

# Asia-Pacific Patient Advocacy Consensus for Patient Safety

Global Patient Safety Action Plan (GPSAP)

on Patient and Family Engagement

Co-Creation Consensus Workshop Report

3<sup>rd</sup> Asia-Pacific Patients Congress 17 November 2021

Jointly organized by the SingHealth Duke-NUS Institute for Patient Safety & Quality (IPSQ), International Alliance of Patients' Organizations (IAPO), Philippine Alliance of Patient Organization (PAPO) and Patient Academy for Innovation & Research (PAIR).



Institute for Patient Safety & Quality









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#### 1. BACKGROUND

The 72nd World Health Assembly (WHA) adopted resolution WHA 72.6 'Global action on patient safety' on 25 May 2019. The resolution recognized patient safety as global health priority and call for global solidarity and concerted action by all countries and international partners.

The World Health Organization (WHO) formulated a global patient safety action plan in consultation with Member States and all relevant stakeholders and released "Global Patient Safety Action Plan 2021-2030" (GPSAP). The global action plan provides a framework for action through seven strategic objectives and is further elucidated through 35 strategies, five under each of the strategic objectives, to create a seven by five matrix.

#### 2. OBJECTIVES

As the co-organizers of the 3rd Asia-Pacific Congress (APPC), SingHealth Duke-NUS Institute for Patient Safety & Quality (IPSQ), International Alliance of Patients' Organizations (IAPO), Philippine Alliance of Patient Organization (PAPO) and Patient Academy for Innovation & Research (PAIR) took this opportunity to work together with various stakeholders to explore action plans and opportunities of co-production, fundraising, collaborative partnerships.

The workshop aimed to achieve the following objectives:

- 2.1 Create awareness of strategic direction and recommendations from the 5 strategies in the WHO Global Patient Safety Action Plan on Strategic Objective 4: Patient and Family Engagement (Engage and empower patients and families to help and support the journey to safer health care)
- 2.2 Facilitate consensus building by Patient Advocate Leads in Asia Pacific. The session should lead to agreement and support for an Asia-Pacific Patient Advocacy Consensus for Patient Safety as guided by the 5 strategies in Strategic Objective 4: Patient and Family Engagement, namely:
  - i. Engage patients, families and civil society organizations in co-development of policies, plans, strategies, programmes and guidelines to make health care safer (Strategy 4.1)
  - ii. Learn from the experience of patients and families exposed to unsafe care to improve understanding of the nature of harm and foster the development of more effective solutions (Strategy 4.2)
  - iii. Build the capacity of patient advocates and champions in patient safety (Strategy 4.3)
  - iv. Establish the principle and practice of openness and transparency throughout health care, including through patient safety disclosure to patients and families (Strategy 4.4)
  - v. Provide information and education to patients and families for their involvement in self-care and empower them for shared decision-making (Strategy 4.5)



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#### 3. METHODS

From attendees of the 3<sup>rd</sup> APPC, a total of 52 participants from over 6 countries were invited to attend the virtual workshop. They joined the workshop in their roles as a patient, patient advocate, caregiver, healthcare professional and industry representative. The workshop was led by the organizers virtually and supported by 18 facilitators from Asia-Pacific region. For the list of participants and facilitators, please refer to Annex A - Asia-Pacific Patient Advocacy Consensus for Patient Safety Workgroup.

The workshop was crafted to support GPSAP Strategic Objective 4 which advocates for engaging and empowering patients and families to help and support the journey to safer health care. It brought together various stakeholders, particularly patients and patient advocates to discuss how they can share views and suggest action plans to contribute in accelerating GPSAP Strategic Objective 4. Voices from patients offers a different perspective in the care process and it is important to integrate their opinions into designing a safer healthcare system. For patients to be empowered, all stakeholders in the health system need to recognize the importance of shared decision.

A pre-workshop briefing session was organized for the facilitators to align the objectives, expected deliverable outcomes and roles and responsibilities. Participant information slides and the WHO GPSAP document were also disseminated to participants for their reading and preparation prior to the workshop.

