

The Cochrane Consumer Network and the WHO/ Patients for Patient Safety

Silvana Simi

Cochrane Collaboration Consumer Network

WHO/PFPS

6th International Conference on Patient Safety / 19th Cochrane Colloquium,
Madrid Oct 19 -20, 2011



NEW STATEMENT OF PATIENTS' RIGHTS:

***“You have the Right to remain silent.
Anything you say can and will be used against you.”***

From 'The Onion Newspaper': <http://www.theonion.com>

On the contrary, patients have to give voice to their ideas, as they

- are the only ones entitled to their health
 - have the right to have their will and experience respected
 - can bring to the table a valuable perspective which comes from being the receiving end of health services
 - can determine new directions and priorities
 - can focus on issues that researchers are not aware of
 - are markers of how services are working
 - can build a partnership between who makes medicine and who uses it

Euro Health Consumer Index:



The Euro Health Consumer Index (2009) ranks Italy : " technically excellent in many places, but poor geographical equity. Autocratic attitude from doctors prevents Italy from scoring high in a consumer index. A power shift to patients necessary".

Two international organizations:



- **The Cochrane Collaboration**

Working together to provide the best evidence for health care

[http:// www.cochrane.org](http://www.cochrane.org)



- **World Alliance for Patient Safety**

<http://www.who.int/patientsafety/en/>

From the Cochrane Collaboration website:

*The aim of any medical care is to benefit patients.
Ultimately, the best person to judge whether any
healthcare intervention has been beneficial is
the patient.*

<http://consumers.cochrane.org/>



Cochrane Consumer Network

ccnet

Helping consumers access the best evidence in healthcare

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Subsc

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⇒ More than 700 consumers from 50 countries

From the Cochrane Manual:

3.4.8 The Consumer Network

The Cochrane Consumer Network ([CCNet](#)) supports consumer participation within The Cochrane Collaboration. Registered with The Cochrane Collaboration in October 1995, the Consumer Network encourages consumer involvement within The Cochrane Collaboration's range of activities.

People with consumer perspectives play an integral and unique role in many aspects of The Cochrane Collaboration's work. Their perspectives particularly influence:

1. Descriptions of the full range of benefits, problems and ethical issues of healthcare interventions and the clinical trials that determine the usefulness of these interventions;
2. The ready accessibility and ease of understanding of Cochrane reviews for a wide range of readers, particularly the general public;
3. The role that consumer advocacy organisations can play in promoting the use of Cochrane reviews by the general public

The aims of the Consumer Network are:

1. To support both consumers and the Cochrane entities who seek the participation of consumers;
2. To make Cochrane reviews easy to understand and accessible to the general public;
3. To increase public awareness about the importance of: synthesizing evidence from clinical trials, as in Cochrane reviews; registering ongoing clinical trials so that the information is readily accessible to consumers and review authors who synthesise the findings; being transparent about the protocols of clinical trials and enrolment status.

- Accessibility and promotion of Cochrane reviews to the general public
- Consumers perspectives in commenting the Cochrane reviews

From the Cochrane Consumer Network (CCNet) executive: a 2011 report

7. **Work in progress**

Work continues in the areas of training, communications with special attention to not-English first language people, global involvement, consumer integration and consumer support.

**N:B::HIGHLIGHT TO GET PAST LANGUAGE
BARRIERS .Translation PLS**

Natalizumab for relapsing remitting multiple sclerosis

Review information

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Plain language summary

The use of the monoclonal antibody Natalizumab (NTZ) in patients with relapsing remitting multiple sclerosis (RRMS)

It is currently thought that inflammation is crucial in MS, leading to a disruption in the ability of nerves to conduct impulses. NTZ is the first of a new generation of anti-inflammatory treatments for MS, which is given intravenously every 4 weeks. It is usually prescribed once other drugs have failed or when the disease is rapidly worsening.

The Authors of this review evaluated the efficacy, tolerability and safety of NTZ in patients with RRMS. Among the pertinent literature, 3 studies met the inclusion criteria of methodological quality, comprising a total of 2223 participants. The results show that NTZ treatment reduces the number of patients who experienced relapses and the number of patients who progressed at 2 years. Also Magnetic Resonance scans show evidence of a beneficial effect of NTZ on disease activity.

