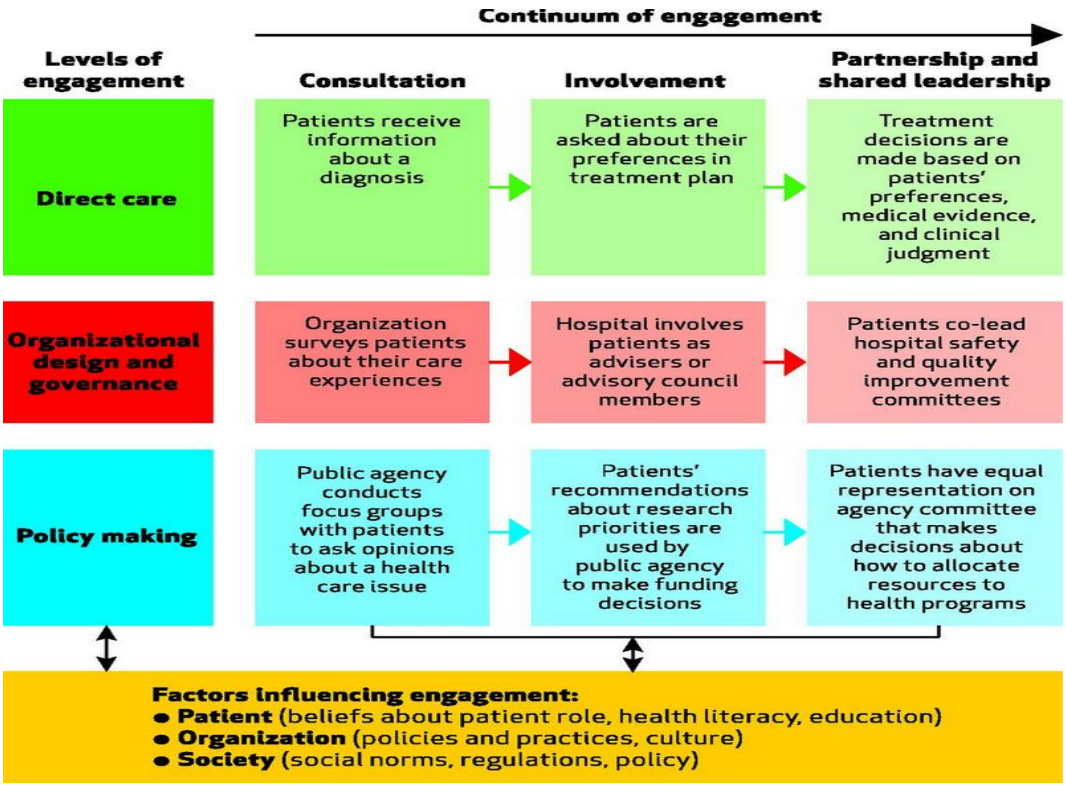
Appendix [1]

WHO African Region (46)	WHO Region of the Americas (35)	WHO South-East Asia Region (11)	WHO European Region (53)	WHO Eastern Mediterranean Region (21)	WHO Western Pacific Region (27)
Algeria, Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cape Verde, Central African Republic, Chad, Comoros, Congo, Côte d'Ivoire, Democratic Republic of the Congo, Equatorial Guinea, Eritrea, Ethiopia, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia,	Antigua and Barbuda, Argentina, Bahamas, Barbados, Belize, Bolivia, Brazil, Canada, Chile, Colombia, Costa Rica, Cuba, Dominica, Dominican Republic, Ecuador, El Salvador, Grenada, Guatemala, Guyana, Haiti, Honduras, Jamaica, Mexico, Nicaragua, Panama, Paraguay, Peru, Puerto Rico (associated), Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Suriname, Trinidad	Bangladesh, Bhutan, Democratic People's Republic of Korea, Timor-Leste, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand	Albania, Andorra, Armenia, Austria, Azerbaijan, Belarus, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Luxembourg,	Afghanistan, Bahrain, Djibouti, Egypt, Iran (Islamic Republic of), Iraq, Jordan, Kuwait, Lebanon, Libyan Arab Jamahiriya, Morocco, Oman, Pakistan, Qatar, Saudi Arabia, Somalia, Sudan, Syrian Arab Republic, Tunisia, United Arab Emirates, Yemen	Australia, Brunei Darussalam, Cambodia, China, Cook Islands, Fiji, Japan, Kiribati, Lao People's Democratic Republic, Malaysia, Marshall Islands, Micronesia (Federated States of), Mongolia, Nauru, New Zealand, Niue, Palau, Papua New Guinea, Philippines, Republic of Korea, Samoa, Singapore, Solomon Islands, Tokelau (associated), Tonga, Tuvalu, Vanuatu, Viet Nam