The participants were grouped into 5 groups. Each group was assigned a strategy from the GPSAP Strategic Objective 4 Patient and Family Engagement, supported by 2 facilitators. Each group had a good representation mix of patients, patient advocates, caregivers, healthcare professionals and industry representatives.

In their respective breakout rooms, the groups reflected and discussed on the strategy for proposed consensus statement and to refine the statement if need to, before finally attaining agreement on the consensus statements with supporting statements and proposed actions.

#### 4. **RESULTS**

In the past, patients and families played a passive role in their course of treatment and understanding of medicines and devices, technology used are limited. Healthcare professionals welcome the active role of patients and families as it promotes self-care management and improves the clinical and patient safety outcomes. It is clear from the consensus workshop meeting that we should embrace and enhance this partnership with patients and families to create a safe and holistic healthcare system. Involvement from patients and families come in various forms - being more engage in their own care as a partner, sharing and speaking up from past experiences, participating in the review and co-production of policies, services and co-design of healthcare infrastructure and patient safety systems when necessary. Partnership with patients and families provides an excellent platform for exchanges of information, knowledge and experiences while maintaining transparency and openness in the care process.

With the partnership and empowerment of patients and families, it becomes important to educate, train and build their knowledge and capability, so to contribute and play the functional role in the whole care process and journey. The training should encompass different aspects and domains of patient safety discipline such as patient safety, healthcare quality improvement, root cause analysis, safe culture, design thinking, human factors and self-care mindfulness.



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Below were the discussions on the 5 consensus statements and actions put together by patients and families, patient organizations and healthcare professionals from the workshop.

4.1 GPSAP Strategy 4.1 – Engage patients, families and civil society organizations in co-development of policies, plans, strategies, programmes and guidelines to make health care safer

The first consensus statement is [Engage] Partner and Engage patients, families and civil society organizations in co-development of policies, plans, strategies, programmes and guidelines to make health care safer.

The word "*Partner*" was suggested to be included in the consensus statement, to highlight patients and families as *partner and stakeholder* working alongside in the care design and improvement journey. An effective partnership is where all parties involved get to share and listen to constructive opinions and working together to achieve the best outcome. Healthcare strategies, policies and services must be patient and family centric focus rather than just focusing on organization's needs.

- A. The following supporting statements were made to help elaborate on the focus areas and how they can be translated into proposed actions to work on:
  - i. Any patient safety strategy or policy, to be effective, must be patient and family centric, and inclusive. The focus should be the needs of the patients, and their values, and not just staff or organization needs.
  - ii. A common language platform for effective co-production by having policies, strategies, and services in both medical and plain language, which patients and families can easily understand.
  - iii. Partners are empowered for true co-production of solutions, strategies and policies. We should, listen to and respect their opinions, share information and the rights to make decisions and trust their decisions.
- B. To transform the consensus statement into actionable plan, the group had also suggested actions which will help to build the patient and families' competency and involve them in the co-production of strategies, policies and services:
  - i. Promote active recruitment of Patient and Family Advisory Council (PFAC) members within institutions, and provide support for Patient Organizations, and equip them with the necessary knowledge and skills.
  - ii. Hardwire patient engagement/involvement in the wording and presentation of policies and strategies that directly or indirectly impact patients, before roll-out and implementation so that the purpose and outcomes of these can be easily understood and measured.
  - iii. Appoint a PFAC Representative to planning committees to determine stage and extent of patient engagement for projects.



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4.2 GPSPA Strategy 4.2 - Learn from the experience of patients and families exposed to unsafe care to improve understanding of the nature of harm and foster the development of more effective solutions

The second consensus statement is [Learn] Learn from the experience of patients and families exposed to unsafe care to improve understanding of the nature of harm and foster the development of more effective solutions.

The group agreed to the consensus statement, and agreed that there is a gap of available pathways on reporting of patient and family experience, and depository to contain the records. The experiences are invaluable learning resources to enhance the current healthcare system and future design. It is necessary to provide pathway to specify the ownership, storage and control of such information and how the information is disseminated for learning purposes.

