



# **European Regional Patients for Patient Safety Workshop**

Dublin, Ireland  
3-5 September 2007

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## **Executive Summary**

Learning from patients who have been affected by a health care related incident, by listening to their experience, their acquired knowledge and their intrinsic wisdom is a vital component in the process of improving the performance of health services around the world.

The WHO World Alliance for Patient Safety advances this view through its Patients for Patient Safety strand. Within this framework, patients and health providers are brought together to enhance open communication and a team approach towards improving quality and safety in health care.

Forty-two participants (affected patients and health care professionals) from 21 countries across the WHO European region attended the first patients for patients' safety regional workshop to share, discuss and develop strategies fostering patient safety initiatives.

The workshop programme provided an opportunity for sharing of personal experiences, for constructive dialogue and for creating, in partnership, action plans promoting the empowerment of patients and their families, including issues like health literacy and communication.

As a result of this event a dedicated network has been created of courageous and passionate individuals committed to champion patient safety in healthcare. Action plans and recommendations have been developed to support individuals and country 'teams' to work together at local and national level, to widen their networks and partnerships across the region.

## **Introduction**

Patients for Patients' Safety (PFPS) is one of the strand areas of the WHO World Alliance for Patient Safety. Its purpose is to ensure that the patient and family voice is increasingly recognized and ingrained in the design and development of safer healthcare systems around the world.

Patients bring a different perspective and it is essential that their experience, their knowledge and their wisdom are listened to in order for the health care systems to learn and for the patient safety initiatives globally to be appropriate and effective.

As part of that mission the PFPS programme is developing a global network of patient champions from different countries around the world, many of whom have suffered directly, either themselves or a family member, from a patient safety incident. They are individuals who have experience of how their health care services perform and are committed to make a difference: to raise awareness on patient safety issues and to work in partnership with health care professionals and policymakers to shape effective improvement actions.

During the inaugural global workshop in November 2005, patients came together to share their experiences and learning, and the London Declaration (annex 1) emerged as the

guiding vision of this programme. A series of regional level events for each of the WHO regions followed to further develop and support implementation of the mandate.

This report is an overview of the 1<sup>st</sup> European regional workshop, which took place September 2007, in Dublin, Ireland. The event brought together representation from 21 Member States (28 patients/family members and 14 health professionals/policy makers) across the WHO European region.

The aim of the meeting was to orient workshop participants to the vision/mission of the WHO World Alliance for Patient Safety - Patients for Patient Safety initiative, and to expand the network of consumer champions in Europe, engaged in contributing with their experience, wisdom and knowledge to improving patient safety.

The short and long term goals were:

- (1) To identify, recruit and develop consumer champions who will work in effective partnerships at local, national, and international level, promoting the team approach between patient safety advocates and their organizations and healthcare providers throughout Europe
- (2) To promote awareness within Europe of the World Alliance work and the Patients for Patient Safety Initiative
- (3) To foster and build collaboration and links between the existing range of patient safety efforts at national and regional level, so that lessons can be shared and partnerships created, for
  - building connections and cross learning between patients and patients safety organizations
  - sharing information on places to turn to for support if a patient safety incident occurs
- (4) To develop and implement programs with specific patient safety goals, consistent with or complementary to the goals of the WHO World Alliance for Patient Safety
- (5) To articulate values, principles and commitments, within the framework of the London Declaration, that will govern PFPS consumer partnerships and work across the region
- (6) To identify specific priority areas where patients and family members can make meaningful contributions to patient safety efforts throughout the region, disseminate information to the public and raise awareness of patient involvement in patient safety work
- (7) To identify support requirements so that champions can be more effective, particularly regarding a better understanding of the importance of being health-educated consumers/patients, their role and value in moving forward patient-centred health care.

## Workshop overview

A full programme for the meeting can be found in the annexes of this document (annex 2)

The event was led by Mrs Margaret Murphy, Ireland, a globally recognized patient safety champion and member of the Patients for Patient Safety steering group. The context for the workshop was set by sharing her own experience of the needless loss of her 21-year-old son.

Motivations for becoming a change agent have been highlighted, such as damage limitation efforts, learning opportunities, patient engagement and concerted initiatives among patients and providers. Defensiveness when failures occur and absence of partnership and collaborative opportunities were some of the barriers identified.

The patients' perspective often highlights details that even the most dedicated healthcare professional does not see. They need to be listened to and be equipped with the appropriate knowledge to better understand and sustain the process of health care.