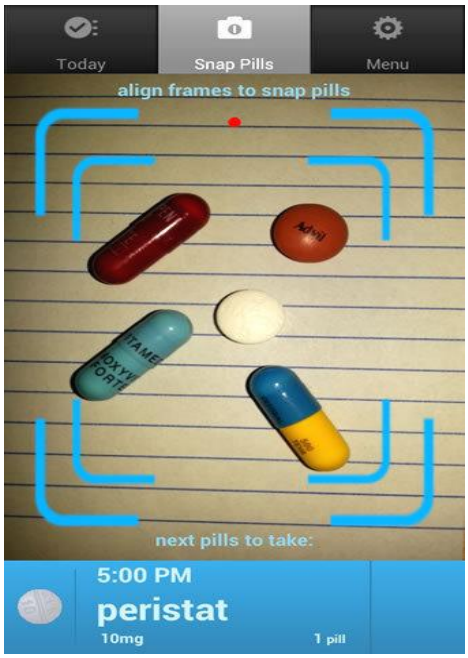
Madagascar, Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Sao Tome and Principe, Senegal, Seychelles, Sierra Leone, South Africa, Swaziland, Togo, Uganda, United Republic of Tanzania, Zambia, Zimbabwe	and Tobago, United States of America, Uruguay, Venezuela (Bolivarian Republic of)		Malta, Monaco, Netherlands, Norway, Poland, Portugal, Republic of Moldova, Republic of Montenegro, Romania, Russian Federation, San Marino, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, The Former Yugoslav Republic of Macedonia, Turkey, Turkmenistan, Ukraine, United Kingdom of Great Britain and Northern Ireland, Uzbekistan, Vatican (observer).		

Appendix [2] NeHC Framework, US, 2008

Appendix [3] PCPCC Patient Engagement Framework, US,2006



Appendix [4] Irody MyPillSense



Appendix [5] Ubitru

Appendix [6] Glow cap

Appendix [7]




Patient Engagement in Medication Safety

Hosted by: the Government of Australia and the International Alliance of Patients' Organizations (IAPO) in collaboration with the WHO Patient Safety Programme

Thursday 23 May, 12.30-14.00

Venue: Salle VII (7)

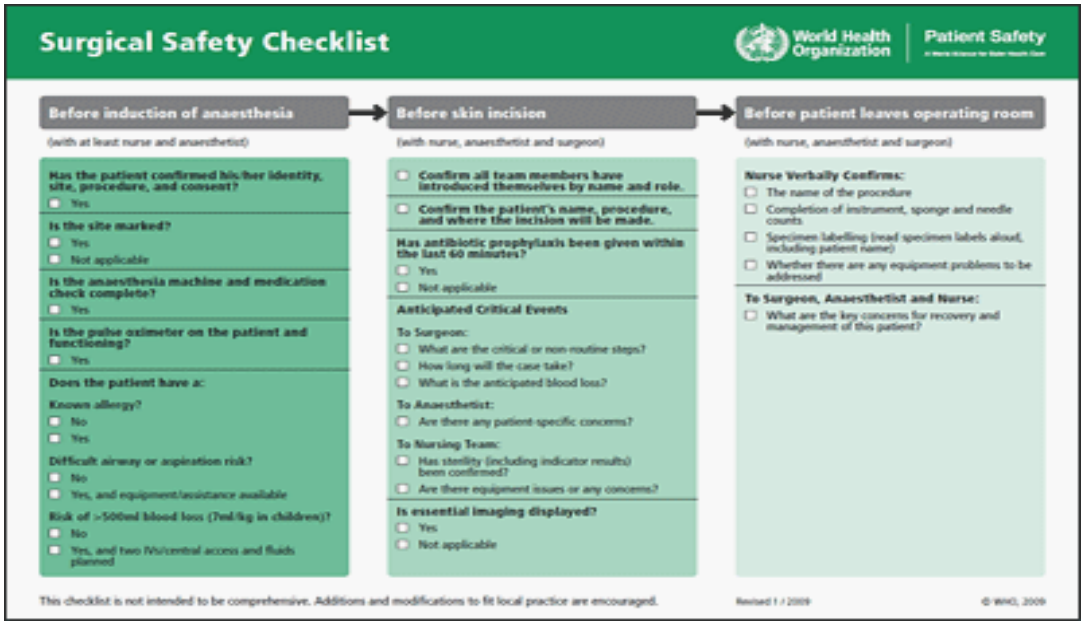
This session will raise awareness of the importance of patient engagement and empowerment in improving health-care safety, share country experiences of patient and family engagement and serve as a call to action to promote patient and family engagement in medication safety.

