PATIENTS FOR PATIENT SAFETY (PFPS)

Project Implementation Guide

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Every individuals involved in the first pilot project of PATIENTS For Patient Safety in Malaysia
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INTRODUCTION

PATIENTS For Patient Safety (PFPS) is a group of patients or family members who are interested in improving patient safety through engagement and empowerment. This is achieved through:

- Patients taking ownership of their care;
- Bringing the voices of patients and people to the forefront of health care;
- Patient, family and community partnerships with health professionals (health-care providers, policy-makers, researchers).

This guide is produced to assist organizations in establishing PFPS group to conduct a specific project either to promote patient safety in general or to conduct a specific project to reduce harm in healthcare. This guide is produced based on Malaysia experience which has collaborated with World Health Organization in implementing this initiative.

This guide does not consist of rules that need to be followed strictly. Instead, it can be modified to produce a customize model of PFPS based on individual organizational resource and support.

EVOLUTION OF PFPS IN MALAYSIA & FRAMEWORK ADOPTED FOR PFPS ENGAGEMENT IN MALAYSIA

In Malaysia, PFPS initiative started with the stewardship of MSQH Committee which emphasizes commitment to actively engage patients and consumers in the Healthcare Facilities and Services Accreditation Program, since 2008, with the introduction of Patients and Family Rights Standards in the 3rd Edition of the MSQH Hospital Accreditation Standards. Furthermore participation of patients and consumers is also part of ISQua Organisation certification standard requirement.

MSQH then collaborate with Ministry of Health Malaysia to establish PATIENTS For Patient Safety Malaysia. First “PATIENTS for Patient Safety Country Workshop” was conducted by MSQH and Ministry of Health in collaboration with WHO on 5th-6th September 2013. Following this, “PATIENTS For Patient Safety Malaysia (PFPSM)”, voluntary organization was established on the 1st October 2013. Currently PFPSM is under MSQH. PFPSM was launched by Honorary Minister of Health Malaysia on 29th April 2014. Patient representative read out Putrajaya Declaration during this ceremony (Appendix 1).

Positive and constructive patient engagement which is supported by policy and regulations are principles in PFPS. These include:

1. Informed, empowered patients & community
2. Aware, competent, committed professionals
3. Visionary, passionate and supportive leadership

It is hoped that this will lead to better healthcare outcome-safe, high quality, integrated, customer-centered health care. (Diagram 1)
Patients, healthcare providers and organizations need to raise awareness, improve capacity, establish good relationships and create strong partnership to improve patient safety (Diagram 2).

**Diagram 1 - Engaging Patients/Consumers In Malaysian Healthcare Services**

**Diagram 2 - Role of Patients and Healthcare Providers/Organizations**
PATIENTS For Patient Safety Malaysia can be empowered to assist healthcare providers as an advocate in patient safety. The specific roles of PFPSM are:

• Be well-informed patient advocates and be the voice for all people
• Commit to positive and constructive engagement
• Work collaboratively as partners with professionals and policy-makers
• Promote patient empowerment and patient safety culture
• Raising awareness of health care quality and patient safety
• Facilitate systems for patient safety reporting and organizational learning
• Define and promote best practices in dealing with healthcare harm

MSQH and Ministry of Health Malaysia will improve patient safety by facilitating patient engagement with relevant stakeholders at different levels (Diagram 2):

1. Global and country level in collaboration with World Health Organization; national level through Patient Safety Programme and PATIENTS For Patient Safety
2. Government, National bodies, organizational and institutional
3. Professionals which include healthcare providers, professional associations, academic and research institutions
4. Patients, consumers, community and civil society

Diagram 3 - Relevant Stakeholders
VARIOUS MODELS OF PFPS ORGANISATIONS

- **Model 1**: PFPS consists of patients who had experienced patients safety incident or their family members.
- **Model 2**: PFPS consists of members who are passionate about patient safety. May or may not experience patient safety incident.
- **Model 3**: PFPS consists of patients who are employed by healthcare organization to educate patients on patient safety.
- **Model 4**: PFPS consist of healthcare staff who had experienced patients safety incident or involved in patient safety incident (i.e. second victim).
- **Model 5**: PFPS consist of members of disease based NGOs (e.g.: Kidney Foundation, Cancer Patients Association etc.) who are passionate about patient safety.

METHOD OF ESTABLISHMENT

- PFPS organization initially established by NGO involves in quality improvement and patient safety activities (e.g National accreditation body). May collaborate with relevant stakeholders such as Ministry of Health. After PFPS matures, it becomes a stand alone NGO.
- PFPS organization established initially with the assistance of healthcare management. Initially receive guidance and funding of activities from the management, later on may act independently.

SELECTION CRITERIA OF COUNTRY

- Country has shown commitment to patient safety and continuous quality improvement nationally and at facility level
- Country has demonstrated good collaboration efforts between organizations both nationally and internationally
- Country has “leaders” on patient safety to support PFPS program at national and facility level
- Country has “champions” on patient safety to initiate PFPS program at national and facility level
- Country has possible patients candidates who can engaged in PFPS

*At least one criteria is fullfilled*
SELECTION CRITERIA OF PATIENT REPRESENTATIVES

- Patient has interest to improve quality of healthcare and patient safety
- Patient is reasonably healthy (i.e. does not require frequent inpatient care)
- Patient has the ability to communicate effectively with others
- Patient has the ability to work with others
- Patient is willing to give commitment as Patient Representative - in terms of ideas, time and activity
- Patient is “non-bias”
- Patient is willing to learn
- Patient is willing to give ideas, constructive criticism
- Patient is willing to work voluntarily
- Patient can work independently
- Patient has no vested interest in this project
- Patient has experience “patient safety incident” and willing to share his/her experience with others (optional & bonus)
- Patient can communicate using multiple languages (optional & bonus)