Patients and their families can:

- Report medical errors
- Contribute to solutions based on knowledge
- Participate in research
- Partner in policy making
- Contribute to the development of the concept and integrated movement of patient empowerment

*“Today you have in your hands a unique opportunity and the power to co-create something very valuable (...) – that you must nourish and nurture with great care – that has the potential of making a significant difference in the future of patient safety in the EURO region... and the world.*

*Have the courage and the grace to speak up and pursue partnerships never imagined before...”*

**Susan Sheridan**  
**Lead of Patients for Patient Safety**

Learning from patients' stories is taking advantage of existing and unused resources for improvement, evidence based outcomes and solutions development

The message of Susan Sheridan, lead for the Patients for Patient Safety programme (unable to attend), was shared with the participants.

## World Alliance for Patient Safety

Participants were given a brief orientation to the structure and work of the WHO World Alliance for Patient Safety.

On October 27, 2004 WHO launched a World Alliance for Patient Safety dedicated to bringing significant benefits to patients in countries rich and poor in all corners of the globe. The Alliance was established in response to Resolution WHA 55.18, approved by the 55<sup>th</sup> World Health Assembly in May 2002, which urged Member States to pay the closest possible

attention to patient safety and establish science-based systems for improving safety and the quality of care. More information on the World Alliance is available at <http://www.who.int/patientsafety/en>.

One of six action areas embodied in the World Alliance, 'Patients for Patient Safety' is designed to ensure that the perspective of patients and families, consumers and citizens – whichever term resonates best - in developed, transitional, and developing countries is a central reference point in shaping WHO's important work. More information on Patients for Patient Safety is available at [http://www.who.int/patientsafety/patients\\_for\\_patient/en](http://www.who.int/patientsafety/patients_for_patient/en).

Patient wisdom and views bring a consistent contribution to dedicated areas of research, hospital design, solutions development and implementation, and reaching a 'common language' for patient safety. Within the framework of the first Global Challenge for Patient Safety, 'Clean Care is Safer Care', patients shared their perspectives as members of the dedicated Task Force. Their participation in a hand hygiene patient survey contributed to the finalization of the guidelines on hand hygiene practices. Additional work has been undertaken to raise awareness on the importance of hand hygiene (amid patients, families and healthcare professionals) across the WHO regions.

Building on the London Declaration and work already undertaken, the workshop provided an opportunity to prioritize patient concerns and further contribute to defining issues around patient safety, supporting dedicated regional strategies for action.

## **Discussions and Group Work**

### **Patient Perspectives**

The first day of the event was dedicated to patient participants only. It offered a time for the sharing of personal experiences and the preliminary identification of

- the problems as perceived by the group's experiences
- what patients can offer to the healthcare system in bringing about change
- the challenges perceived in facing healthcare professionals and policy makers
- the activities and actions that many of the group are already involved with
- the goals the group wished to work on in partnership with the healthcare systems throughout the region.

The patients' ideas and comments were put together as 'Patient Voices for Partnership' (annex 3), outlining issues and perspectives to share with the health care professionals and policymakers who joined the workshop on the second day.

The passion and commitment to tackling issues pertaining to patient safety were evident amongst the patients and family members who are striving for change. Discussions showed active engagement, as well as willingness to share both grief and hope with fellow participants, as part of the team building approach required.

It has been underlined that where a culture of denial exists, this results in further injury to the patient and family. Compounded by this approach, the initial harm often forces the patient towards litigation, which is not necessarily what the patient would choose under normal circumstances. Positive changes require regulatory frameworks that enshrine accountability and explanation in organizations, setting compassionate systems in place.

The myths of perfection which include a culture of faultless medical performance have isolated physicians and must be therefore dismantled, and transparency offered as a viable alternative.

### **Building Partnership**

One of the main expected outcomes of this event was to bring together the voices of patients, health care professionals and policy makers into constructive dialogue. To facilitate the team approach, all participants, including health professionals, divided into 5 teams. Group work has been conducted using the World Café model, with limited time allotted to each group to successively discuss 5 pre-selected areas of intervention. Layers of discussion were created by moving the groups along the listed queries, and allowing participants to build upon ideas listed by the previous groups. The five areas of discussion are outlined below with a summary of key points raised:

- ***Patient Engagement***

There is a variety of levels of engagement, from individual, direct relationships to organizational and policy engagement.

The barriers to engagement often have cultural roots, more work needs to be done to identify the barriers in order to overcome them.

Enhanced access to information is required to enable effective patient engagement

Patient empowerment should be supported by organizational management

There is a need for resource engagement, financial, but also informational and timely

The value of patient organizations in supporting improvements in health care should be recognized

Patient engagement is part of the healing process

- ***Openness/ Disclosure***

Patients have a right to know and a right to be heard

There are cultural and legal issues related to disclosure of information on a country by country basis.