- A. In support of the consensus statement, the group provided few supporting statements to emphasize the importance of having a legitimized framework to govern the procedures on reporting and disclosure to patients on unsafe care and how these incidents can be documented into case studies for learning and improvement purposes:
  - i. Adopt openness and transparency approach to patients and families especially in patient harm incidents. Accountability should be clear.
  - ii. Use an engagement framework for patients to share patient harm stories. The framework to govern the platform and mode disclosure and sharing of patient harm stories, including the people involved. This creates a safe environment for sharing and promote effective solutions and learning.
  - iii. Co-design patient safety reporting mechanisms with a charter to facilitate the reporting of avoidable harm and unsafe care.
- B. The group believed it is important to first build and strengthen the patient advocacy network at national level, to promote a safe platform for sharing and learning to take place. Proposed actions from the group were:
  - i. Develop relevant programme at national level, to build capacity, foster sharing and learning of health care experiences from patients and families. These include reporting of patient safety problems and sharing of solutions for improvement.
  - ii. Create national charters or laws for patient engagement in reporting of patient harm incidents.
  - iii. Create awareness through various media channels to share learnings of avoidable harm and unsafe care stories and emphasize on safe care.

#### 4.3 GPSAP Strategy 4.3 – Build the capacity of patient advocates and champions in patient safety

The third consensus statement is [Capacity Building] Build the capacity of patient advocates and champions in patient safety.



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The group agreed with the consensus statement. For patient advocates and champions to participate and contribute to the system, they need to be competent and familiar in their roles. This creates the needs to build the skills and knowledge of the patient advocates and champions to support the delivery of their roles.

- A. The consensus statement was supported with the following statements to highlight the requirements needed to build the capacity of patient advocates and champions in patient safety:
  - i. Patient advocates and champions should be competent to execute their roles and be the voices of patients and families. Establishment of a comprehensive development framework to build capability, promote continuous learning, sustain skillsets relevancy of patient advocates and champions through community sharing and engagement.
  - ii. Introduction of patient safety council/board in hospitals and healthcare facilities to integrate the roles and representation of patients and families in the healthcare system.
  - iii. Training curriculum with accreditation from established patient or healthcare organizations.
- B. The group suggested the following proposed actions which provided an oversight on the capacity building plan from nomination to training and assessment of competency of the patient advocates and champions:
  - i. Develop a training roadmap to build patient advocates and champions with funding support from government.
  - ii. Identify and nominate potential patient speaker/s in respective therapy area to be trained as patient advocates and champions.
  - iii. Develop training programmes including refresher training.
- 4.4 GPSAP Strategy 4.4 Establish the principle and practice of openness and transparency throughout health care, including through patient safety incident disclosure to patients and families

The fourth consensus statement is [Transparency] Establish the principle and practice of openness and transparency throughout health care, including through patient safety disclosure to patients (and families when permitted).

It was recommended to include "(and families when permitted)" to the consensus statement to emphasize that while patient safety disclosure to patients was expected and deemed important, disclosure to families should be only permitted after and upon patient's authorization.

A. The supporting statements echoed the importance of holding up the principle and practice of openness and transparency of the risk impact of the care process to the patients, in particular. Patients have the rights to know what are the care treatment they are receiving and what are the risks involved. This in turn will build trust and foster shared decision making. Two important tenets are:



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- i. Regardless of the level of risk to the patient, transparency and disclosure is necessary. The increased openness and honesty following adverse events can improve provider-patient relationships, thus facilitating better health outcomes and quality of life.
- ii. Autonomy of patients and families on informed decision and information throughout their care journey.
- B. The group had listed several actions to suggest ways to create an open and safe environment and promote trusting relationships between patient and provider and towards a safer health system:
  - i. Help patients better understand their diagnosis, and to formulate relevant questions for their health care providers, so that they are clear about treatment options, possible side effects and the way forward.
    - Indicator: Number of patient feedback on the support they received from patient advocates or patient organizations against number of support requested.
  - ii. Raise awareness about the rights to correct and complete information, and their entitlements.
    - Indicator: Number of activities conducted by the patient advocates/patient organizations
  - iii. Raise awareness on the rights to seek full open patient safety disclosure related to adverse events and ongoing treatments to take informed decisions.
    - Indicator: Number of Root Cause Analyses done on adverse events and ongoing treatments
  - iv. Patient organizations/advocates should be the voice of patients and families in seeking the following aspects of disclosure:
    - a. the disclosure is relevant, credible and accurate;
    - b. easily accessible, comprehensible and timely communication of disclosure;
    - c. disclosure that includes strategies for prevention of recurrence to ensure safety of patients;
    - d. privacy and confidentiality of the shared disclosure.
      - Indicator: Campaigns made by patient organizations to help patients understand the importance of seeking quality information about their healthcare.
  - v. Patient advocates and patient organizations should encourage the government to create an enabling environment for all members of society to be open and transparent.
    - Indicator: Number of policies being reviewed or lobbied by patient organizations