SELECTION CRITERIA OF HOSPITALS/HEALTHCARE FACILITIES

- Hospital has interest to start this project
- Hospital has shown commitment to patient safety and continuous quality improvement
- Hospital has “leaders” on patient safety, preferably at all levels - hospitals, departments
- Hospital has multiprofessional “leaders” on patient safety
- Hospital staff is ready to engage patients to improve patient safety
  - Willing to receive patients as part of the “hospital team member”
  - Willing to guide patients in terms of understanding certain work process
  - Willing to receive suggestions, constructive criticism from patients
- Hospital has possible patients candidates who can engaged in PFPS

SELECTION CRITERIA OF WARDS/UNITS

- Has higher rate of patient safety incidents compared to other wards/units

SELECTION CRITERIA OF PROJECTS

- Project aim to improve incidents which have higher rate of occurrence compared to other incidents
- There is a possible mechanism for patients to be involved in preventing the incidents
- Projects have objective way of evaluating the outcome
PREPARATION OF PATIENT REPRESENTATIVES

- Undergo specific training. Normally conducted by World Health Organization in collaboration with the interested parties in the country which is interested in establishing PFPS.
- Training should consist at least on these subjects:
  - Provision of Healthcare Services locally
  - Patient safety
  - Patient engagement
  - Effective communication
  - How to handle challenging patients - Patients who refused, patients who break into tears, patients who talk too much
  - Technical/focus area - example patient fall, medication safety, hand hygiene compliance

PREPARATION OF HEALTHCARE STAFF

- Undergo training or at least briefing on patient safety, patient engagement and the project
- Understands the role of patient representative in improving patient safety

PURPOSE OF PATIENT ENGAGEMENT TO IMPROVE PATIENT SAFETY

- Patients or family members share experience on incident, harmful event that happen by educating others on patient safety
- Patients who did not experience incident but interested to improve patient safety by educating others on patient safety

METHODS OF PATIENT ENGAGEMENT

- One to one engagement between Patient Representative and patient/family member
- Focus Group Discussion between Patient Representative and group of patients/family members; healthcare professionals
- Engagement of Patient Representative in a Focus Group Discussion to improve patient safety
- Engagement of Patient Representative as a speaker, moderator, panel member or facilitator or committee member during workshop, seminar, conference
- Engagement of Patient Representative as a Technical Working Group to develop new program, new policy, to develop campaign
PROCESS OF PROJECT PLANNING & IMPLEMENTATION

1. Country has intention to establish PFPS
2. Discussion between country with WHO to establish PFPS
3. Conduct in country workshop between WHO, patient representatives, other relevant partners
4. Establish PFPS
5. Start activities
6. Evaluation
7. Improvement
8. Expansion/termination of project

MONITORING & EVALUATION OF PROJECT

- Number of incidents -Pre and post project implementation
- Number of campaigns/project conducted
- Number of talks given
- Number of campaign/seminar organized
- Evaluation of effectiveness from patient perspective
CONCLUSION & WAY FORWARD

In this challenging era of diversity and complexity, healthcare professions need to work together with patients and their families to improve our healthcare system and reduce harm to patients. PFPS provides an opportunity for both parties to work together and enables engagement as well as empowerment of patients to improve patient safety in a structured manner. Patients and their families can give feedback and ideas to improve patient safety from patients perspective. This will not only improve the healthcare system but will also encourage the internalization of safety culture in the healthcare organization.
APPENDIX 1

Patients for Patient Safety Malaysia, Putrajaya Declaration

We, the participants of the Inaugural Malaysian Patients for Patient Safety Workshop convened in September 2013 will share the profound healthcare experiences in our lives and take forward our call to action to improve patient safety in Malaysia.

We are patients, family members, carers, and health professionals - people from all walks of life. Each of us is a testament to the personal experience of unintended harm healthcare and its continuing impact. Much of that harm was preventable.

We declare:

- We, Patients for Patient Safety Malaysia are committed to the right to safe healthcare. We expect honesty, openness and transparency.

- Patient safety is a basic human right. We will make the reduction of healthcare patient safety incidents a priority to improve the quality of healthcare. When harmed, patients and their caregivers have the right to timely apology, explanation, redress and other remedies meaningful to them.

- Our trusted healthcare providers must recognize that we, your patients and our families are an invaluable asset and resource for improving patient safety. We offer our stories and experiences. Seek to learn from our hard won wisdom and partner with us to make lasting improvement.

- We, have collective responsibility for our healthcare systems and we ask everyone in the community, including healthcare providers and the Government to join us in making the right to safe healthcare a priority for all people at all times.

- We, Patients for Patient Safety Malaysia will be the voice for all people, especially those who are now unheard. Together as partners, we will collaborate in:
  - Devising and promoting programs for patient safety, patient empowerment and patient engagement;
  - Developing and driving a constructive dialogue with all partners concerned with patient safety;
  - Establishing systems for reporting and dealing with patient safety incidents;
  - Identifying best practices to ensure patient safety and promoting those best practices.

This Declaration is our calling. We the Patient for Patient Safety Malaysia invite you to join us and advance patient safety for everyone.

*This is our pledge of partnership*

(Putrajaya, Malaysia, 29th April 2014)