Although information on adverse events (AEs) was limited, as most participants were followed up for 2 years only, infusion reactions, anxiety, sinus congestion, lower limb swelling, rigors, vaginal inflammation and menstrual disorders were found to be more frequent after NTZ treatment. However, the number of patients experiencing at least one AE (including severe or serious AEs) did not differ between NTZ and control groups. On the contrary, significant safety concerns have been raised regarding Progressive Multifocal Leukoencephalopathy (PML), a rare and often fatal viral disease characterized by damage to the white matter of the brain. In the studies included in this review, PML was reported in 2 patients treated with NTZ for more than 2 years. However, our protocol was insufficient to evaluate PML risk as well as other potential rare and long-term AEs (e.g. cancers and other infections) which are important issues in considering the risk/benefit ratio of NTZ. An independent systematic review of the safety profile of NTZ is warranted. NTZ should be used only by skilled neurologists in MS centres under surveillance programs.

All the data in this review came from studies supported by the Pharmaceutical Industry. In agreement with the Cochrane Collaboration policy, this may be considered a potential source of bias.

WHO 1978:

The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.

WHO/Patients for Patient Safety 2008:

Safety will be improved if patients are included as full partners in reform initiatives, and learning can be used to inform systemic quality and safety improvements.

Putting Patient Safety on the World's Agenda:

Patient Safety is a global problem

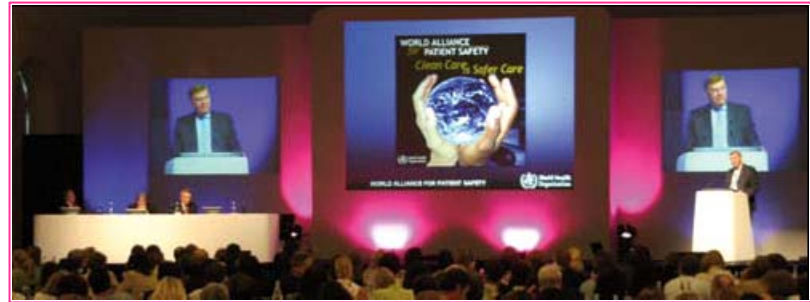
The Fifty-seventh World Health Assembly supported the creation of an international alliance to facilitate the development of patient safety policy.

The World Alliance for Patient Safety was launched in October 2004.

Work in such areas as: research, reporting and learning, designing and implementing solutions, taxonomy, and global patient safety challenges.

Patients for Patient Safety:

Safety will be improved if patients are included as **full partners in reform initiatives**, and **learning can be used** to inform systemic quality and safety improvements.



World Health Assembly, 2002

'...Urging member states to pay the closest possible attention to...patient safety...'

First Patients for Patient Safety workshop/ London 27-30 Nov 2005 :



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

Achievements: Formation of a global Patient Voice – London Declaration

PFPS 2005 - 2010

A Global Network

194 Champions in 47 countries

15 workshops, 11 countries, 600 participants and 7 in-country networks



World Health
Organization

Patient Safety

A World Alliance for Safer Health Care

Patient Safety Champions' activity:



Presence in

- 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

Susan Sheridan, PFPS Chair, USA

Modern Healthcare Magazine, one of America's most well respected trade publications, has named Susan Sheridan, Patients for Patient Safety External Lead, to their list of the Top 25 Women in Healthcare for 2009. Key players in the movement to reform the nation's healthcare system dominate the list, and the programme honours women making a positive difference in the healthcare industry.



Sue one of the 25 American women who made a difference in healthcare

Rebecca O' Malley, PFPS Champion, Ireland



Rebecca: invited as member of the ‘Commission on Patient Safety and Quality Assurance’, set up by the Irish Minister for Health.

“Health chiefs should learn from their mistake, or else step aside”

PFPS/ Danmark

In the autumn of 2008 the Danish Society for Patient Safety will issue a tool kit on how organisations can acknowledge responsibility for staff involved in an adverse event.

This is how we want to be met.
The patient safety champions in Denmark

Take good care of us when we are patients

Show patients and relatives respect

- Talk to us
- Meet us where we are
- Look us in the eye
- Listen to us, and hear what we are saying
- Respect our experiences - they are genuine
- Include us

See us as genuine partners

- Use our knowledge and experience
- Cooperate with us

1. Carry out damage control immediately

- Take responsibility, also when WE experience that something has gone wrong
- Control the extent of the damage
- Control the long term effects

2. Tell the truth and take responsibility

Sara Yaron, Israel



Vision

Shevet, a non-profit organization, will act to build cooperation between patients and their families, and health care professionals with the aim of promoting safe medical care within the health system, and will act to minimize avoidable injury or harm. Shevet's activities will be carried out through development of a culture of transparency, learning from previous incidents, and taking preventative measures to ensure safe medical care. Shevet is affiliated with the international organization 'Patients for Patient Safety' of the World Health Organization.