The difficulty in admitting contribution to error was acknowledged

The vocabulary used in communicating with patients must link with their health literacy

Communication is vital, and particular attention is needed in communicating bad news

Patients expect from health care professionals acknowledgement of error, acceptance of responsibility, and assurance that learning and corrective action took place as a result

Support must be given to re-assess and strengthen the competence of health care staff

- **Partnerships**

The gradient of power can deter partnership

Trust and respect are critical components of partnership

The need for an observatory for healthcare partnership in safety was mentioned

Inequality in partnership is an issue of the different background health knowledge among the various stakeholders (including doctors and patients).

- **Networking**

There is a need for more user friendly access to information, and a well organized structure for this

Where internet access is limited, information should be made available in the form of booklets, patient corners in hospitals etc

The development of a patient safety network is needed as forum of information exchange and shared experiences

The main obstacles to networking appear to be limited resources, lack of translated materials, desire to protect own ideas

- **Patient role in the World Alliance work strands**

There is a need to use what is already known, and contribute to reshaping the critical context around legal frameworks

Open communication is required to enable shared decision making

The myth of doctors' perfection must be realistically re-shaped

Helping the Alliance to shape issues, partnership and patient engagement etc

As the next step participants were grouped according to their geographical distribution, to identify the biggest challenges, opportunities and priorities for action towards patient engagement and patient safety on a sub-regional level. Accordingly, three groups were created, bringing together western European Member States, central European Member States, and eastern European Member States. Some of the group members found this exercise particularly difficult, due to different situations in different countries generating different sets of priorities.

The table below summarizes the main issues identified during these discussions.

Priorities	Challenges	Opportunities
1. Patient engagement: encourage patients to overcome passive behaviour 2. Get involved in education across the	1. Taxonomy and its implementation 2. Fear of healthcare providers of involving patients in patient safety 3. Lack of information and	1. Culture change enhanced by appropriate provision of information 2. Safety culture requires a supportive legal framework and research

<p>health care system.</p> <ol style="list-style-type: none"> <li>3. Raising awareness: educating all stakeholders, inclusion of medical schools</li> <li>4. Creation of a strong network of patient organizations</li> <li>5. Create an environment to help administrators, patients and health professionals to build a joint alliance</li> <li>6. Networking: collaboration and communication among different stakeholders, groups and institutions.</li> <li>7. Improve access to healthcare – address staffing issues</li> <li>8. Creation of patient safety standards guided by one methodology.</li> <li>9. Reporting and learning: analyze, synchronize and define clear aims.</li> <li>10. A national project on PFPS for each country Government funded.</li> </ol>	<p>transparency</p> <ol style="list-style-type: none"> <li>4. Lack of standards based on one methodology</li> <li>5. Lack of clinical guidelines and standards in hospital procedures</li> <li>6. Reporting and learning: lack of statistics and reporting systems of adverse events/ errors - achieving a top down, bottom up approach - examine the reporting to learn from mistakes</li> <li>7. Promoting patients rights, including the silent minorities</li> <li>8. Maintaining trust vs. patient perspective of patient safety</li> <li>9. Providing financial resources for effective patient engagement</li> <li>10. Distinguishing individual engagement from general patient engagement</li> <li>11. Compliance with the laws already in place</li> <li>12. Confidentiality and the requirement of being open with the patient</li> <li>13. Getting the topic into existing medical education curriculum</li> <li>14. Gap between theory and practice</li> </ol>	<p>grants</p> <ol style="list-style-type: none"> <li>3. Disclosure – honest and open dialogue</li> <li>4. Dispel myth of perfection</li> <li>5. Raising awareness</li> <li>6. Education – bringing the patient perspective into the training of medical professionals</li> <li>7. Increase training skills at all levels</li> <li>8. Patient empowerment through greater numbers on health boards, more information etc</li> <li>9. Through reporting systems we can learn for the benefit of future patients</li> <li>10. Accreditation for organizations (hospitals etc.)</li> <li>11. Developing partnerships</li> <li>12. Fundraising work in order to support developments</li> <li>13. Seize the Patient Safety agenda of European Commission to raise the awareness</li> <li>14. EU proposed Patient Safety Network</li> </ol>
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### Generating joint action

The important focus of the workshop process was that individuals and national 'teams' initiate follow up plans of action to continue activities on their return. Participants worked both individually and within country groups for developing and continuing partnership.

Areas of particular interest included: establishing a framework for patient involvement at national level; raising awareness to enhance cultural change; reducing patient passive behaviour and increasing active engagement; establishing a patient reporting programme and fostering national research around patient safety issues.

All participants were committed to continue to work together across the region providing support, sharing lessons and achievements. There was also much enthusiasm for cross country partnerships, particularly where country teams had similar priorities and faced similar challenges.

### **Resources and Support**

The regular PFPS Newsletter and the development of a European Regional Patients for Patient Safety Electronic Community will allow continued discussions to take place, ideas to be shared, resources to be accessed, up to date patient safety news and events to be seen.