# 4.5 GPSAP Strategy 4.5 – Provide information and education to patients and families for their involvement in self-care and empower them for shared decision-making

The fifth consensus statement is [Education & Empowerment] Provide information and education to patients and families for their involvement in self-care and empower them for shared decision-making in relation to patient safety.

The group recommended to add "*patient safety*" to the consensus statement as they felt the original statement is too broad and did not explicitly emphasize on the element of patient safety. The discussion also touched on the lack of information and access to information and policies, which can impact patients



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and families in their care journey. Hence, this brought up the importance of the communication skills and channels between patients, families and healthcare providers, on how shared experiences can be integrated with professional knowledge to create collective wisdom and build health literacy and finally adopting empowerment and shared decision-making model to enhance the care process.

- A. It is equally important to engage patients and families as partner-in-care, and in providing adequate and relevant education to them, to build their knowledge and competency. The supporting statements illustrated the key areas of focus:
  - i. Tailor education to meet varying needs and literacy levels of patients and families and autonomize self-care management and patient safety beyond healthcare facilities.
  - ii. Build communication skills among patients, families as well as healthcare providers and other stakeholders to promote patient safety.
  - iii. Co-create through Patient and Family Partnership programmes and platforms, and transform valuable insights and case studies from patients and families into collective resources for learning and improving patient safety.
  - iv. Leverage on digital innovations to promote self-care management and reporting patient safety data.
- B. The group agreed that healthcare organizations should be proactive and take the lead to drive the initiatives in promoting patient advocacy and patient empowerment. There is no easy or fast route to attain that. Proper planning, collaboration and support from various stakeholders are very much needed to realize the goal. The list of proposed actions from the group was as follows:
  - i. Healthcare organizations should provide the lead in understanding the patient journey and consolidating the insights into a patient journey framework with potential patient safety issues highlighted at each stage.
    - a. Collection of patients' and families' experiences and case studies to build repository and cocreate education resources for learning and enhancing of healthcare system.
    - b. Provision of segmented education to patients and families, addressing varying levels of needs and knowledge gaps.
    - c. Promotion of the use of plain language and communication skill training to healthcare providers.
    - d. Leveraging on digital innovations e.g. social media and apps to educate and empower patients and families to report on adverse events or near misses using digital technologies to co-create patient safety data.
  - ii. Healthcare organizations should lead dynamic and active peer support groups that give opportunities beyond formal channels to patient and family members to raise concerns through dialogue on safety aspects of care



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- a. Design and promote patient advocacy programmes in patient organizations and healthcare facilities.
- b. Explore opportunities for collaborations or invites for patients and families to participate in support groups, advocacy groups, etc. to represent and contribute in their perspectives.
- iii. Healthcare organizations should advocate for creation of formalized platforms where patient advocates can dialogue with regulators and other health authorities to raise their concerns and promote accountability.
  - a. Formulate a framework to establish the pathway of engagement and communication between patient advocates, regulators and other health authorities, providing a legitimatized platform to manage the information and accountability.