Technology Meeting

Sara Yaron, Patients for Patient Safety Champion, Israel



First National Meeting on Patient Safety

Tel Aviv, March 15th 2011

Mingming Zhang, China



Patient safety lessons for clinicians. Chengdu Hospital



Claudia Cattivera, Argentina



Pacientes Online
El sitio para pacientes, hecho por pacientes.

Universidad Maimónides

ENCUENTROS PACIENTE MEDICO
• La relación médico paciente

¿Porqué los Encuentros entre médicos y pacientes? Y...¿Porqué no?

ADECI
ASOCIACIÓN ARGENTINA DE ENFERMEROS EN CONTROL DE INFECCIONES

Auspician
Organización Panamericana de la Salud Ministerio de Salud Presidencia de la Nación

CAMPAÑA NACIONAL PARA LA MEJORA DE LA
HIGIENE DE MANOS

Nagwa Metwally, Egypt

Checklist implementation in an Egyptian Hospital

Mahmoud el Damaty, Patients for Patient Safety Champion, Egypt



The Sharq Al-Madina Hospital faced many events that drew the attention for the great need to implement the Surgical Safety Checklist, such as adverse events and near misses. The following indicates the steps that were taken in implementing the Surgical Safety Checklist at the Sharq Al-Madina Hospital in Alexandria.

First a 'critical mass' group was created, which consisted of staff with the right mix of skills and motivation to take on this task. WHO had recommended that one person be responsible for implementing the checklist, but we found in our hospital this lead to antagonistic relationships with other members of the operating room.

We selected individuals that had good on skills.

Latest Activities in Egypt

Nagwa Metwally, PFPS Champion, Egypt

On May 5, I attended the meeting run by the Egyptian Association of Infection Control, to mark the international hand hygiene day. I presented my experiences in the hospital and the importance of hand hygiene for infection control, the efforts to reduce infection and challenges, etc. In this meeting, the creation of the Egyptian Association of Patient Safety was mentioned, of which I'm one of the founding members. We are in the process of finalizing the structure, vision and mission of the association. We will soon be running a workshop for orientation for those who are interested in working with us and we are hoping to launch the association soon. Dr Riham Elasadly, WHO EMRO, is also a founding member.

As a first step, we are hoping that this association will be the reference to all that concerns patient safety in Egypt and we hope to gradually spread to the rest of the Eastern Mediterranean region. I will send more details once the association is established. This

EMRO Feature

Activities in Egypt

Nagwa Metwally, Patients for Patient Safety Champion, Egypt

This year I am really happy and I started to feel a bit of satisfaction and some reward from the hard work of the past four years. There is now huge awareness, you feel it everywhere in the hospital, from the management to all the staff, this the third management in the hospital we are working with, and I think the best as they have a good will for change and we are working together very well exchanging views and adopting solutions and following them together. Below are two of the important issues showing the great change happening in the hospital currently;

- The general manager of the hospital Dr Rami, established an important committee reporting directly to him for quality control headed by a very efficient lady doctor, Dr Azza AWAD she is very enthusiastic and a good champion for patient safety and a very high believer in the importance of change in the hospital and we are working together in all details discussing, suggesting and following up with her and evaluating every step together.
- A new infection control plan is being implemented. Now the head of infection control in the hospital is another very good lady doctor, Dr Gada Ismail, she is a wonderful person and another very good champion for patient safety with a very good vision and she knows well what to do and we are always in consultation together with the management in all the details and my group is helping as an outsider eye in observation and following up the implementation of the plan.
- Third, this year we are improving the infrastructure of 5 old theatres and creating 4 new theatres which will cost 2 million, 4 hundred Egyptian Pounds. It is a huge project but I managed to find the funding and they will finish in two months. This will make a big change in the safety of the patient plus we are providing what is needed to help to find more fund raising for the equipment.

