Tips for patient/family engagement with health authorities to improve patient safety and quality of care

September 24, 2015
Your line will be muted until the session begins.
Did you join the call correctly?

YES!
See phone icon beside your name.

TRY AGAIN if there is no phone icon beside your name (see next slide)
1. Hang up to disconnect you audio.
2. Click the audio icon.
   
   If needed, rejoin using the original link (enter name and email, click “Join Now”).
3. A popup will display the phone information with a drop down menu. Use the 2nd option if your phone number has an extension.

If there is NO phone icon beside your name
Interacting in WebEx

Click the hand up icon to ask your question or make a comment live (your line will be unmuted)

Type your question or comment here (select “all participants” from the drop-down menu)
Stay Tuned!

We’ll get started in just a few moments!
Tips for patient/family engagement with health authorities to improve patient safety and quality of care

September 24, 2015
About us

Virtual conference room:
- Chat
- Mute/unmute
- Hand up (not for mobile devices)

Getting to know each other:
- City
- Country
- Role
**Program Overview**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Presenter</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Point of Care</td>
<td>Dr. Martinez; Argentina</td>
<td>10’</td>
</tr>
<tr>
<td></td>
<td>All – Discussion</td>
<td>5’</td>
</tr>
<tr>
<td>Organization</td>
<td>Stuart, Dennis, Teresa;</td>
<td>20’</td>
</tr>
<tr>
<td></td>
<td>Canada</td>
<td></td>
</tr>
<tr>
<td></td>
<td>All – Discussion</td>
<td>5’</td>
</tr>
<tr>
<td>System</td>
<td>Dr Abu Bakar; Malaysia</td>
<td>10’</td>
</tr>
<tr>
<td></td>
<td>All – Discussion</td>
<td>5’</td>
</tr>
</tbody>
</table>

What do **YOU** want to learn?
Theresa Malloy Miller

Moderator

Member Patients for Patient Safety Canada
CONGRATULATIONS
for your work

THANK YOU
for the invitation
WELL-INFORMED MOTHERS

- THE BEST AGENTS IN PREVENTIVE MEDICINE
“AN INVITATION TO LIFE”
PROGRAM

- SAFETY – HEALTH – FUTURE

- HOW THE WORLD IS SEEN BY THE CHILDREN’S EYES
“AN INVITATION TO LIFE”
PROGRAM

- MOTHERS-PATIENTS SHOULD "FEEL" LIVING A FRIENDLY – INTERACTIVE AND REAL PROGRAM
STIMULATING

TRUST
MAIN TOPICS

- Main importance of preconception advice and attitudes
- Timing and proper prenatal control
- Babies inside the womb – The First classroom
- How to understand a baby before he will be able to talk
- Breastfeeding – the great gift
- HAND-WASHING Campaign. Timing immunizations-medication safety
- Strategies to avoid sudden infant death
- How to react when facing emergencies
- Why do children have accidents?
- How to face when terrible things happens
- And much more
COMPARE

EARLY EXPERIENCE IN

CHILDHOOD

AND

EARLY EXPERIENCE IN

HEALTH CARE STUDENTS
M.D. message:

“Thank you so much for teaching me concepts that opened my mind to see and practice medicine in a completely new vision.”
CONCLUSIONS

INFORMED PARENTS –
INFORMED PATIENTS –
INFORMED STUDENTS

become active agents for Preventive and safe Medicine
It doesn’t depend on economic resources, it depends on real COMMITMENT.
Many little things
Done by many little people
In many little places
Could change the face of the world.
Discussion
Teresa Mrozek  Stuart Croall  Dennis Maione

Executive Director of the Provincial Cancer and Diagnostic Services Branch within Manitoba Health

Member Sixty project’s Patient Participation Advisory Group

Cancer survivor and author
In Sixty Goal

To reduce the time from suspicion of cancer to first treatment to no longer than 60 days,
in a sustainable manner that improves the quality of the cancer patient experience.
“Nothing about me without me”

- 2 patient representatives as full voting members of the Manitoba Cancer Partnership Steering Committee
- Patient Participation Advisory Group
- Patient Stories

Patient Participation Advisory Group (PPAG)

- To provide feedback to the In Sixty working groups on the improvement initiatives from a patient perspective
- Identify patients’ needs
- Ensure patient needs are met, and not overshadowed by technical and administrative considerations
Who is PPAG?