Session Chair: Sir Liam Donaldson, WHO Envoy for Patient Safety

Confirmed speakers include:

- Sir Liam Donaldson, WHO Envoy for Patient Safety
- Professor Chris Baggoley, Chief Medical Officer, Australia
- Dr Edward Kelley, Executive Coordinator, Patient Safety Programme, WHO
- Carol Bennett, IAPO Governing Board Member and Chief Executive Officer of Consumers Health Forum, Australia
- Jo Groves, Chief Executive Officer, IAPO
- Dr Matthias Weinold, IAPO Member Representative/Patients for Patient Safety Programme (PFPS)
- Barbara Farlow, Patients for Patient Safety Programme (PFPS)

Appendix [8]



Surgical Safety Checklist

World Health Organization | Patient Safety

Before induction of anaesthesia (with at least nurse and anaesthetist)

Has the patient confirmed his/her identity, site, procedure, and consent?
- Yes

Is the site marked?
- Yes
- Not applicable

Is the anaesthesia machine and medication check complete?
- Yes

Is the pulse oximeter on the patient and functioning?
- Yes

Does the patient have a:

Known allergy?
- No
- Yes

Difficult airway or aspiration risk?
- No
- Yes, and equipment/assistance available

Risk of >500ml blood loss (7ml/kg in children)?
- No
- Yes, and two IVs/central access and fluids planned

Before skin incision (with nurse, anaesthetist and surgeon)
- Confirm all team members have introduced themselves by name and role.
- Confirm the patient's name, procedure, and where the incision will be made.

Has antibiotic prophylaxis been given within the last 60 minutes?
- Yes
- Not applicable

Anticipated Critical Events

To Surgeon:
- What are the critical or non-routine steps?
- How long will the case take?
- What is the anticipated blood loss?

To Anaesthetist:
- Are there any patient-specific concerns?

To Nursing Team:
- Has sterility (including indicator results) been confirmed?
- Are there equipment issues or any concerns?

Is essential imaging displayed?
- Yes
- Not applicable

Before patient leaves operating room (with nurse, anaesthetist and surgeon)

Nurse Verbally Confirms:
- The name of the procedure
- Completion of instrument, sponge and needle counts
- Specimen labelling (read specimen labels aloud, including patient name)
- Whether there are any equipment problems to be addressed

To Surgeon, Anaesthetist and Nurse:
- What are the key concerns for recovery and management of this patient?

This checklist is not intended to be comprehensive. Additions and modifications to fit local practice are encouraged.

Revised 1 / 2009

S#	Name of the Department	Date(s) of visit	% of time spent	People met (with designation)
1	Patient Safety	April 8th to June 8th,2013	100 percent	**Sir Liam Donaldson** WHO Envoy for Patient Safety **Dr Edward Kelley** Coordinator, Patient Safety Programme **Dr Benedetta Allegranzi** Deputy Lead, "Clean Care is Safer Care", Patient Safety Programme **Dr Sepideh Bagheri Nejad** "Clean Care is Safer Care", Patient Safety Programme **Dr Itziar Larizgoitia** Research for Patient Safety, Patient Safety Programme **Dr Agnès Leotsakos**

				Leader, Patient Safety Education and Global Capacity Building, Patient Safety Programme **Nittita Prasopa-Plaizier** Manager, Small Grants for Patient Safety Research, Patient Safety Programme **Dr Shams Syed** Programme Manager, African Partnerships for Patient Safety, Patient Safety Programme **Anna Lee** Patients for Patient Safety, Patient Safety Programme **Elizabeth Speakman** Voulnteer **Administrative Staff** Gheorghe Banica Armorel Duncan Laura Pearson
2.	Emergency and Essential Surgical Care Clinical Procedures	April 17th,May 14th,27th		**Dr.Meena Nathan Cherian** Medical Officer **Dr.Selma Khamassi** Medical Officer, Injection Safety
3.	Non communicable diseases and mental health	April 11th, May 6,20th		**Mr Sameer Pujari** Technical Officer at World Health **Dr Vinayak Mohan** Prasad Senior adviser WHO Tobacco Free Initiative