The opportunity to become a patient safety champion was provided to all participants according their desired level of involvement in this work.

## **International Conference on Patient Safety**

### **Irish Health Information and Quality Authority**

During the workshop, participants were introduced to this initiative, and provided their comments on its preliminary outcomes. Subsequently, they were invited to attend the International Conference on Patient Safety hosted by the Irish Health Information and Quality Authority (IHIQA).

The conference marked the official launch of the patient safety project which IHIQA is leading on behalf of the WHO World Alliance for Patient Safety. The project aims to drive learning while supporting patients, families and clinicians in the aftermath of a patient safety incident. As a result, an international consensus guidance on best communication practices and patient support should be developed, based on identified best national and international practices of incident management, and emerging expectations. It will also facilitate more responsive, positive outcomes for parties involved in a patient safety incident, both patients/carers and health professionals/providers - an important step forward in progressing a safety culture.

The broad objectives of this project are to:

- 1) Identify the best and current international practice for communicating with and supporting patients, their families and clinicians.
- 2) Determine the outcomes that patients, families, clinicians and relevant key stakeholders desire, while ensuring that socio-cultural values are respected.
- 3) Develop an International Consensus Guidance that will identify best practice for communicating with and supporting patients, their families and clinicians following an adverse event in order to facilitate more responsive, positive outcomes for all parties.

IHQI and WAPS acknowledged the importance of patient and family opinions and perceptions feeding into the project process from its initiation. Feedback on the workshop discussions was provided accordingly to the conference delegates.

The conference also included an interview session with patients and clinicians. This innovative and powerful session allowed three patient representatives (from the workshop group) to describe their experiences with different European healthcare systems and to highlight the patient safety issues encountered.

The event provided the opportunity for patients from across the WHO European region to contribute directly to this important new initiative.

## **Conclusions and Recommendations**

It is already recognized that patient safety is key to the optimal delivery of care, improved quality of life and patient satisfaction. Patients and family members have a significant role to play in helping identify sources and causes of harm, contribute to the development of solutions and ensure it will not happen again.

Service providers need to promote a culture of openness, fairness, accountability and transparency. When an error occurs, it is necessary to engage in constructive dialogue and recognise that patients can actively contribute to strengthening the quality and safety of health services through direct participation. A clear and unequivocal commitment to a reporting and learning strategy linked to a dissemination process is a pre-requisite to developing a process where each stakeholder knows what to do and what is expected of him/her. The teamwork approach between patients and health professionals is ultimately an ethical obligation and must be supported by appropriate two-way communication, information flow and continuous education.

Building on commonalities identified by the various participating Member States of the Region and taking into account all involved stakeholders are essential for the development of coordinated strategies for action.

The following key recommendations emerged from workshop discussions and interactive work between participants.

### **To Participants**

The information and knowledge gained during the workshop should be reported to the national health authorities and shared with fellow patients and patient groups as well as with other relevant stakeholders.

Discussions and activities should be initiated to promote active collaboration on patient safety within hospitals and health care organizations. These should include the establishment of reference groups, committees and other similar bodies and/or inclusion of patients in existing patient safety committees.

Participation in the World Alliance for Patient Safety, Patients For Patient Safety web based European Electronic Community is encouraged once it becomes functional, as a means for further networking, information exchange and sharing experiences at international and national level.

### **To National Health Authorities**

Consideration must be given to enabling policies that can support and engage patients, families and health care staff working together to improve patient safety.

When establishing the appropriate regulatory framework for reporting systems these must be supported by open disclosure programmes which protect both health professionals and patients without affecting accountability.

Patient empowerment should be given its full importance as a key factor in the process of health care improvement. The required cultural change should be supported by awareness and education campaigns targeting health care professionals, managers, patients and the public at large.

Patients offer a unique perspective, a vested interest in patient safety, and energy to design and develop solutions in partnership. They can support the development of a research agenda that incorporates the experiences of patients and their families and measures the benefits of engaging patients as partners in care.

### **To WHO**

Advocacy of the importance of patient safety as part of national health systems should be enhanced at the highest level in Member States.

Assistance in the development of dedicated patient safety training programmes focused on communication should be provided for various categories of healthcare staff, with patient involvement and partnership. A set of performance indicators related to patient engagement and partnership should be developed and used to monitor improvement.

A follow up meeting should be organized in 2008, to enable progress monitoring and adjustment of planned interventions to increase their efficiency, as well as to strengthen liaisons with important European stakeholders such as the EC, CoE and others.