• Made up of 8 to 10 individuals

• All members have lived experience of cancer, either as individuals living with cancer, in remission, or as a family member of someone who has died of cancer.

• 2 members represent the group at In Sixty steering committee meeting
Patient Needs vs Initiative Objectives

• While patient engagement was part of In Sixty from the outset, initiative goals were set without patient engagement

• Original goal focused only on time to treatment

• Listening to patient stories made it clear that the content and quality of communication with providers and the health care team was more significant, and a greater concern.
Why Tell Stories?

• Refocus the committee on the fact that patients are central to the initiative, and to health care

• Remind the committee why our efforts are integral and the impact we can have

• Connect the committee members with the patient

• Provide the lens of patient experience that can be applied to broader, systemic efforts
Challenges with telling stories

• Inconsistent audience engagement – texting, typing rather than listening
• Explaining away the challenges identified in the story
• Problem-solving specific issues, rather than attentive listening and reflecting
• Trouble hearing a story not conveyed in technical or health provider terminology
• End of stories often resulted in awkward silence or inappropriate or insensitive comments – people tried to fill the silence
• Some sharing lasted 2 minutes, some 45 minutes
What we needed

• Protect patients from risk of secondary harm
• Give the committee permission to hear without feeling guilt or blame
• Set an objective for sharing
• Set expectations for the interaction, for the speaker and the audience
  – Attentive listening
  – Remove opportunity for inappropriate comments
  – Acknowledge the challenge and vulnerability of sharing one’s story
Creating the Guidelines

- At PPAG, we discussed our impressions of, and feelings about, our interactions with working groups and the steering committee.
- We identified a need to reframe the purpose and character of many of these interactions.
- We identified patient stories as the most difficult type of interaction, because it is so personal to the patient.
- We identified what was most important about patient stories, and the biggest challenges in presenting them.
- A decision was made to formalize what we had learned to provide a consistent framework for future interactions, both for the patient presenter and the audience.
Patient Story Guidelines

- Refocus on hearing the story, rather than solving problems
- Emphasize taking time to reflect, rather than immediately reacting, or becoming defensive
- Provide tangible questions for the audience to ponder during the sharing of the stories
- Direct the audience to think broadly, rather than narrowly about the specific story, in terms of reflections and implications
- Mitigate the risk of secondary harm
- Acknowledge the challenge of, and vulnerability created by, sharing one’s story
- Provide follow up opportunities to clarify and enhance understanding
Impact of the Guidelines

- Removed fear or discomfort of hearing the story and not reacting immediately
- Removed the pressure to defend the system and/or people within the system
- Allowed us to focus and reflect on the story itself
- Appreciate the position of the story-teller and our responsibility to respect that position
- Provided a sense of comfort in the silence (if no questions are asked)
- For some, provided reassurance that the story was not going to take too much meeting time
Patient Story Guidelines

Discussion and Questions
Discussion
Dr. Nor’Aishah Abu Bakar

Senior Principal Assistant Director, Head Of Patient Safety Unit
Ministry Of Health Malaysia
Chief of Secretariat, Patient Safety Council Malaysia
"PATIENT ENGAGEMENT IN PATIENT SAFETY: MALAYSIA EXPERIENCE"

WHO Webinar
24th September 2015

DR. NOR’AISHAH ABU BAKAR
PUBLIC HEALTH PHYSICIAN
SENIOR PRINCIPAL ASSISTANT DIRECTOR
HEAD OF PATIENT SAFETY UNIT
SECRETARIAT, PATIENT SAFETY COUNCIL MALAYSIA
MINISTRY OF HEALTH MALAYSIA
EVOLUTION OF PATIENT ENGAGEMENT IN PATIENT SAFETY …MALAYSIA EXPERIENCE