4.	Department of Chronic Diseases and Health Promotion (CHP)	April 15th,May 22,23		**Dr. Poul Erik Petersen** Chief, Oral Health Programme
5.	International Health Regulations			**Dr Rajesh Sreedharan** Medical Officer

References

1. Barello, S., et al. (2012). "Patient engagement as an emerging challenge for healthcare services: mapping the literature." Nurs Res Pract 2012: 905934.

2. Maurer M, Dardess . Guide to patient and family engagement : Contract final report URL May 2012http://www.ahrq.gov/research/findings/final-reports/ptfamilyscan/index.html Accessed online on 18/04/2013

3. "About National health collaborative." Retrieved April 26,2013 from http://www.nationalehealth.org/about-national-ehealth-collaborative

4. Carman, K. L., et al. (2013). "Patient and family engagement: a framework for understanding the elements and developing interventions and policies." Health Aff (Millwood) 32(2): 223-231.
5. " Patient Care- Program Overview and Goals ".Retrieved May 7,2013 from http://www.moore.org/patient-care/

6. Delbanco.T et al "Grants -Open Notes." Retrieved May 8,2013 from http://www.rwjf.org/en/grants/grantees/OpenNotes.html

7. Delbanco. T et al "Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead." Ann Intern Med. *2012;157(7):461-470*

8. Archambault, P. M. (2011). "Wiki Build: a new application to support patient and health care professional involvement in the development of patient support tools." J Med Internet Res 13(4): e114.
9. Christopher, P. (2010). "New electronic health record blueprint to call for increased patient participation." Canadian Medical Association Journal 182(10): E429-E430.
10. Galvin, J. R., et al. (1995). "The virtual hospital. Providing multimedia decision support tools via the Internet." Spine (Phila Pa 1976) 20(15): 1735-1738.
11. Gruman, J., et al. (2010). "From patient education to patient engagement: implications for the field of patient education." Patient Educ Couns 78(3): 350-356.
12. Misiaszek, G., et al. (2008). "Online multimedia teaching tool for Parkinson's disease." J Undergrad Neurosci Educ 6(2): A68-73.
13. Sadasivam, R. S., et al. (2011). "Development of an interactive, Web-delivered system to increase provider-patient engagement in smoking cessation." J Med Internet Res 13(4): e87.
14. Thielst, C. B. (2011). "Social media: ubiquitous community and patient engagement." Front Health Serv Manage 28(2): 3-14.
15. Young, D., et al. (2007). "Patient Engagement and Coaching for Health: The PEACH study--a cluster randomised controlled trial using the telephone to coach people with type 2 diabetes to engage with their GPs to improve diabetes care: a study protocol." BMC Fam Pract 8: 20.