To find out more you can email Nagwa at: nagwametwally@hotmail.com



Jolanda Bilinska, Poland

Regional Health Forum, Poland

Jolanta Bilinska, Patients for Patient Safety Champion, Poland



A regional health forum held in Poland on 8 July for over 70 members of the health care system, resulted in the signing of a 'Safe Hospital, Safe Patient' Declaration. The Declaration emphasizes the importance of involving patients in the decision making process around diagnosis and treatment, the necessity to run a hospital and its medical staff efficiently, and the need to educate patients in health problems and for better communication between doctors and patients.

"Safe hospital, safe patient" Declaration

1. Effective hospital management and initiation of accreditation standards and ISO standards increases patient and medical staff safety.
2. Patient safety depends on a proper level of medical services. Hospital staff attempts to broaden their medical knowledge and apply generally accepted treatment standards.
3. The staff attempts to educate patients in health matters, remind them about prophylactics, which prevents illnesses and reduces costs of treatment.
4. In a safe hospital sanitary and epidemiological rules are observed.
5. Proper patient-personnel communication – involving the patient in decision making process about diagnosis and therapy – makes the treatment easier.



Kilimanjaro in aid of Patient Safety

Jolanta Bilinska, PFPS Champion, Poland

This November I climbed the roof of Africa, the highest crater of Kilimanjaro, at 5895 metres, for the Polish Patient Safety Foundation. Kilimanjaro is a marvellous and majestic mountain. My brother and I planned to take the Machame route– the most difficult one, which the locals call the Whisky Route, as opposed to an easier route, Marangu, i.e. the Coca Cola route, which the other group of 8 doctors decided to take.

Before we left Poland we had a poster made for the Foundation, which we planned to unwind when we reached the peak. The poster had to be light but also very durable material. At a press conference I informed journalists that some members of the Patient Safety Foundation were going to climb Kilimanjaro, I told them about our campaigns to get patients involved in hospital activities and the treatment process by informing doctors, nurses and hospital administration employees about their needs. I wanted to make people interested in issues related to patient safety, emphasize what can be done together and how.

Robinah Kaitirimba, Uganda

Make patient safety a priority in Africa, patients urge

The first African regional Patients for Patient Safety Workshop was held in Uganda from 16 - 18 March. Patients, family members and advocates from Ethiopia, Ghana, Kenya, Malawi, Uganda and Zambia, joined health-care workers and policy-makers to share experiences of harm in health care to work together to improve health-care safety in their countries. Participants urged Member States and health-care providers to make patient safety a priority in Africa.

Participants now join the existing network of PFPS Champions around the world advocating for the belief that patients' and family members must be empowered and placed at the centre of care.

PFPS Champion and advocate, Mrs Robinah Kaitiritimba called on the group to work together and take action. She said: "We have been waiting for this workshop. Now that we have a network we are going to move. We emerge from our time together with a shared passion to listen, learn and progressively improve patient safety in our countries"



African Patient Group Workshop, Kampala

On the 3rd November 2008, the International Alliance of Patients Organizations (IAPO), held a regional workshop in Uganda, bringing together 25 patient groups from across Uganda, Tanzania, Kenya, Nigeria, Ghana, South Africa and Zimbabwe working on a range of issues including Diabetes, HIV/AIDS, Mental Health, Autoimmune Diseases, Haemophilia and Cancer. IAPO is the only global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare worldwide. Robinah Kaitirimba, Patients for Patient Safety Champion, from Uganda, was present as a representative of the Ugandan National Health Consumers Organization, an IAPO member.

The participants worked together discussing the great need for patient-centred healthcare in Africa. IAPO believes health systems can only develop with the meaningful engagement of patient representatives in the development of healthcare policies at all levels. Following the workshop, the patient groups met with Ugandan Ministry of Health officials, the medical and nursing associations and hospital representatives to discuss practical strategies for strengthening healthcare systems in the region.



Silvana Simi, Lucio Patoia, Italy

CHAMPIONS FROM EURO



Education work in Perugia

Silvana Simi / Lucio Patoia, Patients for Patient Safety Champions, Italy

A Continuing Medical Education course on "The improvement of clinical practice and patient safety" took place on Friday 19th December in Perugia (Italy), addressed to healthcare professionals. Lucio Patoia, one of the three Italian PFPS Champions was the organizer and one of the speakers, and another Champion, Silvana Simi was invited to give a talk as well.

It has been a great opportunity to bring again the patient's voice into a professional environment, such as the Italian one, not much used to looking at the patient as a full partner in all the process of health care.