Promotion on patient engagement

Patient engagement is integrated as part of patient safety programs developed by policy makers & healthcare providers

Specific voluntary organisation was developed by WHO, MSQH & Ministry of Health to facilitate patient engagement in Malaysia (PFPSM)

PFPSM is now part of policy maker (Patient Safety Council)

PFPS is involved in improving patient safety in hospital (14 pilot projects)
PROMOTION & EDUCATION ON PATIENT ENGAGEMENT IN PATIENT SAFETY

Dr Lee Fatt Soon, (Hello on 2) – Patient Fall

Dr Nor’Aishah Abu Bakar (Good Morning Malaysia During Flowers Fiesta, Putrajaya) – Patient Safety Campaign

Ms Stephanie Newell WHO Patients for Patient Safety Champion, Australia
INTEGRATION OF PATIENT ENGAGEMENT - HAND HYGIENE COMPLIANCE

COMMUNICATION WITH PATIENT IS PART OF SAFE SURGERY PROGRAMME
PATIENT ENGAGEMENT IN IDENTIFYING RIGHT SIDE/SITE OF SURGERY OR PROCEDURE
ENGAGING PATIENT TO IMPROVE MEDICATION SAFETY

Know Your Medicine Campaign

Know Your Medicine Pamphlet

Patient Allergic Card
SPECIFIC PATIENT SAFETY MOVEMENT AT VARIOUS LEVELS

- Patient Safety Council Malaysia
- Patients For Patient Safety (Hospital)
- PATIENTS For Patient Safety Malaysia (National)
- World Health Organisation

Patient Safety Committee
Official Launching PFPSM - 29th April 2014

1st In country Workshop
Putrajaya, 5th-6th Sept 2013

Minister of Health Malaysia Datuk Dr. S. Subramaniam, Dr. Graham from WHO & Mr Manvir PFPSM

2nd In country Workshop
Putrajaya, 29th-30th Sept 2014

Director, General of Health Malaysia Datuk Dr. Noor Hisham Abdullah with PFPSM members
NEW PILOT PROJECT ON PATIENTS FOR PATIENT SAFETY IN HOSPITALS

- 14 Hospitals – public 8, private 6
- 2 hospital representatives from each hospital
  - 1 hospital director, 1 patient
  - Two projects selected:
    - Prevention of medication error
    - Prevention of fall

Identify selected hospitals & patients

Train them - patient roles

Discuss on small projects

Implement

Measure after 6 months
LESSONS LEARNT

• Promote patient engagement as essential component in improving patient safety among healthcare staff and patients
• Have various strategies in engaging patient to improve patient safety
• Collaborate with WHO, NGOs, healthcare providers and patients to establish a specific patient movement - PFPSM
• WHO, Ministry of Health provide assistance – resource, education, technical support to patient movement
• We need to find suitable patient representative - committed, passionate, healthy

WAY FORWARD

• PATIENTS For Patient Safety Malaysia registered as independent NGOs
• Evaluate Pilot Project of Patients for Patient Safety
• Formulate few models for implementation
• Expand the Patients for Patient Safety to other hospitals
Discussion
Resources

- In-Sixty Manitoba: **Sharing of Patient Stories at In Sixty Steering Committee and Large Group In Sixty Events**
- Manitoba Institute for Patient Safety: **Presentations by Patients and Family to the Board of Directors**.
- International Alliance of Patient Organizations: **Addressing Global Patient Safety Issues. An Advocacy Toolkit for Patients' Organizations**.
- Resources from past World Health Organization and Patients for Patient Safety Canada webinars
  - **Ways to share your story**
  - **Partnering with patients/families on committees**
Next Steps

Theresa Malloy-Miller
info@patientsforpatientsafety.ca
Thank You!!