16. Zimmerman, S. (2011). "Advancing patient care through technology: engagement communications help medical practices tailor the type of information their patients receive, as well as when and how they receive it." Health Manag Technol 32(10): 14.
17. Chou, H. K., et al. (2012). "Engagement in E-learning opportunities: an empirical study on patient education using expectation confirmation theory." J Med Syst 36(3): 1697-1706.
18. Christopoulos, K. A., et al. (2013). ""Taking a half day at a time:" patient perspectives and the HIV engagement in care continuum." AIDS Patient Care STDS 27(4): 223-230.
19. Chunchu, K., et al. (2012). "A patient centered care plan in the EHR: improving collaboration and engagement." Fam Syst Health 30(3): 199-209.
20. Rogers, S. and E. Sedge (2011). "Patient relations office facilitate community engagement: using Internet-based correspondence to encourage discussion at the University Health Network." Healthc Q 14(2): 101-105.
21. Wasson, J. H., et al. (2012). "The medium is the (health) measure: patient engagement using personal technologies." J Ambul Care Manage 35(2): 109-117.
22. (2007). "Program increases patient, family involvement." Healthcare Benchmarks Qual Improv 14(12): 139-141
23. Barham, L. (2011). "Public and patient involvement at the UK National Institute for Health and Clinical Excellence." Patient 4(1): 1-10.
24. Greenwood, L. (2003). "Patient involvement. Complain and simple." Health Serv J 113(5857): 24-25.
25. Hogg, C. N. (2007). "Patient and public involvement: what next for the NHS?" Health Expect 10(2): 129-138.
26. Allsop, J. and K. Jones (2002). "Patient involvement. Hearing voices." Health Serv J 112(5798): 28-29.
27. Donaldson, A., et al. (2007). "Sharing experiences of user involvement in shaping new services: the story of a national patient group." Fam Cancer 6(2): 249-256.
28. Cox, L. M. and L. S. Logio (2011). "Patient safety stories: a project utilizing narratives in resident training." Acad Med 86(11): 1473-1478
29. Ratanawongsa., N et al.(2009) “Teaching residents to know their patients as individuals. The Aliki Initiative at Johns Hopkins Bayview Medical Center”. Summer; 72(3): 4–11
30. “ MyPillSense.” Retrieved May 10,2013 from http://www.irody.com/web4/mypillsense.php?m=1
31. Fischer (2012) “ Technology and your patient.”Retrieved May 18,2013 from http://ehr-evolution.com/technology-and-your-patient/
32 Horowitz. B(2010). “ Electronic Pill Bottle Cap Increases Medication Use, Study Says.” Retrieved May 21, 2013 from http://www.eweek.com/c/a/Health-Care-IT/Electronic-Pill-Bottle-Cap-Increases-Medication-Use-Study-298626/

Other references considered :

32. (2013). "Patient engagement, patient safety, and quality of care." Health Aff (Millwood) 32(2): 432-435.
33. Addison, J., et al. (2013). "How doctors make use of online, point-of-care clinical decision support systems: a case study of UpToDate(c)." Health Info Libr J 30(1): 13-22.
34. Ali, M. K., et al. (2011). "Review of electronic decision-support tools for diabetes care: a viable option for low- and middle-income countries?" J Diabetes Sci Technol 5(3): 553-570.

35. Andersson, A. C. and A. Olheden (2012). "Patient participation in quality improvement: managers' opinions of patients as resources." Journal of Clinical Nursing 21(23-24): 3590-3593.

37 Arsand, E., et al. (2012). "Mobile health applications to assist patients with diabetes: lessons learned and design implications." J Diabetes Sci Technol 6(5): 1197-1206.

36. Baart, I. L. M. A. and T. A. Abma (2011). "Patient participation in fundamental psychiatric genomics research: a Dutch case study." Health Expectations 14(3): 240-249.

39 .Ball, M. J., et al. (2007). "Personal health records: empowering consumers." J Healthc Inf Manag 21(1): 76-86.

40. Baquet, et al. (2008). " Analysis of Maryland Cancer Patient Participation in National Cancer Institute-Supported Cancer Treatment Clinical Trials (vol 26, pg 3380, 2008)." Journal of Clinical Oncology 26(31): 5142-5142.

41 Barry, M. J. (2012). "Shared decision making: informing and involving patients to do the right thing in health care." J Ambul Care Manage 35(2): 90-98.

42.Belcher, V. N., et al. (2006). " Views of older adults on patient participation in medication-related decision making." J Gen Intern Med 21(4): 298-303.

43 Bellazzi, R.et al. (2002). "A telemedicine support for diabetes management: the T-IDDM project." Comput Methods Programs Biomed 69(2): 147-161.

44. Berg, S. K., et al. (2012). "COPE-ICD: patient experience of participation in an ICD specific rehabilitation programme." European Journal of Cardiovascular Nursing 11(2): 207-215.

45. Berman, L., et al. (2011). " Pilot testing of a decision support tool for patients with abdominal aortic aneurysms." J Vasc Surg 53(2): 285-292 e281.

46. Bingham, C. O., et al. (2012). "The importance of patient participation in measuring rheumatoid arthritis flares." Annals of the Rheumatic Diseases 71(7): 1107-1109.

47. Boland, P. (2007). " The emerging role of cell phone technology in ambulatory care." J Ambul Care Manage 30(2): 126-133.

48. Bo-Linn, G. (2012). " Improving patient engagement. Interview by Matthew Weinstock." Hosp Health Netw 86(10): 32-33.

49. Brown, R. F., et al. (2001). "Promoting patient participation and shortening cancer consultations: a randomized trial." British Journal of Cancer 85(9): 1273-1279.