## Annex 1

# 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*

## Annex 2

### Programme outline

#### Monday 3 September

**Primary aim: to allow patient participants to get to know each other and the patient safety activities in their country**

- 8.00 – 8.15**            **Welcomes - Margaret Murphy on behalf of the PFPS SG**  
*Welcome and Introductions from Patients for Patient Safety team*
- 8.15 – 9.15**            **Introduction to World Alliance for Patient Safety and Patients for Patient Safety**  
*Helen Hughes and Margaret Murphy: overview of the WHO World Alliance for Patient Safety and more specifically the Patients for Patient Safety programme.*
- 9.15 – 10.30**        **Getting to know each other: goals and purpose**  
*Participants shared with the group their reasons for attending, their specific aims and goals in relation to the workshop.*
- 10.30 –11.00**        **Break**
- 11.00 - 12.00**        **What's happening? (group work)**  
*Sharing of*  
  - 1) *Patient safety activities already taking place*
  - 2) *Hopes and aspirations*
  - 3) *The challenges in achieving them*
- 12.00 - 1pm**        **Lunch**
- 1.00 – 3.00**        **What's happening (continued)**
- 3.00 - 3.30**        **Break**
- 3.30 - 4.30**        **Where do we fit?**  
*A closer look at the WAPS and European work streams, as well as participants experiences and views - planning to achieve the aims through partnership. Participants' impressions on what, when and where patient involvement can contribute to the work stream*
- 4.30 - 5.30**        **What do we hope for? Vision**  
*Discussions based on the London Declaration, and related cultural challenges specific to the region*
- 5.30 - 5.45**        **Summary of day 1**

#### Tuesday 4 September

**Primary aim: to allow healthcare participants and consumers to interact and develop team work along priority areas identified**

- 8.30 – 10.30**        **Review of day 1 and introduction of new participants**
- 10.30 – 11.00**        **Break**
- 11.00 – 1.00**        **'World Café' group work and discussion**  
*Specific issues considered in more detail:*
  - *Patient engagement*
  - *Openness/honesty/disclosure*

- *Partnerships – what does that mean in EURO*
- *Networking– who are the key players*
- *Alliance work strands – patient role in surgery and hand hygiene – how can patient voices engage in the Alliance work areas?*

<b>1pm - 2pm</b>	<b>Lunch</b>
<b>2pm – 3.30pm</b>	<b>What about our part of the world?</b> <i>Discussions around specific interests and priorities for three subregional teams – eastern, central and western Europe</i>
<b>3.30 – 4.00</b>	<b>Break</b>
<b>4.00 - 5.30</b>	<b>Can we reach consensus?</b> <i>Teams feedback on vision and priorities for patient safety work as per above</i>
<b>5.30 – 6.00</b>	<b>When things go wrong...</b> <i>Hilary Coates, Health Information and Quality Authority introducing the Irish project on learning while supporting patients, families and clinicians in the aftermath of a patient safety incident</i>

## **Wednesday 5 September**

***Primary aim: to initiate drafting of regional action plans***

<b>9.30- 9.45</b>	<b>Review of day 2</b>
<b>9.45– 10.45</b>	<b>Planning the Future I - Opportunities</b>
<b>10.45- 11.15</b>	<b>Disclosure: The Patients for Patient Safety Response</b> <i>Groups' thoughts and perspectives on disclosure, adverse event communication and the Irish project</i>
<b>11.15 – 11.45</b>	<b>Break</b>
<b>11.45- 1.00</b>	<b>Action Planning (group work)</b> <i>Draft strategies and actions building on the three days work</i>
<b>1.00 – 2.00</b>	<b>Lunch</b>
<b>2.00- 2.30</b>	<b>Action Planning: feedback</b> <i>Summarizing connections and links between the plans</i>
<b>2.30 - 3.00</b>	<b>Being a Patients for Patient Safety Champion: Resources</b> <i>The process of becoming a Patients for Patient Safety Champion and related responsibilities</i>
<b>3.00 – 3.30</b>	<b>Moving forward from here</b>
<b>3.30 – 3.45</b>	<b>Closure of the meeting</b>

## Annex 3

### Patient Voices for Partnership

#### I. The event so far:

- We have been listening to each other and shared our experiences with harm in healthcare that could have been prevented.
- We have been learning from one another, identifying things that are common and things that are different from country to country, sharing dreams and goals
- We have begun to form a community made of patients, family members, physicians who want to learn and who are committed to speaking up about repercussion and prevention of medical error and contribute to the change.