"TOGETHER WE CAN", a Regional Meeting, Florence, Italy, September 19, 2008

- *Silvana Simi, Patients for Patient Safety Champion, Italy*

On September 19, 2008 the Tuscany Region organized a one day meeting to launch the new regional web site "we all are patients" (www.salute.toscana.it/sst/grc/rischio-clinico). This meeting also gave the Healthcare Regional Authorities, the Patient Organizations representatives and citizens, the opportunity for a broad discussion on the patient/citizen role in all of the processes of healthcare and what can be done immediately. The motto was "together we can" .

A metaphor:

Patient Education and Counseling 62 (2006) 288–290

www

The flat-pack patient? Creating health together

Harry Cayton

Department of Health, Richmond House 79, Whitehall, London SW1A 2NS, UK

- IKEA: sells flat-pack furniture
 - CUSTOMER: carries it home and assembles it himself
 - IKEA: saves space, time, money and can reduce its prices
 - CUSTOMER: becomes a partner in the manufacturing process and is happy to invest time and efforts in his home.
-
- Flat-pack patient : contributes to define, implement and co-create his own health and health service
 - A win-win situation

A patient centred medicine, a patient driven medicine

Transforming healthcare: a safety imperative

L Leape,¹ D Berwick,^{1,2} C Clancy,³ J Conway,² P Gluck,⁴ J Guest,⁵ D Lawrence,⁶
J Morath,⁷ D O'Leary,⁸ P O'Neill,⁹ D Pinakiewicz,⁴ T Isaac,¹⁰ for the Lucian Leape
Institute at the National Patient Safety Foundation

Five concepts as fundamental to the endeavor of achieving meaningful improvement in healthcare system safety:

- transparency
- care integration
- **patient/consumer engagement**
- restoration of joy and meaning in work
- medical education reform

If health and/or healthcare is on the table, then the consumer (public, patients, family members) must be at the table, every table. NOW.

Alice's Adventures in Wonderland

“ Would you tell me, please, which way I ought to go from here?” said Alice.

“That depends a good deal on where you want to get to. “ said the Cat.

What do we want to get to? Some challenges

for professionals: to receive this message overcoming both the arrogance (self-referentiality) of the technical knowledge and the paternalism inborn in the doctor-patient clinical relationship

for the NHS: to give the way for active public participation

for Patient Associations: not only tutorship, but mentoring
developing autonomy and empowerment
paying attention to conflicts of interest

for patients themselves: from under-informed and over-controlled persons, to become autonomous citizens, leader actors of their health

from patients needing to be reassured, to persons knowing their own rights, able to make choices and to speak up for themselves

The way forward:

- § quality training for public involvement
- § inclusion of patient training issues in research proposal budgets
- § looking at this as an added value to research proposals
- § engaging patients in professional learning
- § get past language barriers

And also :

- § defining criteria of representativeness
- § dedicated budget to refund/support
- § attention to possible conflict of interest

....and:

Will it be easy and quick?

Definitely NO.

Will it be worth?

Definitely YES.

The autonomous patient:

Patients are very clever to identify critical points, if they are given the opportunity to do it

The more patients will be involved the more health research and health services will grow in democracy and will be tailored on people's needs.

Autonomy (what the patient wants) trumps **beneficence** (what the doctor thinks best for the patient) in all the circumstances .

NO SLIDE

LONDON DECLARATION

Patients for Patient Safety WHO World Alliance for Patient Safety



We, Patients for Patient Safety, envision a different world in which healthcare errors are not harming people. **We are partners in the effort to prevent all avoidable harm in healthcare.** Risk and uncertainty are constant companions. So we come together in dialogue, participating in care with providers. We unite our strength as advocates for care without harm in the developing as well as the developed world.

We are committed to spread the word from person to person, town to town, country to country. There is a right to safe healthcare and we will not let the current culture of error and denial, continue. We call for honesty, openness and transparency. We will make the reduction of healthcare errors a basic human right that preserves life around the world.

We, Patients for Patient Safety, will be the voice for all people, but especially those who are now unheard. Together as partners, we will collaborate in:

- ⊖ Devising and promoting programs for patient 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 on a worldwide basis.
- ⊖ Defining best practices in dealing with healthcare harm of all kinds and promoting those practices throughout the world.

In honor of those who have died, those left disabled, our loved ones today and the world's children yet to be born, **we will strive for excellence, so that all involved in healthcare are as safe as possible as soon as possible.** This is our pledge of partnership.

March 29, 2006