#### 5. CONSENSUS STATEMENTS

The Asia-Pacific Patient Advocacy Consensus Statements for Patient Safety reached in the consensus workshop were as follow:

- i. **[Engage]** Partner and Engage patients, families and civil society organizations in co-development of policies, plans, strategies, programmes and guidelines to make health care safer.
- ii. **[Learn]** Learn from the experience of patients and families exposed to unsafe care to improve understanding of the nature of harm and foster the development of more effective solutions.
- iii. [Capacity Building] Build the capacity of patient advocates and champions in patient safety.
- iv. **[Transparency]** Establish the principle and practice of openness and transparency throughout health care, including through patient safety disclosure to patients (and families when permitted).
- v. **[Education & Empowerment]** Provide information and education to patients and families for their involvement in self-care and empower them for shared decision-making in relation to patient safety.

#### 6. CONCLUSION

Through the consensus workshop, participants from Asia Pacific region had come together to discuss, share insights and contribute ideas in their represented roles as patients, patient advocates, healthcare professionals and other health system stakeholders. The groups agreed on 5 consensus statements which are aligned to WHO GPSAP 2021-2030 Strategic Objective 4 Patient and Family Engagement. This consensus can serve as a guide for all, especially patient advocates, patient organizations and healthcare organizations in Asia Pacific region to reference and explore the strategies in strengthening patient and family engagement in eliminating avoidable harm in healthcare.



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#### 7. ACKNOWLEDGEMENT

We would like to thank the participants in the consensus workgroup for their participation, and sharing their invaluable insights and suggestions, bringing a step closer to actualize WHO Global Patient Safety Action Plan (GPSAP) Strategic Objective 4 - Patient and Family Engagement.

We would like to express our gratitude to the facilitators whom have done a fantastic job in facilitating the session and guiding the participants to achieve consensus of the statements and proposing the actions.

Lastly, we would like to thank all our partners for guidance and strong support to make this workshop a success.

Report endorsed by:

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Mr Kawaldip Sehmi Chief Executive Officer International Alliance of Patients' Organizations (IAPO)

Dr Ratna Devi Board Chair International Alliance of Patients' Organizations (IAPO)

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#### Annex A - Asia-Pacific Patient Advocacy Consensus for Patient Safety Workgroup

#### **Overall Workshop Facilitators**

- 1. Professor Tan Kok Hian, Group Director and Senior Associate Dean, SingHealth Duke-NUS Institute for Patient Safety & Quality (IPSQ), Singapore
- 2. Mr Kawaldip Sehmi, Chief Executive Officer, International Alliance of Patients' Organizations (IAPO)
- 3. Dr Ratna Devi, Board Chair, International Alliance of Patients' Organizations (IAPO)
- 4. Ms Zann Foo, Deputy Director (Admin), SingHealth Duke-NUS Institute for Patient Safety & Quality (IPSQ), Singapore
- 5. Ms Mabel Sim, Senior Executive, SingHealth Duke-NUS Institute for Patient Safety & Quality (IPSQ), Singapore
- 6. Ms Dani Mothci, Manager, Member Engagement, International Alliance of Patients' Organizations (IAPO)
- 7. Ms Rachel Githinji, Communications Lead, International Alliance of Patients' Organizations (IAPO)
- 8. Mr Ankit Dabra, Project Officer, Patient Academy for Innovation & Research (PAIR)

#### Breakout Room Group 1

Consensus Statement 1 – [Engage] Partner and Engage patients, families and civil society organizations in co-development of policies, plans, strategies, programmes and guidelines to make health care safer.

S/N	Name	Role	Country
1	Ai-Ling Sim-Devadas	Facilitator	Singapore
2	Ellil Mathiyan Lakshmanan	Facilitator	Singapore
3	Mohan Pillay	Patient Advocate	Singapore
4	Leyden Florido	Patient Advocate	Philippines
5	Robelle Tanangunan	Patient Advocate	Philippines
6	Janet Paguirigan	Patient Organization Representative	Philippines
7	Ma Doris Obias	Healthcare Professional - Nursing	Philippines
8	Shriram Varadharajan	Healthcare Professional - Medical	India
9	Marimel Lasmin	Patient advocate	Philippines
10	Supaluck Chatutavaprasit	Patient	Thailand
11	Nidhi Swarup	Patient Advocate	Singapore
12	Chee Lay Choo	Healthcare Professional - Nursing	Singapore
13	Saowanee Phoyoo	Patient	Thailand
14	Tang Joo Ying (Observer)	Healthcare Professional - Administration	Singapore
15	Michelle Lok (Observer)	Healthcare Professional - Administration	Singapore