#### II. A few of the things that we experienced that could have been prevented (random order):

##### Medical

- Healthcare acquired infections
- Poor hygiene
- Misdiagnosis of medical conditions
- Medication side effects; wrong prescriptions
- Vaccinations that spread disease
- Blood transfusions that spread infection
- Complications from diabetes and other conditions
- Failure to protect individuals with latex allergies
- Injuries that have changed our lives
- The death of loved ones

##### Psycho-social

- Gross neglect of severely handicapped patients
- Violence or disregard of mentally ill patients
- Referrals to psychiatrists instead of treatment of serious medical conditions
- Gross insensitivity (“Go home and save your money” or “Don’t waste your time”)
- Discrimination
- No opportunities for second opinions
- Unequal power in the partnership

#### III. Here are setbacks we have identified during our discussions:

- To make healthcare work, it is like building a house out of blocks. We need all the pieces and one is lacking: “the patient’s voice”
- There is no feedback system: we don’t know about the mistakes that are made, and sometime physicians are not aware when the care they give leads to harm.

- Standards of clinical practice should be available, in place and all medical actions should follow these accurately to minimize risks of error
- Often while discussing when things go wrong, patients are reduced from human beings to statistics (i.e. “the lymphoma in ward 3” or “patient number 42.”) This approach adds insult to the strain experienced as patients or families.
- Healthcare providers worry about being blamed when things go wrong, but patients and families also are often blamed
- There is a “litigation mythology” that exaggerates the number of suits and blames patients and/ or families who bring these claims
- Patients are often not fully informed on the risks related to a medical procedure, and when injury occurs, often no explanatory information is provided
- Cultural changes are required to learn how to talk about errors and overcome fears and progress is much too slow

IV. Here are the assets that we bring as patient partners:

- The energy as people who are imperative about improving patient safety, considering that we are all patients at moments in time of our lives
- The stories of medical mishaps, their details and their impact, from which one can learn and overcome preventable failures
- A strong belief that access to safe health care is a fundamental human right, that could be achieved only through informed and active partnership

V. Here are some of the challenges we bring forward:

- Tell us the whole truth about our condition, even when it is frightening to hear.
- Fully inform us about the risks related to healthcare
- Listen to our complaints – we want you to understand and grasp the learning
- Restore trust by being accountable to patients when things go wrong
- Contribute making patient safety a top priority in our countries
- Work WITH us, not just FOR us.

VI. Here is what we are doing in strengthening patient safety:

- We are using our networks to talk with opinion leaders, and increasingly we find some who will listen to us, appreciate us and take action
- We are asserting patient safety as a fundamental patient right.
- We are working with the media, who always wants to hear our stories.
- We are litigating, because its sometimes the only way to get justice/fairness, compensation when we need it, or the truth about what happened
- We are looking for other ways to achieve fair resolution of claims, such as mediation
- We are educating ourselves about risks and how systems fail.
- We are uniting to support each other

- We are working with the WHO World Alliance for Patient Safety to contribute to, strengthen and spread its programs internationally, regionally and in our individual countries

VII. Please work with us to accomplish these goals:

- Prevention of health care related harm such as that which we have experienced
- Developing evidence-based protocols and algorithms for decision-making and care that help patients and physicians alike
- Reporting of medical errors for both accountability and learning : honest and open disclosure when things go wrong
- Developing a research agenda that incorporates the experiences of patients and their families and measures the benefits of engaging patients as partners in care
- Patient safety and oversight committees that have patients and our advocates on them as members

## Annex 4

### List of participants

#### Bosnia and Herzegovina

Mr Ahmed Novo  
Technical Officer  
WHO Country Office for Bosnia and Herzegovina  
Sarajevo

Email:  
[ano@who.ba](mailto:ano@who.ba)

#### Croatia

Ms Ema Gruber  
President  
Society for improvement of mental health  
and quality of life of mentally ill patients and their families  
Zagreb

Email:  
[emagruber2000@yahoo.com](mailto:emagruber2000@yahoo.com)

Dr Valerija Stamenic  
Senior Adviser  
Board of Professional Medical Affairs  
Ministry of Health and Social Welfare  
Zagreb

Email:  
[valerija.stamenic@mzss.hr](mailto:valerija.stamenic@mzss.hr)

#### Denmark

Ms Birgitte Holmark  
Headmistress  
Copenhagen

Email:  
[birgitte@holmark.dk](mailto:birgitte@holmark.dk)

Ms Marianne Kristensen  
Senior Adviser  
National Board of Health  
Copenhagen

Email:  
[mkr@sst.dk](mailto:mkr@sst.dk)

Ms Birgit Woer  
Danish Association for Patient Safety  
Patient Association Denmark  
Copenhagen

Email:  
[birgitwoer@gmail.com](mailto:birgitwoer@gmail.com)

#### France

Dr Jean Bacou  
Responsable des relations internationales  
Haute Autorité de Santé- HAS  
Saint Denis La Plaine

Email:  
[j.bacou@has-sante.fr](mailto:j.bacou@has-sante.fr)