50 .Bruce, B., et al. (2007). " Participation in patient self-management programs." Arthritis & Rheumatism-Arthritis Care & Research 57(5): 851-854.

51. Bundesmann, R. and S. A. Kaplowitz (2011). " Provider communication and patient participation in diabetes self-care." Patient Educ Couns 85(2): 143-147.

52. Byrne, M. K., et al. (2010). " Training inpatient mental health staff how to enhance patient engagement with medications: Medication Alliance training and dissemination outcomes in a large US mental health hospital." J Eval Clin Pract 16(1): 114-120.

53. Carroll, J. K., et al. (2011). " Patient Participation in Physical Activity Counseling in Primary Care: Analysis of 139 Audio-Recorded Visits Using the 5as Framework." Annals of Behavioral Medicine 41: S72-S72.

54. Cegala, D. J., et al. (2012). " Further examination of the impact of patient participation on physicians' communication style." Patient Educ Couns 89(1): 25-30.

.

55. Chou, H. K., et al. (2012). " Engagement in E-learning opportunities: an empirical study on patient education using expectation confirmation theory." J Med Syst 36(3): 1697-1706.

56. Clancy, C. M. (2011). " Patient engagement in health care." Health Serv Res 46(2): 389-393.

57. Cliff, B. (2012). " Patient-centered care and community engagement." J Healthc Manag 57(4): 234-235.

58. Coughlan, J., et al. (2006). " Evaluating telemedicine: a focus on patient pathways." Int J Technol Assess Health Care 22(1): 136-142.

59.Coulter, A. (2012). "Patient engagement--what works?" J Ambul Care Manage 35(2): 80-89.

60. Coulter, A., et al. (2011). " Implementing shared decision making in the UK." Z Evid Fortbild Qual Gesundhwes 105(4): 300-304.

61. Davis, R. E., et al. (2007). "Patient involvement in patient safety: what factors influence patient participation and engagement?" Health Expect 10(3): 259-267.

62. Deen, T. L., et al. (2013). " Patient acceptance of and initiation and engagement in telepsychotherapy in primary care." Psychiatr Serv 64(4): 380-384.

63. Dentzer, S. (2013). " Rx for the 'blockbuster drug' of patient engagement." Health Aff (Millwood) 32(2): 202.

64. Dillon, P. J. (2012). " Assessing the influence of patient participation in primary care medical interviews on recall of treatment recommendations." Health Commun 27(1): 58-65.

65. Drohan, B., et al. (2009). " Electronic health records and the management of women at high risk of hereditary breast and ovarian cancer." Breast J 15 Suppl 1: S46-55.

66. Evans, D. F., Jr., et al. (2006). " Straight talk new approaches to healthcare. The healthcare quality equation." Mod Healthc 36(44): 43-46.

67 .Flickinger, T. E., et al. (2013). "Higher Quality Communication and Relationships are Associated with Improved Patient Engagement in HIV Care." J Acquir Immune Defic Syndr.

68. Frank, L. (2013). " Active patient engagement in research." Health Aff (Millwood) 32(2): 438-439.

69. Furber, G. V., et al. (2011). " How adolescents use SMS (short message service) to micro-coordinate contact with youth mental health outreach services." J Adolesc Health 48(1): 113-115.

70. Geissbuhler, A. (2008). "Access to health information: a key for better health in the knowledge society." Yearb Med Inform: 20-21.

71. Grant, B. and S. H. Colello (2010). "Culture change through patient engagement." Nurs Manage 41(10): 44-46.

72. Grant, R. W., et al. (2006). "Design and implementation of a web-based patient portal linked to an ambulatory care electronic health record: patient gateway for diabetes collaborative care." Diabetes Technol Ther 8(5): 576-586.

73. Gross, M. and B. Cassidy (1992). "Information technology and today's health care management." Top Health Inf Manage 13(1): 1-10.

74 .Gruman, J., et al. (2010). "From patient education to patient engagement: implications for the field of patient education." Patient Educ Couns 78(3): 350-356.

75. Guise, J. M., et al. (2013). "A practice-based tool for engaging stakeholders in future research: a synthesis of current practices." J Clin Epidemiol 66(6): 666-674.

76. Harris, L. T., et al. (2010). " Two-way text messaging for health behavior change among human immunodeficiency virus-positive individuals." Telemed J E Health 16(10): 1024-1029.