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Brea	kout Room Group 2						
Cons	Consensus Statement 2 - [Learn] Learn from the experience of patients and families exposed to unsafe care to improve understanding of the nature of harm and foster the development of more						
unsa							
effective solutions.							
S/N	Name	Role	Country				
16	Bhupendra Kumar Rana	Facilitator	India				
17	Subhrojyoti Bhowmick	Facilitator	India				
18	Kawaldip Sehmi	Facilitator	London				
19	Russell McGowan	Patient Advocate	Australia				
20	Emmie Cadavillo Palacio	Patient Advocate	Philippines				
21	Prabhani Chathurika	Patient Advocate	Bangladesh				
22	Christopher Knight	Patient Organization Representative	Thailand				
23	Nelia Medina	Patient Organization Representative	Philippines				
24	Mansi Jajodia	Patient	India				
25	Ana Ma. Veronica A. Solano	Patient Support Group	Philippines				
26	Loh Huey Peng	Healthcare Professional – Nursing	Singapore				
27	Felicia Chong Jia Yu	Healthcare Professional – Allied Health	Singapore				
Brea	kout Room Group 3						
Cons	ensus Statement 3 - [Capac	ity Building] Build the capacity of patier	nt advocates and				
cham	pions in patient safety.						
S/N	Name	Role	Country				
28	Ratna Devi	Facilitator	India				
29	Ankit Dabra	Facilitator	India				
30	Chang Sook Mei	Healthcare Professional - Administration	Singapore				
31	Chris Muñoz	Patient Advocate	Philippines				
32	Ekawat Suwantaroj	Patient Advocate	Thailand				
33	Prashanth Mani	Patient	India				
34	Hanijah A Hamid	Healthcare Professional – Nursing	Singapore				
35	Inthira Tripiboonsuk	Patient	Thailand				
36	Lucas Ng (Observer)	Healthcare Professional - Administration	Singapore				



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#### Breakout Room Group 4

Consensus Statement 4 - [Transparency] Establish the principle and practice of openness and transparency throughout health care, including through patient safety disclosure to patients (and families when permitted).

S/N	Name	Role	Country
38	Leonie Ocampo	Facilitator	Philippines
39	Yolanda Robles	Facilitator	Philippines
40	Mike Rollings	Patient Advocate	Singapore
41	George Michael Lim	Healthcare Professional - Nursing	Philippines
42	Ralph Emerson Degollacion	Patient Organization Representative	Philippines
43	Dexter Galban	Healthcare Professional	Philippines
44	Iren Hunyadi	Patient Advocate	Australia
45	Beemajan Yousuf	Patient Advocate	India
46	Pawerisa Assawasoontonnet	Caregiver	Thailand
47	Ugrid Milinthangkul	Patient	Thailand
48	Ding Na	Healthcare Professional - Nursing	Singapore
49	Sirisha Sharma	Patient Advocate	India
50	Karen Alparce-Villanueva	Patient Organization Representative	Philippines

#### **Breakout Room Group 5**

Consensus Statement 5 - [Education & Empowerment] Provide information and education to patients and families for their involvement in self-care and empower them for shared decision-making in relation to patient safety.

S/N	Name	Role	Country
51	Amina Mahmood Islam	Facilitator	Singapore
52	Nikki Kitikiti	Facilitator	Singapore
53	Melissa Lim	Patient Advocate	Singapore
54	Prabu Naidu	Patient Advocate	Singapore
55	Reynaldo Segarra Abacan Jr.	Healthcare Professional	Philippines
56	Abonti Roy	Patient	Bangladesh
57	Asawari Sathaye	Industry Representative	India
58	Sairekha suresh	Patient	India
59	Nicole Sirisophit	Patient	Thailand
60	Malinee Chaiya	Caregiver	Thailand
61	Ang Shin Yuh	Healthcare Professional – Nursing	Singapore
62	Michael Widjaya	Healthcare Professional – Allied Health	Singapore
63	Joan Khng	Healthcare Professional – Allied Health	Singapore