Ms Nicole Diederich  
Sociologist/Researcher  
INSERM  
Representative of FDFA  
Chennevières sur Marne

Email:  
[nicole.diederich@tele2.fr](mailto:nicole.diederich@tele2.fr)

Ms Garance Upham  
Patients for Patient Safety Steering Group  
Preveessin

Email:  
[g\\_upham@club-internet.fr](mailto:g_upham@club-internet.fr)

## **Georgia**

Ms Tinatin Chkhaidze  
Tbilisi

Email:  
[chkhaidze@parliament.ge](mailto:chkhaidze@parliament.ge)

Ms Maka Danelia  
Head  
Research Department  
Georgian Alliance for Patient Safety  
Tbilisi

Email:  
[makadanelia@parliament.ge](mailto:makadanelia@parliament.ge)

## **Germany**

Ms Julie Holzhausen  
Patientenbeauftragte der Bundesregierung  
Berlin

Email:  
[j.holzhausen@gmx.net](mailto:j.holzhausen@gmx.net)

## **Greece**

Ms Aikaterina Nomidou  
Lawyer  
Association of Families and Friends for Mental Health  
County of Serres

Email:  
[wordland@otenet.gr](mailto:wordland@otenet.gr)

## **Ireland**

Ms Margaret Murphy  
Patients for Patient Safety Steering Group  
Cork

Email:  
[m33g33t@yahoo.co.uk](mailto:m33g33t@yahoo.co.uk)

Ms Rebecca O'Malley  
County Tipperary

Email:  
[theomalley@eircom.net](mailto:theomalley@eircom.net)

Ms Mary Vasseghi  
Chairperson  
Sudden Cardiac Death in the Young support group  
Dublin

Email:  
[maryvasseghi@yahoo.ie](mailto:maryvasseghi@yahoo.ie)

## **Israel**

Ms Sara Yaron  
Tel-Mond

Email:  
[aron-i@bezeqint.net](mailto:aron-i@bezeqint.net)

Ms Yael Applbaum  
Director  
Quality Assessment Department  
Ministry of Health  
Jerusalem

Email:  
[yael.applbaum@moh.health.gov.il](mailto:yael.applbaum@moh.health.gov.il)

## **Italy**

Ms Paola Acquaro  
Association of Volunteers  
Europa Donna  
Trappeto

Email:  
[paolaacquaro@hotmail.com](mailto:paolaacquaro@hotmail.com)

Mr Lucio Patoia  
Senior Registrar  
Internal Medicine and Oncology Unit  
Perugia General Hospital CERREA  
Perugia

Email:  
[patoia@unipg.it](mailto:patoia@unipg.it)

Ms Silvana Simi  
PFPS Champion  
Inst. of Clinical Physiology  
Pisa

Email:  
[s.simi@ifc.cnr.it](mailto:s.simi@ifc.cnr.it)

## **Kyrgyzstan**

Mr Mirbek Nuraliev  
Vice Director  
National Hospital  
Head, Committee for quality of medical help and patients care  
Bishkek

Email:  
[trisolf@yahoo.com](mailto:trisolf@yahoo.com)

## **Lithuania**

Mrs Ramune Navickiene  
State Inspector of Medical Audit  
Ministry of Health of Lithuania  
Vilnius

Email:  
[navickiene.ramune@vmai.sam.lt](mailto:navickiene.ramune@vmai.sam.lt)

Ms Monika Nemanyte  
Board Member/Secretary  
Club 13 & Co  
National Association of Persons with Mental Disorders and their Friends  
Vilnius

Email:  
[akinomne@gmail.com](mailto:akinomne@gmail.com)

## **Norway**

Dr Unni Krogstad  
Senior researcher  
Norwegian Knowledge Center for the Health Services  
Oslo

Email:  
[unni.krogstad@nokc.no](mailto:unni.krogstad@nokc.no)

Ms Fatima Maria Lavoll  
Leader  
Norwegian Lupus Association  
Oslo

Email:  
[flavoll@online.no](mailto:flavoll@online.no)

## **Poland**

Ms Jolanta Ewa Bilinska  
PFPS Champion  
Head  
Dept of International Cooperation  
Health Fund Lodz  
Lodz

Email:  
[j.bilinska@nfz-lodz.pl](mailto:j.bilinska@nfz-lodz.pl)

Ms Katarzyna Nowak  
Patient Safety Foundation  
Lodz

Email:  
[wredusek@poczta.fm](mailto:wredusek@poczta.fm)

## **Russian Federation**

Ms Tatiana Belyaeva  
Board Member  
Self-Help Club  
Moscow

Email:  
[tbelyaeva@gmail.com](mailto:tbelyaeva@gmail.com)