77. Heesen, C., et al. (2011). " Decisions on multiple sclerosis immunotherapy: new treatment complexities urge patient engagement." J Neurol Sci 306(1-2): 192-197.

78 .Heggland, L. H. and K. Hausken (2013). " A qualitative identification of categories of patient participation in decision-making by health care professionals and patients during surgical treatment." Clin Nurs Res 22(2): 206-227.

79 .Hickam, D. H. (2010). "Decision aids: evolving from novelties to effective communication tools." Med Decis Making 30(6): 699-700.

80 .Kimmel, Z., et al. (2005). " Personal health records." J Med Pract Manage 21(3): 147-152.

81 Kreofsky, L. (2013). "Engaging staff to engage patients: Patient engagement is essential for meaningful use, and studies show it is becoming more definitively linked to consumer satisfaction." Health Manag Technol 34(2): 12-13.

82 .Land, L., et al. (2011). " Using patient experience to measure the quality of HIV care." Int J STD AIDS 22(7): 366-367.

83. Lehmann, E. D. (2004). " Information technology in clinical diabetes care--a look to the future." Diabetes Technol Ther 6(5): 755-759.

84. Dean, M. (2004). "Drive to improve patient choice within the UK NHS. More patient involvement in treatment decisions could lead to more efficient NHS, experts say." Lancet 363(9405): 302.

85 .Le Rouge, C., et al. (2008). "Patient-centered design: conceptually modeling the health care consumer." AMIA Annu Symp Proc: 1035.

86 .Longtin, Y., et al. (2010). " Patient participation: current knowledge and applicability to patient safety." Mayo Clin Proc 85(1): 53-62.

87. Magill, M., et al. (2010). " Motivational interviewing with significant other participation: assessing therapeutic alliance and patient satisfaction and engagement." J Subst Abuse Treat 39(4): 391-398.

88. Martinez, L. S., et al. (2009). "Patient-clinician information engagement increases treatment decision satisfaction among cancer patients through feeling of being informed." Patient Educ Couns 77(3): 384-390.

89. Misiaszek, G., et al. (2008). " Online multimedia teaching tool for Parkinson's disease." J Undergrad Neurosci Educ 6(2): A68-73.

90 .Nazi, K. M. (2013). "The personal health record paradox: health care professionals' perspectives and the information ecology of personal health record systems in organizational and clinical settings." J Med Internet Res 15(4): e70.

91. Osborn, R. and D. Squires (2012). "International perspectives on patient engagement: results from the 2011 Commonwealth Fund Survey." J Ambul Care Manage 35(2): 118-128.

92. Pernet, A., et al. (2012). "[Patient participation to patient safety in radiotherapy: a reality to be developed]." Bull Cancer 99(5): 581-587.

93. Davis, R., et al. (2012). " Patient involvement in blood transfusion safety: patients' and healthcare professionals' perspective." Transfus Med 22(4): 251-256.

94. Saryeddine, T., et al. (2008). "Patient education as a strategy for provider education and engagement: a case study using myJointReplacement.ca." Healthc Q 11(1): 84-90.

95. Saturno, P. J. (2009). " Strategies for patient participation in continuing improvement of clinical safety ." Rev Calid Asist 24(3): 124-130.

96. Phillips, J. (2010). " Patient involvement. Everybody can benefit from expert patients." Health Serv J 120(6218): 20-21

97. Elberse, J. E., et al. (2012). " Patient involvement in a scientific advisory process: setting the research agenda for medical products." Health Policy 107(2-3): 231-242

98. Burns, H. (2004). "Patient safety: Developing policies for engagement in the prevention of harm to patients." J Prof Nurs 20(1): 4, 75.

99. Weingart, S. N., et al. (2011). " Hospitalized patients' participation and its impact on quality of care and patient safety." Int J Qual Health Care 23(3): 269-277.

100. Wilson, J. (2010). " Breaking down barriers to patient engagement." Br J Nurs 19(8): 473.

101. Benbow, M. (1996). " Pressure sore guidelines: patient/carer involvement and education." Br J Nurs 5(3): 182, 184-187

102. Schwappach, D. and O. Frank (2012). " Patients as vigilant partners - patient involvement in patient safety ." Ther Umsch 69(6): 359-362.

103. "Constitution of the World Health Organization" (PDF). World Health Organization. Retrieved 11 February 2008.

104. "The role of WHO in public health". WHO. Retrieved 26 March 2012