Mr Nikolai VI. Zhurilov  
Chairman  
Otziv-Dzent  
Moscow Medical Academy  
Moscow

Email:  
[nikolayzhurilov@bk.ru](mailto:nikolayzhurilov@bk.ru)

## **Slovenia**

Mrs Vlasta Gjura Kaloper  
Vice President  
Slovenian Diabetes Association  
Skfljica

Email:  
[vlastakaloper@hotmail.com](mailto:vlastakaloper@hotmail.com)

Dr Vladimira Leskovec  
Department for Quality  
Ministry of Health  
Ljubljana

Email:  
[vladimira.leskovec@gov.si](mailto:vladimira.leskovec@gov.si)

## Spain

Mr Adoracion Carpintero Montoro  
Asociacion Espanola De Alergicos Al Latex  
Madrid

Email:  
[info@alergialatex.es](mailto:info@alergialatex.es)

Ms Ana Fernandez-Marcos  
Director  
Studies & Institutional Affairs  
Asociacion Espanola Contra el Cancer  
Madrid

Email:  
[ana.fernandez@aecc.es](mailto:ana.fernandez@aecc.es)

## Sweden

Mrs Christina Fleetwood  
Täby

Email:  
[christina.fleetwood@gmail.com](mailto:christina.fleetwood@gmail.com)

Mrs Eva Stolpe  
Senior Adm. Officer  
Patient Safety Unit  
National Board of Health and Welfare  
Gothenburg

Email:  
[eva.stolpe@socialstyrelsen.se](mailto:eva.stolpe@socialstyrelsen.se)

## Turkey

Mr Mustafa Bulun  
President  
Turkish Patient Safety Association  
Ankara

Email:  
[mbulun@gmail.com](mailto:mbulun@gmail.com)

Ms Rabia Kahveci  
Provincial Health Directorate of Ankara  
Dept. of Family Medicine  
Ministry of Health  
Ankara

Email:  
[drabiakahveci@yahoo.com](mailto:drabiakahveci@yahoo.com)

## Ukraine

Ms Irina Aleksandr Gavrishева  
Zaporozhye Oblast

Email:  
[gavrishev123@mail.ru](mailto:gavrishev123@mail.ru)

Mr Vasyl Kvartiuk  
PFPS Champion  
Kyiv

Email:  
[vasylkvartiuk@tb.org.ua](mailto:vasylkvartiuk@tb.org.ua)

Mr Fedir Petkanych  
Uzhgorod  
Transcarpathian Region

Email:  
[fedir@skarga.net](mailto:fedir@skarga.net)

Mr Igor Shpak  
Kyiv

Email:  
[shpak@moz.gov.ua](mailto:shpak@moz.gov.ua)

Ms Helen Terekhova  
Symu

Email:  
[lena-terehova@mail.ru](mailto:lena-terehova@mail.ru)

### **United Kingdom of Great Britain and Northern Ireland**

Ms Rachel Heath  
Patients for Patient Safety Project Manager  
c/o IAPO  
London

Email:  
[safety@patientsorganizations.org](mailto:safety@patientsorganizations.org)

Miss Monique Narracott  
PFPS Administrator  
c/o IAPO  
London

Email:  
[safetyadmin@patientsorganizations.org](mailto:safetyadmin@patientsorganizations.org)

Ms Helen Hughes  
Head  
WHO Office for Patient Safety  
Patients for Patient Safety Steering Group  
Department of health  
London

Email:  
[hughesh@who.int](mailto:hughesh@who.int)

Mr Peter Mansell  
Director of Patient Experience  
Patients for Patient Safety Steering Group  
NPSA  
London

Email:  
[peter.mansell@npsa.nhs.uk](mailto:peter.mansell@npsa.nhs.uk)

Miss Jo Harkness  
CEO  
International Alliance of Patients' Organizations  
(IAPO)  
London

Email:  
[policy@patientsorganizations.org](mailto:policy@patientsorganizations.org)

Ms Josephine Ocloo  
Manager  
Patients for Patient Safety Project  
Action Against Medical Accidents  
London

Email:  
[joclooo@aol.com](mailto:joclooo@aol.com)

Mr Peter Walsh  
Chief Executive  
Action Against Medical Accidents (AVMA)  
Croydon

Email:  
[peter@avma.org.uk](mailto:peter@avma.org.uk)

### **United States of America**

Mr Martin Jay Hatlie  
P4PS Ltd  
Patients for Patient Safety Steering Group  
Chicago

Email:  
[mhatlie@p4ps.org](mailto:mhatlie@p4ps.org)

**World Health Organization**

**Regional Office for Europe**

Dr Valentina Hafner  
Quality of Health Systems Programme  
Division of Country Health Systems

Email:  
[vha@euro.who.int](mailto:vha@euro.who.int)